

My Journey with Ataxia

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Downingtown, PA



“Soaring Mile High
for a Cure”

National Ataxia Foundation

2015 Annual Membership Meeting

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Presenter Disclosures

- Michael Cammer
- The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:
 - No relationships to disclose or list



My Journey with Ataxia

▶ When I was first asked to talk about my journey, I started thinking about my timeline, I didn't realize I had been on the "Ataxia Cab" for 25 years now!

▶ Just one person can make a difference!

▶ **DON'T BE SHY!!!**



Sunny days ahead! Life before Ataxia

- ▶ Life up to 1989 was pretty good!
- ▶ High school/college
- ▶ Athletics and outdoors
- ▶ Navy
 - ▶ Community college/2nd job
 - ▶ Triathlons
 - ▶ Assistant wrestling coach
 - ▶ Just about everything I did was to prepare to return to school



Getting Cloudy

- ▶ 1990 - 1992
- ▶ Returned to college and started competing again
- ▶ What was happening to me? !!!!!!!
- ▶ 1ST noticeable loss of balance
- ▶ Had two good seasons and led the team with 20+ wins and was Team Captain at Mansfield University
- ▶ Did not return to Nationals, but maybe more rewarding – I was named 1st Team Academic All-American twice and 3 time PSAC Scholar Athlete



Dark Days

- ▶ 1993 - 2006
- ▶ Confusion/the unknown- thought I was hiding symptoms
- ▶ Quit playing softball – could not see ball anymore, loss of pursuit and developed double vision
- ▶ Stopped entering triathlons – could not run or ride bike anymore
- ▶ Worried about my job in law enforcement
- ▶ Visited neurologist on 2002 for 1st time, couldn't find out why so he sent me to PT, PT ask me to squeeze tennis ball???
- ▶ Some light –
 - ▶ Met my wife
 - ▶ Got married and started a family
 - ▶ Became Head Coach of Coatesville HS wrestling team



Stormy Dark Days

- ▶ Got an MRI in 2006 for painful shoulder, was told nothing wrong with shoulder, BUT...
- ▶ Sent to neurologist
- ▶ Diagnosed with spino-cerebellar degeneration
- ▶ First time I heard the word Ataxia and other vocabulary words
- ▶ Not a good experience with neurologist
- ▶ Overwhelming feeling of fear
- ▶ Really noticed speech after phone message



Hurricane Season

- ▶ Anger/resentment
- ▶ Periods of depression/helplessness
- ▶ Loss of identity
- ▶ Sold my H-D Sportster
- ▶ Embarrassment about being handicapped
- ▶ Gave up coaching for family/personal safety

My Family!



Michael Boykin

197 lb at NC State





How Wrestling has helped

- ▶ Tenacity and determination
- ▶ Quickly change direction
- ▶ Don't reach when you fall
 - ▶ Unless it is to protect head/face!
- ▶ TUCK AND ROLL
 - ▶ This may be against all instincts
- ▶ There are many challenges still!
 - ▶ Stairs, cabinets, doorways, buttons and other small objects



Sunshine after the storm

➤ Found NAF!

- Accepted Ataxia by self naming diagnosis –
 - Shoulder Shrug Ataxia
 - The hardest door I ever opened was the one to acceptance!
- New purpose in life
- Became involved with support group
- Do research when available
- Fundraiser at Boscov's
- Ataxia Awareness table in "Times Square" area of VA hospital I work at

The re-discovery of wheels!

- ▶ 1st recumbent trike demo at 2012 DE/PA “Walk, Run n’ Roll”
- ▶ June 2014 - Got my trike!



Ride, Ride, Ride and Go On 3!

- ▶ Found “National Bike Challenge” website
 - ▶ <https://nationalbikechallenge.org/>
 - ▶ I was #6678 out of 47,592 registered riders!
- ▶ Got local paper from hometown announcing the 16th Annual Tour de Shunk
- ▶ My “Go on 3! for Ataxia Awareness” fundraiser was born!
- ▶ Raised just under \$2,000 for NAF and around \$300 for the “ThinkBig Pediatric Cancer Fund”
- ▶ Mission complete for awareness!!! 102.5 mile ride was finished and Ataxia was the buzz word at the “Tour de Shunk” and in the Sullivan Review!
- ▶ Expand “Go On 3! for Ataxia Awareness

Observations about Internet and Social Media

- ▶ It is a great thing for finding information about Ataxia, research and staying connected, BUT
- ▶ It can also be bad, very bad!
- ▶ By not knowing I was pulling in several different diagnosis's and some of it was not pretty
- ▶ It can reach out, but isolate! There are many awesome Facebook pages out there relating to Ataxia to stay connected, but we don't need to spread awareness amongst ourselves. Get out and verbally tell at least one person a day
- ▶ REPEAT! Become involved with support group, don't just be in the support group, BE THE SUPPORT!



Educate, Educate, Educate!

- ▶ Just remember one thing:
 - ▶ ***“Every expert was once a beginner!”***
- ▶ There has to be a beginning and we need to use this for ataxia awareness and educate!
- ▶ Tell at least one person a day about Ataxia!
- ▶ Brain Health Fair in Washington DC on April 18th



We are not alone!

- ▶ Ataxian's fall down enough on our own, we cannot let it keep us down!!!
- ▶ Ataxia is something that we have been dealt. It is a burden we must learn to carry and overcome. We choose to make a difference!
- ▶ You are not alone – There are an estimated 150,000 of us, not including family and caregivers, Researchers and of course the NAF. Use this network for support, to build friendships and spread ataxia awareness.
- ▶ You have all taken the first steps just by being here!

MAINTAIN FITNESS!!!

- ▶ Work-out daily!
 - ▶ Walk the dog!
 - ▶ Get a trike!
 - ▶ Check out adaptive sports.
- ▶ I encourage and challenge you all to get strong and be strong for yourself, your family and friends and for the Ataxia community. If we are strong together we can find an answer and cheat Ataxia.
- ▶ I was told at Kennedy-Krieger Movement Clinic that I was an unfair patient because I've maintained my fitness and she had to come up with ways to make things more challenging!



My Journey with Ataxia

- ▶ In closing, I would like to rephrase a famous presidential quote by JFK:
- ▶ Ask not what Ataxia has done to you, ask what you can do for research and to spread Ataxia Awareness!
- ▶ YOU CAN MAKE A DIFFERENCE!!!

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