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COMMENTARY

VIEW FROM THE PEANUT GALLERY OF PEDIATRIC RHEUMATOLOGY:

A TYPICAL NORTH AMERICAN PEDIATRIC RHEUMATOLOGY CENTER

What are the characteristics of the typical pediatric rheumatology center in North America? In order to get a snapshot of our centers, we surveyed 33 US centers and 4 Canadian centers from late 2002 to late 2003 utilizing an online and mail questionnaire in concert with PRINTO. The questionnaires were returned by 8 eastern US centers, 14 Midwestern US centers, 6 southern US centers, 5 western US centers, and 4 Canadian centers, representing a broad cross-section of North American centers. Not every center answered every question, so that the denominator of the responses varied at times.

I will add that the issues surveyed may seem to some to be the problems of a developed pediatric rheumatology system that other areas of the world might like to have. I am sensitive to that view. But for those of us in North America, developing further and improving our niche is crucial to providing better care for children with rheumatic disease. This snapshot may help all pediatric rheumatologists develop their programs as well. Our system is far from perfect and we have much to work on. But contrary to recent rumors, we are doing fine.

DEMOGRAPHY

The centers employed 79 board-certified pediatric rheumatologists (PR) in 35 centers, either full-time or part-time, or 2.1 PR per center. Ten centers (29%) had only one pediatric rheumatologist. The pediatric rheumatologists practiced in metropolitan areas that supported another 27 PR at other centers. The metropolitan area catchments included 1 area of less than 1 million, 20 between 1-3 million, 8 between 3-5 million, 5 between 5-10 million, and 3 greater than 10 million. The mean age of a typical PR was 47 years. Fifteen percent were between 30-40 years of age, 40% between 40-50 years, 34% between 50-60 years, 7% between 60-70 years, and 2% between 70-80 years.

CHARACTERISTICS OF PR PRACTICE IN NORTH AMERICA

In 25 of the 34 centers, the PR's spend at least 80% of their time in pediatric rheumatology activities. Only 2/34 centers had PR activities comprising 25% or less of their time. A typical PR carried a mean of 268 patients in their case load with 71% of PR's case load falling between 150-400 patients in their practice. Each PR took on a mean of 80 new patients into their practice per year with 30% absorbing over 100 new patients per year (highest 175, lowest 25). The PR inpatient services at these centers ranged between 0 to 8 children with rheumatic disease hospitalized per week (mean=2.8) with 65% with less than 3 admissions per week (highest of 8 per week-2 centers). Inpatients consults per week averaged 3.0 per center (range 0.5-8). The number of outpatient visits per week varied widely from a low

of 6 to a high of 125 visits per center (mean=45). The number of patient visits per week per individual pediatric rheumatologist averaged 23 visits.

Patient care and teaching dominated pediatric rheumatology responsibilities with 24/33 centers reporting >50% time spent on these duties. Only 6/28 centers had any PR doing lab research while 21/28 centers had ongoing clinical research. Administrative duties had a prominent role in many of the routines of the responding rheumatologists with a mean of 18% of their time spent in this activity with a range of 2% to 80% (2 at 80%, one at 60%). Ten centers had fellows in training (2.5 per center). The centers averaged 1.5 nurses per center (range 0-4). Thirteen of 33 centers had a physical or occupational therapist specifically assigned to their section. Most family help associations were the expected local or state Arthritis Foundation, American Juvenile Arthritis Foundation, Ronald McDonald houses in the US and the Arthritis Society in Canada. One PR Center had a support organization specifically for its own center (Cincinnati).

DRUG TRIALS

Drug trial clinical research was very common in the centers surveyed. Thirty-one of 35 (89%) North American PR centers have recently participated in drug trials at an average of 4 in the last 4 years. All but one trial was pediatric. Twenty-four of 32 centers surveyed are currently participating in trials. Twenty-four of 26 centers stated that they could run one trial in parallel with another. Nineteen of 27 stated that they could handle more than 2 trials in parallel or at one time. Thirty-four of 35 stated that they were willing to participate in future PR clinical trials if these were trials that only required a minimal amount of work usually related to a drug already on the market. Twenty of 28 centers suggested that they would participate in a future PR trial that was sponsored by a pharmaceutical company that usually required an extensive amount of work. Of the four centers who offered a reason for why they could not do a pharmaceutical-sponsored trial, the explanations mentioned were no time (3), no support (4), or not enough patients (1).

WORKFORCE

Questions for the workforce issues were modeled after the survey utilized by the American Academy of Pediatrics in 1996-1998 to study pediatric subspecialties in the US. It attempts to take a broad view snapshot of how a subspecialty is doing.

<u>Competition/complexity of illness-</u>

Competition was not a concern. Twenty-eight of 33 respondents believed that they were not experiencing greater competition than previously. Twenty-nine of thirty-two pediatric rheumatologists stated they he/she had not had to alter their practice at all due to competition. The complexity of a patients' illness, though, had been increasing for 20/32 respondents.

<u>Need for pediatric rheumatologists</u>

Thirty of 33 pediatric rheumatologists completing the survey believed that their PR practice was expanding, 3 thought the practice was staying the same, and none believed that the practice was decreasing in size. From their perspective, 21/33 PR's believed that jobs for PR's were increasing, 11 staying the same, and 1 decreasing.

The impression of job flow was evenly mixed. Ten PR's thought that more PR's were entering the field than leaving PR (e.g., retiring, administration, pharmaceutical jobs), 10 believed that more were leaving than entering, and ten believed that the job flow was staying the same, no increase in PR's, no decrease.

Morale

Most PR's believed that our morale is good to excellent (16/30 good, 4/30 excellent). Nine considered the mood to be fair and one poor. Twelve of thirty of the respondents assessed the situation in PR in North America to be improving, six worsening, and 14 staying the same.

Support from the hospital and/or university administration was a big concern. Seventeen of 30 PR's felt insufficiently supported to one degree or another. The deficits were in support for the team approach (mentioned by 8/17 PR's), time for academic activities (2/17), inadequate funding for fellowships (3/17), insufficient funding support for research (3/17), low salary (3/17), and support for another PR faculty member (1/17).

ANALYSIS AND COMMENTS

What to make of all this?

Sampling: Most North American centers had the opportunity to fill out this questionnaire. Some chose not to do so, possibly due to its length and its voluntary nature. Thus we have compiled data on only about a third of the PR centers in the US and Canada. I do believe that the data compiled from 35 centers represents an adequate sample of our centers in 2002-2003, both in number and geographical distribution, and gives us a good picture of what PR centers in North America were like then and likely are now.

Demography: We work in medical centers in big cities-no surprise. We average 2 PR's per center, well-below an optimal 5-6 per center for an academic practice, pointing out an academic vulnerability. Ten centers were especially vulnerable and at risk, with only one pediatric rheumatologist. We are a mean of 47 years old, which compares well to pediatricians in the US (45 years old-American Board of Pediatrics data 2004), considering our extra 2-3 years of training. So our population of PR's is not getting too old-We do have enough young PR's!!! We may not have an adequate supply of older and wiser PR's who stay in our field to give us the benefit of their experience, but that may well be typical of other pediatric subspecialties or of this sampling.

Characteristics of our PR practice: Most of us are nearly full-time or fulltime PR's (80-100% time). Some may have side duties of attending in general pediatrics or running the residency program. Our patient responsibilities and inpatient/outpatient workload vary widely with the mean of 268 patient caseload. We increase our caseload by 80 children per year and we have about 3 inpatients at any one time with 3 admissions per week with a mean of 3 inpatient consults per week. Our centers have a mean of 45 outpatient visits per week with a high of 125 in any one center.

We are clinicians mainly doing clinical research and administrative duties. One-third of the centers queried train fellows, about 2 per center. We do not do much basic science work and that is a major problem. We have 1.5 nurses per center and more than one-third of the centers had a PT or OT specifically assigned to their patients. We have some help from outside organizations, mainly the local

Arthritis Foundation or Arthritis Society.

Drug Trials

We do a lot of drug trials with 31/36 centers very active in drug trials in the last 4 years and 80% currently involved in at least one trial. Most centers are willing to do multiple trials at once. For the few centers unable to participate, a lack of time, staff, or patients were given as the explanations.

Workforce

Most of the pediatric rheumatologists did not feel threatened by competition though we do note that our patients were increasing complex. The great majority of the PR's believed that pediatric rheumatology is a growth industry with enlarging practices and increasing job opportunities. Morale was good to excellent for most PR respondents with more PR's believing that the PR situation in North America is improving than not. A perceived lack of support from the hospitals and universities is a major concern for a majority of the rheumatologists, especially team support.

IN SUMMARY-SNAPSHOT PEDIATRIC RHEUMATOLOGY CENTERS IN 2002-2003

Pediatric rheumatologists in North America work in very big cities with a mean of 3 million people, have a mean of two pediatric rheumatologists per center, as a group are well-distributed by age, do full-time PR, work very hard, do a lot of drug trials, face a large and growing workload, anticipate increasing job opportunities, are optimistic with good morale despite the workload, and need more support from hospital/university administration.

Many thanks to the faculty and staff of the 35 following Pediatric Rheumatology Centers for their tremendous help in filling out these long and complicated surveys: University of Connecticut, University of Pennsylvania/CHOP, Hackensack University Medical Center, University of Rochester, Dupont Institute, Hospital for Special Surgery, University of Vermont, University of Minnesota, Mayo Clinic, Indiana University, Ohio State University, St. Louis University, Creighton University, University of Kansas, University of Chicago/La Rabida Childrens Hospital, Michigan State University, University of Cincinnati, University of Wisconsin-Milwaukee, Childrens Hospital of Michigan, University of Iowa, University of Washington, Childrens Hospital of Los Angeles/USC, Childrens Hospital of Orange County, Childrens Hospital of San Diego, Kaiser Permanente-Sacramento, University of Arkansas, Richmond, VA (HG), LSU/Childrens Hospital of New Orleans, Scottish Rite Childrens Hospital in Dallas TX, University of Mississippi, University of Georgia, Sick Childrens of Toronto, McGill University, Royal University Hospital of Saskatoon, and Childrens Hospital of Eastern Ontario. Two center's data could not be used due to technical computer and fax problems and for this we apologize.

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