

The Neuroendocrine Cancer Awareness Network Newsletter • 2018 Edition



WELCOME!

Non-profit Work is equal parts passion, dedication and relentless inspiration to make a difference.

That's what the Neuroendocrine Cancer Network (NCAN) has been doing for 15 years, making a difference by:

- RAISING AWARENESS OF NEUROENDOCRINE (NET) CANCER
- SUPPORTING THOSE WITH NETS ALONG WITH THEIR CAREGIVERS.
- FUNDING NET RESEARCH

This past year alone, our 501 (C)(3) sent over 1,300 free packets in response to information requests, answered countless emails, and received over 2,500 calls to our hotline, which is answered 9 am to 9 pm every day of the year by a patient or a caregiver because it matters that the person on our end has first-hand knowledge of NET cancer to share.

NCAN 2018

"A YEAR IN REVIEW"

You are the reason we can make a difference, and we thank all who attended, sponsored, helped to organize or donated to an NCAN event in 2018.



TOP RATED NON PROFIT FOR 8 YEARS IN A ROW

NCAN has once again been awarded top rated nonprofit organization status. It's an award bestowed upon us by the community, and we're proud to say that we've been honored with this award every year since 2011.

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SUPPORT WHERE IT MATTERS MOST

Information is helpful but so is a hug or a knowing nod.

Which is why this year we introduced NCAN chapter support groups.

Each group is self-managed, informal and, most importantly, run by a someone with experience caring for someone with NET cancer.

They're a safe, confidential place to talk openly and to exchange ideas about the challenges of living with NETs.

There are currently 26 Support groups nationwide. Join one of our Chapters (link) or if there isn't a NCAN Chapter Support group in your area, consider starting one. Apply online.



LEADERSHIP SUMMIT

April 13th-15th

Creating the Future for NET Support Group Leaders

NCAN chapter support group leaders met to share their ideas on helping people with NET cancer. By becoming NCAN chapters, support groups are able to thrive by getting the best leadership advice possible. At this summit, they talked with experts about many topics like: "How to Help Caregivers Cope", "How Do I Talk About Symptoms", "Treatments/Side Effects & Psychological Concerns" and the "Hows & Whys of a Support Group". They took all they learned back to their groups to make them the most effective they could be.



2018 EXTREME MAKEOVER

May 2019

In May of this year, we launched our new and improved website. It's welcoming, easier to navigate, and gives you access to even more information and connections.

You can easily request an info packet, register for an event, join a support group, make a quick and secure donation or shop in the Zebra Store.

Don't forget to visit often to see what's going on and ways to stay involved.



NATIONAL NET CONFERENCE

September 27th-29th

Held in Las Vegas, this event was three days of self empowering information delivered by some of the most experienced physicians in the world treating NET tumors. They shared their expertise, advances and results to over 500 patients/caregivers from across the country. In addition, there were plenty of social opportunities

to allow for peer connection and fun. The "Zebras Have Talent" show was an epic night where Steve Mazan and Felicia Temple along with other talented patients got to really show their stripes. If you were unable to join us, check out our Resource Room(link) for videos of key presentations. Or consider joining us at one of our upcoming regional conferences.





EXCEPTIONAL ADVOCATE AWARD

September 2019

During the National Conference, Maryann Wahmann received the inaugural "Exceptional Advocate Award." Presented by Casey Arnett Lewis, Amanda Arnett Edwards and Tanya Wilcox, the award recognizes Maryann for her tireless work advocating for NET patients and their families, and was created in memory of our friends Linda Arnett, Steve Wilcox and Alexis Wagner.

In addition, Katie Adams was presented with the "Above and Beyond Award" for her outstanding dedication to the NET community.

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DUNGEON CRAWL FOR THE CURE

August 11th

The first ever Dungeons & Dragons Fundraiser for NET cancer was planned and held by Sean White, a NET patient who turned his love for D&D into a moneymaker for the community. It was a successful, fun night of adventure and intrigue for all who played.



10TH ANNUAL STRIPES FOR STRIPES

October 20th

NCAN hosted the 10th annual "Strides for Stripes." It was a beautiful sunny day, where hundreds of supporters and cancer survivors gathered at Eisenhower Park in East Meadow to raise awareness for NET cancer, to support programs that benefit the NET cancer community and to kick off November as "Neuroendocrine Cancer Awareness Month" in New York State. As an extra bonus, Zippy the Zebra made an appearance for photo opportunities with participants.





3RD ANNUAL STRIPES FOR STRIPES

November 4th

More than 50 people came out to help raise awareness for NET cancer at our Charlotte "Stride for Stripes" Zebra walk. It was a fun and chilly day with our zebra friends in North Carolina where much needed funds were raised for the NET community.

15TH ANNUAL CELEBRATION OF LIFE GALA

November 4th



Traditionally, the gala is the most important night of the NCAN year. A night when we look back at what we did that year, as well as looking ahead to the future. This night was full of friends, old and new, celebrating life. There was, dinner and dancing, basket raffles and a fabulous photo booth. A good time was had by all while raising money for a good cause.

The 2018 "Above and Beyond Award" was presented to Dr. Steve Libutti for his commitment, care and compassion in the treatment of NET Cancer Patients. The honorary chair person for 2018 was Susan Aller from CVS FM Radio.

NANETS

October 4th-6th

Maryann and Bob attended the 2018 NANETS meeting in Seattle, WA. They had the opportunity to network with Doctors who were there to learn more about NET Cancer, which ultimately helps with earlier diagnosis and better treatment options for patients. The NCAN booth handed out literature and zebra branded items to help raise awareness for the NET Cancer community.



LOOKING TO THE FUTURE

CME

June 10th, 2017

NCAN held its first ever CME together with Stonybrook University in the summer of 2017. Program participants discussed the impact several trials and studies as well as other pipeline therapies made on the management of NET patients in the future. The meeting also included discussions on diagnosis, imaging, surgical options and interventional radiological approaches to liver dominant disease.



Neuroendocrine Cancer Patients deserve to be diagnosed quickly. The only way to ensure that this happens is to help physicians and nurses in all specialties understand the symptoms of NET cancer. This is the ONLY program of its type on Long Island and our vision is to continue to offer this program in the future.





























JOIN US FOR ANOTHER EXCITING YEAR

Visit netcancerawareness.org/ upcoming-events/ for updates on all upcoming NCAN Events.

If you have a great idea for a fundraiser you'd like to run, don't hesitate to contact us at netcancerawareness.org/contact-us/

MARCH

Saturday, Mar 2nd NET Patient Conference Charleston, SC Register Today

Saturday, Mar 16th Zebra Gala 2019 Raleigh, NC Register Today

Friday, Mar 22nd to Sunday, Mar 24th Chapter Leader Summit Charlotte, NC

APRIL

Saturday, Apr 13th NET Patient Conference Tulsa, OK

MAY

Saturday, May 4th
NET Patient Conference
Alexandria, VA

SEPTEMBER

Saturday, Sep 14th NET Patient Conference Nashville,TN

OCTOBER

Saturday, Oct 19th "Stride for Stripes" Zebra Walk Long Island, NY

PLEASE CHECK BACK OFTEN FOR NEW EVENTS!

NOVEMBER

Nov 1 – Nov 30th 4th Annual "Virtual" Zebra Walk

Saturday, Nov 2nd "Stride for Stripes" Charlotte, NC

Saturday, Nov 9th "Celebration of Life" Gala Bethpage, NY

Sunday, Nov 10th 11th Annual "NET Cancer Awareness" Day

DECEMBER

Saturday, Dec 7th
NET Patient Conference
West Palm Beach, FL

Most of this important work is funded by private donations. If you'd like to help NCAN continue it's work for the NET Cancer community, please donate below or visit us at netcancerawareness.org.

MAKE A DONATION	
	nember a loved one through a donation to NCAN , ication letter to whomever you designate, and you will
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 NCAI Fort Mill, SC 29707	N Inc. Mail check to: NCAN, 3074 Brookchase Blvd,
Donations made to NCAN Inc. are tax deductible registered with The New York State Charity Bureau	

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

"Everyone has inside of him a piece of good news. The good news is that you don't know how great you can be. How much you can love. What you can accomplish. And what your potential is."

— Anne Frank