

THE
Educated Patient[®]

Carcinoid Syndrome

RESOURCE GUIDE



A collection of resources that provide information and support for patients with carcinoid syndrome and the oncology professionals who treat them.





At Novartis Oncology, we're always thinking about neuroendocrine tumors.

Novartis Oncology continues to demonstrate a commitment to addressing the unmet needs in neuroendocrine tumors.



What Is Carcinoid Syndrome?

Carcinoid tumors are rare, slow-growing tumors that form from the same neuroendocrine cells that produce hormones to control and produce digestive juices and the muscles used to transport food through the stomach and intestines.¹ Sometimes these cells overproduce hormones such as serotonin, one of the body's natural chemical messengers. If overproduced, serotonin may cause symptoms of carcinoid syndrome.^{2,3}

Symptoms normally appear after the slow-growing tumor has spread. It is important to understand that not all people affected with carcinoid tumors develop carcinoid syndrome.²

Awareness of carcinoid syndrome and its symptoms is beneficial in helping to properly diagnose and manage the disease as early as possible.^{2,3}

Symptoms of Carcinoid Syndrome

There are several symptoms of carcinoid syndrome. Most commonly, people with carcinoid syndrome may experience flushing. Flushing of the skin, not accompanied by sweat, appears suddenly on the face, neck, or other areas of the body. Flushing resembles blushing in a deep red or purple color.^{2,3}

Diarrhea, including diarrhea at nighttime, heart valvular lesions, cramping, wheezing, arthritis, nutritional deficiency, and developing skin conditions such as spots and rashes are also symptoms. Swelling of the ankles, legs, hands, arms, neck, or face may also occur.²

Diagnosing Carcinoid Syndrome

Early diagnosis of carcinoid syndrome is important. Several testing procedures are available to help diagnose and monitor carcinoid syndrome.

- **5-Hydroxyindoleacetic Acid (5-HIAA) Test**

Most commonly, your healthcare professional will suggest this urine test, which measures the level of serotonin in the body over a 24-hour period. Elevated levels of 5-HIAA, produced as serotonin breaks down in the body, help detect carcinoid tumors. Your healthcare professional may advise you to avoid foods such as bananas, walnuts, pineapple, tomatoes, and eggplant prior to taking this test.²

- **Chromogranin A (CgA) Test**

This blood test detects CgA, a protein found in carcinoid tumor cells that is secreted into the blood. The test can be performed every 3 to 6 months to monitor the activity of carcinoid tumors and determine elevated levels of CgA. Renal failure, chronic atrophic gastritis, or the use of proton-pump inhibitors may interfere with the results of this test.²

- **Somatostatin Receptor Scintigraphy (SRS) Test**

This imaging test, used to detect carcinoid tumors, specifically reveals tumors and metastases only where somatostatin receptors are present. This test has the ability to image all regions of the body with high sensitivity and helps detect the density of somatostatin receptors.²

Other testing options that may be suggested by your healthcare professional include a biopsy or imaging tests such as a computed tomography (CT) scan, magnetic resonance imaging (MRI), or endoscopic ultrasonography.^{2,3}

Treating Carcinoid Syndrome¹⁻³

Several treatment options, including palliative therapy to relieve symptoms and improve quality of life are available for people diagnosed with carcinoid syndrome. Surgery is also common. The type of surgery and extent of the tumor removal process depends on the location and size of the tumor.

If the tumor cannot be removed, other treatment options may include:^{1,3}

- Ablation, which injects liquid nitrogen, high-energy radio waves, or concentrated alcohol into the cancerous tissue to destroy it
- Hormone therapy
- Chemotherapy
- Radiation therapy

It is important to discuss all treatment options with your healthcare professional.

Health, Diet, and Emotional Support

The best approach to your diagnosis with carcinoid syndrome is to remain proactive. Communicating openly with loved ones and your healthcare team and consuming a healthy diet are lifestyle suggestions to help you manage and cope. It is still important to consult your physician.

Reducing Stress and Optimizing Emotional Support

Becoming comfortable discussing carcinoid syndrome with others may help you manage your condition, reduce stress, and maintain a positive attitude.²

Open communication with your loved ones, caregiver, and healthcare professional is important. Support in any form allows you to discuss your feelings and may help you develop coping skills.⁴ Some people find that by talking, they begin to solve problems and think about other issues as their family and friends ask questions. Friends, family, and caregivers can share their strength and concern with you, and help encourage you along the way.⁵

It is necessary to work closely with your caregiver and discuss how you feel physically and emotionally. Caregivers should set a goal of openness by letting the patient know that they want to be included in their care. With the patient's consent, it is also important that the caregiver create an open relationship with the health care team.⁶

As a patient, discussing your diagnosis and speaking regularly with your healthcare professional is necessary.

Diet²

Avoiding spicy foods and alcohol and making wiser decisions while eating will improve your outlook with carcinoid syndrome.² Some possible dietary suggestions include:

CHOOSE	INSTEAD OF
Rice, wheat, or oatmeal cereal	High fiber cereals containing bran or whole grain
Chicken or turkey (skinless white meat), beef, or fish	Dairy foods (cheese, yogurt, cottage cheese)
White bread	Whole grain breads
Rice, pasta, or potatoes without the skin	High-fiber vegetables such as broccoli, cauliflower, cabbage, and beans
Ripe bananas, pureed vegetables, and canned or cooked fruits such as applesauce or pears	Raw vegetables, fresh or dried fruits, pickles, relishes, nuts, and popcorn
Jam or jelly	High-fat spreads (butter, cream cheese)
Baked or broiled foods	Greasy, fatty, or fried foods
Bland foods	Spicy foods (curry, hot pepper)
Hard candy or pound cake	Caffeinated foods (chocolate candy, brownies)
Animal crackers or pretzels	Butter cookies and doughnuts
Water	Milk
Decaffeinated beverages	Beverages that contain caffeine (coffee, tea, hot chocolate)
Clear broth (chicken or beef)	Creamy soups
Noncarbonated drinks	Juices with pulp or carbonated beverages such as clear fruit juices with a lot of fizz
Pedialyte ³ , Gatorade [*] , and other electrolyte-replacement drinks	High-sugar drinks or carbohydrate-loading sports drinks
Lactose-free beverages such as soy milk or lactose-free dairy products	Milk
Nonalcoholic beverages	Beverages with alcohol

^{*} Pedialyte is a registered trademark of Abbott Laboratories.
Gatorade is a registered trademark of The Gatorade Company.

Questions to Ask Your Physician^{2,7}

An initial diagnosis may be overwhelming. Below are common questions that may be helpful when you sit down to discuss your diagnosis. These questions can help you stay on track and ensure that you gain a full understanding of your diagnosis and treatment options.

- What are the grade and stage of my disease?
- Has my disease spread to other parts of my body?
- How will my disease be managed?
- What can I expect in the near future?
- What should I do to be ready for treatment?
- Do I need to change or modify my diet?
- Do you have a dietitian or nutritionist that you recommend?
- Will my ability to work, travel, or drive be affected?
- Will I need to spend time in the hospital?
- Will I have physical limitations?
- Are there any lifestyle changes I should make?
- What support programs are available for me and my family?
- Who can I speak with about my financial and/or insurance concerns?
- Who can help me navigate the medical system? Is there an oncology social worker or patient advocate available at this hospital?

It can also be helpful to bring another person along to medical appointments. A friend or family member can be supportive, provide an extra set of ears, and ensure that all questions are answered. Recording the meeting is a good way to avoid missing important information. Ask the doctor for permission to record the meeting and then listen to the conversation at a later time, or bring a notepad and pen to write down any notes.

References

1. Gastrointestinal carcinoid tumors treatment. National Cancer Institute website. <http://www.cancer.gov/cancertopics/pdq/treatment/gastrointestinalcarcinoid/Patient>. Accessed August 6, 2012.
2. Carcinoid syndrome. CarcinoidLink website. <http://www.carcinoid.com/patient/understanding-carcinoid-syndrome.jsp>. Accessed August 7, 2012.
3. What is carcinoid syndrome? WebMD website. <http://www.webmd.com/cancer/features/what-is-carcinoid-syndrome>. Accessed August 7, 2012.
4. When cancer doesn't go away. American Cancer Society website. <http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/when-cancer-doesnt-go-away>. Accessed August 10, 2012.
5. Talking with friends and relatives about your cancer. American Cancer Society website. <http://www.cancer.org/Treatment/UnderstandingYourDiagnosis/TalkingaboutCancer/talking-with-friends-and-relatives-about-your-cancer>. Accessed August 10, 2012.
6. What you need to know as a cancer caregiver. American Cancer Society website. <http://www.cancer.org/acs/groups/cid/documents/webcontent/acspc-027595-pdf.pdf>. Accessed August 10, 2012.
7. Questions to ask your healthcare team. Pancreatic Cancer Action Network website. http://www.pancan.org/section_facing_pancreatic_cancer/learn_about_pan_cancer/treatment/specialists/Questions_to_ask_doctor.php. Accessed August 10, 2012.

Carcinoid Cancer Awareness Network

www.carcinoidawareness.org



The Carcinoid Cancer Awareness Network (CCAN) raises worldwide awareness among the medical community and general public about neuroendocrine tumors and carcinoid cancer. Each year, CCAN organizes and attends conferences, trade shows, and medical meetings, as well as distributes information packets, merchandise, awareness items, and financial support to many support groups worldwide. CCAN also contributes to medical research. The group is available 365 days a year to provide information and support to patients and caregivers.

ADDRESS:

2480 Hull Avenue N
Bellmore, NY 11710

CONTACT INFO:

Phone: 516 -781-7814
866-850-9555

E-mail: carcinoidaware@aol.com

Resource Checklist:

- ✓ Toll-free support line
- ✓ Conferences
- ✓ Fund-raisers
- ✓ Clinical trials information
- ✓ Distributable awareness items
- ✓ Free information packets

Carcinoid Cancer Foundation

www.carcinoid.org



The Carcinoid Cancer Foundation has been serving the carcinoid/neuroendocrine tumor (NET) community for over 44 years with the purpose of encouraging and supporting research and education on carcinoid and related neuroendocrine cancers. The foundation increases awareness and educates the general public and healthcare professionals about carcinoid and related NETs so they can support NET cancer patients and their families and serve as patient advocates.

ADDRESS:

333 Mamaroneck Avenue
#492
White Plains, NY 10605

CONTACT INFO:

Phone: 888-722-3132

Resource Checklist:

- ✓ Blog
- ✓ Find a doctor
- ✓ Clinical trials information
- ✓ Mobile application for patients
- ✓ Resources for doctors
- ✓ Support group directory
- ✓ Financial assistance information
- ✓ Mailing list

Caring for Carcinoid Foundation

www.caringforcarcinoid.org



The Caring for Carcinoid Foundation (CFCF) has awarded over \$7 million in research grants and directs 100% of all individual donations toward scientific research of carcinoid cancer, pancreatic neuroendocrine cancer, and related neuroendocrine cancers. In addition, CFCF supports patients, caregivers, family, and friends by providing them with up-to-date information specific to these cancers.

ADDRESS:

198 Tremont Street
Box 456
Boston, MA 02116

CONTACT INFO:

Phone: 617-948-2514

Resource Checklist:

- ✓ Video library
- ✓ Blogs
- ✓ Doctor database
- ✓ Clinical trials information
- ✓ Fund-raising
- ✓ Survivor stories

New Jersey Carcinoid Cancer NETWORK

www.njcarcinoidnetwork.org

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New Jersey Carcinoid Cancer NETWORK

This web site may not be supported by all mobile browsers.

Thanks to the efforts of Michael L., New Jersey Governor Chris Christie has declared November 2011 as Neuroendocrine and Carcinoid Cancer Month. [Click here to see a copy of the proclamation.](#)

After nearly eleven years, we have outgrown our meeting place at Crossroads Christian Fellowship in Union, NJ. Starting with our September 2012 meeting, we will be meeting at a larger facility, the Woodbridge Public Library, 1 George Frederick Plaza, Woodbridge, NJ. All our meeting times and dates will remain the same. Click on the link below for more information on our meetings. We want to sincerely thank Crossroads Christian Fellowship for their hospitality.

The New Jersey Carcinoid Cancer NETWORK (NJCCN) promotes awareness of carcinoid and other neuroendocrine tumors (NETs), and provides information to patients, caregivers, and medical professionals to assist in disease management and educate about treatment and diagnostic options.

ADDRESS:

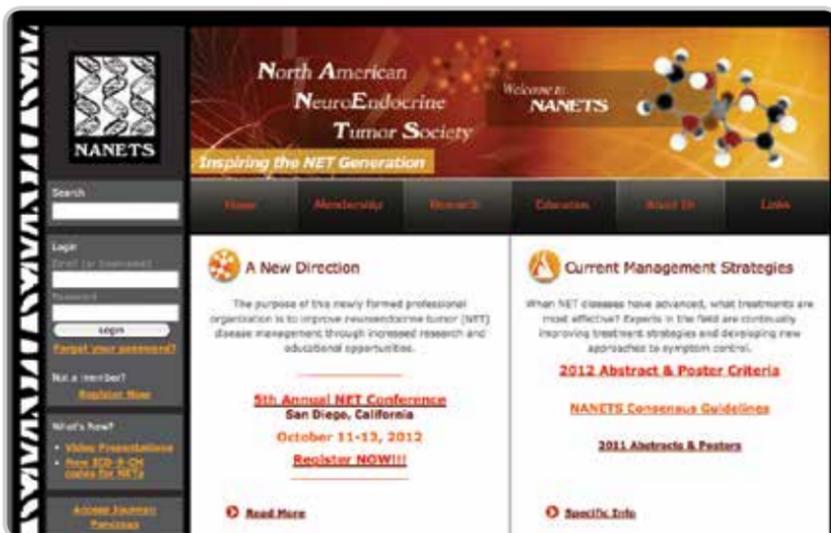
9 Maplewood Drive
Little Egg Harbor, NJ 08087

Resource Checklist:

- ✓ Downloadable newsletters
- ✓ Local monthly meetings
- ✓ Disease-specific information
- ✓ Coping tips

North American NeuroEndocrine Tumor Society

www.nanets.net



The North American NeuroEndocrine Tumor Society (NANETS) is a professional organization dedicated to improving neuroendocrine tumor (NET) disease management. NANETS provides educational opportunities and up-to-date information on the most current research.

ADDRESS:
800 NE Tenney Road
Suite #110-412
Vancouver, WA 98685

CONTACT INFO:
Phone: 360-314-4112

Resource Checklist:

- ✓ Conferences
- ✓ Clinical trials information
- ✓ Research development information
- ✓ Video presentations

National Organization for Rare Disorders

www.rarediseases.org



The National Organization for Rare Disorders (NORD) is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. Information regarding carcinoid syndrome may be found through the Rare Disease Database search engine feature found in the Rare Disease Information drop-down menu.

ADDRESS:

55 Kenosia Avenue
Danbury, CT 06810

CONTACT INFO:

Phone: 203-744-0100
800-999-6673

Resource Checklist:

- ✓ Database of patient organizations
- ✓ Patient assistance programs
- ✓ Patient spotlights
- ✓ Clinical trials information
- ✓ Health insurance, Medicare/Medicaid information
- ✓ Ask-the-nurse feature

Support Groups

The following support groups can be accessed through the Carcinoid Cancer Foundation at www.carcinoid.org.

Arizona

The Wellness Community of Arizona
www.twccaz.org
602-712-1006

California

NorCal CarciNET Support Group
www.NorCalCarcinet.org

Northern California
Neuroendocrine
Cancer Fighters
karbanis@yahoo.com

Colorado

Colorado Carcinoid Cancer
Support Group
www.cccsg.net

Connecticut

Connecticut Carcinoid Initiative
www.ctcarcinoid.com

Georgia

Metro Atlanta Carcinoid
Awareness Group
[http://health.groups.yahoo.com/
group/MACAG](http://health.groups.yahoo.com/group/MACAG)
770-831-4519

Illinois

Chicagoland Carcinoid Fighters
<http://chicagocarcinoid.weebly.com>
224-948-4844

Indiana

Indiana Carcinoid Awareness
Network
www.indycarcinoid.org
groupleader@indycarcinoid.org

Iowa

Iowa Carcinoid Connection
www.iowacarcinoid.wordpress.com
515-205-4565

Louisiana

Louisiana Carcinoid/NET Patient
Support Group
Louisiana.nets@gmail.com
504-835-1710

Maine

New England Carcinoid
Connection, Inc.
www.carcinoid-newengland.org
Nitaobrien@comcast.net
Logcabin89@gmail.com

Massachusetts

Carcinoid and Neuroendocrine
Seminar/Support Group
<http://carcinoid.dfci.harvard.edu>
Jane_Bausch@dfci.harvard.edu
617-632-3309

New England Carcinoid
Connection, Inc.
www.carcinoid-newengland.org
Nitaobrien@comcast.net
Logcabin89@gmail.com

Michigan

Michigan Carcinoid Group
Dave.vickery2008@gmail.com
616-450-0842

Minnesota

Minnesota Carcinoid/NETs
Support Group
Jaxon1248@gmail.com
Bignorske2001@yahoo.com
651-216-6230

Missouri

Heartland Carcinoids/NETs
Support Group
www.heartlandcarcinoids.org

New Hampshire

New England Carcinoid
Connection, Inc.
www.carcinoid-newengland.org
Nitaobrien@comcast.net
Logcabin89@gmail.com

New Jersey

New Jersey Carcinoid Cancer
NETwork
www.njcarcinoidnetwork.org

New York

Carcinoid Cancer Awareness
Network
www.carcinoidawareness.org
1-866-850-9555

Western NY Carcinoid
Support Group
www.wnycarcinoid.org
Betsy@wnycarcinoid.org

North Carolina

Noids in the Carolinas
Nczebragirl12@aol.com
910-545-7513

Ohio

Ohio Carcinoid Support Group
Greg.ziernicki@gmail.com
440-268-9442

Oregon

Pacific Northwest Carcinoid
Support and Advocacy Group
Oregon & SW Washington Chapter
kbrendtro@yahoo.com
360-314-4112

Pennsylvania

Philly NETs
www.phillynets.org
267-288-5642

Rhode Island

New England Carcinoid
Connection, Inc.
www.carcinoid-newengland.org
Nitaobrien@comcast.net
Logcabin89@gmail.com

South Carolina

Noids in the Carolinas
Nczebragirl12@aol.com
910-545-7513

Texas

Corpus Christi Carcinoid
Support Group
wyhtak@aol.com
361-877-7345

Houston Carcinoid NETWORK
carcinoid@comcast.net

The Centex Carcinoid
Fighters Group
judefiller@hotmail.com
512-472-7224

Vermont

New England Carcinoid
Connection, Inc.
www.carcinoid-newengland.org
Nitaobrien@comcast.net
Logcabin89@gmail.com

Washington

Pacific Northwest Carcinoid/
NET Support Group
Washington Chapter
coriedean@comcast.net

Additional Resources

www.carcinoid.com

Carcinoid.com Mapped!®

Visit Carcinoid.com to learn about carcinoid syndrome, a rare disease.

Carcinoid Syndrome

Scroll through a series of tabs to learn more about carcinoid syndrome and take an active role in managing your condition.

Carcinoid Syndrome Symptom Assessor

Use the symptom assessor to learn about frequent health problems caused by carcinoid syndrome, print your personal assessment, and download a symptom diary to track your symptoms.

Virtual Patient Concierge

This section provides interactive answers to some commonly asked questions regarding carcinoid syndrome. Simply select a treatment team member to learn more.

Kari's Journey

Watch this video and learn about Kari Brendtro, a patient living with this rare disease, and hear about her diagnosis, experiences, and tips for others.

Stay Informed

Enroll in CarcinoidLink to receive a series of personalized e-mail communications about living with carcinoid syndrome.

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