

ENDOCRINE MANIFESTATIONS

14th Annual VHL/Medical Research Symposium

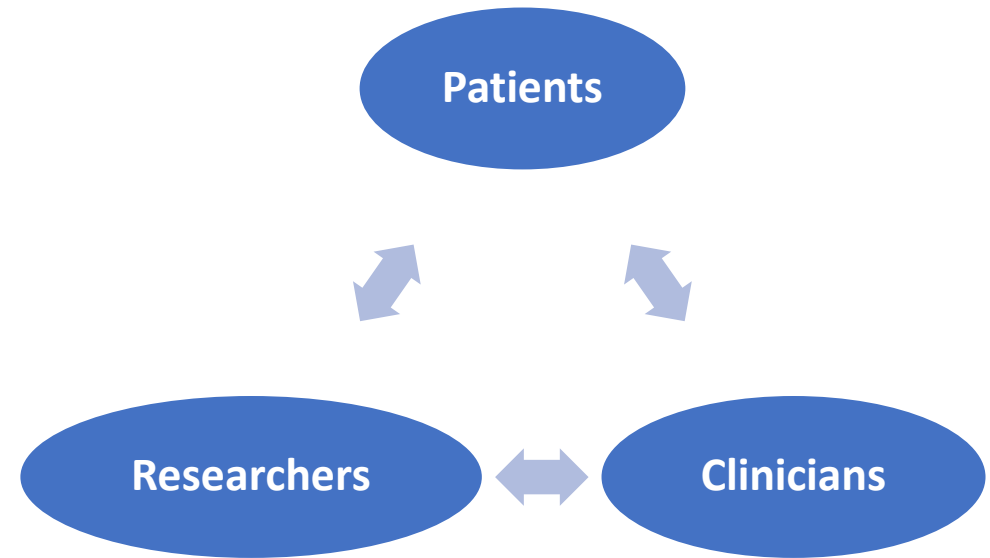
Patient Perspective

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One Goal: *Clinicians, Researchers, Patients*

- Humanity of the work
 - People
 - Life and death



Endocrine Symptoms:

Complexity and Communication

- Complexity of the endocrine system and symptoms
 - Unmet needs
 - Symptom patterns become very important
- Communication is key
 - VHL Alliance Guidelines note unpredictability of the disease overall
 - Terminology
 - Diagnoses – rule outs~?
 - ‘Art of the science’
- *Foundations:*
 - *Neuroendocrine Tumor Research Foundation; US*
 - *Neuroendocrine Cancer UK*
 - *Canadian Neuroendocrine Tumor Society*
 - *International Neuroendocrine Cancer Alliance*
- *Communication:*
 - *How Doctors Think; Jerome Groopman, MD*
 - <https://www.npr.org/books/authors/138324259/jerome-groopman>
 - *Alan Alda Center for Communicating Science®*
 - <https://katebowler.com/guests/alan-alda/>

Living in this Time: *Advances and Momentum*

- Groundbreaking discoveries
 - Neuroendocrine treatment advances
 - Options
 - Tumor boards
 - Health Disparities
 - Knowledge – disease and clinical trials
- *VHLA*
 - *NET Cancer Day 10th November*
 - *Chasing My Cure: A Doctor's Race to Turn Hope Into Action, David Fajgenbaum, MD*
 - <https://www.npr.org/books/authors/855230974/david-fajgenbaum>

Thank You

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