



## **“Advocate”**

Anyone who supports the cause of a person with disabilities or group of people with disabilities, especially in legal or administrative proceedings or public forums.

The parent of a child with neuro-immune disease may need to strongly advocate for an “Other Health Impaired” (OHI) determination with the school, which qualifies the student for full Special Education Services.

## **Federal Definition of “Other Health Impaired” (OHI)**

Having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to:

- 1) Chronic or acute health problems such as, Asthma, Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder, Diabetes, Epilepsy, A Heart Condition, Hemophilia, Lead Poisoning, Leukemia, Nephritis, Rheumatic Fever and Sickle Cell Anemia and
- 2) Adversely affects a child’s educational performance.

### **PLEASE NOTE**

This federal definition does NOT provide an “all inclusive” listing of conditions that qualify for these services.

Your child diagnosed with a neuro-immune disease falls into the category of “Other Health Impaired” (OHI). Armed with a Dr.’s diagnosis letter, knowledge of special education terminology, the willingness to collaborate and effectively communicate with the school, parents can successfully advocate/obtain the educational services that best suit the needs of their child.

## **Final Encouragement for Parents**

Become your child’s advocate. This means represent them, explain their situation clearly, and when necessary, advocate for their rights with the medical community, school district, school personnel, and even friends and family.

Ultimately your child will be the beneficiary of your hard work.

Trust and believe your child; until others are better educated regarding neuro-immune disease you may be one of the only ones who do.

Assist your child in learning to cope with and accept the changes and losses that accompany chronic illness. Listen well, speak less.

Guard your child’s self-esteem. Emphasize the positive. Help them find the things they can do, to see themselves as valuable. Remind them of their own unique and special gifts and talents.

Strategize ways to keep your child as involved with their peers as possible. Be creative: explore safe online programs, instant messaging, SKYPE, arrange short home visits, a movie night, throw a theme party related to a place they would like to visit one day, etc., help them be as “normal” as possible!

Be aware of the impact of your child’s illness on siblings. Spend special time with them. Encourage them to express their feelings about their sibling’s limitations and how it affects their own lives.

Acknowledge your own losses and grief as you learn to deal with redefined goals and expectations for your child’s future. Remember, you are not alone.

Reach out and ask for help. If your child desires to do so, connect them with other children also living with chronic illness. The patient organizations listed in the resource section of this guide are a great place to begin for you both.

Keep a sense of humor. Laugh with one another. Watch silly movies, tell jokes, play jokes on one another. Be there for one another.

Lastly, always carry hope in your heart!

*Hope is like a road in the country;  
there was never a road,  
but when many people walk on it,  
the road comes into existence...*

— Lin Yutang

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# **A Parent Advocacy Guide**

*How to successfully obtain  
educational services  
for children with  
neuro-immune disease.*

This guide contains terminology and definitions of services required to provide children with neuro-immune disease the opportunity for a free and appropriate education under federal law. It clarifies resources available, from whom parents may obtain services and assistance, and offers a brief synopsis of how to collaborate successfully with the school.

*“The foundation of every state is the education of its youth.”*  
— Diogenes

## Terms and Definitions

### **(IDEA) Individuals with Disabilities Education Act:**

Federal law that assures due process rights, mandates, and affirms the right of all disabled children to a “free and appropriate public education” (FAPE) in the “least restrictive environment” (LRE) possible. The emphasis is on special education and related services designed to meet their unique needs and prepare these children for further education, employment, and independent living.

**(LRE) Least Restrictive Environment:** The educational setting in which a student with a disability can be most successful, with the least amount of modifications, while receiving a continuum of services as they are educated with non-disabled peers.

**Due Process:** Federal procedural safeguards that guarantees both parents rights and the rights of their child with a disability.

**Section 504:** Accommodation and modification plan that assures the student with a disability can access all aspects of the educational setting successfully. As a student gets older, the 504 should empower individuals with disabilities to maximize their future ability for employment, economic self-sufficiency, independence, and inclusion and integration into society.

**(IEP) Individualized Education Plan:** The educational plan developed by parents and school personnel that outlines current levels of educational performance, goals and objectives, and the exact amount of time the disabled child will spend participating in the general education program with non-disabled peers.

**(ITP) Individualized Transition Plan:** The interagency plan developed by parents, school personnel, and receiving agency that facilitates a student's transition from high school to post graduation educational, employment, and living settings. (Often begins at age 14 years)

### **State Special Education Advisory Commission:**

IDEA requires that each state have a Special Education Advisory Commission composed of educators, and parents. Contact your State Board of Education for contact information or access [www.iser.com/govt-resources.html](http://www.iser.com/govt-resources.html).

**(HHS) Home Hospital Services:** When a child's disability precludes success in the traditional school setting even with accommodations and modifications, the option of home hospital services (HHS) related to education may be sought. Federal law mandates that when needed, HHS must be provided by the local school district.

## “Advocacy in Action”

- 1) Obtain a diagnosis letter from your child's physician. Request that it include a clear explanation of extent of disability with specifics, including recommendations for accommodations, (ex: rest periods, limited days, lengthened test taking, no P.E., physical limitations, cognitive impairment, etc.), as well as anticipated length of duration of illness as it pertains to the school year.
- 2) Contact your State or County Special Education Advisory Commission. Arrange to meet with a parent advocate for assistance. Their support will prove to be an invaluable tool as you begin this process.
- 3) Establish a collaborative relationship with your school district's registered nurse (RN). Vitaly important, the RN will serve as a liaison between your child's medical and educational needs. Keep them informed of your child's medical needs and provide educational materials pertinent to their diagnosis.
- 4) Submit a written request to your child's school for an educational planning meeting.
- 5) Become well informed. Research the various links and resources contained within this guide to familiarize yourself with the terminology listed here.  
  
Clearly state in writing your expectations regarding your child's educational experience before the first educational planning meeting.  
  
Remember that educational plan services will be selected in accordance with the level of disability as stated by your child's physician. These services may range from a Section 504 for the mildly impaired student, an IEP for the moderately impaired student, to Home Hospital Services (HHS) placement for the severely impaired student.
- 6) Become a proactive partner with the school to ensure success in obtaining the best educational experience possible for your child. Keep comprehensive files/records of the following and bring them to each meeting:
  - a. Educational history, including copies of IEP's, report cards, progress reports, and assessment results.
  - b. Copies of records from any outside agencies you have worked with. (Tutoring facility, etc.)
  - c. Any medical information applicable to your child's ability to perform successfully in school, including changes in treatment protocols, medications, and activity levels, etc.
  - d. Copies of all correspondence related to your child's educational needs.
  - e. Always carry a positive attitude!

## Resources

<http://www.ed.gov/policy/spced>: US Dept. of Education

<http://www.iser.com/govt-resources.html>: Special Ed

<http://www.fape.org>: Families and Advocates Partnership for Education

<http://www.drnj.org/pdf/spedguide.pdf>: Advocacy Guide

<http://www.wrightslaw.com>: Special Ed. law

<http://www.taalliance.org>: Technical Assistance Alliance for Parent Centers

<http://www.iacfs/me.org>: International Association for CFS/ME

<http://www.wpinstitute.org>: Whittemore-Peterson Institute for Neuro-Immune Disease

<http://www.mefmaction.net>: International FM/ME Action

<http://www.ncf-net.org/patient/patient-education.htm>: CFIDS Educational Rights, Responsibilities

<http://www.cfids.org/youth.asp>: CFIDS Association youth site

<http://www.njcfsa.org>: New Jersey CFS Association

<http://www.offerutah.org>: Organization for Fatigue and Fibromyalgia Education and Research : “A Kid's Guide to Surviving and Succeeding in School”

<http://www.pandoranet.info/pediatricpennies.html>: Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy

<http://www.wicfs-me.org/kidspage>: Wisconsin Chronic Fatigue Syndrome Association

<http://www.fm-cfs.ca/Childrens-section.html>: FM-CFS Canada

<http://www.meao-cfs.on.ca/splash.shtml>: The ME Association of Ontario

<http://fmaware.org>: National Fibromyalgia Association

*The Complete IEP Guide: How to Advocate for Your Special Ed Child* By Attorney Lawrence M. Siegel

*Negotiating the Special Education Maze: A Guide for Parents and Teachers* By Winifred Anderson, Stephen Chitwood, Deidre Hayden

*A Parents Guide to CFIDS: How to Be an Advocate for your Child with Chronic Fatigue Immune Dysfunction Syndrome* By David S. Bell, Mary Z. Robinson, Jean Pollard, Tom Robinson, Bonnie Floyd

*TEACH-ME: A sourcebook for Teachers of Young People with ME/ CFS/FM* With Dr. David S. Bell, Dr. Bruce M. Carruthers and the TEACH-ME Task Force