

Andy & Sofia:

A Lesson in Health, Life and Hope

— by J. Doug Gill

It took all of 48 hours for young Andy Treviño to develop his first life-threatening infection. Andy, the then-newborn son of Andrés and Pauline Treviño, would – between the Mexico City hospital in which he was born and the Boston Hospital where doctors provided his cure – eventually log nearly 1,000 days of hospitalization.

“There were many times that Andy was so sick,” Andrés tells me, “that I was pretty sure this story was going to have a different ending.”

Andy was diagnosed with NEMO (nuclear factor kappa B essential modulator), a rare form of immunodeficiency caused by a mutation of the gene on an X-chromosome. NEMO causes sufferers to develop bacterial infections early in life and leads them to increased susceptibility to mycobacterial infections later in what is normally a very short life.

“Andy had infections and viruses all over his body,” Andrés explains, “and his body had no way to fight them. He had infections in his central nervous system, stomach, blood – even in a bone on one of his fingers.”

While the doctors in Mexico City could offer no answers, a friend of the family suggested the possibility of a primary immunodeficiency disease, sending Andrés on a path of painstaking research that eventually led him to Boston’s Children’s Hospital and immunologist, Dr. Jordan Orange.

“The first time I spoke to Children’s Hospital they suggested – given Andy’s vulnerability to disease – that we not fly to Boston. I told them I’d be there the next day.”

The survival rate for children born with NEMO is approximately 50-percent – and that’s with a successful bone marrow transplant – a complex, potentially life-saving procedure made even more difficult by the lack of candidates to provide a perfect match.

According to the National Marrow Donor Program as many as 6,000 people (worldwide) search for a bone marrow match every day, and less than 30-

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percent find one. Those who don’t find a compatible donor either die waiting for one, or find an alternative approach.

In 2002 the Treviño’s chose the latter, and by doing so not only saved their son’s life, but also created a controversy that still rages today.

“We searched public registries worldwide,” Treviño tells me, describing a futile process that would play out for two-and-a-half years.

As the fruitless search continued the Treviños could do little more than watch as this rare genetic disease robbed their son of his life – that is, until a number of doctors (including Dr. Orange) explained a process that could provide young Andy with his life-saving donor.

Instead of seeking a match, the Treviños could make one of their own.

“We didn’t really know what in-vitro fertilization (IVF) was,” Andrés adds, “but Dr. Orange explained the process – including the fact that only 1 in 4 siblings would be a perfect match. But having new bone marrow seemed the only way Andy was ever going to get a chance at life.”

In addition to learning about IVF, the Treviños would also become familiar with pre-implementation genetic diagnosis (PGD), a procedure that would assure Andrés and Paulina that another baby would be free of the inherited disease that was killing Andy.

“PGD allowed us to create a baby with the right genetic profile – a baby whose umbilical cord blood was free of NEMO,” Andrés says, “a baby that would give us the medical miracle with which we could cure our son.”

“We knew we had to deal with the moral and ethical aspect of our decision,” Andrés confides, “but I also knew what my family was facing so we had to make a life-changing choice.”

Yet, Andrés and Paulina didn’t just wade into the contentious waters of stem cells.

“We not only consulted with doctors,” Treviño tells me. “We talked to friends, family and priests who spoke to other priests and all of them had a positive response. Our decision was based on finding a solution that would save my son.”

Once in motion, it took five IVF cycles before the Treviño’s were blessed with a healthy daughter they named Sofia.

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Sofia and Andy Treviño

“It was absolutely the best day of my life,” Treviño says joyously, “when I first heard Sofia crying.”

Even with Sofia’s birth it would still take months before her healthy cells would be able to help heal her brother.

“It was a couple weeks after Sofia’s birth when we found out the number of cells obtained from the procedure would not be enough for Andy’s transplant,” Andrés says, “so we waited six more months until Sofia could donate an additional amount from her bone marrow.”

Today, the Treviños have a third child, two-year-old Tania, and Andy and Sofia are not only thriving, but are the stars of a book – “Andy & Sofia” – that was written by Andrés and Kate Kruschwitz of the Children’s Hospital Foundation.

“Andy doesn’t like the spotlight,” Andrés explains, “but Sofia loves it. She wishes she were a superhero.”

In some ways the now seven-year-old is a superhero – especially to her parents and brother.

Superhero status may even be reached by Andrés, as the father-turned-author is donating part of the proceeds from “Andy & Sofia” to the Immune

Deficiency Foundation’s NEMO Initiative in hopes that Andy’s story (and the Treviño’s financial contribution) may help other patients.

“It was Dr. Orange giving us a copy of the ‘Patient & Family Handbook’,” Treviño admits, crediting that IDF publication with his first exposure to the Foundation. “I was so impressed by the work IDF was doing that I couldn’t wait to attend the 2007 National Conference in St. Louis.”

Andy, meanwhile, is just like any other rambunctious 11-year-old. He plays soccer, loves to dance to Michael Jackson music and is working his way through scouting ranks having just reached the Webelos level.

“Andy’s treatment was about disease disability and potential death,” Andrés concludes, “and nothing else. If medical science offers an opportunity to heal the sick and relieve suffering I find no morality in blocking the path. Hope is a huge part of the human condition, and I’m all for restoring health, life and hope to all who need it.”

A portion of the proceeds from the sale of the book “Andy & Sofia” will be donated to the IDF NEMO Initiative. To order your copy from Amazon, go here for the paperback version: <http://amzn.to/idfnemoinitiative>, and here for the Kindle version: <http://amzn.to/idfnemokindle>.

