Contact
PARENT TO PARENT OF NY STATE

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<thead>
<tr>
<th>Location</th>
<th>Phone 1</th>
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<tr>
<td>Business Office</td>
<td>518-359-3006</td>
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<tr>
<td>Capital Region &amp; Taconic</td>
<td>518-381-4350</td>
<td>800-305-8817</td>
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<td>Finger Lakes</td>
<td>585-424-7211</td>
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<td>Hudson Valley</td>
<td>914-493-2635</td>
<td>800-305-8816</td>
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<tr>
<td>Long Island</td>
<td>631-434-6196</td>
<td>800-559-1729</td>
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<tr>
<td>New York City</td>
<td>646-766-3460</td>
<td>800-405-8818</td>
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<tr>
<td>South Central NY</td>
<td>607-770-0211, ext. 787 or 891</td>
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<td>North Country</td>
<td>518-359-3006</td>
<td>866-727-6970</td>
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<td>North Central NY</td>
<td>315-478-1462, ext. 322</td>
<td>800-305-8815</td>
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<td>Staten Island</td>
<td>718-494-3462</td>
<td>800-866-1068</td>
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<tr>
<td>Southern Tier</td>
<td>607-535-2802</td>
<td>800-971-1588</td>
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<td>Western NY</td>
<td>716-517-3448</td>
<td>800-305-8813</td>
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Advocating Through Letter Writing

Letters...we get letters...we get stacks and stacks of letters

PARENT TO PARENT OF NYS:
Family to Family Health Information Center (F2F HIC)

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PARENT TO PARENT OF NY STATE is a not-for-profit organization with a mission to support and connect parents of individuals with special needs. Parents supporting parents is what this organization is about. We have walked it and lived it, and now we are sharing it. Nothing can replace the experience and knowledge that parents can share with each other.

Parents of children with special needs must learn what seems like a new language when they communicate with health care professionals, insurance agencies, equipment manufacturers, and schools. It is more than we ever expected we would need to know as parents.

When there is a crisis and a need for change, or when we are angry, writing letters can be an important coping skill.

Accessing health care and education for family members requires a certain amount of research and information gathering. Once important information is gathered, caregivers must learn to advocate and communicate with multiple systems. We hope this booklet will help you acquire those necessary skills.

Michele Juda
Executive Director
Parent to Parent of NYS

Resources:
PARENT TO PARENT OF NY STATE — http://www.parenttoparentnys.org

SpecialEdAdvocate.org: Advocating for Your Child — http://specialedadvocate.org/category/advocating-for-your-child/

Wrightslaw: Special Education Advocacy — http://www.wrightslaw.com/info/advo.index.htm

The Listen-Up Web (no longer being updated) — http://www.listen-up.org/haid/haidfund2.htm


FAMILY VOICES — http://www.familyvoices.org/


Kids As Self Advocates (a Family Voices project) — http://www.fvkasa.org/
Educate yourself...(cont’d)
- Before you see the doctor, therapist, or teacher, write down your questions and comments, and always have them handy.
- Create a brief description of your child. Keep it handy.
- Read that brief description of your child aloud at the beginning of every meeting. It will keep you focused and keep the group from wandering off on other questions and concerns.
- Be brief. No one likes a long and drawn-out meeting.
- Redirect folks to the topic.
- Be polite and be informative.

And always remember the one, most important step in advocacy...

Write it Down and Keep a Copy

√Advocating Through Letter Writing

There are many times we are asked, “Put your request in writing.” The bank, your elected official, a credit card company, a boss, a fellow employee, or a local handyman have all asked customers and consumers to “Put that in writing, please.”

For parents of children with disabilities, there are even more reasons to “Put that in writing, please.” We are often requesting information from insurers and from doctors. We request Family Support money in writing, or information from nutritionists or specialists. We might be providing documentation about our child’s disability to strangers.

A request for a meeting with a teacher, a change in your child’s program, an adjustment to your child’s testing schedules — each may require a letter. And not all of us are comfortable writing a letter for these requests — it can be intimidating and time consuming.

In the following few pages you will find some hints, suggestions, or models to use when you are writing your next letter. We hope this booklet helps you to feel confident and to improve your letter-writing skills.
Letter writing can accomplish several things...

- You can help people who aren’t doctors or nurses understand your child’s needs.
- You can organize your aims and goals for your child’s treatment.
- You can provide action steps for those that will implement your child’s IEP (Individualized Education Program).
- You can document an incident.
- You will have a written record of your requests in case someone misplaces or loses your letter.
- You can describe the laws and regulations that apply to your request.
- You can present your hopes and dreams for your child in a clear and concise way, so that everyone understands your wishes.

*Always keep this in mind: You are your child’s first and best teacher and advocate.*

Research supports the role of involved parents, and the IDEA (Individuals with Disabilities Education Act) requires your input and full participation.

**Remember:**
*Write it Down and Keep a Copy.*

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**Know your rights...**

- Talk to the patient advocate at the hospital.
- Ask to speak with the social worker at the hospital or agency.
- Find out about your insurance coverage.
- Ask about lifetime caps on services or prescriptions. Does your insurer pay for equipment or only for medical services?
- Reach out to your local Parent Training and Information Center (PTIC).
- Read the patient’s bill of rights.
- Learn about the IDEA (Individuals with Disabilities Education Act).

**Educate yourself...**

- Ask questions of everyone. There are no stupid questions, just unanswered ones.
- Ask peoples’ names and phone numbers.
- Ask about local elected representatives. Where is the closest office to you? Do the representatives serve on any education or insurance or health committees?
- Go to community meetings and hearings — at schools, hospitals, government agencies, community colleges, or local organizations.
- Get to know people and they will get to know you.

**Remember:**
*Write it Down and Keep a Copy.*
*Keep to the point...*
√ Tips on Advocating for Your Child with Special Health Care Needs

Organize your records...
- It doesn't have to be fancy. Get a box, a three-ring binder, or a journal.
- Keep everything in one place. Keep the box, binder, or journal under the kitchen table.
- Put a desk or table by the telephone.
- Clear out a shelf by the computer.
- Put up a big calendar by the phone and note the day you spoke to the doctor or the therapist or teacher. Get an expanding file folder with alphabetic tabs.
- Do what you feel comfortable with...don't worry about anyone else's system.
- Keep all of your medical/insurance records in one place, and keep all of your education-related information in one place. You will have a chronologically organized source of information about your child that you can go to quickly and with confidence.

Hunt and gather...
- Be on the lookout for pertinent newspaper articles and magazines.
- Ask the librarian questions. Librarians are a good source of a wealth of information about community resources.
- Ask your friends and family to be your eyes and ears when they are in the schools or out in the neighborhood.
- Research using the Internet or the library if you aren’t connected.
- Read every letter or note that comes home to you from the hospital, the doctor, or the school.

√ Effective Letter Writing

Before you write that letter, ask yourself why you are writing. Are you requesting a medical appointment or a copy of your child’s medical records? Are you making an appointment with a specialist or a therapist? Do you need to talk to your child’s teacher?

Before starting a letter, jot down a few notes about your child. Refer to your child by name. Don’t use he, she, his, or hers; it can be confusing to the reader. Remember: The first letter you write is always a draft.

Everyone makes mistakes or forgets to include something. Read the letter aloud to yourself or to a friend. Ask your friend if they understand the points you make.

Most letters are too long. Don’t get bogged down in emotions or blame others. Remember that the reader needs facts and information about your child and the requests you are making. Stories are better told in person, in a face-to-face meeting where you can illustrate your points, not written into a letter.

Make your letter stand out; use colored paper and include a photograph of your child. Putting a face on an issue brings home the urgency and importance of your request.

Remember: Write it Down and Keep a Copy.
√ On The Phone

A phone call is one way to get started when you are advocating for your child. Before you call someone, write out a script with the most important points you need to make. Keep that script by the phone and refer back to it every time you call someone.

Keep in mind that the first person you will reach is usually a receptionist or secretary. You don’t have to tell them the whole story behind the reason for your call.

Ask when the person you need to speak with will be available. If you need to leave a message, spell your name and your child’s name for the receptionist or secretary.

Get names...get names...get names...

Ask for and record each contact person's telephone extension as necessary.

If the person you need to speak with is rushed or cannot spend time on the phone with you, ask to make a telephone appointment. If you make that telephone appointment, keep it.

Always, always, always have a pad and pencil handy before you make that call.

Keep your recent letters or notes close at hand so that you can refer to them when you are talking with a representative of the insurance company or the doctor’s assistant.

If you are calling a school, have your child’s IEP on hand. Use your child’s name when you are talking with the right person. The IEP will have student identification information on it. Use that identifier, usually a nine-digit number, whenever you call a school; this will prevent confusing your child with another in the classroom or program.

Patience is a virtue when you are communicating by telephone. There can be long waits; there also can be confusing links and other numbers to dial. Use that time to organize your thoughts or your papers.

Put the person on speaker phone if you are having trouble handling papers and holding the phone. Try to keep background noise to a minimum when you are on the phone; you don’t want to be standing next to an open window or close to the TV or radio.

Remember: Write it Down and Keep a Copy.