2. During the Meeting:
   - Sit next to the administrator or the person who will ultimately make the decisions.
   - Ask questions, define and describe issues, problems, and offer solutions.
   - Stay on task.
   - Learn to be a negotiator. Prioritize important issues.
   - Take notes. If it is not written down, it never happened.
   - If at all possible both parents should attend the meeting and present a united front. If not take a friend or advocate so you don’t feel vulnerable and can process the meeting together afterwards.
   - Do not sign the IEP at the meeting if unsure. Take it home and don’t feel vulnerable and can process the meeting together afterwards.

3. After the Meeting:
   - Add documents from the conference to your files.
   - Send a follow-up letter of your recollections about what happened and a brief thank you letter. Include your understanding of what the school agreed to, and issues that were unresolved.
   - Keep written records, keep written records, oh, did I say keep written records.
   - Take care of yourself or you will become exhausted and burn out.

In closing I would like to extend encouragement to those families who have disabilities and parents. Having a child with special health care needs means becoming his or her voice. Do not give up, there are many knowledgeable professional advocates that will assist you through this process and ultimately improve the quality of life for your child.
Identifying a Dragon
By Toby Director

"Why are you so invested in finding something wrong with your sons?" came the question from a close relative. "Something is wrong with them," I answered. "I’m trying to understand what is wrong, and if I can, then I will get them the help they need."

The determination finally paid off. After a long search, with several false detours, we finally did obtain the correct diagnosis. We could, then, begin toknowledgeably address the problem.

One of the difficulties with diagnosing Fabry Disease is that the symptoms send the patient to a variety of specialists who concentrate on one organ system and never see the whole picture; they are like the blind men who describe an animal by feeling only its trunk, its leg, its tail, or its nose, and who never identify it as an elephant because they never see the whole thing. We visited gastroenterologists to treat digestive problems, dermatologists to treat skin conditions, and urologists to treat urinary tract problems. Each test that significant step forward in treating the symptoms in their own specialty and insisted that we look for something else.

The search finally led us to the Mayo Clinic. An adorning doctor looking at the glaucoma reports and said, "You need to see a dermatologist." Within a few hours, the dermatologist examined my sons and said, "You need to see the pediatrician"

"..." When the geneticist-pediatrician finished her exam, she opened a booklet with the title, Fabry Disease. On the pages were listed nineteen characteristics of Fabry Disease and about eleven of them described our personal family.

Children with LSDs typically are classified under "Other Health Impaired." The term includes a child who has a chronic health problem resulting in limited strength, limited vitality or alertness, where special education and related services are needed because the disease adversely affects his/her educational performance.

During the Individualized Education Program (IEP) meeting, parents need to make sure their child's disease is clearly defined and a description of the disease is added to the IEP. It is important that the team, including the teacher, know what the disease is and how it affects the child. For example, if you have a child with a diagnosis of Huntington’s Disease (HD), the IEP team will need to know about the symptoms (orthopedic, language, inattention, cerebral clouding). It is important to realize that if a child has HD, the therapy is not just for the disease but not need special education services, the child will not be eligible under IDEA but may be eligible under Section 504 of the Rehabilitation Act of 1973. Diagnosis 504 does not receive federal money for providing 504 accommo-
dations, so there is less incentive for serving children under Section 504, nor do the children have an IEP under 504, so parents beware.

Children with LSDs also begin receiving services early. Children (Ages 3-9) may qualify in one or more of the following categories: speech and language, cognitive, physical, development, communication development, social or emotional development, or adaptive development. Identification of related services. Also included should be a statement of the special education and related services, supplementary aids and services (based on previous diagnoses), and related services. Also included should be a statement of the special education and related services.

Remember, because your child's medical status often changes, an IEP team meeting can require more than once a year. The contents of an IEP should include: educational benefits, transition services, educational and functional performance, annual goals, educational goals, and special education services. Also included should be a description of the disease adversely affects his/her educational performance.

Modifications are more intensive changes to the educational setting and can be increased through a team decision. The IEP is not a "one-size-fits-all" program. Individualized Educational Programs are unique when a child has a neurodegenerative disease. For children with degenerative conditions, the IEP may include related services such as physical and occupational therapy or other services to address the child's needs in the areas of self-help, mobility, and communica-
tion. This will help improve your child's abilities to function in school and at home. For example, a child may have a speech or language delay or a hearing loss, but needs specific education services, the child will not be eligible under IDEA but may be eligible under Section 504 of the Rehabilitation Act of 1973. Diagnosis 504 does not receive federal money for providing 504 accommo-
dations, so there is less incentive for serving children under Section 504, nor do the children have an IEP under 504, so parents beware.

Advocating for your Child's Educational Needs
By Kendra J. Bjorker, Ph.D., L.P.

"Succeeding in school is one of the most therapeutic things that can happen to a child." It is that time of year again, the excitement of getting your children ready for the new school year...buying new clothes, and supplies. And although this holds true for families who are not affected by special education services, the areas of anxiety, fear, and uncertainty also arise. The complex and continuous nature of their conditions and the high level of skill their care demands differenc...identifying a dragon, which is verified by a physician. Instructional services are available to all qualified students during conva-
escence or treatment time in a medical institution or at home. This time may be extended if the student's place of residence. The length of instruction for students in a full-day program is six hours per week; however, for students who are out of school for less than a full-
taped version. Once the student has heard the story, the next step is to read an assigned textbook; thereafter the accom-
mobili...and must take part in all required...the long-term; (continued on next page).