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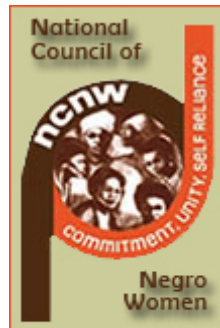
- Gala: February 23
- National Conference: May 3-5

The National Black Family Reunion—Through the Eyes of Family Voices of DC Executive Director, Doreen Hodges

Doreen Hodges, Executive Director of Family Voices in Washington, DC, and the DC Family-to-Family Health Information Center (F2FHIC) Director, had the opportunity to represent Family Voices of DC and the DC F2FHIC at the recent 23rd Annual National Black Family Reunion, held at the National Mall in Washington, on September 7. Originally slated to be a two-day event, plans were changed at the last minute to accommodate the untimely arrival of Hurricane Ike. The weather on Sunday, however, was beautiful, and crowds of people attended this giant networking event, presented by the National Council of Negro Women (NCNW) and Freddie Mac. It is an annual “cultural event celebrating the enduring strengths and traditional values of the African American family” and typically has crowds of 500,000 or more. Vendors, organizations, and administrators set up multiple themed pavilions giving not only DC-area people and groups an opportunity to meet, but also connecting people and groups from around the world.



Doreen Hodges and son, Titus



For more information on the Reunion, visit the NCNW website - www.ncnw.org

Family Voices and our sister organization, the Genetic Alliance, ran a table focused on families of children with disabilities and special health care needs. Doreen provided information to families on national resources, such as Family Voices and F2F HICs, as well as support available in the local DC area. She handed out brochures, took pictures, and urged families to contact Family Voices if they could use the services or wanted to volunteer to help at other events of interest to families with children with special needs.

Families shared stories about their efforts to get the support they needed for their children. Doreen said, “Their stories really weren’t amazing so much as bonding. These are families going through the same kinds of things, and it was comforting to hear stories about how things can pan out.”

Doreen is the mother of two special needs children, a nine-year-old son with Down syndrome and autism, and a one-year-old son born three months preterm. Doreen’s interactions with parents at the Reunion are rooted in her own “been there, done that” experience. Thanks, Doreen!

Learn more about Family Voices of DC at <http://www.familyvoices.org>. Learn more about the Reunion and the NCNW at <http://www.ncnw.org>.

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/fo/index.php>. Please forward this website to those you would like to share Friday's Child with, or they can subscribe to fridayschildnewssubscribe@yahoogroups.com.

From Our National Partners:



www.aap.org

News From AAP

➤ Resources on Sustainability:

- Looking for funding? Check out the [AAP's webpage on resources for finding grant possibilities](#)
- Have funding and hoping to keep it? [Download AAP's simple, 1-page tip sheet on sustainability.](#)

➤ Pediatric Heroes:

Is your pediatrician your hero? Did he or she make a difference in your life, in your community? [Tell the AAP your story.](#)



www.amchp.org

AMCHP:

Keeping Families Involved

➤ Check out the Family Scholars and Mentors Scholarships to AMCHP's 2009 Annual Conference, February 21-25, in Washington, DC. AMCHP, MCHB, and the CDC's National Center on Birth Defects and Developmental Disabilities will award scholarships for family representatives to attend the conference. They will also award stipends for Family Mentors to assist before, during, and after the conference. If you would like to be considered for either of these awards, please check out the [AMCHP website](#). Note that the deadline for applications is NOVEMBER 7, 2008.

➤ AMCHP Pulse Newsletter Features Family Leadership in Action: Read about Family Leadership from the perspective of three Family Voices representatives in the [October 2008 edition of the AMCHP newsletter.](#)



Family Leadership in the States:

♥ Diné for Our Children (DOC) Provides Resource Packets to Navajo families of CYSHCN

The Diné for Our Children (DOC) project, funded by MCHB through an Integrated Services Branch D-70 Grant, under the Navajo Division of Social Services, works to reduce health disparities by improving access to integrated services for Navajo families of CYSHCN. This work is accomplished through teams of family, youth, and services providers at local levels who identify gaps in existing services and provide links to resources.



As a result of a community assessment done by the DOC program, resource packets were developed that include information about child development, resources for families and phone numbers of other parents to whom new parents can connect, as well as supplies such as diapers, receiving blankets, shampoo and other needed items. These resources are being distributed to hospitals around the Navajo nation.

The DOC program was recently featured on the front page of the September 18, 2008, Gallup Independent newspaper (<http://www.gallupindependent.com/2008/09september/091808special.html>) For more information on the DOC program, visit the Diné website at <http://www.doc.navajo.org/>.

♥ One-Stop Shop for Autism Support: University of Missouri's Thompson Center and the "Rapid Response" Project

Another family support-driven project serving a different population is the "Rapid Response" project of the University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders which was recently awarded a federal grant worth nearly \$1 million from the 2006 Combating Autism Act funds. This project seeks to help families "improve early identification of children with developmental challenges, promote timely access to diagnostic and intervention services, and identify family supports," according to Anne Deaton, member of the Thompson Center Advisory Council. Family Voices of Missouri was one of many partners in this effort to provide expanded services to families. For more information, visit the Thompson Center website (<http://thompsoncenter.missouri.edu/>). The MU press release may be found at <http://munews.missouri.edu/news-releases/2008/09.25.08-farmer-rapid-response-grant.php>.



♥ A West Virginia Welcome to Georganne Ickler!

Georganne Ickler, who hails from West Virginia, has joined the Family Voices network of parent leaders. Georganne and her husband, Troy, have two children, one of whom was recently diagnosed with Asperger's Syndrome. In addition to working as a sales representative, Georganne is involved in her children's schools, serves as a parent representative for the Marshall County Partners in Prevention, and is a board member for the Marshall County Starting Points Center, a family resource center. Georganne is anxious to learn more so that she may share information and resources about health care services with families in WV. Welcome, Georganne!

From Our National Partners:



www.nichq.org

NICHQ:
Improving Children's
Healthcare

➤ Submit a Presentation for NICHQ's 8th Annual Forum for Improving Children's Healthcare: Thrive Together.

If you have an innovative approach to improve the quality of healthcare for children that is practical, portable, and sustainable, consider sharing it at next year's NICHQ Forum. Topic areas for the 2009 Forum are patient safety, childhood obesity, chronic conditions, and quality improvement—linked to finance, advocacy, and equity in care. Check out the [website](#) for more information. Deadline for submission has been extended to November 3, 2008.

➤ Seeking Nominations for the 2009 Bergman Award:

Do you know someone who has made a "significant contribution to improve quality and safety of healthcare for children through a sustained program and/or series of projects"? Consider nominating them for NICHQ's 2009 Bergman Award. Learn more information about the [award](#).



News You Can Use: Resources and More

☑ Emergency Preparedness Follow-up: More Resources!

Last month's Friday's Child featured emergency preparedness resources in the wake of the latest hurricane season. Here are links to additional resources:

- Executive Summary of the Second Working Meeting on Disaster Preparation and Emergency Response for People with Disabilities, from the National Consortium on Disaster Preparedness and Emergency Response for People with Disabilities: <http://www.dhss.mo.gov/SeniorsAndDisabilitiesToolkit/Brochures/NatlConsortium.pdf>.



- Tips for First Responders, Second Edition, from the University of New Mexico's Center for Development and Disability: http://cdd.unm.edu/products/tips_web020205.pdf.

☑ Conference Brings Together Researchers, Practitioners, and Families from Underserved Communities

The Opening Doors: State of the Science Conference will be held on November 10-11, 2008, in Bethesda, Maryland. This conference examines the state of the science related to early screening, community inclusion and transition for children and youth from underserved populations, including new immigrant communities. There will be many opportunities for discussion among researchers, clinicians, policy makers, parents, youth and community based organization leaders. For more information, including registration, visit the website (<http://www.openingdoorsforyouth.org/sos/>) or contact Berenise Reyes-Albino, 617-287-4314.

☑ Opportunity to Participate in Discussion on Information Technology and Healthcare

National Dialogue—Health, Privacy, and IT, October 27-November 3, 2008: Participate in a national online dialogue concerning the question: How can we use information technology to improve healthcare, while safeguarding privacy? Visit the National Dialogue website (<http://www.thenationaldialogue.org/>) for more information and to participate in this discussion.

☑ Webinar on New Disability Statistics Report



A free Online Webinar on the new 2007 Disability Statistics Report will be held on November 12, 2008, 12:00-1:00pm EST. This report, compiled by Cornell University's Employment and Disability Institute, is a summary of the most recent demographic and economic statistics on the working-age (ages 21-64) population with disabilities by state in the United States. These statistics are based on the 2007 American Community Survey on disability and employment, education, poverty, household income, and labor earnings. Cornell University experts in disability statistics and research will lead the dialogue and act as guides to the latest information and issues associated

with disability statistics and the circumstances that those with disabilities face. From their website: "The relevance of these statistics to the process of developing and maintaining policies that relate to the people with disabilities in the United States can not be overstated." Visit the website's registration page (<http://www.ilr.cornell.edu/edi/register/rrtc-workerscomp.cfm>) to sign up for this free webinar.

From Our National Partners:



Robert Wood Johnson: Community Health Leaders

➤ The Community Health Leaders Award Nominations:

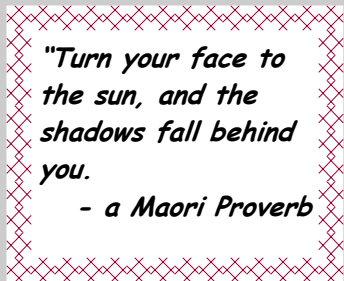
The RWJ Foundation each year honors ten Community Health Leaders who "overcome daunting odds" to improve underserved population health and health care. If you know of someone deserving of this award—and the \$125,000 that goes with it—check out the [Call for Proposals](#).

➤ NEWS FLASH—

One of Family Voices' own has just won this award !



Announced just this week, Donene Feist, of Family Voices of North Dakota, Inc., is one of the 2008 recipients of this prestigious honor! Look for more details in next month's Friday's Child.



☑ Opportunity New Study on Racial/Ethnic Disparities

New CDC Study Finds Racial/Ethnic Health Disparities in People with Disabilities: A recent CDC Morbidity and Mortality Weekly Report (10/2) reports on the results of the 2004-2006 Behavioral Risk Factor Surveillance System (BRFSS), a telephone survey conducted annually by every state and territory's health departments. Results include:

- The prevalence of disability among U.S. adults ranged from 11.6% among Asians to 29.9% among American Indians/Alaska Natives (AI/ANs)
- Within each racial/ethnic population, adults with a disability were more likely to report fair or poor health than adults without a disability, with differences ranging from 16.8 percentage points among Asians to 37.9 percentage points among AI/ANs.

Read more at the Morbidity and Mortality Weekly Report site (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5739a1.htm?s_cid=mm5739a1_e).

Highlights from Family Voices



Family Voices will hold its **Gala, One Heart, Many Voices: Celebrating Families on Monday, February 23, 2009** in conjunction with the AMCHP National Conference. This elegant evening will take place at the Marriott Wardman Park Hotel, Washington, D.C. from 6-10pm. Family Voices will honor:

- The **Fialka-Feldman Family** for their tireless advocacy on behalf of children and youth with special health care needs and disabilities, presented by fellow disability advocate **Yoshiko Dart**
- Hall of Fame quarterback **Jim Kelly** (invited) for his national work raising awareness of and promoting newborn screening, and
- **Peters D. Willson**, retired Vice-President for Public Policy at NACHRI, for his invaluable work with children's hospitals on behalf of children and their families.

To purchase tickets for this event and for more information, visit the [Family Voices website](#) or contact Family Voices' Assistant Executive Director, Rachel Rodriguez—rrodriguez@familyvoices.org or (888) 835-5669.



The Family Voices National Conference is slated for May 3-5, 2009 at the Marriott Wardman Park Hotel in a Washington, DC. The National Conference will open with a reception on Sunday evening, followed by a full day of activities on Monday. The conference will end on Tuesday at noon. KASA, Family Voices Board, Regional Coordinators and Regions, etc. are discussing pre- conference meetings and F2FHICs and D-70 Integrated Services grantees will

add meeting time following the conference. For volunteer opportunities and more information regarding the conference, please contact Family Voices' Executive Director, Sophie Arao-Nguyen, san@familyvoices.org or (888) 835-5669.