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[By Lorna Collier in the Chicago Tribune.]

On his first day of preschool, Danielle Glassburg's son didn't talk to anyone. Not to his teachers, not to the other children. Her son's teachers chalked his non-speaking up to severe shyness, figuring as he got used to school he would relax and, like the other children, soon begin chattering away. But it didn't happen. Week after week went by, and still the boy sat silent in class. Glassburg, a Buffalo Grove resident who at that time lived near Rockford, began taking her son for treatment, trying first one doctor, then another. It took two years before she found a doctor who understood what was wrong with her son: selective mutism, a rare disorder in which the sufferer -- usually a child -- is unable to speak in certain anxiety-producing settings, most often in school or some other public environment. "These children say it is as though their voice box is frozen and the words can't come out," says Dr. Elisa Shipon-Blum, a Philadelphia family physician who specializes in childhood mood disorders and who acts as consultant to the Selective Mutism Group, an Internet-based information and support group. Most people have experienced the paralysis of a nightmare or severe stage fright, where speaking seems impossible. This, experts say, is what children in the grip of selective mutism feel like when they are told to talk in public settings. "It's not that they refuse to speak -- they literally can't speak," Shipon-Blum says, recalling one 5-year-old patient who demonstrated with a stuffed animal what she felt like when she tried to talk in public. "She kept doing something to its throat. I asked her what she was doing and she said, 'I'm opening up my froggie's voice box.'" Selective mutism is thought to affect one in every 1,000 school-age children, though "nobody really knows," says Dr. Lindsay Bergman, a UCLA professor and psychiatrist who is studying the incidence of the disorder in Southern California schools. "It's amazing -- everyone says this is so rare, but I've had people coming out of the woodwork for treatment, traveling 90 minutes each way for treatment, even coming from Hawaii," Bergman says, adding that she fields requests for information "if not daily, at least weekly." One problem with determining how many children have the condition is that it is still so poorly recognized and understood, by doctors as well as school officials, especially in rural areas. Too often, children with selective mutism are dismissed as shy or are thought to be autistic, abused or willful. Some children with the condition have been punished for "refusing" to speak in class. Others have been placed in special education classrooms, although they are not developmentally delayed. "The biggest problem in selective mutism is that doctors simply don't have knowledge of what it is," Shipon-Blum says. "A lot of physicians don't know a blessed thing about it. They'll say the child is shy, that he will outgrow it." Bergman agrees. "I've seen 8-year-olds where the pediatrician is still saying, 'She's just shy,' when that child would not say a word at school, would not use the bathroom, would not eat. The biggest thing the medical community is doing is not taking this seriously." Experts disagree as to whether selective mutism is a form of shyness. Bergman believes it is shyness to the extreme, while Shipon-Blum and Dr. A.J. Allen, a psychiatrist at the University of Illinois at Chicago who treats mutism patients, argue that it is a separate phenomenon. Shipon-Blum points out that some children, once treated, are no longer shy; it is as if the disorder has masked their true personality, which is free to blossom once the anxiety is quelled. Allen also disagrees with many doctors who say selective mutism is a form of social phobia. "It is a cluster of specific behaviors and symptoms that can be due to a number of different causes," Allen says. "Social phobia is the prominent (cause), but it is not the only one." Allen divides mutism patients into three categories: those who have a contributory speech or language problem that is causing them to fear speaking in public; those who suffer from severe social anxiety or phobia; and older children who have developed an oppositional quality to their non-speaking, "almost like it is a power struggle -- one of the things they have control over is whether they talk or not." The latter group is "by far the least frequent of the ones I've seen," Allen says. Selective mutism is best treated when caught early, in kindergarten if possible. A combination of therapy and a short course of anti-anxiety medications often can work wonders; today, Glassburg's son -- who did not speak to teachers throughout preschool and kindergarten -- is a happy 8-year-old who chatters freely in school, both to his many friends and to his teacher. If the condition is allowed to persist, some children may eventually begin to speak in class, Shipon-Blum says, but may be limited in other ways by their untreated anxiety disorder. "The children who are untreated do slowly begin to speak, but they never reach their full potential." Sometimes, even children who are treated -- especially those who are first treated relatively late, at age 8 or older -- are unable to speak throughout their school careers, all the way up to and including their college years. Bob Helta, a Florida office manager, tried to get treatment for his daughter Angelique when she wouldn't talk in kindergarten 10 years ago. At that time, there was much less information available about the disorder than there is now. "I probably wasted six years," Helta says, because he took her to doctors and therapists who claimed they knew what they were doing, but they had no grasp of what selective mutism was. "So many years were lost," he says. Angelique, who uses the nickname Angel, says she can't speak in school because she "feels nervous." She hopes to be able to talk in class some day, though. "I'm waiting 'til I get more comfortable," she says in a phone interview, speaking in a soft voice that's barely above a whisper. When other kids ask Angelique why she doesn't talk in class, she says she tells them simply: "I'm shy." Once his daughter's condition was finally diagnosed, Helta formed the Selective Mutism Group to act as an information clearinghouse and support center for parents, patients, educators and physicians. "To this day, I have people coming on (the site) saying, 'My child is 8 and suffers from this and nobody realized (until now) that there is a name for it,'" says Helta, who adds that he also gets calls and e-mails from doctors asking his advice about how to treat the condition. Despite Helta's access to the latest medical information and research, his daughter has not fully recovered. The 15-year-old 9th grader has tried several medications and is happier now than ever but still is not able to speak in school, Helta says. She can only talk to teachers if it is by phone. Selective mutism appears to be genetically influenced: Studies of twins have shown that identical twins are more likely to share the condition than fraternal twins, and often parents of children with mutism will report a family history of some sort of social phobia or anxiety disorder. Children with selective mutism are often treated with such drugs as Prozac and Luvox, which increase the levels of serotonin in the brain. Low levels of serotonin are believed by many doctors to play a role in anxiety disorders such as selective mutism. The younger the child, the shorter the course of treatment; doctors believe that for many patients, using these medications can cause the brain to begin producing serotonin properly on its own once the medications are discontinued. Doctors say that therapy is also an important component of treatment and works best when coordinated with a child's school. Allen, for example, suggests having children desensitize themselves to the school environment by speaking in an empty classroom. Allen says that parents who suspect their child may have selective mutism should monitor the condition through preschool and the first few

months of kindergarten but should not wait until kindergarten is finished to seek help if their child is not speaking. "I don't want to alarm anyone," Helta cautions. "Just because they might have a shy child, I don't want them to run to a doctor and start pumping the kid with medications. But I'm trying to make them aware that if they notice this is an ongoing thing, maybe they should have it checked out." Experts have these tips for parents who think their child may have selective mutism: - Trust your instincts. If the problem is persistent and you feel it is deeper than shyness, go to your doctor and ask for a referral to a medical professional who is familiar with selective mutism. If your child is still not speaking in class by the middle of his or her kindergarten year, seek help. - Try behavioral modification methods, such as a sticker chart that acts as a reward system for the accomplishment of small, speaking-related goals.

- Don't force your child to speak. Don't say "you can do this." Encourage him with rewards, but do not use force. "The most important thing is to be accepting of your child," Shipon-Blum says. You do not want to introduce any further anxiety into the situation. - Consider switching schools to a new environment where there are no expectations of the child. "This can be a type of cure for some who have mild mutism," Shipon-Blum says. Look for a small, nurturing school where your child can feel comfortable.

- Invite classmates over for play dates as much as possible, usually on a one-to-one basis. - Meet your child's teacher before school starts to explain the problem and coordinate strategies. Tell the teacher not to force your child to speak. - Don't be afraid to medicate. Shipon-Blum says, "If you take 10 kids who are selectively mute and you put them on medication, most will have (improvement). Two or three months of medication will get them ahead of years of therapy." Resources for more information:

- Selective Mutism Group Childhood Anxiety Network Inc.,  
Web site: <http://www.selectivemutism.org>. [sminfo@selectivemutism.org](mailto:sminfo@selectivemutism.org)