

FXTAS - A Family Affair



My name is Nick Hertzog and I am 22 years old. Fragile X has affected me and my family in a lot of ways.

- I have a brother, Jake, who also has Fragile X. He is 17.
- I have an aunt who has the premutation, but it seems more like she has a full mutation.

QuickTime™ and a
decompressor
are needed to see this picture.



- My grandfather, Jack, has FXTAS.
- His mother, Sarah, had it, too, and probably her mother, my great, great grandmother.
- My mom is starting to show some signs.

- My brother and I were diagnosed with Fragile X in 2001, when I was 9 1/2 and Jake was 4.
- My grandfather was diagnosed with FXTAS in 2004 when we went to the MIND Institute.



Sarah

- 1990 - Sarah, my grandmother, was 74 when my father noticed a big change
- Food, hobbies, exercise
- No longer leading the family
- Repetitive behaviors
- Jack continued to monitor the situation
- Dementia? Mini strokes? Alzheimers?

Deterioration of the family

- 10 trips to Florida in 1 year period 1991/1992
- Sarah's adult FX daughter and dependent husband resistant to Jack's intervention
- Assisted living - 3-4 months
- Nursing home - 2 years
- In home care - 8 years

Sarah's daughter - Jeanie



- Withdrawn
- Resistant
- Hallucinating
- Separation anxiety
- Nervous breakdown

Sarah's decline



- Lack of awareness to eat
- Lack of awareness of bodily functions
- Walking to walker to invalid
- Stopped speaking
- Hands became claw like

Jack - my father



- 1991 Jack married Kathy
- 1994 at 52, foot issues: cold, tingling, cramps, pain
- 1995 early retirement
- 1996 - Lahey Clinic diagnosed CMT
- 1994-2003 leg cramps, drop foot, intense foot pain, balance issues, slight tremors

Early stages for Jack

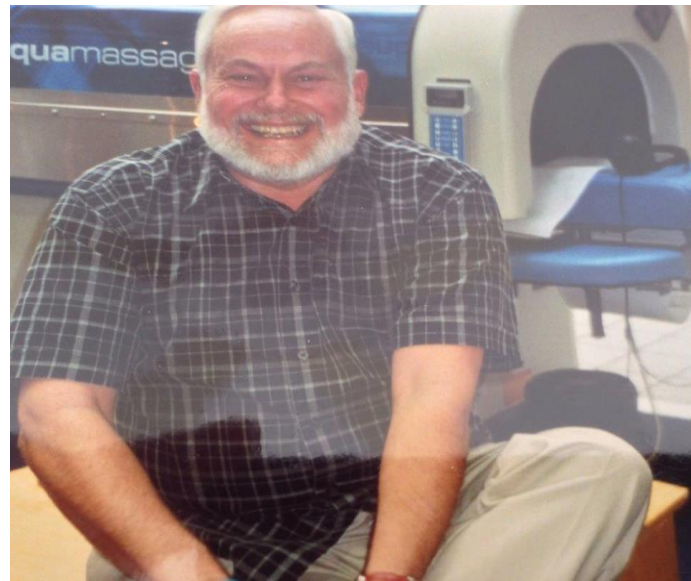
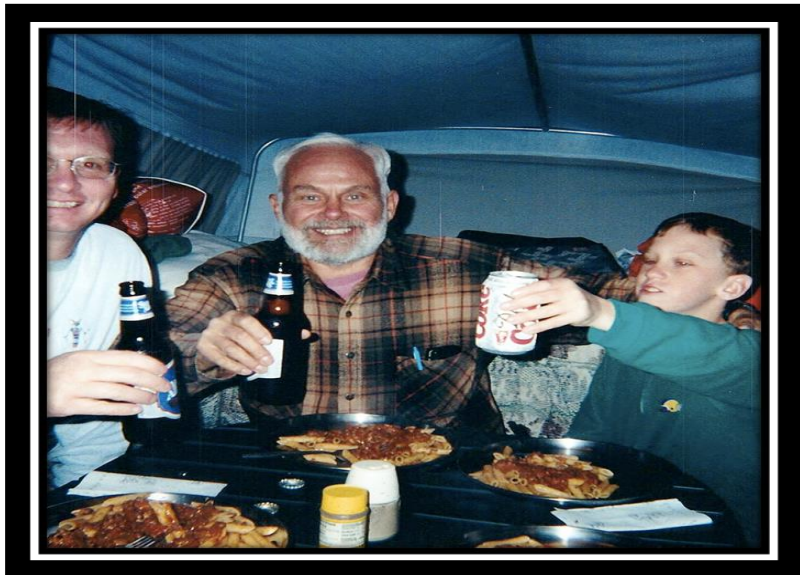


- 2001 learned about Fragile X - Nick and Jake diagnosed. Jack, Jean, and I carriers.
- 2002 My first conference and spoke with Randi Hagerman about Jack and Sarah
- 2004 - MIND Institute diagnosed FXTAS at 62
- 2005-06 numerous falls
- 2006 serious fall with concussion - cane

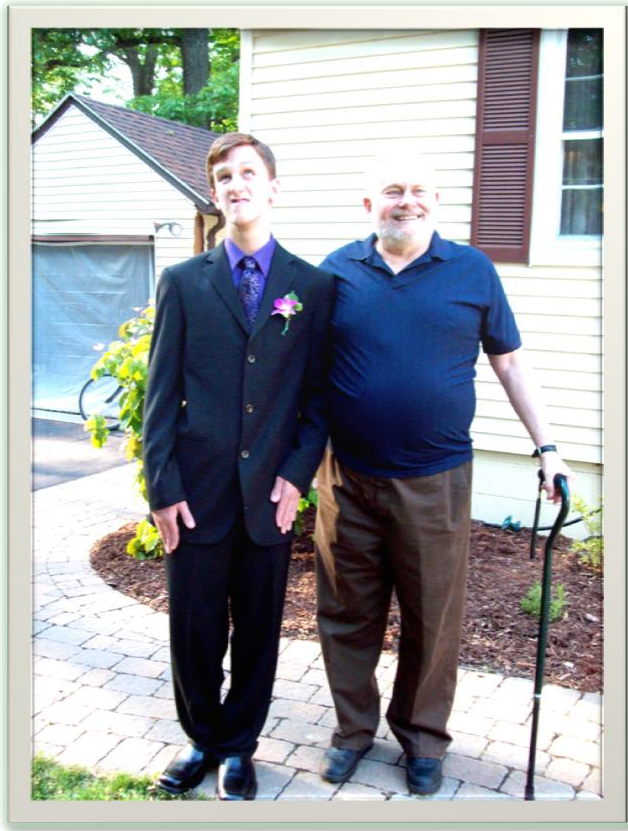
Later stages

- 2007-08 prostate cancer/radiation
- 2009 diabetes led to walker full time
- 2011 scooter/van with lift
- 2012 began home care 12-16 hrs/wk
- 2013 home care 43-70 hrs/wk
- 2014 motorized wheelchair with handicapped van

Jack



Realities of FXTAS



- Vibrant, outgoing, dynamic
- Sedentary, distant
- Needed lots of rest and became “old” long before he should have
- Decline in cognitive functioning
- Disinhibition, irritability

Changes for Kathy, his wife

- Physical and mental changes overwhelming
- Now married to a “different” person
- Acknowledge feelings of frustration, grief, anger, resentment, feeling tethered
- Need to take charge of house, money, all decisions, and care for Jack becomes the new normal
- Living in a fishbowl
- Remember to pat yourself on the back.

The Caregiver



- Recognize your limitations
- Find new ways to take care of yourself
- Do not let yourself become socially isolated.
- Acupuncture, massage, yoga, meditation, deep breathing
- Seek professional help!!

Finances of in home care

- Making your home accessible
- Handicapped vehicle
- Hiring staff
- Medical supplies
- Cost of maintaining home
- PT & OT
- Hospital bed, lift

“Tears”

by Washington Irving



There is a sacredness in tears.

They are not a sign of weakness, but a sign of power.

They speak more eloquently than 10,000 tongues.

They are messengers of overwhelming grief, of deep contrition, and of unspeakable love.

