

What's New on Carcinoid.org

Iowa Carcinoid Cancer Connection

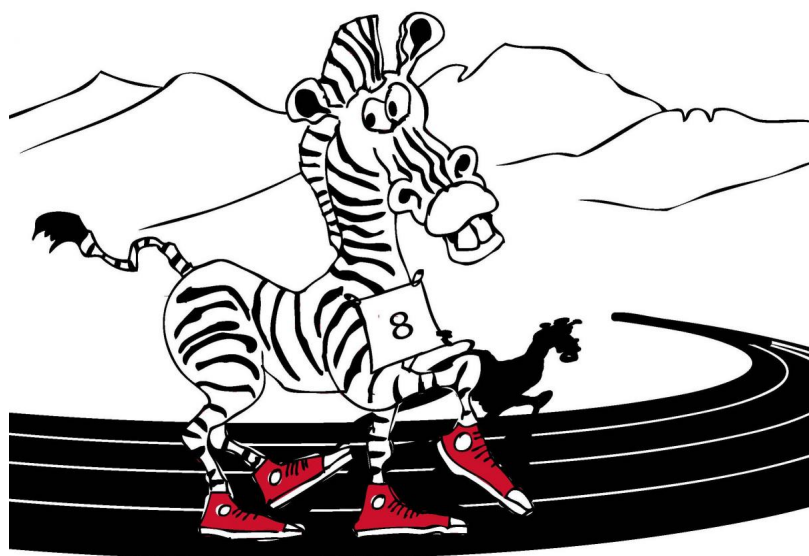
Welcome to the newly formed **Iowa Carcinoid Cancer Connection** support group! Group leader **Jennifer Holm** invites all carcinoid cancer patients, their family, friends and caregivers to join the group. Check out their website by [clicking here](#) and connect with Jennifer at iowacarcinoid@yahoo.com. This is a wonderful new resource for all in the carcinoid community who live in Iowa!!

Rare Disease Day, February 29, 2012

February 29, 2012 marks the fifth international **Rare Disease Day**. On this day hundreds of patient organizations from more than 50 countries worldwide are organizing awareness-raising activities converging around the slogan "Rare But Strong Together." The **Carcinoid Cancer Foundation** is proud to be **Rare Disease Day Partner**. Read more about Rare Disease Day, [click here](#).

Colorado Carcinoid Cancer Support Group

The **Colorado Carcinoid Cancer Support Group** has a terrific new website. Check it out: <http://www.cccsg.net/>. The Survivor Stories are especially inspiring. Thank you to all who have shared their journeys.



Spotlight on The Unicorn Foundation

What's New on Carcinoid.org

Published on The Carcinoid Cancer Foundation (<http://www.carcinoid.org>)

Seeking to raise awareness of NET cancers and funds for research, **The Unicorn Foundation** is the only nonprofit medical charity dedicated to the needs of Australian NET survivors. Meet **Dr. John Leyden**, Chairman of the Foundation; **Kristen Leknius**, NET patient; **Professor Rod Hicks**, Peter MacCallum Cancer Centre; and **Robert Doyle**, Lord Mayor of Melbourne. [Click here](#) to read more about The Unicorn Foundation.

World Cancer Day -- February 4

World Cancer Day is the occasion to unite the world in the fight against cancer by raising awareness, educating the public, and lobbying for change. Together we can reduce the global cancer burden. **Sign and share the World Cancer Declaration** by [clicking here](#).

HealthWell Foundation Reopens Program for Carcinoid

IMPORTANT NOTICE, January 13, 2012: The **HealthWell Foundation**, which assists with numerous disease states and their medications, has **reopened its fund for Carcinoid Tumors and Symptoms Related to Carcinoid Tumors**. This is a first-come, first-served program.

What does the **HealthWell Foundation** do? It provides financial assistance to eligible individuals to cover coinsurance, copayments, healthcare premiums and deductibles for certain treatments. To determine eligibility for the program, [click here](#).

For further information, visit the **HealthWell Foundation's** website, <http://healthwellfoundation.org/>, or call (800) 675-8416, 9:00 am to 5:00 pm Monday through Friday, Eastern Time. E-mail inquiries can be sent to info@healthwellfoundation.org.

New Support Group Forming in Mobile, Alabama

If you are a NET cancer survivor, caregiver, family member or friend living in the Mobile, Alabama area, the 1st Neuroendocrine Cancer Support Group Meeting will be held on **Saturday, February 4, 2012** at 2:00 pm at the **Mobile Infirmary Medical Center Auditorium**. [Click here](#) to learn more about the meeting and to **RSVP by January 27**.

Holiday Message from the Carcinoid Cancer Foundation

The **Carcinoid Cancer Foundation** wishes the carcinoid/NET community happy holidays and a wonderful New Year. Please consider supporting our mission of education and awareness, support, and patient advocacy as we expand on our work in 2012. [Read more](#) about our **Annual Appeal**.

Special Announcement from the Carcinoid Cancer Foundation on NET Cancer Day, November 10, 2011

What's New on Carcinoid.org

Published on The Carcinoid Cancer Foundation (<http://www.carcinoid.org>)

In recognition and support of [Worldwide NET Cancer Awareness Day](#), the Carcinoid Cancer Foundation is pleased to announce a new video series that will begin in 2012. This series, made possible by the generosity of **Kim, Heather and Lauren Simpson** and other family and friends, has been created "In loving memory of **Cheryl Stanley Simpson** (pictured below) of Gainesville, Florida. Cheryl was a loving and incredible wife, mother, sister, daughter, teacher and friend. May her courage and dignity in fighting carcinoid cancer and this program help save the life of



someone else in her memory."

Throughout this unique series we will focus on topics of importance to carcinoid and neuroendocrine tumor (NET) community. Why is the series unique? Because we're reaching out to the community for requests on topics of interest related to carcinoid and NETS. Please send an email to carcinoid@carcinoid.org with your suggestions for video topics.

Once the most requested topics are selected, we will announce the speakers who will be featured in the videos and you will have an opportunity to submit questions that can be answered by these speakers. We hope to provide answers to questions for which information is not readily available on our website or other carcinoid/NET websites. Dr. Richard R.P. Warner, Medical Director of the Carcinoid Cancer Foundation, will review all submitted questions and choose the ones to be answered by the speakers.

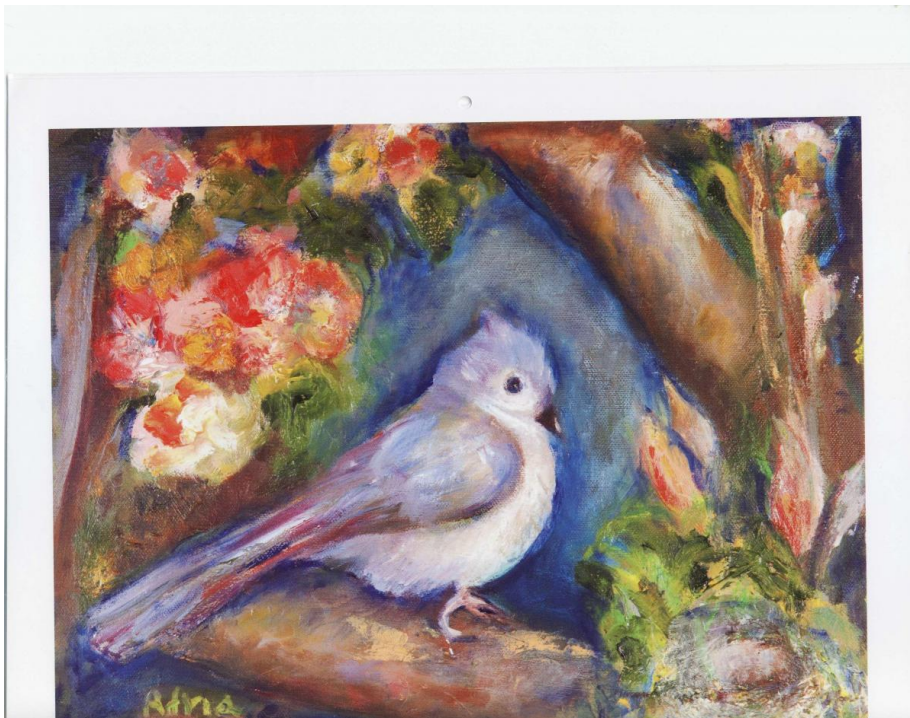
Awareness and education are the first critical components in the fight against carcinoid and NET cancers. Early detection and diagnosis can both enhance the quality of patients' lives and extend their lives. The Carcinoid Cancer Foundation is dedicated to bringing about this awareness as advocates for all who are currently living with carcinoid and related neuroendocrine tumors, their families, and those yet to be diagnosed. We are honored to be of service to this community and hope that our efforts continue to make a difference in your lives.

New Website for the Pancreatic Neuroendocrine Tumor Community

Posted August 14, 2011 -- **Pfizer Oncology**, in partnership with the **Pancreatic Cancer Action Network**, has created a new website dedicated to helping foster stronger connections throughout the pancreatic NET (neuroendocrine tumor) community and to raising awareness through education and information. The site includes excellent videos of patients and caregivers talking about their experience with pancreatic NETs. Visit the site at: <http://www.pannetconnections.com>.

Carcinoid Cancer Featured in ASCO 2011 Expressions of Hope Calendar

Posted January 17, 2011 -- Carcinoid cancer is the focus of the April calendar page for the 2011 Expressions of Hope calendar published by the **ASCO (American Society of Clinical Oncology) Cancer Foundation**. The calendar illustrations have been created by cancer patients, family members, friends, and caregivers to share their emotions through art and inspire hope in others. The oil painting "**The Song Bird Keeps Singing**" is the work of **Adria Di Maria**, mother of carcinoid patient **Marlena Johnston**, who was diagnosed with carcinoid cancer in 2010. "While [her most recent surgery] was successful, the recovery was difficult with a slew of minor complications which wore down her spirit; my song bird seemed to have lost her voice," said Ms. Di Maria about her daughter. "I reassured her that this latest challenge could be met . . . with grace and dignity."



Ms. Di Maria's painting of a song bird reaffirmed her daughter's renewal and sense of hope as she healed. Ms. Johnston, a high school English teacher, is an extraordinary advocate for carcinoid and neuroendocrine cancers. She chronicles the challenge of surviving carcinoid cancer in her blog, "[Channeling Jackie-O.](#)" In the introduction to her blog, she writes: "Everybody needs a hero; for me, it's Jacqueline Kennedy Onassis, affectionately known as Jackie-O. For as long as I can remember, when things became difficult, my mother would always tell me to think of Jackie-O and how she would handle the situation - with perfect grace."

In November, Ms. Johnston, along with hundreds of students at **Paramus Catholic High School in New Jersey**, joined in the global awareness campaign for NET (neuroendocrine tumor) cancer. In addition to awareness efforts on **November 10, 2010, the first Worldwide NET Cancer Awareness Day**, Ms. Johnston and her colleagues worked throughout November to educate the Paramus Catholic High School community about carcinoid cancer. They obtained an amazing number of signatures - **792** in one day! - for the Worldwide NET Cancer Awareness Day Proclamation. [CLICK HERE](#) to sign the Proclamation digitally and join over 4,600 people on six continents who are supporting the campaign. To read more about Paramus Catholic High School's participation in the NET awareness campaign, [CLICK HERE](#).

Thank you, **Marlena**, for all you do for **carcinoid and NET cancer awareness**. **Adria**, your beautiful painting is a tribute to your daughter and all members of the carcinoid/NET community. To see more of Adria's artwork, visit her [online gallery](#).

The North American Neuroendocrine Tumor Society (NANETS) Guidelines

Posted January 3, 2011 -- The publication of the first **North American consensus guidelines for NET disease management** was a major achievement for the carcinoid/NET community in 2010. These guidelines include early detection procedures for diagnostic purposes, imaging, histopathology, biochemical evaluation, surgical procedures, and evidence-based treatments emphasizing a multidisciplinary team-based approach to patient care. The NANETS Guidelines Working Group consists of 38 carcinoid/NET specialists writing guidelines in the areas of Epidemiology and Genetics, Pathology, Radionuclide Therapies, Biochemistry, Symptomatic Control, Surgery, Imaging and Liver-Directed Therapies, Systemic Treatments, and Follow-up. The guidelines have been published in **Pancreas**, Volume 39, Number 6, August 2010. They are as follows:

[The North American Neuroendocrine Tumor Society \(NANETS\) Guidelines: Mission, Goals, and Process.](#)

Authors: Kvols, Larry K. MD *; Brendtro, Kari L. +
DOI: DOI: 10.1097/MPA.0b013e3181eb7451

[The Pathologic Classification of Neuroendocrine Tumors: A Review of Nomenclature, Grading, and Staging Systems.](#)

Authors: Klimstra, David S. MD *; Modlin, Irvin R. MD, PhD +; Coppola, Domenico MD ++; Lloyd, Ricardo V. MD, PhD [S]; Suster, Saul MD [//]
DOI: DOI: 10.1097/MPA.0b013e3181ec124e

[NANETS Consensus Guidelines for the Diagnosis of Neuroendocrine Tumor.](#)

Authors: Vinik, Aaron I. MD, PhD *; Woltering, Eugene A. MD +; Warner, Richard R. P. MD ++; Caplin, Martyn MD [S]; O'Dorisio, Thomas M. MD [//]; Wiseman, Gregory A. MD [P]; Coppola, Domenico MD #; Go, Vay Liang W. MD **
DOI: DOI: 10.1097/MPA.0b013e3181ebaffd

[NANETS Treatment Guidelines: Well-Differentiated Neuroendocrine Tumors of the Stomach and Pancreas.](#)

Authors: Kulke, Matthew H. MD *; Anthony, Lowell B. MD +; Bushnell, David L. MD ++; de Herder, Wouter W. MD, PhD [S]; Goldsmith, Stanley J. MD [//]; Klimstra, David S. MD [P]; Marx, Stephen J. MD #; Pasiaka, Janice L. MD **; Pommier, Rodney F. MD ++; Yao, James C. MD ++++; Jensen, Robert T. MD [S][S]
DOI: DOI: 10.1097/MPA.0b013e3181ebb168

[The NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Well-Differentiated Neuroendocrine Tumors of the Jejunum, Ileum, Appendix, and Cecum.](#)

Authors: Boudreaux, J. Philip MD *; Klimstra, David S. MD +; Hassan, Manal M. MD, PhD ++; Woltering, Eugene A. MD *; Jensen, Robert T. MD [S]; Goldsmith, Stanley J. MD [//]; Nutting, Charles DO [P]; Bushnell, David L. MD #; Caplin, Martyn E. MD **; Yao, James C. MD ++
DOI: DOI: 10.1097/MPA.0b013e3181ebb2a5

[The NANETS Consensus Guidelines for the Diagnosis and Management of Gastrointestinal Neuroendocrine Tumors \(NETs\): Well-Differentiated NETs of the Distal Colon and Rectum.](#)

Authors: Anthony, Lowell B. MD *; Strosberg, Jonathan R. MD +; Klimstra, David S. MD ++; Maples, William J. MD [S]; O'Dorisio, Thomas M. MD [//]; Warner, Richard R.P. MD [P]; Wiseman, Gregory A.

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MD #; Benson, Al B. III MD **; Pommier, Rodney F. MD ++

DOI: DOI: 10.1097/MPA.0b013e3181ec1261

[The North American Neuroendocrine Tumor Society Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Pheochromocytoma, Paraganglioma, and Medullary Thyroid Cancer.](#)

Authors: Chen, Herbert MD *; Sippel, Rebecca S. MD *; O'Dorisio, M. Sue MD, PhD +; Vinik, Aaron I. MD, PhD ++; Lloyd, Ricardo V. MD, PhD [S]; Pacak, Karel MD, PhD, DSc [//]

DOI: DOI: 10.1097/MPA.0b013e3181ebb4f0

[NANETS Consensus Guideline for the Diagnosis and Management of Neuroendocrine Tumors: Well-Differentiated Neuroendocrine Tumors of the Thorax \(Includes Lung and Thymus\).](#)

Authors: Phan, Alexandria T. MD *; Oberg, Kjell MD, PhD +; Choi, Junsung MD ++; Harrison, Lynn H. Jr MD [S]; Hassan, Manal M. MD, PhD [//]; Strosberg, Jonathan R. MD [P]; Krenning, Eric P. MD, PhD #; Kocha, Walter MD **; Woltering, Eugene A. MD ++; Maples, William J. MD +++++

DOI: DOI: 10.1097/MPA.0b013e3181ec1380

[The NANETS Consensus Guidelines for the Diagnosis and Management of Poorly Differentiated \(High-Grade\) Extrapulmonary Neuroendocrine Carcinomas.](#)

Authors: Strosberg, Jonathan R. MD *; Coppola, Domenico MD +; Klimstra, David S. MD ++; Phan, Alexandria T. MD [S]; Kulke, Matthew H. MD [//]; Wiseman, Gregory A. MD [P]; Kvols, Larry K. MD *

DOI: DOI: 10.1097/MPA.0b013e3181ebb56f

Maryann Wahmann Receives 2010 Warner Advocacy Award

Posted November 17, 2010 -- **Maryann Wahmann** of the **Carcinoid Cancer Awareness Network** (CCAN) has been chosen as winner of the [2010 Warner Advocacy Award](#), established last year by **Novartis Oncology** to commemorate the life and work of the late **Monica Warner** of the Carcinoid Cancer Foundation. The award is given annually to the individual who best embodies the spirit, passion, and dedication of Monica Warner.

Among the criteria used to review the nominations were number of patients assisted, innovation of patient-focused project(s), area of outreach, facilitation of positive change, and evidence of collaboration with group leaders.

A carcinoid patient herself, Maryann has made it her mission to support and educate patients, caregivers, and families affected by carcinoid or other neuroendocrine tumors (NETs). She founded the Carcinoid Cancer Awareness Network (CCAN), www.carcinoidawareness.org, in 2004 to help achieve this goal.

Maryann said, upon learning that she was the recipient of the award, that she is “honored to be recognized with the 2010 Warner Advocacy Award, especially because it was established in memory of my dear friend and fellow patient advocate, Monica Warner. Working with Monica helped me grow as an advocate. I admire all she did for the carcinoid/NET community and I will always miss her.”

The Warner Advocacy Award recipient receives an individual award of recognition (nonmonetary). Novartis Oncology directs a \$10,000 donation to an approved 501(c)(3) charitable organization of the winner's choice.

The **2010 Warner Advocacy Award** was presented by **Novartis Oncology** to Maryann Wahmann at **CCAN's 7th Annual Celebration of Life Gala**, held on November 13th in Bethpage, New York. **Congratulations, Maryann!!!**

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Published on The Carcinoid Cancer Foundation (<http://www.carcinoid.org>)



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