

INVITATION TO PARTICIPATE IN SURVEY

On behalf of Novartis Oncology I would like to invite [name of group] members to participate in a quality of life survey.

Your Opinion Counts!

Your members are invited to take part in an anonymous national quality of life survey for people with carcinoid syndrome and related neuroendocrine tumors. We're inviting patients because patient experience is important and can help us to educate others.

What is Quality of Life?

You may have heard doctors and nurses talk about "quality of life" or even use the term "QoL." But what does it mean, and more importantly, what does it mean for *you*?

In healthcare, quality of life (QoL) is measured by asking a series of standard questions about a person's overall emotional, social, and physical well-being. QoL addresses a person's ability to perform ordinary tasks, such as dressing yourself, shopping, going to the doctor, or socializing with others. QoL can suffer when someone can no longer live the way they want to.

A study examining the quality of life of patients with neuroendocrine tumors was recently conducted in Norway. The study compared the quality of life of patients with neuroendocrine tumors with the quality of life of the Norwegian general population. The results of the study have helped to improve the understanding of the effect of neuroendocrine tumors on patients' quality of life.

Purpose of the Survey

A survey is being done to better understand the specific issues related to QoL for people living with carcinoid syndrome and related neuroendocrine tumors. Results of the anonymous survey will be shared with cancer scientists, doctors, and public health plans to improve patient care and help them better understand the impact of the disease.

- Conducted by Northwestern University, Chicago, the 2009 survey for patients who have carcinoid syndrome and related neuroendocrine tumors will take place between August 5 and August 19.
- The survey is sponsored by Novartis Pharmaceuticals, Corporation.
- Summary results will be presented at a scientific meeting and will be submitted to a medical journal for publication, and shared in future e-newsletters.

Why Take Part?

Here are three reasons why your members may want to take part in this important survey:

- It is completely anonymous, will take very little of their time, and Novartis Oncology will make a donation to the carcinoid organization the participant selects as a “thank you” for your participation. The donation made to each group will be capped at \$10,000 for each organization. If any organization has reached this amount, a donation will automatically go to one of the other groups.
- Sharing their experience will help others to better understand patients with carcinoid and related neuroendocrine tumors.
- We will compare the results of this survey with results for the general population in the US to learn more about the impact of this disease.

Please feel free to invite members of your group to participate in the Survey Now

- Complete the anonymous survey.
- After the survey, participants will be asked to check (✓) a carcinoid organization they would like us to make a donation to—this is our way of thanking participants for taking part in the survey.

Click here to start now

<http://www.assessmentcenter.net/ac1/Assessments/NETsurvey>

The Carcinoid Organizations.

When a participant completes the survey, \$25 will be donated support carcinoid research and advocacy, by selecting an organization:

Carcinoid Cancer Awareness Network (Long Island, NY)

The mission is to intensify awareness of Carcinoid Cancer and Neuroendocrine Tumors in both the medical community and general public, locally and around the world.

www.carcinoidawareness.org

Carcinoid Cancer Foundation, Inc. (White Plains, NY)

Devoted to supporting, conducting and encouraging research, awareness, and education regarding carcinoid and related neuroendocrine tumors.

www.carcinoid.org

Caring for Carcinoid Foundation (Boston, MA)

Dedicated to discovering a cure for carcinoid and related neuroendocrine tumors while working to eliminate the suffering of patients, families, friends and caregivers affected by neuroendocrine tumors.

www.caringforcarcinoid.org

North American Neuroendocrine Tumor Society (NANETS) (Vancouver, WA)

Committed to improving neuroendocrine tumor (NET) disease management through increased research and educational opportunities for healthcare professionals.

www.nanets.net

Our Thanks

Thank you for considering taking part in the **2009 *Quality of Life National Survey***. It is our hope that your group members' participation will help healthcare professionals understand patients better, and may lead to better care for patients.

Sincerely,

Mildred Ortu Kowalski, RN, PhD
Director
Patient Advocacy and External Affairs