

# Tips to Take to School!

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When I am out presenting educational programs in the bleeding disorder community, I often bring up the subject of Section 504/IEP plans as a resource for our children in school. The response is often mixed with anxiety. What are those? Who can get them? Should my child have one? Why haven't I heard about this? How can I possibly figure out how to make it happen?

My response is always - relax. These are good things, and they aren't as complicated as you think. Most parents have a successful journey with their child's school as they navigate establishing a plan for their child. But understanding why they exist and how they are executed can make all the difference. Based on my research, discussions with school personnel, medical teams and parents across the country, and also my own experiences having three children with bleeding disorders now in college and high school, I offer these tips on the matter of Section 504/IEP plans:

- 1. Understand the basic differences between Section 504 and IEP plans and evaluate if one or both are applicable for your child's situation.** Your child's rights to equal educational opportunities are protected under two Federal laws, Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA). A Section 504 plan is based on a physical or mental disability (bleeding disorders come under this) only. This plan looks at whether special accommodations are needed to allow full participation in school and related school activities by a student with a physical or mental disability. The IEP (Individualized Education Program) which addresses educational goals and outcomes, is looking at how your child is achieving in their learning and provides for special education and related services to reach specific, individualized educational goals developed by the team at school and the parents.
- 2. Gather your paperwork.** You will need medical documentation of your child's disability (bleeding disorder). Often times this can be a "travel letter" from your hematologist, but sometimes additional documentation, a letter specifying the need of a 504/IEP plan will be requested, or perhaps authorization for your child to have medications available at school.
- 3. Request an initial face to face meeting with all necessary school personnel.** Consider including the 504 coordinator assigned to your child, the school nurse, and all of your child's teachers. Also encourage your child to attend and speak. Your child will be the one at school everyday, not you. This also encourages independence and responsibility for their own medical care. The meeting is an important step in fostering good communication and understanding with the people your child will see on a regular basis.
- 4. Write down exactly what you are requesting for your child ahead of time and bring your notes to the meeting.** You are the parent and know your child's needs the best. Although plans may be modified along the way, the more you address in the initial plan the easier it is. Think through what would be needed if there is an injury, a longer bleeding event interrupting school work, and field trip needs. Your child may not call upon everything in the plan, but better to be prepared than have to figure out what to do in the middle of an active medical situation. Some accommodations I and other parents have requested for our children are:

Permission to carry a cell phone and use if needed.

A bathroom or nurse's pass that allows them to leave class without delay when needed.

Ensure all school personnel that come in contact with your child on a regular basis are informed about the plan and any other details you feel necessary (including substitute teachers).

Outline clear procedures for injuries/bleeds at school and be sure to provide appropriate contact information and state clearly when you want to be notified.

A second set of books to be issued to keep at home to avoid the physical stress of carrying heavy backpacks or bags to and from school.

Special testing accommodations when needed, allowing for breaks or rescheduling if medically necessary.

Assistance with any needs (medication transport, storage and administration for example) while away on school sanctioned field trips or other outside of school events.

Provision for medication storage and administration at school if needed.

Limitations or accommodations needed to participate in physical activities (PE class, extracurricular sport activities, etc.)

These are just some suggestions, your child may not need all or need additional accommodations that you have identified.

**5. Take time to communicate the what and why of the plan.** Remember, most school personnel will not be familiar with a bleeding disorder and how it affects a child's school experience. Look at this as an opportunity to educate the educators. Explain your child's bleeding disorder, medication needs, and why you are requesting these accommodations. Keep in mind this maybe scary to them, assure them that your child won't be bleeding all over the place everyday in their classroom!

**6. Keep reinforcing the focus of the plan - for your child to have a safe and quality educational experience.** Thank them for taking time to learn more about your child and for helping in the process.

**7. Make sure everything is documented and saved.** An email or note to a teacher recapping a phone conversation can be very helpful. Save emails and copies of all paperwork, make notes on phone conversations and verbal communications.

**8. Acknowledge your and your child's responsibilities to alleviate potential concerns.** Let the school know that you and your child understand these accommodations are to help in your child's education and not to be abused. State if they have any concerns about your child abusing privileges (bathroom breaks, cell phone, etc.) that you would like to be contacted directly (not your child during school avoiding potentially embarrassing or inappropriate confrontations). You in turn will set up for the three of you to discuss it further. Also assure them that every effort will be made by your child to keep schoolwork on track and communicate about make up plans when a medical situation is interferes. Tell them you will do your best to schedule any medical appointments outside of school time when possible.

In your meetings with the school remember to listen, and be assertive not aggressive. You are beginning a partnership with the school system striving for the best educational experience for your child.

**9. Call upon resources for help.** You are not the first parent starting a Section 504/IEP plan. Contact your medical team, Chapter, ask others in the community for help when needed. You can bring someone with you to your school meeting for support, and there are reliable resources on the internet for more information. Along with sites maintained by our local school district, here are a few that may be helpful:

National Hemophilia Foundation's Steps for Living  
<http://www.stepsforliving.hemophilia.org/next-step/school>

Hemophilia Federation of America  
<http://www.HemophiliaFed.org>

Center for Parent Information and Education Resources (US Dept. of Education)  
<http://www.parentcenterhub.org/resources/>

Many websites have printable materials on bleeding disorders and school accommodations you can distribute at the school as a resource. Website information, forms and print materials are often available in different languages, be sure to inquire if needed.

**10. I firmly believe all children with a bleeding disorder should have a Section 504 plan.** Even if your plan is just to make sure the school personnel are aware of your child's medical condition, to mandate access to the nurse and have a plan in place for a medical issue or emergency, it's worth it. A Section 504 plan assures a continuum of information exchange throughout your child's school experience providing important safety measures. The plan will follow them each school year, alerting the new teachers to the situation. It also reinforces your family's legal rights should there be a dispute in the future.

These tips are just a few thoughts that may help as your child goes through the school years. There is a wealth of information concerning Section 504/IEP plans available, along with information on related issues such as VPK, transitioning to college, and playing sports. My last bit of advice would be to educate yourself, ask questions and have a positive attitude working with your schools. The end result - a successful school experience for your child - will be worth it!

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