

# Online Support and Discussion Groups

In addition to support groups that hold regular meetings, there are also online support groups and e-list discussion groups (US and international) that you may find helpful.

## US Elists

- [Smart Patients Carcinoid and Neuroendocrine Tumor Community](#)

The Carcinoid Cancer Foundation is excited to announce a new online community for carcinoid and neuroendocrine tumor (NET) patients, their families and friends. We are partnering with Smart Patients to build this community and hope that combining CCF's experience educating patients about carcinoid and NET cancers with Smart Patients' experience with online peer support will result in more patients getting information they need even faster. Join Smart Patients, ask a question, and support others who can learn from you.

[Click here to join the Smart Patients Carcinoid/NET Community](#)

- [ACOR: Carcinoid Cancer Online Support Group](#)

A non-moderated e-list with strong emphasis on support in addition to medical information. For all those suffering from rare cancers, ACOR is likely to be the only place of support and the main source of accurate information about their treatment options. Thousands of people are alive today because of the information they found on an ACOR eCommunity.

[Click here to sign up for this on line support group](#)

[Click here to access the ACOR archives](#) (a username and password is required)

- [CARCINOID \(Yahoo\) Online Information and Discussion Group](#)

This is a moderated e-mail list for patients or primary caregivers, researchers, and physicians to discuss clinical, nonclinical issues and advances pertaining to carcinoid/gastric NETs. This includes patient experiences, hormone-induced psychological issues, new research, clinical trials, and discussions of current treatment practices. The list has several physicians as members or patients who provide answers to questions on all fields of research and treatment of the gastric group of neuroendocrine tumors. This list has never been a support list and has always been moderated to maintain a low noise to valuable message ratio so its archives comprise almost 19,000 entries of useful information about the disease. The membership of this list has been in excess of 1,000 for the last 5 years or longer. The owner is a 34 year survivor with active carcinoid cancer.

This is an INFORMATION/DISCUSSION e-list. This is NOT a support group. As with all lists, the archives are available to anyone with a password and username.

[Click here to access the archives or to sign up for this group](#)

- [CARCINOID CAREGIVERS GROUP \(Yahoo\)](#)

This is an online support group for caregivers of people with carcinoid. It's a small but caring group

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started in the spring of 2005. Click to join:  
<http://health.groups.yahoo.com/group/caregivers4carcinoid/>

- [CARCINOID SUPPORT](#)

The purpose of this unique support group on Yahoo called Carcinoid Support is for "cancer survivors (mostly carcinoid) who today have no prospect of going into remission but whose treatment regimens are geared towards making their cancer a chronic condition. Here we discuss more about learning to live with carcinoid, day by day--not the medical aspect but the emotional adjustment."

To sign up, [click here](#).

- [Heartland Online Support Group](#)

This is a support group for carcinoid cancer survivors and caregivers in the heartland of America, including members from Missouri, Kansas, Nebraska, Iowa, Tennessee and Oklahoma at the present time. We are a dynamic, proactive growing group that was started in July 2008. Interested parties should send a request stating your preferred email address, your location, your carcinoid story, and your reason for wanting to join this group to: [Heartland\\_Carcinoids-subscribe@yahoogroups.com](mailto:Heartland_Carcinoids-subscribe@yahoogroups.com) or [Heartland\\_Carcinoids@yahoo.com](mailto:Heartland_Carcinoids@yahoo.com)

- [NET Islet Cell Tumor E-Group](#)

An information and education group for patients, family members, and medical professionals focused on Islet Cell Tumors. This list is monitored by medical professionals, and is a good place to ask questions about the disease and to share clinical experiences. This is NOT an emotional support group. To join, [click here](#).

- [MACAG Online Support Group](#)

The Metro Atlanta Carcinoid Awareness Group (MACAG) was established in November 2004. The group was established as an informal communications enabler for those who reside in Georgia and have been diagnosed with carcinoid cancer. Family members and medical professionals who wish to share information with members are also welcomed. To join [CLICK HERE](#)

- [MEN1 Support Group](#)

MEN1 is a hereditary syndrome that causes tumors—mostly endocrine—in different organs. Sometimes, but not often, carcinoid tumors develop. This list was created for patients, family members, and caregivers to offer caring, support, guidance, and up-to-date information on living and coping with Multiple Endocrine Neoplasia Type 1 (MEN1). All are welcome to join. Just enter the link above. Hope to see you there.

- [NOID Friends](#)

On Topica, we are here to serve everyone's needs, and encourage people to post without fear of retribution. "We are here to share about all kinds of topics -- carcinoid (of course), medical articles, health insurance, medicines, treatment options, member experiences, symptom management, medical providers, case management, dealing with doctors and other medical providers, Social Security Disability (carcinoid qualifies), emotional issues, family concerns, caregiver info and support, understanding procedures, learning to be a better patient, dealing with a chronic illness,

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specialty labs, and so much more. If you can think of it, we can discuss it! We are all in this together."

To join, send an email to [noids-subscribe@topica.com](mailto:noids-subscribe@topica.com).

- [LUNGNOIDS](#) (you must be a member of Yahoo to sign up, once signed up search for Lungnoids to join the group)

This is a carcinoid online group dedicated to lungnoids and other foreguts. This group was started because the standard of treatment for lung/stomach/pancreatic noids is different than the intestinal noids.

- [INSPIRE FOR LUNG CANCER SURVIVORS](#)

INSPIRE, the online support community, has added a new section for Neuroendocrine (NETS) / Carcinoid Tumors in the Lung Cancer community. This group is already engaged in several discussions and all who are interested are invited to join. INSPIRE connects patients, families, friends and caregivers for support and inspiration. [CLICK HERE](#) for more information.

- [INSPIRE FOR PANCREATIC NEUROENDOCRINE TUMOR \(PNET\) COMMUNITY](#)

INSPIRE, the online support community, has added a new section for the Pancreatic Neuroendocrine Tumors (PNETs) community. INSPIRE connects patients, families, friends and caregivers for support and inspiration. [CLICK HERE](#) or on the logo below for more information and to join.

Connect NOW with a  
**PNET Inspire**  
Patient Community

Go now

**Inspire**

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- [ZES \(Zollinger-Ellison Syndrome\) online support group](#)

This is a support group for patients, caregivers, and family members. It is our hope to offer current information, support, and knowledge so we can all be "in the know," for only in knowledge can we truly be a partner with our healthcare team. Join us and welcome.

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- **Facebook Support Groups:**

For those who use **Facebook**, there are many carcinoid/NET groups including different nonprofit pages, closed groups (you need to request to become a member), individual advocate pages, etc. When you are on the Facebook site, use the search box to find these groups. And please visit and Like the **Carcinoid Cancer Foundation's Facebook page** by [clicking here!](#)

There is an especially active group for the **lung carcinoid community** called **Lovable Lungnoids**. Click here to request membership: <https://www.facebook.com/groups/lovablelungnoids/?fref=ts>.

- There are a number of states that do not yet have carcinoid/neuroendocrine tumor (NET) support groups that meet in person. We express our deepest appreciation to **Jennifer Holm**, leader of the Iowa Carcinoid Cancer Connection support group, for creating Facebook groups for the states listed below so that carcinoid/NET patients and caregivers can connect with others in their state. Please be in touch with the Carcinoid Cancer Foundation if you are considering becoming an in-person support group; we are happy to help!

- **FACEBOOK Support Groups by State**

[Alaska Carcinoid Cancer Connection](#)

[Delaware Carcinoid Cancer Connection](#)



[Hawaii Carcinoid Cancer Connection](#)

[Idaho Carcinoid Cancer Connection](#)

[Iowa Carcinoid Cancer Connection](#)

[Kansas Carcinoid Cancer Connection](#)

[Kentucky Carcinoid Cancer Connection](#)

[Mississippi Carcinoid Cancer Connection](#)

[Montana Carcinoid Cancer Connection](#)

[Nebraska Carcinoid Cancer Connection](#)

[New Mexico Carcinoid Cancer Connection](#)

[North Dakota Carcinoid Cancer Connection](#)

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[Oklahoma Carcinoid Cancer Connection](#)

[Tennessee Carcinoid Cancer Connection](#)

[Wisconsin Carcinoid Cancer Connection](#)

[Wyoming Carcinoid Cancer Connection](#)

## International Elists

### Canada

- [Carcinoid-NETS-Canada](#)

A Listserv/Website dedicated for Canadians and their neuroendocrine cancers. To join [CLICK HERE](#).

### Sweden

- **CARPA** Mailing List (primarily in Swedish)

[carpa@kanalen.org](mailto:carpa@kanalen.org)

Mailinglistan vänder sig till patienter med hormonproducerande tumörer, t ex carcinoider, endokrina pankreastumörer, binjurebarkscancer och liknande. Även anhöriga och vårdpersonal är välkomna.  
Owner: Marina Walström

 [support.jpg](#)

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