

How to Advocate for Your Child

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A Father's Plea For Help

I need your help... My family has a severe history with HHT - My father died of a lung AVM and was officially diagnosed with HHT, my 34 year old sister was diagnosed with HHT and Amyloidosis and died of Amyloidosis, and my 51 year old sister and her son have been diagnosed with HHT as well. My son and I suffer from at least 1 severe nosebleed per day and both have SEVERE MIGRAINES. (Several have landed me in the emergency room)

My problem with my son is that he is in the 8th grade and he gets a nosebleed every single morning and sometimes 1 or 2 more per day. His main problem is that he gets severe migraines in school and has trouble concentrating and he has been getting in-school detention and after-school detention for not being able to complete his work in class. He has also gotten in trouble for running out of the classroom without permission when his nose has bled severely. (He has to hold his hands under his nose and go to the bathroom and clean up the blood from his clothes and face...) Several times I had to pick him up for migraines and blood on his clothing.

I had spoken with the school regarding this condition (HHT), to ask them to give him special permission to leave the classroom during a nosebleed and to allow him more time to complete his schoolwork if he has a migraine. They told me that if I can get a doctors note stating that if you have this condition that it can lead to migraines and loss of concentration that they can give him special permission to do so.

I think it is unfair that my child is getting punished for this condition in school. It is very frustrating for him and myself...

I don't know about you, but this boys' situation makes my blood boil! As if dealing with a bloody nose in school every day isn't bad enough, this school system is punishing him for it. So what can a parent do to help their child manage HHT and succeed in school?

HELPING YOUR CHILD SUCCEED IN SCHOOL

I went to the experts at the National School Nurses Association with this boy's situation and here is what I learned.

The American with Disabilities Act (ADA) is federal legislation designed to prevent discrimination based on a medical condition. Section 504 of ADA is a civil rights document guaranteeing a child's right to access their public education. Section 504 and Title II of the ADA are broad civil rights statutes designed to promote equal access to and participation in programs and services. The regulations implementing these laws require that students with disabilities receive benefits and services comparable to those given their nondisabled peers. Specifically, these laws make it illegal for schools to discriminate on the basis of disability. In this situation, the child does not have a special education need (which would be covered by IDEA of the ADA), he just has a condition that is affecting his access to his education and he needs the school to "accommodate" his condition.

Who is eligible for benefits under ADA Section 504?

Anyone who has a problem that affects their ability to receive a public education. The Section 504 regulations require that school systems receiving federal funds provide a free appropriate public education to children with disabilities in accordance with the Section 504 requirements regarding less restrictive setting, evaluation and placement, and procedural safeguards.

The definition is very broad in nature and includes anything (i.e., nosebleeds) that affects major life activities, including but not limited to, the ability to concentrate, learn, work, or communicate.

What accommodations can be made under ADA Section 504?

It is up to the parent to determine the specific accommodations needed for their child to access their public education. Making accommodations and modifications means changing the way things are usually done in order to take into account a child's disability-related needs. Examples of accommodations and modifications include modifying rules, policies or practices; removing architectural or communication barriers; or providing aids, services, or assistive technology. Using this example, a reasonable accommodation(s) might be to (1) let the child leave the classroom, without question or consequences, to deal with their nosebleed; and (2) allow the child additional time to complete classwork missed while dealing with the nosebleed.

What should a parent do if they have a child in a similar situation?

1. Research ADA Section 504 — Here are a few websites:
 - www.ada.gov/cguide.htm
 - www.wrightslaw.com/info/section504.ada.peer.htm
2. Realize that, although the American with Disabilities Act is a federal law, the recognition and implementation of Section 504 may vary from state to state or from one school district to another. Virginia, for instance, does not require a medical diagnosis to enact a 504 Plan.
3. Draft a letter to your school administrator requesting a 504 Plan meeting for your child. This letter should be handed to the administrator as you verbally request the 504 Plan meeting.
4. Contact patient / child advocacy organizations for guidance. Here are just a few.
 - www.patientadvocate.org
 - www.familiesusa.org

MANAGING YOUR CHILD'S HHT

If HHT runs in your family, regardless of your child's symptoms (or lack of), you need to:

- (1) contact an HHT Center pediatrician and get your child screened; and
- (2) attend the National Patient Conference in St. Louis, MO this October 22-24 where we will be presenting a Kids Track for the first time.

Dr. Andy White, Co-Director of the Washington University HHT Center, is one of the leading pediatricians specializing in HHT in North America and he and his team will be there to answer your questions.

In March 2008, the National School Nurses Association attended the "HHT Health Initiatives for the 21st Century" conference hosted by the Centers for Disease Control and Prevention (CDC). Through this meeting, a partnership was forged with the HHT Foundation and, in September 2008, a representative from the National School Nurses Association agreed to conduct a workshop at the HHT National Patient Conference in Chicago.

Our children are our future and the HHT Foundation truly appreciates the National School Nurses Association's willingness to join forces and make a difference in the lives of children affected by HHT.