

THE REST OF YOUR LIFE

Raising a Child With Special Needs

It's been 10 years since Elyse May was born with congenital adrenal hyperplasia, but her mother, Michelle May, M.D., remembers the experience as if it were yesterday.

Dr. May suspected that her daughter had congenital adrenal hyperplasia, but adrenal disorders "are not my area of specialty, so my husband ran to the medical library for books that might help," recalled Dr. May, a family physician who practices in Phoenix, Ariz. "There I was, having given birth about 12 hours before and reading medical textbooks in my hospital bed."

Once the diagnosis was confirmed, Dr. May and Elyse were discharged home without starting treatment. The endocrinologist told her it was unclear whether Elyse had the mild form of the disease or the severe form. "He said that if we started to treat the mild form, it would mask the severe form," Dr. May said. Then the endocrinologist went out of town.

Once home, Elyse began vomiting and she became jaundiced and dehydrated. "By the time they decided to start her on the steroids, she was so sick that we put her in the hospital for 3 days," Dr. May said. "I couldn't get anyone to listen to me about how sick she was until I finally begged them to let me take her into the hospital. The doctor there said that she probably could have died within 12 hours."

Today, Elyse manages her condition by taking oral steroids three times daily. She wears a MedicAlert bracelet that attracts interest from her peers at school.

"Kids are starting to ask, 'Why do you wear that?'" Dr. May said. "She doesn't want to stand out. She doesn't want to be different. Because of the nature of her condition, if she goes to a sleepover or a birthday party, I have to let parents and other caretakers know about the potential seriousness if she does become ill or injured. I tell them you have to make a double effort to notify us if something happens because she could die of this if she's not treated appropriately."

Although the prognosis is excellent for Elyse "as long as she never has an adrenal crisis that is mismanaged, we still have to make sure we do the follow-up appointments and the routine blood work," Dr. May said. "I am now more empathetic to patients who have chronic medical conditions that require a lot of attention. It's easy to get into a role of complacency, or you get busy and you don't do what you should right on time."

Mark Heinz-Graham has a different set of special needs. Born with a moderate range of intellectual functioning, the 27-year-old currently reads at the pre-first grade level, "although he's very motivat-

ed to learn how to read," said his mother, Lee Combrinck-Graham, M.D., a psychiatrist who practices in Fairfield County, Conn. "In fact, he has just started with a reading teacher who hopes that now that he is an adult, there are more strategies for helping him to learn. Numbers are elusive [to Mark]. Math is not in his repertoire."

She noted that Mark relishes his full-time job as a grocery store bagger. He also likes to watch TV, play computer games, swim, play the drums, and listen to opera. "He's also in an art class," she said. "He's learning to be more deliberate, careful, and thoughtful."

She said the most difficult part about having a child with special needs is observing the social isolation that occurs. "For example, they can go to a birthday



Dr. Michelle May and her daughter, Elyse May, who was born with congenital adrenal hyperplasia.

party with regular kids or with special-needs kids. But somehow their participation in it or their 'getting it' is at a different level, so they're sort of on the fringes," Dr. Combrinck-Graham explained.

"If you have a birthday party with six special-needs 6-year-olds, they're all into their own thing. So it's not really a social occasion except they're there and the parents are whooping it up."

She added that families of special-needs children "shouldn't feel ashamed or try to hide their kid and shouldn't feel reluctant to invite people in to help. For instance, Mark is fairly independent. Sometimes we go away overnight and might say to one of our friends, 'Would you give him a call and say hi and see if he's alright?' Or sometimes when we go away someone will stay with him in the house. We do this so he has a larger circle of people paying attention to him while we're away."

Elisa Nicholas, M.D., reiterated the importance of focusing on the assets of a child with special needs. But she pointed out that the competitive, achievement-focused culture of medicine can pose a challenge to that effort.

"If you sit around a doctor's dining room and everybody's talking about their over-achieving child, and you're simply trying to get your child to walk and talk, it is very difficult," said Dr. Nicholas, whose 16-year-old son, Tom, has cerebellar ataxia.

Tom—the first physically challenged student to be fully integrated into the

Hermosa Beach (Calif.) School District—wears braces on his feet and uses a walker, crutches, or a wheelchair for mobility. "He can dress himself, but he will never be able to put his braces on by himself," said Dr. Nicholas, a pediatrician who directs The Children's Clinic, Serving Children and Their Families, a system of six not-for-profit community health centers in Long Beach, Calif. "He's always going to need some assistance."

Dr. Nicholas also knows that the caregiver role consumes many parents. "I think trying to achieve a balance is truly a great challenge," she said. "I want Tom to reach his greatest potential. If that means I have to make personal sacrifices, I will do that. But it's very difficult to find that balance, because it can become all-consuming."

Dr. Nam Nguyen can identify with that notion. His 4-year-old daughter, Uyen, was diagnosed with autism when she was 18 months old. "Any activity we do at home is tailored or geared to part of therapy," said Dr. Nguyen, chief of the division of pediatric surgery at the University of California, Irvine. "We put signs and toys in every room. Everywhere we go, every setting is a therapy for her. It's very much a constant thing."

He credits his wife, Lan Nguyen, M.D., with providing the bulk of Uyen's therapy. She left her full-time anesthesiology practice to care for Uyen, and now works just 2 days a week. She spends the rest of her time at home engaged in exercises to help cultivate Uyen's communication skills and reading skills, and taking her to weekly speech therapy appointments.

"Rather than shy away, we usually take [Uyen] to a lot of social events, every little thing that she can benefit from, so she can learn what the social cues are," Dr. Nguyen added. "It's hard for my older daughter, because everything [is centered around] Uyen. We had to change our per-

Helpful Reading

These books may be helpful to physicians who have children with special needs:

► "You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children With Disabilities," edited by Stanley D. Klein, Ph.D., and Kim Schive (New York: Kensington Publishing Corp., 2001).

► "Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child With a Disability," by Robert A. Naseef, Ph.D. (Baltimore: Brookes Publishing Co., 2001).

► "Uncommon Fathers: Reflections on Raising a Child With a Disability," edited by Donald J. Meyer (Bethesda, Md.: Woodbine House, 1995).

► "Since Owen: A Parent-to-Parent Guide for Care of the Disabled Child," by Charles R. Callanan (Baltimore: Johns Hopkins University Press, 1990).

► "A Difference in The Family: Living With a Disabled Child," by Helen Featherstone (New York: Penguin Books, 1981).

spective in how we conduct things every day so she doesn't feel rejected or [feel] animosity toward Uyen."

"You're going to have different phases in working with your child with special needs, just like with any child," Dr. Nicholas observed. "Help them reach their greatest potential and accept them for who they are. I think all parents need to do that. But I think when you have a special-needs child you're forced to do that earlier. Be grateful for who your child is." ■

By Doug Brunk, San Diego Bureau

INDEX OF ADVERTISERS

American Cancer Society		New England Journal of Medicine	
Corporate	69	Corporate	55
Astellas Pharma US, Inc.		Novo Nordisk Pharmaceuticals, Inc.	
Adenoscan	45-46	Corporate	28
Bristol-Myers Squibb Company		NovoLog	65
Corporate	5	P & G	
Bristol-Myers Squibb / Sanofi Pharmaceuticals Partnership		Prilosec	57
Plavix	30a-30b	Pfizer Inc.	
Forest Pharmaceuticals, Inc.		Viagra	3
Lexapro	6a-6b	Zoloft	33-34
Namenda	23-27	Caduet	38-41
Combunox	49-52	Lipitor	53-54
Campral	70a-70b	Roche Laboratories Inc. and GlaxoSmithKline	
Hoffmann-La Roche Inc.		Boniva	13-14
Corporate	29	Sanofi Pasteur Inc.	
King Pharmaceuticals, Inc.		Pertussis	36-37
Sonata	10a-10b	Santarus, Inc.	
LifeScan, Inc.		Zegerid	34a-34b
OneTouch	8	Sepracor Inc.	
Eli Lilly and Company		Lunesta	59-62
Cymbalta	18-20, 75-76	Solvay Pharmaceuticals, Inc.	
Merck & Co., Inc.		AndroGel	9-10
Zetia	14a-14b	U.S. Air Force	
Fosamax Plus D	21	Recruitment	17
Fosamax	42a-42d, 43	Wyeth Pharmaceuticals Inc.	
Discount Prescription Program	44	Effexor XR	66a-66d
Zocor	46a-46b		
Vytorin	62a-62b, 63		