



New York's Family to Family

Health Care Information and Education Center

Fostering Family Leadership and Family Professional Partnerships

NYS Affiliate Organization of Family Voices

Links Digest- Volume 140

June 2016

As part of the Family to Family Health Care Information 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 for others.

- ***Families as Partners-*** *Families of children with special healthcare needs will partner in the decision-making at all levels and will be satisfied with the services that they receive*

It is important to know your family health history when discussing healthcare with your provider. Using this toolkit a family member can capture information on heredity, diet, environment, and patterns of disease. Family health history tells more than just what diseases run in a family. It includes information about where the family has lived and what kind of work and activities they do. This tool can help families and physicians alike see potential health risks and plan a course of action.

<http://www.geneticalliance.org/sites/default/files/GuideToFHH/GuidetoFHH.pdf>

- ***Adequate Insurance and Financing-*** *Families of children with special healthcare needs will have adequate and/or public insurance to pay for the services that they need*

United Healthcare Children's Foundations grants provide financial help/assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan. The Foundation aims to fill the gap between what medical services/items a child needs and what their commercial health benefit plan will pay for.

<http://www.uhccf.org/apply/>

- ***Medical Home-*** *Children with special healthcare needs will receive coordinated, ongoing, comprehensive care within a medical home*

Family members are the primary caregivers and support in a child's life. Practices and health care organizations that are family-centered provide care in equal partnership with families, caregivers, and children. This page includes tools, resources, and links to information that will assist families in successfully partnering with their child's medical home. (If you are asked for a username and password, click cancel to bypass this screen and arrive at the resource.)

<https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx>

- ***Early, Continuous Screening-*** *Children will be screened early and continuously for special health care needs*

As parents of special needs kids, we are often hearing what our child does NOT do. Here is a hands-on activity to identify your child's strengths. By looking at the whole individual, parents and providers can devise a comprehensive treatment plan.

<https://www.understood.org/en/friends-feelings/empowering-your-child/building-on-strengths/download-hands-on-activity-to-identify-your-childs-strengths>

- ***Community Based Services-*** *Service systems must be organized so families can use them easily and are satisfied*

You can locate genetic and specialty care centers using this Google Maps based tool. Drag your mouse over the location that you are interested in and the map will provide you contact information for specialty care departments located at that facility.

<https://findahealthcenter.hrsa.gov/#>

- ***Transition to Adulthood-*** *Youth with special health care needs will receive the services necessary to make transitions in all aspects of adult life, including adult healthcare, work, and independence.*

The American College of Physicians (ACP), announced the release of specialized toolkits to facilitate more effective transition and transfer of young adults into health care settings. The [new transition toolkits](#) contain several condition-specific tools modeled after Got Transition's Six Core Elements of Health Care Transition.

- General Internal Medicine (for young adults with [intellectual/developmental disabilities](#) and those with [physical disabilities](#))
- Cardiology ([congenital heart disease](#))
- Endocrinology ([type 1 diabetes](#), [turner syndrome](#), [growth hormone deficiency](#))
- Hematology ([general hematology](#), [sickle cell disease](#), [hemophilia](#))
- Nephrology ([end-stage renal disease](#))
- Rheumatology ([juvenile idiopathic arthritis](#), [systemic lupus erythematosus](#))
- Gastroenterology (inflammatory bowel disease - coming soon)

Other Links:

“Complex Child” is a monthly on-line magazine with articles written by parents and caregivers of children with special health care needs and disabilities. These articles are intended to be informational by sharing the personal experiences of parents in a language that is easily understood. <http://complexchild.org>

The Virtual Hope Box (VHB) is a smartphone application designed for use by patients and their behavioral health providers as an accessory to treatment. The VHB contains simple tools to help patients with coping, relaxation, distraction, and positive thinking. Patients and providers can work together to personalize the VHB content on the patient's own smartphone according to the patient's specific needs. This is also a great tool for family caregivers to use in the management of their own needs. <http://t2health.dcoe.mil/apps/virtual-hope-box>

- Have you found valuable links and you would like to share? Please sent them to Lin Perry at lperry@ptopnys.org
- If you would like to speak with someone regarding your child with special health care needs, we would be happy to hear from you:
 - Lin Perry at (607) 786-9063 ext. 787 (Upstate NY families).
 - Silvia Verga at 1-800-405-8818 (Downstate NY families and those who speak Spanish or Portuguese)
- ✓ Visit our website at www.ptopnys.org
- ✓  www.facebook.com/ParenttoParentNYS

***Michele Juda, Executive Director, Parent to Parent of NYS
500 Balltown Rd, Schenectady, NY 12304***