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"This has been an outstanding opportunity to learn, network, have a few light bulbs go off. Thank you for opening up and allowing more family leaders to attend."

"This was a very good conference overall! Good contacts were made. Great ideas were formed. I really have a lot I want to do when I get back."

Family Voices 15th Anniversary Gala and National Conference: Family Advocates and Friends Take Children's Health Messages to Washington

"There is no greater power than a community discovering what it cares about. Ask 'What's possible?' not 'What's wrong?' Keep asking. Notice what you care about. Assume that many others share your dreams. Be brave enough to start a conversation that matters."

- Margaret "Meg" Wheatley



Over 200 family and youth/young adult leaders, professionals and national and state policy makers gathered in Washington, DC for the Family Voices 15th Anniversary Gala and National Conference, May 23-26, 2007 to celebrate a community of families that began with a shared dream for children and youth with special health care needs, and to celebrate with those that started the conversation and those that have continued the

conversation that mattered most to us—how supports and services for our children could and should be.

The Family Voices 15th Anniversary Gala, held at the Decatur House on May 23, certainly was a night to remember. Throughout the beautiful spring evening, our guest MCs, Jana Stanfield, award-winning composer, performer and motivational speaker, and Mitch Hamilton, former KASA board member, inspired and entertained us—family leaders and youth with disabilities and friends -- as we reflected, celebrated, and looked forward to the years ahead. Family Voices honored **C. Everett Koop, MD**, former Surgeon General of the United States, **Merle McPherson, MD**, former Director of the Division of Services for Children with Special Health Care Needs, and **Thomas J. Tauke**, Verizon Executive Vice President and former Congressman from Iowa with Lifetime Achievement Awards for their contributions to improving the lives of children and youth with special health care needs.

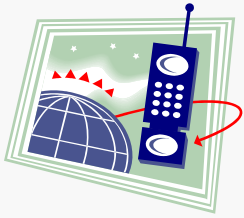


Polly Arango and C. Everett Koop, MD

The Family Voices National Conference, "***Moving Forward the Future of Health Care for Children and Youth: Families, Partners and Communities***," was held May 24-26, 2007 at the Grand Hyatt Washington DC. Conference participants met to share information and strategies for improving health care for children and youth with special health care needs. Our friends and partners joined us in exploring the opportunities and possibilities we have to create even greater systems change in the years ahead. Family Voices leaders shared their expertise and their passion about health policies, family-centered care and much more.

As **Polly Arango**, board member, co-founder, former staff member, family member and friend said, "What we have in our grassroots frontline experts who combine personal experiences with systems knowledge and passion cannot be duplicated by anyone anywhere." Watch the Family Voices website, <http://www.familyvoices.org> for more information on conference proceedings.

Upcoming Topical Calls Something for Everyone



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 June:

- **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! To register, visit

http://www.familyvoices.org:80/info/topical_calls/

Family Voices gratefully acknowledges the generous contribution made by Family Voices Region 1 (CT, MA, ME, NH, RI, VT) to our 15th Anniversary Celebration book. We regret the omission of their ad from the book.

HRSA Awards \$2.9 Million for Family-to-Family Health Information Centers

May 23, 2007, HRSA Press Office —The Health Resources and Services Administration has announced 30 grants worth \$2.9 million to support new and continued Family-to-Family Health Information Centers for parents of children and youth with special health care needs. Twenty-four new and six continuing statewide centers will each receive grants of \$95,700 beginning June 1, 2007. “The centers help parents access information about health care, community resources, support services and technical assistance that they can use to make informed decisions regarding their children’s care,” said HRSA Administrator Elizabeth M. Duke.

Family-to-Family Centers employ parents of children with special health care needs who have experience navigating complex health care and social service systems to help other parents who may be facing similar circumstances. . .

These grants respond directly to President Bush’s New Freedom Initiative, which seeks to reduce barriers to community living for people with disabilities by addressing families’ lack of access to needed services and assistance.

New grantees are:

- Raising Special Kids (AZ)
- Support for Families of Children with Disabilities (CA)
- Family Voices of District of Columbia, Inc (DC)
- Parent to Parent of Georgia, Inc. (GA)
- Hawaii Pediatric Association Research and Education Foundation (HI)
- The Indiana Parent Info Network, Inc. (IN)
- Bayou Land Families Helping Families (LA)
- The Parents’ Place of Maryland (MD)
- Federation for Children with Special Needs (MA)
- University of Southern Mississippi (MS)
- PTI Nebraska (NE)
- Family TIES of Nevada, Inc. (NV)
- Statewide Parent Advocacy Network of New Jersey (NJ)
- Parents Reaching Out to Help (NM)
- Parent to Parent NYS (NY)
- Exceptional Children’s Assistance Center (NC)
- Family Voices of North Dakota, Inc. (ND)
- Oregon Family Support Network (OR)
- Parent Education and Advocacy Leadership Center (PA)
- Rhode Island Parent Information Network, Inc. (RI)
- South Dakota Parent Connection, Inc. (SD)
- Texas Parent to Parent (TX)
- Utah Parent Center (UT)
- Family Voices of Wisconsin (WI).

Continuing grantees are:

- Florida Institute for Family Involvement (FL)
- Arc of Illinois (IL)
- Maine Parent Federation (ME)
- PACER Center, Inc. (MN)
- Tennessee Disability Coalition (TN)
- Parent to Parent of Vermont (VT)

"The Whys of Risky Teen Behaviors!"



Just Released - The Spring 2007 issue of Bright Futures: Family Matters, The Whys of Risky Teen Behaviors!, provides insights into the challenges faced by youth during adolescence, including smoking and drinking. Learn more about behavioral risk factors, encouraging healthy behaviors, talking to your teen, etc.

- Partner highlight- National Governors Association (NGA) Center for Best Practices
- Family Resource Corner- helping teens quit smoking, safe prom and graduation celebrations, Educating 11-13 year olds about alcohol, and Advertising and media messages
- What's New in Research- the influence of alcohol and cigarettes in the media
- Tidbits- May is Lyme Disease Awareness Month

Download this latest issue at <http://www.brightfuturesforfamilies.org/2007issues.shtml> or subscribe by emailing Peggy Curran -pcurran@familyvoices.org.



Network News

We are pleased to announce that **Debi Tucker** has joined Family Voices as a Network member in Georgia. Debi, mother of two, is new to Family Voices but not to issues affecting children and youth with special health care needs or non profit work. She and her family encountered many specialists, and her son underwent several tests while waiting almost a year for a diagnosis. She is the Executive Director of Parent to Parent of GA, a new F2FHIC grantee, and serves on the Parent Leadership Coalition, a statewide coalition that focuses on capacity building and family supports. Debi and her staff look forward to sharing information and resources with families of CYSHCN, and to building partnerships with other parent/ family led organizations, professionals and key stakeholders in GA. Please join us in welcoming Debi!



News You Can Use: Resources and More

Under One Roof: Primary Care Models that Work for Adolescents

Incenter Strategies, an affiliate of the Maternal and Child Health Policy Research Center, has recently released a new report profiling innovative programs delivering integrated primary care for adolescents. Under One Roof: Primary Care Models that Work for Adolescents, by Marian Sandmaier, Alyssa D. Bell, Harriette B. Fox, Margaret A. McManus, and Jane E. Wilson, describes a comprehensive, interdisciplinary model of physical, behavioral, and reproductive health care that operates in different health care settings – a hospital-based adolescent medicine clinic, a private practice, and a federally qualified community health center. Mount Sinai Adolescent Health Center (NYC), Wake Teen Medical Services (Raleigh, NC), and Erie Teen Health Center (Chicago) tailor their services to adolescents' unique needs through multidisciplinary staffing, team-based approaches, staff sensitivity, teen-friendly environments, and a focus on positive youth development. This report also describes the financing challenges associated with providing integrated care and the strategies all three programs pursued to obtain additional funding support. For more information on this report, visit



<http://www.incenterstrategies.org> or contact Stephanie Limb at slimb@incenterstrategies.org.

Second Edition of "Tips for First Responders" Tip Sheets Released

The Center for Development and Disability at the University of New Mexico, with support from the New Mexico Department of Health, Office of Health Emergency Management, the American Association on Health and Disability, the New Mexico Governor's Commission on Disability, and the Research and Training Center on Independent Living, has released the 2nd Edition of a series of tip sheets for first responders. These sheets, while not meant to be comprehensive, can be read either before or while responding to an incident. To view these sheets or to find out how you may order copies, go to <http://cdd.unm.edu/products/>.



**ARC REMINDER. . .
SCHIP
Reauthorization: Tell
Your Story**



Families of children with special health care needs and disabilities know the importance of sharing 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 about this 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.

New Report on Latino Infants and Toddlers

A new report from the National Council of La Raza examines school readiness for Latino infants and toddlers. *Buenos Principios: Latino Children in the Earliest Years of Life* provides demographic profiles of Latino babies, and makes policy recommendations for investment in high-quality, comprehensive early childhood education programs. The report "concludes that investing in high-quality, comprehensive early childhood education programs could help narrow the growing school readiness gap between Latino and other children." For more information, visit their website, <http://www.nclr.org/content/publications/detail/45609/>.

Kids As Self Advocates (KASA) White Paper: *Rethinking Standardized Testing & Exit Exams*

In the past few years, exit exams have been added to the regimen of standardized testing for high school students. While used as a tool for states to improve education practices, exit exams are controversial as they have become a requirement for graduation. KASA has examined the development of exit exams and has chosen "to speak out in order to influence those in power to listen and act as allies in creating change" to systems that effect youth with disabilities. With input from youth around the country, the KASA Task Force has written a white paper, "Standardized Testing: What Youth with Disabilities Have to Say." This report:



- Discusses the problems with testing as identified by young people
- Examines how standardized testing has historically impacted people with disabilities, and
- Makes recommendations on how to improve test accessibility and knowledge of rights.

This white paper will be available shortly. For more information, visit the KASA website, <http://www.fvkasa.org>.