



NF NEWS

NEUROFIBROMATOSIS NORTHEAST

Promoting Research, Awareness and Advocacy since 1988



Lindsay Rosenfeld and Andrés Lessing with twins Elliana and Mateo

Facing NF's Biggest Challenges Head-On

When Lindsay Rosenfeld started dating the man who is now her husband, Andrés Lessing, she had no idea what neurofibromatosis (NF) was; however, for almost a decade, it has affected almost every aspect of her life, including how the couple would plan their family.

They were four months into their relationship when Andrés told Lindsay that he has NF type 1. Four months after that, he underwent his first NF-related surgery to extract what they thought was a nonmalignant tumor. He was subsequently diagnosed with a Stage 3 malignant peripheral nerve sheath tumor (MPNST) with rhabdomyosarcomatous elements (a triton tumor, rare even among sarcomas).

Andrés Lessing was 9 months old when he was diagnosed with NF1. His NF was the result of a spontaneous mutation and for most of his life seemed to be a rather mild case. He had scoliosis and some fine motor control issues that affected his handwriting early on, but he did well in his undergraduate studies at Brandeis University and went on to receive his MBA from Boston College.

Then came the shocking and threatening diagnosis of MPNST. In the first occurrence, he required major surgery, radiation, and chemotherapy. With the two subsequent recurrences, he required surgery and brachytherapy, and then "just" surgery. Seven years have passed since his last recurrence in July 2009, just after he and Lindsay were married.

Andrés and his extended family have been active within our community for many years, and one of his most critical contributions to NFNE was to develop our first website. Along with his father, Miguel, he also helped organize Friends Ride for NF, a bike ride on Cape Cod - which not only raised money and awareness for neurofibromatosis, but also provided the framework for the hugely successful Coast to the Cure Bike Ride for NF.

From the day that Andrés told Lindsay that he has NF, they agreed that their choices for starting a family would be driven by the 50% chance that they could pass the NF gene on to a child.

continued on page 4

IMPACT! - How can you help?

On page 3 you will see numbers that help demonstrate the impact that NF Northeast has made this year in the fight against NF. We are mindful that we never could have achieved those numbers without your support, but we must keep asking for your help until the fight is won!

One critical contribution you can make (that won't cost you a cent) is to write to your Senators and Representative in Congress to urge them to support federal funding of NF research. We can't predict how the new President and Congress will act in regards to our research programs, and now, more than ever, we must be a loud voice for everyone who lives with NF.

On page 5 you will see a compelling letter written by Dr. Tina Kell to her Senator in Maine. The NF Advocacy group delivered her letter to Senator King's office when they were on the Hill



continued on page 5