

**AMERICAN
PEDIATRIC
SOCIETY**

**ASSOCIATION OF MEDICAL
SCHOOL PEDIATRIC
DEPARTMENT CHAIRS**

**SOCIETY FOR
PEDIATRIC
RESEARCH**

Public Policy Council

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FROM: Myron Genel, M.D., Chair
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SUBJECT: 2010-2011 Interim Activities Report

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The Public Policy Council is now in its 27th year as a vehicle for the three academic pediatric societies - the American Pediatric Society (APS), the Association of Medical School Pediatric Department Chairs (AMSPDC) and Society for Pediatric Research (SPR) – who created it in 1984 to succeed the tri-society legislative committee founded by NICH director Norman Kretchmer. I have served as the Public Policy Council's chair since its founding with staff support provided by the Academy of Pediatrics' Office of Federal Government in Washington, DC, now headed by Mark DelMonte, JD.

Membership of the Public Policy Council has remained unchanged since my last report to the Councils and AMSPDC Executive Committee last spring. APS representatives continue to be Steve Berman, and Rick Bucciarelli. Leona Cuttler replaced Elena Fuentes-Afflick as one SPR representative at the 2010 PAS meetings in Vancouver; Tom Green remains the other SPR representative. Bonnie Stanton, current president of AMSPDC, has replaced Russ Chesney as one AMSPDC representative and joins David Clark who also serves as chair of AMSPDC's Advocacy Committee. Under new operating guidelines each sponsoring society appoints two representatives for up to two three-year terms commencing after the annual PAS meetings. Traditionally representatives have served simultaneously as liaison representatives to the Academy's Committee on Federal Government Affairs (COFGA) and as representatives to AAMC's Council of Academic Societies. This has been continued except for AMSPDC, whose representative to the Council of Academic Societies now is Marianne Felice.

Until last June, the Public Policy Council's Washington Coordinator was one of the assistant directors of the Academy's Washington office, Nan Schiavo until 1991 and subsequently Karen Hendricks, who left the Academy on May 29, 2009 for a position as Director of Policy Development with the Trust for America's Health. Subsequently, the Washington Coordinator has been the director of the AAP's Washington office, initially Jackie Noyes who retired January 1 and subsequently, following his appointment in late January, Mark DelMonte, JD. Since April 2010, Mr. DelMonte has been ably assisted by James Baumberger, who has assumed responsibility for the day-to-day operations and communications of the Public Policy Council. Mr. Baumberger accompanied me when we met with the APS and SPR Executive Councils at the 2010 PAS meetings.

Operationally, the Public Policy Council continues its regular monthly conference calls, supplemented by mailings and email correspondence from the Academy's Washington office. Since my last report, the principal activities have revolved around long-range planning regarding the composition and functions of the Public Policy Council, highlighted by the Strategic Planning retreat sponsored by the Academy and held June 27-28 in Washington, together with planning for the traditional programs sponsored by the Public Policy Council during the 2011 PAS meetings in Denver. These will follow upon a particularly successful Public Policy Council program at the Vancouver meetings, where we had a standing room audience for the early morning Legislative Breakfast moderated by Rick Bucciarelli, which examined "Healthcare Systems for Children in Canada vs. the United States" and an almost capacity audience for the annual Public Policy Council Plenary Symposium, organized and chaired by Steve Berman, on "Vaccine Public Policy". The annual Plenary Symposium devoted to the National Children's Study, organized and moderated by Elena Fuentes-Afflick, also attracted a sizable audience, notwithstanding being held in the convention center annex. A "hot topic" symposium,

organized and chaired by Steve Berman on “Healthcare Reform: What Went Right and What Went Wrong”, attracted a sizeable and very active audience notwithstanding being held late on the last day.

The program for the 2011 PAS meeting will look closely at the evolving transformation of the healthcare system with implementation of the Affordable Care and Patient Protection Act or ACA. Leona Cuttler will moderate the Monday morning Legislative Breakfast which will be devoted to “Health Reform and New Delivery System Models: What do Emerging Accountable Care Organizations (ACOs) mean for pediatrics?” with brief presentations by Mark DelMonte, Paul Wise, Director of the Center for Policy, Outcomes and Prevention at Stanford, and Richard Antonelli, Medical Director for Integrated Care at The Children’s Hospital of Boston. The Public Policy Plenary Symposium on Saturday, April 30 has been organized and will be moderated by David Clark on “Implementation of Healthcare Reform, the State Perspective” with speakers who are all past presidents of the American Academy of Pediatrics. Judy Palfrey will describe efforts in Massachusetts, David Tayloe in North Carolina and Steve Berman in Colorado. Dr. Clark served previously as Chair of the Academy’s Committee on State Government Affairs (COSGA). Once again there will be a special plenary session devoted to the National Children’s Study, which has just announced a significantly new recruitment strategy. This is being organized by PPC member Tom Green; Elena Fuentes-Afflick, no longer a member of the Public Policy Council, is a member of the NCS Federal Advisory Committee. Speakers and topics for the session will be determined in discussion with the NICHD new director, Alan Guttmacher, who is expected to participate, and the NCS acting director, Steve Hirschfeld, but are expected to deal with the new recruitment strategies and modifications of the NCS Study Plan. Finally, Steve Berman has again organized a “hot topic” session devoted to “Healthcare Reform: Are we Making Progress for America’s Children?” The program notably will include two former RWJ Health Policy Fellows, David Keller and Shale Wong, who were engaged in the healthcare reform process during the last Congressional session, Dr. Wong while serving the Office of the First Lady.

The Strategic Planning Retreat held June 27-28, was organized and funded by the Academy with active participation by the Public Policy Council chair in the agenda’s planning. A number of converging events led to the decision to step back and review the functions and composition of the Public Policy Council, among these the previously outlined changes in Academy staff supporting the Public Policy Council, anticipated transition in Public Policy Council leadership, emergence of new pediatric organizations as well as changing roles of older organizations raised the need for critical examination of the advocacy vehicle represented by the Public Policy Council. In particular, the substantial and increasing impact of Federal policy and funding in an era of rapid communication required thoughtful and critical analysis. Eight organizations participated in the Strategic Planning Retreat including all members of the Public Policy Council, as well as retiring member Russ Chesney. In addition to the Public Policy Council’s three parent organizations, attending were representatives from the Association of Pediatric Program Directors, the Council of Pediatric Specialties, the Academic Pediatric Association, the National Association of Children’s Hospitals and Related Institutions (NACHRI) and of course the Academy of Pediatrics which in addition to staff was represented by its Executive Director Errol Alden and President Judith Palfrey. The Federation of Pediatric Organizations was also represented through its Executive Director, Ted Sectish. A summary of that meeting has been prepared by the conference facilitator, Ken Slaw, and circulated. It was concluded that involvement of a new and broader coalition model should be explored, perhaps utilizing infrastructure from both the Academy and NACHRI’s Government Affairs arm, the National Association of Children’s Hospitals or NACH. Each organization was asked to identify their major advocacy priorities which Ken Slaw has tabulated on a grid to identify common, overlapping priorities. Finally, each organization has identified an individual who will represent that organization to develop a concrete plan for potential implementation. APS is being represented by Bruder Stapleton, SPR by Tom Shanley and AMSPDC by Bonnie Stanton on this group, which has yet to meet as of preparation of this report, but is expected to convene by conference call prior to the joint APS/SPR Council meetings November 4-5. Of course, while these discussions are continuing, the Public Policy Council continues to operate in its previously established mode.

An updated Legislative Report will accompany this interim activities report and thus I will note only some highlights. Implementation of provisions of the Patient Protection and Affordable Care Act (preferred acronym ACA) are now emerging six months after passage. Among the first, relevant to children, was expansion of coverage to include children up to age 26 under their parents’ plan and a requirement that coverage for children cannot exclude a pre-existing illness. As recounted in press reports, the latter provision has resulted in limiting availability or increased premiums for child-only policies and limiting services for children under so-called “grandfathered” plans. The Public Policy Council societies co-signed a letter to HHS urging modification of the interim final rule.

The Public Policy Council societies also co-signed a letter urging funding of the ACA provisions authorizing a program of loan forgiveness grants to pediatricians pursuing subspecialty training and who serve in areas of documented subspecialty need. Pediatrician Don Berwick, was named by President Obama to head the Centers for Medicare and Medicaid Services (CMS) on July 7 via a recess appointment which generated some controversy though it is unlikely that he could have been confirmed by the Senate without substantial political rhetoric. Nonetheless, the appointment was lauded by the vast majority of health policy experts.

After a six-month's search process Alan Guttmacher was named Director of the *Eunice Schriver* National Institute of Child Health and Human Development (NICHD) on July 22 having served as Interim Director from December 1, 2009 and previously as Deputy Director of the National Human Genome Research Institute and its Acting Director for a year prior to moving to NICHD. Dr. Guttmacher has announced development of an ambitious strategic plan or "Scientific Vision" to cover the forthcoming decade along nine themes 1) development, 2) plasticity, 3) cognition, 4) behavior, 5) reproduction 6) pregnancy and pregnancy outcomes, 7) developmental origins of health and disease, 8) environment and 9) diagnostic and therapeutics together with a number of methodologic and epidemiologic crosscutting issues. NICHD is now organizing workshops in each of these and work groups will meet in Bethesda during 2010-2011 with responsibility for drafting a white paper summarizing concepts emerging from the workshops. The process is expected to culminate in a conference planned for June 2011. Input from society members has been solicited by NICHD and is reflected in the October SPR member letter. Significant modifications in the plan to implement the National Children's Study were announced, in particular with regard to the recruitment strategy, which will initiate a modified recruitment plan at 30 study centers which, in addition to household-based recruitment, will include women/families referred from medical providers and less-intensive household-based recruitment based on response to surveys and questionnaires. Some modifications in the original study plan are also anticipated for budgetary purposes. Steven Hirschfeld continues to serve as the Acting Study Director. Finally, during the last days of the Congressional session, the House of Representatives passed HR 758, the Pediatric Research Consortia Establishment Act, providing authorization for NIH to establish up to twenty pediatric research consortia funded up to \$2.5 million per year with one "leading" pediatric medical center as its hub. This effort has been led for several years by David Williams, now at Boston Children's, and a number of APS and SPR members. A companion bill introduced by Sens. Sherrod Brown and Kit Bond awaits action.

The disruption in embryonic stem cell research which following an August judicial ruling that federal funding violated a Congressional ban on funding for research destroying human embryos (Dickey-Wicker Amendment) has been amply covered in the lay and scientific press and has been closely monitored by the Public Policy Council. The Public Policy Council has joined in appeals to the Congress, Administration and Courts to restore permanent funding, which has temporarily resumed after the Administration's motion to stay the injunction was granted. In September the Academy alerted its advocacy network to contact their representatives urging passage of enabling legislation. Whether Congress will act during a short lame-duck post-election session is uncertain.

AAP Committee on Federal Government Affairs (COFGA):

COFGA has not met since my annual report and plans to meet October 24-25 in Washington. Clearly a major agenda item will be implementation of the pediatric provisions of the Patient Care and Affordable Care Act and maintenance of funding for key pediatric research and training activities. Olson Huff continues to serve as the COFGA Chair and Jay Berkelhamer, Past President of the Academy, serves as Chair of the COFGA Subcommittee on Health Insurance Coverage and Access to Care.

AAMC Council of Academic Societies (CAS)

The AAMC's Council of Academic Societies meet November 5-9 in concert with the AAMC's annual meeting in Washington, DC. Note that the meeting in part overlaps with the November 4-5 meeting of the joint APS/SPR Councils. I plan to attend representing APS. The spring meeting of the Council of Academic Societies will be in Providence, RI March 3-5, 2011. Kathy Nelson, Senior Associate Dean for Faculty Development at the University of Alabama in Birmingham (UAB), who has served for a number of years as the Academic Pediatric Association's representative to the Council of Academic Societies, has been nominated for Chair of the CAS's Administrative Board for a term beginning November 2011. Kathy will be the 3th pediatrician in the last twenty years to serve as the CAS Chair following myself and Paul McCarthy, who also represented APA. Tim Oliver and Virginia Weldon previously served in the 1980's as both CAS chair and chair of the AAMC.

Submitted by Myron Genel, M.D, Chair, Public Policy Council

