# Additional US and International

This is a list of websites that you may find useful in your search for additional information about research, financial assistance, and other related medical information.

# International

• European Neuroendocrine Tumor Society (ENETS)

The European Neuroendocrine Tumor Society is an international professional association composed of physicians and researchers, whose main area of study is related to neuroendocrine tumors. Society members, currently numbering around 200, bring a variety of expertise to ENETS, such as oncology, pathology, endocrinology, surgery and gastroenterology. ENETS is supported via membership dues, as well as through educational grants from the pharmaceutical community.

It is administratively-based in Berlin, Germany.

European Neuroendocrine Tumor Network (ENETS)

# **United States**

• The Alliance for Nonprofit Management

For Nonprfit management <u>The Alliance for Nonprofit Management</u> is the professional association of individuals and organizations devoted to improving the management and governance capacity of nonprofits - to assist nonprofits in fulfilling their mission.

• American Association for Cancer Research (AACR) For Scientists

Survivor and Patient Advocacy Program For cancer survivors and advocates

AACR encourages survivors, advocates and scientists to share their knowledge and experiences and to learn from one another. We hope that these partnerships will promote a better understanding of cancer and improve research aimed at preventing and curing cancer. Patients, survivors and advocates will find clear and accurate information about research findings, support and advocacy groups, clinical trials and biomedical terminology. Scientists and doctors will find inspiration, insights and guidance that the AACR hopes will improve their roles in advancing research and care.

Calendar of Conferences and Events

• American Cancer Society, Inc

A complex and expansive website helpful for those that have recently been diagnosed with cancer. The American Cancer Society (ACS) provides cancer information services; holds meetings and conferences; provides support for cancer patients, friends, family and survivors; and much more.

www.cancer.org or call 800-227-2345

What is Lung Carcinoid?

What is a Gastrointestinal Tumor

# <u>AllRefer Health</u>

A medical and health information resource containing outstanding database of health articles and reference materials. Consumers and health professionals alike can depend on it for information that is authoritative and up-to-date.

### • The American Cancer Society

Resources for health information seekers.

Excellent and most informative sites regarding diagnosis, treatment, staging, what to ask your doctor, references etc. for lung and gastrointestinal carcinoid.

# <u>American Institute for Cancer Research (AICR)</u>

is the cancer charity that fosters research on diet and cancer prevention, interprets the evidence, and educates the public about the results.

# • <u>ASCO</u>

The American Society of Clinical Oncology welcomes you to ASCO Online, an interactive resource for oncology professionals and cancer patients. ASCO Online provides a range of professionally edited information, as well as interactive services for ASCO members.

#### • People Living With Cancer (PLWC)

People Living With Cancer, the patient information website of the American Society of Clinical Oncology (ASCO), provides oncologist-approved information on more than 50 types of cancer and their treatments, clinical trials, coping, and side effects. Additional resources include live chats, message boards, a drug database, medical dictionary, and links to patient support organizations. The site is designed to help people with cancer make informed health-care decisions.

• R.A.Bloch Cancer Foundation

One H&R Block Way Kansas City, MO 64105

TEL: 816-854-5050 1-800-433-0464 FAX 816-854-8024

"Having cancer is bad enough! Not knowing what to do about it is even worse."

The R.A. Bloch Cancer Foundation's goal is to help people diagnosed with cancer achieve the best and quickest possibility of recovery. We advocate getting a second opinion upon diagnosis and becoming well-educated about cancer and its treatments. Our mantra for people diagnosed with cancer is to seek prompt, proper and thorough treatment. Founded in 1980, our services are free, and we never solicit financial donations from the people whom we serve.

• Cancer Care, Inc.

"When you don't know where to turn", Cancer Care can help.

If you or someone you know has just been diagnosed with carcinoid cancer—or has been living with carcinoid cancer for some time—you may have questions or need support. This web site define the five areas of service we offer for carcinoid cancer patients and their families.

• CMP Medica / <u>Hematology</u> by Cancer Network

<u>Cancernetwork.com</u> provides an array of informative content. We are committed to supplying up-to-date oncology/hematology news and articles including extensive avenues for earning CME online. Direct access to e-textbooks and guides filled with current helpful information. CMPMedica is a leading healthcare media company providing news and education to communities of general practitioners, specialist doctors, pharmacists, nurses and patients across 26 countries.

#### Click here for carcinoid references

Comment: Excellent up to date full text peer-review medical articles regarding all aspects of carcinoid/NETS.

• Complementary and Alternative Therapies by the American Cancer Society

Making Treatment Decisions:

The terms "alternative" or "complementary" are used to refer to non-traditional methods of diagnosing, preventing, or treating cancer. Many cancer patients find that these therapies relieve symptoms or side effects, ease pain, and enhance their lives during treatment. How can you know if these approaches are safe and if they can help you?

#### Genetic Alliance

Genetic Alliance is a coalition of more than 600 advocacy organizations serving 25 million people affected by 1000 conditions. The organization works to transform leadership in the genetics community to build capacity in advocacy organizations and to educate policymakers by leveraging the voices of individuals and families. Genetic Alliance increases the capacity of genetic advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions.

#### • <u>Helping Patients.org</u>

Helping Patients brings together America's pharmaceutical companies, doctors, patient advocacy organizations and civic groups to help low-income, uninsured patients get free or nearly free brand-name medicines. Its mission is to increase awareness of and enrollment in existing patient assistance programs for those who may be eligible. Through this site, Helping Patients offers a single point of access to more than 275 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies.

#### • <u>Healthcyclopedia</u>

The Complete Guide to Health Care Resources on the Internet

Very comprehensive information regarding carcinoid and related neuroendocrine tumors with excellent links to relevant subjects.

For direct access to carcinoid subjects go to www.healthcyclopedia.com/cancer/carcinoid.html

We also urge you to visit their main page. This site is a beautifully designed, easy-to-navigate website with a multitude of health-related subjects.

• HealthWell Foundation Launches New Program To Help Patients With Carcinoid Tumors

Gaithersburg, MD (February 1, 2007) – The HealthWell Foundation® is pleased to announce a new program to assist patients diagnosed with carcinoid tumors and symptoms related to carcinoid tumors. The HealthWell Foundation is an independent, non-profit organization working to reduce barriers to medical care for patients with chronic or life-threatening diseases. The new program provides financial assistance to help underinsured patients afford their copayments and other out-of-pocket costs for treatments for carcinoid tumors and related symptoms.

"As patients continue to face rising out-of-pocket medical costs, the HealthWell Foundation is working to help reduce financial barriers to care," said Stephen M. Weiner, President of the HealthWell Foundation. "We have assisted more than 23,000 patients in over 22 disease areas and are excited to expand our program to help patients with carcinoid tumors afford their medical treatments as well."

Additional information about the new carcinoid tumors program and the HealthWell Foundation is available online at <u>www.healthwellfoundation.org</u>

• <u>Hematology</u> by Cancer Network

<u>Cancernetwork.com</u> provides an array of informative content. We are committed to supplying up-to-date oncology/hematology news and articles including extensive avenues for earning CME online. Direct access to e-textbooks and guides filled with current helpful information. CMPMedica is a leading healthcare media company providing news and education to communities of general practitioners, specialist doctors, pharmacists, nurses and patients across 26 countries

Comment: Excellent up to date full text peer-review medical articles regarding all aspects of carcinoid/NETS

• <u>The Lance Armstrong Foundation</u> unites people to fight cancer.

We offer information and services to help cancer survivors live life on their own terms. We take aim at the gaps between what is known and what is done in the cancer fight. We engage people to make cancer a national priority

JOIN THE FIGHT- GET INVOLVED

LIVESTRONG SurvivorCare program, Get One-on-One Support

Through the LIVESTRONG SurvivorCare program, you can request help dealing with your cancer experience, including:Call 1-866-467-7205 to request help

# Mayo Clinic-Carcinoid Tumors Diagnosis and Treatment Options

Mayo Clinic specialists have been diagnosing and treating carcinoid tumors for more than 40 years. A team from oncology, radiation oncology, surgery, pathology, cardiology, diagnostic radiology, gastroenterology, and other departments provides comprehensive and compassionate care for each patient. The National Cancer Institute has designated the Mayo Clinic Cancer Center as a comprehensive cancer center. This designation is given to cancer centers whose cancer researchers and clinicians meet stringent standards. Mayo physicians are also committed to conducting clinical trials to develop innovative treatment strategies for carcinoid tumors. <u>MedlinePlus</u>

Welcome to MedlinePlus, a goldmine of good health information from the world's largest medical library, the National Library of Medicine. Health professionals and consumers alike can depend on it for information that is authoritative and up to date.

#### • <u>Medscape</u>

The Online Resource for Better Patient Care®. Medscape is the leading medical information Web site and is designed to give healthcare professionals and consumers the healthcare information and digital data they need, regardless of where or when they need it.

• National Organization for Rare Disorders (NORD)

The National Organization for Rare Disorders is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases. We invite you to explore this exciting web site and familiarize yourself with the full range of NORD's services. Read our acclaimed newsletter the Orphan Disease Update or search the Rare Disease Database, the Organizational Database, and Orphan Drug Designation Database for information on specific rare disorders.

• NCI- General Information About Gastrointestinal Carcinoid Tumors

On the National Cancer Institute website.

• <u>OncoLink</u>

OncoLink is the first multimedia oncology information resource placed on the Internet. OncoLink is accessible worldwide to anyone with Internet access, has been established with the following objectives: Dissemination of information relevant to the field of oncology, Education of health care personnel, education of patients, families, and other interested parties, and Rapid collection of information pertinent to the specialty.

Oncology by OncologySTAT

Elsevier's Oncologystat.com recently upgraded its website.

OncologySTAT's mission is to improve worldwide cancer care and prevention by providing healthcare professionals with immediate integrated access to the most authoritative evidence-based information available. OncologySTAT's commitment to international health ensures that news, research, education, and analysis from all regions of the world are covered in a publisher, society, and sponsor-neutral online environment. Newly updated - Colon Cancer Resources.

Colon and Rectum Cancer Resources from Elsevier's OncologySTAT

#### • Office of Rare Diseases (ORD)

The National Institute of Health's website of Office of Rare Diseases (ORD) provides information on more than 6000 rare diseases, including current research, clinical trials, publications from scientific and medical journals, completed research, ongoing studies, and patient support groups.

Pancreatica.org

For patients with neuroendocrine pancreatic cancer this site is MUST visit. It is a well designed and easy to navigate site which includes comprehensive information on all aspects of pancreatic cancer and has the largest database in the world of clinical trials against pancreatic cancer. The Frequently Answered Question section has information well worth reading for adenocarcinoma( adenocarcinoid) patients.



In 1989 <u>Research!America</u>'s founders came together with the realization that there was a vast deficiency in medical research funding — and that such a gap would be detrimental to Americans for years to come. Through their mutual belief in the fundamental importance of medical research, these visionaries formed the Research!America alliance.

The Carcinoid Cancer Foundation supports their mission of making research to improve health a higher national priority.

# • <u>Quackwatch</u>

Don't let desperation lead you to try things just because someone advises you to do so. Read the information on this web site thoroughly. This site was created by Dr. Stephen Barrett, a noted "quackbuster" of what he considers to be useless treatments and irresponsible practitioners.

Surviving Cancer in Greater Washington DC

An online resource provided by the Greater Washington Coalition for Cancer Survivorship.

Whether you are newly diagnosed, a long-term survivor, caring for a loved one with cancer, or providing professional services for cancer survivors and patients, we are here to help you. We provide a directory of support groups and a calendar of cancer-related events in the Washington, DC area, and we serve as a clearinghouse for general information about surviving cancer.

• YES (Yttrium 90 Microspheres Education and Support)

"When the impossible is possible"

This site gives information and support to patients who have undergone treatment with Yttrium 90 Microsphere.

Their toll free survival number is 1-877-937-7478

WebMD Health - Cancer Information Center

A comprehensive information site on cancer in general.

• <u>Wikipedia</u>

support.jpg

Source URL: <u>http://www.carcinoid.org/support/resources/additional-us-and-international</u>