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After the Storm: Families Helping Families

For those of us who live away from the Gulf Coast, watching the aftermath of the “alphabet soup” of hurricanes to hit this area is surreal. For those families living in the midst of a hurricane-ravaged area, this becomes a frightening reality—especially for families of children and youth with special health care needs. Evacuation to a shelter or another city goes way beyond packing a toothbrush, some clothes, and a gallon of fresh drinking water—life saving medication, machines that may require electricity, even vital medical records become necessities to be planned out ahead of time. And coupled with the physical logistical challenges of such an evacuation, there are also the very real emotional scars that can compound fears of those who have experienced one storm and are awaiting the next.



Fortunately, people care. Not the least of these caring people are the many volunteers who work with Family Voices and the Family to Family Health Information Centers. Karen Scallan, Program Supervisor for Louisiana's Family to Family Health Information Center at Bayou Land Families Helping Families, recently wrote:

We survived Gustav unscathed except that our large sign outside blew down the street and we lost power. We're back up and running and have gone into emergency relief mode. We have received monetary donations from some groups and purchased cleaning supplies, basic over the counter medicines, and some other necessities. Kim had purchased before the hurricanes shelter kits with essentials and we're distributing them in the Special Needs shelters and to those with special needs in the general shelters as we go to each shelter.

Karen also mentioned that one positive result of these storms is that during their visits to these shelters they find families in need of their services that they might not otherwise have found.

The Louisiana F2FHIC has produced a wonderful series of one page “Do You Have a Plan” handouts on hurricanes, packing for evacuation, and evacuation. For copies of contact Bayou Land Families Helping Families, Inc. at (985) 447-4461 or toll free at 1-800-331-5570. Visit their website at <http://www.blfhf.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.

Highlight:**National Child Health Day**

This year's National Child Health Day targets the serious obesity epidemic that affects 1 in 6 children between the ages of 2 and 19. Obesity strikes the individual— young, old, special needs, etc.—but it will take a community effort to put an end to the epidemic.

One simple way to help is to take the US Surgeon General's Pledge, and ask your co-workers and others who work with children to do the same:

I pledge to:

- Be a role model by making healthy choices for myself.
- Help children be physically active through everyday play and participation in sports.
- Support children's healthy eating habits.

A healthy future is our gift to our children. Visit the National Child Health Day website, <http://mchb.hrsa.gov/childhealthday/> for more information and ideas.

From Our National Partners: Biopsychosocial-Spiritual Model of Health

From the NCCC website: Body/Mind/Spirit: Toward a Biopsychosocial - Spiritual Model of Health presents the current ongoing discussion in scientific literature on the relationship of spirituality and religion to healthcare – their role in helping individuals cope with illness, their influence in healthcare decision-making, and their potential impact on health outcomes. Visit the NCC website, <http://www11.georgetown.edu/research/gucchd/nccc/>.

There are a variety of resources to help families cope with the emotional turmoil of these situations. Children—who may remember the chaos and upheaval from Katrina three years ago— can be especially hard hit. Here's a short list of resources to help. Note that many of these are not just about hurricanes, but can be useful in helping with any disaster or major trauma.

- After The Storm: A Guide to Help Children Cope with the Psychological Effects of a Hurricane: <http://www.7-dippity.com/other/AfterTheStorm.pdf>
- Disaster Planning Guide for Families: http://www.fifionline.org/resources/disaster_english.pdf
- After the Disaster: A Children's Mental Health Checklist: http://www.fema.gov/kids/tch_mntl.htm
- Emergencies, Mental Health, and Traumatic Stress: <http://mentalhealth.samhsa.gov/cmhs/EmergencyServices>
- Disaster Preparedness for Families with Children: <http://www.aap.org/healthtopics/disasters.cfm>
- Mental Health Services in Disasters and Major Trauma: <http://www.childwelfare.gov/highlights/disaster/mental.cfm>

If you would like to know how to help, contact the Down Syndrome Association of Greater New Orleans. See their website at <http://www.dsagno.org>

May the Best Candidate Win. . . .

Turn on the evening news, and rarely a broadcast concludes without “talking politics.” As people who care about family health issues, we have the opportunity and responsibility to make choices about the candidates we want to see running the country—and we have the opportunity to make sure that our elected officials are “keeping families at the center of children’s health care” (Family Voices, Inc, 2008).

Family Voices cannot and will not tell you who to vote for, but we can provide some information that you can think about and use as you dialogue with candidates for office. Here is a list of questions from our new resource: [Election Season Guidelines](#) for Family Voices Network Members, Board, and Staff. Think about these as you pose questions to candidates and as you make your own important voting decisions:

1. Once elected, what actions will you take to directly improve the lives of families of children and youth with special health care needs?
2. What is your position on entitlement programs such as Medicaid?
3. Specifically what is your position on EPSDT within the Medicaid program?
4. What will you do to protect EPSDT and expand it to include more children and youth?
5. What is your understanding of the term “medical home?” What programs and policy changes are necessary, in your opinion, to improve access to quality health care for all children?
6. What are your plans to decrease health care disparities among vulnerable and diverse populations?
7. The Title V program of the Social Security Act provides assistance to families of children and youth with special health care needs in every state. This program is consistently underfunded. What actions will you take to strengthen this program?

Another excellent resource comes from New Mexico Voices for Children: “A New Mexico Citizen’s Guide to Children’s Issues: Why Kids Need You to Vote on November 4th” To download a pdf copy of this booklet, point your web browser to: <http://www.nmvoices.org>. Note that you’ll need to print this on legal size paper (8 ½ x 14).

From Our National Partners: **AMCHP Seeks Senior Manager**

The Association of Maternal & Child Health Programs (AMCHP) is recruiting for a Senior Manager for Children and Youth with Special Health Care Needs. This position is accountable for development, implementation and evaluation of program activities related to children and youth with special health care needs (CSHCN), birth defects and developmental disabilities, early childhood development, and family involvement. The Senior Program Manager will assist in the tracking, analyzing, and reporting on national and state programs impacting CSHCN, birth defects and disabilities and early childhood. Visit the [Career Section](#) on the AMCHP website to learn .

MCHB Block Grant Rating

The On September 15, 2008, the White House Office of Management and Budget announced that the Title V MCH Services Block Grant received the highest possible rating, sharing that distinction with only 19% of federal programs.

Michael Fraser, Ph.D., CEO of AMCHP, provided a context of the significance of this recognition: "The new effectiveness rating for the Title V MCH Block Grant is a substantial achievement. This new PART rating reflects the importance all states and the leadership of the Maternal and Child Health Bureau (MCHB) have put on performance measurement and accountability. It is a recognition that is well deserved and worth celebrating, and we congratulate all state MCH program leaders and staff, as well as our partners in the federal MCHB."

"We welcome this vote of confidence that the dollars American taxpayers invest in vital MCH programs are being used effectively. AMCHP remains concerned however that the documented success of the program has not translated into an adequate level of resources needed to meet the clearly documented MCH needs that remain. This new rating reinforces our message of why full funding of the MCH Block Grant is needed."



Family Leadership in the States:

♥ **Youth Leadership in the States: Tyler Green—The Council for Exceptional Children's 2008 "Yes I Can" Award Winner!**

Congratulations to high school senior Tyler Greene, from Waterloo, Iowa, for winning one of 29 "Yes I Can" awards from the Council for Exceptional Children recently. Tyler wrote and produced a DVD, "I'm Tyler," that emphasizes what individuals with disabilities can do. Over 4000 copies of the DVD are being used around the country to inspire others. He's also a member of the Kids as Self Advocates (KASA) National Board. To learn more about Tyler and view his video, visit <http://www.imtyler.org>. It's amazing. His is a compelling message to us all to make a difference. KASA, a project of Family Voices, is a national grassroots network created by youth with disabilities to share support and information with one another and the larger community of families and professionals. Visit <http://www.fvkasa.org>.

♥ **Save the Date: "The Role of Youth in Making High Schools Inclusive" Teleconference, October 15th**

Speaking of KASA, make plans to attend an exciting teleconference featuring youth leaders on the role of youth with and without special needs in making high schools more inclusive. The national teleconference is sponsored by the LRE Part B TA Community of Practice, the Statewide Parent Advocacy Network of New Jersey, Family Voices, and Kids As Self-Advocates.

For more information and call-in instructions, contact Diana MTK Autin, Executive Co-Director Statewide Parent Advocacy Network, at diana.autin@spannj.org.

Network



News

♥ **Welcome Anna Cyr of Maine**

Family Voices is pleased to announce that Anna Cyr has joined Family Voices of Maine as a parent leader/ Network member. Anna is the mother of 2 daughters, Mallory (23) and Maisy (15). Both were born with Microvillous Inclusion Disease which prevents them from digesting food so they are fed intravenously (Total Parenteral Nutrition - TPN). MID is an extremely rare disease and those born with it rarely survive to their second birthday. There are numerous complications which can be life threatening and Mallory and Maisy have experienced just about all of them. The family's philosophy is that MID takes a back seat to LIFE so the girls are very active. Mallory graduated from University of Maine at Farmington last year and is now a Youth Coordinator for Healthy and Ready to Work and Maine Support Network. She also volunteers for the local community theater doing publicity as well as appearing in musical productions. Maisy is also involved in theater and art. Maisy's first love, however is her horse and she is President of her 4 H Club. Anna, happily married to Michael for 25 years, has been active in health care reform efforts since shortly after the birth of their first child. Please join us in welcoming Anna!



News You Can Use: Resources and More

Families USA: Accepting Applications for the Villers Fellowship for Health Care Justice and the Wellstone Fellowship for Social Justice

Families USA, <http://www.familiesusa.org/>, is a nonprofit organization working for high quality, affordable health care for all Americans. Based in Washington, DC, they combine grass-roots advocacy with such activities as writing reports, acting as a clearinghouse for information about health care, and keeping a close eye on governmental actions with respect to health care. They offer two year-long fellowships in the DC area, the Villers Fellowship for Health Care Justice and the Wellstone Fellowship for Social Justice.



From the Families USA Website:

“Villers Fellows work in our health policy department and assist our organization's efforts to improve access to health coverage for all Americans, especially for low-income and other vulnerable communities.”

“The Wellstone Fellowship for Social Justice aims to advance social justice through health care advocacy by focusing particularly on the unique challenges facing communities of color.”

For more information and downloadable application forms, visit the Families USA website to find more information on the Villers Fellowship Program and the Wellstone Fellowship Program.

MCH Timeline: History, Legacy and Resources for Education and Practice



So when was the Maternal Child Health Bureau established? How did families get involved in the Title V block grant process? How can we use knowledge of where we've been to help us chart where we need to go? The MCHB can provide answers to these questions and more with their MCH Timeline. The founding of Family Voices in 1992 is included on the timeline, <http://mchb.hrsa.gov/timeline/>, along with a description and links to the website.

From the MCHB website: “Welcome to the MCH Timeline which traces the history of maternal and child health in the U.S., provides in-depth modules on topics such as MCH 101, MCH Systems of Care, Infant Mortality and MCH Performance and Accountability, and allows you to search for topical areas of interest to you. If you are interested in MCH history and its legacy, this site is for you. We hope that it will be used as an orientation tool for those new to the MCH profession, for grantees of the Maternal and Child Health Bureau and MCH students. We also hope that those with experience in the field will find it a rich resource and a source of inspiration.”

The MCH Timeline has been updated and the Oral Histories section has another addition: “Title V: The Evolution of Family Partnership.” Be sure to check out this online timeline on the MCHB website- <http://mchb.hrsa.gov/timeline/>,

The University of Illinois at Chicago Department of Disability and Human Development Announces “Health and Lifestyles of Teens with Disabilities” Survey

A new survey is being conducted with parents and teens to study the potential risks and consequences that are associated with overweight and obesity in adolescents with disabilities.

The Department is seeking parents who are concerned that their child eats too much junk food, spends too much time on TV, computer or Nintendo, and has limited access to sports and exercise, as well as teens between the ages of 12 and 18 with physical or cognitive disabilities to participate in this online survey.

For more information about the survey and to participate in it, go to: <http://www.healthforyouth.org> and plug in the access code: ARC1.

“While we try to teach our children all about life, our children teach us what life is all about.”