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# Discovering strength by defying the odds

Despite disabilities, children with Down syndrome can work hard -- and achieve

By KRISTIN HARTY, The News Journal

Posted Tuesday, June 19, 2007

Watching Jon Stoklosa dead lift 380 pounds, it's hard to imagine that when he was a baby his neck was so weak he couldn't hold his head upright.

Now 25, Stoklosa, who has been featured as a powerlifter in Muscle Magazine, has an 18 1/2-inch neck and can bench press a raw 350.

But the moment Hank Stoklosa held his new baby boy on Sept. 12, 1981, he knew something was wrong.

His wife, Liz, had given birth to two healthy sons in previous years. The Stoklosas, who weren't offered prenatal tests for genetic disorders, had no reason to expect any problems.

"I thought he was fine," said Liz Stoklosa, who was 32 when she had Jon. "He was born on a Saturday. It wasn't until probably the next day when our pediatrician said he suspected something was wrong with Jon. He said it was something with his eyes. I remember saying to him, 'Is he blind?' He said, 'No, no, no. I think



John Stoklosa, 25, a powerlifter with Down syndrome, can bench-press 350 pounds. (Buy photo)

The News Journal/GINGER WALL



At first, John's parents kept his condition a secret.





he has Down syndrome."

Jon would be "mentally handicapped," the doctor said. Beyond that, there was little information.

For the Stoklosas -- Liz, a registered nurse, and Hank, a systems engineer at DuPont -- the diagnosis was overwhelming.

The couple took the infant home and told no one that anything was the matter.

"We kept this deep, dark secret that this baby was perfectly fine,"

Liz Stoklosa said. "And he wasn't."

The American College of Obstetricians and Gynecologists has taken steps to allow parents to avoid such a traumatic experience. In a controversial decision in January, the group recommended that all pregnant women -- not just those older than 35 as in the past -- be tested for Down syndrome.

Most agree that having information early is good. But in Delaware and across the county, many families of Down children are stunned -- and outraged -- by the recommendation.

Several studies over the last decade show that about 90 percent of pregnant women who learn they are carrying a Down child have chosen to abort.

"If it's used for the purpose of selecting someone with a disability to be born or not to be born, then it's atrocious," said Daniese McMullin-Powell of Wilmington. A member of American Disabled for Attendant Programs Today, she is pro-choice on abortion.

"It's a very hard choice to make, as to whether a child can fit into your life," McMullin-Powell said. "But to make that decision based on disability is unacceptable. ... People with Down syndrome are humans. They should not be euthanized before they even have a chance to breathe."

Wilmington resident Alice Whitelock was 18 weeks pregnant when she found out through amniocentesis that her child had Down syndrome. A Catholic, Whitelock struggled to decide whether to carry her baby to term.

Today, she's president of the Down Syndrome Association of Delaware, and her son, Andrew, is 7. On medication for asthma and attention deficit disorder, he isn't potty trained and doesn't speak yet.

Raising a Down child, she said, is difficult.

But "he's the most loveable thing in the world," said White-lock, who has a teenage son without Down syndrome. "I think it's wonderful we offer all this prenatal



John Stoklosa attended elementary school and went on to earn a varsity letter in wrestling at Newark High School, where he graduated in 2000.



John Stoklosa with his parents, Liz and Hank Stoklosa.

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Andrew Whitelock, 7, has Down syndrome. His mother, Alice, who is president of the Down Syndrome Association of Delaware, found out he had the condition through amniocentesis when she was 18 weeks pregnant. (Buy photo)

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Jon Stoklosa starting lifting weights with his two older brothers when he was a teenager. His final dead lift in the powerlift competition

testing. But I also think it's kind of unethical if people use it just because they don't want a child with Down syndrome."

Across the country, Down support groups -- including Delaware's -- are trying to enhance outreach so that families expecting a Down syndrome child get good information about the disease.

The National Down Syndrome Society issued a resolution imploring health-care providers to make sure expectant parents are not unduly influenced to terminate a pregnancy because of a Down diagnosis. Besides being warned of difficulties, families should be told that "rich and fulfilling lives are possible for people with disabilities."

"Many individuals with Down syndrome learn to read, hold jobs, marry, have recreational and social lives," said Michael Gamel McCormick, director of the Center for Disability Studies at the University of Delaware, who believes prenatal testing should be accompanied by intensive counseling.

at the Special Olympics was 390 pounds.
(Buy photo)

The News Journal/GINGER



Jon Stoklosa, a 2000 graduate of Newark High School, gets some suggestions from his strength trainer, Brandon McGovern.

(Buy photo)

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"More information is always a good thing," Gamel McCormick said. "My concern about information out of context is that in many cases, families may not be given information about what children with Down syndrome might be like. Some information might be out of date or misrepresented."

Twenty-five years ago, Pat Maichle's Delaware pediatrician gave her a diagnosis with these words: "Your baby is Mongoloid."

Maichle, whose daughter, Tara Bustard, was born with Down syndrome in 1981, was in her 20s and didn't receive pre-natal tests.

"A week after Tara was born, the pediatrician told me we should put her in a state institution and forget we ever had her," said Maichle, of Middletown. "He said she would never be able to do anything."

In August, Bustard, 26, will celebrate her eighth anniversary as an employee at Bank of America. She lives in an apartment by herself in Middletown, pays taxes and enjoys writing romance stories on her computer.

Complaints about getting misinformation -- or not enough information -- are common, said Dr. Lou Bartosheski, a pediatrician and clinical geneticist at Alfred I. duPont Hospital for Children. It's difficult to give specific information about how an individual child will manifest Down syndrome, Barto- sheski said.

"No two people are alike. No two people with Down syndrome are alike," he said.

"Their cognitive level is lower than the average, but the range of cognitive delay is wide. Almost all people with Down syndrome have to be in special education. The likelihood of living a totally independent life is fairly low."

Jon Stoklosa, who started lifting weights with his two older brothers when he was a teenager, still lives with his parents. But one day, he hopes to get married, drive a car and live in an apartment.

In 2000, he graduated from Newark High School, where he earned a varsity letter in wrestling.

"His biggest line is, 'Teach me. Show me,' " said Bobby Atallian, a receiver at the Acme supermarket where Stoklosa works four days a week as a bagger. "He takes initiative. He's a good kid. He's got a big heart."

Atallian and several other Acme employees -- and one regular customer -- attended Special Olympics Delaware's Summer Games earlier this month to watch Stoklosa compete in powerlifting.

Squatting and stretching his arms out before attempting his final dead lift -- at 390 pounds -- Stoklosa drew a roar from the crowd.

"You can't write these kids off," said Liz Stoklosa, who said she knows Down parents who received sympathy cards after giving birth. "I can't imagine my life without Jon. He has changed our lives for the good. He's made us better people."

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#### ABOUT DOWN SYNDROME

Down syndrome causes mild to severe mental retardation and other medical conditions, including increased risk for heart defects and respiratory and hearing problems. Down children typically have low muscle tone, a small stature and an upward slant to the eyes. About 350,000 people have Down syndrome in the United States. About 1,000 children with Down syndrome are born in the United States each year.

Until this year, only women older than 35 were routinely offered a Down screening, which carries a slight risk of miscarriage. But new types of tests -- including ultrasound and blood tests -- can provide fairly accurate information more safely and earlier in pregnancies.

Chorionic villus sampling (CVS) is done at 10 weeks' gestation; amniocentesis is done at 14 to 16 weeks; a "triple screen test" using blood samples is done at about 14 weeks.



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