



Why Should I Be My Own Advocate?

Neuroendocrine
Tumor Patient
Regional Meeting

Roswell Park
Cancer
Institute
August 2015

**Maryann
Wahmann
President
NCAN**



Thank you to Dr. Renuka Iyer and the
Roswell Park Cancer Institute for
inviting me to this important event.

.... And to all of you for attending!



I have what??

A Simple Understanding of NET / Carcinoid Cancer



A cancer that
grows in the hormone
producing cells
found throughout
the body.



The Long, Exhausting Journey Begins



7 Years

7 Doctors

I Need Answers!

NOTE:



My journey is not unusual. NETs are frequently misdiagnosed. Patients on an average are treated for five to seven years for the wrong disease.

Washington 2010, (3), Kim, 2010, Shin 2010, Onozato, 2010, Ambrosini, 2010, Korse, 2009, Yao, 2008, Coleman, 2008, Campana, 2007, Dakin, 2006, Pommier, 2004



How it feels to be told
'you've had cancer for 7
years'



Looking for Support





We knew help was needed...

Patients need a place where they can get the facts & talk to someone who understands firsthand what they're going through



Facts taken from the folks
at patient support groups:

Common Misconceptions

My doctor told me that:

- It's benign, no mets, no follow-up needed
- Nothing new as far as treatments
- Tumor removal cures



- “Most patients only receive an accurate diagnosis of NETs when metastasis is present. Physicians are unaware of the surgical and hepatic directed therapy options.”

Pitt, 2008, Kennedy, 2008, Osborne, 2008, Christante, 2008



- “Patients with progressive neuroendocrine tumor disease have few approved treatment options for disease stabilization and or remission. A majority of doctors are not aware of the treatment options currently available.”

Yao, 2010, Sword, 2010, Kulke 2009, Caparso, 2009, Kulke 2008, Kwekkeboom, 2008, Zhang, 2007



What is patient advocacy?

Helping a patient deal with issues and with people who have an effect on the patient's health

A patient advocate helps resolve issues about health care and other issues related to a patient's medical condition.

Cancer advocacy groups try to raise public awareness about important cancer issues, such as the need for cancer support services, education, and research.

Such groups work to bring about change that will help cancer patients and their families.



How Does Advocacy Work?

Basically, you meet a lot of people, do lots of research and do a lot of talking!

Sometimes the situation is really serious and, as patient advocates, we are able to help people who are being left out in the cold to face the most desperate time of their lives.

Take the case of Joe from Long Island, NY...

We also talk to patients every day and are able to let them know they are not alone. We try to connect them with the services and care they need and are searching for.



Patients get the information they need to be their own advocates at patient conferences

The experts.....

Share their knowledge with patients and caregivers





What a Success the 2014 National NET Cancer Patient Conference in Charlotte, NC Was!



NET PATIENTS- heard from a fantastic lineup featuring 20 or so
WORLD CLASS NET EXPERTS and networked with hundreds of
other patients who knew what they were going through.

[See the videos at netcancerawareness.org](http://netcancerawareness.org)

Announcing...

The 2016 National NET Cancer Patient Conference
Coming in September 2016 in New Orleans

**The perfect opportunity to build your knowledge and become a
better advocate for your health!**

Why Should You Be Your Own Avocate?

Save your life by making sure you are getting the best treatment plan possible!





Practical Advice on Being Your Own Advocate

Keep Networking

Keep Learning

Keep Following Up

Reach Out To NET Cancer Specialists

Reach Out to NCAN

Always Ask Questions

If You're Not Getting What You Need, It May Be Time to Find A New Doctor

Once you start being proactive about your own future, maybe you'll decide to help others do the same...

**Here are some other things you might
consider doing**

**Make sure your doctors join
North American NeuroEndocrine Tumor Society**

NANETS contact info:

www.nanets.net

360-314-4112





Start or lead a support group

Patient support groups- a place to talk about your worries!

www.all4nets.org



Talk to people about NETS

EXPLAIN NETS IN 10 SECONDS:

Neuroendocrine cancer grows in the hormone producing cells found throughout the body.

They commonly occur in the digestive system, lung and pancreas, but also arise in many other parts of the body.



Show Your Stripes!



Have a fundraiser!

Attend, volunteer and support

NET advocacy events

Sign up for NCAN's Virtual Walk!!

www.netcancerawareness.org





Here are a few highlights from awareness initiatives we've gotten involved in...

Payin




State of New York
 Executive Chamber

Proclamation

Whereas the Empire State places a high priority on supporting initiatives that raise public awareness of serious health issues, including carcinoïd cancer; and

Whereas carcinoïd cancer is a rare and slow-growing form of cancer that can develop in several areas of the body, usually in the gastrointestinal tract or in the lungs; and

Whereas carcinoïd tumors are generally asymptomatic in their early stages, however, carcinoïd cancer can spread to other organs and ultimately lead to death; and

Whereas carcinoïd cancer is a type of neuroendocrine cancer; it is estimated that more than 100,000 people are diagnosed annually with neuroendocrine cancer in the United States; and

Whereas risk factors for carcinoïd cancer are not well understood, but correlations have been identified suggesting higher incidence rates among individuals based on pre-existing conditions and family history; and

Whereas it is important that New Yorkers are aware of all health-related issues, however rare they may be, and therefore we support the goals of this observance, which works to bring attention to carcinoïd and neuroendocrine cancer, and research that can lead to better methods of early detection, more effective treatment options, and greater insight into the causes of this disease;

Now, Therefore, I, Andrew M. Cuomo, Governor of the State of New York, do hereby proclaim November 16, 2013 as

CARCINOID CANCER AWARENESS DAY

in the Empire State.

© I B E N under my hand and the Privy Seal of the State at the Capitol in the City of Albany this eighth day of November in the year two thousand thirteen.


 Governor


James Sabatino
 Secretary to the Governor





John Klein
Julie Richman
Richard Nelson
Francis Leib
Dr. Sathyan
WORLDWIDE NET AWARENESS DAY PROCLAMATION
Robert Kober MD
Jim Kopans
Ann Kirk
HEALTH
Starr Rosemont

HEREAS neuroendocrine tumors/tumours (NETs) often develop into cancer and, if left untreated, result in serious illness and death; and
 HEREAS all too often healthcare professionals underestimate the malignant and metastatic potential of neuroendocrine tumors/tumours; and

SHOW YOUR STRIPES- 6th YEAR! Novartis helped initiate the first WNCAD

World NET Awareness Day November 2010



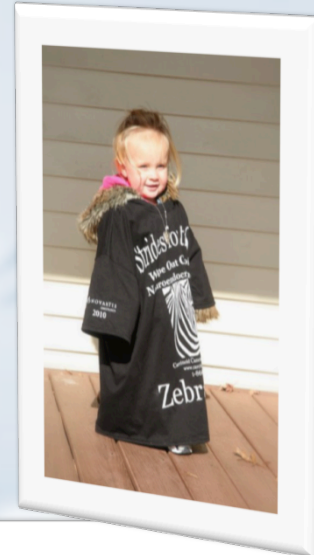
Davidella
Harvey S. Markoff
Michael F.
Ed Day
M. No
Algo
Conrad
Jackie Ward
Charles Flynn
James G. ...
Mag...

Strides for Stripes Zebra Walk

October 24, 2015



Getting the Community Involved



Coming up- 12th Annual Gala November 14th, 2015



‘Celebration of
Life!’

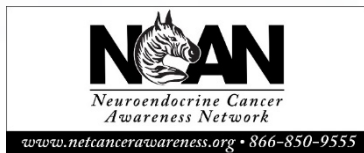


The Carcinoid Cancer Awareness Network

For 11 years NET cancer patients, including carcinoid patients, have looked to us for information and encouragement.

We're now

The Neuroendocrine Cancer Awareness Network!





Why NCAN?

If you had a NET other than carcinoid you might not know to call us- and we were founded to help ALL NETs!

- NetCancerAwareness.org
- Same email addresses
 - carcinoidaware@aol.com
 - netcanceraware@aol.com
- Same phone numbers
 - 866-850-9555
 - 516-781-7814

I know you've been wondering
about the zebra...

Why is the ZEBRA our mascot?





Medical school students are taught:
'When hearing hoofbeats, think horses, not zebras.'

NET cancer is relatively rare so it may be thought of
as a 'zebra.'

AND- Every zebra's stripes are unique! No 2 zebras
are the same.



Zebra- you need to be your own advocate!

How can your doctor find a zebra when he/she is looking for a horse?

What if it's a little of both?

He told me to take 2 aspirins and call him in the morning.



2010 Warner Advocacy Award

A Final Thought-

When Life Gives You Lemons Make Lemonade





Neuroendocrine Cancer
Awareness Network

www.netcancerawareness.org • 866-850-9555



There has been a lot of progress in the past 12 years!
Make sure that
'Your Future's So Bright You'll Have to Wear Shades'





Neuroendocrine Cancer
Awareness Network

www.netcancerawareness.org • 866-850-9555



Thank YOU!

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