- o 25 years old
- Leibler-Yavneh
   College until year 10
   with teacher aide,
   speech therapy, OT
   & special education
- ORitalin & Zoloft



- o Work experience Delamere SAH
- o TAFE Certificate III in Hospitality
- o Catering Assistant Montefiore Homes for the Aged
- o14hrs pw on M, W, Th





- o Drivers license '08
- o Carer for grandparents
- o Cooking, cleaning, finding lost glasses, driving to errands and doctors visits



#### OUR CAR





o I enjoy fishing, computer, watching TV, listening to music, dog training and I'm getting better at bowling





# What helped me in school (curriculum modification)

#### o Teacher made subject easier by:

- Showing picture book
- Watching video
- Using internet / newspaper eg weather
- Using my interests with reading e.g. cars, number plates, animals
- Using humour, smiling, relaxed vibe

#### WHAT DIDN'T HELP

oPutting me 'on the spot'
e.g. "Michael, tell us about this topic"
oLots of written information with no pictures
oLots of talking without breaks
oNoise, loud, stern voices made me anxious
oChanges in timetables without preparation

ANY QUESTIONS?

## Aaron Joseph Heisel

Cincinnati, Ohio

32 years old





Diagnosed 1999

FXS Full Mutation

## My Family



**Above:** Brother's – Dan and Scott – Sister's – Kris, Amy, Becky, Paula, and Leah – Mom and Dad

At Right: Extended Heisel Family (Nieces, Nephews,

Brothers, Sisters, and In-Laws

**Below:** Sister Paula and Niece Chelsea (Both have FXS Full Mutation



## Heisel Family



# GROWING UP Unaware of Fragile X

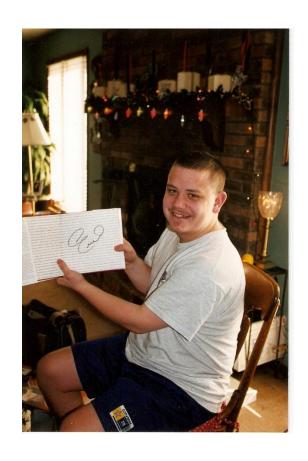




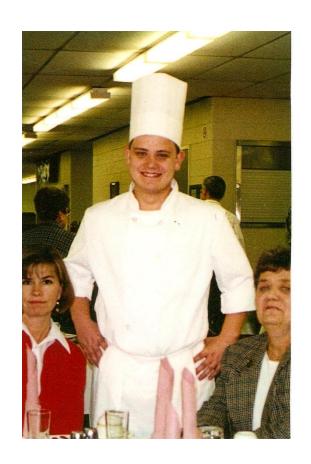




## Chef Training



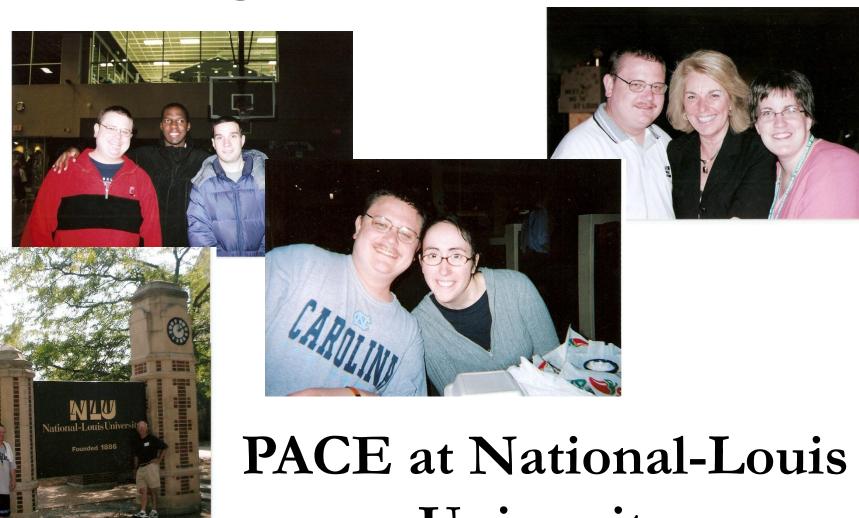




Emeril Lagasse

Work World=Discouraged

## "Change my life"



University



Graduation





Caffe Barista and Deli

## **PACE – Transition in Evanston**



### Home and More Lessons



**Above:** Batting in Special Olympics **At Right:** Special Olympic friends – Travis and Mike





At Left: Personal Trainer – Laurie Below: Bowling at Western Bowl



#### Activities

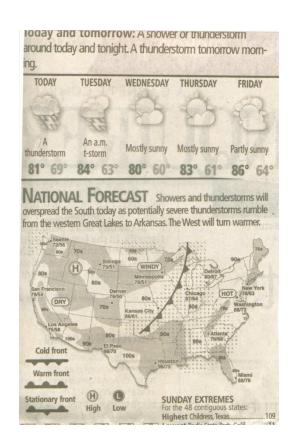
#### BIGGEST PROBLEM - ANXIETY

- Medication difficulties
  - PACE Transition Program 2009
  - Weaning off medications for drug study 2010-2011
- Medication Management
  - Tim Freemon, MD Family Practice
  - Craig Erikson, MD Psychiatry/ FXS Specialty
- Still working to get right combination/dosage

#### Causes of Anxiety

- Severe Weather
  - Since a very young age





#### Causes (continued...)

- New Situations
- Not knowing expectations of others
- o Uncertainty/what to do
- Unclear/misunderstood direction
- Criticism from others especially harsh tone of voice
- o Rush
- Feeling of too much to do OVERWHELMED

#### REACTIONS WHEN ANXIOUS

- Shuts down can't leave home
- o Fear
- Anger
- o Panic attack
- Explosion/implosion

## DIFFICULTIES CREATED BY ANXIETY/REACTIONS

- Keeping jobs
- o Misunderstanding with family and friends
- Frightens others

#### HELP FOR ANXIETY

- 1. Medication
- 2. Hot, hot, HOT food
  - Trip to Wild Mikes for "stupid hot" wings
  - AJ adds hot sauce, red, cayenne, and Jalapeno

peppers to everything

- 3. Breathing exercises
- 4. Calming Music



#### KEEPING BUSY

- Helps with anxiety
- o Walking and working out at Bayley Place
  - Trainers Laurie, Carmen and Maureen
  - Up to 5+ miles
- Monthly events with Starfire
  - Lazer Tag
  - Sporting events
  - Movies
  - Dinner





#### GOING OUT WITH FRIENDS



Movies, dinner, and Reds games

#### SPECIAL OLYMPICS

- Soccer
- o Basketball
- o Baseball
- o Bowling



#### FAVORITE SPECIAL OLYMPIC SPORT

#### Weight Lifting

- has won many metals







#### WHAT'S NEXT?

- Finding a job!!
  - Help from Hamilton County Disabilities Services
- Dream Job?
  - Working at Kroger's on Delhi

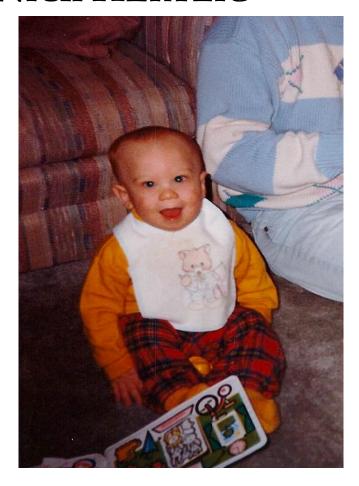


#### PRESENT JOB

- Helping out with his Nephew Larry
  - He is 15 years old and has FXS too
  - Especially going out to lunch, bowling and hitting golf balls



#### NICK HERTZIG









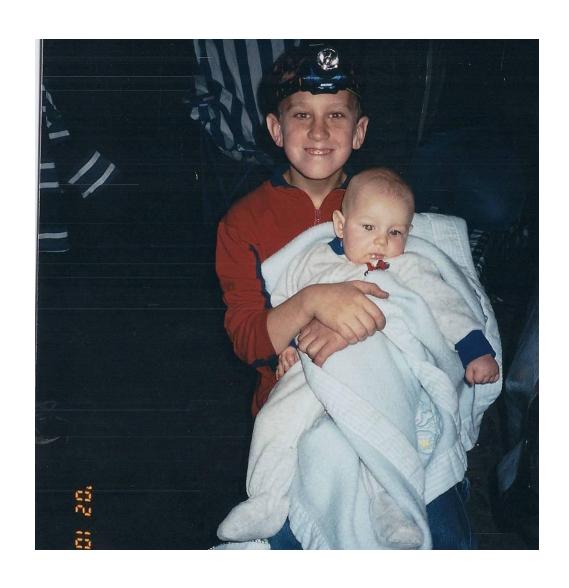
My Sister

#### My Great Grandma





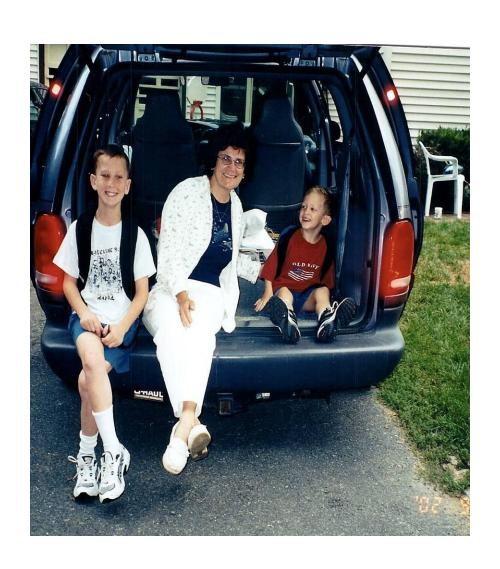
#### MY BROTHER



#### **EDUCATION**

- Elementary School Regular class, Resource room, classroom aide, OT, Speech, Adaptive PE, Counseling
- Middle School Integrated class, 1:1 aide, Reteach/Resource, Speech, Counseling
- BOCES (Vocational) CNA class, TOPS class
- High School Regular classes, Resource, 1:1 aide, Counseling

#### FIRST DAYS OF SCHOOL



#### SCHOOL VOLUNTEERING

- Craft fair cashier
- Basketball timekeeper
- Stage crew
- Golf Tournament
- Fundraising

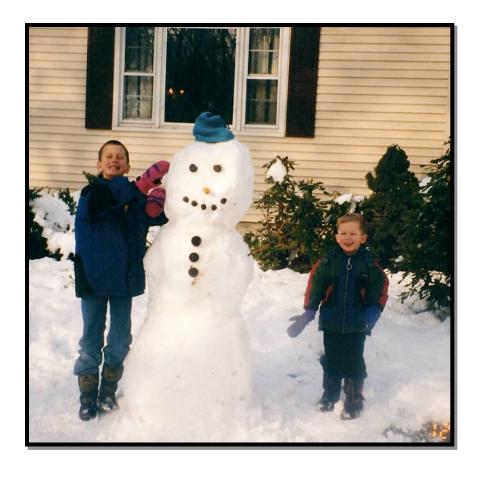
# **SPORTS**





# \*WINTER FUN\*





#### BASKETBALL!





# MY FIRST COMMUNION





My Confirmation

#### MY PIANO RECITAL

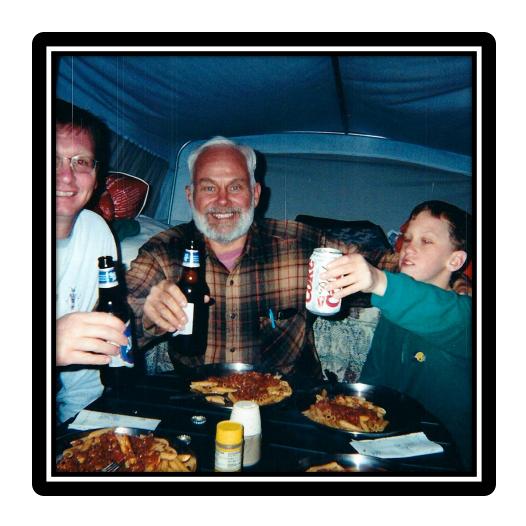


#### SUMMER "VACATION"



# MY BROTHER AND SISTER





HANGING WITH THE GUYS

# JUNIOR PROM NIGHT



#### MY ACCOMPLISHMENTS IN HIGH SCHOOL

- Algebra Award − 3 years in a row
- Inducted into National Honor Society
- Eagle Scout
- Pride of Ulster County from Legislature

# Eagle Scout



#### **VOLUNTEERISM**

- o Road cleanup
- Food pantry
- Food Drive
- o Meatloaf
- Christmas caroling
- Town Library improvements

# WORKING HARD

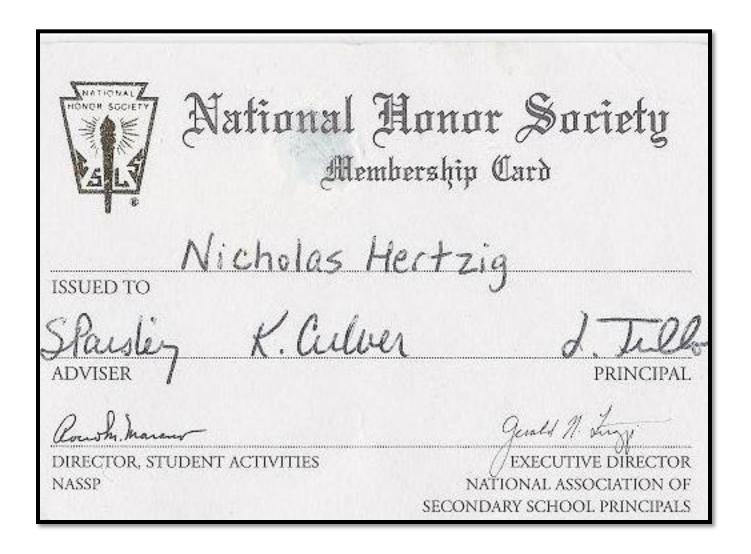




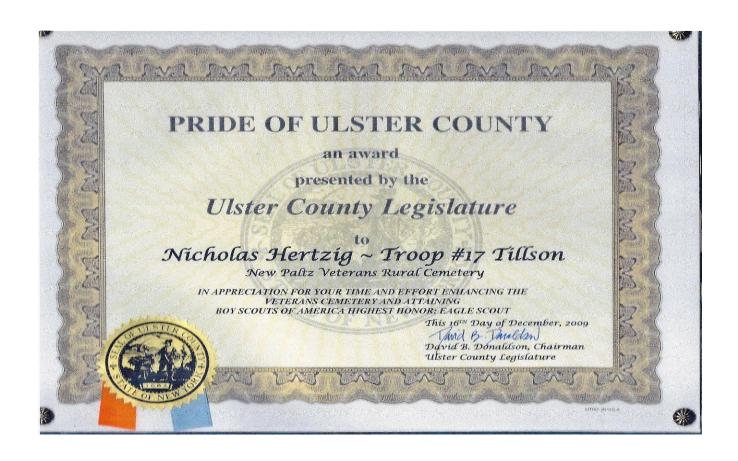
## JOB EXPERIENCE

- Town weed crew
- Scout camp CIT
- Vocational High School half day community job training
- Scout camp Staff

#### NATIONAL HONOR SOCIETY



#### PRIDE AWARD



#### SENIOR PROM NIGHT





# 2011 HIGH SCHOOL GRADUATION



#### TRIPLE "C" AWARD

# STATE OF NEW YORK OFFICE OF THE ATTORNEY GENERAL

# Triple "C" Award

Presented to

Nicholas Hertzig

In recognition of your tremendous COMMITMENT to bettering yourself, your school and your community; your strength of CHARACTER, which has helped you to achieve your goals and will guide you in making the right decisions in the future; and your remarkable COURAGE, which will aid you in meeting all of the challenges ahead.

ERIC T. SCHNEIDERMAN
Attorney General

06/02/2011

#### I AM A BOY SCOUT LEADER

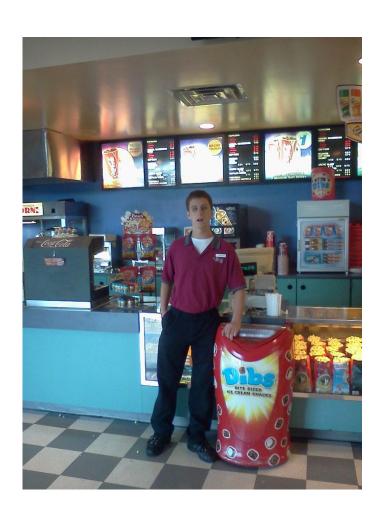


## FRAGILE X ADVOCACY DAY





#### EMPLOYEE OF THE MONTH



o I work at the movie theater, and I get to see all the movies I want. My family can go for free, too, as long as they buy the popcorn!

#### POPPY AND ME



o When I am not working at the movie theater, I take the bus to my grandpa's house to help him out because he has FXTAS.

# THIS IS MY DOG, SAM

