

University of Iowa
NCAN Patient NETs Conference
October 14, 2017

<http://www.earnyourzebrastripes.org/> - All PowerPoint slides will be posted at some point in the future.

Agenda

Thomas O'Dorisio MD - overview of care

Targeted Therapies - Chandrikha Chandrasekharan, Oncologist

PRRT - David L. Bushnell Jr. MD, Nuclear Medicine

PRRT - Yusef Menda, MD, Nuclear Medicine

Surgical Therapies for Neuroendocrine Cancer Patients - James R. Howe, Surgeon

A New Way to Control Carcinoid Syndrome Symptoms - Joseph Dillon, MD - Associate Professor of Internal Medicine - Endocrinology and Metabolism

Life for the Neuroendocrine Cancer Patient - Tom O'Dorisio MD, Maryann Wahmann, Ronda Ayala RN

Research Findings from Iowa NET SPORE - M. Sue O'Dorisio MD; SPORE stands for Special

Kim Miller, RN - Kim onboards new patients

Kristin Gaimari-Varver, RN

Question and Answer Session

Physician Panel

Summary

- The attendance was more than expected - perhaps 100+?.

- The speakers were all extremely well qualified in their areas of expertise and as most NETs patients realize, the University of Iowa is one of the leading NETs centers of excellence. We always walk away with new learning from NCAN conferences.
- Q&A's included typical questions about Octreotide versus Lanreotide, Ga-68, dangers of too much radiation exposure, newer pharmaceuticals for the control of diarrhea, PRRT, tumor markers, insurance coverage, etc. This NCAN conference was video recorded so should be available in the future.
- As we know PRRT is hopefully right around the corner. My contacts at Mayo, UW Health in Madison, WI and University of Iowa all believe PRRT will gain approval early 2018. There was a great deal of discussion about its benefits.
- Dr. O'Doriso presented a revised NETs 'schema' or 'algorithm' as Dr. Woltering refers to it I believe. This is attached to this post.
- The importance of being seen at a NET speciality center was emphasized, even if local care is provided. The rationale was greater expertise, multi disciplinary team to review each case, more consistent labs and more expertise in scanning, etc.

What could enhance patient directed NETs conferences?

Venue. The meeting room, vendor tables and food service lines were extremely tight and the flow was poor. Overall, not at all a good venue.

Raised platform. Besides the speaker at the podium, we couldn't see the panel members when they spoke as they were sitting.

Pre Submitted questions. Panelists could be given questions well in advance of the conference so they would have time to develop responses and have their material answer the questions raised by those attending.

Breakouts. It might make sense to have a breakout or to focus on the needs of specific patients.

Presentations. Naturally not all presenters are comfortable presenting, nor as effective. This was the case. Much of the material was too clinical and therefore likely not absorbed. Dr. Howe or Dillon simplified complex graphs to make them easily comprehensible by patients. One presenters delivery and highly technical, complex slides were of little to no value to those attending.

Summary

These conferences are valuable for newbies and those who have been dealing with NETs for sometime. That's why I don't want to sound ungrateful to those who plan and arrange them, the professionals for donating their time and the vendors for funding them. It's just a matter of striving for constant improvement so they better meet the needs of patients.

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