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International Congress

By Jennifer Cernoch, outgoing Executive Director, Family Voices



The 9th International Congress on Community Services for Children, Youth and Families with Special Health Care Needs brought over 500 individuals from 62 countries to the Marriott Wardman Park Hotel in Washington, DC on

December 4-7, 2006. The United States (Department of Health and Human Services - Office on Disability) was the host country for this 9th Congress with Canada, Argentina, and Norway hosting the three previous Congresses. While the roster of nations and number of people participating in the Congress has grown over the past 15 years, the underlying principles of the Congress have remained the same: 1. including all children, particularly children with special needs, in all activities in their communities; 2. the primary importance of families and their vital partnerships with professionals; and 3. the importance of an approach that brings together professionals from different disciplines to create and maintain supports and services at local levels. The 9th Congress featured many activities including: various panel discussions on issues relevant to community services (promoting full access to community life, health and medicine, educational and vocational opportunities, transportation options, workforce development, assistive technology, home ownership); keynote presentations with a special appearance by Vivian Fernandez de Torrijos, First Lady of Panama; video presentations from various countries; and fun activities, such as an international disco, trolley tour of Washington, DC, and gala celebration.

Family Voices staff and Network members were involved in many of the planning activities of the Congress and were the hosts of the 'Family Day' – the first day of the Congress to bring together and support families from various countries throughout the Congress. Our primary goals for Family Day were to get to know other families in the various countries and to support their needs throughout the Congress. Polly Arango, Jennifer Cernoch, Barbara Popper, Patti Hackett, Conni Wells, Rodney Farley, Naomi Ortiz, Susan Goodman, Eileen Forlenza, Becky Hamblin, Stacy Justiss, Lindsay Phillips, Richard Roberts, and Kim Stamper were the family/youth representatives (or part of Family Voices) from the United States. During Family Day, we took time for introductions and getting to know one another, presented various materials to the participants, held interactive sessions for families/professionals, and developed 'solution boards' for families to share their experiences in their countries. Throughout the Congress, we met with families, shared experiences, and strategized on ways to improve community services for our children and youth. Family Voices also hosted a hospitality suite for families to share their country experiences and a time to relax. Family Voices has also developed an international list serv of families and professionals wanting to continue to network and share experiences.

Our sincere thanks to Dr. Merle McPherson who started the International Congress back in 1992 and to Dr. Margaret Giannini for taking the lead with the 9th Congress in the Office on Disability. We appreciate your help and support in allowing families and youth to be such an integral part of the 9th International Congress. If you would like more information about the Congress, please contact Barbara Popper at bpopper@fcsn.org or Polly Arango at polly@algodonesassociates.com.

Online Survey about Health and Wellness for CSHCN



The Family Voices and Tufts University research team invite you to complete an anonymous online survey about Health and Wellness for Children with Special Health Care Needs. The team is looking for as many responses as possible from families who have children, 6 - 18 years old, with special health care needs (this includes special mental health/behavioral/emotional needs). Please go to <http://go.tufts.edu/familymatters> to access the survey.

SAVE THE DATE!



Family Voices 15th Anniversary Gala and National Conference
May 23-36, 2007
Washington, D.C.

Join Family Voices in our nation's capital for a celebration of 15 years of family/professional partnerships and accomplishments! Meet with veteran and emerging family and youth leaders and national and state partners from across the country. Gain new understanding of current critical issues! Working together as families, partners, and communities, we can move forward the agenda of health care and build a better future for our children.

FEATURED EVENTS:

- May 23, 2007: Leadership Institute, a 1-day training at the Grand Hyatt (registration limited)
- May 23, 2007: 15th Anniversary Gala Celebration, an evening of celebration at Decatur House
- May 24-26, 2007: National Conference, 2 1/2 days of key-note sessions, workshops, networking opportunities, and more at the Grand Hyatt

Watch for more information and online registration at <http://www.familyvoices.org>.



Network News



Family Voices Board of Directors announces new Family Voices Executive Director

The Board of Directors of Family Voices, Inc. is pleased to announce the hiring of **Sophie Arao-Nguyen, Ph.D.** as its Executive Director effective January 8, 2007. Sophie is a parent of two children with ADHD and Autism. She completed her Ph.D. in Transpersonal Psychology at the Institute of Transpersonal Psychology (ITP) in 1996, and continues to serve as an adjunct research faculty member at ITP.

Since 1978 Sophie has worked as a cultural competency and organizational development consultant to various programs and industries. Sophie's work experience includes serving as Director of Satellite Services, Training & Technical Assistance for Parents Helping Parents (PHP) in California. Sophie worked with two of Family Voices partners—the Maternal and Child Health Bureau (MCHB) and the National Center for Cultural Competence (NCCC)—when she worked at PHP. She was also Executive Director of the Filipino Youth Coalition, Inc. (FYC, Inc.), a non-profit agency whose mission is to work with high-risk youth and their families in various high schools in Santa Clara County, CA. In addition, she has served as a consultant to the NCCC. Most recently, Sophie worked as the Clinical Supervisor for Asian American Recovery Services, Inc. Sophie's solid work experience, education and above all, her passion for making sure the needs of children are first and foremost in the minds of agencies and policy makers will serve Family Voices well. Please join the Family Voices Board, Staff and Network in welcoming Sophie Arao-Nguyen.

News You Can Use: Resources and More

Through the Same Door: Inclusion Includes College

Just released—*Through the Same Door: Inclusion Includes College*, a film by Paul Rossen featuring **Micah Fialka-Feldman**, KASA (Kids as Self Advocates) board member.

Meet Micah Fialka-Feldman, a man who knows what he wants. In many ways, the 21-year-old student enjoys a typical life: making friends, participating in college activities, and volunteering in the community and in politics. Less typically, he travels the country speaking. But for all of his life, there have been people telling him that he could not have a regular life.

Micah has a cognitive disability. This inspiring film documents the new movement of fully inclusive education by exploring Micah's desire for a life without boundaries. As a high school student, Micah wanted the college experience and he got it. See how it's done, learn how it works, and witness how Micah's journey challenges us all to reexamine what we believe possible. To learn more about this award winning DVD or view a clip from the movie, go to www.throughthesamedoor.com/.

Micah is available to do presentations at conferences. To learn more, visit: <http://www.danceofpartnership.com/micah.htm>.

North Dakota Family Stories Booklet

Family Voices of North Dakota, home of the ND Family to Family Health Information Center, has just released North Dakota Family Stories: Raising and Caring for Children and Youth with Special Health Care Needs. This 34-page booklet uses family stories, data from the National Survey of Children with Special Health Care Needs 2001, and data from the Catalyst Center to powerfully "bring home" the impact access to services and health care coverage has on children and youth with special health care needs and the families who care for them. Visit <http://www.geocities.com/ndfv/ndfvpage7.html> to read and download this booklet.

YOU CAN HELP Family Voices Help Families



During this new year, please consider making contributions to Family Voices through secure, on line donations, purchases of Family Voices Merchandise or purchases from Amazon.com through the link on our web home page. Simply visit our website, 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, Inc.
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The **Family Voices Store at Cafe Press**— www.cafepress.com/shopfv has lots of fun FV t-shirts, mugs and more.



When buying books from **Amazon.com**, don't forget to link to Amazon through the Family Voices website home page at www.familyvoices.org. A portion of the sales is given back to Family Voices.

News You Can Use: Resources and More, *continued*

☑ **HRSA Releases New Chartbook on Rural Health**

The Health and Well-Being of Children in Rural Areas: A Portrait of the Nation 2005, based on the National Survey of Children's Health, indicates that children in urban and rural areas are reported to be equally healthy, with about 84 percent in both groups reported in excellent or very good health. But children living outside urban areas are less likely to be breastfed and more likely to live in households with a smoker, the report says. The chartbook is available on the Data Resource Center - http://www.nschdata.org/documents/NSCH_Rural_Health_Chartbook.pdf.

☑ **President Bush Signs Critical Respite Bill for Family Caregivers - Lifespan Respite Care Act of 2006 (HR 3248)**

From the National Respite Coalition Task Force Washington, DC (December 21, 2006)

The Lifespan Respite Task Force, a coalition of over 170 national, state, and local organizations, applauds the signing of The Lifespan Respite Care Act of 2006 (HR 3248) into law. The bill was introduced and championed in the US House of Representatives by Rep. Mike Ferguson (R-NJ) and James Langevin (D-RI). A companion bill in the Senate was cosponsored by Senator Hillary Clinton (D-NY) and Senator John Warner (R-VA). The Lifespan Respite Task Force includes a diverse group of national and state organizations: state respite and crisis care coalitions; health and community social services; disability, mental health, education, faith, family caregiving and support groups; groups from the child advocacy and the aging community; and abuse and neglect prevention groups.

The new law would authorize \$289 million over five years for state grants to develop Lifespan Respite Programs to help families access quality, affordable respite care. Lifespan respite programs are defined in the Act "as coordinated systems of accessible, community-based approaches to health and health care problems faced by immigrants and refugees.

Remember not only to say the right thing in the right place, but far more difficult still, to leave unsaid the wrong thing at the tempting moment.

--Benjamin Franklin

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 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.

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