Health Care Notebook

This notebook is for:

_____

Compiled by the the Parent to Parent of NYS
Family to Family Health Care
Information and Education Center

A publication of PARENT TO PARENT OF NYS

Table of Contents:

PARENT TO PARENT OF NYS

Health Care Notebook

NAME:

Section 1: Introduction

A Parent and Child's Health Care Notebook

The goal of a Health Care Notebook is to provide a central location for important information regarding your child's special health care needs. Record keeping is a must when parenting a child with special health care needs. Parent to Parent of NYS has created this notebook to provide an invaluable reference tool that will make keeping your child's records easy and convenient. Imagine being able to find information at a moment's notice? Well, you can with this notebook. We are parents of children with special needs and understand the need for locating information at a moment's notice!

The Health Care Notebook has value that far exceeds simple organization. It is a crucial tool to help in developing a partnership with the professionals who provide care to your child. As you become more organized you will develop the skill of when and then. You will approach your health care professionals thinking, "When this happens then I will...."

You might realize that you need more of a particular page. The pages are on the Parent to Parent of NYS website available for downloading. For anyone without access to the Internet, our offices can mail or fax the pages you need.

There are various Health Care Notebooks in use and available on the Internet. No single book will completely address every child's needs. We have included a listing other notebooks in the references section, which can be downloaded and combined with any of the Parent to Parent of NYS pages to add to your notebook, creating a personalized notebook that works for you.

NAME:

Quick Tips Before Getting Started

What is a Health Care Notebook?

A Health Care Notebook is an organizational tool for families who have children with special health care needs. Using a Health Care Notebook can help you keep track of important information about your child's health, providers and health history.

How can this help me?

In caring for your child with special health care needs you will receive information from many sources. This Health Care Notebook will help you organize information in one central place. It will help you track changes in medication and or treatments and it provides a place where you can refer back to health care professionals who have provided past services (i.e. speech therapist from Pre-K, first ENT, etc.). It is a place to keep phone numbers, doctors, locations of testing, vendors of durable medical equipment, serial numbers, authorizations/approvals, etc., in one place.

The process of organizing the records will improve your ability to effectively partner with your child's health care providers in the decision-making process. Additionally, the Health Care Notebook can be used as a tool to support the development of health care related skills for the child who is transitioning to adulthood.

What are some helpful hints for using my child's health care notebook?

- Keep this notebook where it is accessible (not in a closet or in the attic).
- Add new information daily, monthly, weekly or after medical appointments or phone calls regarding your child's health care.
- It may be beneficial to bring the Health Care Notebook to medical appointments.
- The more this notebook is updated, the more valuable it will become to you and to your child.

NAME:

Section 2

Emergency Medical Contact Information Form

Directions to Your House

Family Directory

Family Medical History

NAME:

Emergency Contact and Medical Information for a Child

Child's Name _____

Date of Birth _____ Sex ☐ M ☐ F

_____ Parent's/Guardian's Name	_____ Parent's/Guardian's Name
Home Phone (_____) _____	Home Phone (_____) _____
Work Phone (_____) _____	Work Phone (_____) _____
_____ Address	_____ Address
_____ City ST ZIP Code	_____ City ST ZIP Code

Alternative Emergency Contacts

_____ Primary Emergency Contact	_____ Secondary Emergency Contact
Home Phone (_____) _____	Home Phone (_____) _____
Work Phone (_____) _____	Work Phone (_____) _____
_____ Address	_____ Address
_____ City ST ZIP Code	_____ City ST ZIP Code

Medical Information

Hospital/Clinic Preference _____

Physician's Name _____ Phone Number (____)_____

Insurance Company _____ Policy Number (____)_____

Allergies/Special Health Considerations _____

_____

I authorize all medical and surgical treatment, X-ray, laboratory, anesthesia, and other medical and/or hospital procedures as may be performed or prescribed by the attending physician and/or paramedics for my child and waive my right to informed consent of treatment. This waiver applies only in the event that neither parent/guardian can be reached in the case of an emergency.

Parent's/Guardian's Signature _____ Date _____

NAME:

Directions to Your House

(This information will be available in the event you panic or freeze and forget your address when calling 911 or, to leave for a babysitter, nurse or relative watching your child at your house.)

_____

STREET ADDRESS

_____

CROSS STREETS

_____

PHONE NUMBER

DIRECTIONS: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

NAME:

Family Directory

Parent(s) or Guardian(s)

Name _____ Relationship _____

Address _____

City _____ State _____ Zip Code _____

Phone: Home (_____) _____ Cell (_____) _____ Work (_____) _____

Name _____ Relationship _____

Address _____

City _____ State _____ Zip Code _____

Phone: Home (_____) _____ Cell (_____) _____ Work (_____) _____

Other Non-Sibling Relatives

Name _____ Relationship _____

Address _____

City _____ State _____ Zip Code _____

Phone: Home (_____) _____ Cell (_____) _____ Work (_____) _____

Name _____ Relationship _____

Address _____

City _____ State _____ Zip Code _____

Phone: Home (_____) _____ Cell (_____) _____ Work (_____) _____

Name _____ Relationship _____

Address _____

City _____ State _____ Zip Code _____

Phone: Home (_____) _____ Cell (_____) _____ Work (_____) _____

NAME:

Family Directory (continued)

Siblings

Name ______________________ DOB__________ Gender: ☐ M ☐ F
Address ______________________________________
Phone: Home (_____) __________ Cell (_____) __________ Work (_____) __________

Name ______________________ DOB__________ Gender: ☐ M ☐ F
Address ______________________________________
Phone: Home (_____) __________ Cell (_____) __________ Work (_____) __________

Name ______________________ DOB__________ Gender: ☐ M ☐ F
Address ______________________________________
Phone: Home (_____) __________ Cell (_____) __________ Work (_____) __________

Name ______________________ DOB__________ Gender: ☐ M ☐ F
Address ______________________________________
Phone: Home (_____) __________ Cell (_____) __________ Work (_____) __________

Name ______________________ DOB__________ Gender: ☐ M ☐ F
Address ______________________________________
Phone: Home (_____) __________ Cell (_____) __________ Work (_____) __________

Name ______________________ DOB__________ Gender: ☐ M ☐ F
Address ______________________________________
Phone: Home (_____) __________ Cell (_____) __________ Work (_____) __________

NAME:

Family Medical History Form

Child's Name: First _____ M.I. _____ Last _____

Date of Birth _____/_____/_____ Gender ☐ M ☐ F Ethnicity _____

Current Physician(s): Name _____ Phone (_____)_____

Name _____ Phone (_____)_____

Please list the current status of your child's immediate family:

Grandparents Name(s)	Living/Deceased	Age (Now or at Death)	Comments or Cause of death

Parents Name(s)	Living/Deceased	Age (Now or at Death)	Comments or Cause of death

Siblings Name(s)	Living/Deceased	Age (Now or at Death)	Comments or Cause of death

NAME:

Family Medical History Form (continued)

Please indicate all known health conditions that apply to your child and members of their immediate family, including parents, grandparents and siblings, below:

Health Condition	Me	Age of onset/type	Family Member(s)	Age of onset/type
Alzheimer's				
Arthritis				
Asthma/Allergies				
Aneurysm				
Blood Clots				
Blood Disorders				
Cancer:				
Breast				
Colon				
Prostate				
Lung				
Other				
Diabetes				
Epilepsy/Seizures				
Eye Condition				
Heart Disease				
High Blood Pressure				
High Cholesterol				
Kidney Disease				
Lung Disease				
Osteoporosis				
Mental Disorders				
Smoking				
Stroke				
Thyroid Disorders				
Tuberculosis				
Other:				

NAME:

Section 3

Child's Medical History
Allergies
Growth Tracking Form
Dental Information
Vision Information
Medication Log
Hospitalizations, Surgeries, Medical Procedures
Lab Work, Diagnostic Tests
Activities of Daily Living
Daily Treatments
Durable Medical Equipment (DME)

NAME:

Child's Medical History

Child's Name: First _____ M.I. _____ Last _____

Nickname _____ Date of Birth _____/_____/_____ Gender ☐ M ☐ F

Child's Social Security: _____ - _____ - _____

Address _____

City _____ State _____ Zip Code _____

Diagnosis

Date	Physician	Diagnosis

Immunization Record

Enter the date the following immunizations are receieved in the boxes.

Hep B						
DtaP/Tdap						
Hib						
Polio						
PCV						
MMR						
Varicella						
Hep A						
MCV4						
TB Status						
Other						
Other						
Other						

NAME:

Allergies

(Medication, Food, Insects)

Allergy _____

Type of Reaction _____

Signs & Symptoms _____

Management (including antidote with dosage) _____

_____

Allergy _____

Type of Reaction _____

Signs & Symptoms _____

Management (including antidote with dosage) _____

_____

Allergy _____

Type of Reaction _____

Signs & Symptoms _____

Management (including antidote with dosage) _____

_____

Allergy _____

Type of Reaction _____

Signs & Symptoms _____

Management (including antidote with dosage) _____

_____

Allergy _____

Type of Reaction _____

Signs & Symptoms _____

Management (including antidote with dosage) _____

_____

NAME:

Growth Tracking Form

Age	Height	Weight	Checked By

NAME:

Dental Information

Dentist

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____ Contact Person _____

Show location of crowns, bridges or other major dental work done. Mark the diagram and give a brief description.

Description _____

_____

_____

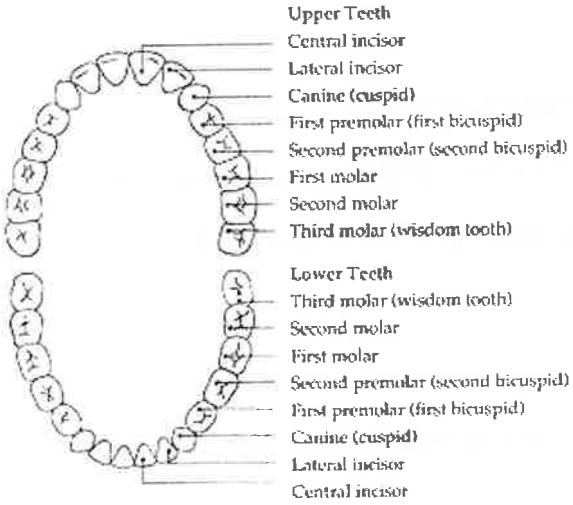
_____

_____

_____

_____

_____



Orthodontist or Oral Surgeon

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____ Contact Person _____

Braces ☐ Yes ☐ No Appliance Worn _____

Instructions _____

NAME:

Vision Information

Ophthalmologist/Optometrist

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____ Contact Person _____

Current Prescription _____

Contact Lenses Type _____

Daily Wear and Care Instructions: _____

_____

Date of Last Exam _____/_____/_____ Any Changes _____

Eyes Injuries _____ Date _____

_____ Date _____

Optical Store Name _____

Address: _____

Phone (_____) _____ Contact Person _____

NAME:

Medication Log

(Including supplies that don't require an Rx)

Medication (with Concentration) _____

Physician _____ RX # _____

Reason _____

Dosage & Route _____

Time Administered _____ Date Ordered _____ Date Discontinued _____

Medication (with Concentration) _____

Physician _____ RX # _____

Reason _____

Dosage & Route _____

Time Administered _____ Date Ordered _____ Date Discontinued _____

Medication (with Concentration) _____

Physician _____ RX # _____

Reason _____

Dosage & Route _____

Time Administered _____ Date Ordered _____ Date Discontinued _____

Medication (with Concentration) _____

Physician _____ RX # _____

Reason _____

Dosage & Route _____

Time Administered _____ Date Ordered _____ Date Discontinued _____

NAME:

Hospitalizations, Surgeries & Procedures

Date _____ Procedure _____

Admitting Physician _____ Surgeon _____

Hospital / Facility _____

Address _____

Phone Number (_____)_____ Date Discharged _____

Instructions_____

_____

_____

Date _____ Procedure _____

Admitting Physician _____ Surgeon _____

Hospital / Facility _____

Address _____

Phone Number (_____)_____ Date Discharged _____

Instructions_____

_____

_____

Date _____ Procedure _____

Admitting Physician _____ Surgeon _____

Hospital / Facility _____

Address _____

Phone Number (_____)_____ Date Discharged _____

Instructions_____

_____

_____

NAME:

Lab Work & Diagnostic Tests

Date	Physician	Test Results	Comments

NAME:

Activities of Daily Living

Use this page to talk about your child's abilities to care for himself/herself or the specific needs they have. Reference additional sheets if necessary.

Nutrition _____

_____

_____

Respiratory _____

_____

_____

Communication _____

_____

_____

Mobility _____

_____

_____

Sleep _____

_____

_____

Social/Play _____

_____

_____

Coping/Stress _____

_____

_____

Toileting & Personal Hygiene _____

_____

_____

NAME:

Daily Treatments

This page is designed to be an overview of daily care activities in the event parents are called away suddenly and a relative, nurse or aide is filling in. The idea behind this page is for parents to keep an updated daily schedule on file. You may consider creating a personalized regimen for each of these areas as applicable and filing your notes behind this page in the notebook.

Vital Signs _____

_____

_____

Respiratory _____

_____

_____

Trach _____

_____

_____

G-Tube _____

_____

_____

Bowel/Bladder Regimen _____

_____

_____

Adaptive Equipment _____

_____

_____

NAME:

Durable Medical Equipment ("DME") Or Supplies
(Including glasses, hearing aides, & items that requires Rx)

Equipment or Supply _____

Vendor _____

Contact Person _____

Address _____

Phone Number (_____) _____

Serial Number _____ Date Obtained _____

Repairs _____

Authorization No. _____

Current Settings / Dosage _____

Equipment or Supply _____

Vendor _____

Contact Person _____

Address _____

Phone Number (_____) _____

Serial Number _____ Date Obtained _____

Repairs _____

Authorization No. _____

Current Settings / Dosage _____

NAME:

Section 4

Checklist of Specialty Physicians

Health Care Providers Directory

School Information

Family Support & Local Resources

Contacts Log

NAME:

Specialty Physicians Check List

Check the box next to specialists included in your child's care.

- ☐ Anesthesiologists
- ☐ Dermatologists
- ☐ Endocrinologists
- ☐ Family Medicine
- ☐ Gastroenterologists
- ☐ Gynecologists
- ☐ Immunologists
- ☐ Internists
- ☐ Nutritionists
- ☐ Social Workers
- ☐ Other _____
- ☐ Other _____
- ☐ Other _____
- ☐ Neurosurgeons
- ☐ Oncologists
- ☐ Neurologists
- ☐ Ophthalmologists
- ☐ Orthopedists
- ☐ Otolaryngologists
- ☐ Pediatricians
- ☐ Podiatrists
- ☐ Psychiatrists
- ☐ Radiologists
- ☐ Urologists
- ☐ Other _____
- ☐ Other _____

NAME:

Health Care Provider Directory

Primary Care Provider/Physician (PCP)

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____ Emergency No. (_____) _____

Hospital(s) affiliated with _____

_____

Name of office personnel that were helpful _____

Primary Care Provider/Physician (PCP)

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____ Emergency No. (_____) _____

Hospital(s) affiliated with _____

_____

Name of office personnel that were helpful _____

NAME:

Health Care Provider Directory, continued

Specialists

Specialty ______________________________
Name ______________________________
Address ______________________________
City ______________ State ________ Zip Code ____________
Phone (_____) __________ Fax (_____) __________ Emergency No. (_____) __________
Hospital(s) affiliated with ______________________________
____
Name of office personnel that were helpful ______________________________

Specialty ______________________________
Name ______________________________
Address ______________________________
City ______________ State ________ Zip Code ____________
Phone (_____) __________ Fax (_____) __________ Emergency No. (_____) __________
Hospital(s) affiliated with ______________________________
____
Name of office personnel that were helpful ______________________________

Specialty ______________________________
Name ______________________________
Address ______________________________
City ______________ State ________ Zip Code ____________
Phone (_____) __________ Fax (_____) __________ Emergency No. (_____) __________
Hospital(s) affiliated with ______________________________
____
Name of office personnel that were helpful ______________________________

NAME:

Health Care Provider Directory, continued

Home Care Agency

Agency _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____ Emergency No. (_____) _____

Contact Person _____

Pharmacies

Local Pharmacy _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Contact Person _____

Mail Order Pharmacy _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Contact Person _____

Specialty Pharmacy (Compounding, Intravenous Medications, etc)

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Contact Person _____

NAME:

Health Care Provider Directory, continued

Therapists

Speech Therapist

School/Agency _____

Phone (_____) _____ Fax (_____) _____

Email Address _____

Physical Therapist

School/Agency _____

Phone (_____) _____ Fax (_____) _____

Email Address _____

Occupational Therapist

School/Agency _____

Phone (_____) _____ Fax (_____) _____

Email Address _____

Respiratory Therapist

School/Agency _____

Phone (_____) _____ Fax (_____) _____

Email Address _____

Other _____

School/Agency _____

Phone (_____) _____ Fax (_____) _____

Email Address _____

NAME:

School Information

School _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Key School Personnel

Principal _____

Phone (_____) _____ Ext. _____ Email Address _____

Principal's Secretary _____

Phone (_____) _____ Ext. _____ Email Address _____

Current Teacher _____

Phone (_____) _____ Ext. _____ Email Address _____

School Nurse _____

Phone (_____) _____ Ext. _____ Email Address _____

School Psychologist _____

Phone (_____) _____ Ext. _____ Email Address _____

Chairperson of CSE _____

Phone (_____) _____ Ext. _____ Email Address _____

Transportation / Bus # _____

Phone (_____) _____ Ext. _____ Email Address _____

NAME:

Family Support Information

Service Coordination/Case Management

Agency Name _____

Service Coordinator/Case Manager's Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Email Address _____

Respite Services

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Email Address _____ Contact Person _____

Parent to Parent of NYS

Regional Office _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Email Address _____ Contact Person _____

Website: www.parenttoparentnys.org

Support Group

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Email Address _____ Contact Person _____

NAME:

Family Support Information, continued

Child's Diagnosis Foundation

Agency Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Email Address _____ Contact Person _____

Advocacy Group

Agency Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Email Address _____ Contact Person _____

Religious/Church Affiliation

Agency Name _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

Email Address _____ Contact Person _____

NAME:

Contacts Log

Date	Contact	Reason	Result

NAME:

Section 5

Health Insurance

Financial Support

Out-of Pocket Expenses

NAME:

Health Insurance

Primary Insurance Carrier _____

Name of Plan _____

Subscriber (Name of Policy Holder) _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

ID# _____ Group # _____

Case Manager/Care Coordinator/Case Worker

Name: _____

Phone (_____) _____ Fax (_____) _____

E-Mail Address _____

Secondary Insurance Carrier _____

Name of Plan _____

Subscriber (Name of Policy Holder) _____

Address _____

City _____ State _____ Zip Code _____

Phone (_____) _____ Fax (_____) _____

ID# _____ Group # _____

Case Manager/Care Coordinator/Case Worker

Name: _____

Phone (_____) _____ Fax (_____) _____

E-Mail Address _____

NAME:

Financial Support

SSI – Supplemental Security Income

Contact Person _____

Phone Number (_____)_____ Email _____

Address _____

Website _____

Medicaid

Contact Person _____

Phone Number (_____)_____ Email _____

Address _____

Website _____

Care At Home/HCBS Waiver

Contact Person _____

Phone Number (_____)_____ Email _____

Address _____

Website _____

Physically Handicapped Children's Program ("PHCP")

Contact Person _____

Phone Number (_____)_____ Email _____

Address _____

Website _____

NAME:

Out-Of-Pocket Expenses

There may be opportunities for reimbursement through a Flex Plan or a medical deduction on income tax returns. Documentation of Out-of-Pocket Expenses might be needed to meet a Spend Down requirement. If records are kept throughout the year (i.e. mileage, parking, over the counter medications, medical supplies, etc.), the information will be readily available when needed. Consider adding a pocket folder behind this page to store receipts.

Date	Item / RX	Travel Expense	Out of Pocket Cost

NAME:

Section 6

Additional Health Care Notebook Links

About Parent to Parent of NYS

Parent to Parent of NYS Offices

NAME:

Links to Other Health Care Notebooks

http://www.medicalhomeportal.org/living-with-child/caring-for-children-withchronic-conditions/managing-and-coordinating-care/care-notebook
- Utah, includes a Spanish version

http://www.health.state.ri.us/family/disability/cc-notebook.php
- Rhode Island

http://cshcn.org/planning-record-keeping/care-notebook
- Seattle Children's Hospital

http://www.medicalhomeinfo.org/tools/CarePlans/CHMCC%20notebook.doc
- Ohio

http://www.ccids.umaine.edu/archive/maineworks/carenotebook.htm
- Maine

http://www.medicalhomeinfo.org/Tools/care_notebook.html
- American Academy of Pediatrics

Links to Other Health and Safety Info

Emergency Contact Sheet
http://kidshealth.org/parent/firstaid_safe/sheets/emergency_contact.html?tracking=P_RelatedArticle

When Your Child Needs Emergency Medical Services
http://www.aap.org/family/frk/EMSFRK.pdf

Power of the Parents, A Safety & Awareness Program
http://www.powerofparentsonline.com/

New York State Institute for Health Transition Training
www.healthytransitionsny.org

NAME:

Parent to Parent of NYS Overview

Parent to Parent of NYS is a statewide not for profit organization with a mission to support and connect families of individuals with special needs. We are a point of contact for many parents who are 'getting started' on their journey of parenting a child with developmental disabilities. There are 14 offices throughout NYS, staffed by Regional Coordinators, who are parents or close relatives of individuals with special needs. A website is maintained to provide information and events listings - **www.parenttoparentnys.org**

A Support Parent Network of over 1200 parents is the backbone of the ***Parent Matching Program.*** It has been created and is maintained by Parent to Parent Regional Coordinators. This is a model program used across the country to put parents in touch on a one to one basis with other parents who have a child with a chronic illness or disability. "Support Parents" are parents of individuals with special needs who have made the offer to speak one to one with "new" parents and share their experiences. Support parents are the key to this program. The organization recognizes the need for emotional support as well as the importance of parents knowing they are not alone.

When parents agree to be Support Parents, they are provided a skills building training, which includes an overview of how the program works, an understanding of the stages and emotions a parent or caregiver may be experiencing, as well as listening skills. New parents are welcome to join the Support Parent network and to share their experience.

In addition to the Parent Matching program, the organization fields telephone calls from parents of children with special needs who are looking for resources, services and information. Calls include parents looking for information about medical services and therapies and those looking for information specifically about an illness or disability. There are often questions about special education. All programs are based on the philosophy of parents helping each other, drawing on a network of parents helping parents. Coordinators are there to assist, but draw on other parents to help. There is no charge for services.

The Family to Family Health Care Information Center assists families with access to health care, health care recordkeeping and transition from pediatric to adult health care. Information about this program can be viewed at the website.

NAME:

Contact Parent to Parent of New York State...

ADIRONDACK
Clinton, Essex, Franklin & Hamilton Counties
P.O. Box 1296
Tupper Lake, NY 12986
1-866-727-6970, 518-359-3006
Fax 518-359-2151

CAPITAL REGION
Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren & Washington Counties
500 Balltown Road
Schenectady, NY 12304
1-800-305-8817,
518-381-4350
Fax 518-393-9607

FINGER LAKES
Livingston, Monroe, Ontario, Yates & Wayne Counties
The Advocacy Center
590 South Avenue
Averill Court
Rochester, NY 14620
1-800-650-4967, 585-546-1700 ext. 242; Fax 585-223-2481

HUDSON VALLEY
Orange, Rockland, Sullivan and Westchester Counties
WIHD / Cedarwood Hall
Valhalla, NY 10595
1-800-305-8816,
914-493-2635
Fax 914-493-8066

LONG ISLAND
Nassau and Suffolk Counties
415-A Oser Ave.
Hauppauge, NY 11788
1-800-559-1729, 631-434-6196
Fax 631-434-6151

NORTH CENTRAL NY—SYRACUSE
Cayuga, Cortland, Herkimer, Lewis, Madison, Oneida, Onondaga and Oswego Counties
Exceptional Family Resources
1820 Lemoyne Ave
Syracuse, NY 13208
1-800-305-8815,
315- 478-1462,x 322
Fax 315-478-1467

SEAWAY VALLEY
St. Lawrence & Jefferson Counties
PO Box 753
Canton, NY 13617
1-800-603-6778, 315-379-1538
(fax is the same)

SOUTH CENTRAL NY-ONEONTA
Broome, Chenango, Delaware, Otsego, Tioga, & Tompkins Counties
The Family Resource Network
46 Oneida Street
Oneonta, NY 13820
1-800-305-8814, 607-432-0001
Fax 607-432-5516

SOUTHERN TIER
Chemung, Schuyler, Steuben & Seneca Counties
P.O. Box 205, 210-12th St. #210
Watkins Glen, NY 14891
1-800-971-1588, 607-535-2802
(fax is the same)

TACONIC
Columbia, Dutchess, Greene, Putnam and Ulster Counties
26 Center Circle,
Bldg. 59, Rm. B46
Wassaic, NY 12592
1-877-725-4322
845-877-0654
(fax is the same)

WESTERN NY
Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans & Wyoming Counties
1200 East & West Road
Building 16, Room 1-131
West Seneca, New York 14224
1-800-305-8813, 716-517-3448
Fax 716-517-2385

NEW YORK CITY
Serving the Five Boroughs
75 Morton Street
New York, NY 10014
1-800-405-8818, 212-229-3188 or 212-741-5545, Fax 212-229-3146

STATEN ISLAND
c/o IBR, 1050 Forest Hill Road, #108
Staten Island, NY 10314
1-800-866-1068, 718-494-3462
Fax 718-494-0319

BUSINESS OFFICE
P.O. Box 1296
Tupper Lake, NY 12986
1-866-727-6970, 518-359-3006
Fax 518-359-2151

NAME:

RESEARCHING HEALTH CARE INFORMATION ON THE INTERNET

Research Tips

Where once healthcare information was hard to come by, today we can be buried by the volume of information turned up by a single internet search. Since anybody can put anything on the internet, it is very important to sift through the search engine results carefully. Here are some tips to help parents identify quality information to assist them in making good healthcare decisions.

Types of information

- Determine if you are looking for factual information, opinions, or both.
- Factual information should be able to be verified from a primary information source which should be provided by the author.
- If the information is an opinion it should be clearly stated as such and the author should identify what qualifications put him or her in the position to be offering this opinion.

Source of Information

- Determine who owns or sponsors the website and why they are providing the information.
    - Check the domain name for your first clue
        - Web addresses that end with .gov are government owned websites; those that end with .edu are owned by an educational institution; web addresses that end with .org are generally owned by a nonprofit organization
        - .com websites are commercially driven or for profit ventures. By eliminating the .com sites when beginning a search, it significantly narrows the search down to sites that are most likely to have evidence-based information.
    - Check the website's homepage
        - If it is not immediately apparent who is behind the website's existence, try scrolling down to see if there is contact information at the bottom of the page.
    - Check sections of the website such as "Contact Us" and "About Us"

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1-800-305- 8817 or 1-800-559-1729

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- Do not assume the website owner or sponsor is the author of the information on the website. Look for a byline or for author's information in the footer of the article or web page. You should be able to easily determine what makes the author qualified to provide the information.

- Uncover the author's purpose of providing the information Consider the difference in perspectives of an employee paid to write the information and, for example, a customer who writes an essay about their experiences with the company's product.

- Check to see if the author's contact information is provided.

Dated Information

- Verify that each page of the website indicates when the last update was performed

- Make sure the article includes the date it was published or last updated

- Evaluate if the information is current enough for the topic you are researching.

For Further Information

- *Online Source Credibility* www.unc.edu/~briman/berry/?flushAccelerator=true

- *A User's Guide to Finding and Evaluating Health Information on the Web* www.mlanet.org/resources/userguide.html

- *How to Find the Most Trustworthy Health Information Web Sites* http://www.canadian-health-network.ca/

- *Tips for Health Surfing Online* www.ihealthcoalition.org/content/tips.html

- Tutorials on Evaluating Online Information and Finding Health Information http://www.lib.unc.edu/instruct/tutorials.html

Healthcare Information on the Internet

MEDICAL PRESCRIPTION TIPS

Practical tips and questions to ask once a decision is made to prescribe a medication:

- Clarify the dose, the number of times taken daily and the name of the medication in case there is confusion on the part of the pharmacist or doctor.
- If a doctor is prescribing a 3-4 times a day medication ask if there is another prescription that is equally as effective but given only once or twice a day, thus reducing chance of forgetting to give medication;
- Indicate what type of medication is best for your child (i.e. if they cannot swallow pills request a liquid medication).
- The pharmacist will give you a print-out of side effects. Ask the doctor if there are any common or frequent side effects that you should keep an eye out for (i.e. some medications say to stay out of the sun or don't take with dairy products).
- Ask the pharmacist if there are special instructions for taking a prescription, e.g., avoid dairy for one hour, take at bedtime if a medication causes drowsiness, take before eating, etc.
- Ask if you should be taking something else with the medication (i.e. prednisone you should take calcium).
- Don't be afraid to ask the doctor for samples especially if it's a medication that you will be using for short-term use or if you are doing a trial.

Medical Prescription Tips for Parents and Caregivers

- Do not change the form of any medication without speaking to your pharmacist (i.e. some medications can crushed, chopped and mixed with juice). Always ask before altering a medication's form. Sustained release pills should not be crushed and some capsules should not be opened. Check with your pharmacist.
- If a medication tastes awful or if your child has many medications see about purchasing empty capsules and putting the medications into it so that your child won't have to taste them or swallow as many.
- Instead of leaving numerous prescription bottles on the counter of your kitchen designate a shelf in a cabinet. If there are a lot of prescription bottles, consider purchasing a three level spice rack.
- Color code bottles for each family member to make them easy to find.
- On your calendar write down the date to call a prescription and the prescription number so that you don't forget to renew it. This is critical with the 90 day mail away prescriptions since you have to wait to receive it. Some pharmacies have a monthly renewal reminder system. Inquire if your pharmacy can and will automatically renew prescriptions that are ongoing.
- If you are having difficulty with a pharmacy, request to have your insurance carrier intervene (if they are overseeing your prescription coverage).
- If your child is young and you are getting a medication in liquid form ask the doctor for extra to allow for spillage in case your child spits it out!
- Learn the brand and generic names and doses of medications your child is taking. This can help avoid prescription mistakes.
- If a refill prescription looks different than a previous supply, confirm with the pharmacist that the medication is indeed correct.

The information you will find in this Medical Notebook has been adapted from two primary sources:

1. Kid in a Book: Organizing your child's medical and educational Records Compiled by Down Syndrome Resource Center original material came from: Center for Children with Special Needs a Program of Children's Hospital & Regional Medical Center, Seattle, Washington

Extra Care Notebook pages may be downloaded and printed from http://www.cshcn.org

2. Health Care Notebook: Compiled by Parent to Parent of NYS Family to Family Health Care Information And Education Center

Other helpful information can be Downloaded from www.parenttoparentnys.org

The Advocacy Center is hopeful you will find this Medical Notebook beneficial to the family and child it supports. Many parents from the Advocacy Center came together to determine what information they found most helpful when advocating for their child's health needs and wanted to pass that information along to you. Please update often. We have included duplicate pages in the back of the binder.

YOUR CHOICES ■ YOUR ISSUES ■ YOUR RIGHTS

THE ADVOCACY CENTER
Putting People First