

## **Parent to Parent of NYS**

***New York's Family to Family***

***Health Care Information and Education Center***

***Links Digest - Volume 48***

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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.

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

[http://www.longislandpress.com/?cp=227&show=article&a\\_id=7362](http://www.longislandpress.com/?cp=227&show=article&a_id=7362) - article on taking charge of your child's IEP

<http://www.chw.org/display/PPF/DocID/32977/router.asp> - Site that contains listings on various medical issues in the form of patient handouts/teaching sheets.

**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://www.urban.org/UploadedPDF/901016\\_vulnerablechildren.pdf](http://www.urban.org/UploadedPDF/901016_vulnerablechildren.pdf) - Children in Vulnerable Families: Fact and Figures. Triple Jeopardy for Vulnerable Children- A research brief 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://info.insure.com/health/claimdenial.html> - how to avoid insurance claim denial and what to do if you can't

**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.broward.k12.fl.us/studentssupport/psychologicalservices/pdf/ESE-504Issues.pdf> - 504 plan and accommodations for students with ADHD

<http://departments.weber.edu/teachall/504/handbook.html> - Handbook on common questions on Section 504

**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.aap.org/advocacy/washing/FinalJoint.pdf>. - Leading Child Health Groups Present Key Priorities for SCHIP Reauthorization-Leading child health organizations --- the American Academy of Pediatrics (AAP), March of Dimes, and the National Association of Children's Hospitals --- joined the Georgetown University Center for Children and Families to release a report that identifies key issues that must be addressed in reauthorizing the State Children's Health Insurance Program (SCHIP).

<http://www.kff.org/medicaid/upload/7610.pdf> - State Children's Health Insurance Program at a glance state-by-state.

**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.massgeneral.org/news/releases/090605weissman.html> - Medical student/residents dealing with culturally diverse patients

<http://www.nhlbi.nih.gov/health/public/lung/asthma/guidfam.pdf> - Students with chronic illness: Guidance for families, students and schools

**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://familydoctor.org/838.xml> - Creating a health journal

<http://www.aafa.org/pdfs/asthmaactioncardchildcare.pdf> - allergy/asmatha management guide/plan

- 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.medicalhomeinfo.org/publications/Downloads/MHArticleGELESKE.pdf> - Building a medical home "brick by brick".

<http://www.childrensdisabilities.info/advocacy/advocacy-healthprofessionals.html> - how to talk so health care professionals will listen

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

<http://content.healthaffairs.org/cgi/content/full/hlthaff.26.2.w271/DC1-> Article on "Is Medicaid Sustainable? Spending Projections for the Program's second 40 years?"

<http://www.cbpp.org/11-13-06health.htm> - Are Medicaid expenditures growing "out of control"? This paper reports new data showing that Medicaid expenditures did not grow at all in fiscal year 2006 and are expected to grow only modestly in 2007.

- 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.hrtw.org/healthcare/ins\\_reg.html](http://www.hrtw.org/healthcare/ins_reg.html) - insurance laws and statutes

<http://www.usatoday.com/money/perfi/columnist/block/0025.htm> - establishing a special needs trust

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

<http://www.iidc.indiana.edu/irca/IRCAarticles/fgeneralarticles.html> - training articles written by staff members of the Indiana Resource Center for Autism.

<http://www.researchautism.org/resources/reading/documents/TransitionGuide.pdf>

*A Guide for Transition to Adulthood*, the fourth book in the *Life Journey through Autism* series of resource guides published by the Organization for Autism Research (OAR), is now available free of charge.

## **11. Other Links and Information**

<http://ghr.nlm.nih.gov>. - Genetics Home Reference Information Rx" on Newborn Screening and Related Genetic Disorders-After a doctor sees a patient, he or she often prescribes medications. But what if such as doctor also wants to direct a patient to up-to-date, reliable, consumer-friendly information about a genetic condition, or an explanation of the basics of genetic science? Pediatricians can refer their patients to Genetics Home Reference, a free, patient-friendly Web site of the National Institutes of Health (NIH). This project makes it easy to refer patients directly to Genetics Home Reference with a free and convenient Information Rx prescription pad.

<http://web.ku.edu/~beachsvy/GPWDINFO/Info2.htm> - The Beach Center is conducting this study to better understand the views that people with disabilities or chronic health conditions have about genetics and their implications.

<http://www.chw.org/applications/TeachingSheets/1675EN.pdf> - Asthma fact sheet

***Have you found valuable links that you would like to share?  
Please email them to Rosemary Randazzo, Parent to Parent of NYS  
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