



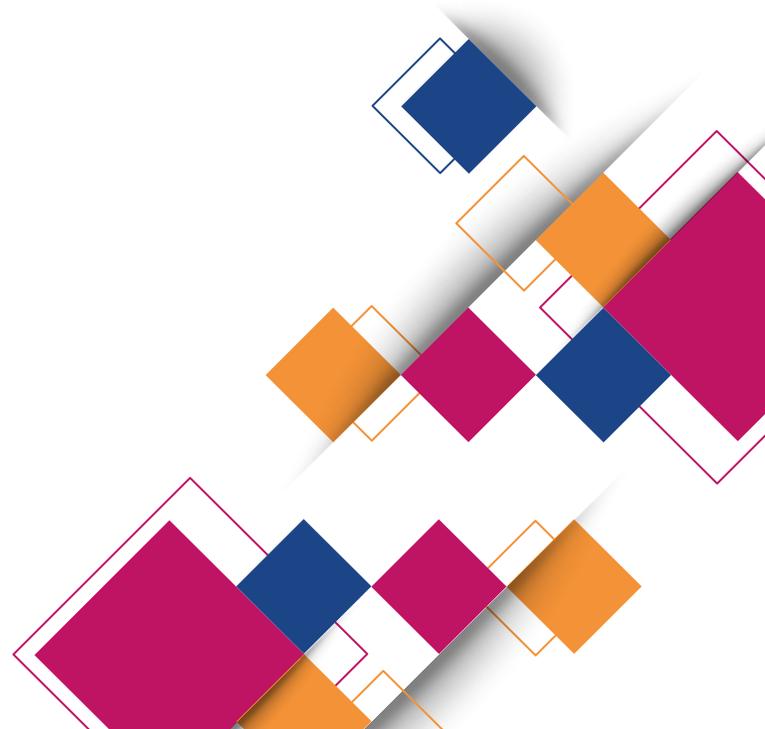
IBM

Hello! I'm Rod Jansen.

Dysphagia, 15 Years Ago

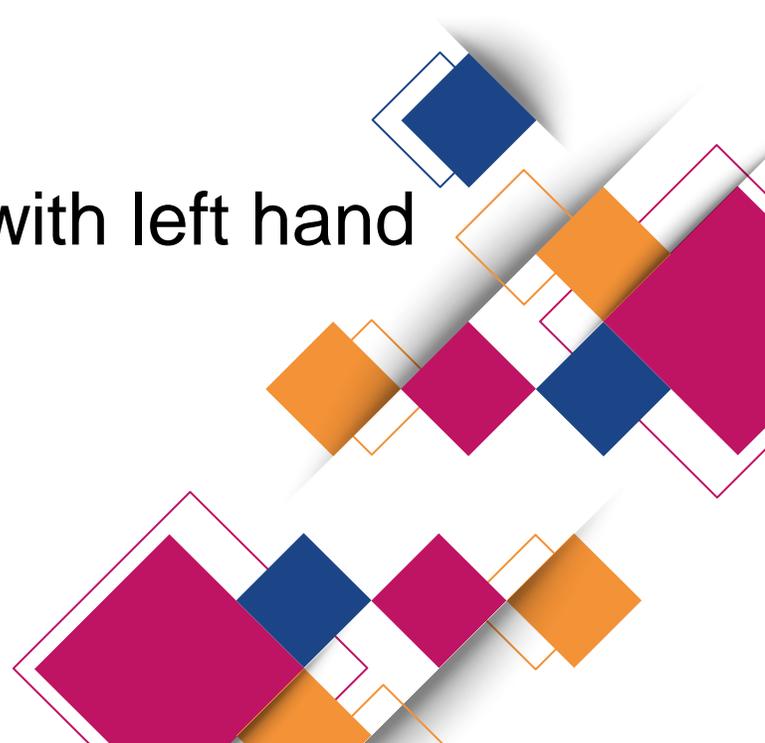
Dysphagia, 15 years ago

- Consulted Gastroenterologist and ENT – both said nothing wrong
- Learned to live with swallowing issues
 - Diet, care swallowing
 - Heimlich training with family



Other IBM Symptoms, 8 Years Ago

- Occasional falling on tennis court, became more frequent over 2-3 years
- Falling at home
- Problems with stairs and steps
- Inability to open dishwasher and screen door with left hand



Consulted Family Doctor, 3.5 Years Ago

- Family doctor thought I had ALS and referred me to a Muscular Neurologist
- Specialist happened to be leading expert on IBM in Canada at Hamilton McMaster University Hospital
- EMG and strength tests
 - Diagnosed IBM same visit – no muscle biopsy needed
- Diagnosed within 1 week of first doctor visit (national average time to diagnosis 5.5 years)
 - Avoided misdiagnosis and mismedication
 - Prescribed exercise program
 - Referred to Speech Pathologist and Gastroenterologist who work with IBM patients
 - Esophageal Dilation performed last year for dysphagia

Living With IBM

- Supervised exercise twice a week at local university which supports people with disabilities
- Use a walker/rollator, installed stairlift, purchased scooter, renovated bathrooms to make accessible
 - Significant costs to living with IBM – more to come
- Occasional falls with varying degrees of injury and constant fear of falling
- Take Creatine (3 grams/day), CoQ10, vitamin D, Omega 3
- Follow-up with neurologist every year
 - Strength testing each year measured against baseline from year one
 - 50% loss in legs, arm strength the same, loss in flexors on left hand significant
- IBM becomes isolating
 - Can't visit friends or family because of accessibility
 - Constantly aware of accessibility
 - Even doctor's offices and hospitals are difficult
- Travel very difficult – especially air travel
- IBM very hard on family, especially as condition deteriorates
- Future may bring assisted care
 - Possible insurmountable expense



The Future

- A Cure!
 - While we cannot restore damaged muscle, anything that would slow progression would be wonderful!

