

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 47

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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.

- ✓ *Check out Parent to Parent of NYS' Home Medical Care On-Line Training at*

<http://www.parenttoparentnys.org/onlinetrainingcenter.htm>

Learn how to keep your home a home and not a hospital and how to be an effective health care employer in your home.

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

http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=999 - communicating with your Doctor

http://www.fvkasa.org/edu_IEP.asp - how to get the most out of your IEP

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)**

http://209.85.165.104/search?q=cache:Bt_PYTAguoYJ:www.ins.state.ny.us/extapp/extappl.pdf+new+york+state+fair+hearing+office+decisions - New York State external appeal application if you are denied of health services by your insurer or HMO as not medically necessary, experimental, or investigational treatments.

<http://www.uhccf.org/aboutus.html> - The United Healthcare Children's Foundation is committed to enhancing the quality of life for children who have health care needs not covered by their commercial health insurance. The Foundation provides financial assistance toward the family's share of the cost of medical services.

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)

http://www.associatedcontent.com/article/122178/section_504iep_plans_and_accommodations.html - -504 Plans and IEPs for children with ADHD

<http://sss.usf.edu/504tutorial/Module3/CommonErrors.html> - Common Errors in the Development/Implementation of a 504 Accommodation Plan

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?

<http://www.urban.org/url.cfm?ID=901016> - Triple Jeopardy for Vulnerable Children-A new Rand research brief, available at, reports on recent research that indicates that health insurance is necessary but not sufficient to ensure children's health. Vulnerable children, the report finds, often lack access to a medical home and access to high quality medical care when they need it. The research brief explores administrative structure of state insurance programs, language barriers to access, and related issues.

<http://www.chw.org/applications/TeachingSheets/1162EN.pdf> - Finding the right doctor for your child

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?)

<http://www.amsa.org/programs/gpit/cultural.cfm> - cultural competency in medicine

<http://www.suite101.com/course.cfm/17572/lessons> - creating and/or finding an on-line support group

- 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.**

http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=851 - checklist on important papers

http://www.permanente.net/homepage/handbook/healthwisehandbook/ch_20/ch_20_home_medical_records.htm = maintaining home medical records

- 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 providers 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?**

http://www.lifescrypt.com/channels/healthy_living/Life_Tips/whats_wrong_with_your_doctor-patient_relationship.asp - Article on "What's wrong with your doctor-patient relationship"?

http://nationalservicerresources.org/epicenter/practices/index.php?ep_action=view&ep_id=1020 - understanding the basic elements of collaboration.

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

www.emedny.org/info/formfile - A blue box will pop up and where it says Find Formulary File information in the Field and Sort drop down boxes put in Description and in the Value box put the name of the medicine (either the regular name or the generic name). After you hit Search another page will pop up and let you know if it is covered.

<http://www.kff.org/medicaid/7491.cfm> - This issue brief discusses the challenges and implications for young people with disabilities when they become adults and lose their Early and Periodic Screening, Diagnostic and Treatment benefits and how recent changes to the Deficit Reduction Act give states an opportunity to increase the availability of services that allow disabled individuals to lead as normal a life as possible as they move into adulthood.

- 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?

<http://www.ins.state.ny.us/hprovrght.htm> - The Insurance Law and Public Health Law include important protections for health care providers with respect to network participation, provider contracting, claims processing, and prompt payment for health care services.

http://www.oag.state.ny.us/health/wheelchair_law.html#quest - The lemon law for wheelchairs

10. Autism Connection – links regarding autism and accurate information about autism treatments

<http://www.nimh.nih.gov/publicat/autism.cfm> - medications given to children with Autism

<http://www.chw.org/applications/TeachingSheets/1132EN.pdf> - Fact sheet on Autism

11. Other Links and Information

<http://www.chw.org/display/PPF/DocID/32789/router.asp> - treating common childhood ailments

http://www.ynhh.org/choice/ped_patient.html - keeping children safe in the hospital

http://www.law.duke.edu/aidsProject/400_01/poverty_level.pdf - 2007 poverty guidelines

*Have you found valuable links that you would like to share?
Please email them to Rosemary Randazzo, Parent to Parent of NYS
Coordinator for Long Island at rosemarylip2p@aol.com*

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