



A Brief History

NCAN IS A 501 (C) (3) NON-PROFIT INCORPORATED IN 2004. OUR MISSION IS TO INTENSIFY AWARENESS OF NEUROENDOCRINE TUMORS & CARCINOID CANCER IN BOTH THE MEDICAL COMMUNITY AND GENERAL PUBLIC – LOCALLY AND AROUND THE WORLD. NCAN ALSO ASSISTS PATIENTS AND CAREGIVERS BY PROVIDING ACCESS TO IMPORTANT INFORMATION ABOUT THE DISEASE. WE PROVIDE FUNDING FOR RESEARCH INTO CARCINOID CANCER AND OTHER NEUROENDOCRINE TUMORS.

For the past 13 years NCAN has provided information and support to NET patients and caregivers through e-mail, our web site, and toll free phone number, (866) 850-9555. Our phone line is open 7 days a week 9 am - 9 pm EST. The phones are answered by a patient (*myself*) or a caregiver (*my husband*). Thousands of free information packets have been mailed to patients and other interested parties on request. We've provided many support groups worldwide with information, merchandise, awareness items and financial support.

Did you ever wonder where the Zebra mascot got started, or those stuffed zebras and zebra bracelets came from? Designed by NCAN back in 2003. You can say we were **"The Original ZEBRA"**. We decided since no two Zebras stripes are the same and no NET Cancer patients are the same to use it. Since then over 350,000 bracelets have been distributed to date. We also distribute other awareness items such as sweatshirts, hats, tote bags, rulers, lapel pins, christmas ornaments and car magnets.

NCAN 2016

"A YEAR IN REVIEW"

Thank you for making NCAN a top rated nonprofit again! Being on the Top-Rated list gives donors and volunteers more confidence that this is a credible organization. The reviews by volunteers, clients and other donors show the on-the-ground results of this nonprofit. This award is a form of recognition by the community.

NCAN has been honored with GreatNonprofits Top-Rated Award every year since 2011.

JANUARY 23

ASCO GI Convention

- **Early NETTER-1 Results:**
Novel Targeted Radiotherapy Excels in Midgut NET
- **Breakout Session:** Imaging and Therapy of Neuroendocrine Tumors – Clinical Advances With PET and PRRT
- **Tom Hope, MD – UCSF Helen Diller Family Comprehensive Cancer Center**
Ga68-Dotatate PET Imaging of Neuroendocrine Tumors and Beyond:
Current Status, Logistics, & the Future

(continued on next page)

- **Jonathan R. Strosberg, MD – Moffitt Cancer Center Lu177 – Dotatate Therapy of Neuroendocrine Tumors:** Current Status, Logistics, and the Future
- **Arturo Loaiza-Bonilla, MD – Abramson Cancer Center of the University of Pennsylvania:** The Oncologist's Perspective on PET and PRRT for Neuroendocrine Tumors

FEBRUARY 1

Lexicon Talk

Living with NET Cancer – A Patient's Journey

- Lexicon gathered their headquarters staff at Basking Ridge, NJ to hear Maryann present the patient's perspective on living with neuroendocrine cancer. Patient advocates have a great opportunity to show the employees of pharmaceutical companies what the end result of their work is from the human perspective, not the business perspective. This can leave a lasting impression on how they view their impact on patients suffering from the disease.

FEBRUARY 24

Healing NET Foundation Summit

Maryann Wahmann represented NCAN at the inaugural international Healing NET Foundation Summit. The purpose of the summit was to bring key discussions on diagnosis and care for the complicated NET-Cancer to the forefront of debate by many of the world's leading physician



and research experts. Summit organizers acknowledged that the meeting is a first step in examining and debating protocols for how patients with NET-Cancer are viewed by clinicians in locations across the United States. The overall goal is to diagnose the disease earlier and help define the best course of treatment once people are diagnosed.

MARCH 24

NCAN Blogs!

The date of the first post on NCAN's blog, <https://netcancerawarenessblog.org>. A Tricia Knatz initiative, the blog has become an important outlet for news in the NET community. Check in often!

JUNE 11

Denver Lungnoid Patient Conference

Not many conferences focus on lung neuroendocrine cancer. In June, NCAN produced a conference for lung NET patients. Dr. Eric Liu and his mentor Dr. Kjell Oberg, of Sweden's Uppsala University – one of the pioneers in the field of NETS – reunited for the conference. For the patients who attended, the conference was an opportunity to learn about treatment advances, and to see that though they may have a disease practically no one has heard of, they aren't alone.

AUGUST 27

Uncork A Cure for Neuroendocrine Cancer

Uncork A Cure for Neuroendocrine – our first ever East End event to provide NET Cancer patients with information about their disease and raise awareness as we continue to advocate for patients and caregivers. Our first event at Osprey's

Dominion Vineyards proved to be a success due in part to the winery's generosity. Folks who attended our first ever awareness and wine tasting event were treated to a nice wine tasting, bottle of wine, excellent lunch by Big Daddy's of Massapequa and live music. The biggest surprise is that 4 different families with loved ones afflicted by neuroendocrine cancer showed up at the winery that day, not knowing that our event was happening. It appears that neuroendocrine cancer is not quite as rare as believed!



SEPTEMBER 14

Tricia Knatz Appointed to the NANOE Board of Governors

The National Association of Nonprofit Organizations and Executives (NANOE) has announced the appointment of Tricia Knatz to NANOE's prestigious 2017 Board of Governors. Knatz will be honored alongside fellow Governors March 7-8, 2017 in Columbia, SC at NANOE's 2017 Capacity-Building Convention & Expo. This 2-day caucus is critical to charity's future and will rely on a myriad of industry experts to renew, improve, strengthen and distribute a new set of guidelines that super-charge nonprofit capacity-building. This esteemed group has completed phase one and will submit 60 new key practices to NANOE's Board of Governors for evaluation. Governors will review, expand and/or redact these key practices during annual convention and will emerge with a new set of competencies that increase sector impact.

Headquartered in Washington, D.C. NANOE is the only unifying nationwide association for charitable organizations and executives who serve the human welfare, education, healthcare, faith-cause, environmental and arts sectors.

SEPTEMBER 22

***National Patient
Conference***

Some of the most experienced physicians in the world treating neuroendocrine tumors, shared their expertise, advances and results at the **2016 National Neuroendocrine Tumor (NET) Patient Conference**. Over 500 patients from across the country participated in this conference. A very interesting part of the conference is that it was structured differently than most other annual medical meetings. At this meeting, everything was geared toward patients. As with other NCAN patient conferences it provided a venue where patients could learn the latest information directly from the world's leading experts in their disease and ask questions directly from these experts. The patient panel, Judy Golz, Ronda Ayala and Dana Test, are all registered nurses AS WELL as patients! Their discussion was one of the most amazing parts of the conference.

OCTOBER 22

LI Zebra Walk

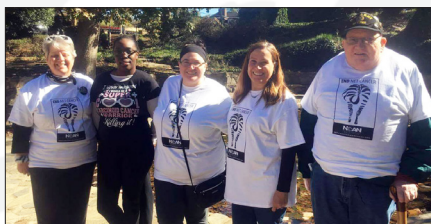
NCAN hosted the 8th annual "Strides for Stripes" walk. In spite of the inclement weather, hundreds of supporters and cancer survivors gathered at Eisenhower Park in East Meadow to raise awareness of this deadly disease, donate to support programs that benefit neuroendocrine cancer patients and to kick off November as "Carcinoid Cancer Awareness Month" in New York State.



NOVEMBER 5

Charlotte Zebra Walk

You have to start somewhere- and Tricia Knatz pioneered the first annual Zebra Walk in North Carolina. It was an enthusiastic crowd that came out to bring awareness to neuroendocrine cancer. We can't wait until next year's walk!



NOVEMBER 10

Neuroendocrine Cancer

***Ipsen Invites NCAN to Share
NET Cancer Day***

- We were honored with the invitation! Ipsen's entire New Jersey staff was on-hand to hear the neuroendocrine cancer patient's story from Maryann and from Ronda Ayala. Then everyone shared a nice lunch, complete with terrific zebra striped cupcakes! Afterwards, Ipsen's President and CEO- North America, Cynthia Schwalm, took time from her busy schedule to brainstorm with us for over an hour regarding how we can all work to improve the lives of neuroendocrine cancer patients.

NCAN's Zebra Ribbon Campaign.

- Bellmore learned about Neuroendocrine Cancer. Volunteers assembled at the Bellmore train station and hung hundreds of ribbons with cards explaining what neuroendocrine cancer is on November 9th. Rush hour commuters by the hundreds found out what this disease is!
- To the hundreds of patients and their friends who hung zebra ribbons around your community in order

to help create some buzz surrounding NET Cancer- THANK YOU for the overwhelming response. We're absolutely swamped with the pictures you sent and are working to get them posted soon.

NOVEMBER 12

Celebration of Life Gala

Traditionally, the gala is most important night of the NCAN year, a night when we look back at what we did, as well as looking ahead to the future. This was the 13th annual Celebration of Life Gala featuring the Above and Beyond Recognition Award. We honored the many brave patients and their families who have blessed our lives and honored Dr. Edward M. Wolin for his the commitment and accomplishments in treating neuroendocrine cancer patients.



NOVEMBER 18

***Academy of Oncology
Nurse and Patient Navigators
"Hero of Hope" Award***

Maryann was extremely honored when the master of ceremonies announced her as the 2016 Hero of Hope Award winner over 5 other extremely qualified nominees – LIVE at the AONN National Meeting!

This special award is given to an individual who:

- Makes outstanding contributions to his/her community through fundraising and association/ organization leadership

(continued on next page)

- Serves as a role model to other people with cancer and survivors
- Exudes extraordinary spirit, grace, and optimism in the face of adversity

Our thanks to all of you- it's a privilege to be acquainted with you!



DECEMBER 10

Long Island Patient Conference

Has not yet been held as we go to press for this newsletter.

NYS PROCLAMATION 2016

New York State has declared November "Carcinoid/NET Cancer Awareness Month" each year since 2006.

It is challenging to find support for NET Cancer Awareness Initiatives and we want to thank the state of New York and the governors for their tremendous support through the years. Why not get on board and have your state, city or town declare a 'NET Cancer Awareness' time every November!

EYEING THE FUTURE

The neuroendocrine cancer specialists that we know and love won't be able to treat patients forever. NCAN is seeking to ensure that the neuroendocrine cancer specialists of the future are being mentored. An ongoing program is needed to ensure that each year several Neuroendocrine Cancer Experts are being prepared through Focused Medical Fellowships. This is a program offering a physician the opportunity to make him/herself an expert in the field of NETs. It focuses exclusively on the professional development of the fellow. Several of these fellowships are planned on an annual basis. It is an ambitious program which seeks to expand leadership in the diagnosis and treatment of Neuroendocrine Cancer.

MAKE A DONATION

Most of this important work is funded by private donations. Your generosity will help us do more to support patients & research.

If you would like to honor someone special, or remember a loved one through a donation to NCAN, you will also be helping others. We will send a notification letter to whomever you designate, and you will receive an acknowledgement letter.

MY NAME _____

ADDRESS _____

PHONE () _____ ☐ In Memory of ☐ In Honor of (check one only)

Please Notify:

NAME _____

ADDRESS _____

☐ I've enclosed a check made payable to **NCAN Inc.** Mail check to: NCAN, 2480 Hull Ave, North Bellmore, NY 11710

Donations made to **NCAN Inc.** are tax deductible per our 501 (c) (3) non - profit status. **NCAN** is registered with **The New York State Charity Bureau** and the national database www.guidestar.org

Donate online at: www.netcancerawareness.org, or by phone: (866) 850-9555

"When fate hands us a lemon, let's try to make lemonade."

- Dale Carnegie

SAVE THE DATES

Sunday
February 26, 2017
NET Support Group Meeting
North Bellmore, NY

Saturday
March 25th 2017
NET Patient Conference
Charlotte, NC

Saturday
April 22, 2017
NET Patient Conference
Lexington, KY

Saturday
May 6, 2017
NET Patient Conference
Seattle, WA

Sunday
May 21, 2017
NET Support Group Meeting
North Bellmore, NY

Sunday
September 10, 2017
NET Support Group Meeting
North Bellmore, NY

Saturday
October 14, 2017
NET Patient Conference
Iowa City IA

Saturday
October 21, 2017
9th Annual 'Strides for Stripes'
East Meadow, NY

Saturday
November 2017
Virtual 'Strides for Stripes'
Zebra Walk

Saturday
November 10, 2017
NET Cancer
Awareness Day

Saturday
November 11, 2017
'Celebration of Life' Gala
Bethpage, NY

Please Check Back for New Events!