

# You are not alone

A GUIDE TO LIVING WITH **NEUROENDOCRINE TUMORS (NETs)**

*Based on the findings of a multinational survey of patients with NETs*



# Table of Contents

About	<b>2</b>
The Path to a NET Diagnosis Can Be Long and Difficult and Often Comes as a Surprise	<b>3</b>
Seeking Information About NET Cancer is Key	<b>4</b>
Disease Management of NETs Involves a Number of Doctors, Tests and Travel Time	<b>6</b>
Living with a NET Can Strongly Impact a Person's Daily Life	<b>10</b>
People Living with NETs Make Many Changes to Their Lives	<b>13</b>
Career and Work Life May Be Affected by NETs	<b>14</b>
Resources   References	<b>16</b>

# About Neuroendocrine Tumors

Neuroendocrine tumors (NETs) are a rare type of cancer arising from cells that produce and release different hormones that control bodily functions. NETs can occur throughout the body; however, most are found in the gastrointestinal<sup>1</sup> (GI) tract, lungs and pancreas<sup>2</sup>.

Only 5 out of every 100,000 people in the world are diagnosed with NETs each year<sup>2</sup>. As a result, there is a general lack of awareness about NETs and what it is like to live with the disease. Since NETs are rare, sometimes patients can feel as though their needs are not well understood.

This guide has been created to provide support to people living with NETs and help patients manage the journey together. The tips in this guide are based on results from the first Global NET Survey, which captured experiences and perspectives of people with NETs from around the world\*. The International Neuroendocrine Cancer Alliance and Novartis collaborated on the Survey, which gathered information from 1,928 people who reported that they were diagnosed with a NET. While it can sometimes feel lonely living with a rare disease, it's important to know that others are facing similar experiences and that you are not alone.

**5/100,000**   
**diagnosed with NETs each year** 

\*Participants were recruited by INCA member organizations through flyers, website postings, e-mails, social media and other channels. The Survey was a collaboration between INCA and Novartis, and funded by Novartis. Hall & Partners, a communications research agency, fielded and analyzed the results. The design and fielding of the Global NET Survey aligned with industry standards for surveys of this nature. However, there are several aspects that may have impacted results such as a patient-reported design was employed without independent verification; life quality was evaluated using a multiple choice questionnaire and did not utilize a standardized, validated quality-of-life assessment; recruitment was conducted primarily through patient advocacy groups and online sources<sup>3</sup>.

# The Path to a NET Diagnosis Can Be Long and Difficult and Often Comes as a Surprise

It can take years to diagnose a NET, and often comes after visits to multiple doctors. As demonstrated by the Global NET Survey, patients reported that they saw an average of six doctors before they were diagnosed with their NET<sup>4,5</sup>. Almost half (48%) of respondents had five or more doctor visits prior to their NET diagnosis, and 35% said they had seven or more visits before receiving their diagnosis<sup>3</sup>.

The Survey results found that it took an average of four years for the respondents to receive a NET diagnosis, and 27% of respondents said they received more than one other diagnosis for their symptoms before a NET was identified. The most common diseases or conditions the respondents said they were first diagnosed with included irritable bowel syndrome (IBS) (39%), gastritis or other digestive disorders (38%) and anxiety or psychosomatic-type condition (22%)<sup>3</sup>.

Patients often sought an answer for years, and reported feeling shock, uncertainty, sadness and isolation once the NET diagnosis was made. In addition, more than half of the patients surveyed said the cancer diagnosis came as a surprise. In fact, prior to their NET diagnosis, 76% of respondents did not suspect cancer as the cause of their symptoms<sup>3</sup>.

## STEPS YOU CAN TAKE

- If you have persisting symptoms that aren't going away, don't be afraid to follow your instincts and discuss with your doctor
- Don't hesitate to get a second opinion
- If you've been diagnosed with something else, but your treatment doesn't seem to address your symptoms, consider speaking with your healthcare team to explore other diseases that may be causing your symptoms
- Learn from the experiences of other patients and contact a NET Center of Excellence or patient advocacy group to gain more information
- Through your diagnosis process consider using the Survey findings to inform your conversations with the members of your healthcare team

# Seeking Information About NET Cancer is Key

If you find it difficult to know where to go for more support and information about living with a NET, you are not alone: 45% of respondents said that immediate access to NET patient support groups needs to be improved<sup>3</sup>.



# 45%

RESPONDENTS SAID THAT **IMMEDIATE ACCESS TO NET PATIENT SUPPORT GROUPS NEEDS TO BE IMPROVED**

Getting a correct diagnosis is the first step in managing a NET, but you may feel confused and have questions about the disease and the path forward. Many Survey respondents reported that NETs made them feel concerned, anxious/worried and uncertain<sup>3</sup>.

Being fully informed about your NET may help you cope better with how the disease may affect your life. 51% of patients from the Survey said they were only somewhat knowledgeable about NETs<sup>3</sup>.

In addition, 60% of respondents said they would like clearer information on the long-term effects of the disease and 53% felt the need for more immediate access to doctors with experience managing NETs<sup>3</sup>.



# 60%

WOULD LIKE **CLEARER INFORMATION ON THE LONGER TERM IMPACT OF THE DISEASE**



# 53%

FELT THE NEED FOR MORE **IMMEDIATE ACCESS TO DOCTORS WITH EXPERIENCE MANAGING NETS**

## STEPS YOU CAN TAKE

Knowledge is empowering. Take the time to understand your NET and how it may affect your life to help prepare for and get used to your new lifestyle. There are a number of steps you can take to make sure you are well informed:

- Stay up to date on the latest research and news about NETs
- Become familiar with commonly used words about NETs. You can find some of these terms on [www.NETCancerExperience.com](http://www.NETCancerExperience.com)
- Visit [www.INCAIliance.org](http://www.INCAIliance.org) for a list of patient groups in your country or region for information and support
- If available, read NET guidelines from healthcare organizations within your country (these guidelines can be technical but include valuable information)
- Consider attending a NET educational conference. In addition, many conferences post videos and meeting materials online, so you may be able to look up archived content
- Ask your doctor or nurse for more detailed information

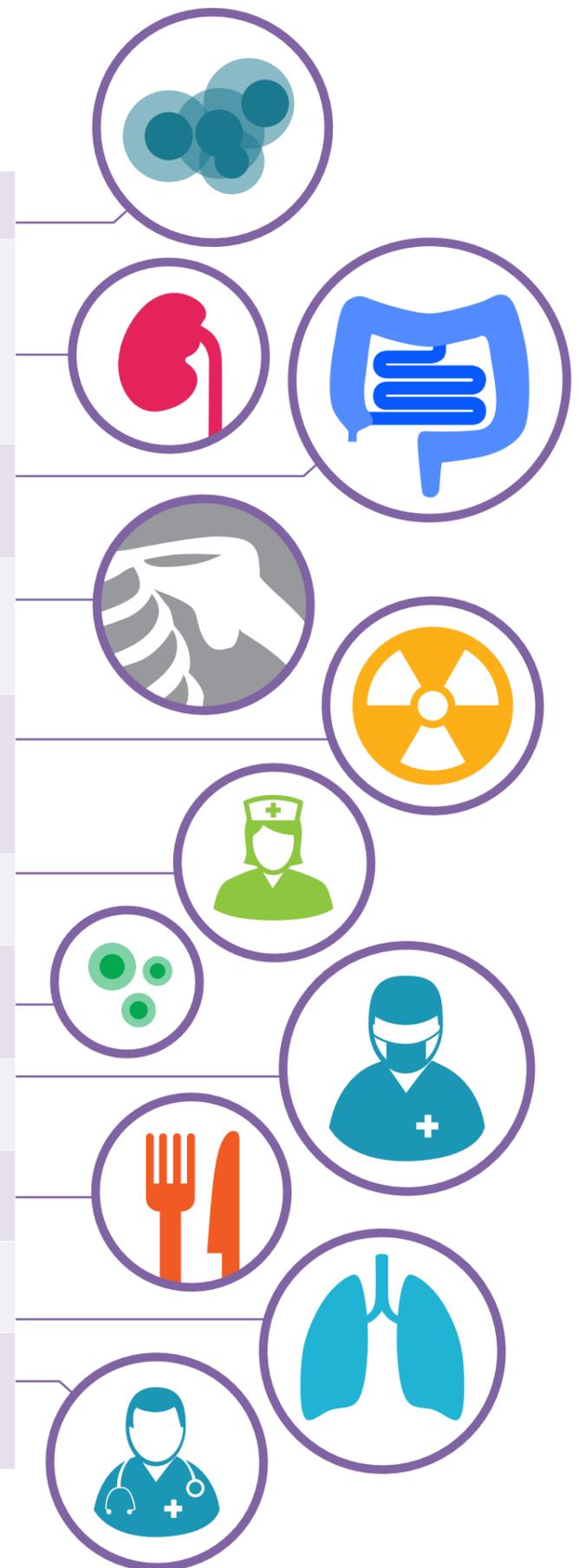


## Disease Management of NETs Involves a Number of Doctors, Tests and Travel Time

A NET affects different parts of the body and therefore requires management by multiple medical specialists who concentrate on different areas of the body. Respondents from the Survey said they saw an average of three different healthcare professionals (HCPs) for their ongoing NET care. This is important because research shows the results are better for patients whose NET is managed by a team of doctors and HCPs who have different areas of expertise (a “multidisciplinary team”). Doctors with different specialties can work together to care for a patient even if they don’t work directly together in the same office<sup>3</sup>.

### A MULTIDISCIPLINARY TEAM MAY INCLUDE:

<b>Oncologist</b>	Doctor who specializes in treating cancer
<b>Endocrinologist</b>	Doctor who specializes in the diagnosis and treatment of disorders of the endocrine system, which controls growth, sexual development, sleep, hunger and the way the body uses food
<b>Gastroenterologist</b>	Doctor who specializes in diagnosing and treating disorders of the digestive system
<b>Interventional Radiologist</b>	Doctor who specializes in creating and interpreting scans (such as x-rays and MRIs) of areas inside the body
<b>Nuclear Medicine expert</b>	Doctor who works with medicine that uses small amounts of radioactive substances to show different processes and markers inside the body
<b>Nurse</b>	HCP trained to care for people who are ill or disabled
<b>Pathologist</b>	Doctor who identifies diseases by studying cells and tissues under a microscope
<b>Surgeon</b>	Doctor who removes or repairs a part of the body by operating on the patient
<b>Dietitian</b>	HCP with special training in nutrition who can help with food choices
<b>Pulmonologist</b>	Doctor who specializes in treating diseases of the lungs
<b>General Practitioner</b>	Doctor responsible for the overall care of patients and provides preventive care and health education to patients



*Disease Management of NETs Involves a Number of Doctors, Tests and Travel Time (continued)*

Specialty care teams, made up of multiple HCPs, can be difficult to find and sometimes patients have to travel long distances to receive care at a center that focuses on NETs. For example, 33% of patients who took the Survey said they had to travel 1 – 20 kilometers (1 – 12 miles) to see their NET care team, and 16% said they traveled more than 200 kilometers (125 miles)<sup>3</sup>.

Although it may be more difficult, seeing a doctor or team that specializes in NETs can make a difference in how patients feel about their care. Results from the Survey found that 85% of respondents who visited a center or team that specialize in NETs at least once a year were more likely to believe they received the best possible care compared to 67% who had not visited one<sup>3</sup>.

In addition<sup>3</sup>:

**60%** of respondents who visited a specialist center at least once a year **felt their doctors functioned as a well-coordinated team** compared to 36% of respondents who did not

**57%** of respondents who visited a specialist center at least once a year were more likely to **want to work in partnership with their NET healthcare team** compared to 48% of respondents who did not

**76%** of respondents who visited a specialist center reported having **better relationships with their HCPs** compared to 61% of respondents who did not

**66%** of patients who visited a center or a team that specializes in NET at least once a year **felt the overall quality of NET treatments available was good to very good**, compared to 46% who had not visited one

**90%** of Survey respondents who visited a NET specialist center reported discussing more topics compared to those who had not visited one, **including the results of ongoing tests** (90% vs. 79%), changes in symptoms (78% vs. 67%) and physical health (77% vs. 65%)



## STEPS YOU CAN TAKE

- Talk to your primary doctor about different specialists you should see, and whether there might be a doctor or healthcare team that specializes in NETs in your area
- Visit [www.TheNETAlliance.com](http://www.TheNETAlliance.com) or [www.carcinoid.org/patient/treatment/find-a-doctor](http://www.carcinoid.org/patient/treatment/find-a-doctor) to find a NET specialist in your area
- If there is not a specialist listed near you, talk to your doctor about what he or she recommends to help make sure you have a well-coordinated and multidisciplinary approach to care
- If your doctor does not have a lot of experience taking care of NETs, direct him or her to [www.carcinoid.org/for-doctors/other-resources/online-discussion](http://www.carcinoid.org/for-doctors/other-resources/online-discussion) so they can consult with a NET specialist
- Understand the types of specialists that should be involved in your treatment journey and the roles they will play in the management of your disease
- Encourage the members of your healthcare team to talk to one another to ensure you receive well-coordinated care

# Living with a NET Can Strongly Impact a Person's Daily Life

Living with a NET can directly impact how you feel emotionally and physically, which can affect how you live your life. 71% of respondents from the Survey reported that their NET impacted their life in a negative way. The most common feelings they had as a result of the NET were worries about an uncertain future and anxiety or stress. For example, 58% said they worried a lot about the uncertainty of the future and 43% thought about their inability to do activities they used to enjoy<sup>3</sup>.

Respondents also said that NETs affected many parts of their life – with more than half saying their disease affected their overall energy levels (70%), emotional health (60%) and ability to participate in leisure activities (54%). The most common symptoms reported by Survey respondents were general fatigue/weakness (56%), diarrhea (48%), abdominal (stomach) issues (41%) and skin reactions (37%). More than half of respondents reported that they experienced general fatigue, muscle fatigue and weakness<sup>3</sup>.

This lack of energy can affect your day-to-day life, but there are ways to try to cope. In fact, 65% of patients reported having a caregiver who helped manage day-to-day activities (for example, to go with them to doctor visits, help make treatment decisions, help with daily household tasks and provide emotional support)<sup>3</sup>.

It can be difficult to explain the everyday effects of NETs to your co-workers, friends and even your doctors in a way that helps them understand what you are going through. Survey respondents reported their co-workers, friends and doctors were somewhat understanding of how NETs affected their life, although respondents felt other people in general were not at all understanding of their disease<sup>3</sup>.

Fortunately, Survey respondents said they felt doctors, caregivers, co-workers, family, friends, other people with NETs and NET patient support groups were all extremely supportive. Among these groups, respondents felt family and caregivers provided the most support<sup>3</sup>.

## STEPS YOU CAN TAKE

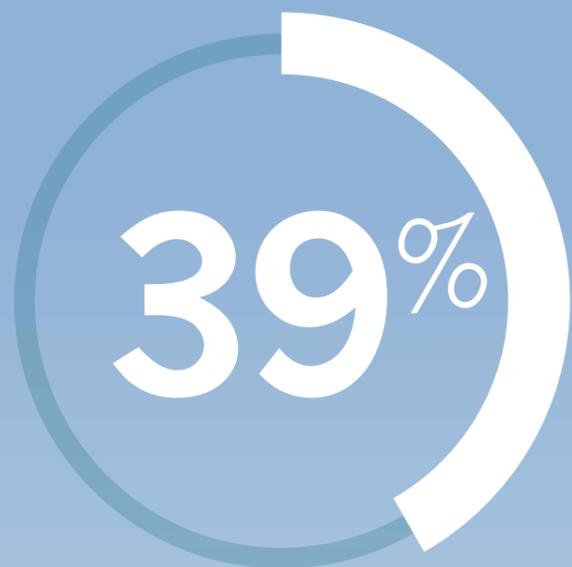
Finding the energy to complete everyday tasks when you are living with cancer can be difficult. The following tips may help make living with a NET more manageable.

- Learn as much as you can about NETs to help prepare for how the disease may affect your everyday life
- Be aware of how you feel and share those feelings with your friends and family
- There are magazines and websites designed for people with NETs, and for people with cancer in general; you may find the trends in research, patient stories and general guidance in these resources useful



- Check out services in your area designed to help people with cancer, such as **housekeeping**, **food delivery** and **laundry services**
- Try keeping a journal of your daily routine (for example: diet, sleep patterns, activities)
- Take time to take care of yourself and don't be afraid to make adjustments to your life in order to better manage your disease
- Look for help or guidance from a therapist, social worker or other trusted advisor who can talk with you about your feelings and help develop ways to live with and manage your NET
- Know that you are not alone in your experience with NET

- Visit [www.NETCancerExperience.com/resources](http://www.NETCancerExperience.com/resources) to learn how the disease has impacted other patients



SAID IT HAD  
**NEGATIVE IMPACT**  
**ON THEIR ABILITY**  
**TO CARE FOR**  
**THEIR FAMILY**



## People Living with NETs Make Many Changes to Their Lives

If your life looks and feels different than it was before you were diagnosed with NETs, you are not alone. More than 90% of the Survey respondents said they had made some type of lifestyle change because of their NET, including changes to their diet and what they eat (59%), increased time spent traveling to and from medical appointments (52%), increased spending on travel for these appointments (51%) and reduced or stopped physical activities (49%). In addition, 51% of the respondents said NETs had a negative effect on their social life and 39% said it had a negative impact on their ability to care for their family<sup>3</sup>.

### STEPS YOU CAN TAKE

- Your healthcare team is your first source of information but remember there are many people who are able to help you manage the everyday challenges of living with a NET
- Visit [www.INCAIalliance.org](http://www.INCAIalliance.org) for a list of NET patient organizations in countries around the world
- Create a strong support network with family, friends, advocates and other people with NETs
- Reduce or stop certain activities that make you too tired and start other, less tiresome, activities:
  - Be open with your family, friends and doctors about your energy levels
  - Read and do brain teasers, such as cross-word puzzles
  - Try to get outside for fresh air as often as you can
- Talk to other people with NETs for tips on how they manage their disease

# Career and Work Life May Be Affected by NETs

In addition to changing their day-to-day lives and energy levels, the Survey respondents also said living with a NET had a big effect on their work lives.

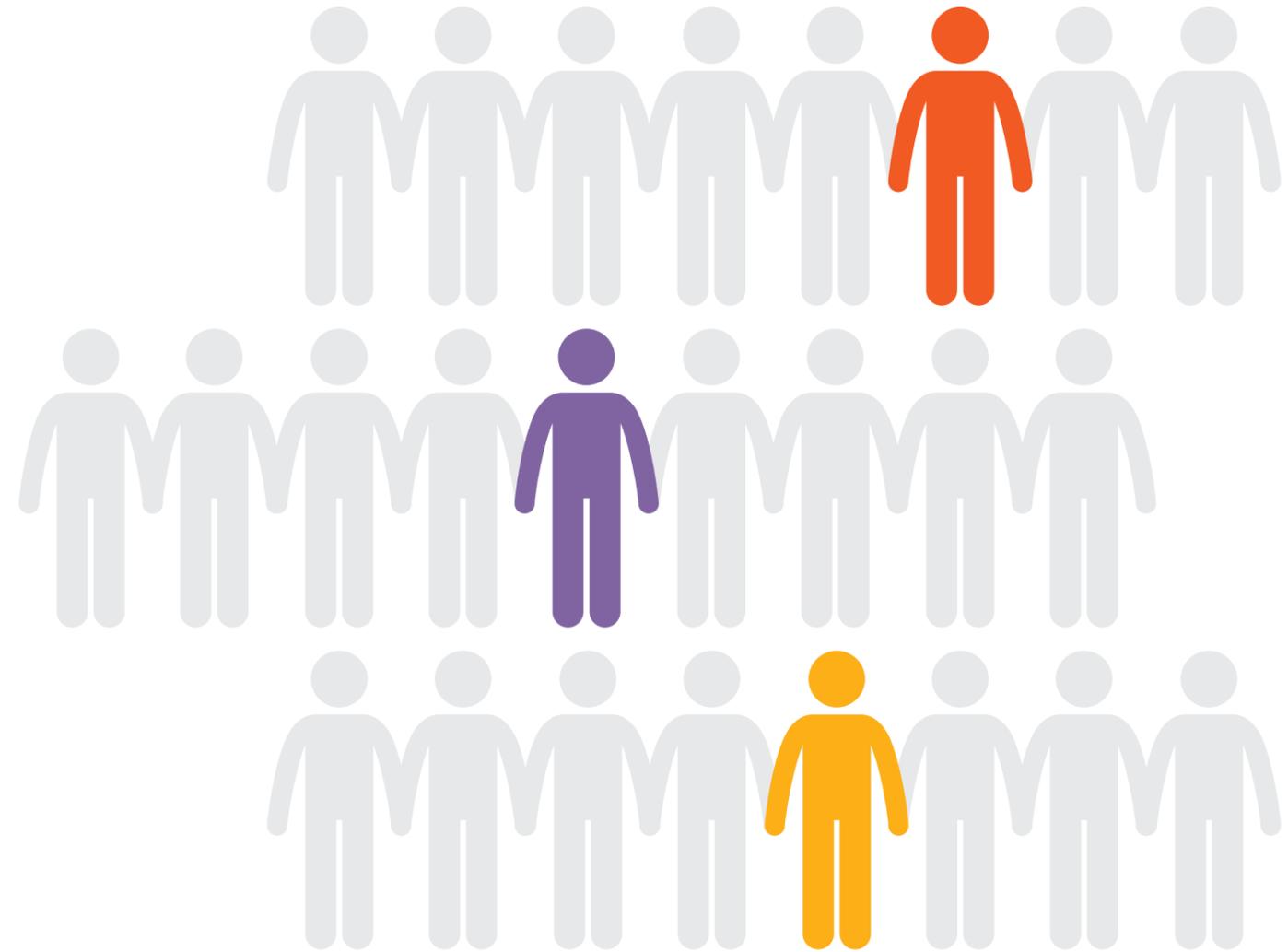
For example, 50% said that having a NET had a negative impact on their finances. Among those who were working (39% of Survey respondents), half (49%) said they had taken days off because of their NET. Among those respondents who were not working or were unemployed due to medical disability (22% of Survey respondents), 82% said they had to stop work because of their NET. NETs also affected patients who were nearing the end of their career. Among respondents who had already retired (31% of Survey respondents), 29% said they had stopped working earlier than they had planned<sup>3</sup>.

Telling your co-workers, especially your supervisor, about your diagnosis can be a difficult decision and may add stress to your work life. Respondents said co-workers, friends and people in general were not at all aware of NETs, and only 45% of supervisors were aware of their disease. The top three reasons respondents gave for not telling their supervisor about their disease included being private (43%), not wanting to be viewed differently (38%) and because their supervisor knows little about NETs making it difficult to explain (32%)<sup>3</sup>.



# 50%

SAID THAT HAVING NET HAD A **NEGATIVE IMPACT ON THEIR FINANCES**



## STEPS YOU CAN TAKE

- Connect with patient advocacy groups and other NET patients through online communities
- Don't be afraid to share more with people you trust, such as family members, friends and other people living with NETs
- Ask your doctor about patient assistance and government programs available in your country
- Reach out to the patient group in your region to find information on financial assistance programs that may help cover the cost of your NET care

## Resources

The following resources are available to help keep you informed and to connect you with local support groups in your area:

## References

1. National Cancer Institute. Dictionary of Cancer Terms. Available at: <http://www.cancer.gov/dictionary>. Accessed January 2017.
2. Yao, et al. One Hundred Years After "Carcinoid:" Epidemiology of and Prognostic Factors for Neuroendocrine Tumors in 35,825 Cases in the United States. *J of Clin Onc.* 2009;26(18): 3063-3072.
3. Novartis and INCA Global NET Patient Survey Report: Global Results. Data on File.
4. American Society of Clinical Oncology. Neuroendocrine Tumor. Available at: <http://www.cancer.net/cancer-types/neuroendocrinetumor>. Accessed January 2017.
5. Mamikunian, et al. Neuroendocrine Tumors: A Comprehensive Guide to Diagnosis and Management: 4th ed. Available at: <http://www.interscienceinstitute.com/docs/Neuroendocrine-Tumors-4th-Edition.pdf>. Accessed January 2017.
6. American Cancer Society. Gastrointestinal Carcinoid Tumors. Available at: <http://www.cancer.org/acs/groups/cid/documents/webcontent/003102-pdf.pdf.%20Accessed%20December%202015>. Accessed January 2017.

[www.NETCancerExperience.com](http://www.NETCancerExperience.com)



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G-NEA-1154356

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