

Olivia's Life Changing Stem Cell Testimonial
25 April 2016

Olivia is a vibrant thirteen year old girl. She loves the beach, animals, art, music, soccer and has always dreamed of becoming a veterinarian. We live in Bermuda and she is a true island girl at heart.

Olivia was diagnosed with Systemic Onset Juvenile Rheumatoid Arthritis (SoJRA) at age three and a half and we were immediately referred to a top pediatric hospital in New England because there are no pediatric specialists in Bermuda. We struggled through seven years of debilitating inflammation, excruciatingly high fevers, chronic joint pain and deterioration. During these years, we would travel every two to New England every three months for medical evaluation and treatment. We worked with the best team of pediatric rheumatologists, ranked number one in the US, and despite their best medical efforts, we were never able to bring the disease fully under control.

In February, 2013, we received the heartbreaking news that Olivia had developed an overlap of pediatric Systemic Lupus Erythematosus (SLE). She was ten years and four months old. This was the beginning of an aggressive flare that resulted in numerous hospital admissions over the next few months and on May 22, 2013, we were on an air ambulance from Bermuda to New England for what we thought was a blocked artery in Olivia's wrist. Upon arrival in the pediatric ER, it was ascertained that the Olivia's heart was failing. She had no previous cardiac history and we could not comprehend what the doctors were saying at the time. Olivia was in immediate danger and we were told that she may not survive the next twenty-four to forty-eight hours. Olivia was admitted straight to Cardiac ICU for what was the start of a series of unimaginable events.

Olivia was on a ventilator, in and out of heavy sedation, with nineteen iv medications running at the same time because at that point, nobody could confirm with any certainty what was causing the damage to Olivia's heart so they were treating her for every possibility. Seven days after admission to Cardiac ICU, Olivia underwent a seven hour open heart surgery to repair her aortic valve. One of the aortic leafs had deteriorated, and was continuing to fail. Olivia's heart was unable to pump healthy oxygenated blood throughout her body and to the rest of her organs. The final conclusion for the cause of this heart condition was Libman Sacks Endocarditis caused by SLE and chronic inflammation. Thankfully, the aortic valve repair was successful.

Five days post-op, while still in Cardiac ICU, Olivia experienced her first grand mal seizure. It was then confirmed that Olivia had inflammation on her brain, which was caused by the Lupus. Two months later, on August 16, 2013, she had another major seizure at home in Bermuda.

In late August, 2013, we were informed that Olivia's lung function was suppressed, and she had inflammation in the lining of her lungs. Again, SLE was the culprit. From there, the Lupus began to attack her skin. Olivia developed ulcers and open lesions all over her face, arms, stomach, genitals, in her mouth and in her ears. Through all of this, she was still experiencing excruciating joint pain from the arthritis, along with dangerously high fevers, extreme fatigue and chronic inflammation. The Lupus was raging out of control and because of the disease, we decided to home school Olivia. She was unable to navigate a traditional school environment, but she desperately missed her friends and learning in the classroom setting.

In April, 2014, Olivia underwent orthopedic surgery on her left knee in an attempt to repair damage from osteonecrosis (dead bone) that was caused by our long-term use of steroids to treat the SoJRA and SLE.

In June, 2014, Olivia was admitted again for a severe Lupus flare. This was our first experience with intravenous chemotherapy and biologic medications, which seemed to work for a few months. She had an enjoyable summer, but by September, she was deteriorating very rapidly. In October, 2014, she was admitted for a second round of chemotherapy in combination with the biologic. A repeat of the treatment combination from June. It didn't work this time, and on November 14, 2014, we were on an air ambulance again, which eventually resulted in a three week stay in ICU due to a kidney injury that developed as a result of aggressive medical treatment for the Lupus and a flare of the shingles that had developed from the chronic inflammation. We were in New England for a solid four months, from October, 2014 through to January, 2015, during which time Olivia began a new biologic medication, in combination with a dozen other prescription medications she had previously been taking to suppress her immune system, manage her seizures and help control her heart condition. Upon discharge, our follow up visits and treatments were scheduled on a four week rotation and we began traveling from Bermuda to New England once a month. Olivia was still being home schooled during this time.

Despite everyone's best efforts, Olivia's condition continued to deteriorate. Her heart had developed two new issues, involving both the left and right chambers. Her lung function was down to less than 40%, the lowest it had ever been. She was still struggling with open sores and lesions, and the inflammation on her brain had worsened. Our medical team was at a loss as to how to bring the Lupus under control and resolve the chronic inflammation that was wreaking havoc on Olivia's body. She was deteriorating before our eyes and we all felt helpless.

Cardiology had consulted with her surgeon and they were looking to schedule her second open heart surgery, but were reluctant to do so until the Lupus had settled. Olivia was in a dangerous situation and rheumatology was pushing for a stem cell transplant as our only remaining option. We met with the stem cell transplant team in December, 2014, while Olivia was in ICU. Based on what they described of the process, a higher than normal mortality rate for Lupus patients going through this treatment, and an uncertain predictability for the outcome, we found it difficult to reconcile the risks against the possible benefits. We were facing a grave decision and it was at this time that we began feverishly researching all there was to know about stem cell transplants, and specifically stem cell transplants for pediatric lupus patients, which had not been done previously by our hospital in New England. Olivia would have been the first, and one of only a small handful of pediatric patients anywhere in the world to undergo this risky procedure in hopes of resetting her immune system.

In June, 2015, after an exhausting day of medical appointments and having been told by the cardiologist that he had consulted with Olivia's surgeon for her second open heart surgery; and having had another long conversation with rheumatology about the possibility of a stem cell transplant; we returned to the hotel and I began researching "stem cell treatments" instead of "transplants". In my mind, there had to be a better and safer alternative treatment for Olivia. My first generic search turned up "Stem Cell of America" and our life changing experience began from there.

I spent the next several weeks communicating with the clinic and learning all I could about the process; the types of stem cells; how they were administered; reading patient testimonials; interviewing Dr. Radar and the mother of a teenage patient who had a previous experience very similar to Olivia and had a remarkable recovery after receiving her stem cells through Stem Cell of America. Once we were satisfied that this treatment was a viable option and there were no known risks or potential side effects, we then made the decision to schedule the treatment and Olivia was booked for the next available treatment date. In our minds, the only risk was that if the treatment didn't work for Olivia, there would be a large financial loss. However, if it did work, the treatment could literally be life changing for Olivia, and for us as a family. We did not have the cash available at the time we confirmed her treatment date, but we had faith and confidence that everything would work out, and it did. Everything fell into divine order, including our ability to pay for Olivia's treatment without having to secure a loan.

Olivia was literally in a wheelchair traveling to the clinic. She could not sit, stand or walk without losing her breath because her heart and lungs were in such bad shape. She was in constant pain, and we were cautiously optimistic that this stem cell treatment would work for her, but maintained a realistic position that the treatment works differently for each patient. Not

everyone sees the same results, and some don't see any change at all. We hoped for the best and were prepared for the worst.

At 5:40am on Saturday, August 22, 2015, we were collected from our hotel and driven to the treatment clinic. We were nervous, not knowing fully what to expect, but Olivia was eager to get going with the treatment. We were escorted into a reception area, and a short while later moved into a treatment room next door. The clinic was warm and inviting. The staff were friendly and welcoming. They did their best to put everyone at ease. Olivia was seated in a reclining treatment chair and a team of nurses entered the room. Dr. Radar and his anesthesiologist followed shortly thereafter to ask if we had any unanswered questions.

When our conversation was finished, the nurses placed an iv in Olivia's left arm and began running normal saline through the line. Olivia then received four sub-cutaneous injections in the fat of her belly and she said they stung a bit at the injection site. The stinging lasted for approximately one minute.

Immediately following the four injections, the second set of stem cells were injected directly into the iv line. Fifteen seconds after injection, Olivia exclaimed "Oh, I feel something funny in my left knee!" When asked to describe the "funny" feeling, she couldn't put it into words. Olivia simply said "It's sort of like a tingling, but not really. It's a good funny, not a bad feeling." Immediately after that, she felt the same sensation in her left ankle and then in her right knee. It made sense to us that, if the stem cells were working, she would have felt those sensations in the joints she described because those are the three joints that are most severely damaged from the years of chronic inflammation and arthritis deterioration.

The clear saline continued to run for approximately thirty minutes after the second set of stem cells had been injected into the iv line. Once the iv was removed, Olivia leapt from the treatment chair exclaiming "I feel great! I have a lot of energy! Can we go now?" We were escorted back to the main reception area and a short time later, the shuttle returned us to the hotel. In total, we were at the clinic for less than two hours and the actual treatment itself took approximately forty minutes. Our round-trip travel time that day was less than four hours, and by 10:00am, we were enjoying breakfast at the hotel.

Immediately after breakfast, Olivia asked if we could go to the gym in the hotel and then go swimming. We were encouraging her to take a rest, but she declared that she really was feeling great and full of energy. Olivia insisted on going to the gym, which we did, and she proceeded to ride the exercise bike; run on the treadmill; engage in core exercises on the balance ball and work with the dumbbells. This workout was absolutely pain-free and lasted for about an hour, then she

was ready to jump in the pool. We continued to swim for another hour, before making her return to the room for a bit of a rest. Remember that this is a child who, four hours before, had been wheeled to the shuttle and supported/carried into the clinic (pre-treatment).

The next day, we visited the safari park and Olivia proceeded to walk unassisted for an estimated two miles in total around the entire park. The day after that, we paid a visit to Sea World, and again, she walked the entire park from open to close, all day. We rode the roller coaster at least two dozen times and she loved every second of it!

Nine days post stem cells, we returned to New England for Olivia’s once monthly check ups and biologic treatment. Our first appointment on September 1, 2015, was with Cardiology and Olivia had an ECHO done before seeing the doctor that morning. The cardiologist entered the exam room with a completely baffled look on his face, and we were bursting with anticipation. When asked what were the results of the ECHO, the doctor just shook his head and said “It’s a miracle. I don’t know how to explain it.” and then he proceed to describe what the ECHO showed:

Pre-Stem Cells (June 2015) ECHO	Post Stem Cells (September 2015) ECHO
Tricuspid Regurgitation - Severe	Tricuspid Regurgitation - Mild
Mitral Valve Regurgitation – Borderline Severe	Mitral Valve Regurgitation – Insignificant (Could Not Identify Any Quantitative Regurgitation From The ECHO)
Aortic Valve Regurgitation (Previously Surgically Repaired) – Borderline Severe	Aortic Valve Regurgitation - Unchanged

Olivia immediately started laughing and jumping with excitement saying “Mom, can I tell him what we did?!?!” and I was crying uncontrollably (tears of relief and joy). She then blurted out “I had stem cells and I feel great!” I had to quickly regain my composure and explain the procedure, the research that led to our decision, and relate the entire story of our experience with Stem Cell of America. Our cardiologist was grinning from ear to ear and simply said “It just goes to show you that sometimes doctors don’t have all of the answers. You took a risk and it paid off.” He then gave us a huge hug and sent us on our way, but not before paging Olivia’s entire team of medical specialists and telling them the story and the unbelievable results.

Our other appointments that week included pulmonology, neurology, rheumatology, just to name a few. Without describing all of the various components that make up a pulmonary function test, Olivia’s overall lung function had improved significantly and her gas exchange rate between her heart and lungs was the highest it had ever been:

Pre-Stem Cells (July 2015) PFTs	Post Stem Cells (September 2015) PFTs
Average Lung Function 70%	Average Lung Function 81%

She received the all clear from neurology and rheumatology was cautiously optimistic, but was amazed at how well Olivia looked upon exam. There were no signs of inflammation in any of her joints and they confirmed that all of Olivia’s labs, including her inflammatory markers and lupus indicators, were completely normalized. This was the first time in more than a decade that Olivia’s labs were normal.

Olivia returned to mainstream middle school in September, 2015. Two days later, she joined the girls’ soccer team at school, and in January, 2016, she received first honors for academic excellence during her first semester of middle school. Olivia has had an amazing journey during her thirteen short years, and we are grateful that Stem Cell of America is part of her life story.

It took me a while to write this testimonial. 1) I wanted to see consistency before reporting on the longevity of Olivia’s remarkable results with the stem cell treatment; 2) we’ve had some bumps along the way with what I refer to as “mini flares” and minor illnesses; and 3) I wanted to be very clear and concise in my reporting of our experiences.

Over the past seven months, Olivia has enjoyed mostly good health. We have slowly and steadily been decreasing her prescription medications on an approved taper with her medical team. Olivia’s labs remain completely normal; her heart is stable; and her lung function has improved by another five points. Her skin has cleared and the inflammation on her brain is unchanged, which is a good sign of stability. She has had a few mini flares, which include mostly joint pain and some occasional shortness of breath. The mini flares have lasted anywhere from three to five days, and Olivia has generally rebounded well and returned to normal within a short period of time. January was the most difficult month and the weather in Bermuda was extremely brutal with almost constant tropical storm conditions, which has always had a negative impact on Olivia’s health. Olivia was in a constant flare for most of January, 2016, but it was nowhere near to the extreme of her previous lupus flares, many of which had resulted in extensive hospital admissions. Olivia’s body seemed to catch up and she was feeling better once we entered February and the weather cleared up a bit.

Olivia's battle with Lupus may be a lifelong challenge, but I can say with certainty that Stem Cell of America provided an absolutely life changing treatment for our daughter and we would not hesitate to repeat the treatment if need be in the future. This stem cell treatment and the team of caring professionals at Stem Cell of America would be our first option over any traditional medical treatment at this stage. This experience has provided significant healing for Olivia and has literally improved every aspect of her life, and the overall well-being of our family.

Update: 22 June 2016

It has been exactly ten months to the day from Olivia's stem cell treatment and I can say with certainty that she is currently in full medical remission. Olivia's medical team confirmed this state of remission during her recent clinic visits, and Olivia has since been cleared to stop taking all previously prescribed medications. Labs remain stable and there are no signs of disease activity. Olivia's heart remains stable and her lung function continues to improve. We give thanks every day for being guided to Stem Cell of America and for the blessings we have received. We are eternally grateful for the miracles that are happening in Olivia's life!

Lovingly submitted by,

Olivia's Mom