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## NORTH DAKOTA FAMILY OPPORTUNITY ACT IS SIGNED!



North Dakota families of children with chronic illness have another option to help pay for medical expenses. Governor Hoeven today signed a bill to relieve some of the strain put on these families of children with disabilities. North Dakota is the first state in the nation to implement this program. It falls under the Family Opportunity Act, passed by Congress in 2005. The bill allows uninsured or underinsured families to pay a premium for Medicaid services. **"Health care certainly is a basic right for children," says Donene Feist, North Dakota**

**Family Voices.** "So I believe this bill supports the Family Opportunity Act and embraces the rights of families."

Please join us in congratulating Donene and the families of children with special health care needs in North Dakota for working tirelessly to become the first in the nation to adopt the FOA in their state. Donene was instrumental in bringing other families together to see that this bill was passed. Well done, Donene! For more information about Family Voices of North Dakota, please visit their website, <http://www.geocities.com/ndfv/>.



Donene Feist,  
Executive Director  
Family Voices of North Dakota



## See You in Washington at the Family Voices 15th Anniversary Gala and National Conference



Only FOUR WEEKS until family leaders, state and national partners and policy makers gather in Washington, DC for the Family Voices 15th Anniversary Gala Celebration and National Conference. We look forward to you joining us!



You will have opportunities to meet with veteran and emerging family and youth leaders and national and state partners from across the country, and to gain new understanding of current critical issues including Medicaid policy, information technology, family-centered care, quality assurance, wellness, transition, youth perspective, cultural competence and much more. Be sure to take advantage of **Early Registration, which ends May 2nd**. MAKE PLANS NOW to join us in Washington, DC, May 23-26, 2007 for the Family Voices National Conference. You'll be glad you did! For more information and to register on line, please visit our <http://www.familyvoices.org/info/nc/index.php>.



## Upcoming Something for Everyone: Topical Calls

Topical calls are a great way to gain knowledge directly from the experts! The calls are free and provide opportunities for information sharing, discussion, questions and answers. The National Center for Family / Professional Partnerships (NCFPP) at Family Voices is pleased to be hosting several topical calls on a variety of topics. Here's what's coming in May and June:

- **Risky Business: Treatment and Prevention of Organizational Risk** with Conni Wells, Thursday, May 3, 2007, from 1-2:30 PM ET
- **Developing Partnerships for Sustainability** with Christy Blakely, FV CO and Leolinda Parlin, FV HI, Monday, May 7 from 1:30-3 PM ET
- **Building Consensus Without Really Trying** with Steve Davis of FacilitatorU.com, Wednesday, May 9, 2007 (rescheduled from Wednesday, April 25th), from 3-4:30 PM ET
- **Oral Health for CYSHCN** with a panel of parent leaders and professionals, Thursday, June 7, 2007 at 3:00 PM ET
- **Facilitative Leadership** with Steve Davis of <http://www.FacilitatorU.com>, Wednesday, June 20, 2007 from 3-4:30 PM ET

Mark your calendars now and make plans to join us! Registration information will be shared as it becomes available for each of the calls.



## Network News

We are pleased to announce that **Donna Graham** has joined Family Voices as a Network member in Tennessee. Donna, mother of three adult children, is not new to Family Voices. She first served for two years on the FV TN Board before resigning from the board and accepting the position as FV East TN Health Information Resource Specialist and Advocacy Coordinator. Donna now joins Julie Sullivan as the Co-Director of Family Voices of Tennessee and the state's Family to Family Health Information Resource Center. Please join us in welcoming Donna!



## News You Can Use: Resources and More

### FOA in the States

It is an exciting time for families as states consider offering a Medicaid buy-in program following the passage of the Family Opportunity Act as part of the Budget Reconciliation Act of 2005. We would like to track the status of each state as they make changes to their Medicaid program. Family Voices is compiling a Family Opportunity Act (FOA) status report for each state. This chart will be posted on the Family Voices website and regularly updated. Please help us keep this chart current! Let us know what your state is doing to enact the Family Opportunity Act (Medicaid buy-in for middle-income families). If you have a brief status report or a new update, please email Janis Connallon, Family Voices Policy Coordinator at [jconnallon@familyvoices.org](mailto:jconnallon@familyvoices.org).

### SCHIP Reauthorization: Tell Your Story

Families of children with special health care needs and disabilities know the importance of sharing your stories with partners and policy makers. Your stories have impacted legislation for children and families over the years. With SCHIP Reauthorization now before Congress, you and families you know have an opportunity to educate your elected officials on the importance of this vital program. The SCHIP (State Children's Health Insurance Program) program provides a critical layer of America's safety net for children and youth. Family Voices, along with many other child health advocacy organizations, is asking Congress to fully fund SCHIP at \$50 billion over five years.

The Family Voices Legislative Action Center (LAC), funded solely by private dollars, affords you a simple way to communicate directly with elected officials in your states and to let them learn from your experiences. Take a few minutes to visit the LAC at <http://www.familyvoices.org/lac> to make your voice heard on this and other issues of importance to families of children and youth with special health care needs.



## Publications to Help Families Partner with Professionals



When families work in collaboration with the professionals who provide services for their CYSHCN, the quality of health care is likely to be improved. Family Voices has developed two publications to help families partner with providers and managed care organizations.

Families Partnering with Providers is a seven-page booklet of tips on communicating with a child's health care providers in preparing for an office visit, talking with providers, learning more, and helping your provider help other families.

Parents Partnering with Managed Care Plans is a seven-page booklet of topics and questions about services for CYSHCN. It can help to guide discussions among families and managed care plans and suggests ways to partner to improve services for this population.

Small quantities of these booklets may be ordered free through the Family Voices Online Catalog - <http://www.familyvoices.org/catalog.php>.

## ☑ New York-Mid-Atlantic Consortium for Genetic and Newborn Screening services announces Focus Group Meetings

The New York-Mid-Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC), is partnering with family organizations, including FV-NJ @ SPAN and FV-NY, in the region to host focus group meetings to hear from consumers and lay advocates for children and others with special health care needs. Family members from DE, DC, MD, NJ, NY, PA, VA and WV are invited to attend one of these focus groups to share their thoughts and recommendations to improve the health and well-being of those with special health care needs in your area.

- Saturday, April 28, 2007: Robert Wood Johnson Medical School Clinical Academic Building, One Robert Wood Johnson Place, New Brunswick, NJ
- Tuesday, May 1, 2007: Hyatt Regency Bethesda, 7400 Wisconsin Avenue, (One Bethesda Metro Center), Bethesda, MD
- Saturday, May 5, 2007: Binghamton, NY

The goal of NYMAC is "to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home that provides accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective care in the New York-Mid-Atlantic region." The purpose of these meetings is to talk directly to those most involved in the care of people with special health care needs – parents and families – to discuss the problems you have encountered and the ways you have found to get what is needed. Although registration for the meeting in Brunswick is full, and Binghamton is approaching capacity, there are still openings for consumers to attend the meeting in Bethesda. For more information, please contact Katharine B. Harris at [kbh02@health.state.ny.us](mailto:kbh02@health.state.ny.us).

*Excellence is the result  
of habitual integrity."*

-- Lenny Bennett