



Alice's Journey

Living with Erdheim Chester Disease

Facts

- 36 yrs old
- Normal childhood
- Started falling in my 20s
- First CT and MRI fall 2005 (26 yrs old)
- Diagnosed with ECD feb 2011

Long Journey

- Been to 3 hospitals, many doctors..countless MRIs, biopsies
- Doctors practically gave up calling it an unspecified neurological disease

Symptoms

- Stumbling a lot
- Bad balance
- Stiff legs
- Dizzy
- Peeing and drinking nonstop

Saved by Dr. Tzoulis

- Referred to Haukeland Hospital fall 2010.
- Admitted for 2 weeks in december.
- Took same tests
- Dr had a suspicion about ECD by then
- Final bone biopsy gave answer

Medication

- Started interferon 3 x week
- Little effect – lots of fatigue
- Botox in legs – little effect

Erdheim Chester Global Alliance

- Quickly after diagnosis got in touch with the ECD Alliance.
- Numerous emails
- Knowledgeable people, Norway knew so little.
- NIH fall 2011 and 2012.

BRAF +

- Heard about BRAF gene and new medicine.
- Sent email to Dr. Estrada- needed biopsy to test for it.
- Took 9 months until tested.
- Answer came quickly I was positive.

Vemurafenib (Zelboraf)

- Cancer drug for melanoma
- Same gene
- Start dose 2 +2 – enormous joint pain
- Reduced to 1 + 2 after 3 weeks
- 1 month check there was change on my MRI
- Lesion in my spine was 3 mm smaller

Clinically before zelboraf

- Walking got worse from 2011 to 2013
- Could now walk only 500 m with walking sticks
- Life in wheelchair was getting closer
- Losing strength

After zelboraf

- 1 month later joined a gym
- Did lots of walking on treadmill
- 1 km – 2 km- 3 km – 4 km
- Weightlifting

Zelboraf cont..

- 3 month checkup even better
- 6 month checkup normalized lesion in spine
- Now scar tissue

Exercise

- Dependent on exercise
- Physical therapy 2/week
- Personal trainer 1-2/week
- Workout at gym on my own almost daily
- Walks with walking sticks
- Warm water exercise classes 1/week

Exercise cont..

- More exercise I get the better I feel.
- Can not sit more than one hour- legs stiffen
- Exercise is my new way of life not just because it is healthy but is much needed.
- Would not be where I am today without hard workouts, walks, not giving up

Motivation

- See small differences to the better so this motivates me.
- Set goals for myself and don't give up easily.



Dalsnuten
spring 2015



Kvinesdal
Summer 2015



Personal Trainer

Spring 2015



Pulpit Rock sept 2015