Health Care Notebook

For

_____

Compiled by

Family to Family Health Care
Information and Education Center

Table of Contents

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.

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, etc., authorizations/approvals 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 is 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 after 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.

Section 2

Emergency Contact and Medical Information for a Child

Child's Name | Date of Birth | M F Sex

Parent's/Guardian's Name | Parent's/Guardian's Name

( ) Home Phone | ( ) Work Phone | ( ) Home Phone | ( ) Work Phone

Address | Address

City, ST ZIP Code | City, ST ZIP Code

Alternative Emergency Contacts

Primary Emergency Contact | Secondary Emergency Contact

( ) Home Phone | ( ) Work Phone | ( ) Home 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

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**:** _____

Family Directory

Parent(s) or Guardian(s)

Name: _____Relationship _____

Address: _____

_____

Phone Home (___) _____Cell (___) _____ Work (___) _____

Name: _____Relationship _____

Address: _____

_____

Phone Home (___) _____Cell (___) _____ Work (___) _____

Other Non-Sibling Relatives

Name: _____Relationship _____

Address: _____

_____

Phone Home (___) _____Cell (___) _____ Work (___) _____

Name: _____Relationship _____

Address: _____

_____

Phone Home (___) _____Cell (___) _____ Work (___) _____

Name: _____Relationship _____

Address: _____

_____

Phone Home (___) _____Cell (___) _____ Work (___) _____

Name: _____Relationship _____

Address: _____

_____

Phone Home (___) _____Cell (___) _____ Work (___) _____

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 (___) _____

Family Medical History Form

Child's Name

First _____M.I._____ Last_____

Date of Birth_____Gender M__F__ Ethnicity_____

Current Physician(s) _____

_____

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 Names	Living/Deceased	Age (Now or at Death)	Comments Or Cause of Death

Siblings Names(s)	Living/Deceased	Age (Now or at Death)	Comments Or Cause of Death

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:				

Section 3

Childs Medical History

Child's Name: _____
(Last) (First) (Middle)

Nickname: _____

Date of Birth: ____/____/____ **Sex**: (check) ☐ Male ☐ Female

Child's Social Security Number: _____

Address: _____

_____

_____

Diagnosis

Date	Physician	Diagnosis

Immunization Record

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

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) _____

Growth Tracking Form

Age	Height	Weight	Checked By

Dental Information

Dentist

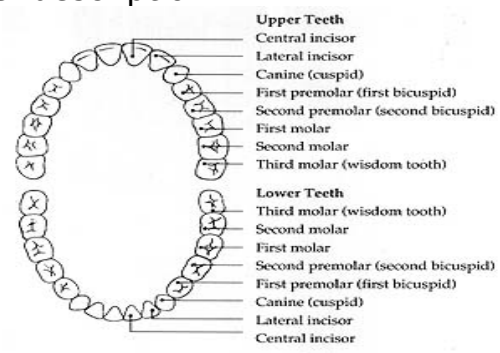
Name _____

Address _____

City _____ State _____Zip _____

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 _____

Phone _____Fax _____Contact Person _____

Braces Yes ____ No____ Appliance Worn _____

Instructions _____

Vision Information

Ophthalmologist/Optometrist

Name _____

Address _____

City _____ State _____Zip _____

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_____

Medication Log

(Including supplies that don't require an Rx)

Date Ordered	Physician	RX #	Reason
Date Discontinued	Medication with Concentration	Dosage & Route	Time Administered

Date Ordered	Physician	RX #	Reason
Date Discontinued	Medication with Concentration	Dosage & Route	Time Administered

Date Ordered	Physician	RX #	Reason
Date Discontinued	Medication with Concentration	Dosage & Route	Time Administered

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_____

_____

_____

Lab Work & Diagnostic Tests

Date	Physician	Test	Results	Comments

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

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:

("DME") DURABLE MEDICAL EQUIPMENT 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_____

Section 4

Specialty Physicians Check List

Highlight or place a √ checkmark to next to specialists included in your child's care.

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

HEALTH CARE PROVIDERS DIRECTORY

Primary Care Provider/Physician (PCP)

Name_____

Address_____

_____

Phone No. _____

Fax _____

Emergency No._____

Hospital(s) affiliated with: _____

_____

Name of office personnel that were helpful: _____

Primary Care Provider/Physician (PCP)

Name_____

Address_____

_____

Phone No. _____

Fax _____

Emergency No._____

Hospital(s) affiliated with: _____

_____

Name of office personnel that were helpful: _____

Specialists

Specialty_____

Name_____

Address_____

_____

Phone No. _____

Fax _____

Emergency No._____

Hospital(s) affiliated with: _____

_____

_____

Name of office personnel that were helpful: _____

Specialty_____

Name_____

Address_____

_____

Phone No. _____

Fax _____

Emergency No._____

Hospital(s) affiliated with: _____

_____

_____

Name of office personnel that were helpful: _____

Home Care Agency

Agency_____

Address_____

Phone No. _____

Fax _____

Emergency No._____

Contact Person: _____

Pharmacies

Local Pharmacy

Name_____

Address_____

Phone No. _____

Fax _____

Contact Person _____

Mail Order Pharmacy

Name_____

Address_____

Phone No. _____

Fax _____

Contact Person: _____

Specialty Pharmacy (Compounding, Intravenous Medications, etc)

Name_____

Address_____

Phone No. _____

Fax _____

Contact Person: _____

Therapists

Speech Therapist

School/Agency_____

Phone No. _____

E-Mail Address _____

Physical Therapist

School/Agency_____

Phone No. _____

E-Mail Address: _____

Occupational Therapist

School/Agency_____

Phone No. _____

E-Mail Address _____

Respiratory Therapist

School/Agency_____

Phone No. _____

E-Mail Address _____

Other

School/Agency_____

Phone No. _____

E-Mail Address _____

SCHOOL INFORMATION

School_____

Address_____

Telephone No._____

Fax Number_____

KEY SCHOOL PERSONNEL

Principal_____

Phone Number_____Ext._____ E-mail_____

Principal's Secretary_____

Phone Number_____Ext._____ E-mail_____

Current Teacher: _____Subject_____

Phone Number_____Ext._____ E-mail_____

School Nurse: _____

Phone Number_____Ext._____ E-mail_____

School Psychologist: _____

Phone Number_____Ext._____ E-mail_____ _____

Chairperson of CSE_____

Phone Number_____Ext._____ E-mail_____

Transportation / Bus #_____

Phone Number_____Ext._____ E-mail_____

FAMILY SUPPORT INFORMATION

Service Coordination/Case Management

Agency Name _____

Service Coordinator/Case Manager's Name _____

Address _____

Phone No. _____ Fax No. _____

E-mail Address _____

Respite Services

Name _____

Address _____

Phone No. _____ Fax No. _____

E-mail Address _____

Contact Person _____

Parent to Parent of NYS

Regional Office _____

Address _____

Phone No. _____ Fax No. _____

E-mail Address _____

Website: www.parenttoparentnys.org

Contact Person _____

Support Group

Name _____

Address _____

Phone No. _____ Fax No. _____

E-mail Address _____

Contact Person _____

Family Support Information (continued)

Child's Diagnosis Foundation

Agency Name_____

Address_____

Phone No._____Fax No._____

E-mail Address_____

Website_____

Contact Person_____

Advocacy Group

Agency Name_____

Address_____

Phone No._____

Fax No._____

E-mail Address_____

Contact Person_____

Religious/Church Affiliation

Name _____

Address _____

Phone No._____ Fax No._____

E-mail Address_____

Contact Person_____

Contacts Log

Date	Contact	Reason	Result

Section 5

HEALTH INSURANCE

Primary Insurance Carrier_____

Name of Plan_____

Subscriber (Name of Policy Holder) _____

Address_____

Telephone Number (___) _____ Fax (___) _____

ID#_____Group # _____

Case Manager/Care Coordinator/Case Worker

Name: _____

Phone Number (___) _____ Fax (___) _____

E-Mail Address_____

Secondary Insurance

Name of Plan_____

Subscribers (Name of Policy Holder) _____

Address_____

Telephone Number (___) _____ Fax (___) _____

ID# _____Group #_____

Case Manager/Care Coordinator/Case Worker

Name: _____

Phone Number (___) _____Fax (___) _____

E-Mail Address_____

Financial Support

SSI – Supplemental Security Income

Contact Person_____

Phone Number_____

Address_____

Phone Number_____

Website_____

MEDICAID

Contact Person_____

Phone Number_____

Address_____

Phone Number_____

Website_____

CARE AT HOME/HCBS WAIVER

Contact Person_____

Phone Number_____

Address_____

Phone Number_____

Website_____

Physically Handicapped Children's Program ("PHCP")

Contact Person_____

Phone Number_____

Address_____

Phone Number_____

Website_____

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

Section 6

REFERENCES TO OTHER

HEALTH CARE NOTEBOOKS

http://www.medicalhomeportal.org/living-with-child/caring-for-children-with-chronic-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 Concerns

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

Parent to Parent of NYS Overview and Listing of Offices

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.
http://www.parenttoparentnys.org/Family2Family/familytofamily.html

Contact Parent to Parent of NYS

ADIRONDACK
Clinton, Essex, Franklin & Hamilton
22 US Oval, Suite 116
Plattsburgh, NY 12903
1-866-790-2555, 518-324-5732
(fax is the same)

CAPITAL DISTRICT
Albany, Columbia, Fulton, Greene, 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 and 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
Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster and Westchester Counties
WIHD / Cedarwood Hall, Room 335
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
1065 James Street
Syracuse, NY 13203
1-800-305-8815, 315- 478-1462,x 322
Fax 315-478-1467

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

BRONX
c/o AHRC Blue Feather
228O Wallace Ave.
Bronx, NY 10467-9504
1-877-231-3694, 718-231-3614
Fax 718-231-3615

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

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, and 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 and 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)

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

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