The North American Neuroendocrine Tumor Society (NANETS) Guidelines

**Mission, Goals, and Process**

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The North American Neuroendocrine Tumor Society (NANETS) had its initial organizational meeting in Portland, Oregon on September 28, 2006 to establish a professional society with the primary purpose to improve neuroendocrine tumor disease management through increased research and educational opportunities. This founding group was comprised of scientists, physicians, and surgeons representing a variety of specialties, all with a particular interest in neuroendocrine tumors (NETs).

During this initial assembly, by-laws were adopted, officers were elected, and specific objectives were prioritized. The NANETS was registered and granted nonprofit 501(c)(3) status by the Internal Revenue Service on February 21, 2007. The first project decided by the organization was to develop an authoritative consensus guideline containing appropriate NET disease management to serve as a practical resource for health care providers. These guidelines would incorporate early detection procedures for a definitive diagnosis, various aspects of imaging, histopathology, biochemical evaluation, surgical interventions, and evidence-based treatments with emphasis on a multidisciplinary team-based approach to patient care.

To begin the development of the guidelines, we reviewed all the evidence-based literature published on the management of NETs and evaluated the practice guidelines developed by other academic societies such as the European Neuroendocrine Tumor Society, World Health Organization, and National Comprehensive Cancer Network. In addition, we determined the best working format and procedures to develop the NANETS standards.

The next and most important step in the writing process was to assemble various recognized authorities representing a wide range of disciplines from the United States, Canada, and Europe specializing in these challenging diseases (Table 1). This was done at a separate assembly in Bermuda on October 2, 2008 before the beginning of the NANETS first annual symposium.

This entire group was challenged to not merely summarize other consensus papers but to enhance the already published data and assure the NANETS standards are “distinctive” and applicable to available and approved treatments in North America. Therefore, the main objective for each of the specialty panels was to assess and compare supporting publications and formulate draft position papers for their working subgroup. Each writing chair was given the responsibility for the coordination of communication and exchanging of information within their subgroup.

After the Bermuda meeting, it was determined that the manuscripts would address key aspects of neuroendocrine tumor diagnosis and treatment by organ site. The position papers from all subgroups were then completed and the contributions compiled and distributed to all participants for additional input. Two lead authors volunteered to assimilate the submitted data, edit, and complete one of each of the following manuscripts. These primary authors reviewed the material to determine what information was still needed and obtained additional contributions regarding their topics from each of the writing group chairs.

The manuscripts and lead authors are as follows:

1. The NANETS Consensus Guideline for the Pathologic Classification of Neuroendocrine Tumors: A Review of Nomenclature, Grading and Staging Systems—Klimstra/Suster
2. The NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Well-Differentiated NETs of the Stomach and Pancreas—Kulke/Jensen
3. The NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Well-Differentiated NETs of the Jejunum, Ileum, Appendix, and Cecum—Yao/Boudreaux
4. The NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Well-Differentiated NETs of the Distal Colon and Rectum—Pommier/Athony
5. The NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Well-Differentiated NETs of the Thorax (Includes Lung and Thymus)—Phan/Maples
6. The NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Pheochromocytoma, Paraganglioma, and Medullary Thyroid Cancer—Chen/Pacak
7. The NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Poorly Differentiated (High Grade) Extrapulmonary Neuroendocrine Carcinomas—Strosberg/Kvols
8. The NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Diagnostic Approach to NETs—Woltering/Vinik

Once the draft copies of each paper were complete, they were posted on a secure page on the NANETS website for all writing group members to review and make comments. All input was then collected and forwarded to the appropriate lead authors for evaluation and inclusion of applicable remarks. The revised manuscripts were then reviewed by select NANETS officers to assure the content was in the required format and complete for all sections. Finally, the last draft of each guideline was circulated to the NANETS Board of Directors, Executive Committee, Advisory Board, and Writing Group chairs for consensus and approval for publication. The final review was completed in May 2010.

In closing, the following 8 manuscripts are the result of a cooperative project beginning in 2008 and involving numerous experts who have committed an enormous amount of time and energy with enthusiasm, dedication, and patience. Each individual’s contributions have been valuable in creating the final product. Our hope is that these guidelines will provide the practical information necessary for professionals from a variety of...
TABLE 1. The NANETS Guidelines Working Group

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<th>Epidemiology and Genetics</th>
<th>Pathology</th>
<th>Radionuclide Therapies</th>
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<td>Steve Marx*</td>
<td>Cesar Moran*</td>
<td>Dave Bushnell*</td>
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<td>Sue O’Dorisio</td>
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<td>Aaron Vinik*</td>
<td>Gene Woltering*</td>
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<td>Martyn Caplin</td>
<td>Wouter de Herder</td>
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<td>Bill Go</td>
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<td>Rod Pommier*</td>
<td>James Yao*</td>
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<td>Greg Wiseman*</td>
<td>Matt Kulke</td>
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<td>J.C. Choi</td>
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<td>Stan Goldsmith</td>
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specialties to reach a proper diagnosis and develop a treatment plan for their NET patients. In particular, we anticipate that these will be useful resources for busy clinicians who may only encounter these tumors infrequently. The NANETS anticipates continued interactions with professionals from all areas of medicine to update and enhance the guidelines throughout the upcoming years when new evidence-based studies are available. The NANETS also looks forward to and encourages collaboration with all providers managing NET patients to develop the most effective management strategies by using a multidisciplinary approach that will improve patients’ quality of life, optimize survival, and lead to the most positive outcomes.

Finally, we want to acknowledge our European colleagues, European Neuroendocrine Tumor Society officers, and consensus guideline committees for their time and expertise during this collaborative endeavor. The experiences they shared about development and execution of the guideline process were invaluable. We look forward to further input from the membership of NANETS and other professional groups and health care providers for updating the NANETS Guidelines in the near future.

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