

A journey to successful protection with Scenesse.

#SuccessWithScenesse

Our son, JT von Seggern has Erythropoietic Protoporphyrria, EPP. EPP negatively effects the liver, results in vitamin D deficiencies and causes excruciating pain – all from exposure to the sun. JT has experienced the painful effects of EPP since he was 2 years old. It took us 9 years of extensive research and numerous doctors' visits, including a trip to Johns Hopkins to finally get a diagnosis for what was causing our child so much pain. While gaining a diagnosis was a huge relief, learning that there were no treatments and no cure for EPP quickly knocked the air out of our initial relief. Exactly how does one go about protecting their now 11 year old, sports loving son, from exposure to the sun?

Daunting.

Through the ensuing years, JT experienced frequent pain, swelling, scarring, missed school days, and numerous rounds of Prednisone to bring down the swelling caused from exposure to the sun. Flash forward to the spring, 2015. The years of dealing with EPP and the understandable anxiety that accompanies such a cruel disease started to really take a toll on JT. By the time we picked him up from college at the end of the spring semester, it was agonizingly apparent that this cycle could not continue.

In May, 2015, we asked Dr. Silverman, the doctor treating JT if there were any new developments in treating EPP. There were none in the U.S. but Dr. Silverman mentioned a promising drug containing afamelanotide. I indicated that I wanted JT on that drug and while Dr. Silverman was sympathetic to JT's plight, he informed us that it would be next to impossible to get access to the drug for JT.

At that point, the mama bear in me went into full fight mode to protect. Through a miraculous array of previous untraveled avenues, a happenstance meeting in New York, calls to Australia, Italy the U.K. and finally a contact in Zurich.

*12, 670 miles traveled
2 cab rides
2 Trams
1 hotel
1 hospital
1 implant
2-3 months of vital protection*

JT received his first implant of Scenesse in Zurich, Switzerland on August 11, 2015.

The protection that JT received from this first implant of Scenesse was nothing short of miraculous and life changing. A whole new world has opened up for JT. He only missed one day of classes due to over exposure, his grades went up across the board, and he gained back his confidence and left anxiety in the dust of his shadow.

...a shadow that was made possible by the successful protection from Scenesse.

The journey to successful protection with Scenesse is not an easy one, but it is the only option available until the FDA accelerates approval for afamelanotide 16 mg.

As we pulled up to Dulles Airport for JT's second implant scheduled for January 12, 2016, a beautiful rainbow greeted us and we knew we continued to be on the right path.



JT was all smiles as we awaited our flight to Zurich

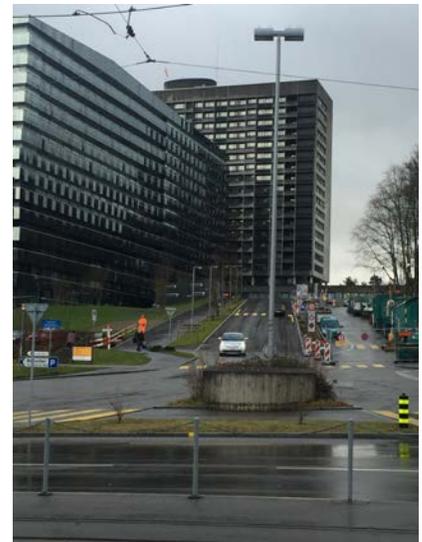


We arrived in Zurich at 7:55 am on Monday the 11th. JT rested up and prepared himself mentally for the procedure.

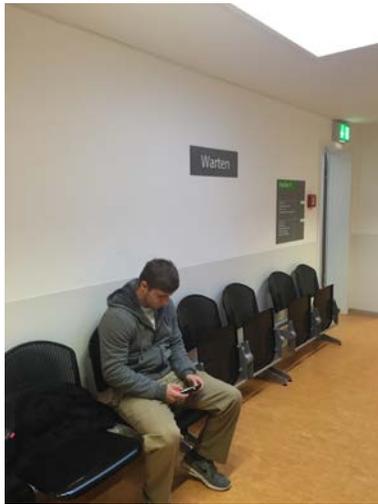


Tuesday morning we arose early, ate and walked a few blocks to the closest Tram station and took the #14 to Triemli Hospital

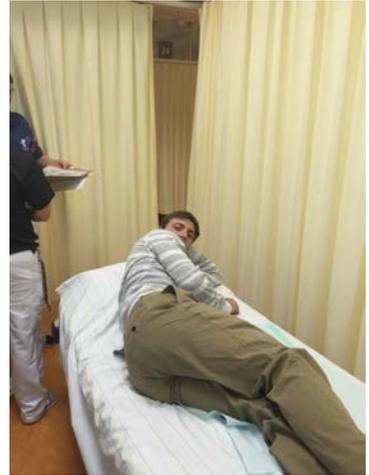
The hospital is just up the hill from the Tram station and off we trekked to Pavillion F in the hospital where the implant would take place. We were MUCH better at navigating this adventure since we had done this during our first trip in August.



After we arrived at the designated spot, we waited for JT to be called into the procedure room.



JT was called into the procedure area where we met with Dr. Minder and her assistant. Dr. Minder went over the procedure and then she prepped JT for the implant.



The numbing patch that Dr. Minder had given me in August to apply to JT's side did not totally numb him so after cleaning his side with iodine, Dr. Minder gave him an injection to thoroughly numb the area.



Next up, the actual implant! After it was all done and JT was bandaged up, JT rested for a bit just to make sure he was fine to make the trek back to the hotel.



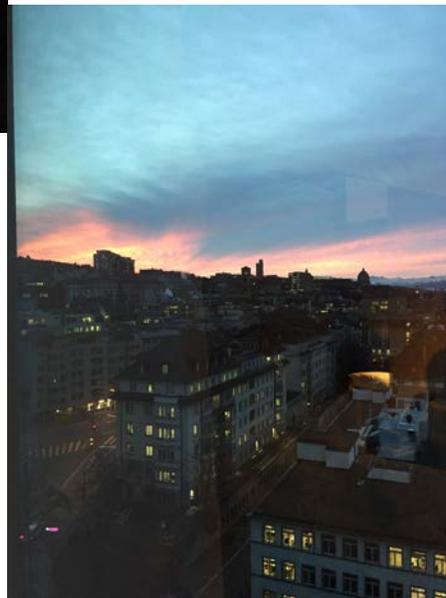


Knowing Scenesse was in his body and would soon be protecting him from the sun made even this rainy Tuesday one full of hope and promise. Singing in the rain was not out of the question! ☺

We walked back to the #14 Tram for the 20-minute ride back to the stop near our hotel.
JT rested the rest of the day.



Dr. Minder, Rocco Falchetto and Jasmin Barman joined us for a send off dinner. Both Rocco Falchetto and Jasmin Barman are EPP patients as well and being successfully treated with Scenesse.



After a good nights rest, we left our hotel and boarded our flight back to Virginia.



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JT's confidence knowing he is protected from pain for another 2 months shows on his face!

All this will be repeated again on March 8 for JT's 3rd implant of Scenesse.

The lengths to which one will go through to protect their child are incredible.

My question is, why? Why must we as American citizens go to such lengths to provide successful, safe protection from the sun? Accelerated approval for Scenessee (afamelanotide 16mg) is needed NOW. No EPP patient should be needlessly suffering.



And no EPP patient should have to endure all of this to live a pain free, healthy life.

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FDA, Approve Scenesse