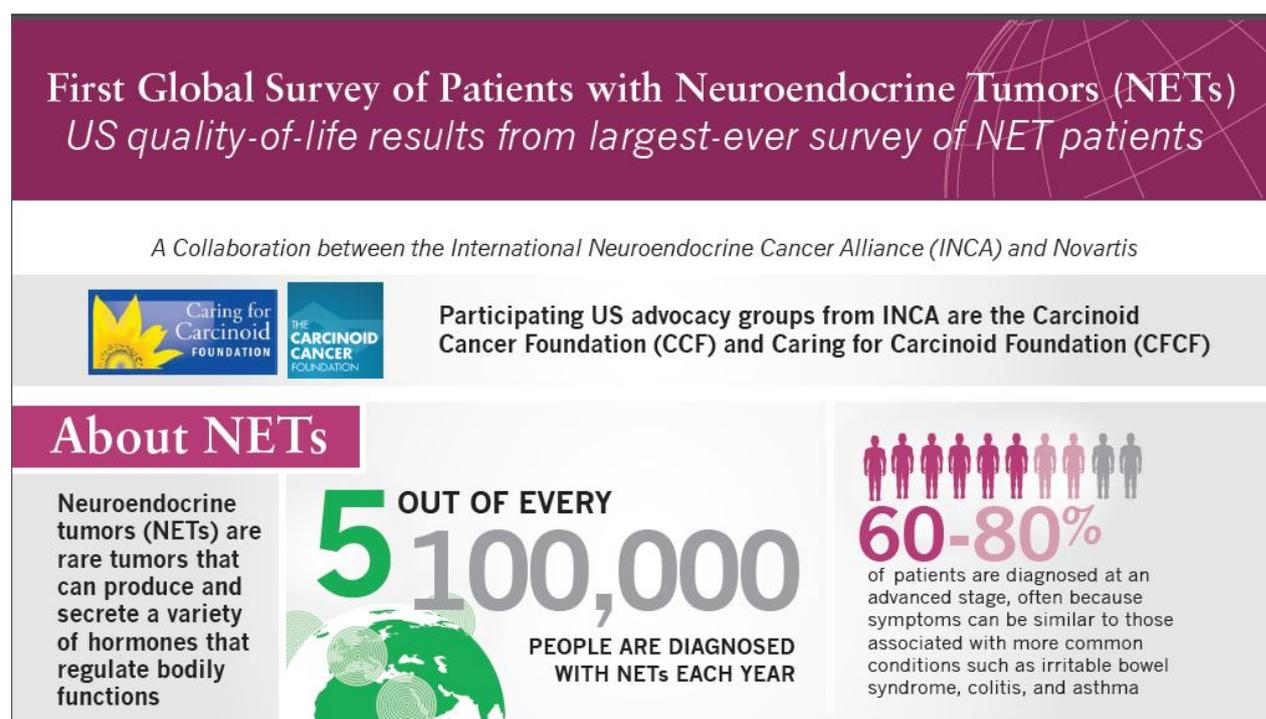


US Results from First Global NET Patient Survey

The **Carcinoid Cancer Foundation** and the **Caring for Carcinoid Foundation**, member organizations of the **International Neuroendocrine Cancer Alliance (INCA)**, together with **Novartis Pharmaceuticals Corporation** have announced the US results from the first global survey of patients with neuroendocrine tumors (NETs), a rare type of cancer. According to the survey, the vast majority (74%) of patients in the United States with NETs reported their quality of life was negatively affected by their disease. These quality-of-life findings are the first in a series of results from the survey being released in conjunction with **Worldwide NET Cancer Awareness Day (WNCAD), November 10**.

US results from first global survey of neuroendocrine tumor (NET) patients reveal **the profound impact of this rare cancer on patients' quality of life**. Results show 94% of patients made lifestyle modifications as a result of their NET, including changes to diet, work, physical activities and social life¹.

[Click here to see the complete infographic of the US survey results](#). (Please note the page may take a while to load)



[Click here to see an infographic of the Global NET Patient Survey results](#).

In the US, 758 NET patients took part in the survey, representing 39% of the total global survey population of 1,928 patients. Of the 42% of US respondents who were currently working, nearly two-thirds had to take days off of work due to their NET (62%)¹. Additionally, among the patients who were not employed or not able to work because of medical disability (25%), the majority (79%) had stopped working as a result of their NET¹. Furthermore, patients needed to increase the amount of money (60%) and time (57%) spent on medical appointments¹.

“This collaboration between INCA and Novartis has yielded tremendous information about the

experience of living with NET cancer and gives a voice to patients in the US and worldwide,” said **Grace Goldstein, immediate past president of INCA and chief operating officer of the Carcinoid Cancer Foundation**. “The survey found that as many as 94% of US patients made lifestyle modifications as a result of their NET, which confirms the significant impact of this disease that we have long observed in the patient community.”

The survey results also illustrate the **numerous changes in lifestyle and emotional health that US NET patients experience as a result of their disease**¹. More than half of respondents (58%) noted that their emotional health had been affected “a moderate amount” or “a lot” by their NET, and that they have significant stress and anxiety levels (58%) and worry about the uncertainty of their future (57%)¹. Almost half (47%) feel confused about the management of their disease¹. Additionally, patients reported that their NET affects their overall energy levels (71%), diet (64%), ability to participate in leisure activities (54%), and social life (46%), and limited their physical activities (57%), with close to half (45%) unable to participate in activities they used to enjoy¹.

Since NETs are uncommon, awareness about the disease is very limited. Neuroendocrine tumors arise in different tissues and organs throughout the body that contain neuroendocrine cells; most are found in the gastrointestinal (GI) tract, lungs and pancreas, and they are categorized as symptomatic (functional) or asymptomatic (non-functional)^{2,3,4,5}. Signs and symptoms of NETs include, but are not limited to: flushing, diarrhea, intermittent abdominal pain, wheezing, coughing and bloody sputum^{6,7}. Nonfunctional NETs do not produce any hormonal symptoms and can be more difficult to diagnose⁵. Even symptomatic patients are often misdiagnosed because their symptoms can be similar to those of other diseases and conditions (e.g., colitis, irritable bowel syndrome and asthma)⁷. For these reasons, NETs are often initially diagnosed at an advanced stage⁵.

“In my daily contact with families and during our educational and research events, I have heard numerous stories from patients about the devastating impact NETs have on their ability to lead a normal life,” said **Ron Hollander, Executive Director, Caring for Carcinoid Foundation**. “We hope that the results of this extensive survey can help accelerate awareness about this cancer in which people can look healthy but are actually dealing with a debilitating illness that they know can become quite aggressive and even deadly.”

The Novartis collaboration with INCA is part of the company’s longstanding commitment to improving knowledge and management of NETs, engaging with patient groups to better understand the patient experience and helping the patient community to raise its voice. **Results from the survey related to quality of life were presented at the North American NeuroEndocrine Tumor Society (NANETS) symposium in Nashville, Tennessee, October 10-11, 2014.**

About the survey

The **goal of the Global NET Patient Survey was to increase understanding of the experiences, needs and challenges of NET patients, and provide insights and learnings between countries and regions to advance NET care on a global level**¹.

The **Global NET Patient Survey was fielded between February 2014 and May 31, 2014, and included 1,928 patients from 12 countries**¹. The survey was made available in **eight languages**, and participating INCA member organizations invited NET patients to participate in the **25-minute online anonymous survey** via flyers, website postings, emails and social media channels¹. **Paper surveys** were developed in several languages and distributed at patient group meetings and through healthcare professionals to reach patients without access to the Internet. The data are being analyzed at the global, regional and country levels¹.

The survey gathered information on the NET patient experience, including diagnosis, disease impact and management, quality of life, and knowledge and awareness levels. **The**

quality-of-life results are the first data to be released and additional findings will follow.

The survey was developed through **a collaborative effort between INCA and Novartis Pharmaceuticals Corporation** and was **fielded by Hall & Partners USA, LLC**, a research organization based in New York with offices around the world. Survey participation was voluntary and not subject to any compensation¹.

About Novartis

Novartis Pharmaceuticals Corporation researches, develops, manufactures and markets innovative medicines aimed at improving patients' lives. We offer a broad range of medicines for cancer, cardiovascular disease, endocrine disease, inflammatory disease, infectious disease, neurological disease, organ transplantation, psychiatric disease, respiratory disease and skin conditions. The company's mission is to improve people's lives by pioneering novel healthcare solutions. For more information, please visit <http://www.novartis.com>.

About the Carcinoid Cancer Foundation (CCF)

The Carcinoid Cancer Foundation (CCF) is the oldest nonprofit carcinoid/and related neuroendocrine tumor organization in the United States, founded in 1968. The mission of the foundation is to increase awareness and educate the general public and healthcare professionals regarding carcinoid and related NETs, to support NET cancer patients and their families, and to serve as patient advocates. For more information, visit <http://www.carcinoid.org>.

About the International Neuroendocrine Cancer Alliance (INCA)

The International Neuroendocrine Cancer Alliance (INCA) is a network of charitable organizations and patient groups from 14 countries that aims to be the global voice in support of people living with neuroendocrine tumors (NETs). The organization is dedicated to being the global advocate for NET patients and works toward a world where all NET patients get a timely diagnosis, the best care and ultimately a cure. For more information on INCA visit <http://netcancerday.org>.

References

1. Novartis and INCA Global NET Patient Survey Report: Global Results. Data on File.
2. National Cancer Institute. Dictionary of Cancer Terms: neuroendocrine tumor. Available at: <http://www.cancer.gov/dictionary>. Accessed October 2014.
3. 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 Clin Onc*. 2008; 26:3063-72.
4. Akerstrom, et al. Timing and extent of surgery in symptomatic and asymptomatic neuroendocrine tumors of the pancreas in MEN 1. *Langenbecks Arch Surg*. 2002; 386(8):558-69.
5. Modlin, et al. Priorities for Improving the Management of Gastroenteropancreatic Neuroendocrine Tumors. *J Natl Cancer Inst*. 2008; 100:1282-1289.
6. Hage, et al. Update in Pulmonary Carcinoid Tumors: A Review Article. *Ann Surg Oncol*. 2003; 10:697-704.
7. 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 October 2014.

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