

LETTER FROM THE PRESIDENT



*President,
Dr. Robert Armstrong*

This newsletter will reach you just before you begin to think about a break over the summer period. While I do not want to interfere in a significant way with those thoughts I would ask you to save a little time to think about the Academy. At the Board meeting in March we agreed that it was time for us to review our strategic plan and chart the direction for the next few years. So, in March of 2005 the Board will be extending their mid-year meeting to develop a new plan. Dr. Lou Dias, incoming President, will lead this process but we will want your thoughts about the key strategic directions that would support you in your professional roles.

The unique feature of our Academy is the bringing together of a broad cross-discipline professional group focused on advancing our knowledge and practice related to cerebral palsy and developmental medicine. Through your hard work we have developed a strong, financially sound organization that is clearly recognized as a leader in the field. So, how can we utilize our current position to support your work and ensure that we remain at the forefront of advances in the field of child development and cerebral palsy?

Over the summer we will be mapping out the structure for input. Prior to the meeting we will provide you with a background document that summarizes our existing strategic plan, what we have accomplished, and some of the issues you might want addressed in the new plan. Our committees will work during the meeting and beyond and we will have opportunity for individual members to contribute their ideas. I encourage your creative thinking while getting some relaxation this summer!

Planning for the Fall meeting is complete and you will soon receive registration information. We have a great venue for the meeting and an outstanding program so I know you will want to be in Los Angeles. Perhaps

what you could do is not only come yourself but bring someone who hasn't come before or wasn't planning on coming! We want to encourage more participation in the meeting and active involvement in the Academy and what better way to do this than a personal invitation from you to them.

LETTER FROM THE LOCAL HOST



Welcome to Los Angeles, the City of the Angels, anchor city, center of trade and commerce of the West Coast of the United States, entertainment Capital (sorry New York) and one of the easiest to get to, a most exciting and vibrant location yet to host the AACPD. Welcome to Hollywood and all of those great locations you are used to seeing on TV and in the movies. Stargazing has a different connotation in Los Angeles for good reason. For those of you curious about the entertainment scene, you will not be disappointed. The Century Plaza Hotel, frequently the home of Presidents when visiting LA, will be our home for the meeting at rates (\$160 per room) unlikely to be repeated ever again. These rooms normally go out at \$389 to \$3400. Look at their website via the links on ours, and you will see what I mean.

REGISTER EARLY FOR THE AACPD M ANNUAL MEETING – SEPTEMBER 29 - OCTOBER 2, 2004

Plan to attend the 2004 Annual Meeting at the Century Plaza Hotel and Spa in Los Angeles, California. Preliminary Program and online registration available at www.aacpdm.org mid-June.

BOARD OF DIRECTORS UPDATE

On March 20, 2004 the Board of Directors of the AACPD M met in Rosemont, Illinois, for the annual mid-year board meeting. The treasure's report demonstrated that the Academy is sound financially to the point that it could survive two years without additional income. The board recognizes the importance of vigilance with the finances so as not to fall into a pattern of deficit spending. The key to the academic and financial viability of this Academy is the retention and recruitment of members. This recurring theme dominated much of the planning and decision making process of the board through out the day.

The Academy's finances are deliberately divided into three funds: the Endowment Fund, a Board Designated Fund, and a General Fund. This gives the board the maximum flexibility to meet current expenses, plan for the future, and to begin providing new educational and research opportunities. Through the International Committee, grants are now being offered to qualified professionals from developing countries to enable them to attend the annual meeting. A \$25,000 research grant has been established which is available to AACPD M members only. Through the Continuing Education Committee, grants are available to Academy members to provide funds to facilitate local CME courses. It is hoped that the membership will take advantage of these and future opportunities.

The Continuing Education Committee has established a series of tutorials where members can spend a day as part of a small group studying a topic of childhood disability. The tutorials are focused and designed to improve the clinical knowledge and skills of participants under the direct teaching of a recognized expert. These tutorials are intended to be financially affordable to all Academy members.

The structure of the annual meeting was discussed. Although the established pattern of instructional courses is considered one of the strengths of the meeting, there was concern that only a small percentage of the free papers could be observed by any one attendee.

The relative value of the lectureships, free papers, seminars, posters, and instructional courses was debated. Several formulas were proposed to change the format of the annual meeting. No consensus was reached. I would encourage the membership to share their comments with any board member, or this newsletter editor.

The role of the Advocacy Committee in providing direct advocacy for people with disabilities was reaffirmed. It was felt at one time that the Academy's 501C3 status prohibited direct advocacy. However, after review, it was found that direct advocacy from an organization such as the AACPD M is allowed if it consumes less than 5% of the budget. This is clearly true in our case.

The nomination and election process for officers and board members was discussed at length. This review was spurred by the confusion at last year's membership meeting, but fueled by the board's desire to increase the participation of a greater percentage of the membership in the nomination and election processes. Three issues need to be considered: 1) the nomination of candidates, 2) the selection of the slate, and 3) the process of voting (e.g. annual meeting, electronic, paper mail). Several models and the pros and cons of each were discussed thoroughly. Some models would require a change to the bylaws of the Academy. Once again, it is important for the membership to express their ideas and opinions to the board as this most important issue continues to be examined.

The potential collaboration and development of meetings between the AACPD M and other international academies focused on childhood disabilities was discussed. Everything from "A World Congress of Cerebral Palsy" to regional focused workshops were considered. Should there be an International Federation of Childhood Disability some day? What is the role for teleconferencing in sharing ideas and research internationally?

continued next page

BOARD OF DIRECTORS UPDATE, *continued*

Dr. Peter Baxter, the editor of *Developmental Medicine and Child Neurology*, gave a presentation. He reported that DMCN is number one in reviews of journals focused on childhood disabilities, and has a very high citation index. The refereeing of articles continues to be very rigorous and authors are encouraged to employ an economy of words per article to allow for the maximum number of articles in a journal. One third of journal subscribers are AACPDM members who receive a discounted subscription rate. DMCN functions as a nonprofit charity in England and thus cannot make a profit. The future of academic journals in general is somewhat uncertain given the development of electronic versions. At this time, DMCN continues as the preeminent journal in the field.

A review of the efforts of the Academy over the last several years has revealed that a majority of the goals of its strategic plan have been met or exceeded. It was proposed and accepted that it was time to reestablish a new Strategic Planning Committee to set the goals for the next phase of the Academy. Dr. Lou Dias was named chairman of this committee which will begin functioning immediately and work throughout the coming year.

Membership is probably the most critical issue that will determine the viability of this Academy in the future. Clearly, this is the preeminent multidisciplinary organization of professionals dedicated to the care of people with disabilities. We have the most cited journal on childhood disabilities in the world. The Treatment Outcomes Committee continues to produce some of the finest objective reviews seen in any health related field. The annual meeting is superb and packed from morning to night with more interesting sessions than any one person can possibly take in. The focus on quality of reporting and research methodology has increased the excellence of free papers. The number of submissions to the annual meeting for papers, posters, and instructional courses is impressive. The web site is popular with professionals and lay people alike. The newsletter is developing into a frequent point-of-contact between the leadership and the membership of the Academy. Research, education, and scholarship funds are now being offered. All point to a vibrant, scholarly academy that, in difficult times, is committed to pursuing the goal of improving the lives of people with disabilities.

Joseph Dutkowsky, MD
Editor

HEALTH VOLUNTEERS OVERSEAS OPPORTUNITIES

I have just returned from a month of teaching about early identification and care of developmental disabilities at the Angkor Hospital for Children (AHC) in Siem Reap, Cambodia, under auspices of Health Volunteers Overseas. The hospital is located in north-west Cambodia, at the head of Tonle Sap Lake. It is a beautiful rural, ancient farming area, known internationally as the site of the Angkor Wat temples dating from 900 A.D. It is a very pleasant and safe place in which to stay. Living conditions at the hospital were excellent.

This is a modern teaching facility providing advanced training for Cambodian doctors and nurses, with capabilities in general surgery, a bustling outpatient service, and a strong outreach program extending to villages in the surrounding area.

I conducted a two-day workshop each week using a Power Point presentation in English for both doctors and nurses, and developed a training manual that will be used by staff for future training of others. Concepts of normal and abnormal development and early diagnostic features, caught on easily and were quickly adapted by the staff. I think this was due in part to the large volume of developmental pathology with which they are constantly confronted. Cerebral palsy and congenital/genetic disorders such as Down Syndrome, club foot, and cleft palate, were common. The course helped crystallize and focus these conditions to the same level of consciousness as acute diseases. It has resulted in more awareness of on-going family and home care needs. And there is a very good facility for orthotics and ambulatory equipment at the nearby Handicap International program which works closely with AHC.

The Cambodian program is among many under auspices of Health Volunteers Overseas (HVO). This is a non-profit organization dedicated to improving global health through education. I would urge AACPDM members with an interest in participation to contact HVO at any of the following: PO Box 65157, Washington, DC 20035-5157; Tel: (202) 296-0928 www.hvouusa.org.

Best wishes,
Alfred L. Scherzer, MD

NAMES IN THE NEWS

On June 21st, the Hospital for Special Surgery will present **Dr. Leon Root** with their first **Lifetime Achievement Award** for his dedication, mentorship, clinical care and leadership, and for his legendary work in caring for countless numbers of disabled children.

ENDOWMENT FUND CONTRIBUTIONS

The AACPDMD would like to thank the following members for their contributions to the Endowment Fund.

\$251 - \$500

Robert P. Christopher, MD

\$10 - \$250

James A Blackman, MD

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WINGS FOR CHILDREN

Wings for Children is a 10-year-old Pittsburgh based non-profit organization that provides free air transportation to children with serious illnesses or disabilities. It is easy to make a referral to Wings for Children. All you need to do is call the Mission Flight line at (412)401-4529 or our office at 1(800)743-5527.

More information about this organization is available via e-mail at wingsfc@city-net.com.

HELP US FIND THESE MEMBERS...

Do you know the whereabouts of the members listed below? If so, please contact the Academy office so that we can update our records. Addresses given are the last known addresses.

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Emeritus Member: **Andor A Weiss, MD**
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THE IMPORTANCE OF FRIENDSHIP: RESEARCHERS STUDY NEW WAYS TO BOOST SOCIAL LIVES OF CHILDREN WHO HAVE A DISABILITY

By Sean Cunningham, MS, and Sunny Roller, MA

Ann Arbor, MI— A grant awarded to principal investigator Pamela Dixon, PhD, by the United States Office of Special Education Programs, has helped to launch a three-year set of studies titled the *Adult Facilitation of Social Integration Studies (AFSIS)*. Dixon intends to examine parents' and teachers' methods of social facilitation that will best predict the successful social integration of children with brain dysfunction. Specifically, AFSIS will identify "best practices," or most effective friendship-making strategies and programs in homes and at schools that parents and teachers can become involved in. It is predicted that these will not only benefit children with disabilities, but their classmates, too.

What Can Parents and Teachers Do to Help?

The AFSIS Project is a collaborative study conducted by the University of Michigan Health System, Pediatric Rehabilitation Program and Division of Rehabilitation Psychology and Neuropsychology, and the Washtenaw County Intermediate School District. The Project Investigators include Pamela Dixon, PhD, Seth Warschausky, PhD and Mary Spence, PhD.

As Dixon's study begins to uncover what adults can do to help children build friendships, this information will be used to influence school programming and parenting practices as well. Preliminary findings from the AFSIS have been presented at national and local conferences. These offer early insight into the ways that parents and teachers can help boost the social life experienced by children with brain dysfunction. For more information, go to the project web site: <http://www.med.umich.edu/pmr/afsis/index.htm> or contact Dr. Dixon at (734)936-7052.

Reflections from a Different Journey. What Adults with Disabilities Want All Parents to Know edited by Stanley D. Klein, PhD, and John D. Kemp is now available at <http://www.disabilitiesbooks.com> at a discount price. Table of Contents, excerpts, reviews, and information about the editors are all at <http://www.disabilitiesbooks.com>.

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Chair, AACPDM Research & Awards Committee
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18 Sept. 03

Dear Dr. Aiona,

I was fortunate enough to be a recipient of an AACPDM travel award for the 2003 conference in Montreal, Canada and would like to thank the AACPDM committee for providing this opportunity to attend.

I found both the presentations and instructional courses at the conference to be extremely valuable and enjoyed the chance to meet 'experts' in the field.

I would like to thank the AACPDM for running a stimulating and enjoyable conference and allowing me the financial opportunity to attend. Attending the conference has provided me with renewed enthusiasm and inspiration to continue with my research and I look forward to attending the future conferences.

Many thanks,
Kind regards,

Anna Mackey
PhD Student
University of Auckland, New Zealand

GRANTS AVAILABLE RESEARCH FUNDING OPPORTUNITIES

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, visit <http://www.hrsa.gov/grants.htm> or call the Grant Application Center at (877)477-2123.

INTERESTING WEB SITES

CME Resources

Patricia King, writing for *HealthLeaders News* on April 13, 2004, offers security compliance ideas in her article "The Next HIPPA Compliance Hurdle." For those facing this compliance date, she breaks the issue down into three phases with very specific steps to follow. You can view the article at: <http://www.healthleaders.com/news/feature1.php?contentid=53795>.

Easter Seals

The Easter Seals Adult Day Services Network continues to grow, now encompassing 20 affiliates who operate 44 centers in 16 different states. For further information on the programs offered or on other topics related to in-home or center-based care for adults, please contact Jed Johnson, a.v.p., Adult and Senior Services, at jjohnson@easterseals.com or visit www.easter-seals.org.

"Technology Working to Help Disabled get Jobs," published in the *LaFayette-West Lafayette, Indiana Journal and Courier*, March 15, 2004, covered a demonstration of Easter Seals Crossroad's Assistive Technology Work Station. For more information visit: www.easter-seals.org.

National Council on Disability (NCD) Releases Disability Statistics Paper

On January 9, NCD released *Improving Federal Disability Statistics*, a position paper that describes critical issues involving federal disability data. The paper

describes an urgent need for the Departments of Commerce and Labor to address matters related to the collection of disability data through the Decennial Census, the American Community Survey, and the Current Population Survey. You can view the paper at: <http://www.ncd.gov/newsroom/publications/improvedata.html>.

International Update

During the 2003 observance of International Day of Disabled Persons on December 1 at United Nations (UN) headquarters in New York City, NCD chairperson Lex Frieden moderated a panel discussion on the importance of a UN convention on the human rights of people with disabilities. The panel discussion is available at <http://www.un.org/esa/socdev/enable/disid2003.htm>. For more information on the convention, please see NCD's *UN Disability Convention - Topics at a Glance: History of the Process* at http://www.ncd.gov/newsroom/publications/history_process.html.

Working Group

The Working Group established by the Ad Hoc Committee met January 5 - 6, 2004 to draft the text of an international convention on the rights of persons with disabilities. A Virtual Forum was launched to facilitate dialogue on the disability convention between members of the Working Group and among all interested parties. For more information, go to <http://www.un.org/esa/socdev/enable/rights/ahcwg.htm>.

3RD ANNUAL INTENSIVE WORKSHOP ON GRANT WRITING, PREPARATION AND SUBMISSION IN REHABILITATION RESEARCH

A 5-day workshop that includes lectures, small group discussions and individual mentoring, as well as sessions on grantsmanship, writing, research design and hypotheses generation is offered at the Boar's Head Inn in Charlottesville, Virginia.

Junior and mid-level faculty in a medical rehabilitation discipline who have either not submitted a grant application to or who have not been successful in obtaining research funding from the NIH.

Beginning July 1, 2004, applications will be accepted on-line at <http://erris.med.virginia.edu>. (Application deadline September 30, 2004). Thirty participants will be selected through a competitive application process.

The Committee will award partial scholarships to all 30 participants who meet criteria. The scholarship will apply to hotel costs, all meals, training materials, and logistical support. Each participant will be charged a nominal fee of \$500. Transportation costs and incidentals are the responsibility of the participant.

For complete information, visit the ERRIS web site at <http://erris.med.virginia.edu> or

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