After IVF with PGD: Where Do We Go From Here?
Background
My Dad and I a couple of months after his diagnosis. He passed away 6 years later at the age of 58.

My uncle with his daughter and son-in-law. He developed GSS and passed away at the age of 57.
If my disease progression is similar to my father’s, in my early 50’s I will start to display the first symptoms of GSS and by the time I reach my late 50’s, I will be dead.
“Our borders and our obstacles can only do two things to us; stop us in our tracks or force us to get creative.”

-Steve Jobs
Why did I do IVF with PGD?

- For myself
- For my children
- For my dad
- For future generations to come
- For Bradley
Five years later…

• Why did I go public with my family’s story?

  – To hopefully raise awareness of prion diseases

  – Help at least one person feel like life is still worth living

  – To let others affected by a genetic disease (including genetic prion diseases) know that if they are considering starting a family, but are concerned about passing on a genetic disorder, there are reproductive options available. IVF with PGD is just one of those options. *Other options are listed on the last slide. For more details about these options, please feel free to contact me.*

  – To give others hope and the courage to get creative.

  – When life gets tough, put on your boxing gloves. Find your way to fight back. Robin Roberts said it perfectly, “Make your mess a message. Find the meaning behind whatever it is you are going through because everybody’s got something.” I’m using my something to help others who are going through similar struggles.
Options Available

- Natural Conception
- Prenatal Diagnosis
- Termination of Pregnancy
- Preimplantation Genetic Diagnosis
- Gamete (egg or sperm) donation
- Adoption

Amanda Kalinsky, RN BSN
Reproductive Options Consultant for the CJDF
amandakalinsky@gmail.com