

## **Parent to Parent of NYS**

*New York's Family to Family*

*Health Care Information and Education Center*

*Links Digest- Volume 96      May 1, 2010*

**As part of the Family to Family Health Care Information and Education Center, Parent to Parent of NYS has established the Links Digest to provide links relevant to the issues of health care. Below is the most recent listing of website links which we have found valuable and hope they will be of benefit to others.**

*Happy Mother's Day to all women who provide care and support!*

### **The Experience of Uncertainty**

The National Human Genome Research Institute at the National Institutes of Health is conducting a survey to learn more about how parents of children with an undiagnosed medical condition think and feel about their child's condition. A link to the survey is posted on the homepage of Syndromes Without A Name, but it is unclear how long the survey will be posted so act quickly:  
<http://www.undiagnosed-usa.org/>

### **Opportunity to Influence the Pediatric Research Agenda**

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) has extended a special invitation to Family Voices and affiliates to submit nominations of drugs, biologic or medical devices that need further study in children. This is a valuable opportunity as they have specifically reached out to families to be a part of the process.

The nomination form, background information, and the prioritization process by which all nominations will be considered and evaluated can be located in a Request for Information (RFI) in the National Institutes of Health Guide:  
<http://grants.nih.gov/grants/guide/notice-files/NOT-HD-10-010.html>.

The RFI is titled "Call for Nominations for NICHD's 2010-11 BPCA Priority List of Needs in Pediatric Therapeutics." The RFI contains a link to an online form and also provides the option to email, fax or mail the completed form to NICHD. Nominations will be accepted through **May 30, 2010**.

**1. Advocacy 101 – items that help strengthen advocacy skills – (Communication skills, parenting skills, letter writing, speaking with professionals, asking questions)**

May 6<sup>th</sup> marks the 5<sup>th</sup> anniversary of National Children’s Mental Health Awareness Day. Learn about the initiative here:

<http://www.samhsa.gov/children/>

And for more in-depth information on understanding and addressing children’s mental health needs, a report from the April 2009 interdisciplinary summit on children’s mental health sponsored by the Society for Research in Child Development can be found here:

[http://www.srcd.org/index.php?option=com\\_docman&task=doc\\_download&gid=838](http://www.srcd.org/index.php?option=com_docman&task=doc_download&gid=838)

May is National Foster Care Month. Learn about the American Academy of Pediatrics’ Healthy Foster Care America initiative here:

[http://www.aap.org/fostercare/PDFs/HFCA\\_flier%204.7.10.pdf](http://www.aap.org/fostercare/PDFs/HFCA_flier%204.7.10.pdf)

**2. Financing issues – health insurance and other ways to finance the costs of needed services (including grievances, denials and appeals – i.e. Strategies for Appealing Health Plan Decisions)**

Governor Paterson has announced that New York State will participate in the temporary federal high risk pool made available through health care reform:

<http://www.ins.state.ny.us/press/2010/p1004302.htm>

The health care reform bill outlaws denial of insurance to those with preexisting conditions. But this change won’t take full effect for years. The following article provides the basics as it relates to health care reform bill recently passed:

<http://www.csmonitor.com/USA/Politics/2010/0324/Health-care-reform-bill-101-rules-for-preexisting-conditions>

**3. 504 Accommodation Plans related to Health Conditions (i.e. what are the legal obligations of schools to provide health-related services and therapies? Accommodations needed for equal access)**

The following “issue brief” gives an overview of school nursing services role in healthcare. It includes Federal and State laws:

<http://www.nasn.org/Default.aspx?tabid=348>

An Individual Health Plan (IHP) is a tool that can be compiled by the school nurse, health care providers and parents and incorporated into the students IEP or 504 Plan for students with special health care needs. The link below includes comprehensive forms that can be used to develop a students IHP:

<http://www.opi.mt.gov/pdf/health/healthcareneeds.pdf>

**4. Who helps with what? Which state agencies are involved in health care and health coverage? What do medical and managed care terms mean? What should families look for in selecting a provider? What questions should families ask?**

HealthReform.gov, an official government website managed by the U.S. Department of Health and Human Services, provides ongoing news and information regarding health care reform implementation. Secretary Sebelius and health care reform experts answer questions from the public via live weekly web chats; the site maintains an archive of previous chats. The effect that health care reform is anticipated to have on New York State specifically can also be found by utilizing the "Health Reform Where You Live" feature:

[www.healthreform.gov](http://www.healthreform.gov)

In response to health care reform legislation, the Office of Consumer Information and Insurance Oversight has been created. This office will be responsible for ensuring enforcement of the new insurance market rules, providing guidance and oversight on the state-based health care exchanges, and administering the temporary high-risk pools that are currently being established. Additionally, it will compile and maintain data for public dissemination via the internet on available insurance options:

<http://www.hhs.gov/ociio/>

**5. Parent-to-parent support skill-building (How can parents provide support and assistance to families without substituting their judgment? Understanding and respecting cultural diversity. How can parents be culturally competent in working with diverse families? How can parents emotionally support, inform, and educate parents so that they are strong, knowledgeable, and confident in caring for their child with special health needs?)**

The following article gives an in depth look at why it is important to understand cultural differences as it relates to supports and services for families who have special needs:

<http://www.ncset.org/publications/essentialtools/diversity/partIV.asp>

The American Academy of Pediatrics has published "Racial and Ethnic Disparities in the Health and Health Care of Children" a technical report which reviews and synthesizes the published literature on racial/ethnic disparities:

<http://pediatrics.aappublications.org/cgi/content/abstract/125/4/e979>

**6. Keeping Records is a learned skill. Parents will learn what kinds of records are important and how to record necessary information. Your child's health care providers rely on your records to help them make sound medical recommendations.**

A glossary of medical abbreviations commonly used in hospital, medical, and dental records can be found here:

<http://www.jdmd.com/glossary/medabbr.pdf>

Knowing your child's medical history is important especially during an emergency. The following article includes information about personal health records, why it's important and what it should contain:

[http://www.myphr.com/index.php/phr\\_news\\_stories/article/2247/](http://www.myphr.com/index.php/phr_news_stories/article/2247/)

**7. Parent-professional collaboration strategies. How can families work with their health care provider to secure quality care and coverage for their child? How can health care provider and families communicate more effectively? What are effective health advocacy strategies? What is a "medical home" and how can parents access it for their child with special health needs?**

The following article from "PULSE", the monthly newsletter from the Association of Maternal & Child Health Programs, explains the medical home model, its history, current practices and future development:

<http://www.amchp.org/AboutAMCHP/Newsletters/Pulse/April2010/Pages/article.aspx>

This brief video from Champions for Inclusive Communities explains the 6 core elements of an effective system of care for children with special health care needs:

<http://www.championsinc.org/about/intro/>

**8. Understanding Medicaid funded Waiver Services (Including the philosophy of individual and family-centered supports)**

The following link provides information about person-centered and family-centered planning. It includes the basic concepts, key characteristics and possible limitations:

[http://www.aamr.org/content\\_191.cfm?navID=68](http://www.aamr.org/content_191.cfm?navID=68)

The Pathways to Independence Natural Supports project, conducted by the University of Wisconsin, seeks to discover, support and disseminate creative and promising practices for supporting youth with disabilities to participate more fully in school, work and community activities utilizing natural supports. There are many resources related to natural supports and inclusion available on the website:

<http://www.waisman.wisc.edu/naturalsupports/>

**9. Legal information - what are the rights of children to medical coverage under Medicaid, SCHIP, fee-for-service coverage. How can families use complaint, arbitration, and grievance procedures to resolve disputes? What are the legal obligations of schools to provide health-related services and therapies?**

Insure.com provides information on appealing a health plan decision, sample letters to dispute denials and an explanation of the different type of appeals (internal or external):

<http://www.insure.com/articles/healthinsurance/claim-denial.html>

The Commonwealth Fund provides information about the timeline for Health Care Reform implementation here:

<http://www.commonwealthfund.org/Content/Publications/Other/2010/Timeline-for-Health-Care-Reform-Implementation.aspx>

**10. Transition from Pediatric to Adult Health Care and Self Determination in Health Care (the important leadership role that individuals with disabilities and their families must play in moving from pediatric to adult health care).**

The following link defines "self-determination" and includes suggestions on how educators from early elementary school through high school can promote self-determination by their students with disabilities:

<http://www.athealth.com/Consumer/disorders/selfdetermine.html>

The Family Center on Technology and Disability (FCTD) has a guide to preparing for successful transitions (birth to grade 12 and post-secondary) for children and young adults who use assistive technology:

<http://www.fctd.info/show/newfig>

**11. Fathers – from Jim Swart, Fathers Network Coordinator**

The Philly.com community page recently had a story regarding The Arc of Montgomery, Berks and Bucks Counties' Father's Group. This group helps dads understand and support their child who has a disability:

<http://www.philly.com/community/pa/bucks/89693942.html?cmpid=15585797>

From The Iowa State University "Me and My Dad: Strengthening Relationships Between Dads and Kids" newsletter; Joani Gent, a freelance writer, shares thoughts from within families of children with disabilities. This also includes links to father's groups, books to read with your child and activity ideas for father and child:

[http://www.extension.iastate.edu/dads/stages/4\\_2001.htm](http://www.extension.iastate.edu/dads/stages/4_2001.htm)

## 12. Other Links:

Monica and David, a film about the relationship and struggle for independence shared by this couple with Down Syndrome won the award for Best Documentary Feature at the Tribeca Film Festival in April. See the story and a trailer for the film here:

<http://www.disabilityscoop.com/2010/04/30/monica-david/7878/>

The Joshua O'Neil and Zeshan Tabani Enrichment Fund offers financial assistance to young adults (18+) with Down Syndrome who wish to continue to enrich their lives by enrolling in postsecondary programs or by taking classes that will help them enrich life through employment, independent living skills, life skills or another way. To download the application (deadline July 16, 2010), visit:

<http://www.ndss.org/>

- *Have you found valuable links that you would like to share? Please send them to Michele Juda at [f2fhealthtools@verizon.net](mailto:f2fhealthtools@verizon.net) 1-800-305-8817*
- *If you would like to speak to someone regarding your child with special health care needs, contact Michele at the above-referenced number.*
- *Would you like to speak to Jim Swart, Regional Coordinator supporting our Fathers' Network? Call 1-800-305-8817 or email [jmswart1@verizon.net](mailto:jmswart1@verizon.net)*

✓ our website at [www.parenttoparentnys.org](http://www.parenttoparentnys.org)

**Janice Fitzgerald, Executive Director, Parent to Parent of NYS**  
**P.O. Box 1296, Tupper Lake, NY 12986**