



## **Report to Congress**

# **The Pediatric Rheumatology Workforce: A Study of the Supply and Demand for Pediatric Rheumatologists**

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HEALTH SERVICE ACT

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A Study of the Supply and Demand for Pediatric Rheumatologists**

Department of Health & Human Services  
Health Resources and Service Administration  
Bureau of Health Professions

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## *Executive Summary*

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### **Legislative Charge**

The Public Health Service Act in Section 763, Pediatric Rheumatology states, “The Secretary, acting through the appropriate agencies, shall evaluate whether the number of pediatric rheumatologists is sufficient to address the health care needs of children with arthritis and related conditions, and, if the Secretary determines that the number is not sufficient shall develop strategies to address the shortfall.” (Public Law 106-310 authorized in the Public Health Service Act, Title VII, Part E, Subpart 1, Section 763). This report was prepared to fulfill that mandate by:

- Reviewing the existing literature on children’s access to pediatric rheumatology care in the United States in regard to pediatric rheumatologist supply and the role of other physician providers in treating these children;
- Analyzing available data to assess the supply of and demand for pediatric rheumatologists in the United States; and
- Determining if a shortage of pediatric rheumatologists exists and, if so, discussing those factors that would affect the shortage and describing possible options for ameliorating local and nationwide shortages.

The contract for this study, University of North Carolina at Chapel Hill (Dr. Michelle Mayer, Ph.D.), was awarded by the U.S. Department of Health and Human Services, Health Resources Services Administration (HRSA). HRSA staff was responsible for overseeing this study. In addition, staff of the American Board of Pediatrics, American Academy of Pediatrics, Arthritis Foundation, and the Pediatric Section of the American College of Rheumatology provided invaluable professional insight.

### **Pediatric Rheumatologist Specialty**

Pediatric rheumatologists care for children and adolescents with diseases characterized by inflammation of joints, muscles, and/or tendons. The most prevalent pediatric rheumatic diseases are juvenile rheumatoid arthritis (JRA) and systemic lupus erythematosus (SLE). These diseases, along with several other less common ones, affect approximately 285,000 children in the United States. Only pediatric rheumatologists have been trained as specialists to treat the complex, severe, and sometimes life-threatening rheumatic diseases of childhood. Given the potential for severe illness and disability associated with pediatric rheumatic diseases and the potential for a markedly improved outcome with optimal treatment, an adequate supply of pediatric rheumatologists is essential to provide children suffering from these diseases with access to expert care.

### **Key Findings**

- The evidence indicates that there is a shortage of pediatric rheumatologists in the United States.
- Pediatric rheumatology is characterized by a small number of providers concentrated in a limited number of areas in the United States; 13 States lack a pediatric rheumatologist, and throughout the Country provider to population ratios exceed practice capacity.
- Pediatric rheumatologists who were surveyed unanimously perceive a national shortage. Additionally, there is evidence of substantial reliance on internist rheumatologists (i.e.,

those that specialize in the care of adults with rheumatic diseases) to compensate for the lack of sufficient pediatric rheumatologists.

Contributing to the shortage, the majority of pediatric rheumatologists practice in academic medical settings where they function as patient care providers, medical educators, and researchers. These diverse roles compete for pediatric rheumatologists' limited time and decrease the availability of patient care they are able to provide. Efforts to increase the availability of clinical time for current pediatric rheumatologists and attempts to increase their numbers are warranted at this time.

## **Data Sources**

This report synthesizes the results of previously published studies identified by a systematic review of the pediatric subspecialty workforce literature. In addition to these published studies, analyses were conducted using data from a variety of sources. Slightly more recent data may be available by the time of publication, but the data presented in this report were the most up-to-date at the time of analysis. More detailed information about data analyzed for this report can be found in the appendices listed below:

- Appendix C describes 2003 data from the American Board of Pediatrics (ABP), which certifies pediatric rheumatologists and other pediatric subspecialists. Appendix C also contains 2001 and 2004 membership data from the American College of Rheumatology (ACR), the professional association of rheumatologists.
- Appendix D details data from the United States Bureau of the Census, the HRSA Bureau of Health Professions Area Resource File and the ABP that were combined to estimate distances to care.
- Appendix E provides detailed information on a 2004 survey of practicing pediatric and internist rheumatologists, performed by the Arthritis Foundation and the American College of Rheumatology.
- Appendix F describes the methodology for a 2004 survey of pediatric residency directors on the role of pediatric rheumatologists in the education of general pediatrics residents and how the current supply of these providers affects graduate medical education.

Additional information from the North Carolina Medicaid Program, American Academy of Pediatrics, the American College of Rheumatology, and the American Board of Pediatrics was used.

## **Chapter Summaries (Significant Findings Listed)**

*Chapter 1. Background on Pediatric Rheumatology and Pediatric Rheumatic Diseases* highlights the unique characteristics of pediatric rheumatology workforce in the United States and provides a brief introduction to childhood rheumatic diseases.

- Only pediatric rheumatologists have been trained as specialists to treat the complex, severe, and sometimes life-threatening rheumatic diseases of childhood.
- Pediatric rheumatic diseases affect nearly 300,000 children in the United States.
- The most common juvenile rheumatic disease, juvenile rheumatoid arthritis, is unique to children and can affect children as young as infants.
- As a group these conditions are among the most common chronic illnesses of childhood and involve considerable disease burden and disability.

- Pediatric rheumatic diseases require frequent and ongoing medical care: physician visits, laboratory work, infusion therapy, and physical and occupational therapy. Long travel distances between patient and caregiver can impede continuity of care and access to important ancillary healthcare services.

**Chapter 2. The Pediatric Rheumatology Workforce: Current Supply** describes the current status of the pediatric rheumatology workforce in the United States, including the number and distribution of pediatric rheumatologists, training requirements, and perceptions of supply.

- Fewer than 200 certified pediatric rheumatologists currently practice in the United States, making it one of the smallest pediatric subspecialties.
- Thirteen States, including heavily populated States such as Arizona, South Carolina, and Alabama, lack a pediatric rheumatology provider within their borders.
- On average, children in the United States travel 57 miles to reach the nearest pediatric rheumatologist. In contrast, children need to travel less than 25 miles to reach pediatric specialists in cardiology, endocrinology, and many other fields.
- Pediatric rheumatologists unanimously perceive that there is a national shortage of pediatric rheumatology providers; two-thirds also perceive a local shortage in their practice area.
- Pediatric rheumatologists attribute the current shortage to low salaries, inadequate reimbursement, and poor working conditions. At the assistant professor level, pediatric rheumatologists' annual salaries average \$115,022. In contrast, average salaries for pediatric cardiology, neonatal medicine, and pediatric critical care medicine at this academic rank are more than \$144,000.
- The limited supply of pediatric rheumatologists often results in long wait times for appointments, delayed diagnosis or treatment, and possibly leads to misdiagnosis and inappropriate treatment.
- One third of institutions housing pediatric residency programs would like to hire a pediatric rheumatologist but are unable to do so for financial or other reasons.
- The majority of pediatric rheumatologists work in a small number of academic medical centers where they are also responsible for performing basic and/or clinical research and educating medical students, residents, and fellows. Thus, other professional activities limit the time they have available to provide patient care.
- As many as one-third of pediatric rheumatology patients are insured through Medicaid, which reimburses physicians at levels below those of private insurers and Medicare. Low reimbursement rates limit clinical revenue for pediatric rheumatology practices and threaten their financial viability.

**Chapter 3. Estimating Pediatric Rheumatology Workforce Requirements** uses prevalence estimates, pediatric population data, and pediatric rheumatologist supply to estimate the demand for pediatric rheumatologists in the United States and presents data on available positions.

- In some States, demand models estimate that there are over 3,000 children with rheumatic diseases per pediatric rheumatologist, a number that far exceeds the average practice capacity of 443 children.
- Using State level population data, models developed for this report estimate that at least 337 pediatric rheumatologists are needed to meet patient care needs. Given the current number of pediatric rheumatologists, there needs to be a 75 percent increase in the number of pediatric rheumatologists.

- The majority of recently trained pediatric rheumatologists practice in a county that has another pediatric rheumatologist in practice. If maldistribution of supply continues, increases in supply may not ameliorate regional, statewide, or local shortages unless there are incentives to locate in areas that currently lack providers.
- While there were 23 advertised pediatric rheumatology positions in September 2004, only 10 pediatric rheumatology fellows completed training in the 2003-2004 academic year, suggesting that current training levels are not sufficient to fill vacant positions.

**Chapter 4. *Substitutes for Pediatric Rheumatologists? Primary Care Providers and Internist Rheumatologists Involvement in Pediatric Rheumatology Care as Evidence of a Shortage*** discusses the involvement of primary care providers and internist rheumatologists in caring for children with rheumatic diseases.

- Substitutes for pediatric rheumatologists are limited.
- Internist rheumatologists play a prominent role in the care of children with rheumatic diseases due, in part, to the limited availability of pediatric rheumatology care. Many internist rheumatologists limit their involvement to the care of adolescents and feel less comfortable than do their pediatric rheumatologist peers managing the care of children.
- By virtue of their training in the care of adults, internist rheumatologists may have limited experience with the rheumatic diseases common to childhood and lack an understanding of the unique clinical and psychological needs of pediatric patients.
- Primary care providers, like family practitioners and general pediatricians, play a limited role in the care of children with rheumatic diseases. Only one percent of primary care providers diagnose and treat juvenile rheumatoid arthritis independently and these providers generally feel uncomfortable caring for these children and refer them to pediatric or internist rheumatologists.
- There have not been investigations of differences in the quality of pediatric rheumatology care across physician types (i.e., pediatric rheumatologists, internist rheumatologists, or primary care providers).

**Chapter 5: *Important Issues Facing the Pediatric Rheumatology Workforce*** details the non-clinical roles of pediatric rheumatology providers and highlights their relevance to the shortage.

- One-third of medical schools and 40 percent of pediatric residency programs have no pediatric rheumatologist available to provide patient care or educate physicians in training.
- Many medical students and general pediatrics residents receive little training in the diagnosis and management of children with rheumatic disease, which may lead to unwillingness to care for these children and perpetuate low levels of interest in this field.
- While specific effects of the current shortage of pediatric rheumatologists on research activities are unknown, the pressures of meeting patient demand in the face of a provider shortage leaves limited time for research activities and may impede the advancement of medical science in this field and delay the development of treatments.

**Chapter 6. Potential Solutions** discusses the relative merits of various solutions to the access problems facing pediatric rheumatology. There are several approaches to increasing access to pediatric rheumatology care.

- The number of pediatric rheumatology fellows has increased in recent years; however, existing programs fail to fill all their available fellowship positions. Financing fellowship positions continues to be a challenge. Enhanced availability and financing of fellowship training will increase the number of trainees in the field.
- Efforts to increase the number of trainees should include incentives to practice in relatively underserved areas after completion of training.
- Increases in the number of trainees as well as increases in the number of pediatric rheumatologists locating in underserved areas will require reallocation of resources. Some potential areas for financial support include using existing programs, such as loan repayment programs, to target pediatric rheumatology.
- Improve the financial viability of pediatric rheumatology practice in academic settings.
- Enhance the ability of internist rheumatologists and primary care providers to provide care to children with rheumatic diseases through education and training.
  - Advocate for changes in the requirements for internist rheumatology fellowship training to include the care of adolescents (i.e., similar to requirements for endocrinology, diabetes, and metabolism fellowship).
  - Develop practice guidelines for juvenile rheumatoid arthritis to encourage internist rheumatologists to provide more care to children with juvenile rheumatoid arthritis.
  - Facilitate general pediatricians' exposure to pediatric rheumatology during residency through programs to encourage pediatric rheumatologist placement at centers that lack these providers and/or through telecommunications, like telemedicine and on-line training programs.
  - Augment programs like Pediatric Rheumatology Visiting Professorship Programs to increase exposure to pediatric rheumatology in medical schools and pediatric residencies.
  - Survey pediatric rheumatologists to determine their access to telecommunications and their willingness to provide training using these media. Survey training programs about their interest in using these media as part of physician training.
  - Pilot telecommunications-based educational programs that link pediatric rheumatology centers and residency programs without pediatric rheumatologists and evaluate their effectiveness at improving knowledge, skills, and comfort levels.
  - Pilot telecommunications-based patient care networks that link pediatric rheumatologists with distant providers and evaluate patient and providers outcomes.
- Use nurses, advanced-practice nurses, and physician assistants to extend pediatric rheumatologists. Delegation of certain tasks, such as referral coordination or telephone triage, to these providers allows pediatric rheumatologists more time to concentrate on patient care and other professional activities.

**Chapter 7. Conclusions** are that a pediatric rheumatology shortage exists and a 75 percent increase is needed.

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## Chapter 1. Pediatric Rheumatology, Pediatric Rheumatic Diseases and Pediatric Subspecialties

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*...although the diseases that kill attract much of the public's attention, musculoskeletal or rheumatic diseases are the major cause of morbidity throughout the world, having a substantial influence on health and quality of life, and inflicting an enormous burden on health systems...rheumatic diseases include more than 150 different conditions and syndromes with the common denominator of pain and inflammation. -- World Health Organization 2003*

Rheumatology is the study of diseases that are characterized by inflammation of joints, muscles, and/or tendons. While several rheumatic diseases affect children, the most prevalent types are juvenile rheumatoid arthritis (JRA) and systemic lupus erythematosus (SLE). These diseases, along with several less common ones, affect approximately 285,000 children in the United States. Each disease varies in symptoms, severity, and trajectory, requiring close medical supervision across several disciplines (detailed descriptions of these diseases are provided in Appendix A). The care of a child with a rheumatic disease ideally involves a pediatric rheumatologist in both the diagnostic and treatment phases; only these providers have been trained as specialists in the medical care of pediatric rheumatic diseases.

Given the complexity of treating childhood rheumatic diseases, a significant burden is placed on those professionals and families caring for children affected by these diseases. Rheumatic diseases as well as the drugs used to treat them can lead to a variety of problems across multiple systems of the body. The charge of the pediatric rheumatologist is to prevent or minimize the consequences of the illness and manage the treatments so as to maximize function while minimizing side effects. Children are often cared for by a team of physicians and other health care professionals in a collaborative model that might include a pediatric rheumatologist, an internist rheumatologist, a general pediatrician, occupational and physical therapists, a dietician, an ophthalmologist, a psychologist, and/or a social worker. The pediatric rheumatologist must coordinate the various medical services received by these children, educate the children and their families about the illness, and encourage treatment adherence. Long distances to care providers increases family burden and decreases access to a continuum of important ancillary health services.

Patient care activities must take into consideration the family system as well as the developmental stage of the child. As such, pediatric rheumatologists, who have trained as pediatricians as well as pediatric rheumatologists, are particularly well-suited to provide this care. The outcomes of these diseases have improved with the new multidisciplinary approaches to treatment, including the availability of new medications, which emphasize the benefit of facilitating access to experts in pediatric rheumatic diseases.

### **Pediatric Subspecialist Supply and Access to Care**

Pediatric rheumatologists belong to a larger class of physicians referred to as pediatric subspecialists. Pediatric subspecialists care for children with complex, chronic medical conditions in addition to those with acute problems normally beyond the scope of primary care practice. Pediatric subspecialists offer not only the benefit of advanced training in the diseases in which they specialize but also the breadth of experience, knowledge, and comfort that comes

from treating large numbers of children with relatively rare, highly variable disorders. With the exception of asthma and attention deficit/hyperactivity disorder (ADHD), primary care providers may have very limited experience with individual chronic pediatric conditions, such as JRA. Adult subspecialists have limited experience in the care of children as well as diseases unique to children. In the case of pediatric rheumatology, pediatric rheumatologists must care for a wide range of rare diseases with serious and, sometimes, life-threatening complications. Few primary care providers or internist rheumatologists have extensive training in the care of children with rheumatic diseases, limiting their ability to substitute for pediatric rheumatology care. More detailed information on the unique features of the pediatric subspecialty workforce is described in Appendix B.

A recent study of primary and subspecialty care use among chronically ill Medicaid children found that use of pediatric subspecialty care was uncommon for all study conditions.<sup>1</sup> Only 18 percent of children with juvenile arthritis saw a pediatric subspecialist. In this study, use of pediatric subspecialty care was significantly greater among Medicaid children living in urban areas than among their rural peers.<sup>1</sup> Disease-specific studies have found a relationship between rural residence and a lower probability of seeing a specialist for asthma,<sup>2</sup> internist-subspecialists involvement in the care of pediatric cancer and rheumatic diseases,<sup>3-6</sup> and delays in referral for congenital heart disease.<sup>7</sup> An analysis of the National Survey of Children with Special Health Care Needs likewise found that low levels of pediatric subspecialist supply were associated with an increased likelihood of having an unmet need for specialty care.<sup>8</sup> Thus, the location and availability of pediatric subspecialists have important implications for the use of their services. This is particularly worrisome for pediatric rheumatology, which is characterized by a small, geographically concentrated workforce.

### **Unique Challenges of Assessing the Pediatric Rheumatology Workforce**

A unique feature of the many pediatric subspecialties, especially pediatric rheumatology, is that the majority of these physicians practice in academic medical centers. In most cases pediatric subspecialists still function as the proverbial “three-legged stool,” providing patient care, educating young physicians, and performing research to understand and treat pediatric conditions. An inadequate supply of these providers limits their availability for patient care; however, it also negatively affects medical education. A pediatric subspecialty shortage may limit medical student and resident exposure to diseases treated by these providers and perpetuate discomfort and an unwillingness to care for children with complex medical conditions among general pediatricians. This lack of exposure may also perpetuate low levels of interest in a select number of fields.<sup>9</sup> A shortage of pediatric subspecialty providers also increases demand for patient care services experienced by each individual provider, leaving them less time for research activity and diminishing their ability to make advances in the understanding, diagnosis, treatment, and management of diseases that shorten or negatively affect the lives of children.

It is neither possible nor practical to assess the supply of pediatric subspecialists only in terms of their availability to provide patient care: one must consider the affects of their other professional roles, not only on the supply of these providers, but also the demand for them.<sup>10</sup> Academic medical centers are the primary employers of these physicians. Their perceived need for providers as well as their ability to generate sufficient revenue to employ these providers have important implications for the availability of pediatric subspecialty care. Moreover, the expectations of the academic medical center with regard to the professional activities of individual physicians (i.e., the distribution of time in patient care, research, and educational activities) will heavily influence the availability of patient care. In this report, we

consider the diverse professional roles of pediatric rheumatologists and discuss the implications of the roles for the adequacy of supply.

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## Chapter 2. The Pediatric Rheumatology Workforce: Current Supply

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### Current Supply of Pediatric Rheumatologists: Numbers

In the United States, pediatric rheumatology is among the smallest of the clinical pediatric medical subspecialties (Table 1). The American Board of Pediatrics (ABP) first offered a certifying exam in pediatric rheumatology in 1992; as of December 2002, the Board has certified 192 pediatric rheumatologists.

**Table 1: Number of Board Certified Physicians by Pediatric Subspecialty**

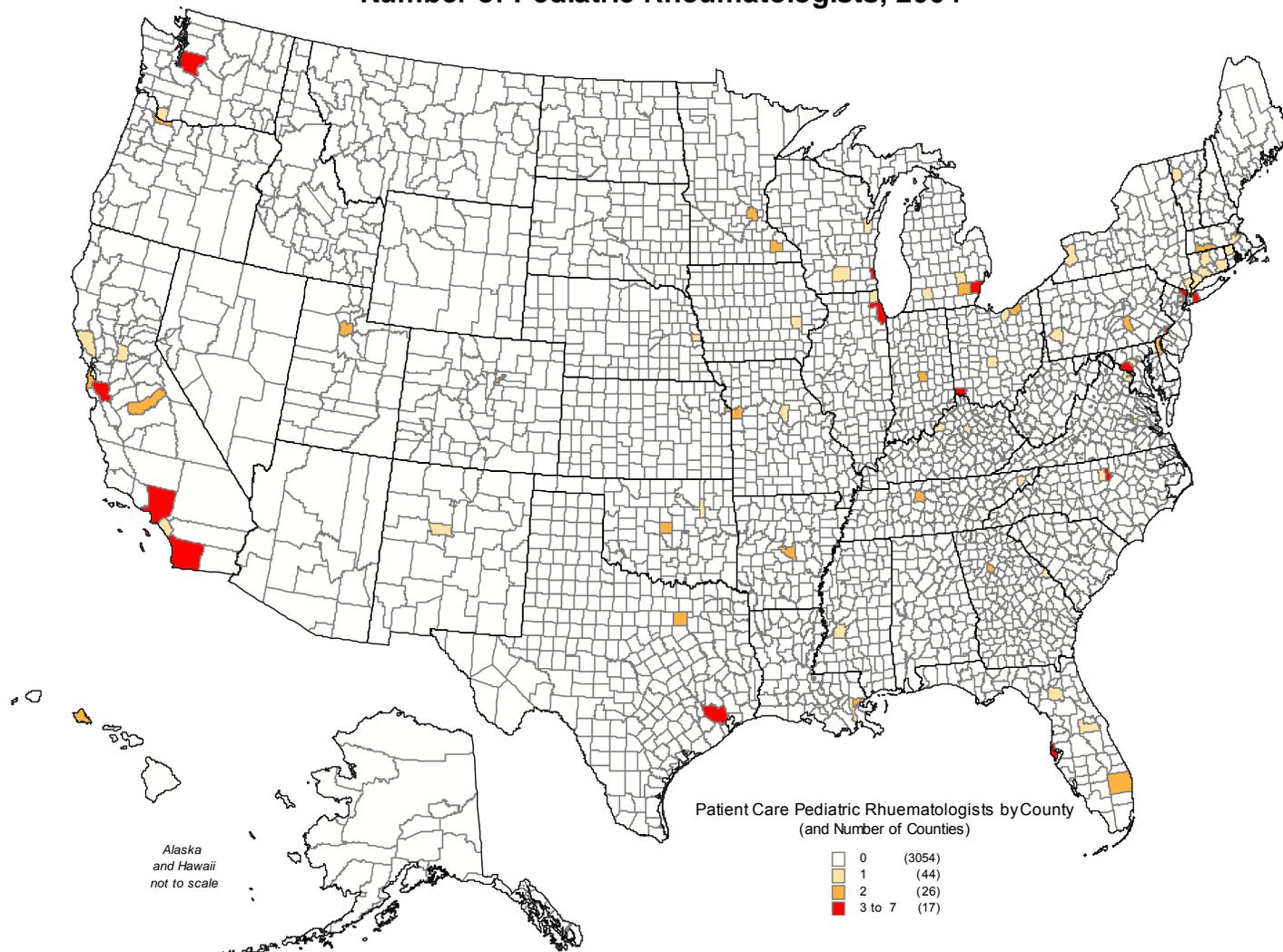
Pediatric Subspecialty	Year of First Certification Exam <sup>1</sup>	Number of Certified Physicians <sup>2</sup>
Neurodevelopment 2001		138
<b>Rheumatology</b>	<b>1992</b>	<b>192</b>
Sports Medicine	1993	86
Development/Behavioral Pediatrics	2002	299
Adolescent Medicine	1994	435
Nephrology 1974		582
Pulmonology 1986		702
Gastroenterology 1990		781
Infectious Diseases	1994	906
Endocrinology 1978		966
Critical Care	1987	1,129
Emergency Medicine	1992	1,165
Cardiology 1961		1,637
Hematology/Oncology 1974		1,675
Neonatal Perinatal Medicine	1975	3,820

<sup>1</sup> Source: American Board of Pediatrics available at <http://www.abp.org/STATS/WRKFRC/Menu1.htm>

<sup>2</sup> Source: 2003 American Board of Pediatrics Diplomate File

Not all pediatric rheumatologists certify, however. Data from the 2004 American College of Rheumatology (ACR) Membership Directory reveal that 185 non-trainee physicians in the U.S. identified themselves as pediatric rheumatologists (i.e., Board-certified and non Board-certified) or reported being Board-certified in pediatric rheumatology. In addition, there were 25

## Number of Pediatric Rheumatologists, 2004



Sources: American College of Rheumatology Membership File, 2004; Census Bureau, 2003.

Produced By: North Carolina Rural Health Research and Policy Analysis Center,  
Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.

pediatric rheumatology trainee members of the ACR. ACR and ABP data sources are described in Appendix C.

## Distribution of Pediatric Rheumatologists

While access to pediatric rheumatology care may be constrained for a variety of reasons, the most conspicuous reason for decreased access is the small number of these providers and their uneven distribution.<sup>4, 11</sup> Past studies have shown that the overwhelming majority of pediatric rheumatologists practice in academic rheumatology settings,<sup>6, 12</sup> and nearly all pediatric rheumatologists practice in metropolitan areas.<sup>11</sup> Based on 2004 ACR data, approximately 3 percent of counties in the United States currently have one or more pediatric rheumatologists involved in patient care (Figure 1) and 13 States have none at all: Alabama, Alaska, Arizona, Idaho, Maine, Montana, Nevada, New Hampshire, North Dakota, South Carolina, South Dakota, West Virginia, and Wyoming.<sup>6</sup>

**Table 2: Percent of Pediatric Population Living Within Selected Distances of Board Certified Pediatric Subspecialists, American Board of Pediatrics**

<b>Board Certified Specialty</b>	<b>Percent of Population more than 50 miles from a provider</b>	<b>Percent of Population more than 100 miles from a provider</b>
Adolescent Medicine	27%	10%
Critical Care Medicine	16%	4%
Development Behavioral Pediatrics	29%	12%
Neonatal and Perinatal Medicine	7%	2%
Neurodevelopmental Disabilities	42%	21%
Pediatric Allergy	16%	6%
Pediatric Cardiology	13%	3%
Pediatric Emergency Medicine	23%	8%
Pediatric Endocrinology	18%	4%
Pediatric Gastroenterology	19%	6%
Pediatric Hematology/Oncology	14%	4%
Pediatric Infectious Disease	19%	5%
Pediatric Nephrology	23%	9%
Pediatric Pulmonology	19%	6%
<b>Pediatric Rheumatology</b>	<b>35%</b>	<b>18%</b>
Pediatric Sports Medicine	47%	25%

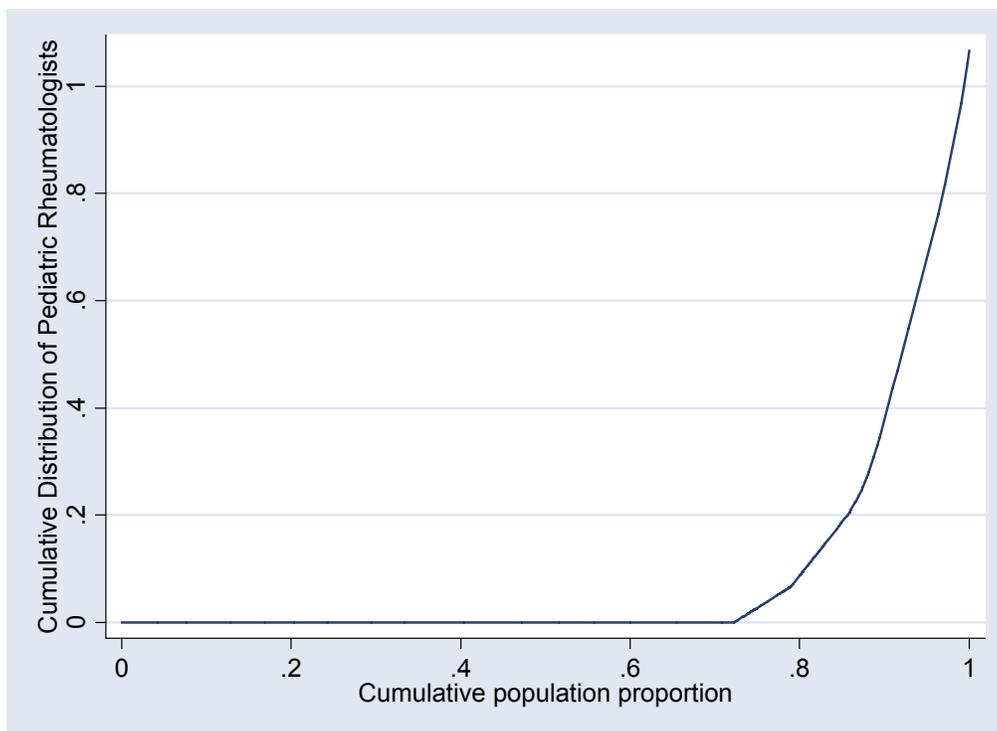
The current distribution of pediatric rheumatologists creates a situation in which a substantial portion of the under-18 population in the United States lives more than 50 miles from a provider (Table 2). Thirty-five percent of the pediatric population in the United States lives more than 50 miles from the nearest pediatric rheumatologist;<sup>11</sup> approximately 18 percent live 100 or more miles from such a provider. In contrast, less than 10 percent of the pediatric population lives 100 or more miles from a provider for 11 of 16 pediatric subspecialties studied. The average population-weighted distance between a county in the United States and a pediatric rheumatology provider is 57.9 miles, making it one of the least geographically accessible of the pediatric subspecialties (Table 3).

**Table 3: Average Population-Weighted Distance to the Nearest Provider by Pediatric Specialty**

	<b>Average Miles to a Provider</b>
Neonatal Perinatal Medicine	12.58
Pediatric Cardiology	19.04
Pediatric Hematology/Oncology	23.56
Critical Care Medicine	23.66
Pediatric Endocrinology	24.16
Pediatric Pulmonology	28.06
Pediatric Infectious Diseases	28.54
Pediatric Allergy	28.76
Pediatric Gastroenterology	29.88
Pediatric Emergency Medicine	33.19
Pediatric Nephrology	34.30
Adolescent Medicine	39.74
Development Behavioral Pediatrics	42.48
<b>Pediatric Rheumatology</b>	<b>57.89</b>
Neurodevelopmental Pediatrics	71.49
Pediatric Sports Medicine	76.66

In Figure 2, a Lorenz curve is used to depict the equality of the distribution of pediatric rheumatologists versus the distribution of the under-18 population in the United States. Over 70 percent of the pediatric population lives within a county that lacks a pediatric rheumatologist; approximately 60 percent of rheumatologists are located in counties where only 10 percent of the pediatric population lives. Based on the area between the 45-degree line and the Lorenz curve, the Gini coefficient is used to quantify inequality and ranges from 0 (in cases of perfectly even distribution) to 1 (in cases of perfect inequality). For pediatric rheumatologists in the United States, the Gini coefficient equals .84, suggesting a very inequitable distribution.

**Figure 2: Cumulative Distribution of Pediatric Rheumatologists in United States Counties Weighted by the Population Under-18 Years of Age**



## Population

It is important to consider the ratio of pediatric rheumatologists to the under-18 population at a market level. Because of the low incidence rates of pediatric rheumatic diseases and the geographic concentration of providers, the relevant market for a pediatric subspecialist is likely quite large. Using the Metropolitan Statistical Areas (MSAs) as a proxy for a market, the relative supply of pediatric rheumatologists was compared to the relative supply of other pediatric subspecialists. These ratios use “head counts” of providers rather than counts that adjust for percent time involved in patient care because individual level data on percent time in patient care do not exist for all providers. Furthermore, the percent of time an individual spends in other professional activities likely varies with supply. That is, providers at institutions with more pediatric rheumatologists may spend more time in research than those in institutions with a single pediatric rheumatologist. Thus, a single adjustment (i.e., considering every rheumatologist to be involved in patient care at 0.6 FTE) is inappropriate and will not change the relative differences across MSAs.

Only 23 percent of MSAs in the United States have a pediatric rheumatologist available (Table 4). For all rural (i.e., non-metropolitan) areas, the number of pediatric rheumatologists per 100,000 children under 18 years of age is 0.01. For all MSAs there is one pediatric rheumatologist per 100,000 children on average. In the 40 most-populated MSAs, there is one

pediatric rheumatologist per 233,000 children on average. The ratio varies widely in these most populated MSAs from 0.09 per 100,000 children under 18 in Riverside-San Bernardino, California to 1.62 per 100,000 children under 18 in Cincinnati, Ohio.

**Table 4: Ratio of Board Certified Physicians to Under-18 Population (in 100,000) by Pediatric Subspecialty**

	Percent of MSA with a Provider	Average Ratio of Subspecialist To Under 18 Population (in 100,000)			Range (40 Most Populated MSA)	
		Rural	All	40 Most	Min	Max
			MSA	Populated MSA		
Pediatric Sports Medicine	15.7%	0.02	0.88	0.23	0.04	0.63
Neurodevelopment	21.0%	0.04	0.91	0.48	0.08	1.70
<b>Pediatric Rheumatology</b>	<b>22.8%</b>	<b>0.01</b>	<b>0.96</b>	<b>0.43</b>	<b>0.09</b>	<b>1.62</b>
Dev't Behavioral Pediatrics	31.8%	0.04	1.25	0.61	0.08	2.69
Adolescent Medicine	33.0%	0.07	1.13	0.92	0.09	3.14
Pediatric Nephrology	34.9%	0.11	1.81	0.96	0.16	1.86
Pediatric Emergency Medicine	39.8%	0.11	2.32	2.28	0.37	6.26
Pediatric Pulmonology	42.9%	0.04	1.92	1.17	0.09	2.88
Pediatric Infectious Diseases	43.2%	0.18	1.98	1.57	0.18	3.14
Pediatric GI	45.4%	0.07	1.81	1.43	0.43	4.17
Pediatric Endocrinology	47.2%	0.10	2.08	1.80	0.39	5.64
Pediatric Critical Care	47.5%	0.14	2.66	1.95	0.46	3.79
Pediatric Allergy	50.6%	0.22	1.60	0.83	0.09	2.28
Pediatric Hematology Oncology	52.5%	0.25	3.24	2.90	0.83	6.27
Pediatric Cardiology	59.6%	0.20	3.32	2.72	1.20	7.84
Neonatal Perinatal Medicine	75.9%	0.73	6.56	6.14	2.50	14.42

Source: 2003 ABP Diplomate File  
MSA: Metropolitan Statistical Area

Across all pediatric subspecialties, pediatric rheumatology has the lowest ratio in non-MSAs, the third lowest ratio for all MSAs, and the second lowest ratio in the 40 most populous MSAs. Some of the differences in supply across specialists reflect, in part, differences in the incidence of diseases treated by these various providers. The relevant market area may differ across large and small pediatric specialties, too.

### **Pediatric Rheumatologists' Perceptions of the Pediatric Rheumatologist Supply**

The Arthritis Foundation (AF), in conjunction with the American College of Rheumatology (ACR), created and fielded a survey of pediatric rheumatologists and internist rheumatologists in the United States in March 2004, hereafter referred to as the AF/ACR Survey. Detailed information on this survey, including descriptive statistics, is provided in Appendix E. In this survey, pediatric rheumatologists were asked to assess the current supply of pediatric rheumatology care locally and nationally. Nearly two-thirds of responding pediatric rheumatologists reported a local shortage of pediatric rheumatology care and all respondents reported a national shortage of pediatric rheumatology providers (Table 5). Responding

pediatric rheumatologists were also asked to specify the average wait time for an appointment in their practice: less than 1 week, 1 to 2 weeks, or 2 or more weeks. Sixty-five percent of responding pediatric rheumatologists reported that the wait time for an initial patient appointment exceeded 2 weeks in their practice.

Respondents were asked to select from among a list of potential causes of the shortage; the majority of providers indicated that poor reimbursement contributed to the current shortage. This finding is not surprising given that Medicaid patients comprise one-third of pediatric rheumatologists' patients and a recent study showed that the Medicaid-to-Medicare fee ratio was 0.69 (i.e., Medicaid pays 69 cents for every dollar paid by Medicare) in 2003.<sup>13</sup> Other common factors cited as contributing to the shortage included poor working conditions and salary concerns. Among those providers who wrote a specific concern in the open-ended section (n=30), many stated that lack of exposure to pediatric rheumatology during training and lack of mentors contributed to the current shortage.

There was near universal agreement among responding pediatric rheumatologists that the current shortage had important consequences for patients, including increased wait times, delays in diagnosis and treatment, misdiagnosis, and inappropriate treatment. Among those who responded in the open-ended section (n=11), most reported that the involvement of other physician providers (i.e., general pediatrician and internist rheumatologists) in the care of children and poor outcomes were adverse consequences of the current supply and distribution of pediatric rheumatologists.

**Table 5: Pediatric Rheumatologists' Perceptions of Workforce Shortage, AF/ACR Survey (n=104)**

	<b>Percent</b>
<i>Perceive that a local shortage exists</i>	64.4
<i>Perceive that a national shortage exists</i>	100.0
<i>Factors limiting supply include</i>	
Lack of training programs	42.3
Reimbursement	78.8
Working conditions	74.0
Salary	68.3
Debt from medical education	40.4
Lack of funding for training	51.0
<i>Other</i>	
Lack of exposure, models, mentors	11.5
Lack of institutional/departmental support	6.7
Financial concerns	6.7
Other	3.8
<i>Consequences of shortage:</i>	
Lengthened patient wait time for appointments	89.4
Delay in diagnosis	89.4
Delay in treatment	94.2
Misdiagnosis	87.5
Inappropriate treatment	89.4
Other	10.6

The results of the AF/ACR survey also provided useful insight into how retirement and other activities influence pediatric rheumatologists' involvement in patient care. Just over one-fourth of pediatric rheumatologists have decreased their time in clinical care in the 5 years preceding retirement, with an average reduction of 32.2 percent in their patient care hours (Table 6). The primary reason reported is having obtained salary support from a research source (39.3 percent). Many providers also reported decreasing their patient care time because another pediatric rheumatologist joined their practice (32.1 percent); they changed employers or career (17.9 percent), or other reasons (25.0 percent). Of note, seven pediatric rheumatologists reported decreasing time due to retirement or semi-retirement and one responding pediatric rheumatologist was excluded from analyses because s/he had completely retired.

**Table 6: Changes in Patient Care Time, Pediatric Rheumatologists  
AF/ACR Survey**

	Percent
<i>Decreased time spent in clinical care in the last 5 years (n=104):</i>	
No	72.7
Yes	26.3
Not sure	1.0
<i>Reason (among those who decreased, n=28):</i>	
Another pediatric rheumatologist joined practice	32.1
Not enough patient volume	7.1
Changed career/employer	17.9
Obtained salary support from research source	39.3
Obtained salary support from another clinical source	10.7
Obtained salary support from business source	10.7
Other reason	25.0
<i>Plans to decrease time in clinical care in the next 5 years (n=103):</i>	
No	55.8
Yes	31.7
Not sure	12.5
<i>Reason (among those who plan to decrease, n=33):</i>	
Retirement	21.2
Change career or employer	15.2
Obtained salary support from research source	45.5
Obtained salary support from another clinical source	15.2
Obtained salary support from business source	18.2
Other reason	27.3

About one-third of physicians plan to decrease their time in clinical care in the next 5 years with an average planned decrease in clinical hours of 33.1 percent. The primary reason for planning a decrease in time is obtaining salary support from a research source (45.5 percent); however, many also report retirement (21.2 percent), salary support from a business source (18.2 percent), and other reasons (27.3 percent). About 15 percent (n=6) of responding pediatric rheumatologists indicated that they expected their clinical rheumatology involvement to decrease due to funding from another non-pediatric rheumatologist clinical source. Those shifting to another clinical area reported expected percent reductions in rheumatology patient

care time ranging from 5 percent to 50 percent; thus, they would still be involved in pediatric rheumatology care part-time.

## **Pediatric Residency Directors' Perception of the Adequacy of Pediatric Rheumatologist Supply**

Pediatric residency directors oversee the residency training of all pediatric residents in the United States; as such, they have a unique perspective on the current and future supply of general pediatricians and pediatric subspecialists. In a 2004 survey of pediatric residency directors, described in detail in Appendix E, pediatric residency directors were asked to describe the adequacy of pediatric supply in their catchment area. The majority of those responding to this question felt that either the supply was inadequate (41.7 percent) or the supply was adequate to allow patient care but inadequate to allow time for research and teaching responsibilities (26.0 percent). Significantly more directors in institutions that lacked a pediatric rheumatologist felt supply was inadequate (65.0 percent vs. 23.6 percent,  $p=0.001$ ). The majority of directors similarly felt that the statewide supply of these providers was inadequate (48.8 percent) or adequate for patient care only (14.5 percent). Programs without pediatric rheumatologists were significantly more likely to describe the statewide supply as inadequate (61.8 percent vs. 38.9 percent,  $p<0.01$ ); however, only 12.5 percent of programs with a staff pediatric rheumatologist described the statewide supply as adequate for patient care as well as other responsibilities.

Many residency directors expressed concerns about the shortage of pediatric rheumatologists in their facilities. Some relevant quotes from the open-ended "comments" section of the survey are provided here.

- *"Pediatric rheumatologists are in short supply. We often have to rely on adult rheumatologists to consult on our inpatients, and always have to send away [patients] for outpatient referrals."*
- *"Pediatric rheumatologists are like gold."*
- *"We desperately need a ped[iatric] rheumatologist and have now for the 2nd yr [year] in a row secured a visiting prof[essor] in same through the Amer[ican] Coll[ege] of Rheumatology ... a finger in the dike both for our pts [patients] care and our housestaff education."*
- *"There appears to be a tremendous need for trained pediatric rheumatologists."*
- *"There is clearly a shortage of Pediatric Rheumatologists."*
- *"We need a ped[iatric] rheum[atologist] in the DC metro area."*

Clearly, pediatric residency directors share pediatric rheumatologists' sentiments that the current supply of pediatric rheumatologists is inadequate for patient care and medical education.

Both from the perspectives of current pediatric rheumatologists as well as pediatric residency directors who oversee the training of pediatricians, the current supply of pediatric rheumatologists in the United States is inadequate. Several factors may contribute to inadequate supply, including training capacity, salary concerns, and competing professional demands. These are discussed, in turn, in the rest of this chapter.

## **Pediatric Rheumatologist Training**

To become a pediatric rheumatologist, one must pursue 10 years of training after completion of their undergraduate degree: 4 years of medical school, a 3-year pediatric residency at an accredited institution and a 3-year pediatric rheumatology fellowship at an accredited program. After successful completion of this training, a physician is eligible to take the Pediatric Rheumatology Board certification exam.

### *Pediatric Training Program Requirements*

As of July 2002, a pediatric rheumatology program must meet multiple requirements to gain accreditation. According to the Accreditation Council for Graduate Medical Education (ACGME)<sup>14</sup>, they include:

- The program must provide 3 years of continuous training;
- There must be at least two Board-certified pediatric rheumatologists on faculty;
- Physicians in related disciplines, particularly pediatric orthopedics, must be available at the institution for consultation and collaboration;
- Registered physical and occupational therapists must be available;
- The patient population must be sufficiently large and varied to provide residents exposure to both common and uncommon rheumatic diseases; and
- Full support services must be present at the facility, including nuclear medicine, pediatric rehabilitation services, and clinical immunology and electromyography laboratory services.

These requirements are designed to ensure that physicians completing this training are proficient in the diagnosis and treatment of children and adolescents with rheumatic diseases. While some rheumatic diseases exist in both pediatric and adult populations others are unique to children. A pediatric rheumatology fellowship provides trainees with the knowledge and skills needed to treat these diseases in the physical, emotional, and developmental contexts of childhood and adolescence. Exposure to related physician disciplines and allied health professions provides trainees with opportunities to learn the roles of these providers. Fellowship training also prepares physicians to function as educators and researchers.

### *Pediatric Rheumatology Training Programs*

According to the American College of Rheumatology (ACR), there are currently 23 pediatric ACGME-accredited rheumatology fellowship programs in 14 States.<sup>16</sup> According to the American Board of Pediatrics, 19 physicians entered their first year of pediatric rheumatology fellowship training in 2003 and 10 entered their third year of fellowship training. Over the past 6 years the total number of pediatric rheumatology trainees in the United States has increased from 24 trainees in 1998 to 47 in 2003 (Table 7). This increasing trend in the number of trainees has been noted for all pediatric subspecialties in recent years.<sup>17</sup>

**Table 7: Pediatric Rheumatology Fellowship Trainees by Medical School and Gender, American Board of Pediatrics**

Year	Total Number of Trainees	Percent USMG	Percent IMG	Percent Male	Percent Female
1998	24	58.3	41.7	45.8	54.2
1999	33	54.5	45.5	36.4	63.6
2000	31	67.7	32.3	25.8	74.2
2001	38	68.4	31.6	31.6	68.4
2002	44	59.1	40.9	40.9	59.1
2003	47	57.4	42.6	31.9	68.1

Source: American Board of Pediatrics<sup>15</sup>

In January 2004, program directors or their administrative assistants were contacted and asked to provide information about the number of first year and total pediatric rheumatology fellowship positions available at their institution as well as the number of positions currently filled (Table 8). Three-quarters of available pediatric rheumatology fellowship positions were filled in 2003. The reasons for the failure to completely fill available fellowship slots is not clear; however, some programs did report that insufficient funding constrained the number of slots they could fill. Because cognitive pediatric subspecialties often do not generate sufficient revenue to support fellows for their entire 3 years of fellowship, programs often depend on grant funds to support their training programs. Support for the clinical year is variable from institution to institution and may impact the ability to attract and retain fellows. Because the availability of funding in this field has been limited for several years, the ability of programs to offer pediatric rheumatology in the future is often uncertain.<sup>18</sup> Given these factors it is not clear that the goal of substantially increasing the number of pediatric rheumatologists can be achieved without dedicated funding sources.

**Table 8: Total Number of Pediatric Rheumatology Fellowship Slots by Program**

State	Program	First Year Positions	Total Available Positions	Filled Positions (2003)
California	Children's Hospital of Orange County	1	4	4
	Stanford University	1	3	3
	UCSF	1	3	2
Delaware	Thomas Jefferson University/Dupont Hospital for Children	1	2	1
Illinois	McGraw Medical Center of Northwestern University	0	1	1
	University of Chicago	1	1	1
Massachusetts	Children's Hospital/Boston Medical Center	1-2	3	3
	New England Medical Center	1	3	2
Michigan	University of Michigan	1	2	1
Missouri	St. Louis University Medical School	1	1	0
	Washington University School of Medicine	2	6	4
New York	Schneider's Children's Hospital (Albert Einstein)	1	3	3
	New York Presbyterian Hospital/Cornell Medical Center	1	4	4
	Children's Hospital of New York – Presbyterian	1	2	2
North Carolina	Duke University Medical Center	1	2	2
Ohio	Children's Hospital Medical Center/University of Cincinnati	2	6	5
Pennsylvania	Children's Hospital of Philadelphia	2	6	4
	Children's Hospital of Pittsburgh <sup>i</sup>	2	2	0
Tennessee	University of Tennessee	1	1	1
Texas	Baylor College of Medicine	1	3	2
	UT Southwestern Medical School	1	2	2
Washington	University of Washington	1	3	3
Wisconsin	Medical College of Wisconsin <sup>ii</sup>	1	1	1
Total		24	64	48

### *The Role of International Medical Graduates*

The role of international medical graduates (IMGs) in pediatric rheumatology training is unclear; in 2003, over one-quarter of pediatric rheumatology fellows were IMGs. A past report suggested that many pediatric rheumatology fellowship programs relied on IMGs to fill about half the positions.<sup>19</sup> Over the past 6 years, IMGs represented 32-46 percent of all pediatric rheumatology trainees (Table 7). Pediatric rheumatology training programs are, consequently, relatively reliant on IMGs.

### *Professor Salary Concerns*

As previously mentioned, salary concerns were frequently cited as a cause of the current shortage of pediatric rheumatologists. In a recent report from the Medical Group Management Association, the median salary for a pediatric rheumatologist at the assistant professor level was \$115,022, which was comparable to other cognitive pediatric subspecialties (i.e., those

<sup>i</sup> Program starting in July 2004

<sup>ii</sup> Program recently started.

specialties that do not perform procedures); however, it is far below salaries for intensivist and procedural pediatric specialties, such as neonatology (\$155,202), pediatric critical care (\$144,933), pediatric cardiology (\$149,159).<sup>20</sup> Furthermore, the average pediatric rheumatologist's salary is comparable to the salary of a general pediatrician (\$113,343) that has not spent an additional 3 years in training. Thus, the financial return on the educational and time investment to become a pediatric rheumatologist is low. No estimates were available for salaries at higher academic ranks due to the small sample sizes; salaries for more junior positions were also not available.

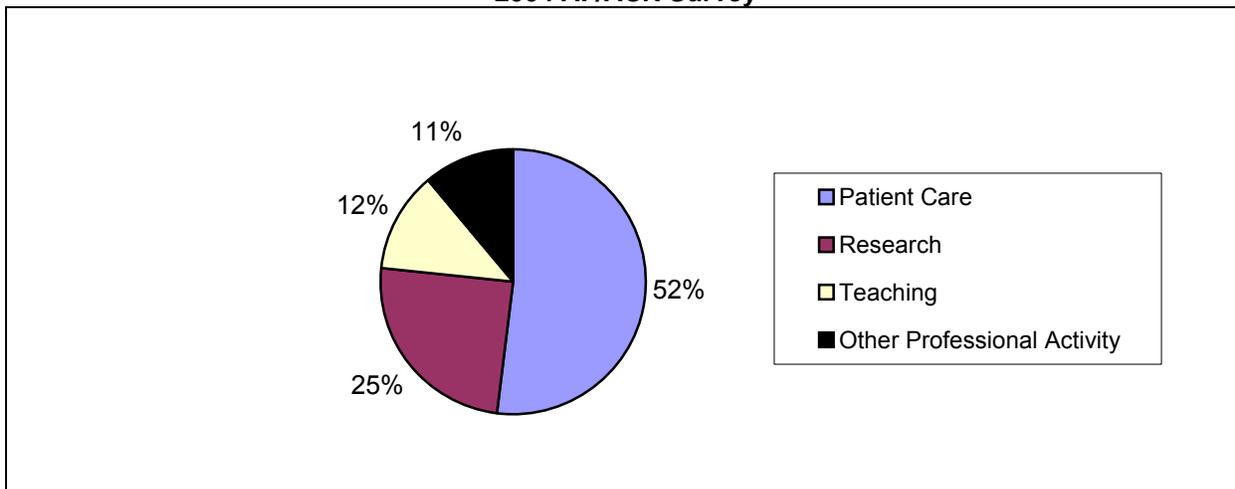
### *The Impact of Competing Professional Demands*

The supply of pediatric rheumatologists is particularly sensitive to the effects of competing professional demands. Pediatric rheumatologists are significantly more involved in research and teaching and spend a smaller percentage of their time in patient care than their internist peers. This is due largely to differences in the practice locations of pediatric and internist rheumatologists: the majority of internist rheumatologists are in private practice, but the majority of pediatric rheumatologists practice at academic medical centers where they are generally expected to see patients, perform research, and educate trainees.

The 2004 ACR Membership File lists up to three professional activities for each provider. While 93 percent of practicing (i.e., excluding trainees) pediatric rheumatologists were involved in patient care, only 67 percent listed patient care as their primary professional activity. Nearly three-fourths of all pediatric rheumatologists listed teaching as one of their professional activities while one-quarter and one-half listed basic and clinical research as an activity, respectively. Past studies have shown that pediatric rheumatologists are significantly less likely than their internist peers to list patient care as a primary professional activity and significantly more likely to be involved in teaching and research.<sup>11</sup> **Thus, the same pool of pediatric rheumatology providers that diagnose and treat children and adolescents with rheumatic diseases is also responsible for medical education and research.**

The 2004 AF/ACR Survey, like previous studies, found that responding pediatric rheumatologists spent a substantial percentage of their time in research and teaching (Figure 3). Likewise, previous studies have found that pediatric rheumatologists spend significantly less time in patient care<sup>21, 22</sup> and see significantly fewer patients per week than internist rheumatologists.<sup>22</sup> Again, these discrepancies reflect differences in the practice locations of these providers as well as differences in the average complexity of adult versus pediatric patients with rheumatic diseases. Consequently, even when a pediatric rheumatologist is geographically accessible, their availability for patient care may be constrained.

**Figure 3: Average Distribution of Professional Effort Among Pediatric Rheumatologists (n=107)  
2004 AF/ACR Survey**



## Summary

Less than 200 pediatric rheumatologists practice in a limited number of areas in the United States. On average, children need to travel 57 miles to reach a pediatric rheumatologist and 20 percent of the pediatric population in the United States lives more than 100 miles from a practicing pediatric rheumatologist. Thirteen States, including heavily populated states such as South Carolina and Arizona, do not have any pediatric rheumatology providers. Pediatric rheumatologists unanimously feel there is a National shortage and that this shortage leads to delays in diagnosis and treatment and suboptimal care. Pediatric residency directors, who oversee the education of pediatric residents and are well-acquainted with the current and future trends in the supply of general and subspecialty pediatricians, echo pediatric rheumatologists concerns about the supply of pediatric rheumatologists. While the number of pediatric rheumatology trainees has increased over the last several years, one-quarter of rheumatology fellowship positions go unfilled. Finally, pediatric rheumatologists practice primarily in academic medical centers where the competing professional demands of research and teaching limit their availability for patient care. Efforts to address the shortage of pediatric rheumatologists must consider the effects of the multiple professional roles that they occupy.

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## *Chapter 3. Estimating Pediatric Rheumatology Workforce Requirements*

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In 2002, the chair of the American Academy of Pediatrics Section on Pediatric Rheumatology called for a doubling of the number of United States pediatric rheumatologists to 400.<sup>23</sup> The appropriateness of this goal has yet to be evaluated and depends, in part, on the geographic distribution of pediatric rheumatologists and patient demand for pediatric rheumatology care. Moreover, academic medical centers continue to be the primary employers of pediatric rheumatologists; as such, the educational and research needs of these institutions heavily influence the demand for these providers.

### **Patient Demand for Pediatric Rheumatology Care by State**

Estimating demand for pediatric rheumatology care is challenging. Because of low incidence rates, national sample surveys of the general population generally fail to identify sufficient patients with juvenile rheumatic diseases to generate reliable estimates. Using an exhaustive list of 48 possible International Classification of Disease (ICD-9) codes, the National Ambulatory Medical Care Survey (NAMCS) contains only 16 records for rheumatic diseases visits among children under 18. National Hospital Ambulatory Care Survey (NHAMCS) similarly contains 57 visit records for rheumatic conditions among children under 18. As a result, reliable estimates of patient demand for care are not possible using such data.

In the absence of a measure of need for pediatric rheumatology services or even utilization of these services, prevalence rates<sup>iii</sup> allow estimates of patient to provider ratios as a proxy for patient demand. Using state-level population data from the Bureau of the Census<sup>24</sup> and physician data from the American College of Rheumatology (ACR) Membership File and American Board of Pediatrics (ABP) Diplomate File, ratios of pediatric population to pediatric rheumatologists were generated for each State. State level ratios were used because many States have either no pediatric rheumatologist or only one pediatric rheumatologist. As such, a state-level analysis helps identify relatively underserved States and provides an estimate of the number of pediatric rheumatologists that are needed nationwide. As in analyses of the MSA-level ratios, these estimates rely on “head counts” and do not adjust for the percentage of time that a pediatric rheumatologist is involved in patient care as these data are not available for each pediatric rheumatologist in the United States.

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<sup>iii</sup> A national prevalence rate of 390 per 100,000 children was used, which corresponds to a national estimate of 285,000 children with rheumatic diseases.

**Table 9: Ratio of Pediatric Population to Board-Certified Pediatric Rheumatologists, 2003 American Board of Pediatrics Diplomate File**

	Number of Board-Certified Pediatric Rheumatologists	Under 18 Population	Number of Children per Rheumatologist	Estimated Number of Children with Rheumatic Diseases per Rheumatologist
Alabama	0	1,066,177	N/A	N/A
Alaska	0	196,825	N/A	N/A
Arizona	0	1,334,564	N/A	N/A
Arkansas	1	660,224	660,224	2,575
California	20	8,923,423	446,171	1,740
Colorado	2	1,065,510	532,755	2,078
Connecticut	4	828,260	207,065	808
Delaware	2	182,450	91,225	356
Florida	10	3,569,878	356,988	1,392
Georgia	3	2,056,885	685,628	2,674
Hawaii	3	289,340	96,447	376
Idaho	0	350,464	N/A	N/A
Illinois	8	3,181,338	397,667	1,551
Indiana	2	1,528,991	764,496	2,982
Iowa	1	719,685	719,685	2,807
Kansas	3	698,637	232,879	908
Kentucky	2	965,528	482,764	1,883
Louisiana	4	1,190,001	297,500	1,160
Maine	0	290,439	N/A	N/A
Maryland	7	1,309,432	187,062	730
Massachusetts	11	1,468,554	133,505	521
Michigan	7	2,561,139	365,877	1,427
Minnesota	5	1,271,850	254,370	992
Mississippi	1	752,866	752,866	2,936
Missouri	7	1,399,492	199,927	780
Montana	0	223,819	N/A	N/A
Nebraska	1	443,800	443,800	1,731
Nevada	0	491,476	N/A	N/A
New Hampshire	0	304,436	N/A	N/A
New Jersey	4	2,003,204	500,801	1,953
New Mexico	1	495,612	495,612	1,933
New York	15	4,440,924	296,062	1,155
North Carolina	4	1,940,947	485,237	1,892
North Dakota	0	160,092	N/A	N/A
Ohio	12	2,844,071	237,006	924
Oklahoma	3	882,062	294,021	1,147
Oregon	2	827,501	413,751	1,614
Pennsylvania	9	2,852,520	316,947	1,236
Rhode Island	1	241,180	241,180	941
South Carolina	0	955,930	N/A	N/A

**Table 9: Ratio of Pediatric Population to Board-Certified Pediatric Rheumatologists, 2003 American Board of Pediatrics Diplomate File, cont.**

	Number of Board-Certified Pediatric Rheumatologists	Under 18 Population	Number of Children per Rheumatologist	Estimated Number of Children with Rheumatic Diseases per Rheumatologist
South Dakota	0	198,037	N/A	N/A
Tennessee	3	1,340,930	446,977	1,743
Texas	6	5,719,234	953,206	3,718
Utah	2	707,366	353,683	1,379
Vermont	1	139,346	139,346	543
Virginia	6	1,664,810	277,468	1,082
Washington	6	1,486,340	247,723	966
Washington, DC	2	95,290	47,645	186
West Virginia	0	403,481	N/A	N/A
Wisconsin	5	1,348,268	269,654	1,052
Wyoming	0	126,807	N/A	N/A

Ratios were calculated separately using the ACR and ABP files; States without pediatric rheumatology providers are highlighted in yellow in Tables 9 and 10. Using the ABP file, Washington D.C.<sup>iv</sup> has the lowest ratio of children to pediatric rheumatologists at 47,645:1; Texas has the highest with a ratio of 953,206:1 (Table 9). Assuming a prevalence of pediatric rheumatic conditions of 390 per 100,000 children, ratios range from 186 children with rheumatic disease per provider in Washington D.C. to 3,718:1 in Texas. Among States that lack Board-certified pediatric rheumatologists, the population size ranges from 126,000 in Wyoming to over 1.3 million in Arizona.

<sup>iv</sup> It is important to note that the ratio in Washington D.C. may be underestimated, however, as some of these providers may work at the National Institutes of Health as researchers rather than patient care providers.

**Table 10: Ratio of Pediatric Population to Self-identified Pediatric Rheumatologists,  
2003 American College of Rheumatology**

	Number of Self-described Pediatric Rheumatologists (ACR)	Under 18 Population	Number of Children per Rheumatologist (ACR)	Estimated Number of Children with Rheumatic Diseases per Rheumatologist (ACR)
Alabama	0	1,066,177	N/A	N/A
Alaska	0	196,825	N/A	N/A
Arizona	0	1,334,564	N/A	N/A
Arkansas	2	660,224	330,112	1,287
California	22	8,923,423	405,610	1,582
Colorado	2	1,065,510	532,755	2,078
Connecticut	4	828,260	207,065	808
Delaware	2	182,450	91,225	356
Florida	7	3,569,878	509,983	1,989
Georgia	3	2,056,885	685,628	2,674
Hawaii	2	289,340	144,670	564
Idaho	0	350,464	N/A	N/A
Illinois	7	3,181,338	454,477	1,772
Indiana	2	1,528,991	764,496	2,982
Iowa	1	719,685	719,685	2,807
Kansas	2	698,637	349,319	1,362
Kentucky	2	965,528	482,764	1,883
Louisiana	3	1,190,001	396,667	1,547
Maine	0	290,439	N/A	N/A
Maryland	6	1,309,432	218,239	851
Massachusetts	7	1,468,554	209,793	818
Michigan	7	2,561,139	365,877	1,427
Minnesota	4	1,271,850	317,963	1,240
Mississippi	1	752,866	752,866	2,936
Missouri	5	1,399,492	279,898	1,092
Montana	0	223,819	N/A	N/A
Nebraska	1	443,800	443,800	1,731
Nevada	0	491,476	N/A	N/A
New Hampshire	0	304,436	N/A	N/A
New Jersey	6	2,003,204	333,867	1,302
New Mexico	1	495,612	495,612	1,933
New York	11	4,440,924	403,720	1,575
North Carolina	4	1,940,947	485,237	1,892
North Dakota	0	160,092	N/A	N/A
Ohio	10	2,844,071	284,407	1,109
Oklahoma	3	882,062	294,021	1,147
Oregon	2	827,501	413,751	1,614
Pennsylvania	8	2,852,520	356,565	1,391
Rhode Island	1	241,180	241,180	941
South Carolina	0	955,930	N/A	N/A

**Table 10: Ratio of Pediatric Population to Self-identified Pediatric Rheumatologists<sup>1</sup>, 2003 American College of Rheumatology (continued)**

	Number of Self-described Pediatric Rheumatologists (ACR)	Under 18 Population	Number of Children per Rheumatologist (ACR)	Estimated Number of Children with Rheumatic Diseases per Rheumatologist (ACR)
South Dakota	0	198,037	N/A	N/A
Tennessee	3	1,340,930	446,977	1,743
Texas	6	5,719,234	953,206	3,718
Utah	2	707,366	353,683	1,379
Vermont	1	139,346	139,346	543
Virginia	6	1,664,810	277,468	1,082
Washington	6	1,486,340	247,723	966
Washington, DC	1	95,290	95,290	372
West Virginia	0	403,481	N/A	N/A
Wisconsin	5	1,348,268	269,654	1,052
Wyoming	0	126,807	N/A	N/A

<sup>1</sup>Excludes trainees and physicians who are not involved in patient care

The ratios change slightly using the ACR data on Board-certified pediatric rheumatologists. The ratio of the pediatric population to pediatric rheumatology providers ranges from a low of 91,225:1 in Delaware to a high of 953,206:1 in Texas (Table 9). In terms of the number of children with rheumatic diseases per provider, these ratios translate into approximately 356 children with rheumatic diseases per pediatric rheumatologist in Delaware to 3,718 children with rheumatic diseases per pediatric rheumatologist in Texas. Three States that lack Board-certified pediatric rheumatologists have pediatric populations in excess of 950,000; the remaining 10 States have pediatric populations of fewer than 500,000.

### Projected Need for Pediatric Rheumatologists

Previous studies of physician market entry have assumed that the population size needed to support a physician entrant increases with the level of specialization.<sup>25</sup> One model estimated, for example, that the population needed to attract the first family practice physician to an area is 3,300; in contrast, a population of 69,000 was needed to attract the first cardiologist to a market area. This study also showed that the population increments needed to attract additional providers were smaller than the population needed to attract the first provider.

**Table 11: Estimated Number of Pediatric Rheumatologists Needed by State**

	Number of Self-described Pediatric Rheumatologists (ACR)	Under 18 Pop'n	Estimated Number Needed	Estimated Number Needed with Current Number as Minimum	Current Deficit
Alabama	0	1,066,177	5	5	-5
Alaska	0	196,825	0	0	0
Arizona	0	1,334,564	6	6	-6
Arkansas	2	660,224	3	3	-1
California	22	8,923,423	44	44	-22
Colorado	2	1,065,510	5	5	-3
Connecticut	4	828,260	4	4	0
Delaware	2	182,450	0	2	0
Florida	7	3,569,878	18	18	-11
Georgia	3	2,056,885	10	10	-7
Hawaii	2	289,340	1	2	-1
Idaho	0	350,464	2	2	-2
Illinois	7	3,181,338	16	16	-9
Indiana	2	1,528,991	7	7	-5
Iowa	1	719,685	3	3	-2
Kansas	2	698,637	3	3	-1
Kentucky	2	965,528	5	5	-3
Louisiana	3	1,190,001	6	6	-3
Maine	0	290,439	1	1	0
Maryland	6	1,309,432	6	6	0
Massachusetts	7	1,468,554	7	7	0
Michigan	7	2,561,139	13	13	-6
Minnesota	4	1,271,850	6	6	-2
Mississippi	1	752,866	4	4	-3
Missouri	5	1,399,492	7	7	-2
Montana	0	223,819	0	0	0
Nebraska	1	443,800	2	2	-1
Nevada	0	491,476	2	2	-2
New Hampshire	0	304,436	1	1	-1
New Jersey	6	2,003,204	10	10	-4
New Mexico	1	495,612	2	2	-1
New York	11	4,440,924	22	22	-11
North Carolina	4	1,940,947	9	9	-5
North Dakota	0	160,092	0	0	0
Ohio	10	2,844,071	14	14	-4
Oklahoma	3	882,062	4	4	-1
Oregon	2	827,501	4	4	-2
Pennsylvania	8	2,852,520	14	14	-6
Rhode Island	1	241,180	0	1	0
South Carolina	0	955,930	5	5	-5
South Dakota	0	198,037	0	0	0
Tennessee	3	1,340,930	6	6	-3
Texas	6	5,719,234	28	28	-22
Utah	2	707,366	3	3	-1
Vermont	1	139,346	0	1	0
Virginia	6	1,664,810	8	8	-2
Washington	6	1,486,340	7	7	-1
Washington, DC	1	95,290	0	1	0
West Virginia	0	403,481	2	2	-2
Wisconsin	5	1,348,268	6	6	-1
Wyoming	0	126,807	0	0	0

<sup>†</sup> Excludes trainees and physicians not currently involved in patient care

One previous report has suggested that a total population base of 1 million is needed to provide sufficient patient demand for a pediatric rheumatologist;<sup>19</sup> therefore, estimates presented here use this population size as a starting point. Given that children represent approximately 25 percent of the United States population, a pediatric population of 250,000 was used as a threshold for identifying States that could support their *first* pediatric rheumatologist. Since a previous study has shown that the population increment needed to attract the second provider is smaller than the population size needed to attract the initial provider,<sup>25</sup> the model assumed that each additional pediatric population increment of 200,000 could support an additional pediatric rheumatologist. The results that presented here used State level data from the ACR; however, the calculations using ABP data are comparable.

Assuming that a pediatric population of 250,000 is needed to support a pediatric rheumatologist, 9 of the 13 States that currently lack a Board certified pediatric rheumatologist could generate enough demand to support a pediatric rheumatologist. As Table 11 shows, the population under age 18 in Alaska, North Dakota, South Dakota, and Wyoming are below the 250,000 threshold and, therefore, may not generate sufficient patient demand to support a pediatric rheumatologist. However, combined regions, such as North and South Dakota may be able to support a pediatric rheumatologist. Assuming that entry continues with an additional rheumatologist for each additional 200,000 children, a minimum of 331 rheumatologists would be needed in the United States. Table 10 shows that several States, especially those with training programs, have more pediatric rheumatologists than are “needed” based on population size. **Many of these providers may be primarily involved in research and teaching, creating a situation in which “head counts” lead to an overestimate of actual supply.** If one allows States with training programs to have more rheumatologists than are clinically needed based on population size and considers the current supply per State as a minimum, the number of rheumatologists needed nationwide is 337.

The 250,000 threshold, however, may be unreasonably high. Given a prevalence rate of 390 per 100,000, this threshold translates into 975 children with rheumatic diseases per rheumatologist. Given the multitude of needs that characterize this patient population, it is unlikely that one rheumatologist could care for nearly 1,000 patients. A previously unpublished survey of pediatric rheumatology programs found that the average number of children seen annually by each pediatric rheumatology unit was 443.<sup>v</sup> Only 12 percent of pediatric rheumatology units, including those with multiple providers, saw more than 1,000 children a year. Therefore, the actual number of patients that a pediatric rheumatologist is able to treat may be far lower than 975. These estimates easily allow the use of different population thresholds or prevalence rates to estimate the pediatric rheumatology workforce requirements.

Estimates of pediatric rheumatology workforce requirements should also consider the roles of internist rheumatologists and primary care providers (PCPs) in caring for this population. The role of PCPs appears to be very limited, especially for diagnosis, initial management, and refractory cases. While PCPs may be able to extend pediatric rheumatologists by managing or co-managing mild cases, their role is likely to be limited by the small number of cases in which they are involved. Past research has shown, conversely, that internist rheumatologists figure prominently in the care of children with rheumatic diseases<sup>4, 6, 21, 22</sup> and may provide nearly one-half of the care to children under age 18 with rheumatic diseases.<sup>22</sup> There is also evidence that the involvement of internist rheumatologists is largely

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<sup>v</sup> While 45 percent of survey pediatric rheumatology units had only one pediatric rheumatologist, 55 percent had more than one. Thus, the actually number of children seen per provider will deviate from 443.

due to the lack of available pediatric rheumatology providers. The quality of care provided by internist rheumatologists to children with rheumatic diseases and the extent to which they adequately substitute for pediatric rheumatologists remains unknown and has important implications for the supply of pediatric rheumatologists. The role of pediatric and internist rheumatologists is discussed in greater detail in Chapter IV.

### **Open Positions and Salary Concerns**

In September 2004, the “Job Openings” page of the American Academy of Pediatrics Rheumatology Section<sup>26</sup> listed 25 advertised positions at 21 institutions or practices. Of the 23 positions in academic medical centers, one was at the level of division chair; 9 at the level of full, associate, or assistant professor; 7 positions of unspecified rank; and 6 research positions, some of which were also open to non-physician researchers; 2 positions were in private practice. A few of the listings suggest a level of desperation at the recruiting institutions.

A listing from Tennessee reads:

*“... We would prefer someone who does research, who would be willing to do some clinical but could have protected time. We are open, however, to considering any Pediatric Rheumatologist who might be interested. They would become the second pediatric rheumatologist.”*

Another from Plano, TX describes an area with particularly constrained access:

*“The nearest, and only, pediatric rheumatologist is in Dallas and serves both the Dallas and Fort-Worth cities. The next nearest pediatric rheumatologists are in Oklahoma City and Houston, both are more than two hours away. As a result, this one rheumatologist in Dallas has over a six-month waiting list. The practice is in a well-established hospital that specializes in high quality medical care, with the largest private practice neonatal intensive care unit in the area. The hospital has a significant pediatric staff (over 40), and all pediatric sub-specialists. A significant demand for pediatric rheumatology exists in this area and at the hospital. The hospital and community are making a very good offer for the qualified applicant.”*

While not all advertised positions were at the entry level, it is safe to assume that positions vacated by senior faculty would need to be filled by either another senior pediatric rheumatologist or a newly graduated fellow. As noted in the previous chapter, only 10 pediatric rheumatology fellows entered their final year of training in 2003. One expects, therefore, that these 10 fellows were available on the job market in July 2004. Given that 23 positions were open in September 2004, there appears to be either excess demand for, or a shortage of, pediatric rheumatologists.

### **Geographic Distribution of Recently Graduated Pediatric Rheumatologists**

The practice location decisions of recent pediatric rheumatology fellowship graduates provide important insights into the persistent tendency for these physicians to locate in certain areas. Using 2003 diplomate data from the ABP file, physicians Board certified in pediatric rheumatology who graduated from medical school after January 1, 1987 were classified as “recent” graduates (n=55); allowing for 16 years for physicians to complete residency and

fellowship and to certify; all others were classified as non-recent graduates. Graduation date was used to classify diplomates rather than certification date because the first certifying exam in pediatric rheumatology was not offered until 1992. These data were used to study the practice locations of recent graduates.<sup>vi</sup>

Over 80 percent of recent diplomates practice in a county that also has at least one non-recent pediatric rheumatology diplomate (Table 12). Only eight United States counties currently have a pediatric rheumatologist who recently graduated but no pediatric rheumatologists who graduated prior to 1987: Johnson, IA (city: Iowa City); Hampden, MA (city: Chicopee); Norfolk, MA (City: Norwood); Livingston, MI (City: Brighton); Jackson, MO (city: Kansas City)<sup>vii</sup>; Multnomah, OR (City: Portland); Providence, RI (city: Providence) and Dane, WI (City: Madison). These data suggest that the geographic distribution of pediatric rheumatologists may remain unchanged without incentives to practice in underserved areas.

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<sup>vi</sup> It should be noted that the ABP file has either a home address or work address for a physician, depending on which one the physician reports. It is possible that some of the pediatric rheumatologists work in counties that differ from their home address.

<sup>vii</sup> Though not board-certified, Kansas City, KS had two pediatric rheumatologists who graduated prior to 1987.

**Table 12: Board-Certified Pediatric Rheumatologists by County and Graduation Cohort, American Board of Pediatrics, 2003**

State	County	Total Number	Number of Recent Diplomates (Graduation after 1/1/87)	Number of Non-recent Diplomates (Graduation before 1/1/87)
Arkansas	Pulaski	1	0	1
California	Fresno	2	1	1
	Los Angeles	4	1	3
	Orange	2	1	1
	San Bernardino	1	0	1
	San Diego	2	0	2
	San Francisco	3	1	2
	San Mateo	1	0	1
	Santa Clara	3	0	3
	Colorado	Denver	2	1
Connecticut	Fairfield	1	0	1
	Hartford	1	0	1
	New Haven	2	0	2
Delaware	New Castle	2	1	1
Florida	Alachua	2	0	2
	Palm Beach	2	1	1
	Pinellas	3	1	2
Georgia	Dekalb	1	0	1
	Fulton	1	0	1
	Richmond	1	0	1
Hawaii	Honolulu	3	1	2
Illinois	Cook	8	1	7
Indiana	Marion	2	1	1
Iowa	Johnson	1	1	0
Kansas	Wyandotte	3	1	2
Kentucky	Fayette	1	0	1
	Jefferson	1	0	1
Louisiana	Jefferson	2	1	1
	Orleans	1	0	1
Maryland	Baltimore City	1	0	1
	Howard	1	0	1
	Montgomery	5	1	4
Massachusetts	Hampden	2	2	0
	Middlesex	4	3	1
	Norfolk	1	1	0
	Suffolk	3	0	3
Michigan	Kalamazoo	1	0	1
	Livingston	1	1	0
Minnesota	Washtenaw	5	2	3
	Hennepin	3	1	2
	Olmsted	2	0	2
Mississippi	Hinds	1	0	1

**Table 12: Board-Certified Pediatric Rheumatologists by County and Graduation Cohort  
American Board of Pediatrics, 2003, cont.**

State	County	Total Number	Number of Recent Diplomates (Graduation after 1/1/87)	Number of Non-recent Diplomates (Graduation before 1/1/87)
Missouri	Boone	2	0	2
	Jackson	1	1	0
	St. Louis	4	3	1
Nebraska	Douglas	1	0	1
New Jersey	Bergen	2	0	2
	Essex	2	1	1
New Mexico	Bernalillo	1	0	1
New York	Erie	1	0	1
	Monroe	1	0	1
	Nassau	2	1	1
	New York	9	5	4
	Onondaga	1	0	1
	Westchester	1	0	1
North Carolina	Durham	2	0	2
	Orange	1	0	1
	Pitt	1	0	1
Ohio	Cuyahoga	3	2	1
	Franklin	2	0	2
	Hamilton	7	4	3
Oklahoma	Oklahoma	2	0	2
	Tulsa	1	0	1
Oregon	Multnomah	2	2	0
Pennsylvania	Allegheny	1	0	1
	Chester	1	0	1
	Dauphin	2	1	1
	Philadelphia	5	2	2
Rhode Island	Providence	1	1	0
Tennessee	Davidson	2	0	2
	Shelby	1	0	1
Texas	Dallas	2	0	2
	Harris	4	0	4
Utah	Salt Lake	2	1	1
Vermont	Chittenden	1	0	1
Virginia	Albemarle	1	0	1
	Henrico	2	0	2
	Norfolk City	1	0	1
	Richmond City	1	0	1
	Roanoke	1	0	1
Washington	King	5	2	3
Washington, DC	District Of Columbia	2	0	2
Wisconsin	Brown	1	0	1
	Dane	1	1	0
	Milwaukee	3	2	1

## Summary

Given the size of the pediatric population and the number of providers in each State, it appears that a number of States have rheumatologist to patient ratios that exceed typical pediatric rheumatology practice capacity. It is estimated that 60 percent of States have more than 1,000 children with rheumatic diseases per pediatric rheumatologist. Assuming that a pediatric population of 250,000 is needed to attract an initial provider and increments of 200,000 are needed to attract additional providers, it is estimated that a minimum of 337 pediatric rheumatologists is needed nationwide. Thus, there is a national deficit of approximately 135 to 145 providers. Furthermore, the number of trainees completing fellowship is less than the number of advertised positions. Thus, there is considerable evidence that the current supply of rheumatologists is not adequate to meet employer demand and results in a distribution of providers that limits access for a substantial segment of the pediatric population.

Practice location analyses of certified pediatric rheumatologists demonstrate, however, that 80 percent of recently trained pediatric rheumatologists (i.e., those who completed medical school in or after 1987) practice in a county that also has an older pediatric rheumatologist. These results suggest that newly trained rheumatologists are not necessarily entering underserved areas.

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## *Chapter 4. Substitutes for Pediatric Rheumatologists? General Pediatricians and Internist Rheumatologists Involvement in Pediatric Rheumatology Care as Evidence of a Shortage*

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The approximately 200 practicing pediatric rheumatologists in the United States practice in a limited number of geographic areas. As a consequence, other physicians---internist rheumatologists and primary care providers---may substitute for pediatric rheumatologists in some regions. Several studies suggest, for example, that internist rheumatologists play a prominent role in the care of children with these diseases.<sup>1, 4, 21</sup> A 2000 report revealed that one-third of children with a known rheumatic disease received their care from an internist rheumatologist.<sup>27</sup> A study of Medicaid children eligible for Supplemental Security Income (SSI) found that only 18 percent of children with juvenile rheumatoid arthritis (JRA) saw a pediatric subspecialist and 30 percent saw an internist subspecialist.<sup>1</sup>

### **Receipt of Care by North Carolina Medicaid Children with Juvenile Rheumatoid Arthritis**

North Carolina Medicaid claims data provide an opportunity to characterize physician utilization among North Carolina Medicaid enrollees with JRA. North Carolina ranks 33<sup>rd</sup> in the Nation in the ratio of children to pediatric rheumatologists. It is also a predominantly rural State with pediatric rheumatologists (n=4) located only in Chapel Hill, Durham, and Greenville. Pediatric rheumatology care is available also in bordering areas such as Knoxville, TN, Richmond, VA, and Norfolk, VA.

Children who had two or more physician visits with one of the following ICD-9 CM diagnosis codes in a given year were considered to have JRA: 714.3, 714.30, 714.31, 714.32, and 714.33. Analyses were limited to children who were continuously enrolled for one or both of the following time periods: July 1, 1998 through June 30, 1999 or July 1, 1999 through June 30, 2000.

Physician specialty codes were used to classify JRA-related physician visits<sup>vii</sup> by provider specialty. Unfortunately, North Carolina Medicaid claims data from hospital-based physician practices usually do not identify the specific physician for whom the claim was generated. For example, claims from the Private Diagnostic Clinic at Duke University Medical Center and those from University of North Carolina (UNC) Physicians and Associates come from the overall physician practice without an individual provider identifier; as a result, one cannot definitively identify the treating physician. JRA claims from these types of physician practices were classified as visits to pediatric rheumatologists when, according to the American College of Rheumatology, the center had a pediatric rheumatologist available and the primary diagnosis was JRA.

Internist rheumatologists were identified in two ways: using the specialty code specific to rheumatology and comparing the list of multispecialty and “other” providers with the American College of Rheumatology file to identify misclassified rheumatologists. Internist rheumatologists may be underrepresented because care received at physician practices based in medical centers, like North Carolina Baptist Hospital or Carolinas Medical Center, do not list the specific physician seen. Thus, the “multispecialty” and “other” categories may also include care provided by internist rheumatologists.

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<sup>vii</sup> Visits in which JRA was not listed as one of the nine diagnoses were excluded from this analysis.

To avoid including children with a one-time “rule-out” diagnosis, the analyses included only children with two or more physician claims with a diagnosis of JRA. The analysis included only continuously enrolled children to ensure that we had all physician claims for each study child. In 1999 and 2000, respectively, 67 and 68 continuously enrolled Medicaid children had two or more physician visits with a diagnosis of JRA (Table 13). Of these, slightly more than 50 percent had at least one visit to a center with a pediatric rheumatologist in each year.<sup>viii</sup> In both years only 40 percent of all JRA-related physician visits were to a pediatric rheumatologist or a medical center with a pediatric rheumatologist. General pediatricians and internist rheumatologists provided 15 to 20 percent of all JRA-related visits to this population.

**Table 13: Number of Medicaid-Enrolled Children with JRA in North Carolina and Distribution of JRA-related Physicians Visits**

	July 1, 1998 to June 30, 1999	July 1, 1999 to June 30, 2000
<b>Number of Children</b>		
Continuously enrolled children with 2 or more MD visits with a JRA diagnosis	67	68
Seen at a pediatric rheumatology center for JRA	36	39
<b>Percent of all JRA-related physician visits by MD types</b>		
Internist Rheumatology	15.4	15.4
Pediatric Rheumatology	43.4	40.7
Pediatrics	19.0	19.3
Ophthalmology	5.2	7.0
Family Practice	3.4	3.0
Multispecialty clinic	4.0	8.0
Radiology	2.4	2.6
Orthopedics	2.4	0.9
Other	4.7	1.5

North Carolina Medicaid data were also used to characterize the JRA-related physician management of children. Using only visits with a JRA diagnosis, children were classified into groups based on the involvement in their care of a primary care physician (PCP), pediatric rheumatologist and/or an internist rheumatologist. Children seen by a family practice physician or a pediatrician, but not seen by any rheumatologists, were classified as “PCP only;” those with JRA-related claims from pediatric rheumatologists only or internist rheumatologists only were classified accordingly. Those with JRA-related claims from both a PCP and a pediatric rheumatologist were classified as having their care co-managed by these providers and those seen by both a PCP and an internist rheumatologist were similarly classified.

Physician management of JRA care was fairly evenly distributed across types in 1999, with “PCP Only,” “PCP with a Pediatric Rheumatologist,” and “Internist Rheumatologist Only” each accounting for around 20 percent of visits (Table 14). “Pediatric Rheumatologist Only” was the most common management type, accounting for over 30 percent of children with JRA.

<sup>viii</sup> It is essential to note that visits to centers with pediatric rheumatologists may have involved a visit to another type of physician, such as an ophthalmologist. Thus, the percentage of visits to pediatric rheumatologists may be overstated.

In FY 2000 the percentage of children treated exclusively by a PCP declined nearly 6 percentage points and the percent being co-managed increased by nearly the same amount. While these figures suggest that more than one-half of Medicaid enrolled children with JRA in North Carolina have been seen at a center with a pediatric rheumatologist on staff, one cannot ascertain that the visits to these centers involved a visit to a pediatric rheumatologist. Nonetheless, it is clear that primary care providers and internist rheumatologists play an important role in the care of Medicaid-enrolled children with JRA.

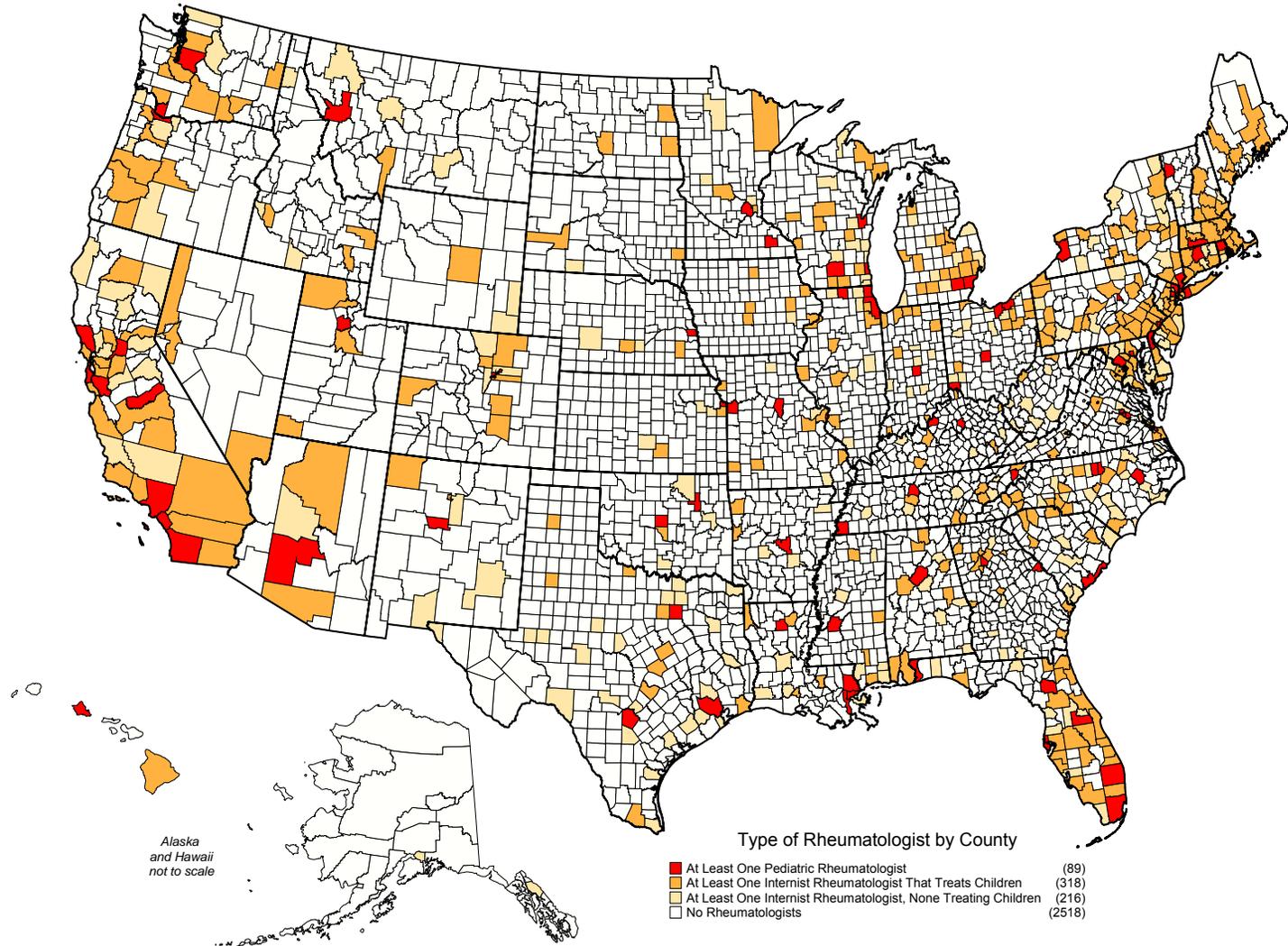
**Table 14: Classification of JRA-related Physician Care among Medicaid-Enrolled Children with JRA, North Carolina**

Classification of JRA Care	July 1, 1998 to June 30, 1999 (%)	July 1, 1999 to June 30, 2000 (%)
PCP only	19.4	13.2
PCP with Pediatric Rheumatologist	20.9	26.5
PCP with Internist Rheumatologist	0.0	1.5
Pediatric Rheumatologist Only	32.8	30.9
Internist Rheumatologist Only	17.9	17.7
Other 9.0		10.3

### **Internist Rheumatologists as Providers of Pediatric Rheumatology Care**

A 2002 study of physician members of the ACR (n=4,673) divided these specialists into three groups: those who treat pediatric patients only, internist rheumatologists who treat adults only, and internist rheumatologists who treat both adults and children. After restricting the sample to physicians who provide at least some patient care (n=4,304), 224 were classified as pediatric only providers, 3,030 as internist rheumatologist who treated adults only and 1,050 as internist rheumatologists who also treated children. Of the 3,141 counties in the United States, 623 (20 percent) have an internist or pediatric rheumatologist involved in patient care on at least a part-time basis (Figure 4).

## Access to Rheumatology Care: Pediatric Rheumatologists and Internist Rheumatologists by County



Sources: American College of Rheumatology Membership File, 2001; Census Bureau, 2001.

Produced By: North Carolina Rural Health Research and Policy Analysis Center, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.

As Table 15 shows, the authors found that approximately 50 percent of the population under age 18 of the United States lived within 50 miles of a pediatric rheumatologist. When the parameters were expanded to include internist rheumatologists who treat adults and children, the percentage of children living within 50 miles of a provider of pediatric rheumatology care (i.e., an internist who treats children or a pediatric rheumatologist) increased to 90 percent. This indicates that internist rheumatologists are more geographically diffuse than pediatric rheumatologists and, therefore, their involvement in the treatment of children substantially reduces the distances that must be traveled to obtain care.

**Table 15: Percent of the Population Living within Selected Distances of Rheumatology Providers by Rheumatology Provider Type**

Miles to Nearest Provider	Percent of Pediatric Population		Percent of U.S. Population
	Pediatric Rheumatologist Only	Pediatric or Internist Rheumatologist who Treats Children	Any Rheumatologist
Less than 10	22.7	53.2	70.4
10 to 50	31.4	34.9	25.2
51 to 100	19.4	8.7	3.7
101 to 200	18.4	2.5	0.5
200 or more Miles	8.0	0.7	0.01

Source: Mayer ML, Mellins ED, Sandborg CI. Access to pediatric rheumatology care in the United States. *Arthritis Rheum* 2003; 49:759-65

A survey of California rheumatologists found that children under the age of 18 represented a small percentage of internist rheumatologists' patients.<sup>22</sup> Respondents were asked how many patients they treat by age group (under 18 years, and 18 years and older); in addition a separate question asked if they "treat pediatric rheumatology patients." Among internist rheumatologists who reported treating pediatric patients, approximately 3 percent of their patients are under the age of 18. While the number of pediatric patients seen by individual internist rheumatologists is small, collectively they treat a large number of patients under 18. Using self-reported data on patient volume, this survey estimated that, as a group, internist rheumatologists who report treating children saw a total of 217 under 18 patients per week. In addition, many internist rheumatologists who reported not treating pediatric patients did, in fact, report treating patients under the age of 18. These providers, as a group, treat approximately 202 patients under the age of 18 in a week. Collectively, internist rheumatologists were seeing almost as many patients as were pediatric rheumatologists who treated an estimated 550 patients under 18 per week.

### **Factors Influencing Internist Rheumatologists Involvement in the Care of Children**

Distance to the nearest pediatric rheumatologist appears to be an important determinant of internist rheumatologists' involvement in the care of children. The aforementioned 2002 national study of ACR members found that, controlling for a variety of other factors such as practice type and non-clinical professional activities,<sup>6</sup> distance to pediatric rheumatology care was significantly related to internist rheumatologists' involvement in the care of children. Moreover, a study found that internist-rheumatologists in Washington State found those who

reported treating children lived a significantly greater average distance from a pediatric rheumatology referral center than those who referred children (101 miles vs. 21 miles) and distance was the most frequently reported reason (66 percent) for not referring a child to a pediatric rheumatologist.<sup>4</sup> A survey of California rheumatologists found that internist rheumatologists practicing between 10 and 50 miles from the closest pediatric rheumatologist were significantly more likely than those within 10 miles of a pediatric rheumatologist to treat children. The odds of treating pediatric patients among those practicing 50 or more miles from the nearest pediatric rheumatologist were nearly 7 times higher than among those practicing within 10 miles of a pediatric rheumatologist.<sup>22</sup>

The AF/ACR Survey conducted in 2004 found that internist rheumatologists involved in the care of children practiced a significantly greater distance from a pediatric rheumatologist, on average, than those who do not treat children (66.2 vs. 46.1 miles,  $p=0.017$ ). In multivariable analyses that controlled for provider characteristics, such as age and distribution of work hours, distance did not maintain its significance. These results should be interpreted with caution, however, as it is estimated that the response rate among internist rheumatologists in this survey was less than 20 percent.

Among California internist rheumatologists who treat children, 79 percent indicated that personal expertise in pediatric rheumatology motivated them to treat children. Patient preferences and distance to the nearest pediatric rheumatologist also were selected as motivating factors by 73.3 percent and 65.8 percent, respectively, of internist rheumatologists who treated children. Among internist rheumatologists who do not treat children, the overwhelming majority (85.2 percent) refrain from seeing children because of inadequate personal expertise in pediatric rheumatology. Most internist rheumatologists (70.3 percent) also cited the availability of nearby pediatric rheumatology care as a reason for their decision not to treat children with rheumatic diseases. Among Washington State rheumatologists, the most common factor in an internist rheumatologist's decision not to refer a child to a pediatric rheumatologist was distance (66 percent), with the second most common reason cited as inconvenience to the child's family (60 percent).

Data from the California survey also suggested that practice setting may play a role in internist rheumatologists' involvement in the care of children; those practicing in multispecialty clinics were significantly more likely to be involved in the care of pediatric patients than those who practiced in other settings. Interestingly, when queried about their reasons for treating pediatric patients, 46.2 percent of those in multispecialty practices cited insurance barriers to referral versus only 28.8 percent of those in other practice settings. It is possible that physicians in these types of groups may be more involved in independent practice associations (IPA). IPAs may be less likely to include pediatric subspecialists and providers may face disincentives to referring outside their network of providers,<sup>28, 29</sup> which might explain the somewhat increased tendency, among those in multispecialty settings, to report insurance barriers as a motivating reason for treating children.

## **Comments from Internist Rheumatologists**

While quantitative analyses are useful in summarizing survey data, qualitative data can provide rich and varied insights into the context of physician practice decisions. A sample of comments from California rheumatologists surveyed suggests that some internist rheumatologists treat children only because of the lack of available pediatric providers and appear to be uncomfortable with their involvement in the care of these patients. In contrast,

other internist rheumatologists feel they are fully capable of meeting the needs of this population and are not called upon to do so often enough. The following comments are from this survey.

#### Distance/Access

- *“There is a major shortage of pediatric rheumatologists. I treat some pediatric populations out of inaccessibility to pediatric rheumatologists – I would like to not treat any or get more training.”*
- *“I love kids, and feel that we desperately need more pediatric rheumatologists but with no pediatric experience in residency, only 12 clinics in fellowship, I am unprepared to see kids. I could easily handle mild JRA cases with MTX/NSAIDs [methotrexate/non-steroidal anti-inflammatory agents], pain injections, but the biggest hold back is my comfort with diseases of children. Legally and medically, I would be asking for trouble.”*
- *“Straight forward pediatric rheum [atology] or older pediatric patients I am comfortable taking care of. If there is an element of doubt, I refer to Children Hosp LA.”*
- *“Because of the shortage of pediatric rheumatologists, I do not mind seeing old pediatric patients (> 13 yrs) if I have to. But I definitely prefer not to treat anyone under 13 years of age because my training in internal medicine did not prepare me to treat pediatric patients.”*
- *“I rarely receive referrals from ‘peds’ [general pediatricians] for questionable reasons. ‘Peds’ may feel we are incapable of treating children with rheumatic disorders even with training/experience.”*
- *“The major obstacle to the treatment of pediatric rheumatology cases in our area is the hesitance by the local pediatricians. They all seem to shy away from the care of really sick children and prefer not to be involved in their care. Thus, they almost always refer them out of the area, causing great inconvenience and, often, suboptimal care for the patients. I would strongly suggest that pediatricians be made aware that most rheumatologists are quite experienced and able to care for pediatric rheumatology patients.”*
- *“Pediatricians were never taught to do joint exams. Therefore, they don't recognize a swollen joint when they see it, so the child gets referred to an orthopedist, who does the "only" sensible thing: they "cast" it. Weeks later the cast comes off, oops, now we have a contracture. So they refer to the university where the child disappears - where the child never gets referred back to me (unless HMO insists). I like kids and could do your follow-ups locally, save the ‘ped rheum’ time (and the pts/family time for appointments). But you never ask and patients are never even referred back to me.”*

#### Practice Constraints

- *“Because my office is not set up for children, I only deal with teens who like being treated like an adult.... I am more at ease with prescriptions.”*
- *“Too busy with adult patients to see pediatric patients. Not really interested in seeing pediatric patients.”*
- *“In Fresno...there are two excellent pediatric rheum [atology] MDs but there is a shortage of adult rheum [atologist]s.”*
- *“I choose not to tx [treat] pediatric patients as I never did a pediatric rotation in my training. Even if I had done one month of ped [iatric] rheum [atology] training, I probably would not treat this population due to professional liability concerns (I wouldn't be Board certified in pediatric rheumatology). Currently, I have a five month waiting period to see adult patients - I have little incentive to see pediatric patients as well.”*

Additional comments, not presented here, underscore the finding of the quantitative analysis that internist rheumatologists generally restrict their involvement in pediatric rheumatology to the care of adolescents and suggest that some of these providers also limit their involvement to children with mild forms of the more common rheumatic diseases.

It is important to note that while many internist rheumatologists currently treat a small number of children and adolescents with rheumatic disease, their role in caring for the under-18 population may decrease in coming years. The aging of the “baby-boomer” generation will increase adult demand for the services of internist rheumatologists and limit their availability to care for children.

## **Role of Primary Care Physicians in Treating Children with Rheumatic Diseases**

A 2001 national survey of physicians' involvement in the care of children with rheumatic diseases and factors contributing to current referral patterns within pediatric rheumatology found that 11 percent of pediatricians and 38 percent of family practitioners had not seen any suspected or confirmed cases in the 5 years prior to the survey.<sup>30</sup> Only 3 percent and 1 percent of pediatricians and family practitioners, respectively, saw more than 10 cases; only one percent of respondents diagnose and treat patients with JRA on their own.<sup>30</sup> Forty-two percent of pediatricians and 32 percent of family practitioners refer all JRA diagnosis and management to subspecialists. Most of the respondents indicated that they refer patients to a pediatric rheumatologist (92 percent of pediatricians and 76 percent of family physicians); a substantial percent of family physicians indicated, however, they refer to general rheumatologists (37 percent). This may be because many are located in rural areas where access to a pediatric rheumatologist may be limited.<sup>30</sup>

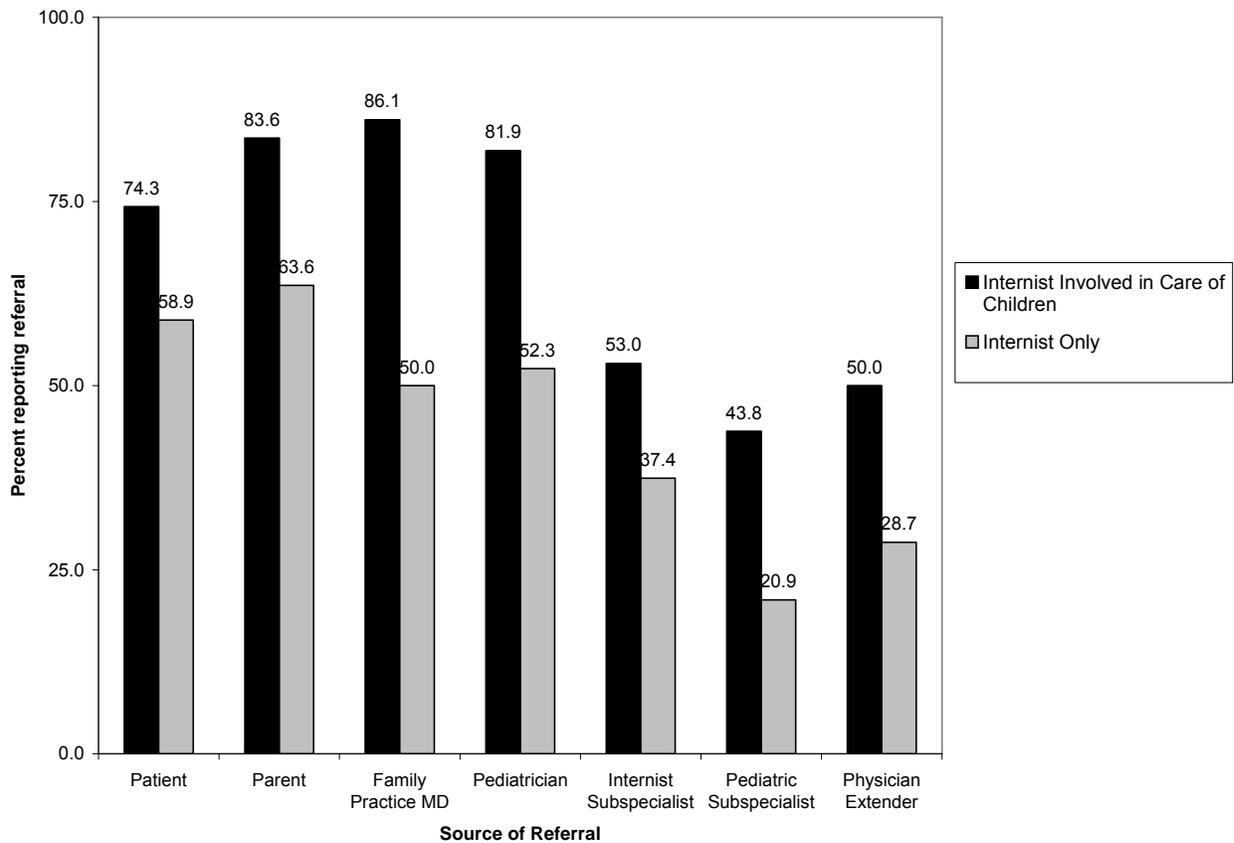
In analyzing survey responses from general pediatricians and family physicians, Freed et al.<sup>30</sup> found that 42 percent of pediatricians and 19 percent of family practitioners felt comfortable diagnosing JRA, but only 18 percent of pediatricians and 12 percent of family practitioners felt they were adequately trained to diagnose and treat JRA. Only 10 percent and 4 percent of pediatricians and family practitioners, respectively, described themselves as current on the latest JRA treatments. Bivariate analyses indicated that PCPs who reported having inadequate training in diagnosing JRA were twice as likely to refer patients as those who described their training as adequate, implying that improvements in training may enhance primary care providers willingness to be involved in the care of children with rheumatic diseases.<sup>30</sup>

## **Reported Pediatric Referral Sources**

The 2003 survey of California internist rheumatologists asked providers to indicate which groups had referred children with rheumatic diseases to them. Compared with internist rheumatologists who did not report treating children, internist rheumatologists who did report treating children were significantly more likely to be contacted by all referral sources (Figure 5).<sup>22</sup> It is not clear if internist rheumatologists decide to treat children because they are asked to, or if these providers have a reputation for treating children and, as a consequence, are more frequently approached for treatment. It is also notable that internist rheumatologists who do not treat children frequently reported being contacted about seeing a pediatric patient with a known or suspected rheumatic condition despite their unwillingness to treat children.

In their National survey, Freed and colleagues found that internist rheumatologists reported that their primary referral sources of JRA patients were family physicians, followed by pediatricians, then orthopedists. Seventeen percent of internist rheumatologists reported that they never refer JRA patients to another specialist, and 11 percent reported referring all of their juvenile patients. Ninety-six percent of all referrals from internist rheumatologists were to a pediatric rheumatologist.<sup>30</sup>

**Figure 5: Percentage of Internist Rheumatologists Reporting Requests to See Pediatric Patients by Requesting Source**



### Comfort in Treating Children

Freed and colleagues found that 88 percent of internist rheumatologists reported they are “adequately trained to diagnose JRA” and 72 percent felt they were “adequately trained to manage JRA.”<sup>30</sup> Internist rheumatologists reported, nonetheless, that they often referred these patients to pediatric rheumatologists. Factors that were considered most important in the referral decision were age of patient, parental request, and refractory clinical course.<sup>31</sup> In a focus group composed of internist rheumatologists, several indicated that they would begin treating a patient with JRA and only refer them to a specialist if there was no improvement. Most agreed that proximity to such a specialist also played a large role in the decision to refer.

There is evidence that internist rheumatologists limit their involvement in the care of children to adolescents. California internist rheumatologists were significantly less likely to treat children ages 0-5 and 6-11 than pediatric rheumatologists.<sup>22</sup> Patients ages 16-17, on average, represent over 50 percent of internist rheumatologists' pediatric patients. The diseases treated did not differ significantly, however, between these providers; for both pediatric and internist rheumatologists the majority of patients had JRA or SLE.

Compared to pediatric rheumatologists significantly fewer California internist rheumatologists were comfortable treating each of 18 listed conditions.<sup>22</sup> The majority of internist rheumatologists were comfortable treating the JRA subtypes, SLE, dermatomyositis, and spondylarthropathy; however, less than half of those responding were comfortable treating Kawasaki's disease, Wegener's granulomatosis, polyarteritis nodosa, reflex sympathetic dystrophy, psychogenic rheumatism, and fever of unknown origin. Most Washington State internist rheumatologists similarly reported comfort with treating children with common diseases such as JRA; however, the percentage of surveyed physicians who reported comfort treating rarer diseases that typically affect younger children was much lower.<sup>4</sup>

Analyses of the recent AF/ACR survey by the Arthritis Foundation and the ACR had similar findings. Internist rheumatologists who treat children were less likely than those who do not treat children to report that there is an age below which they are uncomfortable diagnosing or treating pediatric patients. Even among those who treat children the majority do report being uncomfortable diagnosing (78.3 percent) and treating (80.3 percent) children below a certain age. The average age below which they are uncomfortable diagnosing is lower for those who treat children than those who do not (9.5 years vs. 14.9 years, respectively,  $p < 0.001$ ). Likewise, the minimum average age at which a provider feels comfortable treating a child with a rheumatic disease is lower for those internist rheumatologists who treat children than among those who do not (9.8 years vs. 15.3 years, respectively,  $p < 0.001$ ). As expected, internist rheumatologists who care for children are significantly more likely than those who do not treat children to report being comfortable treating pediatric rheumatic diseases. As shown in Table 16, internist rheumatologists who treat children are most uncomfortable treating Kawasaki's disease (67.1 percent), periodic fevers (54.3 percent), somatiform disorders (46.9 percent), and pediatric vasculitis (42.1 percent). Those who do not treat children are significantly more likely than those who treat children to report being uncomfortable treating all reported illnesses.

**Table 16. Comparison of Internist Rheumatologists By Involvement in Care of Children AF/ACR Survey (N=523)**

	<b>Treats children</b>	<b>Does not treat children</b>
<i>Uncomfortable treating in children:</i>		
Pediatric vasculitis (%)	35.6***	55.6
Kawasaki's disease (%)	56.8**	70.5
Systemic onset JRA (%)	20.1***	45.3
Polyarticular JRA (%)	9.0***	39.3
Pauciarticular JRA (%)	9.3***	39.7
SLE (%)	17.3***	39.7
Scleroderma (%)	23.5***	46.2
Osteoporosis (%)	32.9***	47.4
Periodic fevers (%)	47.4***	65.8
Myositis (%)	22.2***	41.5
Somatiform disorders (%)	40.5***	60.7
Other illnesses (%)	3.8	6.8

\*\*p<0.01, \*\*\*p<0.001; from Pearson  $\chi^2$  for binary variables; from two-sided, two sample t-test of mean differences for continuous variables

## Practice Guidelines

Freed and colleagues also explored the need for continuing education for general practice physicians and internist rheumatologists who are likely to treat children with rheumatic diseases. In a survey 71 percent of pediatricians, 73 percent of family physicians, and 73 percent of the internist rheumatologists indicated that they saw a need for a JRA practice guideline to be disseminated to physicians within their specialty;<sup>30</sup> among focus groups, however, the results were less consistent. Most pediatricians agreed that practice guidelines were not necessary because they usually refer potential JRA patients to specialists; they indicated that even if guidelines were available they would most likely not use them. Opinions from the family physicians were mixed; some were skeptical of the benefit of guidelines because they see potential JRA cases so infrequently. Those family physicians who were likely to play a significant role in the management of JRA care thought that guidelines would be especially relevant and helpful. Of the internist rheumatologists who participated in a focus group, most agreed that a guideline would be helpful to keep them updated on recent developments in the treatment of JRA patients.

## Summary

Internist rheumatologists play a prominent role in the care of children with rheumatic diseases; evidence suggests that the lack of available pediatric rheumatologists influences the involvement of internist rheumatologists in the care of children. Nonetheless, studies suggest that they may limit their involvement to the care of adolescents and those with mild cases. The practice locations of internist rheumatologists are more geographically diffuse than those of pediatric rheumatologists and, as such, their involvement in the care of children with rheumatic disease certainly decreases the distances that children need to travel for care. Efforts to

enhance the ability of internist rheumatologists to provide quality care to children with rheumatic diseases may help ameliorate the current shortage.

In contrast to internist rheumatologists, primary care providers appear to play a smaller role. Primary care providers' lack of involvement in the care of children with rheumatic diseases may reflect the lack of pediatric rheumatology training available in many pediatric residency programs, especially those programs with a high percentage of trainees who enter primary care practice. Enhanced training of primary care providers may enable them to perform initial evaluation on children with suspected rheumatic diseases and minimize the number of unnecessary referrals, which increase the demand for pediatric rheumatology care. Moreover, enhanced training of primary care providers may increase their willingness and ability to co-manage the care of children with rheumatic diseases and ease some of the patient care burden affecting pediatric rheumatologists.

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## *Chapter 5. Important Issues Facing the Pediatric Rheumatology Workforce*

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There are three major issues that present significant challenges to both the short and long-term ability of the pediatric rheumatology workforce to meet the demand for patient care. They are: (1) lack of faculty and training availability; (2) insufficient clinical care cost recovery; and (3) research requirements limiting patient care access.

### **Issue 1: Lack of Faculty and Training Availability**

There are currently 80 medical schools in the United States with a pediatric rheumatologist on faculty, leaving over one-third of the Nation's 125 medical schools without physicians in this subspecialty.<sup>19</sup> A shortage of these providers not only limits the ability of these institutions to care for children with rheumatic diseases, but it leaves many medical schools and pediatric residency programs unable to adequately expose trainees to the pediatric rheumatology field. Limited exposure to pediatric rheumatology during medical training intensifies the effects of the pediatric rheumatology shortage in two important ways:

- 1) Leaving general pediatricians and family physicians ill-prepared to be involved in the initial diagnosis and management of children with suspected or known rheumatic diseases, thereby increasing demand for pediatric rheumatologists, and
- 2) Decreasing the pool of students interested in pursuing a career in this field.

As discussed in Chapter IV, past studies have shown that having training in the care of children with rheumatic diseases may enhance providers' willingness to care for children with rheumatic disease. One previous study found a relationship between adequacy of training and referral patterns for JRA among primary care providers; consequently, pediatric rheumatology training is particularly relevant to prepare primary care physicians and pediatricians to identify children with rheumatic diseases and participate in their care.<sup>30</sup>

Exposure to pediatric rheumatology is also important during training because of its effects on career choice. Studies also found an association between exposure to a subspecialty during training and intentions to pursue it as a career.<sup>9, 32, 33</sup> Since pediatric rheumatologists must first complete medical school and pediatric residency training before entering a pediatric rheumatology fellowship, exposure to pediatric rheumatology at earlier stages of physician training may generate their interest in the field.

### *Availability of Pediatric Rheumatology Training in General Pediatrics Programs*

In the spring of 2004, all 195 pediatric residency directors in the United States and Puerto Rico were surveyed to assess the status of pediatric rheumatology training in general pediatric residency programs. The survey questioned (1) the availability of pediatric rheumatology training in general pediatrics residency, (2) the relationship between the characteristics of pediatric rheumatology training in general pediatrics residency and the presence of pediatric rheumatologists at the training institution, and (3) the adequacy of pediatric rheumatology supply locally and statewide. Details about the survey are provided in Appendix F.

Of the 195 programs surveyed, 127 (65 percent) responded. Descriptive statistics are presented in Table 17. Respondents were asked to indicate the number of pediatric rheumatologists with patient care responsibilities at their institution. Seventy of the responding programs (56.7 percent) had one or more pediatric rheumatologists on staff, including two institutions that reported sharing a provider with another institution. The number of pediatric rheumatologists in these programs ranged from one to six, with a mean of 1.8. Programs with pediatric rheumatologists on staff were significantly larger, in terms of pediatric residents, than those without these providers and had significantly fewer residents pursuing general pediatrics careers. Thus, pediatric rheumatologists are located at larger, more academically-oriented training programs.

**Table 17: Characteristics of Responding Pediatric Residency Programs, 2004 Survey of Program Directors**

	All Programs Mean (n=127)	Programs without Pediatric Rheumatologists Mean (n=55)	Programs with Pediatric Rheumatologists Mean Percent (n=72)
Number of Years Program in Existence	32.2	28.2	35.1%
Number of General Pediatrics Residents	41.1	29.9	49.6%
Any Internal Medicine (IM)/Pediatrics Residents	59.6	59.5	59.7%
Number of IM/Pediatrics Residents <sup>a</sup>	15.5	12.2	17.6%
Any Combined Pediatrics Residents	15.6	9.5	19.4%
Number of Other Combined Pediatrics Residents <sup>b</sup>	4.9	2.5	5.7%
<b>Pediatric Rheumatologist on Staff at Affiliated Institution</b>			
Yes	56.7	N/A	N/A
No	43.3	N/A	N/A
	All Programs Percent (n=127)	Programs without Pediatric Rheumatologists Percent (n=55)	Programs with Pediatric Rheumatologists Mean Percent (n=72)
<b>Percent of Graduates in Primary Care</b>			
Less than 25	0.0%	0.0%	0.0%
26 to 50	26.0%	10.9%	37.5%
51 to 75	58.3%	70.9%	48.6%
More than 75	15.8%	18.2%	13.9%
<b>Percent of Programs with a Pediatric Rheumatology Rotation</b>			
On-site Rotation Available	57.5%	9.1%	94.4%
"Away" Rotation Available	22.0%	45.4%	4.2%
No Rotation Available	20.5%	45.4%	1.4%

<sup>a</sup> Among those programs with any Internal Medicine/Pediatric Residents

<sup>b</sup> Among those programs with any Combined Pediatric Residents

Residency directors also were asked if their program offered a pediatric rheumatology rotation, either on-site or as an away elective; overall, 57.5 percent of programs offered a rotation on-site and an additional 22 percent offered a rotation as an away elective (Table 18). Over 90 percent of residency programs with a pediatric rheumatologist on staff reported offering a pediatric rheumatology rotation on-site. Among those programs without a pediatric rheumatologist on staff, 9 percent offered a pediatric rheumatology rotation on-site and 45 percent offered the rotation as an away elective. Forty-five percent of programs without a pediatric rheumatologist on staff did not offer a pediatric rheumatology rotation.

**Table 18: Characteristics of Pediatric Residency Training by Availability of a Pediatric Rheumatology Rotation, 2004 Survey of Program Directors**

	Overall (n=126)	On-site Training (n=73)	"Away" Rotation (n=28)	None (n=26)
<i>Percent of Graduates in Primary Care**</i>				
26% to 50%	26.0	35.6	17.9	7.7
51% to 75%	58.3	52.1	53.6	80.8
75% or more	15.8	12.3	28.6	11.5
<i>Percent of General Pediatrics Residents Doing a Pediatric Rheumatology Rotation</i>				
None	15.1	1.4	0.0	72.0
Less than 10%	33.3	20.6	71.4	28.0
10 to 25%	22.2	27.4	28.6	0.0
26% to 50%	15.1	26.0	0.0	0.0
51% to 75%	7.1	12.3	0.0	0.0
76% or More	4.8	8.2	0.0	0.0
All, it is required	2.4	4.1	0.0	0.0
<i>Percent of Programs by Type of Physicians Involved in Rotation<sup>a</sup></i>				
On-site Pediatric Rheumatologist***	55.1	91.8	10.7	
Off-site Pediatric Rheumatologist***	25.2	11.0	82.1	
On-site Internist Rheumatologist	4.7	6.9	0	
Off-site Internist Rheumatologist	1.6	1.4	3.6	
General Pediatrician	2.4	2.7	0	
Other	5.5	5.5	10.7	
None	18.9	0.0	0.0	

<sup>a</sup> Programs could choose more than one provider.

\* Difference between program types significant at p<0.05

\*\* Difference between program types significant at p<0.01

\*\*\* Difference between program types significant at p<0.001

Programs that lack pediatric rheumatology rotations were significantly more likely to report having a greater percentage of graduates in primary care positions (Table 18). Directors from 64 percent of programs with on-site rheumatology training estimated that one-half of their graduates practiced in primary care. In contrast, over 90 percent of directors in programs

without a pediatric rheumatology rotation available estimated that over half of their graduates practiced in primary care.

Despite the availability of formal pediatric rheumatology rotations in 79 percent of pediatric residency programs, few pediatric residents elect to take these rotations; only three of these programs (2.4 percent) require a pediatric rheumatology rotation. In addition, only 11.9 percent of program directors estimate that more than 50 percent of their residents do a formal pediatric rheumatology rotation. Compared to programs with away electives programs, on-site rotations report having a significantly higher percentage of residents doing a rheumatology rotation. In programs with on-site training, one-half of directors estimate that more than one-quarter of their residents do a pediatric rheumatology rotation during their training. Among those programs with an away elective, all directors estimate that 25 percent or less of their residents elect to take this rotation.

Directors were asked to indicate which faculty were involved in four curriculum components relevant to rheumatology: joint exam, rheumatology laboratory evaluation, JRA diagnosis and JRA treatment. Directors could choose from one or more of the following: pediatric rheumatologist, internist rheumatologist, general pediatrician/continuity clinic, and lectures/guest speaker. Programs were classified into one of nine mutually exclusive categories. Programs were characterized by the involvement of a pediatric rheumatologist either alone or in combination with other providers; programs that did not report using pediatric rheumatologists in a curriculum component, were then assessed for their use of internist rheumatologists and others.

Pediatric rheumatology curriculum components were taught largely by pediatric rheumatologists independently or in combination with other faculty or guest speakers (Table 19). A small percentage of programs relied upon internist rheumatologists with or without the involvement of general pediatricians and/or guest lectures to cover these components; a small number of programs relied on general pediatricians. With the exception of the joint exam component, at least two-thirds of directors indicated that a pediatric rheumatologist was involved in the curriculum components studied.

**Table 19: Faculty Involvement in Pediatric Rheumatology Curriculum, 2004 Survey of Program Directors (n=126)**

	Joint Exam (%)	Lab Work (%)	JRA Diagnosis (%)	JRA Treatment (%)
Pediatric Rheumatologist Only	17.3	21.3	23.6	33.1
Pediatric Rheumatologist and Other <sup>a</sup>	47.2	47.2	44.9	37.8
Internist Rheumatologist Only	0.8	3.2	2.4	3.9
Internist Rheumatologist and Other <sup>b</sup>	7.9	11.0	11.0	11.0
General Pediatricians with Lectures or Other Non-rheumatologist	12.6	9.5	11.0	6.3
General Pediatrician Only	10.2	3.9	2.4	3.2
Lecture Only	1.6	0.8	1.6	1.6
Other non-rheumatologist	0.8	0.8	1.6	1.6
None Listed	1.6	2.4	1.6	1.6

<sup>a</sup> "Other" includes internist rheumatologist and/or general pediatrician and/or lectures/guest speakers and/or other rheumatologist.

<sup>b</sup> "Other" includes general pediatrician and/or lectures/guest speakers and/or other rheumatologist.

When one examines faculty involvement in the pediatric curriculum components by availability of a staff pediatric rheumatologist, the importance of having a pediatric rheumatologist on staff becomes more readily apparent. Faculty involvement was collapsed into three mutually exclusive categories: pediatric rheumatologist involved, internist rheumatologist involved without a pediatric rheumatologist, and general pediatrician or other provider. These classifications were compared between programs with and without staff pediatric rheumatologists for each of the four curriculum components.

Programs without pediatric rheumatologists at their institutions were significantly more likely to rely on internist rheumatologists and/or general pediatricians to address these curriculum areas (Table 20). For each curriculum component, nearly 100 percent of the programs with a pediatric rheumatologist on staff at their affiliated institution report their involvement in these training areas. In contrast, more than two-thirds of programs without pediatric rheumatologists at their affiliated institutions report that training in these areas was the domain of internist rheumatologists, general pediatricians, continuity clinics, and lectures and/or non-rheumatologists. It is interesting to note that approximately one-third of the programs without pediatric rheumatologists on staff nonetheless were able to involve them in their resident training.

**Table 20: Faculty Involvement in Pediatric Rheumatology Curriculum Components by Availability of a Staff Pediatric Rheumatologist on Site, Pediatric Residency Director Survey (n=126)\*\*\***

	Joint Exam (%)		Lab Work (%)		JRA Diagnosis (%)		JRA Treatment (%)	
	No	PR	No	PR	No	PR	No	PR
	PR	PR	PR	PR	PR	PR	PR	PR
Pediatric rheumatologist only or in combination with other providers, continuity clinic and/or lectures	24.5	95.8	30.8	98.6	32.1	97.2	35.9	98.6
Internist rheumatologist only or in combination with other providers, <sup>a</sup> continuity clinic and/or lectures	20.8	0.0	32.7	1.4	30.2	1.4	34.0	1.4
General pediatricians or continuity clinic with lectures and/or other non-rheumatologist	54.7	4.2	36.5	0.0	37.7	1.4	30.2	0.0

<sup>a</sup> Except pediatric rheumatologists

\*\*\* For each curriculum component and faculty classification, the difference between programs with and without staff pediatric rheumatologists are significant at p<0.001.

### *Availability of Pediatric Rheumatology Training in Medical Schools*

Dr. Charles Spencer, president of the AAP Section of Pediatric Rheumatology and Professor of Pediatrics at the University of Chicago and La Rabida Children's Hospital and Research Center, received a three-year award from the American College of Rheumatology to assess the status of pediatric rheumatology education in medical schools. Dr. Spencer found that of 53 responding clerkship directors (50 percent), one-quarter lacked a pediatric rheumatologist at their institutions on at least a part-time basis. Over 20 percent relied on a non-pediatric rheumatologist to teach pediatric rheumatology. More than three-quarters reported that a pediatric rheumatologist does not lecture to medical students during their

pediatrics clerkship. Only one-half of programs offer a pediatric rheumatology rotation to medical students. Thus, exposure to pediatric residency in medical school is quite low.<sup>34</sup>

### *Pediatric Rheumatology Visiting Professorship Programs*

One approach to expanding exposure to pediatric rheumatology training within pediatric residency is Pediatric Rheumatology Visiting Professorship Programs. Through these programs pediatric rheumatologist visiting professor programs are offered to schools that lack a pediatric rheumatology program.<sup>35</sup> However, funding of such programs are limited. Thus, it has only a limited ability to address the needs of the many institutions without pediatric rheumatologists on staff.

## **Issue 2: Insufficient Clinical Care Cost Recovery/ Financing Pediatric Rheumatology Positions**

Initial and follow-up patient visits in pediatric rheumatology are quite lengthy and involved. However, they do not usually include separate billable procedures that generate additional funds. Many other specialists often perform procedures that increase revenue. The revenue from pediatric rheumatologist extended office visits is insufficient to cover costs.

### *Adequacy of Reimbursement*

Medicaid provides health insurance for approximately 12 percent of the under 18 population in the United States. In contrast, pediatric rheumatologists estimate that one-third of their patients are covered by Medicaid.<sup>22</sup> As such, Medicaid reimbursement is particularly relevant to the financial viability of pediatric rheumatology practices.

Although past studies have shown that Medicaid and State Children's Health Insurance Programs (SCHIP) improves access for children who would otherwise be uninsured, Medicaid enrollees are significantly less likely than children with private coverage to receive a referral to specialty care, to receive specialty care, or to receive that care from a Board-certified physician.<sup>7, 36-39</sup> This pattern is similar to previous research, which, while not specific to specialty care, has shown that children with Medicaid have greater unmet needs than children with private insurance and fewer unmet needs than uninsured children.<sup>9, 40-42</sup> Some studies have suggested that the discrepancy in access observed between Medicaid-insured children and their privately insured counterparts is due, in part, to inadequate provider reimbursement.

The existing literature leaves no doubt that the adequacy of reimbursement, especially from public insurers, is insufficient to ensure access to pediatric subspecialty care. A study of access to surgical care for children with government-sponsored insurance found that only 27 percent of surgeons were willing to provide care to children with Medi-Cal vs. 97 percent being willing to treat privately insured children. Excessive administrative burden and low monetary reimbursement from the procedure were cited by 96 percent and 92 percent of respondents. One study in California found that children insured by Medi-Cal experienced significantly greater delays in treatment for fracture than privately insured peers; the authors of this study showed the Medi-Cal reimbursement for a follow-up visit for a broken arm was less than one-half that of Medicare.<sup>43</sup> A study of access to care for enrollees in SCHIP in five States found that that low reimbursement rates dissuaded pediatric subspecialists from participating in the program and contributed to hospitals' inability to retain pediatric subspecialists.<sup>44</sup>

Low levels of reimbursement may not be limited to Medicaid-insured patients, however. A study of developmental-behavioral pediatricians found that inadequate reimbursement was the most commonly reported constraint to seeing more patients.<sup>45</sup> Likewise, a survey of State Title V directors found that 44 percent cited inadequate reimbursement as a significant access barrier to pediatric subspecialty care receipt among children with health care needs.<sup>46</sup> These directors cited increased reimbursement rates as essential to improving the availability of and access to medical homes for children with special needs.

### *Reimbursement & Recruiting Pediatric Rheumatologists*

In the survey of pediatric residency directors, respondents were asked, to the best of their knowledge, if efforts had been made to recruit one or more pediatric rheumatologists to their institutions in the previous 5 years. Nearly one-quarter had successfully recruited one or more pediatric rheumatologists and an additional 11.2 percent had been unsuccessful in their recruitment efforts. Over one-third of programs reported an interest in recruiting a pediatric rheumatologist but an inability to recruit for financial or other reasons. Only 13 percent of the programs felt they did not need such a provider and 16 percent did not know about their institution's interest in hiring a pediatric rheumatologist.

Open-ended comments from these residency directors suggest that financial factors heavily influence their programs ability to hire a pediatric rheumatologist:

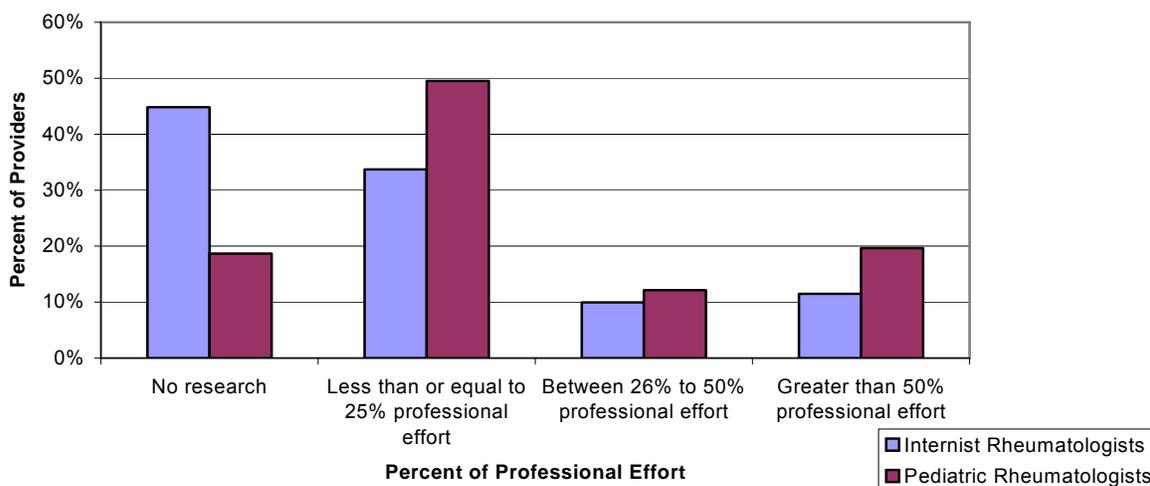
- *"... It should be noted that our rheumatologist functions as a generalist and teacher both in the clinic, newborn nursery and on the pediatric floor. He spends the majority of his time in these endeavors, not in rheumatology ... We would not be able to support a full-time rheumatologist and consider ourselves fortunate to have one who is also such a wonderful generalist and teacher."*
- *"The major barriers to bringing pediatric rheumatology to our center are lack of available ped[iatric] rheumatologists to recruit, funding based on clinically generated dollars (although our referral base is at the level to theoretically support the position), convincing [institution name] re: the financial viability of the position, finding ancillary dollars (education, research, etc) in a community-based academic residency, providing cross-coverage for on-call, etc."*
- *"We probably do not have sufficient patients within our tri-county referral area to justify a full-time on-site Peds Rheumatologist, nor do we have anything close to the budget for same ..."*
- *"To get an on-site specialist we would have to show that it is "cost-effective" to hire them, and with our population this would not be the case."*

### **Issue 3: Research Requirements Limit Patient Access to Care**

Pediatric rheumatologists generally divide their professional time across three activities: patient care, research, and medical education. Past research shows that having an interest in research and medical education is positively associated with pursuit of subspecialty training among pediatricians.<sup>9, 47, 48</sup> In other words, pediatric trainees with an interest in research are significantly more likely than those with lower levels of interest in research to pursue subspecialty training. Therefore, efforts to increase the supply of pediatric rheumatologists may be improved by acknowledging the importance of research opportunities as an incentive to subspecialization.

Data from the AF/ACR survey reveal that the majority of pediatric rheumatologists spend less than 20 percent of their time in research while a small percentage of these providers spend the majority of their time in research activities; suggesting that most pediatric rheumatologists specialize in either research or patient care (Figure 6). The level of research involvement among pediatric rheumatologists was significantly greater than internist rheumatologists, highlighting the relative importance of competing professional demands for pediatric rheumatology.

**Figure 6: Percent of Professional Effort Spent on Research by Specialty**



Source: AF/ACF Survey, 2004

There has been no investigation to date of the extent to which the current supply of pediatric rheumatologists affects their involvement in research; however, one-sixth of pediatric rheumatologists responding to the AF/ACR survey had decreased their patient care time in the previous 5 years because they obtained salary from a research source. As a result, successful receipt of research funding limits the amount of time that these providers are available for patient care.

In addition to personal interest in research, the transition to increased reliance on research-based funding may be due, in part, to incentives inherent in academic medical practice. As a cognitive, or non-procedural, pediatric subspecialty, pediatric rheumatology tends to generate low levels of clinical revenue because it involves mainly outpatient evaluation and management. Due to low levels of clinical revenue, academic medical centers often find it difficult to underwrite the costs of cognitive pediatric subspecialty practices. For this reason as well as the general mission of academic medical centers to foster research, many pediatric rheumatologists experience pressure to obtain research funding. Many research funding sources, such as those discussed in the following sections, require that providers devote a certain percentage of time to research endeavors, thereby forcing a decrease in their involvement in patient care.

## *Pediatric Rheumatology Research Funding*

Using data from the National Institutes of Health's (NIH) CRISP database, all NIH grants awarded to individuals with "pediatrics" or "rheumatology" in the position title between 1999 and 2003 were identified. Data from the CRISP database were merged with pediatric rheumatologists' data from the ACR using the first and last names of the principal investigator. Of 361 unique grants, only 7 were awarded to pediatric rheumatologists listed in the ACR file and all 7 went to the same two doctors. This suggests that few pediatric rheumatologists are successfully competing for NIH funding, but the completeness of the CRISP data for pediatric rheumatologists is not known.

While many NIH grants, such as Small Grant Awards (R03) and Investigator Initiated Grants (R01) do not specify the amount of time that a physician must be involved in the grant, Research Career Awards generally require that the recipient spend 75 percent of their professional effort in research endeavors. Consequently, pediatric rheumatologists receiving these grants spend 25 percent or less of their time in patient care.

### *Additional Funding Sources*

Concerns about fellowship and research funding have led to the development of specific programs that fund either fellowship training or junior researchers. The American College of Rheumatology, for example, has a Clinical Investigator Fellowship Award that provides training in clinical investigation to rheumatology fellows or rheumatologists early in their careers.<sup>49</sup> Similarly, the ACR and the Arthritis Foundation specifically provide awards for fellows during training and for young investigators. Some of these awards target pediatric rheumatologists while others fund both internist and pediatric rheumatologists. The awards provide salary support to physicians in fields where clinical revenues are often insufficient to fund positions; however, they may lead to reductions in the amount of time a provider spends in patient care.

The NIH sponsors a Pediatric Research Loan Repayment Program (Pediatric Research LRP) directed to physician and non-physician researchers active in pediatrics. In exchange for a 2-year commitment to pediatric research, the NIH will pay up to \$35,000 of educational expenses, an additional 39 percent to cover federal taxes, and reimburse awardees for State taxes due on the payments. In 2003 almost 500 people applied for the Pediatric Research LRP; nearly 300 received awards. This program requires, however, that recipients spend 50 percent of their time in research endeavors, again limiting their availability for patient care.

While programs like the Pediatric Research LRP are not specifically targeted to pediatric rheumatology, they provide pediatric rheumatology fellows and young investigators with opportunities to discharge some of the financial burdens of undergraduate and graduate medical education. Along with targeted programs like those available through the American College of Rheumatology and the Arthritis Foundation, these efforts attempt to address some of the potential causes of pediatric rheumatology shortages. While these programs do provide funding for pediatric rheumatologists' salaries, research requirements detract from their availability for full-time patient care and create a tradeoff between the availability of patient care and the scientific advancement of the field through research.

Pediatric rheumatologists largely function as patient care providers, educators, and researchers. Supply constraints limiting their available research time may delay much-needed advances in the cure of pediatric rheumatic diseases. The more time a provider devotes to

research, the less time they have available for patient care. The conundrum is that research is at the expense of clinical care or vice versa.

## **Summary**

Over one-third of medical schools and over 40 percent of pediatric residency programs lack a pediatric rheumatologist on staff, decreasing exposure to this field. As a consequence, medical students and pediatric residents may lack sufficient experience with pediatric rheumatology to develop an interest in the field or to feel comfortable co-managing the care of children with rheumatic diseases. As such, decreased availability of pediatric rheumatologists in training sites may perpetuate shortages and decrease the availability of substitutes for pediatric rheumatology care. This vicious cycle increases demand for pediatric rheumatologists by increasing the number of children referred for evaluation of conditions, such as fever of unknown origin and joint complaints that could sometimes be addressed by adequately trained primary care providers.

A unique feature of pediatric subspecialties, like pediatric rheumatology, is that the same pool of providers sees patients, performs research, and educates physicians-in-training. Several studies suggest that research opportunities are a major motivation to subspecialize among pediatricians; therefore, many pediatric rheumatologists likely entered the field in order to do research as well as patient care. Furthermore, academic medical centers are the dominant employer of pediatric rheumatologists and the demands of academic practice dictate much of their professional behavior. Non-procedural or cognitive pediatric subspecialties often fail to generate sufficient clinical revenue due to low reimbursement rates for non-procedural visits. As such, academic medical centers often rely on research revenue to fund pediatric subspecialty positions. Without these research dollars, fewer academic medical centers may be able to afford pediatric rheumatologists. The survey of pediatric residency directors found that one-third of programs would like to hire a pediatric rheumatologist but were unable to do so for financial or other reasons. Thus, involvement in non-patient care activities, such as research, may be essential to financing positions for pediatric rheumatologists while negatively affecting the amount of time a provider has available for patient care.

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## Chapter 6. Potential Solutions

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Multiple studies have demonstrated that the number and distribution of pediatric rheumatologists in the United States is not sufficient to provide patient care to all children with rheumatic diseases. At a minimum, the number of pediatric rheumatologists needs to increase from the current number of 192-200 to a minimum of 331-337 to achieve comparable provider to patient ratios across States. Furthermore, the availability of pediatric rheumatologists is not sufficient to ensure their involvement in the training of general pediatricians and internist rheumatologists. Additional providers may be needed to ensure the availability of pediatric rheumatologists at medical schools and pediatric residency programs. The effects of the current shortage of pediatric rheumatologists on the progress of research are unknown. The supply of pediatric rheumatologists ideally should be sufficient to allow these providers to participate in basic and clinical research and allow a certain percentage of them to devote the majority of their professional time to advancing the understanding and management of these diseases.

Whenever there are concerns about the availability of physician services, several potential solutions are typically debated. This report discusses several options, including increasing the supply of pediatric rheumatologists, increasing the role of internist rheumatologists and general pediatricians in the care of children with rheumatic diseases, using telemedicine to facilitate patient care and continuing education, developing shared management programs, and using nurses or physician assistants to extend pediatric rheumatologists.

### Increase Supply of Pediatric Rheumatologists

One possible solution to the current supply of pediatric rheumatologists is to increase their numbers. There are approximately 200 pediatric rheumatologists presently in the United States and 49 fellows in training. A small number of these trainees may fail to complete training or may leave the United States; nevertheless, an influx of new rheumatologists over the next several years can be expected. Retirement rates in the field have not been studied; however, the ABP reports that eight pediatric rheumatologists are currently over the age of 60 and data from the AF/ACR survey suggest that one to two pediatric rheumatologists retire annually. It is unclear how many providers will be lost to career changes over time; **assuming a low retirement rate, at current training levels it will take 12-15 years to reach the AAP goal of 400.**

While models described in this report project the need for an increase to at least 331-337 pediatric rheumatologists, the models use a fairly large patient to provider ratio that may not be realistic. More detailed data on actual patient volumes may help refine these estimates and allow a more accurate estimate of the number of pediatric rheumatologists needed nationwide.

Increases in the supply of pediatric rheumatologists would be most helpful to the extent that new pediatric rheumatologists locate in medical schools and geographic areas that currently lack pediatric rheumatologists and have sufficient patient demand to support their services. ABP data have shown that over 80 percent of pediatric rheumatologists who completed training since 1987 practice within a county that also has at least one pediatric rheumatologist who graduated from medical school prior to 1987; consequently, only one in five recently trained pediatric rheumatologists either works in a market that has no other provider or replaced a retiring provider. There are several States, for instance Arizona, South Carolina, and

Alabama, that currently lack pediatric rheumatologists and have pediatric populations that are sufficiently large to support the patient care activities of one or more pediatric rheumatologists. Programs that encourage entry of pediatric rheumatologists seem warranted for those geographic areas that lack these providers despite having an adequate population base.

Areas with large numbers of pediatric rheumatologists, like Cincinnati or Chicago, tend to have one or more academic medical centers; however, many pediatric rheumatologists at these centers may be primarily research physicians and provide limited patient care. As such, supply may be inadequate even in areas with a relatively large number of providers. To assess the need for additional providers in these areas, studies of actual clinical full-time equivalents and wait times for an initial patient appointment may be helpful.

Because salary concerns and reimbursement issues figured prominently in pediatric rheumatologists' assessment of factors contributing to the nationwide shortage of these providers, efforts to increase interest in this field may require improvements in the financial remuneration of pediatric rheumatology practice through increases in provider reimbursement. Increases in reimbursement will also enhance the financial viability of pediatric rheumatology practices within academic medical centers and may provide the necessary funds for the centers to support pediatric rheumatologists.

In addition to concerns about patient care, the supply of pediatric rheumatologists has important implications for the training of general pediatricians. Many pediatric residents and medical students have limited exposure to pediatric rheumatology, which may relate to general pediatricians reluctance to pursue additional training in this field or be involved as primary care physicians in the care of children with JRA.<sup>30</sup> Programs and/or interventions that facilitate the placement of pediatric rheumatologists in residency programs may not only increase the availability of pediatric rheumatology care but also enhance the education of general pediatricians about rheumatic diseases and encourage their involvement in the care of children with rheumatic diseases.

The implications of the current supply of pediatric rheumatologists on the advancement of basic and clinical research are not known and need to be established. A lack of investigators may delay the development of novel remedies for the largely incurable rheumatic illnesses affecting children. Studies of the relationship between patient to provider ratios and successful funding and publication may be enlightening.

*Possible Options:*

1. Increase the supply of pediatric rheumatologists in those areas that currently lack providers despite sufficiently large pediatric populations, have high patient to provider ratios, and lack pediatric rheumatologists' involvement in the training of general pediatricians.
  - Allocate additional resources to fellowship programs to support training.
  - Include pediatric rheumatology as a specific focus area for the loan repayment programs.
  - Target funding for salary or research support to institutions that lack pediatric rheumatologists or have an inadequate number of providers.
2. Assess wait times for initial patient appointments at centers with pediatric rheumatologists to determine if additional providers are needed at these institutions.

3. Review reimbursement policies to improve the financial viability of pediatric rheumatology practices, facilitating hiring of pediatric rheumatologists in centers that lack them due to financial constraints, improving retention and making the field more attractive to current trainees.
4. Assess the tension between provision of patient care and the research and educational demands of academic practice.

### **Increase Reliance on Internist Rheumatologists and/or General Pediatricians**

Another potential interim solution is to increase the involvement of internist rheumatologists and/or general pediatricians in the care of children with rheumatic diseases. The prominent role of internist rheumatologists in the care of children with rheumatic diseases is well established.<sup>4, 6, 21, 22</sup> The American College of Rheumatology Guidelines on the Referral of Children with Rheumatic Diseases acknowledges the capacity constraints facing the pediatric rheumatology workforce and recognizes the value of internist rheumatologists as care providers.<sup>52</sup> Efforts to enhance the involvement of internist rheumatologists in the care of children with rheumatic diseases must ensure their comfort in treating these children, facilitate the provision of quality care, and provide access to pediatric rheumatology expertise. The development and dissemination of practice guidelines may be particularly useful as internist rheumatologists involved in the care of children have expressed interest in the availability of practice guidelines for the treatment of children with JRA.<sup>30</sup>

The role for general pediatricians and/or physician extenders in increasing access to care for children with rheumatic diseases appears to be rather limited at present. One single-center study showed that children with swollen joints are frequently referred to orthopedic surgeons before being referred to pediatric rheumatologists; a more recent national survey found, however, that general pediatricians and family practitioners refer the majority of JRA patients to pediatric and internist rheumatologists.<sup>53</sup> The overwhelming majority of pediatricians and family practitioners lack confidence in their ability to diagnosis and manage JRA and few describe themselves as being current in the treatment of JRA.<sup>30</sup> Primary care providers at most may be willing to co-manage the care of children with JRA; their willingness to be involved in the care of the rarer rheumatic diseases is not known.

The involvement of internist rheumatologists and/or general pediatricians in the care of children with rheumatic disease can be encouraged through a variety of approaches: changes in graduate medical and continuing education, use of telemedicine for patient care and educational purposes, and establishment of shared management networks.

#### *Graduate Medical and Continuing Education*

Exposure to pediatric rheumatology during training may enhance internist rheumatologists' willingness to see children. A previous study found that over 60 percent of Washington State internist rheumatologists who treated children reported having moderate to extensive pediatric rheumatology experience during their fellowship, but only 20 percent who did not treat children characterized their level of exposure to pediatric rheumatology during their fellowship as moderate or extensive.<sup>4</sup> Over 50 percent of California internist rheumatologists involved in the care of children reported having no or minimal exposure to pediatric rheumatology during their fellowship training. Currently, internist rheumatology fellowship training guidelines recommend, but do not require, the inclusion of training in pediatric

rheumatology;<sup>54</sup> consequently, many internist rheumatologists may lack sufficient exposure to clinical pediatric rheumatology during their training to encourage pediatric rheumatic disease care in their practices.

A viable approach to enhancing the involvement of internist rheumatologists in the care of children with rheumatic diseases may be to expand their training to include adolescents, as fellowship training requires in endocrinology, diabetes and metabolism.<sup>55</sup> At least one study suggests that the role of internist rheumatologists in the care of children with rheumatic diseases is fairly limited to adolescents;<sup>22</sup> augmenting their exposure to these patients during fellowship may increase their willingness and ability to care for this subpopulation. Greater availability of elective pediatric rheumatology rotations during adult rheumatology fellowships may further enhance internist rheumatologists' willingness to care for younger children with rheumatic diseases.

Few general pediatrics residents currently do a formal pediatric rheumatology rotation during residency; the relationship between this lack of exposure and their lack of involvement in the care of rheumatic diseases remains unclear. Freed and colleagues<sup>30</sup> found that only 42 percent of surveyed pediatricians felt comfortable treating JRA and only 18 percent described themselves as adequately trained to diagnose/manage JRA. Greater exposure to pediatric rheumatology care during residency may enhance general pediatricians' willingness to be involved in the care of these children and increase interest in the field.

There are several efforts to increase access to pediatric rheumatology care and pediatric rheumatology training. Visiting professor programs increase the availability of training in pediatric rheumatology to pediatric residency programs lacking pediatric rheumatologists on staff. CARRA includes internist rheumatologists involved in the care of children and establishes linkages between these providers and pediatric rheumatologists, which expands access to pediatric rheumatology expertise as well as clinical trials to a wider group of patients.

Annual meetings of the ACR and the American Academy of Pediatrics (AAP) have been, and continue to be, sources of continuing education for non-pediatric rheumatologists interested in the care of children with rheumatic diseases. The Rheumatology Section of the AAP sponsors sessions related to the care of these children at the annual meeting of the AAP; similarly, sessions of pediatric rheumatology for internist rheumatologists are offered annually at ACR. The success of these programs in encouraging the involvement of general pediatricians and internist rheumatologists in the care of children with these diseases has not been established.

Finally, Freed and colleagues demonstrated through surveys and focus groups that internist rheumatologists had an interest in practice guidelines for the treatment of JRA. Development and widespread dissemination of these guidelines to these providers will assist them in providing state-of-the-art care to children with this disease. Pediatric guidelines for the treatment of other rheumatic diseases, like lupus, may also help internist rheumatologists tailor care to the unique needs of children and adolescents.

#### Possible Options:

1. Expand requirements of internist rheumatology training to include adolescents.
2. Develop on-line or CD-ROM-based training programs and make it available to internist rheumatologists, general pediatricians, pediatric residents, and medical students.
3. Develop pediatric guidelines for the most common juvenile rheumatic diseases and disseminate the guidelines, especially to internist rheumatologists.
4. Facilitate general pediatricians' exposure to pediatric rheumatology during residency through programs like the Amgen Pediatric Rheumatology Visiting Professorship or telemedicine, or encourage pediatric rheumatologist placement at centers that lack these providers through targeted young investigator awards or other programs.
5. Monitor attendance and evaluate effectiveness of continuing education sessions offered at annual meetings.

### *Telemedicine and Other Technologies*

Telecommunications, for instance telemedicine and Internet-based seminars, may be useful in ameliorating the poor distribution of pediatric rheumatologists by providing an educational medium in addition to facilitating consultation with distant pediatric rheumatologists. Using telemedicine, internist rheumatologists can consult with distant pediatric rheumatologists on pediatric cases in which they are involved. Patients benefit from the unique training and expertise of pediatric rheumatologists through these consultations and, consequently, receive more effective care. Such interactions also serve as an ongoing teaching opportunity for participating internist rheumatologists.

The use of telecommunications during the medical training of internist rheumatologists, primary care physicians, and general pediatricians may facilitate exposure to pediatric rheumatology. Students could participate in lectures online and have pediatric rheumatologists on "virtual" call during rounds for consultation, providing access to pediatric rheumatologists nationwide. Exposure to pediatric rheumatology during training ultimately may increase the comfort of these physicians in diagnosing and even co-managing care for patients living in areas without pediatric rheumatologists. Similar technologies can be used to supply continuing education to providers.

Studies show the beneficial use of telemedicine to increase access to Continuing Medical Education (CME), especially for rural physicians. In a 21-month study, 927 physicians in rural Vermont and upstate New York were able to attend grand rounds at Fletcher Alan Health Care in Burlington; almost three-quarters of the participants reported that it was "as effective as having the presenter in the room."<sup>56</sup> A similar study was conducted in Nova Scotia, Canada where participants reported that one of the most beneficial aspects was the ability to interact with and engage in discussions with other distant participants.<sup>57</sup>

Telemedicine also may be used to increase access to patient care for children with rheumatic diseases. For children under 12 with rheumatic diseases, especially those living distant from academic medical centers, care may be especially difficult to obtain. It is not clear that training requirements can be changed to include this patient population for all internal medicine rheumatology programs, especially those without access to pediatric rheumatologists. Among the internist rheumatologists involved in the care of children in the California survey,

more than three-quarters indicated interest in obtaining advice from a pediatric rheumatologist via telemedicine or videoconferencing.<sup>22</sup> Slightly more than one-quarter of internist rheumatologists not treating pediatric patients indicated that the ability to obtain advice from a pediatric rheumatologist via telecommunications would influence their willingness to treat pediatric patients.

Past studies of telemedicine have demonstrated high levels of patient and family satisfaction with their telemedicine experiences.<sup>58-60 61</sup> Karp and colleagues found that patient satisfaction with telemedicine was enhanced by the presence of a nurse case manager, the inclusion of a patient orientation before the consultation, and the quality of the equipment. In several studies patients indicated that telemedicine saved them time and travel costs.<sup>59, 60</sup> Another study found that parents of children with special health care needs (CSHCN) living in rural areas often preferred telemedicine over waiting several days to visit a specialist outside their local area.<sup>62</sup> Studies of provider satisfaction have been less consistent than those of patient satisfaction. Some suggest that remote clinicians have less confidence in their diagnostic accuracy than face-to-face providers;<sup>63 64</sup> other studies suggest that provider satisfaction and comfort with telemedicine increases with exposure to telemedicine services.<sup>58, 59</sup>

Some unanswered questions surrounding the widespread use of telemedicine for patient care include by whom and how payment will be provided. Because Medicaid programs are not required to inform the Centers for Medicare and Medicaid Services (CMS) about their practices regarding telemedicine reimbursement, existing data on Medicaid reimbursement for telemedicine are out-of-date. According to 2001 data from the CMS Web site, approximately 18 States reimburse physicians for telemedicine services; these States generally paid providers at the originating site as well as the distant site.<sup>65</sup> Under the Benefits Improvement and Protection Act of 2000, Medicare also expanded coverage for telehealth services; however, Medicaid rules require that the originating site be within a designated rural health professional shortage area, a non-metropolitan statistical area, or a Federal telehealth demonstration project. Little is known about coverage for telemedicine among private insurers.

Other obstacles to widespread use of telemedicine include the availability of remote specialists to be on-call for teleconsultations, the availability of sufficient technology in rural communities to support a telemedicine program, maintenance of confidentiality, adaptation of State licensure laws when the distant provider is out-of-State, and financing of the initial capital investment.

#### Possible Options:

1. Assess the availability of reimbursement for care delivered to children with rheumatic diseases via telemedicine.
2. Survey pediatric rheumatologists to assess their access to telecommunications and their willingness to provide patient care and training using these media.
3. Survey training programs about their interest in using these media as part of physician training.
4. Pilot telecommunications-based educational programs that link pediatric rheumatology centers and residency programs without pediatric rheumatologists and evaluate their effectiveness at improving knowledge, skills, and comfort levels.

5. Pilot a telecommunications-based patient care network that links pediatric rheumatologists with distant providers and evaluate patient and providers outcomes.

### *The Shared-Management Approach*

A shared management model allows community-based physicians, along with university-based specialists, to co-manage the care of patients with special needs. Under such a system the community-based physician refers the patient to a university-based specialist who diagnoses the condition and prescribes a treatment regimen. The patient then returns to the referring physician where treatment is co-managed with the specialist, sometimes using telemedicine. One study found that more than 75 percent of chemotherapy could be provided by community-based physicians participating in such a system with the University of Iowa Pediatric Cancer Center.<sup>66</sup> Survival rates were comparable between those children who received care through the shared management approach and those who received care only from a pediatric oncologist.

The potential benefits of using this approach for pediatric rheumatology patients are many, including increased access for those living in rural areas without a pediatric rheumatologist, economic savings in per-visit costs and travel expenses, and a sense of relief from the anxiety associated with being so far from a physician who is knowledgeable about your individual care needs. Participating primary care physicians also appreciate these arrangements for their educational value, the improved relationships with specialists, and the relief of having another physician with whom to share the stress of patient care. It is also beneficial to the university-based specialist as it increases their referral base.<sup>66</sup>

### Possible Options:

1. Survey pediatric rheumatology programs to assess their current involvement in shared management with other providers.
2. Pilot a shared management program, similar to the University of Iowa Pediatric Oncology Program, for children with rheumatic diseases and evaluate patient and provider outcomes.

### *Increased Reliance on Nurses to Manage Telephone Inquiries*

In some physician clinics, creating a “Telephone Nursing Line” can dramatically decrease the time physicians spend giving telephone advice and increase their available time for office visits.<sup>67</sup> With adequate training nurses can become qualified to address calls about medications, test results, and symptom management, in addition to medical administrative issues. A study conducted in a pediatric neurology outpatient clinic found that nurses were able to respond to 52.9 percent of all incoming calls and to successfully triage the remaining calls to the appropriate physician.<sup>67</sup> While there are some liability concerns surrounding the potential for incorrect diagnoses and breach of confidentiality, it is believed that, with sufficient training, these risks can be minimized. Given the multitude of competing demands on the time of pediatric rheumatologists, increased reliance on nurses appears to be a potential solution to the problem of insufficient time to address medical questions over the telephone – an important component of the continuity of care for families of rheumatic children.

Possible Options:

1. Assess the role of nurses, advance-practice nurses, and physician assistants in extending pediatric rheumatologists by performing selected duties, such as case management and telephone triage.
2. Assess the feasibility of training advanced-practice nurses and physician assistants to provide pediatric rheumatology care in an underserved area, through a care network established with a distant pediatric rheumatologist.

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## *VII. Conclusions*

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Given the potential for severe illness and disability associated with pediatric rheumatic diseases and the potential for a markedly improved outcome with optimal treatment, an adequate supply of pediatric rheumatologists is essential to provide access to expert care for children with these diseases. An increase in the supply of the pediatric rheumatology workforce is appropriate at this time. Given the analyses presented in this report, at least a 75 percent increase in the number of pediatric rheumatologists is needed. To reach the goal of 400 pediatric rheumatologists recommended by the American Academy of Pediatrics Section on Pediatric Rheumatology, the number of pediatric rheumatologists in the United States needs to double. Additional providers should be encouraged to practice in those areas where they are most needed, i.e., States with no or a relatively low pediatric rheumatologist supply. At a minimum the 45 medical schools<sup>18</sup> that currently lack a pediatric rheumatologist on faculty would benefit from the presence of a pediatric rheumatologist for resident and fellowship training programs in pediatrics, internal medicine rheumatology and orthopedics in addition to providing subspecialty care for affected patients. Increases in the supply may be accomplished through institutional support for fellowship training, designated salary and research funding for pediatric rheumatologists, and/or improved reimbursement rates.

In addition to increasing the number of pediatric rheumatologists, efforts to increase the ability and willingness of internist rheumatologists to manage or co-manage the care of these children could be pursued and evaluated. Efforts to increase their involvement may provide a short-term solution while pursuing “pipeline” approaches as well as provide a long-term solution in areas that lack sufficient patient demand to support a pediatric rheumatologist. Some possible approaches already in use include continuing medical education for internist rheumatologists at the annual ACR meeting and for general pediatricians at the AAP annual meeting. The role of telemedicine in extending the catchment area of pediatric rheumatologists, as well as the ability of these providers to co-manage care with distant physicians, should be explored. The creation of pediatric rheumatology care networks that formally establish relationships between centers without such providers and distant pediatric rheumatologists may facilitate shared management of patients using telemedicine and other technologies. Long term approaches to increasing the role of internist rheumatologists and primary care providers include revising ACGME program requirements to include exposure to the care of adolescents and/or younger children in internist rheumatology fellowship training and to increase exposure to pediatric rheumatology in general pediatrics residencies. Efforts to study the relative quality of care associated with different management approaches should coincide with efforts to enhance access to care among children with rheumatic diseases. More research is needed to determine the relative quality of care of these various providers and the implications for patient outcomes.

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## *Appendix A: The Pediatric Rheumatic Diseases*

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### **Juvenile Rheumatoid Arthritis (JRA)**

JRA, which is a unique clinical entity and distinct from rheumatoid arthritis, affects 148-167 per 100,000 children;<sup>68</sup> it is the most common cause of acquired disability in children. In JRA, the overall inflammatory process causes swelling of joints and is often accompanied by pain, rash, and loss of mobility. The disease is classified into three types: pauciarticular onset, polyarticular onset, and systemic onset, each with its own set of symptoms and prognoses.

#### *Subtypes*

##### Pauciarticular

Pauciarticular onset, or oligoarticular onset, is the most common form of JRA accounting for 35 percent to 50 percent of all JRA cases.<sup>68</sup> By definition, pauciarticular JRA affects four or fewer joints and is most often limited to the larger joint--the knee, elbow, or ankle.<sup>68</sup> The effects of this form are usually asymmetrical and symptoms include swelling of the affected joints, stiffness, and mild pain. The peak age for diagnosis is between 1 and 3 years of age; it affects females more commonly than males, the ratio of females to males being 4-5:1.<sup>68</sup>

In addition to joint inflammation, in approximately 10-20 percent of the cases pauciarticular JRA is associated with anterior uveitis (i.e., inflammation of the anterior portion of the uveal tract of the eye). Uveitis most often occurs in patients who develop pauciarticular JRA before the age of 2 and who are ANA positive (i.e., their blood tests positive for antinuclear antibodies). Symptoms of uveitis may occur for many years after the joint-related symptoms of JRA have remitted and may be relapsing or chronic.<sup>68</sup> Patients who fit this classification should be monitored regularly by an ophthalmologist who is familiar with the effects of JRA.<sup>68</sup>

The prognosis of pauciarticular JRA is the most favorable of all three forms infrequently resulting in permanent disability or joint damage. However, 10-20 percent children with pauciarticular onset go on to develop polyarticular JRA (i.e., arthritis that affects five or more joints), sometimes called extended oligoarticular JRA. Long term sequelae of pauciarticular JRA are more common for those who develop the disease at a younger age.<sup>69</sup> For those who develop chronic uveitis, vision problems may persist for many years after joint inflammation has subsided and permanent eye damage may occur.

##### Polyarticular

Polyarticular juvenile rheumatoid arthritis affects five or more joints; the overall symptoms are similar to those of adult rheumatoid arthritis. About 40 percent of children with JRA have this form, with girls accounting for approximately 80 percent of cases.<sup>68</sup> It occurs in two peaks, early childhood and adolescence. While it typically affects the small joints in the hands, it can also affect larger joints or the knee, ankle, hips, neck, and jaw. Polyarticular JRA is a symmetrical form of arthritis and can potentially inhibit growth in affected joints. Many children experience, for example, retarded growth of their temporomandibular joint (TMJ), which causes pain while chewing and brushing; this can lead to decreased appetite and dental problems.

Other symptoms of polyarticular JRA can include low-grade fever, anemia, and inflammation of internal organs. Chronic uveitis, occurring in 10 percent of children, is less common in children with this form of JRA.<sup>68</sup> The prognosis of this form is dependent on the number joints affected and the degree of inflammation. The disease manifestations of polyarticular JRA often continue into adulthood and, similar to pauciarticular JRA, those who experience onset at an earlier age are more likely to see a longer duration of the disease.<sup>69</sup>

### Systemic Onset

Systemic onset JRA is the least common, but most virulent, form of JRA; it affects between 10 and 20 percent of children with JRA and strikes boys and girls at equal rates.<sup>68</sup> The most common symptoms include persistent high-grade fevers, rash, and arthritis of multiple joints. Systemic onset JRA can also cause inflammation of the outer lining of the internal organs (most often the heart and lungs), anemia, high white blood cell and platelet counts, and enlarged lymph nodes, liver, or spleen. Macrophage activation syndrome is an uncommon and potentially fatal complication; uveitis is uncommon with systemic onset JRA.

The prognosis of systemic onset JRA varies widely. One study shows that, unlike pauciarticular and polyarticular JRA, younger age at onset appears to indicate a shorter duration of active disease.<sup>69</sup> Some cases remit within one year but recurrent flare-ups are common. Up to 30 percent of cases disappear completely with no long-term effects, but approximately one-half of cases worsen with time and are marked by increasingly destructive arthritis.<sup>68</sup>

**Table A.1: Characteristics of Juvenile Rheumatoid Arthritis Subtypes**

<b>Characteristics</b>	<b>Pauciarticular Onset</b>	<b>Polyarticular Onset</b>	<b>Systemic Onset</b>
Percentage of JRA cases	35-50%	35-45%	10-20%
Female/Male ratio	4-5: 1	3-4: 1	1: 1
Typical age of onset	1-3 years	Variable/early and late childhood	Variable
Number of joints involved at onset	4 or fewer	5 or more	Variable
Pattern of joints	Large; Asymmetrical	Any; Symmetrical	Any; Symmetrical
Risk of uveitis	High	Medium	Low
Disease duration with early onset	Longer	Longer	Variable
Overall Prognosis	Minority progress to destructive arthritis	Half progress to destructive arthritis	Some remit completely; some worsen to severe arthritis

## **Other Pediatric Rheumatology Diseases**

### *Systemic Lupus Erythematosus*

Systemic lupus erythematosus (SLE), commonly known as lupus, is an autoimmune disease that typically affects the joints, skin, kidneys, heart, lungs, blood, and central nervous system. Symptoms vary greatly across individuals, ranging from fatigue, high fever, skin rashes, and swollen joints to kidney failure, seizures, and cardiac and lung disease. The Lupus

Foundation of America estimates that approximately 1.4 million Americans have some form of the disease.<sup>70</sup> More than 85 percent of patients are women and SLE is most common among minorities, with African American women experiencing the highest incidence.<sup>71</sup> While it is rare for lupus to be diagnosed in pre-pubescent individuals, the Arthritis Foundation estimates that in the United States approximately 25,000 children and adolescents have the disease.<sup>72</sup> There are three other less severe types of lupus: discoid lupus erythematosus, drug-induced lupus, and neonatal lupus, the rare form that affects newborns of women with lupus.

The overall prognosis for SLE is improving over time with 5-year survival rates increasing from 50 percent in 1950 to 80-90 percent in the 1990s;<sup>73</sup> some statistics now show the 10-year survival rate at 90 percent, which is believed to be a result of improved medical care.<sup>68</sup> The treatment of SLE involves the use of NSAIDs, corticosteroids, antimalarials, and immunomodulating drugs. The side effects of some of the drugs can be serious, including weight gain, osteoporosis, anemia, high blood pressure, and immunosuppression, which increase susceptibility to infections. Immunosuppression is a particularly vexing problem as several studies have found infection to be the most common cause of death in SLE.<sup>74, 75</sup> Much like children with JRA, children affected by lupus require close medical supervision to monitor medication side effects and disease flares and access to a continuum of collaborative care across several areas of medicine, including nephrology, cardiology, and others.

### *Other Diseases*

There are dozens of rare rheumatic diseases that can affect children. A few of the more common kinds are:

- Juvenile Psoriatic Arthritis – characterized by nail pitting, psoriatic rashes behind the ears, on the eyelids, and other atypical areas. Long-term effects include permanent joint damage and decreased range of motion and eye problems.
- Juvenile Vasculitis – variants include polyarteritis, Wegener's granulomatosis, and Takayasu's arteritis, but the most common symptoms include rash, arthritis, lung problems, abdominal pain, and renal dysfunction. More serious cases can involve major organs, nerves, and the intestinal tract. Some forms are more common in boys.
- Juvenile Scleroderma – thickening of the skin caused by increased collagen deposits that can lead to growth abnormalities, loss of skin elasticity, and Raynaud's phenomenon. Disease can be localized or systemic, affecting multiple organs, and affects more girls than boys.
- Juvenile Dermatomyositis (JDMS) – skin rash and weakened muscles caused by inflamed blood vessels in skin and muscle tissue. Affects 3,000-5,000 children in the United States.
- Juvenile Spondyloarthropathy Syndromes – family of disorders characterized by arthritis in the spine, sacroiliac and other large joints, and eye inflammation. Occurs more often in boys than girls.

Rheumatic diseases can range from being very localized and mild to systemic and potentially life threatening. Because of the complex nature of the trajectories of pediatric rheumatic disease, it is crucial that a child suspected of having one of these illnesses visit a pediatric rheumatologist early in the illness to either establish or confirm the diagnosis, and to continue to be monitored throughout the duration of the illness to ensure proper use of pharmacotherapies as well as adjunctive therapies. The involvement of a pediatric rheumatologist also enhances access to novel therapies and therapies available only through

clinical trials. In addition, a child with a rheumatic disease may require the care of a team of physicians and other providers to ensure that all physical and emotional symptoms are being addressed.

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## *Appendix B: A Primer on Pediatric Subspecialty Workforce*

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### **Defining Pediatric Subspecialty**

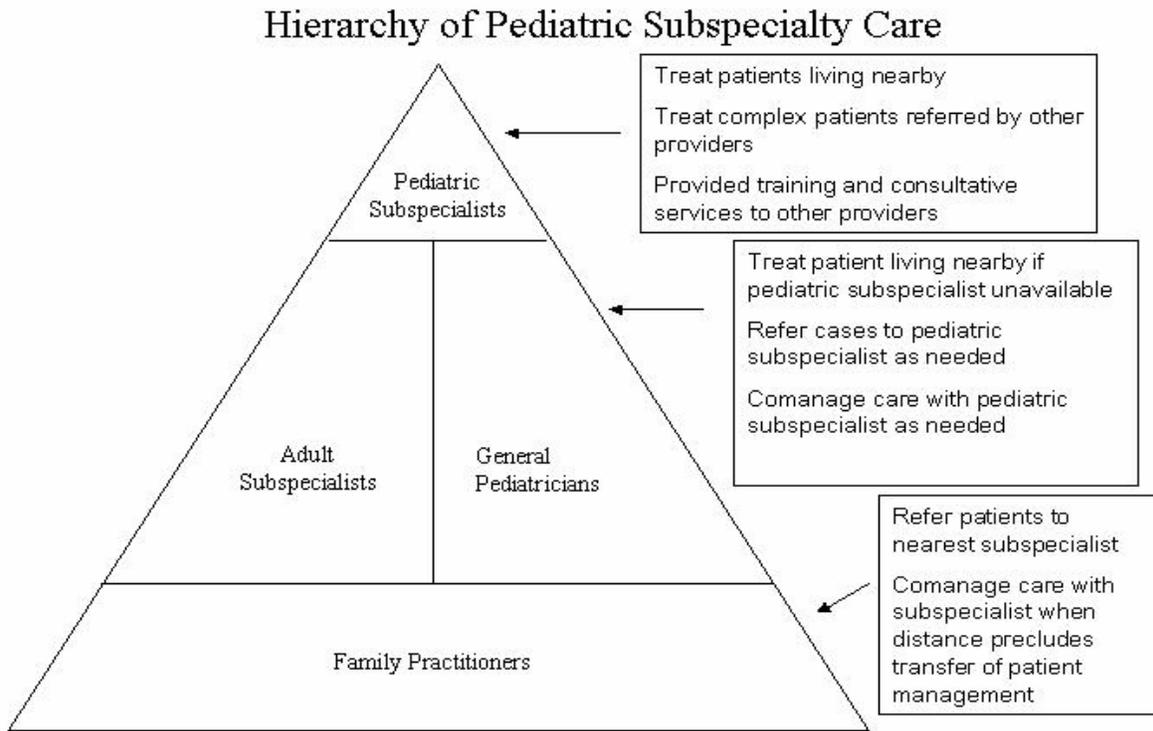
Pediatric subspecialties are those specialties in which a physician provides specialized pediatric medical care beyond the scope of primary care. There are a variety of routes to becoming a pediatric subspecialist. Pediatric medical subspecialists, such as pediatric rheumatologists and pediatric cardiologists, first complete a 3-year residency in pediatrics and then a 3-year fellowship in their subspecialty field. For other fields, such as pediatric surgery, dermatology, and anesthesiology, a physician completes a residency in the field during which he/she care for adults and children and then pursues additional training exclusively in the care of children. The American Board of Pediatrics certifies the pediatric medical subspecialties while other Boards certify pediatric surgical subspecialists and others.

### **The Hierarchy of Pediatric Subspecialty Care: A Theoretical Model**

One can envision pediatric subspecialty care as a hierarchy that depicts not only the increasing level of specialization among the providers involved, but also reflects their relative numbers and geographic dispersion (Figure A.1). At the base family practitioners represent the most common general providers.<sup>76</sup> Family practitioners, available in over 99 percent of towns with populations as small as 10,000 to 20,000, are also the most geographically accessible providers of pediatric care. Pediatricians and physicians double boarded in internal medicine and pediatrics may be considered more specialized than family practitioners in the care of children. In contrast to family practitioners, pediatricians spend their 3 years of residency dedicated to the treatment of the under-18 population. While family practitioners also have a 3-year residency their training programs includes the care of both adults and children; therefore, their pediatric training is less intense. Pediatricians devote their patient care to children; consequently, the breadth and depth of their pediatric experience exceeds that of family practitioners over time. Pediatricians are also less numerous and less geographically diffuse than family practitioners.<sup>76</sup>

In addition to general pediatricians, adult (internist) subspecialists may be an important source of chronic illness care for children and adolescents. While adult subspecialists are not trained intensively to treat pediatric patients, some adult fellowships include opportunities to train in the treatment of pediatric patients in conditions relevant to their specialty area. Endocrinology training, for example, requires training in the care of adolescents with diabetes mellitus. Thus, adult subspecialists are a potential source of care for chronically ill pediatric patients that may be more specialized than the care provided by general pediatricians. The report discusses at length the role of internist rheumatologists in the care of children with rheumatic diseases.

FIGURE 7



Pediatric subspecialists are at the top of the hierarchy for pediatric subspecialty care. Pediatric subspecialists have the most intensive training in the treatment of chronically ill children and represent the optimum source of pediatric subspecialty care. Pediatric subspecialists treat relatively low-incidence diseases; standard economic location theory predicts that these specialists will locate in large urban areas.<sup>77</sup> Furthermore, the location decisions of pediatric subspecialists may be strongly dependent on the location of academic medical centers.

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## *Appendix C: Pediatric Rheumatology Data Sources*

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The results of previously published studies identified by a systematic review of the pediatric subspecialty workforce literature were synthesized for this report. In addition to these published studies, analyses were performed using 2003 data from the American Board of Pediatrics (ABP), which certifies pediatric rheumatologists and other pediatric subspecialists, and 2001 and 2004 membership data from the American College of Rheumatology (ACR).

For most States (n=35) the ABP and ACR files identify equal numbers of non-trainee providers (Table 2); States highlighted in yellow have unequal numbers. Each of these data sources has their unique advantages and disadvantages. The ABP data provide data on all Board-certified pediatric rheumatologists, date of certification, and year of graduation. The file excludes deceased and retired providers; however, from this file one cannot determine if a given diplomate currently is involved in rheumatology patient care. In addition, there are likely physicians who provide pediatric rheumatology care who have not been certified, potentially resulting in an underestimate of the actual supply of these specialists.

The ACR file, in contrast, relies upon self-reported specialty practice to identify pediatric rheumatologists and likely includes providers without formal pediatric rheumatology training. The ACR file has the advantage of providing information on professional activities, practice site, and other disciplines. These additional data allowed the exclusion from the estimates of physicians not currently involved in patient care.

In this report both the 2003 ABP and 2004 ACR files were used to perform analyses of supply. To generate maps of practice locations of pediatric and internist rheumatologists data from the 2004 and 2001 ACR Membership Files, respectively,<sup>ix</sup> were used. For analyses of the practice characteristics and professional activities of pediatric and internist rheumatologists the 2001 ACR Membership File was used; for analyses of practice location by year of graduation, the 2003 ABP data were used.

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<sup>ix</sup> Our 2004 ACR data only includes pediatric rheumatologists.

**Table C.1: Number of Pediatric Rheumatologists by State and Data Source**

State	Number of Board Certified Pediatric Rheumatologists (2003 American Board of Pediatrics)	Number of "Self-Described" Pediatric Rheumatologists (2004 American College of Rheumatology)
Alabama	0	0
Alaska	0	0
Arizona	0	0
Arkansas	1	2
California	20	23
Colorado	2	2
Connecticut	4	4
Delaware	2	2
Florida	10	8
Georgia	3	3
Hawaii	3	2
Idaho	0	0
Illinois	8	7
Indiana	2	2
Iowa	1	1
Kansas	3	2
Kentucky	2	2
Louisiana	4	4
Maine	0	0
Maryland	7	6
Massachusetts	11	8
Michigan	7	8
Minnesota	5	5
Mississippi	1	1
Missouri	7	5
Montana	0	0
Nebraska	1	1
Nevada	0	0
New Hampshire	0	0
New Jersey	4	8
New Mexico	1	1
New York	15	12
North Carolina	4	4
North Dakota	0	0
Ohio	12	11
Oklahoma	3	3
Oregon	2	2
Pennsylvania	9	9
Rhode Island	1	1
South Carolina	0	0
South Dakota	0	0
Tennessee	3	4

**Table C.1: Number of Pediatric Rheumatologists by Data Source, cont.**

State	Number of Board Certified Pediatric Rheumatologists (2003 American Board of Pediatrics)	Number of "Self-Described" Pediatric Rheumatologists (2004 American College of Rheumatology)
Texas	6	8
Utah	2	2
Vermont	1	1
Virginia	6	7
Washington	6	7
Washington, DC	2	1
West Virginia	0	0
Wisconsin	5	5
Wyoming	0	0

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## *Appendix D: Distance to Pediatric Subspecialists in the United States*

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For each pediatric specialty, county level files were created to calculate the distance between each county in the United States and the nearest specialists using latitude and longitude data from the HRSA Bureau of Health Professions Area Resource File (ARF) and physician data from the ABP.<sup>78</sup> Population-level data from the Bureau of the Census were merged to the distance data for each county in the United States. Using pediatric population as a weight, the average population-weighted distance to the nearest provider was calculated for each specialty.

**Table D.1: Average Population-Weighted Distance to the Nearest Provider by Pediatric Specialty**

	<b>Mean Miles</b>
Neonatal Perinatal Medicine	12.58
Pediatric Cardiology	19.04
Pediatric Hematology/Oncology	23.56
Critical Care Medicine	23.66
Pediatric Endocrinology	24.16
Pediatric Pulmonology	28.06
Pediatric Infectious Diseases	28.54
Pediatric Allergy	28.76
Pediatric Gastroenterology	29.88
Pediatric Emergency Medicine	33.19
Pediatric Nephrology	34.30
Adolescent Medicine	39.74
Development Behavioral Pediatrics	42.48
<b>Pediatric Rheumatology</b>	<b>57.89</b>
Neurodevelopmental Pediatrics	71.49
Pediatric Sports Medicine	76.66

For each pediatric subspecialty distance measure, counties were then classified as being within 10 miles, 11 to 50 miles, 51 to 100 miles, 101 to 200 miles, or 200 or more miles of a provider. These estimates assess the percentage of the population that experiences a substantial geographic barrier to care.

**Table D.2. Percentage of the Pediatric Population Living within Selected Distances of a Provider by Pediatric Subspecialty**

<b>Board Certified Specialty</b>	<b>Distance</b>	<b>Percent of Pediatric Population</b>
Adolescent Medicine	Less than 10 miles	44.8
	10 to 49 miles	28.3
	50 to 99 miles	16.7
	100 to 199 miles	8.3
	200 or more miles	1.9
Critical Care Medicine	Less than 10 miles	54.1
	10 to 49 miles	29.7
	50 to 99 miles	12.0
	100 to 199 miles	3.3
	200 or more miles	0.8
Neonatal and Perinatal Medicine	Less than 10 miles	69.8
	10 to 49 miles	23.2
	50 to 99 miles	5.6
	100 to 199 miles	1.3
	200 or more miles	0.1
Development Behavioral Pediatrics	Less than 10 miles	41.2
	10 to 49 miles	29.7
	50 to 99 miles	17.6
	100 to 199 miles	9.2
	200 or more miles	2.3
Neurodevelopmental Disabilities	Less than 10 miles	31.0
	10 to 49 miles	27.5
	50 to 99 miles	20.9
	100 to 199 miles	15.3
	200 or more miles	5.3
Pediatric Allergy	Less than 10 miles	53.9
	10 to 49 miles	29.7
	50 to 99 miles	10.8
	100 to 199 miles	4.2
	200 or more miles	1.4
Pediatric Cardiology	Less than 10 miles	60.1
	10 to 49 miles	27.3
	50 to 99 miles	9.4
	100 to 199 miles	2.9
	200 or more miles	0.3

**Table D.2. Percentage of the Pediatric Population Living within Selected Distances of a Provider by Pediatric Subspecialty, cont.**

<b>Board Certified Specialty</b>	<b>Distance</b>	<b>Percent of Pediatric Population</b>
Pediatric Endocrinology	Less than 10 miles	54.5
	10 to 49 miles	27.6
	50 to 99 miles	13.6
	100 to 199 miles	3.7
	200 or more miles	0.7
Pediatric Infectious Disease	Less than 10 miles	52.9
	10 to 49 miles	28.6
	50 to 99 miles	13.3
	100 to 199 miles	4.3
	200 or more miles	0.9
Pediatric Pulmonology	Less than 10 miles	50.7
	10 to 49 miles	30.7
	50 to 99 miles	12.9
	100 to 199 miles	4.1
	200 or more miles	1.6
Pediatric Emergency Medicine	Less than 10 miles	53.8
	10 to 49 miles	23.4
	50 to 99 miles	14.7
	100 to 199 miles	6.6
	200 or more miles	1.5
Pediatric Gastroenterology	Less than 10 miles	52.5
	10 to 49 miles	28.8
	50 to 99 miles	12.8
	100 to 199 miles	4.6
	200 or more miles	1.3
Pediatric Hematology/Oncology	Less than 10 miles	58.6
	10 to 49 miles	27.2
	50 to 99 miles	10.3
	100 to 199 miles	3.5
	200 or more miles	0.4
Pediatric Nephrology	Less than 10 miles	47.2
	10 to 49 miles	29.5
	50 to 99 miles	14.6
	100 to 199 miles	6.0
	200 or more miles	2.8

**Table D.2. Percentage of the Pediatric Population Living within Selected Distances of a Provider by Pediatric Subspecialty, cont.**

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<b>Board Certified Specialty</b>	<b>Distance</b>	<b>Percent of Pediatric Population</b>
<b>Pediatric Rheumatology</b>	<b>Less than 10 miles</b>	<b>33.2</b>
	<b>10 to 49 miles</b>	<b>31.3</b>
	<b>50 to 99 miles</b>	<b>17.3</b>
	<b>100 to 199 miles</b>	<b>12.4</b>
	<b>200 or more miles</b>	<b>5.8</b>
Pediatric Sports Medicine	Less than 10 miles	22.9
	10 to 49 miles	30.1
	50 to 99 miles	21.8
	100 to 199 miles	17.0
	200 or more miles	8.2

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## *Appendix E: Arthritis Foundation/American College of Rheumatology Survey of Pediatric and Internist Rheumatologists*

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### **Data Sources**

In conjunction with the American College of Rheumatology, the Arthritis Foundation created and fielded a survey of pediatric rheumatologists and internist rheumatologists in the United States. The survey was not formally pilot tested and was fielded using a Web-based format. All physician members of the American College of Rheumatology (n=3627) received an email message describing the survey and providing a link to the online survey. The email message was sent on March 9, 2004 and a reminder on March 23, 2004.

### *Data Cleaning*

The Arthritis Foundation provided access to a comma-delimited version of the survey data. Raw data were converted to a usable format by performing multiple data manipulations. Observations that were obvious duplicates, (i.e., observations that were identical to another observation for all variables, (n=22) were deleted). Observations from non-physicians, non-rheumatologists, retired physicians (n=38), fellows (n=21), physicians practicing overseas (4), physicians with missing data that prevented categorizing them as pediatric or internist rheumatologists (3), and records with no data (4) were excluded. All impossible values for zip code were recoded to missing; all non-US zip codes to missing were recoded to missing. For questions in a series (e.g., “How much time do you spend on each of the following activities?”), recoding of values to missing was done only if all questions in the series do not have data; otherwise, blank values were recoded to zero. Responses of “don’t know” for percentage of Medicaid and uninsured patients were considered missing.

Several questions asked respondents to report time amounts. If respondents reported a range of values (e.g., 10-15 hours), the lower end of the reported range was used. If respondents report a value of greater than or less than (e.g., >40 hours), the value reported was used, without the greater than or less than qualifier. If the total number of hours per week summed to 100, it was assumed that the provider had entered in percentages; these were converted to hours using an assumed workweek of 49 hours.

For questions that require a “Yes/No” response, binary variables were created to indicate an affirmative response. For open-ended questions that requested specification, categorical variables were created that collapsed the responses into a smaller number of categories.

### **Methods**

Respondents were classified as either adult or pediatric rheumatologists or internist rheumatologist using data on their Board certification status and/or their self-description. Internist rheumatologists were further classified as involved in the care of children if they reported that children represented at least some of their patients. Internist rheumatologists who specified that they did not treat children with rheumatic diseases were considered to not be involved in the care of children.

Bivariate analyses were performed using Pearson  $\chi^2$  for categorical variables and two-sided, two-sample t-tests for comparisons of means. In addition, logit analyses were performed to assess the independent association between distance to the nearest pediatric rheumatologist and the likelihood that an internist rheumatologist treated children; distance data were derived from the HRSA Bureau of Health Professions' Area Resource File.

## Results

Of the 3,637 emails sent, 300 failed to reach the intended recipient; 3,337 individuals received the email message; of this number, 706 unique survey responses were received. Among the respondents 63 were ineligible due to: residence outside the U.S. (4), retirement from patient care or misclassification as a rheumatologist (38), or current fellowship status (21) yielding an effective sample of 3,274. Of the 706 responses received, 633 were eligible and could be used in the analyses; the effective response rate was 19.3 percent. Given that approximately 224 physician members of the American College of Rheumatology are pediatric rheumatologists, a figure that includes both fellows and practicing physicians, it was estimated that the response rate among pediatric rheumatologists was considerably higher, closer to 55 percent.

**Table E.1. Provider Type,<sup>1</sup> Arthritis Foundation/American College of Rheumatology Survey**

	All Respondents	
	N	%
<i>Type of provider:</i>		
Pediatric Rheumatologists	110	17.4
Internist rheumatologist who treat children	289	45.7
Internist rheumatologist who do not treat children	234	37.0
Total	633	100.0

<sup>1</sup>Current fellows (n=21) excluded from analyses

Of all respondents, 17.4 percent were pediatric rheumatologists and 82.6 percent were internist rheumatologists (Table B.1). Of the internist rheumatologists in patient care, 55.2 percent spent at least some patient care time treating children.

### *Bivariate Analyses*

Pediatric rheumatologists were compared to internist rheumatologists who did and did not treat children for all responses (Table B.2). In addition, characteristics of internist rheumatologists involved in the care of children were compared with those who did not treat children. Pediatric rheumatologists spent significantly more time than internist rheumatologists in teaching and research and less time in-patient care. Compared to internist rheumatologists who did not treat children, internist rheumatologists who treated children spent significantly more time in patient care and less in research. Pediatric rheumatologists were, as expected, significantly more likely to spend most of the practice time caring for children. Of those internist rheumatologists involved in the care of children, the overwhelming majority reported that children comprise less than 10 percent of their patient care time.

Pediatric rheumatologists were younger than internist rheumatologists and more likely to be women. Internist rheumatologists who treated children were slightly more likely to be men,

however, than those who did not treat children. Internist rheumatologists who treated children were more likely to be white and less likely to be Asian than those who did not treat children.

**Table E.2. Provider and Practice Characteristics by Provider Type, Arthritis Foundation/American College of Rheumatology Survey**

	Pediatric Rheumatologists (N=111)	Internist rheumatologists who treat children (N=289)	Internist rheumatologists who do not treat children (N=234)
<i>Hours per week spent in:</i>			
Patient care	26.1***	34.3###	27.0
Research	13.4**	6.4##	10.0
Teaching	6.2**	4.5	4.6
Other activities	5.5	5.1	5.1
<i>Percent of time caring for children:</i>			
None (%)	1.0***	-	100.0
Less than 10% (%)	1.9	86.4	-
10%-50% (%)	9.3	7.5	-
51%-90% (%)	11.1	1.8	-
More than 90% (%)	76.9	4.3	-
Age	46.6*	49.2	48.3
Male (%)	47.6***	76.0	68.5
Hispanic (%)	6.0	3.3#	7.3
<i>Race:</i>			
American Indian (%)	2.9*	0.7*	0.0
Asian (%)	7.8	8.6	16.1
African American (%)	0.0	1.1	1.8
White (%)	89.2	89.6	82.1

\* p<.05, \*\* p<0.01, \*\*\* p<0.001 comparison of pediatric rheumatologists to all internist rheumatologists; # p<.05 ## p<0.01, ### p<0.001 comparison of internist rheumatologists who do and do not see kids Significance results are derived from Pearson  $\chi^2$  for categorical variables or two-sided, two-sample t-test of mean differences for continuous variables

### *Characteristics of Pediatric Rheumatologists*

Nearly 90 percent of responding pediatric rheumatologists worked in an academic setting or teaching hospital (Table B.3). These providers received the majority of their referrals from pediatricians (61.7 percent); other physician specialties contributed far less to referrals. Almost two-thirds of responding pediatric rheumatologists reported that the current wait time for an appointment was greater than 2 weeks.

**Table E.3. Provider and Practice Characteristics: Pediatric Rheumatologists  
Arthritis Foundation/American College of Rheumatology Survey**

	N	Percent
<i>Patients and Insurance:</i>		
Mean percentage of patients with Medicaid/SCHIP		32.5%
Mean percentage of patients uninsured		8.4%
<i>Primary work setting:</i>		
Academic/teaching hospital	92	89.3%
Private practice	8	7.8%
Other setting	3	2.9%
<i>Mean wait time for a new patient:</i>		
Less than 1 week	7	6.8%
1-2 weeks	29	28.2%
Greater than 2 weeks	67	65.1%
<i>Mean percentage of referrals coming from:</i>		
Pediatricians	--	61.7%
Family practitioners	--	13.3%
Internists	--	3.0%
Orthopedists	--	10.9%
Patient self-referral	--	4.6%
Ophthalmologists	--	3.3%
Other sources	--	3.1%
Has a non-physician clinician in their practice*	47	45.6%
Mean percent of time non-physician clinicians work with respondent		54.0%
<i>Type:</i>		
Nurse practitioner	40	85.1%
Physician's assistant	3	6.4%
Other	4	8.5%

\*Mean number of non-physician clinicians per practice is 1.4.

About half of pediatric rheumatologists used a non-physician clinician in their practice; in most cases the non-physician clinician was a nurse practitioner. Pediatric rheumatologists with a non-physician clinician in their practice spent about half of their practice time working with this person.

About one-third of pediatric rheumatologists planned to decrease their time in clinical care in the next 5 years, with 33.1 percent the average planned decrease. The primary reason for planning a decrease in time was obtaining salary support from a research source (45.5 percent); however, many also report retirement (21.2 percent), salary support from a business source (18.2 percent), and other reasons (27.3 percent). Interestingly, one-third of those who planned

to decrease their patient care time within the next 5 years also had reported already decreasing their patient care time in the previous 5 years.

Just over one-fourth of pediatric rheumatologists have decreased time in clinical care in the preceding 5 years, with an average reduction of 32.2 percent. The primary reason reported was obtaining salary support from a research source (39.3 percent). Many providers also reported decreasing their patient care time because another pediatric rheumatologist joined their practice (32.1 percent); they changed employers or career (17.9 percent), or other reasons (25.0 percent).

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## *Appendix F: Survey Methodology of Pediatric Residency Directors*

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A survey of 195 pediatric residency directors in the United States and Puerto Rico was conducted in the spring of 2004 to assess the status of pediatric rheumatology training in general pediatric residency programs. Specific objectives were:

1. To characterize the availability of pediatric rheumatology training in general pediatrics residency,
2. To explore the relationship between the characteristics of pediatric rheumatology training in general pediatrics residency and the presence of pediatric rheumatologists at the training institution, and
3. To describe pediatric residency directors' assessment of the adequacy of pediatric rheumatology supply locally and statewide.

A new survey instrument was developed to reach these objectives. One pediatric rheumatologist and one pediatric residency director pilot tested the survey; the survey was then revised based upon their comments. An 11-item survey resulted that included questions about 1) program size and characteristics, 2) pediatric rheumatology staffing, 3) resident exposure to clinical pediatric rheumatology, 4) perception of the adequacy of the pediatric rheumatology supply locally and statewide, and 5) recent attempts made by affiliated hospitals and/or academic medical centers to hire a pediatric rheumatologist. The Institutional Review Board at the UNC School of Public Health approved the survey.

Respondents were initially contacted by an e-mail message that explained the study and provided a URL link to the Web-based version of the survey. In addition to the initial e-mail, 3 follow-up messages were sent every 7 to 10 days to non-responders; a paper version of the survey was sent to all non-responders approximately one month after the initial e-mail message. The initial screen of the Web-based survey described the study in detail and asked respondents to formally consent to the study. The mail-based survey included a cover letter, consent letter, and stamped, addressed return envelope; a returned mail survey served as consent. After completing the survey by email, each respondent was sent an electronic gift code worth \$10 to use at Barnes & Noble's Internet store.

Responding programs were tracked using the Web site to allow reminder e-mail messages to be generated; the mail survey was sent to non-responders only. This tracking system allowed the use of incentives to responding directors. In the data cleaning and analysis stage all program director and residency program identifiers were removed; consequently, programs remained anonymous in the analysis phase.

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