



AWARENESS OF CARCINOID AND RELATED NEUROENDOCRINE TUMOR (NET) CANCERS IS NOT WHERE IT SHOULD BE

AN UNFINISHED SAGA

These are messages that support groups and media can disseminate to the general public and the medical community.

Carcinoid and related NETs are rare cancers, but not as rare as previously thought. The NIH/SEER Cancer Statistics Review in 2004 reported that there are more than 11,000 new cases diagnosed per year.

Many patients go undiagnosed or misdiagnosed for many years (two to ten years.) Many patients will go untreated even after diagnosis since it has been generally incorrectly believed that carcinoid/NET tumors are benign (no-cancerous) and slow growing and many physicians are not aware of current treatment options.

Only 15 years ago there were very few treatments available for these rare cancers before hepatic artery chemo embolization, bland embolization, isotope targeted and systemic treatments, chemotherapy, before octreotide, before interferon, before some of the newer chemotherapy drugs were developed. Then, before these treatments were available, in patients where the disease had progressed, the 5 year survival was less than 20% (2-3 years) as compared to statistical data from today of 68% -84% (10 + year survival). The recent advances in modern management of carcinoid and NETs make it essential to be aware of the following key features in these diseases.

BE AWARE THAT --

- Simple ways are available to detect and diagnose carcinoid/NETs, (as long as you at least think of it as a possibility), “Think zebra not horse.”
- There are many ways to determine whether a tumor will act aggressively or not.
- Many treatments are available today that will prolong survival and increase quality of life that was not available two decades ago.
- **If diagnosed correctly and early a cure can result**, survival can be increased, and quality of life significantly improved.
- Carcinoid/NETs are not always slow growing and need to be monitored carefully and, if necessary, treated appropriately.
- Carcinoid/NETs act more like a chronic disease such as diabetes, emphysema, coronary artery disease and need to be monitored carefully and treated if progression occurs.
- People can live with carcinoid/NETs with good quality of life for many, many years.

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