Epilepsy and School

School is a child's workplace; it is a place where your child spends a lot of time, learns many things, and challenges him or herself to grow. The adults at your child's school have accepted the serious responsibility of helping your child become the most informed, responsible person that he or she can be. School can also be a place that is frustrating to children who have difficulties in learning or getting along.

Some strategies are the same for most parents and children: Form a partnership with the teachers and administrators and help out when asked. Most schools have opportunities for parents to help, including going on field trips with the class; providing treats for holiday parties; sharing a special skill or talent; and attending Parent-Teacher Organization meetings. Watch for these opportunities and help out as much as you can. Schools have a difficult job. It is easier to ask for help with your child's issue if the people at school know you as a parent who helps the school.

Most schools pass out student handbooks at the beginning of the school year. Keep the student handbook available so that you can look up how important issues are handled in school policies. For example, most schools have policies on bullying; the student handbook will outline how the school prefers to deal with that. If you think your child is being bullied, you should contact the person listed in the student handbook to address bullying.

Here are some resources on bullying that you might find helpful:

- aacap.org/cs/Bullying.ResourceCenter
- stopbullying.gov/index.html
- nasponline.org/resources/bullying/index.aspx
- cdc.gov/violencePrevention/pub/understanding_bullying.html

Everybody benefits when they have information; keeping your child's school informed about your child's epilepsy is key. Set up a meeting with your child's teacher, the school nurse, the school counselor and all of the key people (bus driver, school aide, etc.) who will be interacting with your child. Create a folder with all the important information about your child's epilepsy, the seizure action plan, the medications and the doctors who are prescribing them. Include a picture of your child and your family to make it more personal. This can help the school understand your child better.

Children with special needs should get acquainted with all of the people at school who can be helpful, including the school nurse (if there is one), guidance counselor, school psychologist and principal. Learning the role of each of these people is important so that you can ask the right person for the kind of help you need. It is important for the school to know about your child's epilepsy. They should know what happens during a seizure and what to do when a seizure happens during school time.

The school should know what antiepileptic medications (AEDs) your child is taking, and when they are increased or decreased so they are more aware of side effects when a change in medication occurs. A seizure action plan (SAP) is an important document that every child with epilepsy should have at
Coaching your child on how to approach the people at school can be helpful. You can set up a role play by saying, “Now, let’s pretend you’re not feeling well at school. I will be (fill in name). Let’s practice asking me for help.” Sometimes, children are afraid to ask to leave class or are told that they shouldn’t ask. You can practice this situation, too. “Let’s practice asking (teacher’s name) to leave class.” The more you practice at home, the more confident your child will be in school.

If your child needs special accommodations, you can have an Individualized Education Program (IEP) written. (This process is described in detail in Section III of the epilepsy booklet.) Your child will participate in observations and testing in order to determine what needs to be in the IEP. At the end of this process, you will be asked to attend a meeting with the team that works with your child. A lot of information will be presented in a short time; the team will ask you to sign the program they have created for your child. Take some time to read the information and react to it. You can also ask to have an educational advocate attend the meeting with you and suggest what you can do as a next step. A Seizure Action Plan (SAP) for your child can be put into the IEP; the IEP can cover all aspects of your child’s school day.

School-based Interventions

Many children with epilepsy may need supportive services at school. Here is some information on how to go about getting needed services for your child. As a parent, you have the right to request a new IEP meeting if you feel your child’s educational needs are not being met. If you have concerns, talk to your child’s teacher and principal. They can help you decide if the IEP team should meet to discuss your child, your concerns and/or your child’s progress.

How to get an IEP for your child

If you have concerns about your child’s performance at school for either medical or behavioral issues, you can ask for a multi-factorial evaluation (MFE) to see how your child is doing. Your doctor also can send a letter asking
the school to evaluate the services provided for your child, and his or her needs. If a child is found eligible for special education, the IEP team has to develop a program that includes:

- Current test scores on the MFE
- How the child’s epilepsy is affecting his or her progress
- A set of annual learning goals that can be measured
- All the services (specialized instructions, special aids, special therapists, services and program modifications) that have to be provided for the child to make sure he or she is benefiting from the educational intervention
- A description of the reason why the child is not to be educated in the regular education school system

Some of the services that may be required to help a child with epilepsy to benefit from special education:

- Speech and language therapy
- Physical therapy
- Occupational therapy
- Transportation services
- Parent counseling and training
- School nurse services
- Behavioral intervention specialist
- Applied behavior analysis
- Reading intervention specialist

Supplementary aid and services:

- Dedicated aide
- Use of communication assistance devices, word processors
- Special seating in class
- Furniture that is tailored to the child’s physical needs
- Use of calculator
- Use of tape recorder
- Eyeglasses
- Use of hearing aid or device

Special accommodations for testing:

- Small group setting
- Extra time when taking tests
- Repeated directions

- Oral or written directions
- Small periodic breaks

Other important interventions that can be requested:

- Behavior intervention plan (BIP)
  For those students with behavioral and emotional disturbances that are affecting their learning
- Extended School Year (ESY) services
  For those students who, during summer vacation, may lose the skills they just learned
- Transportation Plan
  For those students who need transportation services
- Transition Services Plan
  For any student from 14 to 18 years old (if appropriate)

As a parent, you are a key part of the IEP team. Other members of the team include:

- One regular education teacher
- One special education teacher
- A representative from the school district who knows the district’s available resources
- Someone who can interpret results and instructional implications of the MFE results
- In some cases, the child
- If parents request, a parent advocate or others who have important knowledge about the child

Before the conference

- Evaluate all the information that you have about your child. Gather all the important evidence to make your point (notes from different providers, therapists, outside evaluations. You can ask your doctor to write a letter for this meeting.)
- Think about any important questions that you have. Make sure you understand the program; this will be easier if you write your questions before the meeting.
- Think about the big picture of your child’s strengths and needs. Are all your child’s needs addressed in the IEP? Do you have any specific concerns about the current educational program? Is there any evidence that something in the current plan is not working? As a parent, you have the right to request copies of all school
records that are related to your child.

• Make sure you have a copy of all the assessments before
the meeting, and be sure you understand what they
mean. If you don’t, request a meeting with the school or
your mental health provider to discuss any assessment
information.

• If you need any extra support you can always bring
someone with you to the IEP meeting (spouse, friend,
relative, educational or parent advocate). If English is
not your first language, you can request a translator or
bring someone that you trust with you to translate.

The IEP meeting is very important; it is your best
opportunity to share your view about the current
educational program and how it is helping your child.
Nobody else in the room will know your child better than
you; sharing information about how your child is at home,
after school and in other social situations will help the
school create the best plan for your child.

If there are parts of the program that you don’t agree with,
let the team know. Changes can be made if you are able to
explain your ideas and the reason. Although school staff
will want you to sign the IEP at the end of the meeting, you
do not have to. You can ask to take a copy home to review,
or ask someone who cannot be present at the meeting
what they think.

If you feel the teachers and other school staff are doing a
good job, let them know. Recognize the effort and reflect
on the impact that you are seeing in your child.

It may be helpful to ask your child’s physician and others
who know your child well if there are accommodations
that they would recommend. School personnel may
recommend things that they have experience using. If your
child needs a different accommodation, it may be helpful
to have others suggest it to you.

Some children with epilepsy might have problems with
learning at whatever school they are attending. Many
studies have shown that no matter how intelligent kids
are, epilepsy increases the risk of poor performance in
school. It may be for medical reasons (the severity of
epilepsy), or behavioral disorders since those tend to be
underdiagnosed and undertreated in this population.

Some of the behavioral problems that have been
associated with epilepsy have also been related to poor
performance in school. These include:

• Attention Deficit Hyperactivity Disorder (ADHD)
• Major depressive disorder (MDD)
• Anxiety disorders
• Autistic spectrum disorders (ASDs)

These problems can severely affect the way the child deals
with things – how much the child is interested in learning,
how engaged in his or her homework, and how well he or
she interacts socially with peers and school personnel.

If a child is taking many medications at the same time to
control epilepsy, he or she may have side effects that can
affect school performance. Problems with controlling
seizures may help determine which school your child
attends, and may keep him or her out of a mainstream
education.

Sometimes despite all your efforts and the school’s efforts,
you might feel that your child is being discriminated
against because of the epilepsy. There are some Epilepsy
Foundation resources to help parents of children with
epilepsy who have questions or concerns about these
issues: See epilepsylegal.org or call 1.800.332.1000.

Make use of advocacy resources. It is important to have a
good knowledge about epilepsy, your child’s medications,
and their side effects, but you don’t have to do all this
by yourself. There are good resources in the Epilepsy
Foundation’s compilation of materials for parents and
teachers at epilepsyclassroom.com

Resources for Schools

1. Epilepsy Foundation of America National school alert
program
   efwp.org/programs/ProgramsPSA.xml

   a. For educators
      epilepsyfoundation.org/livingwithepilepsy/
educators

   b. Forms for school nurses and parents
      epilepsyfoundation.org/livingwithepilepsy/
educators/socialissues/schoolnurseprogram/
2. Kids on the block
   kotb.com/

3. National epilepsy awareness month
   epilepsyfoundation.org/getinvolved/neam/index.cfm?gclid=CLG1pa_nibYCFYxaMgod4g0AIA

4. Folder about your child
   This resource was created by Epilepsy Foundation Florida, on all the important information that you should know about your child with epilepsy:
   epof.org/index.php/children-and-family-and-resources/resources-a-documents