# Health Care Notebook

## For

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Compiled by

Family to Family Health Care
Information and Education Center

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# Table of Contents

| | Page |
|---|---|
| Section 1 | 1 |
| • Introduction | 2 |
| • Quick Tips Before Getting Started | 3 |
| Section 2 | 4 |
| • Emergency Medical Contact Information Form | 5 |
| • Directions to Your House | 6 |
| • Family Directory | 7 |
| • Family Medical History | 9 |
| Section 3 | 11 |
| • Child's Medical History | 12 |
| • Medication Log | 17 |
| • Hospitalizations, Surgeries, Medical Procedures | 18 |
| • Lab Work, Diagnostic Tests | 19 |
| • Activities of Daily Living | 20 |
| • Daily Treatments | 21 |
| • Durable Medical Equipment (DME) | 22 |
| Section 4 | 23 |
| • Checklist of Specialty Physicians | 24 |
| • Health Care Providers Directory | 25 |
| • School Information | 29 |
| • Family Support & Local Resources | 30 |
| • Contacts Log | 32 |
| Section 5 | 33 |
| • Health Insurance | 34 |
| • Financial Support | 35 |
| • Out-of Pocket Expenses | 36 |
| Section 6 | 37 |
| • Additional Health Care Notebook Formats | 38 |
| • Additional Links | 38 |
| • About Parent to Parent of NYS | 39 |

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# 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.

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# Section 2

# Emergency Contact and Medical Information for a Child

| | | |
|---|---|---|
| Child's Name | Date of Birth | M F<br>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 |


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# 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: ____________________________________

______________________________________________

______________________________________________

______________________________________________

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NAME_________________________________________ DATE: ___________________________________

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# 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 (___) _____________


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# 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____________________________________________ DATE: ____________________________


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# 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 |
|---|---|---|---|
| | | | |
| | | | |
| | | | |

NAME_____________________________________ DATE: ________________________

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# 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: | | | | |
| | | | | |
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NAME_______________________________________________ DATE: ___________________________________

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# Section 3


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# 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 |
|---|---|---|
| | | |
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## Immunization Record

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

NAME________________________________________ DATE: ______________________________

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# <u>Allergies</u>

(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______________________________ DATE: ______________________________

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# Growth Tracking Form

| Age | Height | Weight | Checked By |
|---|---|---|---|
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NAME_____________________________________________ DATE: ____________________________________

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# Dental Information

## Dentist

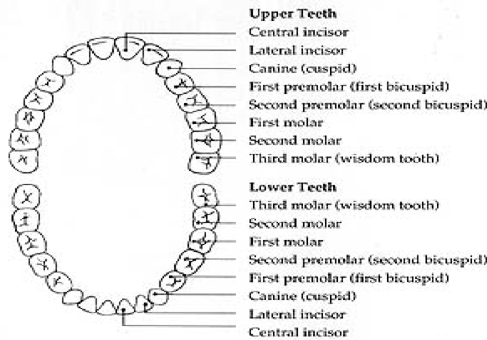
Name ______________________________________________________________

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 _________________________________________________________

NAME_________________________________________ DATE: ________________________

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# 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__________________

NAME__________________________________________ DATE: ____________________________

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# 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 |
| | | | |

NAME_______________________________________________ DATE: ____________________________________

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# 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_______________________________________________________________________

___________________________________________________________________________________

___________________________________________________________________________________

NAME______________________________________________ DATE: ___________________________________

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# Lab Work & Diagnostic Tests

| Date | Physician | Test | Results | Comments |
|---|---|---|---|---|
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NAME_____________________________________________ DATE: ____________________________________

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# 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_____________________________________________ DATE: ___________________________________

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# 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_____________________________________________ DATE: ___________________________________

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# ("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_____________________________________________

NAME_____________________________________ DATE: ________________________

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# Section 4


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# Specialty Physicians Check List

Highlight or place a √ checkmark 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)

NAME_______________________________________________ DATE: ____________________________________

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# HEALTH CARE PROVIDER 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: __________________________


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# HEALTH CARE PROVIDER DIRECTORY, continued

## 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: ______________________________

# HEALTH CARE PROVIDER DIRECTORY, continued

## 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: ______________________________________


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# HEALTH CARE PROVIDER DIRECTORY, continued

## 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 ______________________________________________

NAME_________________________________________ DATE: ________________________________

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# 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________________

NAME__________________________________ DATE: ______________________________

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# 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 ___________________________________________

NAME ______________________________ DATE: ______________________

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# 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____________________________________________


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# Contacts Log

| Date | Contact | Reason | Result |
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NAME_______________________________________________ DATE: ____________________________________

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# Section 5


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# 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______________________________________________

NAME_____________________________________________ DATE: ___________________________________

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# 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___________________________________________

NAME_____________________________ DATE: _______________________

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# 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** |
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NAME_____________________________________________ DATE: ____________________________________

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# Section 6


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# 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

NAME_____________________________________________ DATE: ____________________________________

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

***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***
***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***
***1-800-405-8818, 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***

***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***