



From the CEO

You May Be in It for the Long Haul: Lessons Learned

by E. Clarke Ross, D.P.A.

mY WIFE Beth and I have traveled a difficult path while helping our son Andrew cope with his special learning issues and attention-deficit/hyperactivity disorder (AD/HD). Fortunately, we have been blessed with excellent health insurance and a pediatrician who understands Andrew's needs and is great at referring us to appropriate specialists.

Last year, an editor of the journal *Infants and Young Children* asked us to share some of our experiences with Andrew's early life path. Throughout our journey, we have discovered many strategies that have worked and discarded many tactics that have not. We offer the following suggestions based on our personal experience and the experiences of the other families we have learned from:

- Find a primary care physician with ties to a university or teaching-based medical facility. Look for a doctor who is available by telephone to discuss concerns, respond to questions from parents, and discuss the effectiveness and side effects of treatments. Build a relationship with your primary care clinician and his or her practice. The American Academy of Pediatrics (AAP) and the Bureau of Maternal and Child Health suggest that parents look for a pediatrician that can provide a "Medical Home," in which the primary care physician works in partnership with the family. According to the AAP, "Care within a Medical Home is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective." These practices generally use nurses in the initial review and assessment process. Physicians are limited by time constraints and health insurance in the amount of face-to-face time they can spend with the patient and family. A competent and well-trained nurse can maximize the time spent with a medical professional. Unfortunately, many communities do not have such physicians and nurses.

- Use a medical center with an array of clinicians who specialize in developmental delays and disorders if you suspect that your child may have complicating factors or co-occurring conditions in addition to his or her AD/HD. Your child will benefit from being evaluated by an interdisciplinary team more so than with piecemeal diagnoses and symptomatic remedies. The team may include a developmental behavioral pediatrician, a specialist in neurodevelopmental disabilities, a child psychiatrist or a child neurologist. Look for clinicians who have experience working in a team to diagnose complex childhood disorders. Unfortunately, most Americans do not live near such centers.

- Integrate the reports and recommendations of all the clinicians into your child's treatment plan. You most likely will have to do this yourself. The plan should combine your child's health, mental health and education services. You may need help from your primary care physician as part of the Medical Home, from a member of the team providing the interdisciplinary evaluation or from community agencies. Programs with case coordinators may be particularly helpful with this process.

- Select a health insurance plan that allows your child's pediatrician to make direct referrals to specialists without restrictions in terms of "in network" and "out-of-network" providers. If possible, choose a plan that reimburses you for specialist diagnoses and treatment.

- Enroll your child in early intervention programs. Frequently run by the Department of Education, these federal- and state-supported programs help infants and young children who have or are likely to have a condition that will impair development.

- Take advantage of support groups, clergy, friends, family and other parents. Discussing the difficulties you and your

family face with knowledgeable and compassionate people can help ease the burden. Family-based organizations such as CHADD are neutral locations for parents to share experiences.

- Be a wise consumer of information. Parents can find a wealth of information online and in books; however, not all resources are created equal.

Look for Web sites from reputed organizations that focus on evidence-based information such as CHADD (www.chadd.org), the National Resource Center on AD/HD (www.help4adhd.org), the American Academy of Pediatrics (www.aap.org) and the American Academy of Child and Adolescent Psychiatry (www.aacap.org).

- Understand that you're in this for the long haul. As your child grows and develops, the diagnosis may change and you may need to keep searching for new strategies to help your child cope with life's challenges. Build on your child's strengths while recognizing his or her limitations.

- Take time for yourself. Dealing with children with special needs day in and day out is stressful. By taking time for yourself and taking care of your health, you can be a better advocate for your family and help your child better cope with his or her challenges. ■



Conference Notes

Clarke Ross, D.P.A., will discuss AD/HD, the lived experience, and also stigma and AD/HD during two separate breakout sessions at CHADD's annual conference in Chicago, Ill., Oct. 26-28, 2006. Visit www.chadd.org for more information.

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