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A Magical Partnership Flourishes

by Lauren Huebner, Family Connection of SC

Magical things can happen with collaboration. A year ago, Family Connection of SC/Family Voices of SC (<http://www.familyconnections.org/>), home of the SC Family to Family Health Information Center, was part of such magic. Family Connection was invited by EdVenture Children's Museum in Columbia, SC to be part of a team to dream up ideas for EdCeptional Kids Month to celebrate and recognize children with disabilities and special needs. Family Connection

immediately thought of the possibilities to reach "typical" children during this month so that these children could gain a greater understanding of their peers with special needs. Family Connection has a program called "Awareness: The Key to Friendships" through which students, faculty and administrators in schools have the opportunity to actually experience what it is like to have a disability. Beth Austin, parent and founder of this program, took ideas from this program and crafted special exhibits for the museum. Children step into the shoes of a child with special needs. Through hands-on activities, they experience what it is like to have loss of sight, mobility, hearing or have difficulty with fine motor skills and learning, gaining a whole new view of their peers with special needs.



The events of EdCeptional Children's Month are sure to excite anyone and everyone! September 11 was Family Night, featuring an exhibit from the Rolling Thunder Wheelchair Basketball Team. September 22 and 23 featured Disney World African-rooted storytellers and performers. There was also an animal assistance dog demonstration. September 29 also featured free admission along with information booths, dental screenings and more. Many talented children have their artwork displayed in the

museum. Family Connection and EdVenture would love to see other states create a similar event at their children's museum. If you would like to know how this dream turned into an incredible experience for children, you can call Cindy Detuelo at EdVenture Museum at (803) 400-1153 or Jackie Richards at Family Connection of SC at (800)578-8750.



Child Health Day is an opportunity for everyone who cares about and for children to spread the word about preventing illness and injury to build a healthier, safer, brighter future for every child. Learn more at:
<http://http://mchb.hrsa.gov/childhealthday/>

SCHIP Update

The SCHIP Reauthorization process continues to roll along. Congressional staff worked through the weekend to resolve some of the differences between the House and Senate versions of SCHIP. According to The New York Times, as of Monday, September 17th, there still had not been any agreements reached. However, it seems likely, if any bill sent is sent to President, it will more closely resemble the Senate's approach. The Senate bill authorizes \$35 billion for the program over the next five years; the House version authorizes \$100 billion.

The Administration has repeatedly said that the President will veto any SCHIP bill that provides more than \$5 Billion over the next five years. The SCHIP program will expire on September 30th, if a new reauthorization bill has not been passed and signed by the President. It is likely, that a continuation of the program at last year's funding level's will be passed to continue the program. As many as 16 states will likely run out of SCHIP funds quickly if a reauthorization bill is not signed.

The Administration is concerned that SCHIP will be a spring board for expanding health coverage until it becomes a national health coverage program. The Administration is worried that employers will eventually stop providing health insurance to employees in favor of a public program such as Medicaid or SCHIP. They are also worried that individuals and families will choose to drop their private health insurance for public programs.

We are asking that families and friends of children and youth with special health care needs request full funding for the SCHIP program. Use the Family Voices LAC: <http://www.familyvoices.org/lac> to contact your elected officials! If you have any additional questions, please contact Julie Beckett (waivermom@earthlink.net, 319-365-0227) or Janis Connallon (jlambconn@comcast.net, 510-232-7765).



Network News

Family Voices sends congratulations and well wishes to **Doreen Hodges**, FV DC, on the birth of her son, Jacob Allen. Jacob arrived August 31, 2007, joining big brother Titus and the rest of the family. Mother and son are doing well.

Family Voices welcomes two new Network members to our growing network of parent leaders. **Tammy Thompson** joins Family Voices from Sopchoppy, FL. An advocate and spokesperson with Florida Institute for Family Involvement, Tammy is a mother of a 10-year old with special needs. Tammy works with the Children's Defense Fund, KidCare Council Committee, and One Voice. She also assists Children's Medical Services with Florida KidCare delivering supplies to Wakulla and Franklin County Schools and assisting families if needed. Tammy has spoken to the Florida House and Senate and has presented at the state wide Family Café on Policy.

Nancy Pedro hails from Buffalo, WY, and joins Rick Skagen with Family Voices of Wyoming. Nancy is mother to 26-year old Becky. Nancy is also active with Wyoming Partners in Policymaking. Nancy worked 15 years for the Wyoming PTI and partnered with state agencies, International Parent to Parent, Partners in Policymaking, local, state and federal education entities, parent support organizations, Shrine hospitals, Denver Children's Hospital and others. Most importantly, she has partnered with parents to help them find the information and resources they need. As a FV Network member, Nancy will continue to support families in finding the health care services their children needs and will work to inform health care systems of the needs of families of CYSHCN.

Welcome, Tammy and Nancy!



Family Leader Conferences

The **Maine Parent Federation**, home to the **Maine Family to Family Health Information Center**, is hosting their **CELEBRATING THE FAMILY CONFERENCE** November 2-3, 2007 at the Samoset Resort in Rockport, ME. Participants may choose from four strands of exciting workshops and hear the keynote address given by Dr. Crystal Arlene Kuykendall, considered one of the most dynamic individuals of our time. A highly sought after and savvy speaking sensation, she is an engaging educator, human relations expert, legal analyst/litigator, endearing author and loving mother. For more information contact the Maine Parent Federation at 1-800-870-7746 or parentconnect@mpf.org. Learn more about the Maine Parent Federation at <http://www.mpf.org>.

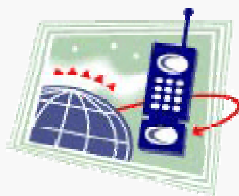


To subscribe to the e-newsletter version of Friday's Child, please send an e-mail to fridayschildnews-subscribe@yahoogroups.com. We invite you to share announcements of news, resources, upcoming events, and other information related to children with special health care needs. Please email us at kidshealth@familyvoices.org 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/fc/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.

Karen Anzola, Editor and Peggy Curran, Layout

TOPICAL CALL: RISKY BUSINESS

A series of 3 calls with Conni Wells, Family Leader and Advocate



RISKY BUSINESS I:

Etiology of the Risk Factor

An introduction to Risk Management and how one can grow and sustain an organization by using risk management to guide planning.

Learning objectives:

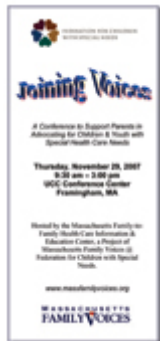
- Participants will learn why family organizations are at risk
- Participants will know what kinds of risk factors are most likely in the family run organization
- Participants will recognize risk factors within their own organization.

Thursday, October 4, 2007,
at 9 AM Hawaii/ 11 AM
Alaska/ 12 PM PT/ 1 PM MT/ 2
PM CT/ 3 PM ET

This call is open to all, but you must register first. Please share this information with your friends and colleagues.

To register, please complete our online registration form at http://www.familyvoices.org/info/topical_calls/index.php

This call is sponsored by the National Center for Family / Professional Partnerships at Family Voices, Inc. - <http://www.familyvoices.org/info/ncfpp/>. Questions? Contact Karen Anzola at kanzola@familyvoices.org or Peggy Curran at pcurran@familyvoices.org.



JOINING VOICES, A Conference to Support Parents in Advocating for Children & Youth with Special Health Care Needs, will be held Thursday, November 29, 2007, from 9:30-3:00 PM at the UCC Conference Center in Framingham, MA. The conference is hosted by the Massachusetts Family-to-Family Health Care Information & Education Center, a Project of **Massachusetts Family Voices @ Federation for Children with Special Needs**. Joining Voices, an annual event, is an opportunity for parents of children & youth with special health care needs to learn specific skills to help them be effective partners in decision-making with health care providers, other providers, systems of care, and with policymakers. For conference information and registration, go to <http://www.massfamilyvoices.org/JV2007.html>.

The 2007 PARTNERS IN CARE CONFERENCE hosted by Parent to Parent Vermont, home of the Vermont Family to Family Health Information Center, will be held December 6, 2007 at the Sheraton Hotel and Conference Center, Burlington, VT. This annual event affords families and



professionals the opportunity to meet with and learn from each other while attending a variety of workshops. Diana Autin, parent, attorney and Co-Executive Director of SPAN (Statewide Parent Advocacy Network) of New Jersey, home of the New Jersey Family to Family Health Information Center, will deliver the keynote address. For more program details and registration information, please visit

<http://www.partoparvt.org/PIC2007.html>.



News You Can Use: Resources and More

Leaders, Learners and Families in Hand: Building Pediatric Palliative Care Best Practice

The Ohio Pediatric Palliative Care and End-of-Life Network (OPENN) will host a three-day all-pediatric palliative care conference October 4-6, 2007 in Akron, OH. The conference will provide the opportunity to discuss current issues in palliative care and best practices and to learn from each other's models and developments. The recommended audience is physicians, hospice leadership, pharmacists, nurses, LPNs, APNs, Social Workers, Counselors, Chaplains, Volunteers, Bereavement Staff, Educators, Child Life Specialists, Palliative Care Teams, and Families.

For the registration brochure and agenda please visit

<http://www.ohpco.org/FINAL%20Reg%20Brochure%20Oct%204-6%202007.PDF>

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



Do you want to know what young people with disabilities have to say about the high school exit exam (a standardized test a student must pass to get a high school diploma) as well as other standardized tests?

If you are an:

- Education organization or association
- Youth leadership organization
- School board and/or local school council
- Disability advocacy organization
- Young person with a disability
- Parent of a youth with a disability
- Or someone who cares about this issue

Here's your chance!

This report shares:

- Youth voice – including many quotes from youth
- Cutting edge ideas to improve test accessibility and knowledge of rights
- How standardized testing has affected people with disabilities in history

Use this report in your education efforts with the:

- Individuals with Disabilities Education Act (IDEA)
- No Child Left Behind (NCLB) and the President's New Freedom Initiative
- Individual rights
- Local and national policies addressing disability and employment

It can also be used to educate policy makers, school boards, state officials, education and special education departments!

Visit the KASA Website -
<http://fvkasa.org> to order this report.

Genetic Alliance Establishes the National Consumer Center for Genetics Resources and Services

Genetic Alliance announced the opening of the National Consumer Center for Genetics Resources and Services (NCCGRS). It is funded by a cooperative agreement from the Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA) Genetic Services Branch of the Maternal and Child Health Bureau. The major purpose of this 5-year, \$500,000/year special project is to mitigate the substantial information and resource deficit for consumers of genetic services. Sharon Terry, President and CEO of Genetic Alliance, and Director of the Center, declared: "Genetic Alliance has tracked the difficulties in obtaining credible information and quality services. We've built substantial systems to alleviate the burden caused by these issues. The establishment of the Center will allow the community to accelerate the development of solutions and resources."

The Center will offer the open access resources developed by Genetic Alliance: Disease InfoSearch, Resource Repository, Understanding Genetics, the Interactive Guide, Strategies for Success, the customizable Family Health History Guide, and the two new resources – WikiGenetics (<http://wikigenetics.org>) and WikiAdvocacy (<http://wikiadvocacy.org>) – to meet the needs of consumers and stakeholders.

WikiGenetics and WikiAdvocacy – user-friendly, user-generated online tools that provide new resources for consumers – embody the ideals of the NCCGRS: to hold open the space for the network, the community as it defines itself, to share resources that will increase access to resources, improve services, and promote the consumer voice. WikiGenetics) is a "by the public, for the public" encyclopedia on human genetics that provides credible and up-to-date information that anyone, including people with no scientific background, can understand. Similarly, WikiAdvocacy is a communal resource for aiding advocacy. It offers a real-time, interactive, online community where advocates contribute to the education and support of their fellows by sharing their own wisdom and experiences. All members of the genetics community are free and encouraged to contribute to both WikiGenetics and WikiAdvocacy. The strength of the resources can only grow through the contributions and collaboration of countless volunteers.

Resources on Minority Health

Several new resources have been developed that address issues of minority health. Check them out! Voices for America's Children and The Annie E. Casey Foundation recently created a new [toolkit entitled Race Matters - http://www.aecf.org/KnowledgeCenter/PublicationsSeries/RaceMatters.aspx](http://www.aecf.org/KnowledgeCenter/PublicationsSeries/RaceMatters.aspx). The toolkit was created to help advocates and leaders address race and power structures within their work to help create equitable opportunities for all.

The Office of Minority Health, along with The Department of Health and Human Services, funded the development of a new tool: A Patient-Centered Guide to Implementing Language Access Services in Healthcare Organizations. The guide was created to assist health care organizations in better serving their clients with limited English proficiency and decrease disparities in access to health care. See <http://www.omhrc.gov/templates/content.aspx?ID=4375&lvl=2&lvlID=107>

The Office of Minority Health (<http://www.thinkculturalhealth.org/>) has launched a new web page, called "Think Cultural Health," that provides a wealth of resources and information on the issues of cultural competence in health care and health care disparities .

**The Family Voices Store at Family Café—
One Stop Shopping
for Family and Friends**



Looking for a way to honor a family member or special caregiver, or seeking just the right thank you gift? Consider making contributions to Family Voices through secure, on line donations, purchases of Family Voices Merchandise at www.cafepress.com/shopfv or purchases from Amazon.com through the link on our web home page. Simply visit our website, <http://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
2340 Alamo SE, Suite102
Albuquerque, NM 87106.

CATCH Residency Training Grants: 2008 Call for Proposals



The Community Pediatrics Training Initiative (CPTI) is teaming up with the Community Access to Child Health (CATCH) Program for the 2nd year to provide a grant opportunity targeting pediatric residency training programs. The mission of this program is to provide support to residency programs in building sustainable opportunities for residents to gain experience working on community-based child health initiatives that increase access to medical homes or specific health services not otherwise available. Grants up to \$12,000 will be awarded on a competitive basis to pediatric residency programs that submit proposals to plan and implement community-based child health initiatives as part of the training curriculum over the course of 16 months. A pediatric faculty member must oversee the project and provide mentorship for residents participating in project activities.

The 2008 Call for Proposals and Application is now available at <http://www.aap.org/commpeps/CPTI/Opportunities.htm>. Proposals are due by no later than 4pm Central on November 16, 2007. For more information, please send questions to: cpti@aap.org.

5th Annual Conference on Children's Health and the Environment

The Save a day for the 5th Annual Conference on Children's Health and the Environment. The conference is organized by the Pediatric Environmental Health Specialty Unit (PESHU) of Region 3, the Mid-Atlantic Center for Children's Health and the Environment (MACCHE). MACCHE is a joint effort between the George Washington University Medical Center and the Children's National Medical Center.

The conference targets health care providers, public health professionals, and the interested public. Topics will explore the intersection between the environment and child health issues and will include:

- A discussion of possible environmental factors influencing autism
- Environmental terrorism and preparedness in school settings
- Environmental changes and their contribution to the obesity epidemic
- Forecasting child health issues due to climate change
- A how-to on greening your medical practice and home
- Air pollution and compromised respiratory function
- A presentation and discussion of case studies in pediatric environmental health

Continuing education credits (CME, CHES & CEU) will be available to participants. Register available at http://guest.event.com/i.aspx?IQ,P1_4DD6D191-0765-45F6-A241-36908DB09946

Cosponsored by: Agency for Toxic Substances and Disease Registry RIII (ATSDR) Centers for Disease Control and Prevention (CDC) Children's National Medical Center (CNMC) Environmental Protection Agency RIII (EPA) George Washington University (GWU).

"The final test of a leader is that he [or she] leaves behind him [or her] in other men [or women] the conviction and the will to carry on.

-- Walter Lippmann