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Greetings !

from Sophie Arao-Nguyen, Executive Director, Family Voices



As the earth experiences rebirth in spring so, too, has Family Voices. Over the past year, following a thoughtful course outlined in the Family Voices Strategic Plan, staff, board members and parent leaders have worked to address all four directions of the strategic plan—**Infrastructure; Policy; Cultural Competence; and Funding.**

Family Voices has begun to build a strong, dynamic and effective infrastructure that includes State Affiliate Organizations, Individual and Organizational memberships, and an expanded technical assistance team including field coordinators and our policy team. Please watch our website for more information about membership opportunities. Our DC-based Policy Team is working to be sure that families have the information and resources needed to engage

in critical policy discussions on health care taking place around the country. Guided by our funding plan, Family Voices continues to work to identify and develop ways to sustain our collective work so that we may realize our vision—every child and youth with special needs receives family-centered care. The Cultural Competence Committee did preliminary work with the Board of Directors in October 2008. Tawara Goode of the National Center for Cultural Competence guided the creation of a framework for putting culturally and linguistically competent values into policy and practice.

Strong connections and partnerships contribute to our continued success. On February 23rd, we held the Family Voices Gala in conjunction with the AMCHP annual conference. We were delighted to meet with our friends and allies, and to honor those who have contributed so much to our organization. As we convene the Family Voices 2009 National Conference this month, we'll connect with and learn from other dedicated parent leaders, providers and partners, and recommit to our mission of achieving family-centered care for all children and youth with special health care needs and/or disabilities. ***We look forward to many of you joining us!***

To subscribe to the e-newsletter version of Friday's Child, please send an e-mail to 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 kanzola@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/nc/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.

News You Can Use: Resources and More



☑ 100 Days/100 Voices Campaign

The Annie E. Casey Foundation is marking President Obama's first 100 days in office by asking concerned citizens to tell them—in 100 words or less, or a video clip lasting no more than 2 minutes-- what is the most important thing that the Obama administration has done for children and families during this first 100 days? What should be next on the agenda? And why is this issue so important?

The Foundation website will feature selected photos, videos, and emails. To add your voice, go to <http://www.aecf.org/100Voices>.

☑ Birth Defects and Developmental Disabilities Website

Established by the Children's Health Act of 2000, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at Centers for Disease Control and Prevention (CDC) is dedicated to helping people live to the fullest. With that goal in mind, they have built a comprehensive website focused on information and resources for people who are especially vulnerable to health risks - babies, children, people with blood disorders, and people with disabilities. Check out these topics:

- Before & During Pregnancy
- Infants
- Child Development & Parenting
- People with Disabilities
- Blood Disorders
- And more!

<http://www.cdc.gov/ncbddd/>



Family Leadership in the States



Children's Arts Program Performs for Utah Legislators

On the last day of the 2009 legislative session, Utah legislators were treated to an outstanding performance by children participating in Kindred Spirits, a non-profit organization that helps empower children with disabilities through experience in the arts. With instruction from Sal Jansaan of the Salt Lake Community Action Program and in partnership with Family Voices of Utah, Kindred Spirits introduced children to the beauty and vitality of Polynesian arts. The children's performance of two Polynesian dances wowed the Senators.

Alice Perreault, the director of Kindred Spirits, believes that "in these times of economic struggles we can still feed our spirits by considering the beauty and dedicated work within our own communities." To learn more about Kindred Spirits, see their website: www.kindredspiritsart.org/.



Senator Jones with Julius Steubing and mom, Alice Perreault



Flooding and the Aftermath in North Dakota—Help Still Needed



Serious flooding—and its aftermath of strain on people and community services—continues in North Dakota reports Donene Feist, Executive Director of Family Voices of North Dakota (FVND). Many families with special health needs have contacted FVND looking for assistance -- cribs, special medical equipment, help with car repairs, warm, dry places to stay, and ongoing emotional support. Mobilizing FVND, Donene reached out to her network of families, who, in turn, actively sought out support from as many other venues as possible. As a result, FV of ND has become a clearinghouse of information and resources from families willing to share such resources as special adaptive equipment or a spare room.

You can help families in ND with a donation:

- Send to FVND, PO Box 163, Edgeley ND 58433 re: FLOOD ACCOUNT - *or* -
- Click the DONATE NOW button on the Family Voices , select Flood Victims in ND

Donene adds:

“Thanks to all who have donated funds.... the families are very grateful. Thank you on their behalf and mine. Even a little smile in their loss makes a day brighter.”

More News You Can Use

Epilepsy and Your Child

A new website, Epilepsy and My Child, has been designed for parents with input from parents. This website contains a wealth of information for families, including:

- About Epilepsy,
- Just Diagnosed,
- Living with Epilepsy,
- Treatment,
- And more.

There are some great tips on how to have an open, positive discussion with your child about epilepsy.

www.epilepsyandmychild.org/

More Resources on Epilepsy

Project Access oversees demonstration projects in eight states focused on early detection, treatment, and seizure control for children and youth residing in medically underserved areas. If successful, the activities conducted under this initiative will spread to other communities across the United States, providing broader, national significance.

www.epilepsyfoundation.org/projectaccess/

News From Our Partners

AAP: Medical Home

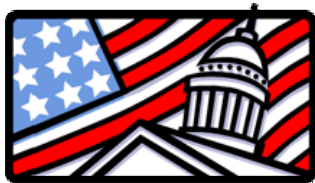
The 4th call in the AAP's Medical Home Implementation Tele-conference series is scheduled for May 21st at 1:00pm EDT. This call will focus on Role of the Medical Home in Family-Centered Early Intervention. Space is limited. Pre-register at:

<https://www2.gotomeeting.com/register/589423194>

AMCHP: New Publication

A Family Delegate Fundamentals fact sheet describes the AMCHP Family Delegate roles and responsibilities in supporting families and programs, and help for states in how to identify potential delegates.

www.amchp.org/SiteCollectionDocuments/Family%20Delegate%20Fund_web_FINAL.pdf



Legislative Corner

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2F HICs)

Funding for the Family-to-Family Health Information Centers is provided through Federal Fiscal Year 2009 by the Family Opportunity Act (part of the Deficit Reduction Act of 2005). NOW we need Congress to appropriate money for FY 2010 in order for F2F HICs to continue. We are requesting an increase for FY 2010 to provide additional funding for states and territories, needed dollars for federal administration and additional opportunities for TA, mentoring and in-person support. However, it is expected that this will be a "lean" year for appropriations (actual allotment of money), so family leaders are mobilizing around the country to let Congress know how important the F2F HICs are to CYSHCN and their families. Contact the policy team -- Brooke Lehmann (blehmann@familyvoices.org) or Janis Guerney (jguerney@familyvoices.org) to learn more, and to find out how you can help.



HEALTH CARE REFORM

Family Voices' public policy team has been active in Capitol Hill discussions concerning health care reform, participating in discussion groups with key staffers to make sure that they do not overlook the needs of CYSHCN and their families. Some of the relevant congressional committees are gearing up to take action soon, but at this time, there is nothing "on paper" to which advocates can respond. Therefore, Family Voices will continue to convey to Congress its general principles for health care reform, including the need for care is universal, comprehensive, community-based, coordinated, and family-centered.

SPEAK NOW FOR KIDS IN HEALTH REFORM CAMPAIGN

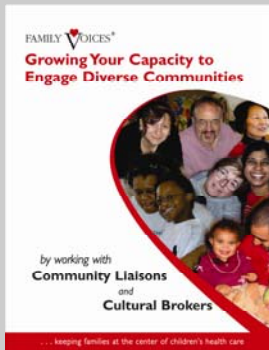
Family Voices has signed on as a supporter of the Speak Now for Kids in Health Reform Campaign, a new national campaign sponsored by the National Association of Children's Hospitals (NACH) to raise the visibility of children's needs in the national health care reform debate.

As focus on the issue has grown in the past month, one thing has become exceedingly clear: If we don't speak up, we won't be heard. There are no better voices for what children need in health care reform than those of the parents, family members, physicians and others who work with children and care about their health. To read more about this campaign to be launched in early May, go to: <http://www.childrenshospitals.net/AM/Template.cfm?template=/CM/ContentDisplay.cfm&ContentID=43897>.



News from Family Voices

☑ New Publication



Growing Your Capacity to Engage Diverse Communities by working with Community Liaisons and Cultural Brokers is a 20-page booklet that describes working with community liaisons and cultural brokers as an approach to family and community engagement. Information included is grounded in the knowledge and experiences of the FV network of family leaders.

☑ New KASA Pocket Guide



KASA's newest pocket guide, *How to be Involved in a Board or Council: Roles and Responsibilities*, is now available. This pocket guide was developed and written by youth who have served on boards and councils successfully and can serve as a companion piece to the KASA Youth as Leaders manual.

Order both the *How to be Involved in a Board or Council: Roles and Responsibilities* and *Growing Your Capacity to Engage Diverse Communities: by working with Community Liaisons and Cultural*

**online at:
[www.familyvoices.org/
catalog.php](http://www.familyvoices.org/catalog.php)**

Perspective: Moving Patient-Centered Care towards Family-Centered Care

by Nora Wells

A concept central to families of CYSHCN is taking on a key role in health care reform discussions. The “patient centered medical home” has become widely supported by reformers, adult primary care providers, employers and insurance plans, driven by the recognition - long believed by families of CYSHCN - that engaging patients in health care improves quality, reduces risks, improves satisfaction and is cost effective.

In the adult health care world, the patient-centered care concept focuses on the relationship between individual patients and their providers, particularly in primary care settings –urging improved communication, culturally competent coordinated care, and use of electronic health records. The importance of a patient’s family as part of the health care team, the role of community resources, and the potential for patients and families to be advisors are less frequently included in discussions.



Nevertheless, this new spotlight on patient-centered care in adult healthcare has brought the ideas of family professional partnerships to a much bigger arena.

Family Voices recently interviewed Dr. Richard Antonelli, of Boston Children’s Hospital, who has been actively engaged, along with Dr. Fan Tait of the American Academy of Pediatrics, in sharing the perspective and experience of the pediatric community with a major adult advocacy initiative, the “Patient-Centered Primary Care Collaborative (PCPCC).” The PCPCC has vigorously engaged in defining and garnering support for patient-centered care concepts. “There is (now) broad endorsement within the medical community that the health care system in the US must evolve... There is a recognition that patients and families need to be part of the solution... We need strategies that integrate families and youth as advisors in both health care design and quality improvement...In the pediatric community we have decades of experiences (with these partnerships) both in the family and provider community...” Antonelli said.

Moving patient-centered care towards family-centered care gained momentum recently at a stakeholders meeting of the Patient Centered Primary Care Collaborative (PCPCC) on April 28. A new set of consumer principles for the patient- and family-centered care, developed by the National Partnership for Women and Families, was endorsed by 24 leading national consumer groups, including Family Voices. See: http://www.nationalpartnership.org/site/DocServer/Advocate_Toolkit-Consumer_Principles_3-30-09.pdf?docID=4821.

Antonelli encourages families, youth and young adults to “**Step up and say what it is you expect. Do everything you can to raise the expectation**” that the tools, methods, and techniques developed within the pediatric model of medical home are included in this movement within adult health care and health care reform.

Learn more about opportunities to participate in the PCPCC at www.pcpcc.net.