

# Supplement to the 2008-9 Annual Report



## HOPE FOR THE FUTURE FROM THE CARCINOID CANCER FOUNDATION

Dear Friends,

Recognizing a long-overdue need for progress in the diagnosis, research, treatment, and care of carcinoid/neuroendocrine tumors (NETs), the National Cancer Institute (NCI) held, in September 2007, the first ever government-sponsored summit meeting devoted to these conditions. Somewhat over "40 leading authorities in the field attended, including basic scientists and clinicians from many diverse disciplines." Representatives of the Carcinoid Cancer Foundation™, were among the invitees to these private sessions.

After prolonged sessions and discussions the deliberations of the group were coalesced into 10 general areas that need to be addressed in order to make progress coping with carcinoid/NETs. Expressed in laymen's language these recommended needs are as follows:

1. Better education for health care professionals and the public  
(Considered the most important need at present)
2. Development of better chemical markers for early diagnosis and monitoring.
3. Standardization of pathology, i.e. everyone should use the same terms and criteria for describing these tumors and their features.
4. Establishment of regionalized centers of expertise where new lab and clinical researchers can be trained and tumor banks could be developed and provided.
5. Development of better imaging techniques to find these tumors earlier or follow them better.

6. Development of more effective treatment of advanced disease, preferably from better understanding of molecular mechanisms and also from animal models.
7. Enhanced trials of new treatments and encouraging new agents for treatment.
8. Development of growth in the laboratory of neuroendocrine tumor cells outside of the body (in vitro) and also in experimental animals.
9. Improved molecular understanding of these tumors via small molecules and genomic related technologies
10. Improvement in knowledge of the body's development of its normal diffuse neuroendocrine cell system in order to better understand the development of abnormalities in these cells leading to tumor formation.

## **Research, Education, Awareness, Compassion, and Hope**

It is obvious on review of these many recommendations that the carcinoid/NETs community of patients is and will be best served by concurrent efforts in many areas. This has been the guiding philosophy and practice of the Carcinoid Cancer Foundation since it was originally established 41 years ago. Indeed, our dual mission is, 1) to educate the profession and the public, and, 2) to encourage, support, and conduct research on carcinoid/NETs for diagnosis, treatment, and cure. Our efforts, work, and accomplishments over the past 40 years prior to this summit conference include nearly all of the 10 areas of need identified by the summit experts.

We are proud of our Medical Director, Richard R.P. Warner, MD's change from voluntary faculty to his appointment to the fulltime faculty as Professor of Medicine tasked with the development of a Center for Carcinoid and Neuroendocrine Tumors at the Mount Sinai School of Medicine. That institution, long devoted to carcinoid/NETs, will even more clearly now grow as a "Center of Expertise" for these diseases. Nonetheless the Carcinoid Cancer Foundation is an independent organization, and, as in the past, will continue to conduct, support and fund research and educational endeavors at many different institutions based solely on the merit of the investigator and the proposed project. This commitment will lead us to an even better fulfillment of the 10 "Summit Needs."

Please bear in mind that the Carcinoid Cancer Foundation is not affiliated with any other organization and should not be confused with any other somewhat similarly named recently established foundations.

We are the oldest and original foundation in the United States devoted to carcinoid/NETs, established in 1968, with a record of millions spent in furtherance of our mission, including funding dozens of research projects leading to more than 100 original scientific publications and meeting presentations. We are **the only** such organization that is accredited by the Better Business Bureau (BBB) having met their stringent, ethical and not-for-profit business requirements.

**Thank you for supporting the Carcinoid Cancer Foundation's mission over the years, making possible the overall betterment of diagnosis, treatment and advances towards the development of a cure. Working together we have made a big difference.**

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1. Modlin IM, Morse SF, Chung DC, et al. Priorities for improving the management of gastroenteropancreatic neuroendocrine tumors. J Natl Cancer Inst 2008; 100: 1282-1289.

<http://www.carcinoid.org/medpro/docs/NIH2007Carcinoid%20Summit.pdf>