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MY NEN LIFE with  
Active Carcinoid  
Syndrome



# MY NEN LIFE with Active Carcinoid Syndrome

- 73 years old
- 2017:
  - Three colonoscopies
  - Large growth in the large intestine – Annual “Keep an Eye on IT” recommendation
  - Second opinion with Gastroenterologist – Still Annual “Keep an Eye on IT” recommendation
  - Until the doctor heard - ~6K weight loss in the previous month

- CT: - Large NEN growth at the Large / Small intestine connection
- Surgery – Tumor removal, a few hyperdense spots detected in the liver and ileum
- G2 / KI67 7%
- Severe diarrhea, occasional stomach pain, weight loss, exhaustion

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Lady Luck!!!



- Sandostatin 30mg / 28 days
- PET CT with GA 68 every six months
- Blood tests + 5 HIAA
- November 2017:
  - Increased uptake on both liver lobes, abdominal lymph nodes and L5 vertebral lesion
  - Weariness, low energy, 7-8 diarrhea episodes daily
  - 5-HIAA 6.3, CgA 313 from 130
  - Started TASECTAN(OTC)
  - Started CREON 75K units x 3 times daily

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- April 2019
  - Weariness
  - Still 6-7 diarrhea episodes daily
  - 1.5kg weight loss
  - GA 68 PET CT:
    - Increased uptake on known lesions
    - CgA increase to 399.6
    - 5-HIAA – 11.7
    - No sign of cardiac issues
  - Sandostatin 60 mg every 28 days
  - Started XERMELO

- December 2019:
  - First round of PRRT
- Small bowel obstruction
- Additional 3Kg weight loss
- Paused PRRT
- March 2020
  - CgA up to 651
  - 5HIAA 20.1
  - GA68 – Stable disease
- Self treated Small Bowel Obstruction

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- CORONA Times
  - Discontinued PRRT
  - Continues Somatuline Depot 30 mg x 2 every 28 days
- Stricter diet to avoid SBO
- Adjusted XERMELO to 1 x 250mg pill a day and then increased to 2 x 250mg as the body adjusted.
- Diarrhea almost disappeared!
- Far more energetic!

- CgA dropped 50% and 5HIAA dropped almost 50% too
- Stable disease
- Now:
  - Gained 2Kg
  - Self cleared another SBO

# MY NEN LIFE with Active Carcinoid Syndrome

- THEN - 2017:

- Frequent Stomach pain
- Constant Diarrhea
- Confusion of trial-and-error
- Weariness
- Weight Loss

- NOW – 2020:

- Stable Disease
- Small weight gain
- Infrequent diarrhea
- More energy
- Acceptable “normal” life except for the Corona life



*Enjoy  
Life!*

