Lullaby and Good Day

Autistic children improving daytime behavior through better sleep

BY NORRKI MACREADY

For most autistic children and their parents, a good night’s sleep is the impossible dream. Experts estimate that as many as 83 percent of children with autism sleep poorly. The children typically have trouble falling asleep, wake up in the middle of the night, stay awake for several hours, then sleep until morn- ing. They often cry, sing, talk, play, or watch TV into the wee hours, disrupting the household routine and leaving the whole family exhausted. And to make matters worse, poor sleep can affect the child’s ability to func- tion during the day.

No one knows that better than Beth Malow, M.D.

Dr. Malow specializes in this field—as director of the Vanderbilt University Sleep Disorders Center in Nashville.

What’s more, she has a unique understanding of the challenges facing these parents—as she mother of a son with autism.

Her son, Austin, was diagnosed with autism in 2001, when he was 2½ years old. And, as a sleep expert, it was only natural for her to become intrigued by the relationship between autism and sleep disorders. Fortunately, Austin was a great sleeper,” she says, “but many children with autism are not.”

So Dr. Malow launched a study at Vanderbilt to explore whether there is a subset of autistic children who sleep well like her son, and if that could be related to their prognosis. “Basically, we want to understand the differences between the good and the poor sleep- ers, and between children with autism and typically developing children,” she says. “If we can determine what makes the good sleepers sleep well and how to influence that, we might be able to improve sleep for the other patients and their parents, and maybe enhance their daytime functioning.”

It was the hope of improving sleep that led Angela McDaniel to enroll her daughter, Tammi, in Dr. Malow’s study two years ago. Tammi, then 6 years old, snored and had many of the sleep prob- lems typical of children with autism. “She would wake up in the middle of the night gasping for air,” Angela recalls. “She slept, I didn’t.”

The next day they visited the science museum in Nashville, then returned to the sleep lab for a second night of observation.

The doctors at Vanderbilt diagnosed Tammi with sleep apnea and recom- mended that she have her adenoids and tonsils removed. And that, says Angela, has produced dramatic results. “She now sleeps through the night,” Angela says. “At first it was actually scary—I had to put my hand on her chest to make sure she was breathing.”

Remarkably, the sleep improvement has produced significant changes in Tammi’s social skills and her ability to focus, concentrate, and respond to stimulation.

“If it’s affected almost every aspect of her behav- ior,” Angela marvels. “She had been making prog- ress before, but the speed jumped by a factor of 10 after she began sleeping through the night.”

Tammi McDaniel isn’t the study’s only success story. “Everyone who’s come in for a sleep study has done well,” says Dr. Malow, its lead investigator. “Many of the kids love it—they’re fascinated by all the wires and machines.”

So far, about 30 autistic children have participated in the study along with 10 to 20 typically developing children as a comparison control group. Dr. Malow, a neurologist whose research focuses on the overlap between sleep disorders and other neurological disorders like autism and epilepsy, would like to enroll anoth- er 20 to 30 autistic children.

To qualify for this study, the children must be 4 to 10 years old, free of sei- zures, and not on psychotropic medication. These requirements are the same for autistic children and typically developing children. [For more information about this study, call 615-936-1646.]

Vanderbilt will reimburse families for local travel expenses, and reward the children with gift certificates to stores and free museum passes. Of course, Dr. Malow hopes the study will yield scientific results that have far more significance for children with autis- tom and their families.

“If we can show that improved sleep leads to better daytime functioning, we can say the sleep patterns are influenc- ing the behavior.” Dr. Malow explains. “Our goal is to ameliorate daytime be- havior by improving sleep.”

Does poor sleep make symptoms of autism worse? The answer just might both of them better.

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A SELF-DESCRIBED ‘MARIONETTE’ As much as Tammi McDaniel loved being wined up, she’s enjoying the study’s significant benefits on her daily life far more.

A Vanderbilt researcher then con- ducted a trial run-through of the study in their home two hours from Nashville, bringing many of the instruments used in the sleep laboratory so that Tammi and the rest of the family could see exactly what’s involved and what the testing would be like.

For the study itself, Tammi and Angela arrived at the Van- derbilt Sleep Disorders Center one day a couple of hours before Tammi’s bedtime.

Tammi was hooked up to the testing equipment by wires with electrodes connected at the end. The wires, she told every- one as they were attached to her head, made her feel like a “marionette.”

Then Tammi turned in for the night. As the instruments re- corded her breathing, heart rate, brain waves, eye movements, leg move- ments, and chin muscle tone, her moth- er stayed on a nearby cot. “She slept, I didn’t,” Angela recalls.

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NorRKI MACREADY is a book author whose health and medical articles have appeared in The Economist, Glamour, and WebMD.

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