

# Health Care Notebook

This notebook is for:

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

A publication of PARENT <sup>TO</sup> PARENT

OF NYS





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# Health Care Notebook

# 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, 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.

## Section 2

Emergency Medical Contact Information Form

Directions to Your House

Family Directory

Family Medical History

## Emergency Contact and Medical Information for a Child

Child's Name \_\_\_\_\_

Date of Birth \_\_\_\_\_ Sex ☐ M ☐ F

Parent's/Guardian's Name \_\_\_\_\_

Home Phone (\_\_\_\_\_) \_\_\_\_\_

Work Phone (\_\_\_\_\_) \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ ST \_\_\_\_\_ ZIP Code \_\_\_\_\_

Parent's/Guardian's Name \_\_\_\_\_

Home Phone (\_\_\_\_\_) \_\_\_\_\_

Work Phone (\_\_\_\_\_) \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ ST \_\_\_\_\_ ZIP Code \_\_\_\_\_

### Alternative Emergency Contacts

Primary Emergency Contact \_\_\_\_\_

Home Phone (\_\_\_\_\_) \_\_\_\_\_

Work Phone (\_\_\_\_\_) \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ ST \_\_\_\_\_ ZIP Code \_\_\_\_\_

Secondary Emergency Contact \_\_\_\_\_

Home Phone (\_\_\_\_\_) \_\_\_\_\_

Work Phone (\_\_\_\_\_) \_\_\_\_\_

Address \_\_\_\_\_

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 \_\_\_\_\_

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 (\_\_\_\_) \_\_\_\_\_

# 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 (\_\_\_\_) \_\_\_\_\_

# 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

# 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

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)

# 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 received in the boxes.

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) \_\_\_\_\_





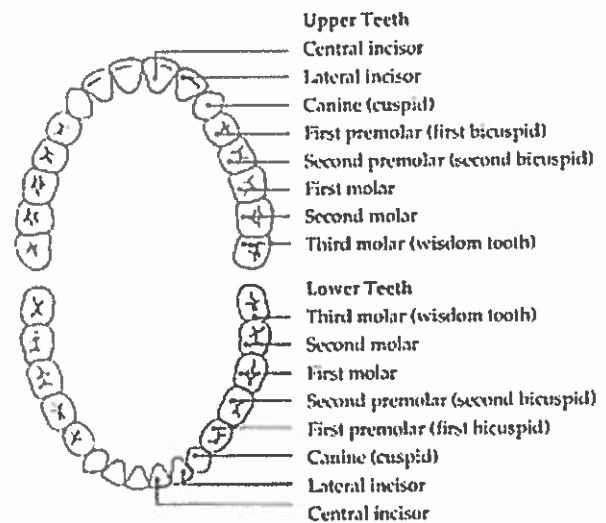
# Dental Information

## 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 \_\_\_\_\_

# 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 \_\_\_\_\_

# 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 \_\_\_\_\_

# 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 \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



# 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 \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## 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 \_\_\_\_\_



## Section 4

Checklist of Specialty Physicians

Health Care Providers Directory

School Information

Family Support & Local Resources

Contacts Log

## 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 \_\_\_\_\_

# 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 \_\_\_\_\_

# 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 \_\_\_\_\_

## 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** \_\_\_\_\_

# 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 \_\_\_\_\_

# 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** \_\_\_\_\_

# 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](http://www.parenttoparentnys.org)

## Support Group

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Phone (\_\_\_\_) \_\_\_\_\_ Fax (\_\_\_\_) \_\_\_\_\_

Email Address \_\_\_\_\_ Contact Person \_\_\_\_\_



## 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 \_\_\_\_\_



## Section 5

Health Insurance

Financial Support

Out-of Pocket Expenses

# 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 \_\_\_\_\_

# 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 \_\_\_\_\_

# 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

Additional Health Care Notebook Links

About Parent to Parent of NYS

Parent to Parent of NYS Offices

## ● 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](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](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](http://www.healthytransitionsny.org)



## 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](http://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.

# Offices of Parent to Parent of NYS

## **1. WESTERN AND FINGER LAKES**

### **WESTERN NY**

*Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans & Wyoming*  
**1200 East & West Road  
Building 16, Room 1-173  
West Seneca, New York  
14224**

**1-800-305-8813**

**716-517-3448**

**Fax 716-517-2385**

### **FINGER LAKES**

*Livingston, Monroe, Ontario, Yates and Wayne*  
**c/o FL DDRO Office  
2165 Brighton-Henrietta  
Townline Road,  
Room #124  
Rochester, NY 14623**

**Mail: 300 Hylan Drive  
PMB 153**

**Rochester, NY 14623**

**585-424-7211**

**(fax is same as phone)**

### **SOUTHERN TIER**

*Chemung, Schuyler, Steuben and Seneca*  
**P.O. Box 205, 210-12th St.  
#210**

**Watkins Glen, NY 14891**

**1-800-971-1588**

**607-535-2802**

**Fax is same as phone**

## **2. CENTRAL**

### **NORTH COUNTRY**

*Clinton, Essex, Franklin, Hamilton, Jefferson & St. Lawrence*

**P.O. Box 1296**

**Tupper Lake, NY 12986**

**1-866-727-6970,**

**518-359-3006**

**Fax 518-359-2151**

### **SOUTH CENTRAL NY**

*Broome, Chenango, Delaware, Otsego, Tioga, and Tompkins Counties*

**213 Tracy Creek Road**

**Vestal, NY 13850**

**607-786-9060 ext. 787**

**Fax 607-786-6483**

**(include a fax cover sheet)**

### **NORTH CENTRAL NY**

*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**

**(include a fax cover sheet)**

## **3. CAPITAL AND HUDSON**

### **CAPITAL & TACONIC**

*Albany, Columbia, Dutchess, Fulton, Greene, Montgomery, Putnam, Rensselaer, Saratoga, Schenectady, Schoharie, Ulster, Warren & Washington*

**500 Balltown Road**

**Schenectady, NY 12304**

**1-800-305-8817**

**518-381-4350**

**Fax 518-393-9607**

### **HUDSON VALLEY**

*Orange, Rockland, Sullivan and Westchester*

**WIHD / Cedarwood Hall**

**Valhalla, NY 10595**

**1-800-305-8816,**

**914-493-2635**

**Fax 914-493-8118**

**(include a fax cover sheet)**

## **4. NEW YORK CITY**

### **METRO NEW YORK**

*Manhattan, Queens, Kings, Bronx*

**75 Morton Street**

**New York, NY 10014**

**1-800-405-8818**

**212-741-5545**

**Fax 212-229-3146**

### **STATEN ISLAND**

*Richmond*

**c/o IBR, 1050 Forest Hill  
Road, #108**

**Staten Island, NY 10314**

**1-800-866-1068**

**718-494-3462**

**Fax 718-494-0319**

## **5. LONG ISLAND**

*Nassau and Suffolk Counties*

**415-A Oser Ave.**

**Hauppauge, NY 11788**

**1-800-559-1729,**

**631-434-6196**

**Fax 631-434-6151**

### **BUSINESS OFFICE**

**P.O. Box 1296**

**Tupper Lake, NY 12986**

**518-359-3006**

**Fax 518-359-2151**



[www.ptopnys.org](http://www.ptopnys.org)



[info@ptopnys.org](mailto:info@ptopnys.org)



[facebook.com/parenttoparentnys](https://facebook.com/parenttoparentnys)



[@PtoPofnys](https://twitter.com/PtoPofnys)