OLIVIA'S STORY

This is the story of Olivia Noel—a child whose life revealed both the devastating consequences of delayed and inadequate treatment for infantile scoliosis and the extraordinary impact of determined advocacy, international collaboration, and early intervention. From infancy, Olivia's rapidly progressing scoliosis challenged conventional medical thinking, forcing her family to search beyond borders for answers. Her journey—marked by innovation, resilience, heartbreak, and courage—became a catalyst for global change in how early-onset scoliosis is understood and treated. Though Olivia's life was far too short, her legacy continues to shape care, research, and hope for children worldwide.

Infantile Scoliosis Outreach Program

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A Difficult Beginning

My pregnancy was difficult due to extreme nausea 24/7. A common symptom for expectant mothers with Ehlers Danlos Sympton (EDS). My weight prior to delivery was 125 lbs. Hospital weigh-in at delivery, 204 lbs.

Olivia was born on Christmas Eve 1997, full term. 36 hours of labor.
Umbilical cord unwrapped from neck followed by quick delivery. Liv took more than a few seconds to announce her presence, but when she did, her little voice was strong.

We went home and she was beginning to pass all milestones on time.

Spinal tap at 3 months for severe fever of 104 degrees. I refused it repeatedly and was told that if I refused it again, they would discharge her without addressing her high fever.

At 4 months old I detected back asymmetry and mentioned it to her pediatricians. The main pediatrician said she was not using the muscles on her right side; therefore, all activities must be focused on the right side of the room. This was done for about 15 minutes unsuccessfully. She was using all her muscles and the advice was daft.

Something was not right. She had severe reflux and the only way she could get to sleep comfortably was to sit slightly upright, propped up in a moving swing.

Diagnosis and Early Decisions

Made an appt. with lead pediatric spine specialist at local Children's hospital in Denver.

X-rays taken and immediately diagnosed with a subluxed (partially dislocated) left hip and scoliosis at 5 months old. Doctors said the scoliosis would resolve on its own. 29 degrees, thoracic.

Hip reset in operating room and placed into Spica cast for 3 months.

Scoliosis was growing more pronounced everyday under Spica cast.

Doctors were asked to heighten/reinforce Spica cast in back to support her growing spine and these pleas were repeatedly denied. Doctors said that the hip must be addressed first to accommodate walking.

Placed into removeable Pavlic harness (hip brace) for 6 months. Treatment was successful and hip-brace discontinued at 9 months old.

Spine progressed from 29 degrees to 75 degrees while addressing the hip issue.

Searching for Answers

National pediatric scoliosis research begins in libraries, pre-internet.

Removeable, clam shell, TLSO (Thoracic-lumbar-sacral-orthosis) brace prescribed. TLSO worn as suggested 23/7.

Requested exercises, knowledge and/or successful alternatives to treating Olivias rapidly progressive situation from doctors and was told to do my research.

All Colorado spine specialists suggested premature spinal fusion except for one.

Spine x-ray over 100 degrees

She said point blank that Olivia needed serial corrective plaster casting and informed me that she didn't do it and couldn't help. She then gave me the name of Dr. Jean Dubousset in Paris, France.

International research begins.

Olivia begins side-stepping at 14 months old (walking).

Letters and x-rays sent to many European pediatric orthopedic spine specialists. In Spain, France, Holland, England, Ireland, Scotland, Germany, Denmark and Sweden.

Olivias thoracic curve progressed to over 100 degrees by age 2, while I watched her little spine bend and rotate every day, to the point of no return.

A Turning Point

First clinical photo, Shriners Intermountain Hospital, Salt Lake City, Utah

Eventually, I received promising information in French about halo gravity traction by Dr. Jean Dubousset by telephone. I understood 50% of his advice because of my understanding of Spanish/latin and was highly grateful to receive his call.

Jacques D'Astous MD., FRCS., just one doctor with whom I'd been communicating with in America and sending x-rays to regarding our desperate situation, had also been communicating with Dr. Dubousset at the same time about Olivia!

Jacques D'Astous, MD., FRCS was the only pediatric orthopedic specialist in America to take Olivia's situation seriously and do something about it. He learned how to properly apply and accommodate halo gravity traction (HGT) from Jean Dubousset and invited us to the Shriners Intermountain Hospital in SLC to try it at age 2 in October 2000. Our local Children's Hospital refused to help and labeled HGT barbaric and experimental. There-

fore, they stated that health insurance companies would deny it.
I began making plans to relocate to SLC immediately and we moved into the hospital within a couple of months.

The first halo was applied at age 2. Combined with a Risser cast that had adjustable turnbuckles built in on each side (left/right). We lengthened the turnbuckles by a few simple rotations every day to distract the cast and spine. Her doctor was a perfectionist and made every accommodation to allow her to live in traction 24/7. She slept in an angled bed that was raised at the head end by a custom built, solid, large wooden box that encased the wheels for safety.

She was fitted with a tiny little walker with a flip down seat, so she could walk, run and be as normal as possible. Afforded the option to be ambulatory also prevented her leg muscles from atrophy because she was using them every day. The walker allowed the full benefits of traction because the weight of her lower limbs assisted in overall spine correction.

Two months later her dangerous 110-degree, thoracic curve decreased by half to a livable 42 degrees, allowing her little lungs to have more growing space for developing alveoli. Thankfully, HGT was a success!

Years of Treatment and Complications

We flew home with a removable Garchoia brace before her 3rd birthday and watched her spine deteriorate quickly in less than a year.

Back to Salt Lake City to begin alternating Risser casts with neck support in winter and braces in summer. This lasted for a few years until her severely rotated, growing spine reverted back to over 100 degrees.


Liv Noel wearing a Risser cast with neck support, age 4

More international research done, Dr. Min Mehta, MD., FRCS located and x-rays sent! My once-a-month phone calls to Dr. Mehta turned into everyday phone calls. She began sharing before and after x-rays with me on young patients she had cured with her EARLY treatment method of EDF casting. I was hooked. Every bone in my body said that we must try it and I invited her to America to train the team at Shriners in SLC. She agreed and I began raising necessary funds on my first infantile scoliosis group on Yahoo titled C.A.S.T. ISOP's first Early Treatment Trail Project was held in May 2005.

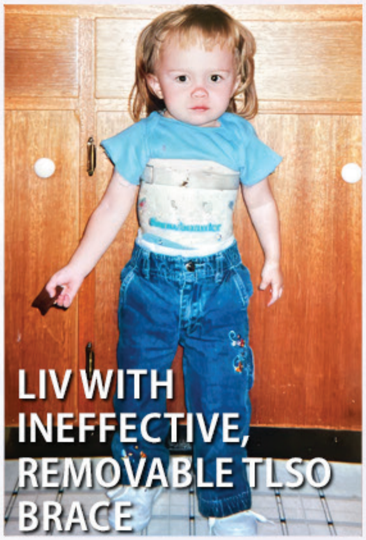

ISOP's first Early Treatment Trial Project. Salt Lake City. Shriners, May 2005

Dr.'s Mehta and D'Astous applied Livs first Mehta cast at age 5. Her big old Risser casts with neck support were no longer necessary, and she had a highly improved quality of life!

Properly applied Mehta casts combined with well-made EDF/TLSO braces got Liv Noel through the next few years. She swam in the summer and went snow sledding in the winter. She attended school with her peers of the same age.

Olivia had been in some kind of spine apparatus since age

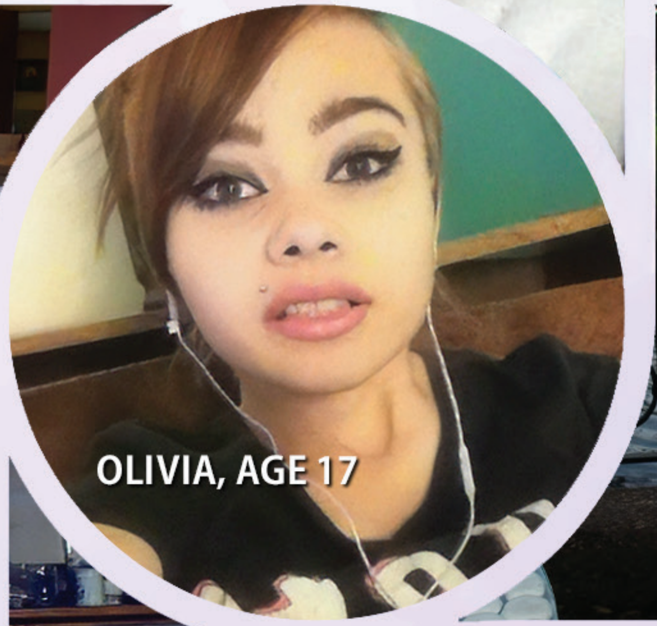
Olivia Through The Years


LIV WITH INEFFECTIVE, REMOVABLE TLSO BRACE


LIV SMILING IN HER FIRST HALO


LIV WITH B-DAY HAT & RISSER CAST


OLIVIA, 2008


OLIVIA, AGE 17


OLIVIA, 2007


LIV WITH 3RD HALO


LIV & DR. MIN MEHTA, MD., 2011

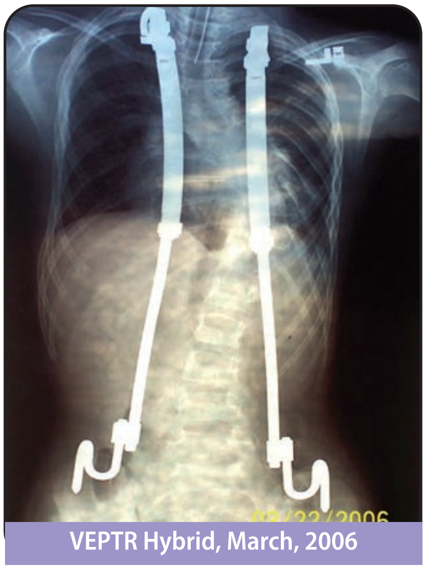

LIV ATOP HER BIKE

> "Heroism is endurance for one moment more."
>
> – George F. Kennan

one and could not stand upright without back support for more than 5 minutes. Without support she experienced major back pain and had to lay down.

Her spine degree had progressed to over 100 degrees again by age 7, so her 2nd halo was applied, followed by her 1st distraction hardware procedure. The dual Veptr (Vertical Expandable Prosthetic Titanium Rib) hybrid was attached at her iliac crests and upper set of ribs. The rods did not touch her spine. They were new, considered experimental and we had to attain compassionate use approval. No published evidence or longitudinal studies on this dual rod system had been accomplished. Naively, I opted for it because it didn't touch her growing spine.

Unfortunately, the Veptr had to be removed by age 9 due to repeated complications that caused 4-6 emergency, salvage surgeries. These complications came with pain, infection, psychological distress and PTSD for us both. The experimental rods created repeated erosion through upper set of ribs 4 times on both sides due to uneven pressure distribution. More visible rib deformities were created near kyphosis (rib hump). Large S hooks eroded so deeply into pelvic structure that they remained there permanently.



VEPTR Hybrid, March, 2006

Dr.'s Mehta and Dubousset insisted the ineffective Veptr hardware be removed immediately. The removal took place in SLC with Olivia's beloved and dedicated surgeon Dr. Jacques D'Astous.

Liv Noel and I were diagnosed with the hypermobile type of EDS by blood test. The true cause of her early spine deterioration.

3rd halo post Veptr removal yielded no correction. Not one degree due, due to 7 years of severe childhood scoliosis, uncorrectable rotation, diminished returns and ineffective, substandard hardware for Liv Noel's scoliosis situation.

Legacy and Lasting Impact

During and after Livs surgical procedures/complications (2005-2009), ISOP brough Dr. Mehta to 9 other pediatric orthopedic hospitals for hands on training. We invited patients to be examined and 99% qualified for proper Mehta casting the next day.

Finally, permanent rods were installed in 2007. She measured 65 degrees, thoracic, and required 3 weeks recovery.

Gratefully, her Colorado and SLC families were able to visit us often while we were in hospital over the years, so we were never alone. This was a positive distraction for our mental stability.

Liv attended Junior High and 2 years of High School post-rod recovery. She had good grades, loyal friends, and cousins to confide in and was able to travel with me to conferences abroad. She accompanied me to

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visit Dr. Mehta in England a couple of times and was a world traveler at age 10.
She grew into a teenager and had normal teen angst amplified by 10 due to the severe scoliosis and everything that comes along with it.

Sadly, her chest wall became extremely rigid by age 16. This combined with thoracic insufficiency syndrome created decreased lung capacity. Oxygen was prescribed and she refused it as a rebellious teen. Physical force was not an option.

By age 18 her lungs were functioning at 25%.

She passed away on February 28th, 2016, at age 18 surrounded by her mom Heather, her Nana Kris, her Aunt Jet and Auntie Gina.

Olivia Noel taught us all A LOT. In 2025 we are still learning. She was a reserved, gentle, brave, intelligent, fiery and physically beautiful girl. She faced ALL her challenges fully determined and with grace 97% of the time.

Her life-threatening situation was the catalyst in bringing international research to the forefront for babies with scoliosis in America. Not just for her, but for every child in the world diagnosed with this ravaging condition! They deserve NO LESS! Her short life inspired everyone around her to love, learn, live and forgive.

OUR HEROES

Dr. Jean Dubousset, MD., FRCS, Dr. Min Mehta, MD., FRCS and Heather, ISOP Founder - Spine conference 2007

Dr. Min Mehta, Olivia & mom, Heather

Dr. Jacques D'Astous, MD., FRCS and Heather, ISOP Founder. Spine conference Dallas, 2008

A Message From Heather Hyatt, Olivia's Mom, and the Founder of the Infantile Scoliosis Outreach Program

Thank you for reading Liv Noels story. Please learn from it and do all necessary research to develop the right care plans for your darlings with scoliosis.

*Research every procedure and discuss short/long term outcomes with other experienced parents.

*Investigate and ask your child's spine doctor about conservative approaches with Mehta/EDF casting at 25 degrees, not 70. Insist on discussing HGT prior to spine surgery, if your child is a candidate for hardware surgery.

*Insist on transparent dialogue between you and all medical professionals.

*If the curve is thoracic, relentless and affects lung space, begin dialogue with Pulmonary dept. to see if there's anything to be done proactively to prevent future respiratory compromise.

*Ask about your child's future and how to go about ensuring they have one.

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Outreach Program
A Program of Ability Connection Colorado

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