

BEING AN EFFECTIVE SCHOOL ADVOCATE FOR A CHILD WITH JUVENILE ARTHRITIS

Tips from Parents

- **Have a plan.** Obtain a 504 plan when your child starts school even if the disease is under control. Many states will not allow accommodations on state mandated tests unless a student has a plan in place.
- **Bring support to meetings.** Bring a family member or friend to meetings with school personnel for moral support and to take notes so you can focus your attention on the group discussion. You might consider inviting your child's doctor or nurse to a meeting if you need help explaining your child's medical condition. You may have to pay a fee, but it might be worth it in the long run.
- **Speak up.** Don't be afraid to ask questions or for more clarification on a particular issue during a meeting.
- **Be organized.** Keep a notebook or folder of written communication with the school, including printouts of emails, doctor's notes and other paperwork.
- **Meet promptly with your child's teacher.** Meet with the teacher or counselor before school starts, if possible. Discuss the disease, medications, and how to recognize if your child is having problems at school. Provide educational materials from the Arthritis Foundation and other credible sources.
- **Be persistent.** Keep following up with teachers and school personnel if accommodations are not being met. It may help if you can identify an administrator at school to be your internal champion.
- **Make your child a self-advocate.** Teach children to advocate for themselves. For example, help a young child feel comfortable asking a teacher if he/she may take a break.
- **Proceed with caution.** Consult credible sources, such as the Arthritis Foundation, federal and state departments of education websites, while searching for information on the Internet. There is a lot of misinformation online.
- **Have a support community.** Build a network of support within your family and the community. Connect with support groups (both online and face-to-face) so you can interact with parents of children living with arthritis and learn from their experiences.

Tips from School Personnel

- **Do your homework.** Educate yourself about the process and know your child's rights. Most schools have special education handbooks available at the school or online. Many school districts have special education and 504 coordinators. Wrightslaw (www.wrightslaw.com) as well as the Department of Education at the federal and state level are good resources.
- **Provide information.** Give teachers relevant information about your child's medical condition and any issues that can affect school performance. This may include personal information, from how the child is emotionally coping with health issues and social situations to what is going on at home, such as a death in the family or a divorce.
- **Take your time.** If you need a day or two to process the information given to you at a meeting, return the paperwork at a later date that is mutually agreeable.

- **Establish a routine form of communication.** One option is to include a notebook in the student's backpack so each teacher or specialist can document what happened during the day. Other options include emails, phone calls or face-to-face meetings on a weekly or monthly basis.
- **Follow the chain of command.** If a problem arises, follow the chain of command to solve it. Start with the teacher, move up to the principal, and then to the school district liaison. Give teachers two or three days to respond before going up the chain.
- **Be careful of your tone.** When emailing a teacher or administrator about a problem, be careful to avoid wording that could be misunderstood. It's easy to misread "tone" in email communications. (Definitely avoid using ALL CAPS, as it may seem like yelling.)
- **Get involved.** Joining the PTA/PTO or other school committees can give you an opportunity to educate parents and school personnel about juvenile arthritis.

Tips from Healthcare Professionals

- **Be prepared.** Educate yourself about 504 plans, and how they are implemented and monitored in your school district. As you develop your child's plan, think of worst case scenarios so your team can devise solutions in advance. If your child is old enough, he or she can create a list of potential issues and solutions. Planning ahead can help to eliminate stress that might occur when you need a fast turnaround for an accommodation.
- **Be proactive.** Schedule meetings as soon as school starts. In preparation for the meeting, develop a list of potential accommodations. Use Sample 504 Accommodations as a helpful starting point. Have additional leave behinds – brochures and fact sheets about juvenile arthritis, doctor's letters and communication forms.
- **Educate the educators.** Many people are unaware that children get arthritis. Address common myths and how arthritis can be an "invisible" disease. It can be very helpful to share copies of the Arthritis Foundation's Juvenile Arthritis: Teacher Guide brochure. You can order up to four free copies.
- **Work with your doctor.** You will need a doctor's letter about your child's medical condition and potential needs. Help your doctor by providing a list of the accommodations you think might be necessary.
- **Document everything.** Keep copies of written communication including letters and emails you have sent and received. Document verbal communication with a follow-up thank you email or note summarizing the discussion and keep a copy.
- **Encourage collaboration.** Ask questions rather than make demands. Be assertive but also collaborative. When discussing your child's needs, ask questions such as "How can we work together to solve this?" or "What have you found successful in similar situations in the past?" This approach encourages positive communication and a shared interest in your child's educational success. Be open and prepared to compromise.
- **Empower your child.** Know your child's strengths and ability to communicate with teachers about his or her needs. You can role-play to help your elementary or middle school student feel comfortable about speaking up. Help your young adult become a self-advocate as he or she prepares to live independently.