

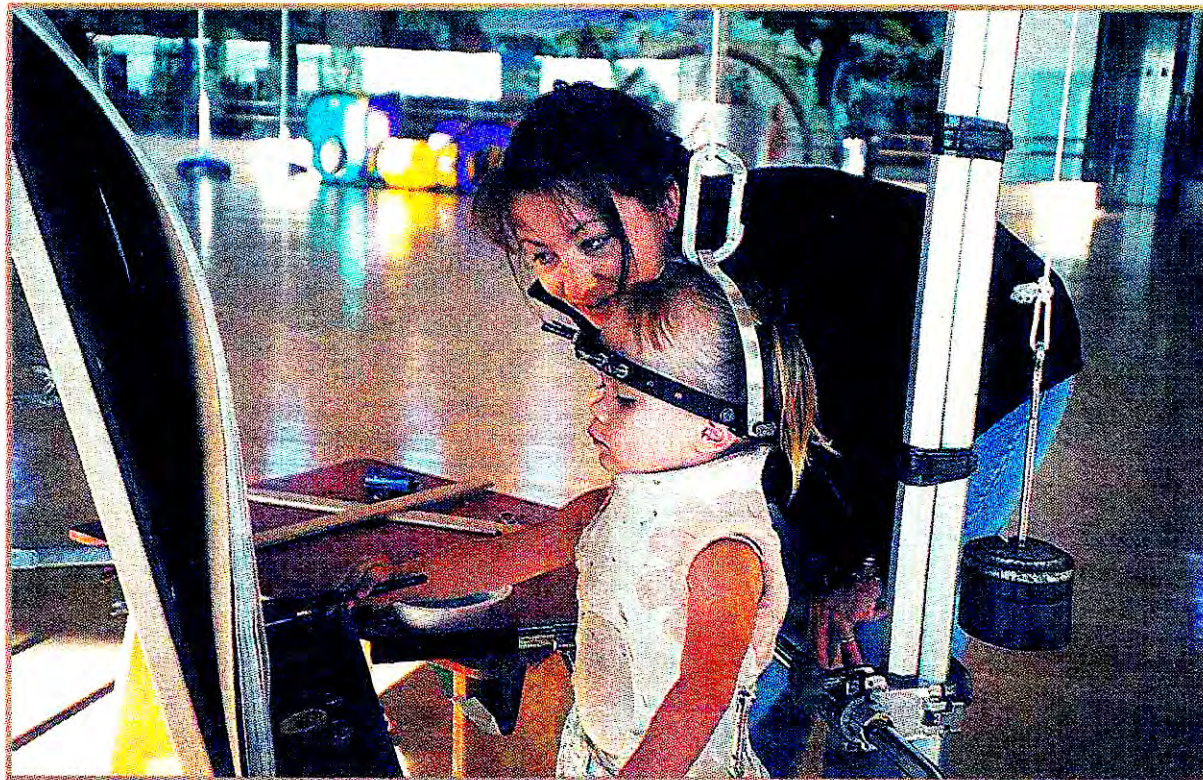
Spotlight



The greatest **Gift**

**Experimental
scoliosis procedure
gives toddler new hope.**

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Olivia Sorensen paints a picture at Shriners Hospital in Utah as her mother, Heather Hyatt, looks on. The 11-pound weight that helped straighten the toddler's severely curved spine hangs behind her.

Photos courtesy of Jeanette Montoya

A story of **BACKBONE**

MOTHER'S DETERMINATION TURNS THE TIDE
IN TODDLER'S SCOLIOSIS FIGHT

The greatest Gift Rare scoliosis procedure gives tot new hope By Debra Melani ~ Denver Rocky Mountain News Staff Writer

When Olivia Noel Sorensen turns 3 on Christmas Eve, her mother will be celebrating the life of her daughter, a happy and rambunctious little girl whose fate looked grim a few months ago.

But thanks to her mother's determination, Olivia is likely to celebrate many more birthdays, as are at least six other children whose parents heard of the Denver residents' story.

Because Heather Hyatt refused to follow doctors' orders in treating daughter Olivia's severe scoliosis, a procedure that's common in France but not in the United States is now

being offered at Shriners Hospital in Salt Lake City. For families like Olivia's, it could be the answer to a prayer.

"If it's successful, it brings up an alternative way of treating infantile (up to 3 years) and juvenile (4 to 10 years) scoliosis, because right now we really don't have a good way," said one of Olivia's Denver spine surgeons, Dr. Courtney Brown.

Doctors had told Hyatt that the best thing to do for Olivia was to keep her in a brace and "hope for the best."

But Hyatt didn't feel like just hoping.

"That's when I began researching," she said in a telephone interview from Olivia's hospital room. After nearly three months in Utah, Hyatt's goal is to bring her little girl home by Christmas.

Hyatt, a single mother, went on a quest to find a viable alternative to what she believed — and doctors agreed — was a death sentence.

Olivia's infantile scoliosis, a condition rarer than its adolescent cousin (11 years and older) but often much more virulent, had contorted her spine to a 96-degree angle by



the time she made it to Shriners Hospital. Hyatt watched helplessly as a growing back hump continued to disfigure her baby.

She found little information on the Internet but received a list of about 10 doctors in Colorado who were associated with the National Scoliosis Foundation. She began visiting each one and sending Olivia's X-rays to prestigious medical institutions across the country. They all stuck by her Denver doctors' suggestion.

Then Hyatt went to Dr. Cathleen Van Buskirk, a spine surgeon in Boulder. That was her turning point.

"She was the only one who recommended a serial corrective plaster cast," Hyatt said. Van Buskirk suggested a treatment done in France by Dr. Jean Dubousset, a renowned expert in the field who Van Buskirk said has probably seen more severe cases like Olivia's than has anyone else in the world.

Scoliosis is much more common in Europe, possibly for genetic reasons, said Dr. Jacques D'Astous, the Shriners Hospital doctor who treated Olivia. He, like Van Buskirk, trained under Dubousset.

"Cases we see in this country are often people of European descent," he said. D'Astous said there is speculation that rates are falling in the United States because of the campaign to place infants on their backs to prevent sudden infant death syndrome. But many forms of scoliosis, Olivia's included, have no known cause.

Hyatt took Van Buskirk's recommendation to her Denver doctors, who refused to perform the treatment, some even calling it

"barbaric," she said. The procedure requires the children to be put in a turnbuckle body cast and a "halo" bolted with eight screws to their heads. Weights are then attached and slowly increased to gradually straighten the spine.

Despite the doctors' negative reaction, Hyatt pressed on. "She was already getting a huge rib hump," she said of Olivia. "It was mangling her ribs."

To prevent the spine from killing Olivia by crushing her lungs or heart, Hyatt said, drastic measures, such as fusing her spine, would have been the ultimate course. "I refused to take that for an answer," she said, explaining that fusion would have shortened Olivia's life. Her 2-year-old trunk would have stopped growing, leaving no room for her organs.

"Those who are saying that this is barbaric in this day and age don't understand what the basic problem is," Brown said.

Van Buskirk agrees. "After a curve becomes 90 degrees is when we start seeing severe cardiopulmonary complications," she said. "I can't predict how long she would have lived, but she would have died in her childhood years."

Doctors want to control curvatures until children are at least 10 or 11, Brown said. Then the spine can be fused, "and you have a much better chance at having a relatively normal child," he said.

Hyatt's persistence — combined with a little luck — paid off. She tried for months to get a response from Dubousset. After resorting to sending her pleas with Olivia's records to

his home in France, he answered.

"We were ready to move to France," Hyatt said, explaining that she had friends in Europe who were going to help her find a home for medically needy kids. Then she learned from D'Astous in Utah that Dubousset would be visiting Shriners to receive a lifetime achievement award before retiring.

Hyatt and Olivia were there waiting.

At Hyatt's urging, D'Astous persuaded Dubousset to evaluate Olivia.

"He came in and picked Olivia up by her head," Hyatt said. A translator told Hyatt that Dubousset was worried Olivia was too young to emotionally tolerate the procedure, but her condition was so severe that something had to be done.

Speaking through the translator, Dubousset told Hyatt: "What your daughter has is the hardest thing to treat in the orthopedic world. That's why I took this on. Instead of crying, you need to fight this disease every day for your daughter and never give up."

Dubousset agreed to train D'Astous and advise him over the phone from France.

Hyatt had learned from friends of a 3-year-old girl in Grand Junction whose condition was almost as severe as Olivia's. She contacted the mother, and that girl and Olivia soon were paving the way for other children whose futures were equally precarious.

It wasn't easy.

"The first week was probably the roughest week of my life," Hyatt said. "I was questioning myself, thinking: 'What am I doing? I hope I don't kill my child.'"

Because Olivia was too young to understand and would be too frightened, she had to be put under general anesthesia, D'Astous said. For older children, local anesthesia can be used to bolt in the halo and apply the cast, which encases all but the arms and legs.

When Olivia awoke, she was confused and in severe pain.

“She was on morphine,” Hyatt said. “The first week is a blur.”

But she said she’ll never forget her daughter’s eyes full of fear.

“She’d say, ‘What are you doing to me, Mommy?’”

With 11 pounds of weight hanging from her head, Olivia had to have a supportive wheelchair or walker with her wherever she went.

But Shriners — a philanthropic, 22-hospital organization that treats burn and orthopedic child patients for free — makes the families feel at home, Hyatt said. Every day, there are activities for children, including visits from traveling pets and sports stars.

After the first week, Olivia — and her Grand Junction cohort, Breann Blackman — rebounded.

“I think they did awesome,” D’Astous said. “I think the girls adapted remarkably well.”

Moreover, their spines responded. Olivia’s 96-degree curve decreased to a livable 45 degrees. “Basically, you are buying time for them,” D’Astous said.

The girls have a daunting road ahead. They will be in and out of body casts and braces for years. And they could face treatment again if their spines revert to dangerous degrees.

In Olivia’s case, that’s likely to happen in one to three years. At that point, it will be up to Hyatt to decide between another cast procedure and seeking other experimental treatment.

The goal is to get her to at least age 10, when a spinal fusion could be done with a better likelihood of giving her a relatively normal life.

Not every child with severe scoliosis will get this procedure. Given the treatment length and the intense medical supervision and aggressive respiratory therapy needed, the cast procedure isn’t likely to be widely offered in the United States, Brown said.

“The reality is that nowhere in the country, except for a Shriners-type environment, could this be done,” he said.

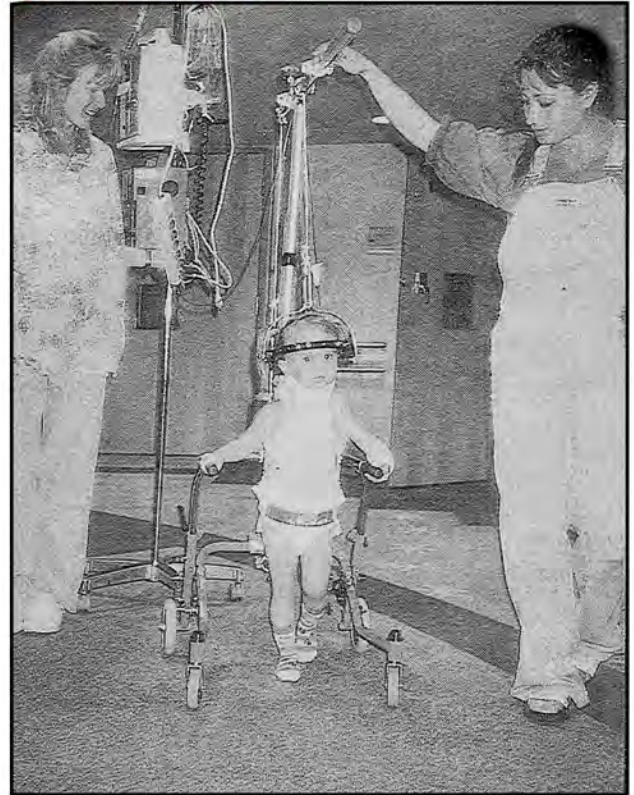
Van Buskirk concurs: “The insurance companies wouldn’t allow us to keep children in the hospital for that length of time.”

Other experimental procedures for children like Olivia are available, but all require surgery. One such treatment Olivia might later undergo involves implanting a titanium rod to help maintain the spine.

But D’Astous said French studies indicate that the results of the procedure that Olivia underwent are far superior to any other experimental treatment.

Once he sees how the girls do now that they’ve been placed in braces to maintain the correction, D’Astous will probably

The greatest Gift



Registered nurse Selene Bleak, left, and Heather Hyatt help Hyatt’s daughter, Olivia Sorensen, walk the halls of Shriners Hospital in Utah. With an 11-pound weight attach to her head, Olivia was unable to move around without a walker or a wheelchair.

encourage his colleagues at Shriners hospitals to consider the treatment, he said. He has already received six requests as a result of publicity generated in Utah, and he plans to grant some of those requests, he said.

“Right now things are looking very encouraging,” he said.

Hyatt said it’s gratifying to know she had a hand in making this treatment available for other children, and she suspects she and Olivia will have a special Christmas with a much-deserved rest.

“To know that there are going to be other kids now is the best feeling in the world,” she said. “Olivia went through a lot. And so did I.”

RockyMountainNews.com.
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 **Infantile Scoliosis
Outreach Program**
www.infantilescoliosis.org