



# Using a Health Care Notebook

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Rochester Regional Center for Autism Spectrum Disorder  
Strong Center for Developmental Disabilities

MEDICINE *of* THE HIGHEST ORDER



# Rochester Regional Center for Autism Spectrum Disorder (RRCASD)

Provides Community Education and Technical Assistance to increase knowledge of ASD and available regional resources

Strives to enhance community resources through new activities and product development:

- Information & Referral
- Webinar Series
- Newsletters
- Information Sheets on ASD-related topic
- Community Presentations & Events
- Parent/Guardian & Professional Development Programs



# House Keeping

To reduce background noise during the webinar, please put yourself on 'mute' through your phone or computer.

Please feel free to type any questions into the 'chat' box on your screen. We will review/answer questions during the Q & A at the end of the webinar.

# HEALTH CARE NOTEBOOK

**Jacqui Liebman**  
**Regional Coordinator**  
**Parent to Parent of NYS**





## ***My reasons for being involved with Parent to Parent of NYS***

My children...  
...our personal  
experiences...



# ***Parent to Parent of NYS is:***

- A parent-driven not for profit that connects and supports families of individuals with special needs.
- Funded by OPWDD (Office for People with Developmental Disabilities) and Maternal Child Health Bureau.
- Regionally-based with offices across the state that cover every county and the 5 boroughs.
- A network of 1,200 trained volunteer support parents.
- Affiliated with Parent to Parent USA.


# ***Parent to Parent of NYS***

- Matches parents, based on their request, with a trained support parent.
- Provides information & referral services to assist families in locating services and in navigating complex service systems.

# ***Additionally we...***

- Provide a variety of trainings, in person and by webinar, on topics including:
  - Preventing Parent Burnout
  - Understanding Services Administered by the Office for People with Developmental Disabilities (OPWDD)
  - Understanding Medicaid Service Coordination (MSC)
  - Autism Insurance Reform
  - Organizing Educational Records
  - Effective Communication
  - Health Care Transition
- For more information:
  - Visit our website, [www.parenttoparentnys.org](http://www.parenttoparentnys.org)
  - Follow us on Facebook and Twitter





Like everyone else who works for Parent to Parent of NYS, I am the parent of a child with special needs, not a professional. This webinar is offered for informational purposes. Parents should consult with professionals to determine what is best for their specific situation as necessary.

# ***Children and Youth with Special Health Care Needs***

According to Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA) and the Maternal and Child Health Bureau (MCHB):

- ❖ Children and youth with special health care needs (CYSHCN) are “*those who **have** or **are at increased risk** for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*”



# ***Section 1: INTRODUCTION***

- The goal of a Health Care Notebook is to provide a central location for important information regarding your child's special health care needs
- It is an organizational tool for families
- Serves as:
  - Medical History
  - Emergency Guide
  - Reference Book
  - Resource Guide



# ***Other Benefits of HCN:***

- Allows for easy access to important medical information
- Saves time
- Less stress
- Information is portable during an emergency
- Information is portable for doctors appointments or meetings
- Positions yourself for advocacy



# ***Section 2: THE BASICS***

Forms include:

- Child's Emergency Contacts and Medical Information Form\*
- Family Directory
- Family Medical History





# Section 2: THE BASICS

- Directions to Your House

## 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:

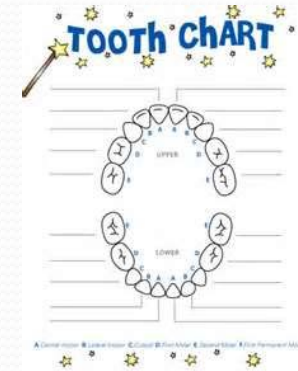


Why would we have this?

# Section 3: CHILD'S MEDICAL HISTORY

Forms include:

- Diagnosis/Diagnoses
- Immunizations
- Growth Tracking
- Allergies
- Dental
- Vision
- Medication Log



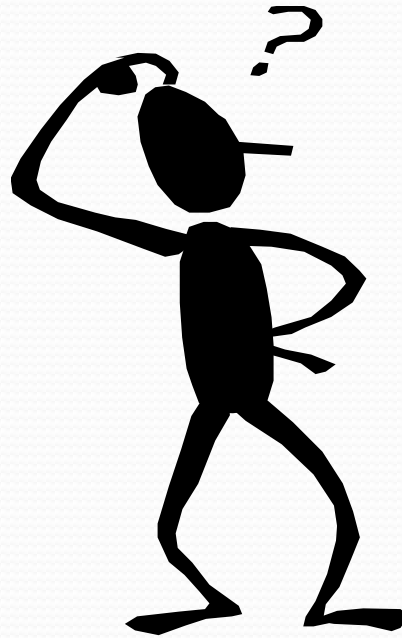
# ***Section 3: CHILD'S MEDICAL HISTORY***

Forms include:

- Hospitalizations
- Surgeries
- Lab & Diagnostic Tests
- Activities of Daily Living
- Daily Treatments
- Durable Medical Equipment & Supplies



# *Questions?*



# Section 4: CONTACTS

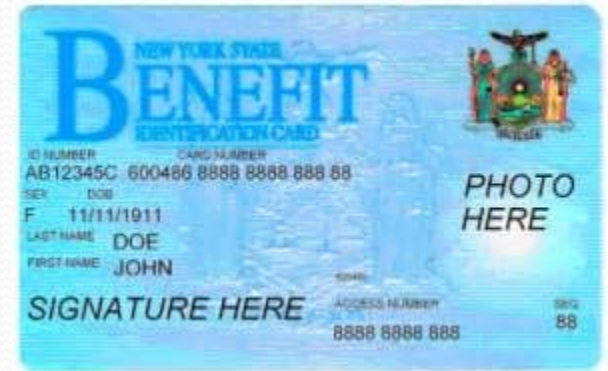
Forms include:

- Checklist of Specialists
- Health Care Provider Directory
  - Including therapists
- School Information
  - Including nurse, teacher(s), administration
- Family Support & Local Resources
  - Including MSC, Parent to Parent of NYS
- Contact Logs





# Section 5: FINANCES

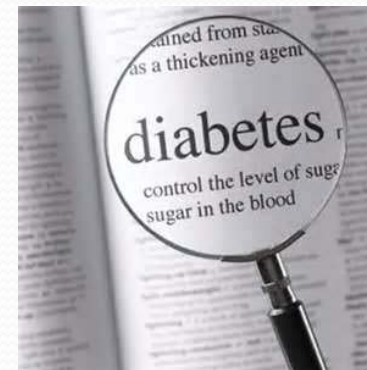
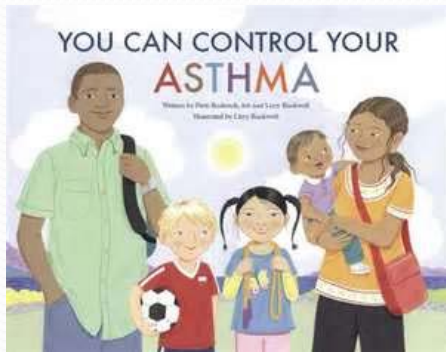


- Health Insurance
- Financial Support
- Out-of-Pocket Expenses



# Section 6: LINKS

- Links to other HCN formats
- Links for other health & safety concerns
- Parent to Parent of NYS Overview
- Parent to Parent of NYS Regional Listings & Contact Information



# ***THINGS TO CONSIDER***

- Instructions for caregivers/babysitters
- List of things/activities your child can do
- Notes
- Transition Planning
- Education



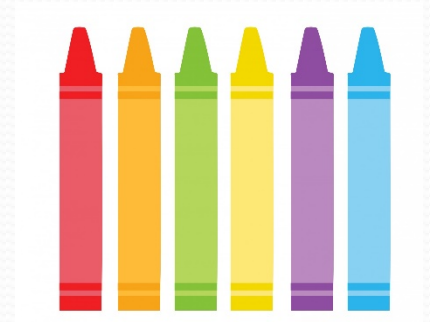
# ***HOW TO START?***

- Hunt and Gather
- Fill in sheets
- ***LOCATION, LOCATION, LOCATION***
- Personalize
- UPDATE often



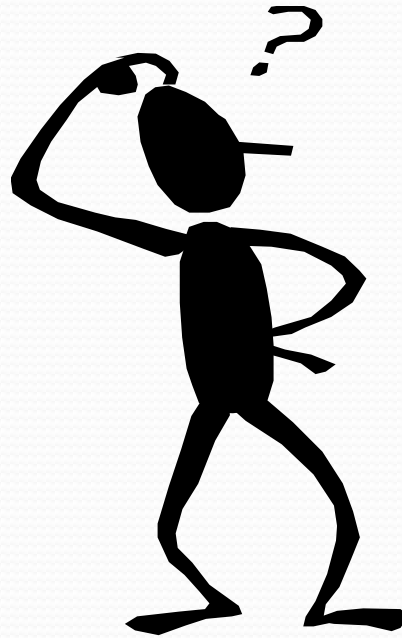
# TIPS

- Personalize
  - Include photo
  - Let child decorate
- Agenda/Questions
- NO SHORTHAND





# *Questions?*





# ***PARENT TO PARENT OF NYS***

Website: [www.ptopnys.org](http://www.ptopnys.org)  
1-800-305-8817

Family to Family Health Information Center

Lin Perry, Project Director (Upstate)  
[lperry@ptopnys.org](mailto:lperry@ptopnys.org)  
(607) 240-4573

Jacqui Liebman, Finger Lakes Regional Coordinator  
[jliebman@ptopnys.org](mailto:jliebman@ptopnys.org)  
(585) 424-7211



Thank you for participating  
in today's webinar!

# Resources

## Rochester Regional Center for Autism Spectrum Disorder (RRCASD)

- Educational resources, webinars, Information & Referral services.
- Contact information:

Website: [www.golisano.urmc.edu/rrcasd-nyautism](http://www.golisano.urmc.edu/rrcasd-nyautism)

Email: [rrcasd@urmc.rochester.edu](mailto:rrcasd@urmc.rochester.edu)

Telephone: (855)508-8485

## Autism Speaks - Website: [www.autismspeaks.org](http://www.autismspeaks.org)

- This site contains various toolkits and guides for home, school, work, safety, health/medical, etc.

# 2016-2017 RRCASD Webinar Series

Anxiety in Autism Spectrum Disorders

**November 16, 1:00 - 2:30 p.m.**

Suzannah Iadarola, Ph.D., BCBA-D, URM

Registration Period: October 26 - November 9





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ROCHESTER  
MEDICAL CENTER

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