Sending children with Brittle Bone Disease to School

Can my child with OI attend regular school?

Children with OI, all types, usually have normal to above-average intelligence, and typically participate in a regular curriculum. Instructional and physical environment modifications may be required for safety and to promote independence.

- Some children with OI benefit from assistive technology devices for energy conservation such as lightweight writing instruments, pencil grips and adaptive scissors.
- Teach all staff that children with OI are capable of functioning at grade level.
- Their small physical stature is not to be mistaken for immaturity.
- They must be treated the same as their peers.
- They should be held accountable to all school rules and standards of behavior.

What types of accommodations are required by the law?

Federal education laws, the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 ensure appropriate test access and modifications for people with disabilities. Accommodations for classroom instruction and/or test modifications may include an extra set of books for home, additional time to travel between classrooms, preferential seating, or a special chair or desk arrangement. These accommodations may be included in a written plan: either an Individual Education Plan (IEP) or a 504 Plan. Contact your state education department and your school system office of special needs for details about local laws. Parent to Parent Information Centers also provide information about the differences between an IEP and a 504 Plan.

How can I make starting school easier?

Before the first day of school, you and your child should meet with all staff who will work with your child. This allows you to familiarize the staff with your child’s individual strengths and needs and helps your child feel comfortable in the school building. Discussing your child’s abilities will ensure more independence in school and minimize everyone’s initial fears or apprehensions. Discuss privacy and agree on what will be said about your child’s OI in front of peers. Consider volunteering to talk to the class about OI. Discuss the best way classroom staff should communicate with you. Everyone who interacts with your child should be knowledgeable about handling day-to-day activities and emergencies.

What other areas should be discussed with school staff?

You may want to discuss the following topics:

- What to do when a fractures occurs at school
- Limitations on mobility
- Use of a personal aide
- The physical environment
- Adaptive seating in the classroom
- Wheelchair/walker use
- Toileting
- Moving between classes
- Fire emergency plans
- Transportation
- Home study – when and if it is needed

How can the school help?

The school nurse needs to be aware of how to assist your child and how you wish emergencies to be handled. The nurse’s office can be a safe place for a child to take a break from sitting in a wheelchair at scheduled times during the day. Physical and occupational therapists who are employed by the school system can provide services to help the child with OI have better access the total learning environment. This can include adapting the PE program, providing safe activities during recess, locating adaptive sports programs, or therapy to improve basic motor skills.

This article was excerpted from the Teacher’s Guide in Jason’s First Day!

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