

## Chairperson's Corner

Chuck Spencer, MD, FAAP



Section on  
Rheumatology

Winter/Spring  
2003

AMERICAN ACADEMY OF PEDIATRICS

# Section on Rheumatology News

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Hello everyone. Things are going well for the AAP Section!

First, our Section is growing as we have added 15 new members in the last 2 years. Secondly, our projects are making progress. The concept of the annual third year fellow's meeting has been approved by the Academy. The proposal is now being fleshed out for final approval and referral to the AAP Development Office for funding. Once funding is obtained, our planning will begin with anticipation of the first meeting to be held in 2004. We have submitted the next project on debt relief for fellows for concept approval. We plan to submit a proposal for a research fellowship for two fourth year fellows per year in 2003. Each project will depend on outside funding from drug companies and we are hopeful that we will get support. The revision of the statement "Guidelines for Ophthalmologic Examinations in Children with Juvenile Rheumatoid Arthritis" has been approved by the Section of Ophthalmology and is ready to move up the ladder of the AAP for imminent approval. We are very grateful to Jim Cassidy and Carol Lindsley for their help in revision of these guidelines.

The rheumatology center map is on our website and the data for each website is being collected by the PRINTO-PRCSG-AAP Section member survey. We hope to eventually display a world map of pediatric rheumatology centers which will be coordinated with the PRINTO world map. Our Section had an educational booth at the ACR meeting in New Orleans in November that was quite successful in alerting pediatric rheumatologists and adult rheumatologists to what the AAP is and what our Section does. We hope to continue the AAP booth at the ACR in the future.

We also signed a memorandum of understanding at the ACR meeting in New Orleans with the ACR and AJAO to coordinate activities of the organizations and advocacy for children with rheumatology disease. It can't be said enough-It is so important that we all work together for the kids and our niche-locally, at the State and national levels. The AAP recently approved the ACR Referral Guidelines and now we are looking at ways to distribute them to the generalists.

At the ACR meeting, the Section presented the James T. Cassidy Award for distinguished service in education in pediatric rheumatology to Dr. Balu

Athreya, a wonderful choice. The Earl Brewer Research Travel Award for clinical research by a pediatric rheumatology fellow was awarded to AnneMarie Brescia, MD for her excellent abstract "Prolonged Synovitis in Pediatric Lyme Disease: A Study on Clinical and Laboratory Predictors."

One of our primary functions is to educate the generalist in rheumatology. Due to the able leadership of Murray Passo and the Executive Committee members, the Section is continuing to increase the programs for the AAP Fall meeting, the National Conference Exhibition. For the November 1-5 meeting next fall in New Orleans, we have 5 programs scheduled: "Unraveling the Chronic Musculoskeletal Pain Syndromes," "Dealing with the Elevated Sedimentation Rate: Working Backwards," "Group A Strep: The Immunologic Trigger to Many Conditions," "Case Based Discussion of Rheumatic Diseases," and "Rheumatology Workshop for the Pediatrician." This will be our strongest program in several years (the average for a Section is 3-4 programs).

The website continues to improve. It continues to have the introduction to the Section, a list of the rheumatology jobs available, the current Section Newsletter, a list of the accredited fellowship programs, a map of the US with the locations of pediatric rheumatology centers, study announcements, and links to other websites (ABP, ACR, AJAO, other AAP).

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## Using the ILAR Classification of Juvenile Idiopathic Arthritis

### Ross Petty, MD, FAAP

The classification of the International league of Associations for Rheumatology (ILAR) was developed to facilitate worldwide communication among clinicians and scientists concerned with the study of children with chronic arthritis by an international group of experienced pediatric rheumatologists. There have been two revisions. It was intended that each category would be clinically homogeneous and would not overlap with other categories. To this end, category-specific exclusions (in brackets) were developed:

1. Psoriasis in the patient or a first degree relative
2. Arthritis in an HLA B27 positive male with onset after 6 years of age
3. Ankylosing spondylitis, enthesitis-related arthritis, sacroiliitis with inflammatory bowel disease, Reiter's syndrome, or acute anterior uveitis in a 1st degree relative
4. IgM rheumatoid factor on at least 2 occasions more than 3 months apart
5. Presence of Systemic JIA

A comparison of the 3 classifications of childhood arthritis is shown in the table.

ACR (JRA)	EULAR (JCA)	ILAR (JIA)
Systemic Pauciarticular	Systemic Pauciarticular	Systemic arthritis (1,2,3,4) Oligoarthritis (1,2,3,4,5) Persistent Extended
Polyarticular	Polyarticular Polyarticular RF +ve ("JRA") Psoriatic Juvenile Ankylosing Spondylitis	Polyarthritis RF - ve (1,2,3,4,5) Polyarthritis RF +ve (1,2,3,5) Psoriatic arthritis (2,3,4,5) Enthesitis related arthritis (1,4,5) Undifferentiated arthritis

(JRA: juvenile rheumatoid arthritis; JCA: juvenile chronic arthritis; JIA: Juvenile idiopathic arthritis; RF: rheumatoid factor)

Arthritis must begin before the 16<sup>th</sup> birthday, and persist for at least 6 weeks. Systemic arthritis requires the presence of the classic fever with at least one of: typical rash, generalized lymph node enlargement, hepatomegaly and/or splenomegaly, serositis. Oligoarthritis is differentiated from polyarthritis by the presence of <5 affected joints during the first 6 months of disease. It is persistent if the number of affected joints never exceeds 4; it is extended if, after the first 6 months, a > 4 joints are affected. RF positivity on two occasions at least 3 months apart is required for classification as polyarthritis, RF positive. Psoriatic arthritis can be diagnosed by the presence of arthritis and psoriasis, or arthritis with 2 of: dactylitis, nail pitting or onycholysis, or a history of psoriasis in a first degree relative. Enthesitis-related arthritis requires the presence of arthritis and enthesitis, or arthritis or enthesitis with 2 of: sacroiliac joint tenderness and/or inflammatory lumbosacral pain; B27; onset of arthritis in a male after age 6 years; history of B-27 associated disease in a first degree relative. Patients in the category of undifferentiated arthritis either fit no category or more than one category.

As with any classification, the ILAR classification should be used precisely. The lack of clarity associated with use and misuse of any classification reflects both inherent problems in the classifications themselves, and careless application. It is hoped that the careful application of the ILAR criteria will facilitate international communication in clinical and basic research, including drug trials, and genetic studies.



## Pediatric Maintenance of Certification Program for Subspecialists (PMCP-S) Murray Passo, MD, FAAP

In response to the Institute of Medicine report "Crossing the Quality Chasm," the **aims of the 21<sup>st</sup>** Century health care system will include six dimensions: safe, effective, patient-centered, timely, efficient, and equitable. The six core physician competencies, as adopted by the ACGME in 1999, include: patient care, medical knowledge, professionalism, interpersonal and communication skills, practice-based learning and improvement, and systems-based practice. The American Board of Pediatrics wants to incorporate the six dimensions of quality care and the six ACGME competencies into the recertification process. The goal of this is "improved care for children."

The recertification process will include four parts: (1) Professional standing; (2) Lifelong learning; (3) Cognitive expertise; and (4)

Performance in practice. Professional standing will include a valid, unrestricted medical license, which is continuous. Demonstration of lifelong learning will be a knowledge self-assessment and decision skills self-assessment evaluated by a computerized home exercise. The third part, cognitive expertise, will be a secured examination conducted at Prometric Testing Centers, both domestic and international. The performance in practice will include peer and patient surveys, as well as practice assessment and a quality improvement component. The quality improvement component will include the new computerized module, eQIPP, which will be developed initially for juvenile rheumatoid arthritis and additional topics in the future. eQIPP will require establishing benchmarks, which are to be determined by a committee of a subspecialty consortium. The consortium includes representation from the American Academy of Pediatrics, American College of Rheumatology, and the American Board of Pediatrics. Drs. Norm Ilowite (ABP), Leonard Stein (ACR), and Murray H.



Passo (AAP) are currently representing the rheumatology component of the subspecialty consortium.

The new recertification program is going to be instituted for all pediatricians recertifying after March 31, 2003. Permanent certificate holders wishing to participate in PMCP-S activities may do so at any time in 2003 and beyond. Prior to 2010, permanent certificate holders who desire a certificate indicating they have successfully completed PMCP-S will only need to complete the licensure and examination activities.

Beginning in 2010, permanent certificate holders will need to complete all PMCP-S activities within a seven-year time frame if they desire a certificate of completion.

Diplomats who are currently enrolled in PRCP-S, and who finish by March 31,

2003, will receive a new certificate that is in effect for another seven-year cycle. To renew the new certificate for another cycle, the information above will apply.

All of the components necessary for Part 4, namely the eQIPP module for JRA, are not available yet but will be forthcoming probably within the next few months. This will require additional volunteer collaboration. Two pediatric rheumatologists, including Mike Miller and Judy Olsen, have volunteered as collaborators in this effort.

More information is available through the American Board of Pediatrics. If anyone is interested, please feel free to contact me regarding opportunities to collaborate.

**Visit EQIPP at:  
[www.eqipp.org](http://www.eqipp.org)**

## New Members!

**The Section on Rheumatology  
welcomes the following new  
members into the Section  
(as of January 2003)**

**Barbara Eberhard, MD, FAAP**

**Deborah Levy Miller, MD**

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## WANTED!

**Fellow-in-Training  
for a position on the  
Executive Committee**

The Section on Rheumatology is looking for one 1st or 2nd year training fellow to serve a two-year term on the Executive Committee.

We need your help! Please encourage training fellows to join the section and contact Laura Laskosz (llaskosz@aap.org) if interested in being involved with the Section Executive Committee.

National Membership dues for fellows in training are \$50 per year. Privileges include:

- ★ AAP News
- ★ AAP Grand Rounds
- ★ AAP BookStore
- ★ CME Courses
- ★ NeoReviews
- ★ PediaLink
- ★ Pediatrics
- ★ Pediatric In Review
- ★ Pediatrics Review and Education Program (PREP)
- ★ PedJobs
- ★ Policy Statements

## Chairperson's Corner

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The Executive Committee is going through many changes. We approved by-law changes creating a Chairperson-Elect position and allowing incumbent candidates to run unopposed. The Chairperson-Elect position will give the next Chairperson an extra year to transition into a job that is quite challenging. This latter change was made to stress continuity as it takes one term on the Executive Committee to understand how to get things done in the AAP. We had previously passed a bylaw change allowing residents to be members of the Section and one rheumatology fellow to join the Executive Committee. We will be electing a fellow member in the near future.

I would like to thank Murray Passo for his terrific work as an Executive Committee member since 1996 and particularly for his efforts as Program Chairperson. Harry Gewanter will be his very able replacement. In the fall, Jim Jarvis, Barbara Ostrov, Ken Schikler, and Rob Sundel will finish their terms. Each did a great job and helped the Section grow and remake itself. Four more Executive Committee members will be elected this spring and begin in the fall. Lastly, Michael Henrickson has been elected Chairperson-Elect and will take over in October 31. He will be an excellent Chairperson. It's time for new faces and new ideas!

In the past three years, I have tried to advocate for help for pediatric subspecialties, especially the cognitive, less procedure oriented areas such as endocrine, rheumatology, pulmonary, allergy-immunology, development, neurology, adolescent health, and nephrology. Although I will be finishing my term as Chairperson of our Section, I will continue to try to help as Chairperson-Elect of the AAP Council of Sections. The AAP provides a window to what other subspecialties are doing. Many face similar challenges to what we do and their efforts can often inform our own. We are not alone in our effort to continue growing and maturing as a subspecialty and together, pediatric subspecialties can help the kids we care for and our stressed subspecialties.

## Development of a New Pediatric Rheumatology Program Barbara Ostrov, MD, FAAP

As we all know, pediatric rheumatology is an underserved specialty. Currently there are approximately 190 board certified pediatric rheumatologists (PR) in the United States. However, it is estimated that one PR is needed to care for the number of children in a 1 million population base, a deficit of about 100 PR. The purpose of this presentation was to review the current status of pediatric rheumatology manpower and raise the possibility that more of us can start new programs to reach underserved populations – patients, medical students and trainees.

In order to attract new pediatricians to our specialty, young pediatric trainees must have exposure to PR. Since 1976, when these data were first tabulated, there have been an increased number of PR at our medical schools. In 1976, 109 of 125 medical school had no PR. In 1996, this number dropped to 45 but there has been no further improvement since that time. Hence, more than 1/3 of medical schools currently have no PR to serve as mentors or to attract trainees.

There are currently 21 first year fellowship slots in the US, only 14 of which are filled. In each year of fellowship training, about 1/2 are filled by international medical graduates. These individuals often have visa constraints and do not remain in our country. Therefore, a small number of new PR come into the work force each year with the ability to reach these underserved populations.

A review of the development of a non-urban pediatric rheumatology center (PRC), the Central Pennsylvania PRC, was provided. There were pediatric rheumatology centers in Pittsburgh and Philadelphia but until 1991, no PRC existed in the large central portion of Pennsylvania, comprising more than 2/3 of the state's area. The PRC is in the small suburban town of Hershey with a population of 18,000. PennState's College of Medicine and Children's Hospital are also in Hershey.

The referral base to the Children's Hospital is about 3.5 million. The PRC inception was in July, 1991 and about 100 new patients were seen the first year. In 1997, a second PR joined the practice along with a part-time nurse. By the 2001-2 academic year, 522 new patients were evaluated. Since 1999, four outreach clinics have been an integral part of our practice, now comprising 20% of our practice. It is clear that even in a relatively small town which has a medical school and a Children's Hospital, a PRC such as ours can be successful.

In order to begin a new PRC, one must assess the patient referral base as well as the availability of other pediatric specialists. A medical school with a children's hospital would be the best site to consider since the referral base is usually well established. One must carefully plan the PRC – staff: nurses, secretaries; clinic space, cross coverage for call, research support/facilities, rehabilitation and in-patient space, as well as infusion room availability. "Advertising" is important – written and verbal communication, lectures, word-of-mouth from patients and involvement with community organizations such as the Arthritis Foundation, American Academy of Pediatrics and the Lupus Foundation can all "spread the word" about your PRC.

In summary, Pediatric Rheumatology is an underserved specialty. The only way we can grow is by attracting new trainees to our field. We must have a presence at every medical school and children's hospital – to care for the children - and to interest and attract new trainees.



## Advocacy Harry L. Gewanter, MD, FAAP



It is extremely difficult to write an article on areas of advocacy at the moment because so many issues are in flux. The current international events are overshadowing much of the discussion on issues that are near and dear to the pediatric rheumatology community. I

would like to highlight areas for each of us to keep in mind as the year progresses.

1) The economy and potential war have created an economic environment that makes the expansion of services for children with rheumatic diseases specifically and children with special health care needs in general unlikely at best. The President has proposed a new initiative for Medicaid that would allow the states to have significantly greater control over their Medicaid programs while capping the Federal budget for Medicaid. This change, if enacted, would result in a greater need to work at the state and local level to ensure that children are appropriately covered. Stay tuned to the AAP MOC and check the Federal and State Governmental Affairs pages for events and actions you can take to help our patients and their families.

2) The NIH in the current budget is to receive a minimal increase in funding (approximately 2%). There is significant concern that this will not allow the rate of progress we have seen in our field over the last few years to continue. This is an area where ongoing communication with your federal legislators may be helpful.

3) The Pediatric Rule of 1998 which required that pharmaceutical companies test their drugs on children was ruled invalid in October, thereby stopping the FDA's efforts to require pediatric studies. The AAP is actively pursuing the reinstatement of this rule both in the courts as well as through legislation. For more details, go to the AAP MOC page.

4) The Individuals with Disabilities Education Act (IDEA) is up for reauthorization again this year and the Administration is interested in making a significant number of changes. There is no push to fully fund this mandate, although a few legislators have proposed legislation to do so (the law states that the federal share would be 40%, but the most that has been funded has been 17%). There is more to the issues than can be discussed in this newsletter, but I would urge everyone to learn more about this important law and its implications on the lives of our patients.

For those of you who wish to remain more current and active on these or other issues, I would recommend that you join the AAP's FAAN email list. This is their Federal Advocacy Action Network and will provide you with monthly updates as well as Action Alerts when urgent issues arise. Other valuable organizations that can supplement the information above include:

### **Children's Defense Fund**

<http://www.childrensdefense.org/>

### **Families, USA**

<http://www.familiesusa.org/index.htm>

### **Family Voices**

<http://www.familyvoices.org/>

### **National Council on Disability**

<http://www.childrensdefense.org/>

### **Committee for Education Funding**

<http://www.cef.org/>

### **The Henry J. Kaiser Family Foundation**

<http://www.kff.org/>

### **The National Health Law Program**

<http://www.healthlaw.org/index.shtml>

### **AAP Members Only Channel**

[www.aap.org/moc](http://www.aap.org/moc)



*To join, visit the Members Only Channel at: [www.aap.org/moc](http://www.aap.org/moc) and select "Federal Affairs"*

## Federal Advocacy Action Network (FAAN)

The Federal Advocacy Action Network (FAAN) is a network of Academy members who help support federal legislative and regulatory activities from their positions as constituents.

### **Make Contact**

You'll choose the level and range of activities that suit your busy schedule, from simply faxing or calling your congressional members about issues of concern to you, to requesting a personal meeting. Over the years, our advocacy network has affected numerous positive gains for children and pediatricians, thanks to AAP member commitment to child health advocacy efforts.

### **It's Easy!**

If you decide to take action on a particular issue—or on lots of issues—the Washington office will offer education and guidance, updated legislative information and notice about legislative conferences.

One of the most exciting things about being an advocate is that your efforts can make a real difference for children and pediatricians. It doesn't take a lot of time; it simply takes the desire to help educate your members of Congress on the needs of children and the challenges of pediatric practice. By participating in the Network, you are becoming part of the legislative process. We will provide the tools and information you'll need to speak effectively with your legislators on a wide range of important issues.

To help you along, the AAP Department of Federal Affairs will provide:

- important information on advocacy, including regular updates on legislative activities
- "special alerts" when your voice is needed and guidance on how to take action
- helpful hints on how to establish a rapport through correspondence, visiting members, testifying, working with the media, and utilizing the Washington office.



**American Academy of Pediatrics  
2003 James T. Cassidy Award  
Call for Nominations  
Deadline: March 3, 2003**

The James T. Cassidy Award recognizes an individual for outstanding achievement in pediatric rheumatology.

**Nominees must be a member in good standing of the AAP Section on Rheumatology and meet one or more of the following requirements:**

- Recognition as an outstanding educator
- History of successfully training pediatric rheumatology fellows
- Contributions to the field of pediatric rheumatology through research, publications, and/or legislation.

A letter of nomination and the nominee's curriculum vitae are required for consideration. Nominations must be in writing and should be limited to one per nominator. The letter of nomination should contain a description of the nominee's achievements and clearly state the basis for the recommendation. **Previous nominations may be resubmitted.** Forward letters of nomination by March 3, 2003 to:

Laura Laskosz, MPH  
Division of Technical and Medical Services  
American Academy of Pediatrics  
141 Northwest Point Boulevard  
PO Box 927  
Elk Grove Village, IL 60009-0927

**Nominations may be submitted electronically to [llaskosz@aap.org](mailto:llaskosz@aap.org)  
or via fax at 847/434-8000 (attn: Laura Laskosz).**

The recipient will receive a \$500.00 honorarium, a plaque, and travel expenses to attend the American College of Rheumatology 2003 Annual Scientific Meeting October 24 – 28, 2003 in Orlando, Florida.

**Please share this announcement with your colleagues.**

# PEDIATRIC RHEUMATOLOGY ONLINE JOURNAL

Welcome to the first issue of the pediatric rheumatology online journal. This peer-reviewed journal is the result of the labors of many pediatric rheumatologists and we are grateful to every single person. Two years ago we asked over 100 international pediatric rheumatologists if it was a good time to start a journal for our subspecialty. Over eighty percent said yes and many volunteered to help. The minority mentioned a number of important issues of concern, e.g., that they're already too many rheumatology journals, the likelihood of a second rate journal, the cost factor, the scarcity of excellent science in our field, and other concerns. We have tried to keep those issues in mind and establish a journal that both complements other rheumatology journals and makes important contributions to pediatric rheumatology.

After many meetings and discussions over the past two years, we've come up with a product we hope will be a useful addition of the field of pediatric rheumatology. It is first of all international. In each country we are a small subspecialty. Internationally we number over a thousand. We have the opportunity to communicate, collaborate, cross-fertilize to help our children and advance our field. We can assist the maturing pediatric rheumatologists in many countries develop their skills, expertise, and research. We invite contributions from all pediatric rheumatologists around the world and wish to emphasize regional issues and problems.

It's free as an internet based journal and easily accessible to everyone. There's no annual subscription fee of 175-300 American dollars that can be prohibitively expensive for many pediatric rheumatologists. We plan to keep PROJ free to everyone.

PROJ will focus on the continuing education of pediatric rheumatologists. We will regularly include reviews of the

literature as well as review articles of clinical and basic science. We will emphasize cutting edge case discussions and case series. We will have regular contributions from members of the pediatric rheumatology team including nurses, physical and occupational therapists, social workers, and post-residency training fellows. It is our desire to be inclusive of all professionals in our field.

PROJ will be receptive to research articles in pediatric rheumatology, both clinical and basic, though at the same time respecting and recognizing the critical role of other journals as forums for these efforts.

Lastly, PROJ will have flexibility. We will be open to suggestions on how to improve the journal and what the needs of the readership are. Please e-mail us your comments or suggestions.

This is an exciting time in pediatric rheumatology. Despite the threats of war, terrorism, economic recession, currency devaluation, tight budgets in universities, and dysfunctional, inadequate health care systems, we have the opportunity to build upon the amazing progress of the first 50 years of our fledgling subspecialty. We are grateful to Barbara Ansell and the many pioneers in Europe, the Americas, and around the world. Following their example, we hope to develop and nurture pediatric rheumatology in every country without the subspecialty and increase the numbers and viability of the pediatric rheumatologists in those countries which already have a good start. We believe that as there are many children worldwide do not have the pediatric rheumatology care they need and deserve, we still have much work to do. We, as editors of PROJ, hope that our online journal may play an important and worthwhile role in this endeavor.

Charles Spencer  
Alberto Martini

**Time is running out!  
Register Today!**



## **Pediatric Rheumatology 2003: Park City and Beyond**

Snowmass Conference Center  
**Snowmass, Colorado**  
March 22-26, 2003

This continuing medical education activity will review cutting edge-topics in pediatric rheumatology including basic, translational, and clinical care research.

For more course information and to register visit  
[www.pedialink.org/cmefinder](http://www.pedialink.org/cmefinder)



**Stuck at Denver  
International Airport?  
Did your final destination  
get snowed in?  
Try these alternatives:**

- \* Work with airline to make alternate flying arrangements
- \* Colorado Mountain Express Shuttle Service  
800/525-6363
- \* Car Rental - discounts through Hertz. Call Hertz directly at 800/654-2240 and mention CVA01570004

# PEDIATRIC RHEUMATOLOGY ONLINE JOURNAL

## Mission Statement

Pediatric rheumatology online journal is a refereed publication designed to meet the educational, reference, and communication needs of the international pediatric rheumatology community. The journal was begun in an effort to explore the educational potential of an online journal for a pediatric rheumatology community widely dispersed throughout the world. PROJ is attempting to serve as an excellent source of relevant information for this international community and as a way to improve how pediatric rheumatologic information is transferred and accessed.

**Alberto Martini, M.D. - Editor in Chief**  
**Angelo Ravelli, M.D. - Associate Editor**  
**Linda Wagner, M.D. - Associate Editor**  
**Charles Spencer, M.D. - Managing Editor**

**[www.pedrheumonlinejournal.org](http://www.pedrheumonlinejournal.org)**

## PROJ Editorial Board Members

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## Memorandum of Understanding

On November 18, 2002, the official signing of the Memorandum of Understanding was completed. The Memorandum of Understanding was developed to enhance collaboration between the AAP Section on Rheumatology, the Pediatric Section of the American College of Rheumatology, and the American Juvenile Arthritis Organization, Arthritis Foundation. Through these collaborative efforts, the three organizations will work together to promote pediatric rheumatology in medical schools and in the pediatric marketplace in ways that will enhance medical care for children with rheumatic disease. It is recognized that combining the expertise and resources of all three organizations will likely benefit the children, pediatric rheumatologists, and general pediatricians.

The purpose of the collaboration includes:

- \* improved communication among the three organizations
- \* collaboration in areas of education including -patients, families, the general public, medical students, residents, and physicians
- \* policy statements
- \* practice guidelines
- \* coding and reimbursement issues
- \* advocacy for children and families with rheumatic disease

A "signing ceremony" of the Memorandum of Understanding took place during the American College of Rheumatology Annual Meeting. To view the Memorandum in its entirety and more pictures from the signing, please visit the section web site at [www.aap.org/sections/rheumatology](http://www.aap.org/sections/rheumatology).



**Visit us on the Web!**  
[www.aap.org/sections/rheumatology](http://www.aap.org/sections/rheumatology)

## ATTENTION SECTION MEMBERS!

### 2003 Section Election Update

It is almost time to elect your representatives on the Executive Committee members for the 2003-2004 year. This year, there are 4 open positions.

Section elections are now conducted via the Internet. To vote:

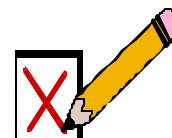
- 1) Log into the AAP Members Only Channel ([www.aap.org/moc](http://www.aap.org/moc)). On the left-hand side of the screen, under the heading "Members," you will see the subheading "My Sections" and a list of all sections to which you belong.
- 2) Select the Section on Rheumatology by clicking on the section's name.
- 3) Select the "2003 Election" link at the top of the page and follow the directions on the ballot page to see a candidate biosketch or vote for your candidate of choice.

To log into the Members Only Channel, you will need your AAP ID#. This number is printed above your name on the mailing label of the postcard that will be mailed at the beginning of March to all section members announcing the elections. In addition, you can find your ID# on your Pediatrics mailing label (eliminate the last digit of the 7-digit number) or by calling our Customer Service Center at 1-866-THE-AAP1. If you have other questions about or difficulty using the Members Only Channel, contact the AAP Customer Service Center, at 866/THE-AAP1 or [csc@aap.org](mailto:csc@aap.org).

**Our Section's ballot will be available from March 3 through April 30, 2003. If you do not have access to the Internet, or if you would prefer to vote by print ballot, contact:**

**Rebecca Marshall**  
Phone: 800/433-9016, ext 4079  
Fax: 847/434-8000  
E-mail: [bmarshall@aap.org](mailto:bmarshall@aap.org)

**Every vote counts!**



# Juvenile Dermatomyositis Study Group Minutes

## Brian Feldman, MD, FAAP

### 1. Dr. Ann Reed – IIM Workshop

Dr. Reed discussed the IIM workshop as well as the International Myositis Outcomes Collaborative Study Group. Those who wish to join should call Lisa Rider or Fred Miller. In terms of the development of outcome measures, the IMACS is working with PRINTO. Improvement definitions for adult and childhood myositis were separately developed at the IIM workshop.

### 2. Dr. Larry Zemel – Needle Muscle Biopsies

Dr. Zemel presented a discussion of needle muscle biopsy. The slides are included (Note – these will follow).

### 3. Dr. Nicolo Ruperto – PRINTO and JDM

Dr. Ruperto reported on the PRINTO activities. There is an ongoing study of disease activity and damage core set variables. The data collection involves active patients, and so far patients have been enrolled from 35 countries. There have been very few patients enrolled from North America. Dr. Ruperto suggested that interested individuals should get in touch with Dan Lovell. The database at the end of the study will be open to any investigators – in order to access the data, an abstract must be sent to Alberto Martini. The PRINTO dataset is looking at some measures that the IMACS group have not looked at, namely the CHQ, Lauren Pachman's DAS, and growth variables. More information is available on their website [www.printo.it](http://www.printo.it).

### 4. Ms. Elizabeth Halkon – Network for Juvenile Dermatomyositis

Ms. Halkon presented details of the Network for JDM. The last meeting was in Stockholm in June 2002. The new Chairperson is Clarissa Pilkington. The Secretary is Liz Halkon. There are 105 members in 30 countries, including the Americas, North Africa and Europe. There are 3 major projects.

The first project is revision of the diagnostic criteria. The PI is Joyce Davidson. The second project is a cross-section of

physical outcome measures in JDM. The PI is J.J. van der Net. The third project is validation of the MITAX tool. The PI is Clarissa Pilkington.

Anyone who would like to receive information from this group just needs to fill out the newsletter application form.

### 5. Dr. Hermine Brunner – JDM Etanercept Trial - Update

Dr. Brunner discussed the JDM etanercept study. There are 15 selected American sites. The enrollment in the study has been held up at this point by the FDA. Because of this, the funding for the study was removed from the MCRC project grant at Cincinnati and resubmitted as an R01. The planned enrollment should begin in July of 2003.

### 6. Dr. Lauren Pachman – JDM Registry

Dr. Pachman presented on the JDM Registry. There are 199 JDM children who have been reviewed at approximately 43 months of follow-up. At this point, 54% are still on treatment. At about 5 years, there has been an interview with 235 parents. 19% have reported prominent joint complaints and hand fatigue. Calcifications have occurred in 15%. 2.6% have developed psoriasis. The group is now investigating lipodystrophy in their follow-up patients, and for this they need fasting blood. More details are available on the Registry website, <http://www.childrensmemorial.org/depts/immunology/jdm/default.asp>.

### 7. Dr. Fred Miller – Calcinosis Study – Update

Dr. Miller presented on the Calcinosis study at the NIH. The group is still looking for calcinosis specimens that have been surgically removed. They have available for potential investigators a kit with consent forms and they can get international specimens.

### 8. Dr. Ann Reed – Rituximab Study – Update

Dr. Reed reported on the Rituximab study. This group has been concentrating on outcome tools and the design of a study

using anti-CD20. The study will be focussed towards patients who have resistant disease. The study's steering committee consists of rheumatologists and neurologists. The study would be international and involve both adults and children. Pediatricians interested in participating should contact Ann Reed or Lisa Rider.

### 9. Dr. Fred Miller – Heterogeneity Study

Dr. Miller then reported on the Heterogeneity study. There have been 350 children collected in the study. Dr. Gulnara Mamyrova is joining the group to continue work on the study. The Myositis Association of America is funding the completion of the study and there is a parallel adult study going on. Dr. Miller's group also has a new study which is looking at twins and siblings. These adult or children might have any of the systemic rheumatic diseases, including RA, lupus, dermatomyositis, etc. They are looking for one affected and one unaffected twin within three years of age.

### 10. Bob Goldberg – Myositis Association of America

Mr. Goldberg reported on the Myositis Association of America Research Grants Program. This year, the MAA has contributed \$900,000 in research funding. 1/3 went to the study of childhood disease. For subsequent funding, there will be a letter of intent, due March 31<sup>st</sup>. The group will fund both research projects and fellowships. Because of a move towards becoming more international in scope, the Myositis Association of America is changing their name to the Myositis Association. Additional projects include a book on JDM (which will be targeted towards patients), poster children, support groups, advocacy groups, a website, annual conference, and e-newsletters.

With this, the meeting was closed with a plan to have our next meeting at the next ACR meeting, chaired by Dr. Bianca Lang.

## Announcements

### Calcinosis Study

Calcinosis specimens from patients with myositis which have been surgically removed or biopsied are needed for a study (paraffin or frozen tissue blocks, H&E slides). The goal is to better understand the composition of these lesions in order to develop a better understanding of the causes of calcinosis and improved ways of treating it.

To refer samples or for additional information, contact Lisa G. Rider, MD, or Frederick W. Miller, MD PhD,

NIEHS, National Institutes of Health,  
DHHS, Building 9, Room 1W107,  
MSC 0958, 9 Memorial Drive  
Bethesda, MD 20892  
Phone: 301-451-6272  
FAX: 301-480-4127  
email: RIDER@niehs.nih.gov or  
MILLERF@mail.nih.gov.

### Debt Relief for Pediatric Rheumatology Fellows

The National Institute of Health will accept applications from any U.S. Rheumatology Post-graduate fellow for their debt -relief, provided that you have some research project, basic or clinical. Although it is competitive, you do not have to have a grant already to apply and can win debt relief without an NIH Grant. This program is very well funded and is currently under-utilized. Contact your department chairman for details.

**More information about the NIH Loan Repayment Programs is available at:**  
**[www.lrp.nih.gov](http://www.lrp.nih.gov)**

**Let the NIH repay your student loans up to \$35,000 per year!**



### Looking for a Job?

**Visit the Section on Rheumatology web site for listings of current job opportunities:**

**[www.aap.org/sections/rheumatology/joblist.htm](http://www.aap.org/sections/rheumatology/joblist.htm)**



The American Academy of Pediatrics Pediatrician Referral Service is intended for use by the general public to allow them quick access to information on pediatricians.

## The Myositis Association Announces Research Program and Juvenile Myositis Book

The Myositis Association (previously named the Myositis Association of America), a patient support group for all patients with adult and juvenile forms of myositis, has announced it is now accepting applications for its second round of grants to support research into myositis. Grant applications for Research Fellowships and Research Grants can be downloaded from the TMA web site at [www.myositis.org](http://www.myositis.org). Letters of intent must be received by March 31, 2003 and the complete application received by April 30, 2003. Grants to be awarded will be announced in October, 2003. Further questions regarding the applications or grants program may be sent to [tma@myositis.org](mailto:tma@myositis.org) or 540/433-7686.

Last year, The Myositis Association issued research grant funding totaling nearly \$1 million over the next two years, with over \$300,000 dedicated to juvenile myositis research. Among the researchers approved for funding were Carol Artlett,

PhD, Thomas Jefferson University; Lauren Pachman, MD, Northwestern University; Ann Reed, MD, Mayo Clinic, and a fellowship for Gulnara Mamyrova, MD, PhD, NIEHS, National Institutes of Health.

The Myositis Association is aggressively seeking to benefit patients with juvenile forms of myositis and has announced it plans to publish a book focusing on the disease from the perspective of juvenile patients and physicians. The book will also cover the entire disease process. Patients with juvenile myositis, as well as their family members, friends, teachers and other important patient contacts, are requested to submit materials for publication in the book (including writings, poems, drawings and other contributions) through the TMA web site (see additional information at [www.myositis.org](http://www.myositis.org)).

TMA has also announced a membership drive to bring more patients and their parents into TMA membership so that

they can benefit from the growing services and resources being made available to juveniles. The Myositis Association is looking at providing complimentary registrations for juveniles with myositis to camps that can provide children with myositis and other diseases a rewarding and enriching summer camp experience.

TMA would like for pediatric specialists and others caring for myositis patients to spread the word about TMA and its services to their patients.

Questions regarding the book and other TMA activities can be directed to Kathryn Spooner, Communications Coordinator, for TMA at [Kathryn@myositis.org](mailto:Kathryn@myositis.org) or 540/433-7686, ext. 15.

**[www.myositis.org](http://www.myositis.org)**

## Executive Summary October 29, 2002

The Section on Rheumatology Executive Committee convened on Tuesday, October 29 2002 in New Orleans, LA in conjunction with the American College of Rheumatology Annual Meeting.

The Section hosted an exhibit booth during the ACR Annual Meeting; presented two awards including the 2003 James T. Cassidy Award to Balu Athreya, MD and the Earl J. Brewer Research Travel Grant to Anne Marie Brescia, MD; and hosted a well-attended workshop. The workshop, "POP" had presentations from Ross Petty, MD on Nomenclature and Manuscript Preparation, Barbara Ostrov, MD on developing a new pediatric rheumatology program, and Murray Passo, MD on the American Board of Pediatrics Program for Maintenance of Certification in Pediatric Subspecialties. Lastly, a "photo-op" signing of the Memorandum of Understanding between the AAP Section, the ACR and the American Juvenile Arthritis organization occurred on October 28, 2002.

Dr Spencer, Section Chairperson, provided an update on Section activities. Dr Spencer thanked Murray Passo, MD on behalf of the Section for his service on the Committee. He also welcomed Harry Gewanter, MD onto the Executive Committee. The Section will again sponsor the James T. Cassidy Award, Earl J. Brewer Research Travel Grant, and Visiting Professor Program in the coming year. Currently, the Section has proposed the revision of "Guidelines for Ophthalmologic Examinations in Children with Juvenile Rheumatoid Arthritis," pending approval; work will begin on the revision. The Academy recently endorsed the ACR Position Statement, "Guidelines for Referral of Children and Adolescents to Pediatric Rheumatologists" and the Section is investigating methods of dissemination to general pediatricians. The Section has also completed a fact sheet entitled, "What is a Pediatric Rheumatologist" that will be available online for pediatricians to download and hand out to parents and patients.

The Executive Committee is working on identifying a 1<sup>st</sup> year fellow to serve a two-year (non-voting) position on the committee. The fellow must be a member of the AAP and the Section. Interested individuals should contact Laura Laskosz at 800/433-9016, ext. 4928 or via e-mail llaskosz@aap.org.

Several proposals have been approved for the 2003 NCE to be held November 1-5, 2003 in New Orleans. They include:

- Juvenile Rheumatoid Arthritis – Meet the Expert
- Unraveling the Chronic Musculoskeletal Pain Syndromes – Selected Short Subject
- Group A Strep: The Immunologic Trigger to Many Conditions - Seminar
- Common Rheumatoid Problems – Meet the Expert
- Case Based Discussion of Rheumatic Diseases – Audience Response Case Discussion
- Rheumatology Workshop for the Pediatrician - Workshop

The Section continues to prepare for "Pediatric Rheumatology 2003: Park City and Beyond," to be held March 22-26, 2003 in Snowmass, CO.

The Section is requesting suggestions for a new "Subspecialty Page" in AAP News. The article can be from any subspecialty group, but must be pertinent to other sections. Lastly, the Section continues to work on the map of pediatric rheumatologists in the United States.

The next SORh meeting will be held in March 2003 in conjunction with the "Pediatric Rheumatology 2003: Park City and Beyond" in Snowmass, CO.

## Executive Committee 2002 - 2003

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