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## ONE FAMILIES LIFE FOREVER ALTERED BY LYME DISEASE

By Anne L. Boles, Palm Beach Post Staff Writer

A Woman and her children contracted the disease on a hiking trip to Wisconsin.

The Palm Beach native plucks vials of antibiotics from an overflowing bin on the kitchen table. By lamplight, she screws on needles and mixes chemicals, taps syringes and squeezes plungers.

Asleep on the couch is 11-year-old Chase, a tube snaking from his chest to a plastic bag strung above him from a metal stand. The bag is empty.

Like his mother, he is blonde and fine-boned. When he awakes, he will be in pain.

Chase has Lyme Disease too, and so does big brother Blake, who comes bounding downstairs with a 14-year-old's energy, all gangly arms and legs and shy grins. And so does Skye, who at 7 is too young and too optimistic to believe that her arthritic limbs will never learn to dance.

Like most victims in Florida, the Parrishes caught Lyme Disease elsewhere -- Wisconsin, in this case -- while outdoors. Because doctors here didn't know to expect it, the disease spread undiagnosed for more than three years.

Only Susan's husband, Wayne Parrish, is spared the chronic aches and sudden seizures that have robbed his family of a normal life and mystified doctors. Countless hours in university libraries and a mother's determination would track down the corkscrew-shaped bacteria that had wormed its way into sinew, bone and nerve; strong medicine and stronger faith would begin its exorcism.

But it may be too late. Chase has had four strokes already. Susan has heart trouble and now has a tangle of blood vessels in her brain.

A new treatment raises hopes for a cure, or at least a respite. Texas A&M University is experimenting with a hyperbaric oxygen chamber, which floods patients with pure oxygen to kill the anaerobic germs en masse.

Texas is far away, and getting there is expensive. The treatment is experimental. It may have painful side effects. It may not work.

Yet it is, quite literally, their last hope.

The Parrishs' light, airy house, with its wood beams and yawning cathedral ceiling, is set amid a network of lakes and trees in a rustic town just north of Tampa.

Susan Hoadley Parrish, 38, grew up in Palm Beach and graduated from Cardinal Newman High School. After college, she married David Wayne Parrish, 39, who works for an insurance company in Tampa.

Their family loves the outdoors, still does, although they can never behold it with the same innocent fascination.

Susan Parrish can remember the last day of normal life clearly, sometime in May 1992. The family was living in Wisconsin then and the big woods beckoned.

She and her three children set off for one of their customary walks, this time abandoning the usual trail to make their own way. Wayne did not accompany them.

She remembers the hip-tall grass and picking asparagus from a field. She remembers everyone wearing shorts and marveling at the forest's emptiness. It did not occur to her that others stayed away for a reason.

That night while showering, oldest son Blake, then 9, pulled a tick from his ear. Otherwise, no one noticed anything unusual.

When Mom and the kids came down with the flu that summer, that was odd. But when Chase, then 6, suffered a stroke, something was clearly, awfully wrong.

"He fell down ... and said, 'My left side won't work, Mommy,' said Susan. "I said, 'What do you mean? Get up.' "

Chase would go in and out of hospitals after that, suffering four strokes in all. He had to relearn how to talk and walk and lost much of the use of his right arm.

With his immune system weakened, Chase could not produce the tell-tale antibodies that show up in tests for Lyme Disease. When the test was done, the results came back negative.

The Parrishes had transferred back to Florida by then, and had begun what would be a frustrating, four-year journey through hospital wards and doctors' offices.

"Meanwhile, the rest of us had weird symptoms," Susan continues. "I had chest pains. Blake had joint pains. Skye was little, around 2. She would walk and just fall right down where she was."

Susan made a list of all their symptoms and went hunting through medical journals and textbooks. Could there be one disease that would do all this?

There was. *Borrelia burgdorferi* is spiral-shaped like the syphilis germ and twists into cells where it hides.

It surfaced in the 1970s in Lyme, Conn., and was traced to the tiny deer tick. Other ticks can carry it as well. Lyme Disease has spread through 43 states quickly and is now second only to AIDS in its growth rate, recent research shows.

The U.S. Centers for Disease Control and Prevention recorded 11,603 new cases of Lyme Disease in 43 states in 1995, according to the most recent statistics. It is still found most often in lower New England and the Middle Atlantic.

Florida recorded 16 confirmed cases in 1995, the last year for which statistics are available. Most caught the disease elsewhere, said state officials, although several people had not traveled out of state, and therefore must have caught it from ticks here.

While the number seems low, diagnosing Lyme Disease is tricky, according to the CDC and other researchers. It is often misdiagnosed because its symptoms can mimic those of the flu, arthritis or even multiple sclerosis.

Nearly half its victims get a bull's-eye rash and then may suffer seemingly unrelated ailments: inflammations, joint and muscle pain, palsies, fatigue, blindness, headaches, hallucinations, depression and seizures, to name a few.

In 1995, Susan finally wore doctors down with her insistence that everyone be tested for Lyme Disease. She was right, but getting the illness successfully diagnosed did not necessarily bring relief.

The Lyme Disease germ reproduces slowly, according to research reports, and can be cured easily if caught early. But the illness had several years head start.

Progress has been slow. Despite the antibiotics dripped into them, Chase and Skye remain too sick to attend school, and complete their lessons at home.

"The germ is sensitive to higher levels of oxygen," said Dr. William Fife, a professor at Texas A&M University's health science center. "It gets into the cell, where there's not enough oxygen to harm the germ. It lives there very nicely, and it makes it hard for antibiotics to get to the germ."

Fife is experimenting with a hyperbaric oxygen chamber, the same device used to cure deep-sea divers of the bends. Patients sit in a compression chamber and wear oxygen masks for about an hour. The germs are flushed out and destroyed, Fife said. Of 23 patients so far, all but one have reported feeling better.

Some have stayed free of symptoms for five or six months so far. Others had symptoms resurface after a few months. Part of his research is determining how many sessions are needed, and for how long, said Fife.

Because it is experimental, the treatment is free. But how to get there? Who would pay for plane tickets, hotels, meals and a million other things?

Two years ago, Susan visited Larry Mills' Bible study class to make a plea for help. "There were 40 or 50 people, and she had us all in tears," said Mills, now a close family friend. "We just formed a circle around her, five and six deep, and everybody just prayed."

The Parrishes have turned to their congregation, the Idlewild Baptist Church at 1515 West Bearss Avenue in Tampa, for strength and help. Church members have done chores that Susan is too weak to perform and raised money toward the nearly \$400,000 in medical bills.

The church set up the Parrish Family Fund, still in existence, and a local newspaper ran a story before Christmas to describe their desperate need for the Texas trip.

"I miss them terribly," Wayne Parrish said over the telephone. "This is harder than I ever anticipated. I missed Valentine's Day. Monday was her (Susan's) birthday. It all adds up."

Wayne spoke from his home in Lutz. His family was in College Station, Texas. From a motel room, Susan Parrish sounded upbeat. They were midway through their treatments.

Susan's father, Thomas Hoadley, had sold his West Palm Beach law practice to care for them and accompanied them to Texas. At first, things didn't go too well. Blake suffered chest pains in a restaurant, Susan said, and put his head on the table and cried.

Then Susan felt pain shooting through her chest.

"I cried all the way home," she said. "I screamed in the hotel room. My father didn't know what to do."

Chase and Skye also had trouble at first.

"Then all of a sudden, they got up and were stomping around with the oxygen masks on their heads, making animal noises," said Susan. "Chase and Skye are completely exuberant compared to what they were."

"Dr. Fife (joked) he was going to reinforce the walls after the Parrish kids had been in there. They're more like normal kids."

Staff researcher Xiao Kai Chen contributed to this report.

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