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## Future of Pediatrics Conference Community Pediatrics, The Medical Home and Beyond

Recently, Family Voices was well represented recently at the American Academy of Pediatrics (AAP) *Future of Pediatrics* Conference, June 29-July 1, 2007 in Orlando, FL. Family Voices Network members and Family to Family Health Information Center staff—Brad Thompson (TX), Gina Pola-Money (UT), Dina Castro, (SD), Grace Williams and Kim McKay (MD), Maria Abinader (NJ), Sarony Young (CO), Lisa Cook-Gordon (MI), and Wendy Longwell (CA)—had the opportunity to partner with professionals and network with other family leaders during this event. Special thanks to Conni Wells, formerly with FV FL, for her on-site support of conference participants!



FV leaders reported that being invited parent leaders allowed them, collectively, to take some crucial “first steps” toward family-centered care and toward further incorporating the family perspective and children and youth with special health care needs in professional information and resources. Participants that had the chance to talk with providers found many pediatricians committed to the concept of Medical Home, to incorporating the concept into their private practices, and to providing better care to CYSHCN. While there have been inroads made to address issues of cultural competence, parent leaders shared that the lack of cultural competency continues to be a barrier to family centered care.

Participants observed that physicians are making an effort to partner with families, both in their own communities and at the state level. Several parent leaders found the sessions in which parents and professionals presented together were the most helpful, and one suggested that shared sessions in the future could take the conversation to the next level—for example, “what can I do tomorrow to improve my practice?” Participants left with information to share on transition, immunization records, emergency preparedness, and residency programs, as well as examples provided to enhance medical notebooks and personal health profiles.

Family leaders learned that we must continue to create opportunities for families and physicians to dialogue. Additionally, we must continue to reach out not just to physicians but to their office staff, who are often the first persons we see when we come in for a visit. As parent leaders, we are grateful for the professionals who work tirelessly with us to advance the concept of Medical Home. As leaders, we need to be sure we are helping each other learn, as Brad Thompson stated, “how to build these relationships in ways that encourage [professional] groups to see us as peers, not just ‘parents.’”

## SCHIP Update

### SCHIP Reauthorization Bill Moves to Conference Committee

After a great deal of debate and political wrangling, both the House and the Senate have passed versions of a bill to reauthorize the SCHIP program. The SCHIP bill will now go to conference. There are significant differences between the two versions of the bill, but the most prominent is the difference in funding. The Senate bill authorizes \$35 billion over the next five years and the House version contains \$50 billion. The Conference Committee will begin their work in September following the August Congressional Recess. SCHIP Advocates worked very hard to move this bill in Congress!!!! There will be more work during September while the bill is conferenced. Perhaps most concerning is that the Administration has gone on the record stating that the President will veto the SCHIP bill because it contains more than \$5 billion for the next five years. Please continue to watch Friday's Child for more information. Please use the Family Voices Legislative Action Center to contact your congressional delegation. Additionally, please gear up families and friends of children and youth with special health care needs to contact the White House regarding the veto in the Fall.

Read more about SCHIP in the August 2 NY Times article by Robert Pear - [http://www.nytimes.com/2007/08/03/washington/03health.html?\\_r=1&n=Top%2fReference%2fTimes%20Topics%2fPeople%2fP%2fPear%2c%20Robert&oref=slogin](http://www.nytimes.com/2007/08/03/washington/03health.html?_r=1&n=Top%2fReference%2fTimes%20Topics%2fPeople%2fP%2fPear%2c%20Robert&oref=slogin)

## Network News



Family Voices continues to grow this vibrant national Network of parent leaders, youth leaders, partners and friends. We are pleased to welcome **Jackie Richards and Andy Pope** as new Family Voices Network members in South Carolina. Jackie is the mother of a son with ADHD and is the Associate Director of Family Connection SC. She is involved in several local and state committees, including FIC (Families, Individuals and Children) Council at United Way Early Childhood Comprehensive Systems Executive Committee. Jackie also partners with other organizations in her work including Children's Rehabilitative Services, area hospitals and United Way.

Andy, the Executive Director of Family Connection SC, also serves on several local and state committees including the Medical Care Advisory Committee; SC Birth Defects Advisory Council; SC Oral Health Coalition; Workgroup on Oral Health for Children with Special Health Care Needs; and SC Interagency Collaborative Council. Andy, with Jackie, oversees the programs and activities of Family Connection, including Family Voices of SC. Both Andy and Jackie are committed to seeing that families of children and youth with special healthcare needs in SC receive helpful information and resources in a timely manner. **Welcome, Jackie and Andy!**



## News You Can Use: Resources and More

### Continuing to Speak Out

**Naomi Ortiz**, Project Director, Kids As Self Advocates (KASA), was recently interviewed for an article in the May/June 2007 issue of SCILife, the National Newspaper of the National Spinal Cord Injury Association. In "Speaking Out in the 21st Century", Naomi, "one of the most dynamic and articulate disability rights activists today," shared how she became an advocate and became involved in KASA, and how technology is used to communicate with others and organize around issues. We are thrilled to have Naomi as part of the National Family Voices staff and appreciate her leadership.

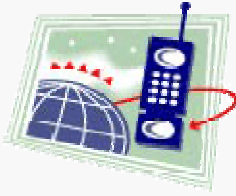
Visit <http://spinalcord.org/members/scilife/scilife16.pdf> to read the entire article.



To subscribe to the e-newsletter version of Friday's Child, please send an e-mail to [fridayschildnews-subscribe@yahoogroups.com](mailto:fridayschildnews-subscribe@yahoogroups.com). We invite you to share announcements of news, resources, upcoming events, and other information related to children with special health care needs. Please email us at [kidshealth@familyvoices.org](mailto:kidshealth@familyvoices.org) with the subject "Friday's Child", and we will try to include your listing in our next issue. This issue of Friday's Child and archived issues are available on the Family Voices website, <http://www.familyvoices.org/pub/fc/index.php>. Please forward this website to those you would like to share Friday's Child with, or they can subscribe to [fridayschildnews-subscribe@yahoogroups.com](mailto:fridayschildnews-subscribe@yahoogroups.com).

**Karen Anzola, Editor and Peggy Curran, Layout**

**TOPICAL CALL:**  
**Dancing with Change,**  
 an interactive, hands on call  
 with Steve Davis,  
 Facilitator U



What do you want to leave behind when you move on from your current position? Wouldn't you like to be remembered fondly, having those you leave behind thriving as a result of your leadership? Join us in this interactive session as we explore the seven principles of sustainable leadership, design the legacy we wish to leave, and begin developing an action plan for making this legacy a reality.

**Wednesday, August 22nd, at 9 AM Hawaii/ 11 AM Alaska/ 12 PM PT/ 1 PM MT/ 2 PM CT/ 3 PM ET**

**This call is open to all, but you must register first. Please share this information with your friends and colleagues.**

To register, please complete our online registration form at [http://www.familyvoices.org/info/topical\\_calls/8-22-2007.php](http://www.familyvoices.org/info/topical_calls/8-22-2007.php).

This call is sponsored by the National Center for Family / Professional Partnerships at Family Voices, Inc. - <http://www.familyvoices.org/info/ncfpp/>

Questions? Contact Karen Anzola at [kanzola@familyvoices.org](mailto:kanzola@familyvoices.org) or Peggy Curran at [pcurran@familyvoices.org](mailto:pcurran@familyvoices.org).

Learn more about Steve Davis and Facilitator U at <http://www.facilitatoru.com>.

**RWJ Grant Opportunity: Consumer Voices for Coverage**

The Robert Wood Johnson Foundation has announced a grant opportunity—Consumer Voices for Coverage: Strengthening State Advocacy Networks to Expand Health Coverage—for consumer advocacy organizations to support efforts to promote health care policies that will expand health care coverage. Up to 10 grants of \$750,000 for a 3 year period will be awarded, no more than one per state. The proposal calls for submitting organizations to demonstrate their plan for creating, solidifying, growing a network of partner organizations representing key consumer groups. Potential applicants were required to register by July 13, 2007 for proposal submission by September 18, 2007.

**Are there groups in your state that might be in the process of applying for this grant? Can you be part of such an application?** For more information on this grant opportunity, go to <http://www.voicesforcoverage.org/>.

**Deadline Approaching To File Claim In Paxil Pediatric Settlement**

*From Prescription Access Litigation (PAL), August 2, 2007 -*

Visit <http://www.paxilpediatricsettlement.com> and file your claim if you purchased Paxil CR or Paxil for a child under the age of 18. Claims must be filed by August 31, 2007.

If you or anyone you know has purchased Paxil or Paxil CR for a child or ward, you are entitled to recover 100% of your documented out-of-pocket expenses. Even if you did not keep receipts or other documentation of your Paxil purchases, you can still recover the amount you spent, up to \$100.

You are a class member and eligible to submit a claim for payment if:

- You live in the United States
- You purchased Paxil or Paxil CR for someone under the age of 18.

For information on how to receive compensation, visit [paxilpediatricsettlement.com](http://paxilpediatricsettlement.com), download a claim form and submit your claim before August 31, 2007. Make sure to follow the claim form instructions carefully and attach copies of your receipts or records if you have them.

You can also call 1-866-494-8404 for more information.

Please help us ensure that all eligible class members are notified of the settlement by adding a link on your own website or blog to the settlement site, <http://www.paxilpediatricsettlement.com/> and also to the following informational sites:

- <http://www.prescriptionaccess.org/lawsuitssettlements/settlements?id=0010>;
- <http://www.paxilpayback.org>

**Please note:**

Nora Wells, Director of National Center for Family/Professional Partnerships, and Peggy Curran, Technical Assistance Coordinator and Program Analyst, have recently moved into new office space closer to home. Please find below the specifics of their new phones, fax and mailing address. Their e-mail addresses remain the same.

Family Voices, Inc

ERG

110 Hartwell Ave., Lexington, MA 02421-3136

Fax: 781-674-2851

Nora Tel: 781-674-7207

Peggy Lexington office: 781-674-7224 or Home office: 781-592-3935

## ADA Celebrates 17 Years

Tuesday, July 26th, marked the **17th Anniversary of the Americans with Disabilities Act**. Much has changed over the past 17 years, but there is still work left to be done. Remember Justin Dart, Jr. when he said, "Beloved colleagues in struggle... Our lives, our children's lives, the quality of the lives of billions in future generations hangs in the balance. I cry out to you from the depths of my being. Humanity needs you! Lead! Lead! Lead the revolution of empowerment!"

## The Family Voices Store at Family Café— One Stop Shopping for Family and Friends



Looking for a way to honor a family member or special caregiver, or seeking just the right thank you gift? Consider making contributions to Family Voices through secure, on line donations, purchases of Family Voices Merchandise at [www.cafepress.com/shopfv](http://www.cafepress.com/shopfv) or purchases from Amazon.com through the link on our web home page. Simply visit our website, <http://www.familyvoices.org>, to make a donation or to learn more about how financial gifts are used. Donations may be sent directly to: **Family Voices  
2340 Alamo SE, Suite 102  
Albuquerque, NM 87106.**

## ☑ Diné for our Children: Hope for parents of children with special needs

*From the Gallup Independent, Gallup, NM, July 30, 2007. Second in a two-part series By Kathy Helms, Diné Bureau*

WINDOW ROCK, AZ—"As the parent of as the parent of a special needs child, it never occurred to Kathleen Hubbell that her nine years of experience could be helpful to a parent just starting out. But through the three-year pilot project Diné for Our Children, she and other mothers, fathers, and even grandparents are helping to improve the quality of services of special needs children on the Navajo Nation. Jenny Rodgers, project director, said the program is all about empowering parents by having them work together with medical professionals, educators, politicians and others to bridge the gap of services for children from birth to 18 years of age. "

Diné for Our Children, a project, federally funded by the Maternal and Child Health Bureau through the New Freedom Initiative, has several components. Capacity building in the community includes supporting parents in learning leadership skills like how to facilitate meetings. Parents are clearly viewed as resources and the experts when other parents seek information and resources. Parents are assisting in the development of materials and products including a tool kit that will list tribal, state and federal resources; and community resources like caregivers, carpenters who can build wheelchair ramps, seamstresses who can make adaptive clothing, and mechanics willing to assist families with what they need to care for their children. Medical professionals from area hospitals are enthusiastic about the tool kit, and are working with project staff to develop a medical home.

Beginning in October 2007, a Navajo Nationwide survey will be conducted to identify what services are available, what is needed, and the gaps in services. To learn more about this exciting project, go to:

[http://www.gallupindependent.com/2007/july/073007kh\\_dineourchldrn.html](http://www.gallupindependent.com/2007/july/073007kh_dineourchldrn.html) for the complete article from the Gallup Independent.

## ☑ National Park's Golden Access Passes Have Been Replaced

The Golden Access Pass, allowing those with disabilities free admission into National Parks like Yellowstone, has been replaced by America the Beautiful National Parks and Federal Recreational Lands Pass Access Pass. This is a lifetime pass for U.S. citizens or permanent residents with permanent disabilities. Documentation is required to obtain the pass. Acceptable documentation includes: statement by a licensed physician; document issued by a Federal agency such as the Veteran's Administration, Social Security Disability Income or Supplemental Security Income; or document issued by a State agency such as a vocational rehabilitation agency. The pass provides access to, and use of, Federal recreation sites that charge an Entrance or Standard Amenity. The pass admits the pass holder and passengers in a non-commercial vehicle at per vehicle fee areas and pass holder + 3 adults, not to exceed 4 adults, at per person fee areas (children under 16 are admitted free). The pass can only be obtained in person at the park. The Access Pass provides a 50 percent discount on some Expanded Amenity Fees charged for facilities and services such as camping, swimming, boat launching, and specialized interpretive services. The pass is non-transferable. Visit [http://www.nps.gov/fees\\_passes.htm](http://www.nps.gov/fees_passes.htm).

*"When possible make the decisions now, even if action is in the future. A reviewed decision usually is better than one reached at the last moment."*

-- William B. Given