

Offices of Parent to Parent of NYS

Adirondack	518-324-5732	866-790-2555
Capital District	518-381-4350	800-305-8817
Finger Lakes	585-546-1700 ext 242	800-650-4967
Hudson Valley	914-493-2635	800-305-8816
Long Island	631-434-6196	800-559-1729
New York City	212-741-5545	800-405-8818
Oneonta area	607-432-0001	800-305-8814
Seaway Valley	315-379-1538	800-603-6778
Syracuse area	315-478-1462	800-305-8815
Staten Island	718-494-3469	800-866-1068
Taconic	845-877-6821 ext 3927	
Tupper Lake	518-359-3006	866-727-6970
Watkins Glen	607-535-2802	800-971-1588
Western NY	716-517-3448	800-305-8813

√ our website www.parenttoparentnys.org
 On-line training center
 Regional events
 Library

Advocating Through Letter Writing



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

*Parent to Parent of NYS - Family to Family Health Care
 Information and Education Center
www.parenttoparentnys.org*

Parent to Parent of NYS 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, lived it and 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 new languages when communicating with health care professionals, insurance agencies, equipment manufacturers and distributors. It is more than we ever expected we would need to know when we became parents.

When accessing health care for our children, there is another level of advocacy and information needed. Learning to advocate, learning to research and learning how to communicate with multiple systems are all skills we have had to acquire.

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Resources

<http://www.parenttoparentnys.org>

<http://www.nichy.org>

<http://www.ldadvocates.com/Requesting-Evaluation-Determination.html>

http://www.wrightslaw.com/advoc/articles/DR_AFT_Letters.html

<http://www.lasikinforcenter.net/Miscellaneous/Authorization%20for%20Release%20of%20Medical%20Records.htm>

<http://www.listen-up.org/haid/haidfund2.htm>

https://munsonhealthcare.patientcompass.com/hc/jsp/letter_b.html

<https://uic.patientcompass.com/hc/jsp/pgstep4.jsp>

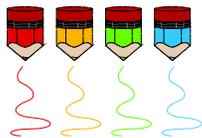
<http://www.patientcenters.com/hydrocephalus/news/insurance.html>

Keep to the point...

- Before you see the doctor, therapist or teacher, write down your questions and comments. Have the list 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 drawn out meeting.
- Redirect folks to the topic.
- Be polite and be informative.

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

For the parents of children with disabilities, there are even more reasons to “Put that in writing, please.” We are often requesting more information from insurers and from doctors. We request Family Support money in writing. We may be requesting 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, all 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 folks who 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 mislays 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 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 to keep copies of every thing you send

- 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.

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 Centers.
- Read the patients 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 your local representative. Where is the closest office to you? Does the representative serve on any education or insurance or health committees?
- Go to community meetings...at schools, hospitals, government, community colleges or community organizations.
- Get to know people and they will get to know you.

✓ 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, 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.
- 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 look out for pertinent newspaper articles and magazines.
- Ask the librarian questions. Librarians are a wealth of information about community resources.
- Ask your friends and family to be your eyes and ears when they are out in the neighborhood or schools.

✓ 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 requesting an appointment with a specialist or a therapist? Do you need to talk to your child's teacher?

Before you write that letter, jot down a few notes about your child. Refer to your child by name. Don't use he or she, 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 your point, or if the letter is too wordy.

Most letters are too long. Don't get bogged down in emotions and don't point fingers at, 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 when you are meeting people face to face and can illustrate your point; 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 to keep copies of every thing you send

✓ On The Phone



The telephone 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. Remember, the first person you will reach is usually a receptionist or secretary. You don't have to tell them the whole story behind your call. Ask when the person you need to speak with will be available.

Make sure you spell your name and your child's name to the receptionist or secretary if you are leaving a message.

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

Be sure and get telephone extensions if 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. Your child will not be confused with another child in the classroom or program.

Patience is a virtue when you are communicating by telephone. There can be long waits. There can be confusing links and numbers to touch 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 and keep background noises 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.