

LETTER FROM THE PRESIDENT



President, Dr. Robert Armstrong

I am always amazed at how quickly time flies by as we go about our busy lives. The 2004 Program Committee is immersed in the planning of the Los Angeles meeting and they will soon be sitting down to review and rank those abstracts and instructional courses that you have worked so hard to submit for

consideration. This is the real meat of the meeting. Our goal as

an Academy is to encourage our membership to submit high quality work to our meeting so that our membership is assured of being at the forefront of knowledge in childhood disability.

I would like to take a moment and reflect on the Montreal meeting. Overall, the meeting was a success. Montreal is a beautiful multi-cultural city, and was the ideal location to host a meeting theme of "Celebrating Difference". Through the plenary sessions, the paper and instructional course presentations, and through interaction with your colleagues, I believe the meeting has served its purpose, increasing your knowledge, challenging you to think about differences, and of course allowing you to network. Thank you all for your participation, for your constructive feedback, and for coming again in 2004 (and please bring along some of your co-workers!). I want to particularly thank the tireless volunteers from your Academy and the support staff who put enormous effort into making the meeting a success.

A special part of the meeting was the tribute to Dr. Martin Bax who is officially retiring as Senior Editor of MacKeith Press. Martin has made

enormous contributions to the childhood disability field, to the Press and to our Academy. We cannot honor him enough for his work.

While the meeting is a big part of our work as an Academy, it is by no means all of what we do. We have a very strongly engaged committee structure working on specific areas of our mandate and developing bold plans for moving us forward as an interdisciplinary professional body. Over the course of this year you will see the evidence of this work as we move to support research projects, increase our focus on treatment outcomes, develop a new model for focused workshops, and continue to upgrade our web-site to make it more useful to you as members.

We really have tremendous strength and I encourage you to get involved in the areas that interest you. I would be happy to hear from you directly if you have ideas or issues that you think need to be addressed (barmstrong@cw.bc.ca). I want to thank you for your membership, encourage you to enroll other members, and work to make the Academy an even more outstanding organization to be part of.

See you in Los Angeles!



Incoming President, Dr. Robert Armstrong thanks Dr. James Blackman, outgoing President, for his leadership and vision

Dates To Remember



September 29-October 2, 2004
AACPD^M 28th Annual Meeting
Los Angeles, California

Mediterranean Meeting on Cerebral Palsy & Developmental Disorders
May 13-16, 2004
Petros M. Nomikos Conference Centre
Santorini, Greece

Any AACPD^M members interested in attending can contact Atigone S. Papavasiliou at infor@era.gr.

Want to Participate in an International Meeting?

In 2001, AACPD^M provided seed money for the first Mediterranean Developmental Disabilities conference. The meeting was a great success. Many Academy members took part as speakers. Since that time, several other international organizations have requested funding. While the AACPD^M recognizes the importance of these meetings in helping developing nations improve the care of children worldwide, the Board of Directors also recognizes its obligation to the membership when resources are scarce. However, they also recognize that many AACPD^M members are interested in international affairs and wish to be involved in outreach to countries developing services for children with disabilities. The Academy would like to start a list of members of all disciplines who would be willing to participate in these meetings as faculty, but at their own expense. In some cases, the host committee might have some money available for hotel and meals. If you are interested, please contact Shannon Caputo at caputo@aaos.org or 847-698-1635.

To All Academy Members

I wonder if I can beg a little personal space in the newsletter. It's really to send a personal message of thanks and gratitude to all the many members of the Academy who were so warm and affectionate to me at the Montreal meeting, which is of course the last I shall be attending as Senior Editor of *Developmental Medicine and Child Neurology*. I was embarrassed and amazed to find myself facing a standing ovation on the first morning, and had of course a wonderful party which many people attended at the Faculty Club. I attempted to say a few words there, to comment that relations between different national groups are not always easy. The relationship between the Mac Keith Press and the American Academy of Cerebral Palsy and Developmental Medicine has for the 40 years which I've been involved have been I believe an enormously successful relationship. This has been due to the extreme friendliness and warmth which I've personally and other members and staff of the Press have received from all members of the Academy and again this was so warmly illustrated to me at the faculty club. I believe our relationship has benefited not only ourselves, but the lives of disabled children across the world. I was pleased to play a small part in this cooperative venture over the past 40 years and I know that my successor as editor of *Developmental Medicine and Child Neurology*, Dr Peter Baxter, is looking forward to continuing our relationship. For my part I'm hoping to play a small emeritus role in the continued development of the Mac Keith Press and as a member of the Academy look forward in joining my many friends in the Academy at many future meetings.

Martin C O Bax

Perspective on Client Services by a Person with a Mixture of Spasticity and Athetosis Cerebral Palsy

Donna K. Williams, Ed.D
Accommodations Counselor; Services for Students with Disabilities
Texas A&M University
Person with Cerebral Palsy

Linda H. Parrish, Ph.D.
Professor, Educational Psychology
Texas A&M University

Physicians, therapists, and social workers are in a unique position to influence the treatment and prognosis of persons with disabilities. Given that fact, it is imperative that these important professionals understand the perspective of the client, patient, or consumer—the person with a disability.

Dr. Williams, an individual with Cerebral Palsy, has been educated through the private and public sector. She has had nine individual surgical interventions; some of them were experimental in nature while others were correctional because of the condition of cerebral palsy. She also has had eighteen years of physical, occupational, and speech therapies. Although medical and educational professionals have played a significant role in Dr. Williams' life, the expertise of each discipline could not stand alone without the other in contributing to her success. Having been a student prior to the passage of P.L. 94-142 Dr. Williams and her family experienced the discrimination against her physical disability as well as the advocacy of several educators. These educators that advocated on her behalf did not have any legislation dictating their response to her education, but rather a heart felt need to help her reach her highest potential.

Her transition from school, post secondary education, and graduate work to a search for gainful employment caused her to encounter many obstacles. One such obstacle was contacting a hundred and fifty six places concerning employment that she was trained and qualified for but was turned down due to the perception of employers about being overeducated for a person with a severe disability. These experiences provided Dr. Williams with a great deal of information to share with other persons with Cerebral Palsy and the professionals who work with them to become a contributing member of society.

Several suggestions that may contribute to a successful practice with individuals with disabilities are based in the assumption that disability is seen as a normal part of human existence and as such, people with disabilities should be treated as people first who happen to have Cerebral Palsy.

All medical and therapeutic procedures and processes should be employed with an eye toward making the individual independent rather than reinforcing dependant behaviors as is often the case when barriers are created within the helping society.

Specific examples of promising practices are to rely on the individual's knowledge of themselves. Information from clinical reports can be of initial assistance to you; however, one should ask the individual their opinion of the appropriateness of given therapies, interventions, and methodologies. Having one's expectations limited by sterile, objective, evaluative reports, without the added value of the individual's perspective on his/her condition is one dimensional, rather than providing the richness of the all the data available for a comprehensive assessment.

This personal addition to the data will allow professionals to be exposed to a unique perspective. Surgeries will not only be measured in positive or negative outcomes for each procedure, but will incorporate the patient's views on the procedure and subsequent therapy. Therapists will not only observe the benchmarks of therapeutic interventions, but will also cooperate with the patient to bring meaning to the progress. Caseworkers will not only document the progress in the transition from dependence to independence, but will gain substantial information that will transfer to other clients in other situations.

These suggestions may be fundamental practices to many in the medical professions; however, from the perspective of an adult with Cerebral Palsy, who has experienced the realm of medical practice from birth to adulthood, it is important to note that the effect of the collaboration of professional and consumer should not be minimized. As a consumer and a provider of expertise in the helping profession it has become evident that these personal practices are essential for the development of the individual with a disability. Looking back over my life, this information validates my experience.

INTERESTING WEB SITES

September 1, 2003, the Medicare Caps on outpatient rehabilitation went into effect. The Centers for Medicare and Medicaid Services has a publication available for distribution to beneficiaries about the cap on services. To get a copy at no cost go to <http://www.medicare.gov/publications/pubs/pdf/10988.pdf>.

In July of 2003, NCD released its annual report, *National Disability Policy: A Progress Report*. Go to http://www.nck.gov/newsroom/publications/progressreport_f inal.html.

In July of 2003, NCD released a policy paper: Does the ADA apply to commercial and other private sector Web sites, and if so, what does it require? See <http://www.ncd.gov/newsroom/publications/adainternet.html>

NCD has released a report *Outreach and People with Disabilities from Diverse Cultures: A Review of the Literature*.” The report is available at http://www.ncd.gov/newsroom/advisory/cultural/cdi_litre-view.html.

Twenty Easter Seals staff members representing 13 affiliates met December 4, 2003, for a conference call to discuss the delivery of in-home services for adults. Information on in-home services for adults including a sample Policies & Procedures Manual can be found on the Easter Seals Extranet site at http://www.affiliate.easter-seals.org/site/PageServer?pagenam+pps_ads_main_inhome. Or call Easter Seals at 312.726.6200.

RETRACTION

The 2003 Annual Meeting final program mistakenly listed Dr. Michelle Macias and Dr. Adrian Sandler as having received honoraria and travel from GlaxoSmith Kline. This information was incorrect. Please accept our apologies for the misinformation.

INTRODUCING THE BOARD OF DIRECTORS

Taking office at the 2003 Annual Meeting in Montreal were: Robert Armstrong, MD, President; Luciano S. Dias, MD, First Vice President; Barry S. Russman, MD, Second Vice President; Virginia S. Nelson, MD, Secretary; Kristie F. Bjornson, PT, Secretary-elect; Henry G. Chambers, MD, Treasurer; Scott A. Hoffinger, MD, Treasurer-elect; James A. Blackman, MD, MPH, Past President; and Michael D. Sussman, MD, Past President. Members at-large are: Annette Majnemer, PhD, Richard D. Stevenson, MD, Anita Bagley, MD, Holly Lea Cintas, PT, PhD, Glen P. Aylward, PhD, and Diane L. Damiano, PhD, PT.

The Board of Directors is in office to work for you, the member. If you have any concerns or suggestions, do not hesitate to contact any one. You are also encouraged to take part in a committee, or contact the President with suggestions for nominations to the Board of Directors. As you can see, every effort has been made to have a balance among the different disciplines and specialties, so the Board reflects the membership.

IN MEMORIUM

We are sorry to report the death of Dr. Arnold J. Capute on November 30, 2003.

International Affairs Committee News from Here and Far.



Dangire Dargine, PT with Laimos Paksienes, Wife of the President of Lithuania

A year ago at the AACPDMD meetings in New Orleans 2002 the Board approved the distribution of \$10,000. for International scholarships that would encourage young, energetic researchers and trainees in countries outside of USA and Canada to be able to apply for scholarships to attend meetings, be able to disseminate information and knowledge they have learnt to colleagues in their own countries. Recipients would be encouraged to share information on the work they are doing through poster and/or platform presentations at the AACPDMD meetings. The International Affairs Committee (IAC) was charged to develop guidelines for such applications to be reviewed on a fair and consistent basis. In the last year the committee has been busy developing these guidelines which are finally completed.. Five scholarships of up to \$2000 would be made available to the recipients who meet the criteria listed. These are available through the AACPDMD office.

At the 2003 AACPDMD meeting the Board also approved supporting International meetings and allotted \$10,000 to be used for one or more meetings. Guidelines for applications for these funds have also been developed by the International affairs Committee.

I would like to acknowledge the work and dedication of each member of the committee who helped in the development of guidelines and reviews for scholarships. Many thanks to each one.

At the annual meeting in Montreal, 2004 our International luncheon speaker was

Lisa Albers, MD a Developmental Pediatrician from Children's Hospital, Boston. She is currently Director of the Adoption Program and Director of fellowships in Developmental and Behavioral Pediatrics. She collaborates with community health centers and consults with the school system. She has traveled extensively abroad and visited a number of orphanages and child-care institutions. She spoke on International adoptions and discussed the long term developmental, emotional and behavioral outcomes in international adoptees.

We welcome submission of topics and or names from our members for presentations to be made at the luncheon. It is one other venue that allows members to share information in an informal setting. We want to encourage participation from our international colleagues.

Dangire Dargine, PT from Vilnius, Lithuania is a member of the International Affairs Committee. She has been busy. Last year she had organized a meeting on Cerebral Palsy and due to the positive

response for another meeting, she organized a second meeting for October 20th, 2004. There were about 160 attendees. The President's wife Laimos Paksienes opened the meeting with very appropriate remarks reflecting her empathy for children with disabilities and the care they need. I was invited as their guest speaker to present on current concepts of Cerebral Palsy, early diagnosis, associated medical problems, spasticity and management. There were several local speakers including therapists, educators and physicians.

This meeting was partly supported by the AACPDMD and members of the International Affairs Committee. It was already under the planning phase as the new guidelines were being established. The positive response from the attendees was overwhelming.

I had an opportunity to visit with the staff and the Director of their Child Development Center the next day. I was impressed at the effort they have placed in collaborating with their local agencies and trying to provide as comprehensive a program as possible.

After the restoration of democracy and independence in 1990 essential changes have taken place. A group of contemporary reform-minded professionals initiated the idea of developing a center for evaluation and treatment of children with developmental and behavioral needs. They envisioned that the center would also be used for training and research. This was established through the University of Vilnius. Since 1997 the center came under the direction of Department of Social Pediatrics and Child Psychiatry. There is a range of inpatient and out patient services being provided including assessment of mother child interaction through videos, individual family therapy, counseling and group therapy for parents. They include music, art and play therapy, and use a Montessori approach for preschoolers. Conduct modification is used for children with behavior disorders. They have established a Children's helpline that is free and can be accessed by children if they are in crisis or fearful of abuse at home or school. The volunteers are trained to take calls and access services for these children. Those children who live a long distance from Vilnius are admitted for 3 weeks and the parents are trained. The children are then referred back to their own communities. This model is different to our but works well for them

Reminder to the readers: The second Eastern Mediterranean Meeting on Cerebral Palsy and Developmental Medicine is planned for May13-16 2004 in Santorini, Greece. For information visit their website www.era.gr or e-mail info@era.gr AACPDMD is partly sponsoring the meeting.

Submitted by

Sarojini Budden M.D
Chair, International Affairs Committee

Nov: 11th 2004

REGISTRATION INSTRUCTIONS

REGISTRATION FEE

Please do not send the fee with your registration form. Confirmation will be sent immediately upon receipt. The *NON-REFUNDABLE* fee is paid upon receipt of your confirmation letter. Check or credit cards are accepted. If your fee is not received within two weeks from the date of the confirmation letter, the next person on the wait list will be notified of an opening. The tutor will be sent a list of registrants and will contact you with the pertinent information regarding the tutorial shortly after receiving the list. ***DO NOT REGISTER WITH THE TUTOR DIRECTLY ON YOUR OWN, ALL REGISTRATIONS MUST BE SENT TO THE AACPDMM OFFICE.***

REFUNDS

No refunds will be granted. ***DO NOT CANCEL YOUR REGISTRATION WITH THE TUTOR DIRECTLY. ALL CANCELLATIONS MUST BE SENT TO THE AACPDMM OFFICE.***

Return your form to the AACPDMM office at 6300 N. River Road, Suite 727, Rosemont, IL 60018-4226. **(DO NOT INCLUDE FEE WITH REGISTRATION)** The registration fee will be required upon confirmation. Forms can be faxed to 847-823-0536.

AACPDMM TUTORIALS

1. Saturday April 10, 2004 Limit 8 Chicago, IL
 Luciano Dias, MD
 Tuition: \$150.00
 “The Orthopaedic Care of the Spina Bifida Child”:
 This tutorial will discuss in-depth all issues related with the orthopedic, physical therapy and orthotic management of the spina-bifida child. Orthopaedic Care: The functional motor levels, characteristic gait patterns, the value of gait analysis, highlighting treatment of the most common orthopaedic pathologies including tethered cord. Physical Therapy: early intervention, muscle test and its importance. Physical fitness and sports. Orthotics: the use of splinting to prevent deformities, different orthotics based on the child’s functional level (RGO, KAFO, AFO and Parapodium, TBS)

2. Saturday, April 17, 2004 Limit 10 Chicago, IL
 Mary Weck, PT; Brigid Driscoll, PT, CO; Beverly Cusick, MSPT; Denise Ibrahim, DO
 Tuition: \$150.00
 “A Lower Limb Serial Casting Program for Long Term Retention of Equines Deformity Correction”
 Participants will review pathophysiological and biomechanical aspects of equines deformities. Pre-casting and inter-casting evaluation and application techniques will be demonstrated in relationship to the Below Knee Serial Casting Program. The contribution of Center of Mass placement in relationship to base of support will be examined. There will be a discussion of the vital role of orthotic intervention and home exercise program. Long-term research results will be presented.

3. Friday, April 23, 2004 Limit 10 Dallas, TX
 Susan Leibold, MS, RN
 Tuition: \$150.00
 “Non-Surgical Approaches to Neurogenic Bowel Management”
 Neurogenic bowel can lead to embarrassing incontinence, impaired social activities, and significant medical problems including constipation and bowel obstruction. An interdisciplinary approach to bowel management leads to continence and control in most situations. Understanding the underlying pathophysiology is necessary prior to initiating an assessment. The step-wise assessment process directs the interdisciplinary team (medical, nursing, dietary and occupational therapy) in design of an individualized program to support the achievement of success: health, continence, and freedom from constipation. This one-day workshop will outline non-surgical approaches for achieving continence and the use of a sense of humor when providing family-centered support.

4. Friday, May 14, 2004 Limit 10 Elgin, SC
 Lawrence Siegel, MD
 Tuition: \$150.00
 “Autism Spectrum Disorders: Assessment and Intervention”

This one-day course will provide an overview of the assessment tools and current intervention practices being used with children with Autism Spectrum Disorders. Participants will view videotape of assessments being conducted with patients and will be trained in the use of the Modified-Checklist for Autism in Toddlers (M-CHAT). Participants will also view a live intervention session with a therapist and a patient. There will be ample opportunity for physicians, and other professionals for interaction with a staff including a PHD Psychologist and educational specialist who work full time with Children with Autism in a university setting.

AACPDM TUTORIALS 2004

Please read the information on the preceding page before registering.

Circle the tutorial(s) you wish to attend, then return your form to the AACPDMD office at 6300 N. River Road, Suite 727, Attention: Shannon Rosemont, IL 60018-4226 or fax to 1-847/823-0536.

(DO NOT INCLUDE FEE WITH REGISTRATION)

1. Saturday April 10, 2004
Luciano Dias, MD
“The Orthopaedic Care of the Spina Bifida Child”
Limit: 8 attendees
Chicago, IL
Tuition: \$150.00

2. Saturday, April 17, 2004
Mary Weck, PT; Brigid Driscoll, PT, CO; Beverly Cusick, MSPT; Denise Ibrahim, DO
“A Lower Limb Serial Casting Program for Long Term Retention of Equines Deformity Correction”
Limit: 10
Chicago, IL
Tuition: \$150.00

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4. Friday, May 14, 2004
Lawrence Siegel, MD
“Autism Spectrum Disorders: Assessment and Intervention”
Limit: 8-10
Elgin, SC
Tuition: \$150.00

Name _____

Address _____

Office Phone # _____ Fax # _____ E-mail: _____

Endowment Fund Contributions for 2004

We would like to thank everyone who has contributed to the Endowment Fund.

\$2,501 - \$5,000

Leon B Greenspan, MD

\$1,001 - \$2,500

Helen M Horstmann, MD

\$501 - \$1,000

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Nominations are being Requested

James Blackman, MD, chair of the Nominating Committee wants to notify the membership that the committee is seeking nominations for the following offices; Second Vice President, the Membership Committee, and Directors at-Large. Two Nominating Committee members will be elected by the membership from nominations made from the floor at the business meeting in Los Angeles. If you know of someone who would like to serve, or if you would like to be added to the slate, please contact James A. Blackman, MD at jab5u@virginia.edu. Do not submit a name without the permission of the person you are suggesting. Only AACPDM active members (Fellows) are eligible for election. Please feel encouraged to nominate someone. The membership benefits when everyone participates.

Continuing Education Grant Application Form

Name of Contact Person: _____ AACPDM Member Yes No

Address: _____

City: _____ ST: _____ Country: _____

Postal Code: _____

Name of Organization: _____

Conference Objectives: _____

Target Audience: _____

Proposed Agenda: _____

Budget: Location/Fee for Space _____
 Speaker Fees: _____
 Meals: _____
 Mailings: _____
 Other: _____
 Total: _____

How will your program be evaluated? _____

Other Sponsors/Donors of Program _____

How Much Money is Requested? _____

When is the money needed by? _____

Do you agree to submit a copy of the overall program evaluation and how the money was utilized? _____

AACPDM COMMITTEE CHAIRS

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GRANTS AVAILABLE

AACPDM ANNOUNCES RESEARCH FUNDING OPPORTUNITY

The Academy is providing a \$25,000 grant. The intent of the grant is to act as seed money to develop a grant request, literature review, or start up for a research project, such as a multi-center study. The grant is open to AACPDM members only. There can be more than one grant. To receive instructions contact Melody Raymond at Raymond@aaos.org. Deadline for applications is March 31, 2004.

United Cerebral Palsy Research and Education Foundation (UCP) provided support for 18 research projects. For information on the 2004 grants available, contact the Foundation at 202-973-7140.

To find what **Health Resources and Services Administration** grants are available go to <http://www.hrsa.gov/grants.htm> or call the Grant Application Center at 877.477.2123.

2003-2004 BOARD OF DIRECTORS

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