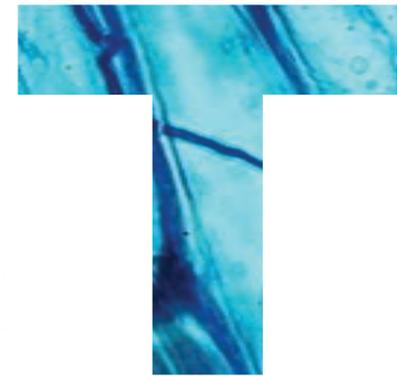
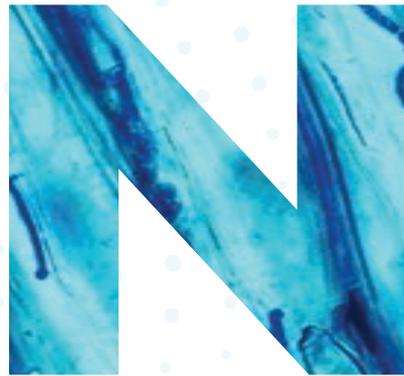


**REACH  
FOR  
THE**



Finding a Cure for Neuroendocrine (NET) Cancer



**Carcinoid-NeuroEndocrine**  
TUMOUR SOCIETY CANADA

# Facts about Neuroendocrine (NET) Cancer



## Fastest growing class of cancers

Neuroendocrine cancer is a rare cancer but the fastest growing class of cancers world-wide.



## Everywhere

Cancer of neuroendocrine cells, which can be found everywhere throughout the body.



## Stage 4

By the time most patients are diagnosed, the cancer has metastasized and is at Stage 4.



## Terminal

Because of the long time to diagnosis, NET cancer is **sometimes** terminal.



## Misdiagnosis

NET cancer is often misdiagnosed. The average time taken to diagnose it accurately is 5 to 7 years.



## Symptoms

Common symptoms of NET cancer include diarrhea, abdominal cramps, wheezing, pounding of the heart and a skin rash.

# Message from CNETS Canada's President Jackie Herman



“

**At the age of 38 I was told I had cancer that had spread to my liver. My first thought was how could I possibly survive this?**

”

There is no cure for NET cancer and I will never be able to say that I am in remission. However, I am one of the lucky ones because my tumours aren't growing as fast as other cancers. My medical team have often gone above and beyond thinking and acting outside of the box to keep me alive as long as possible.

About a year into my cancer journey, I reached out to CNETS Canada for support. The introduction to this organization and the ensuing education days and patient support meetings changed my life and quite frankly empowered me to fight for my life. This education and support eventually eased my worry about my cancer and the fear was replaced with realism, hope, optimism and a desire to help other people. I started volunteering with CNETS Canada, which has been the most rewarding experience of my life.

Knowledge leads to personal empowerment, which I try to pass on to others. I have watched many patients lose their battle over the years, which saddens me immensely but propels me forward to continue to fight for change for myself and my fellow patients. The diagnosis of NET cancer brings with it

the burden of extreme self-advocacy because this rare cancer is often not well understood by medical professionals. Early and accurate diagnosis is critical for survival and a huge challenge. We need access to effective diagnostics, treatment options and knowledgeable multi-disciplinary NET experts.

There is no cure for NET cancer as of now, but in future, we have to work towards making cancer just a chronic ailment like diabetes or stroke where with modern therapeutic options and constant vigilance, people can have a long life after initial diagnosis of NET cancer. Those who are able to survive do so with a great deal of support from family, friends, other NET patients and organizations such as CNETS Canada, the only patient advocacy organization for NET cancer in Canada. We offer in-person and virtual support, sponsor research specific to NET cancer, advocate on behalf of our patient community and raise awareness of NET cancers. With the support of our amazing donor community we will continue to provide the critical resources NET cancer patients need to face the most challenging journey of their lives.

# Our History



“

**We look forward to continuing to build towards the dream of a better future for NET patients.**

”

- Late Maureen Coleman

CNETS Canada was started by neuroendocrine (NET) cancer patient Maureen Coleman. Maureen became the pillar and champion for the fight against NET cancer in Canada and assumed the role of President of CNETS Canada upon incorporation of the organization in 2007.

Under her tremendous leadership, CNETS Canada became a prominent organization for the cause of patients with NET cancer and achieved national and international recognition. CNETS Canada was granted charitable status in February 2008. It is the only Canadian organization that supports patients who have NET cancer.

Maureen stepped down as President in late 2012 and sadly lost her battle with NET cancer on August 31st, 2013. This was a day of immense loss for the NET cancer community as we said good bye to one of the greatest champions of our cause.



## Meet Dan Opoku



“

CNETS Canada has made a difference to me as a patient by hosting a conference that was life changing. I got great information I could use directly to get on the right treatment plan and connected with people that I have a relationship with to this day.

As a patient, I have benefited tremendously. I am part of a national group of volunteers and a support group leader. Now I want to help others.

”

- **Daniel Opoku of Montreal, QC**

# Mission, Vision & Values



## MISSION STATEMENT

CNETS Canada provides support and education for Canadians on all aspects of neuroendocrine Tumours (NETs). We help Canadian NET patients seek and obtain personalized diagnostic and therapeutic options. We also advocate on behalf of individual patients and for policies to support NET patients. The organization does its work in collaboration with medical and scientific experts, stakeholders and partner associations.



## VISION STATEMENT

CNETS is widely recognized by patients and the medical community across Canada as an organization that improves the quality of life and survival for NET patients in three ways: 1) by raising awareness of the disease and the latest available diagnostics and treatments; 2) making sure that patients, caregivers, health care professionals and others have the information they need in the areas of medical and scientific research, treatment and support; and 3) by supporting patients and helping them navigate the best care options.

## CORE VALUES

**Integrity**

**Caring**

**Respect**

**Collaboration**

**Knowledge**

**Commitment**

## Meet Jane Brennan



“

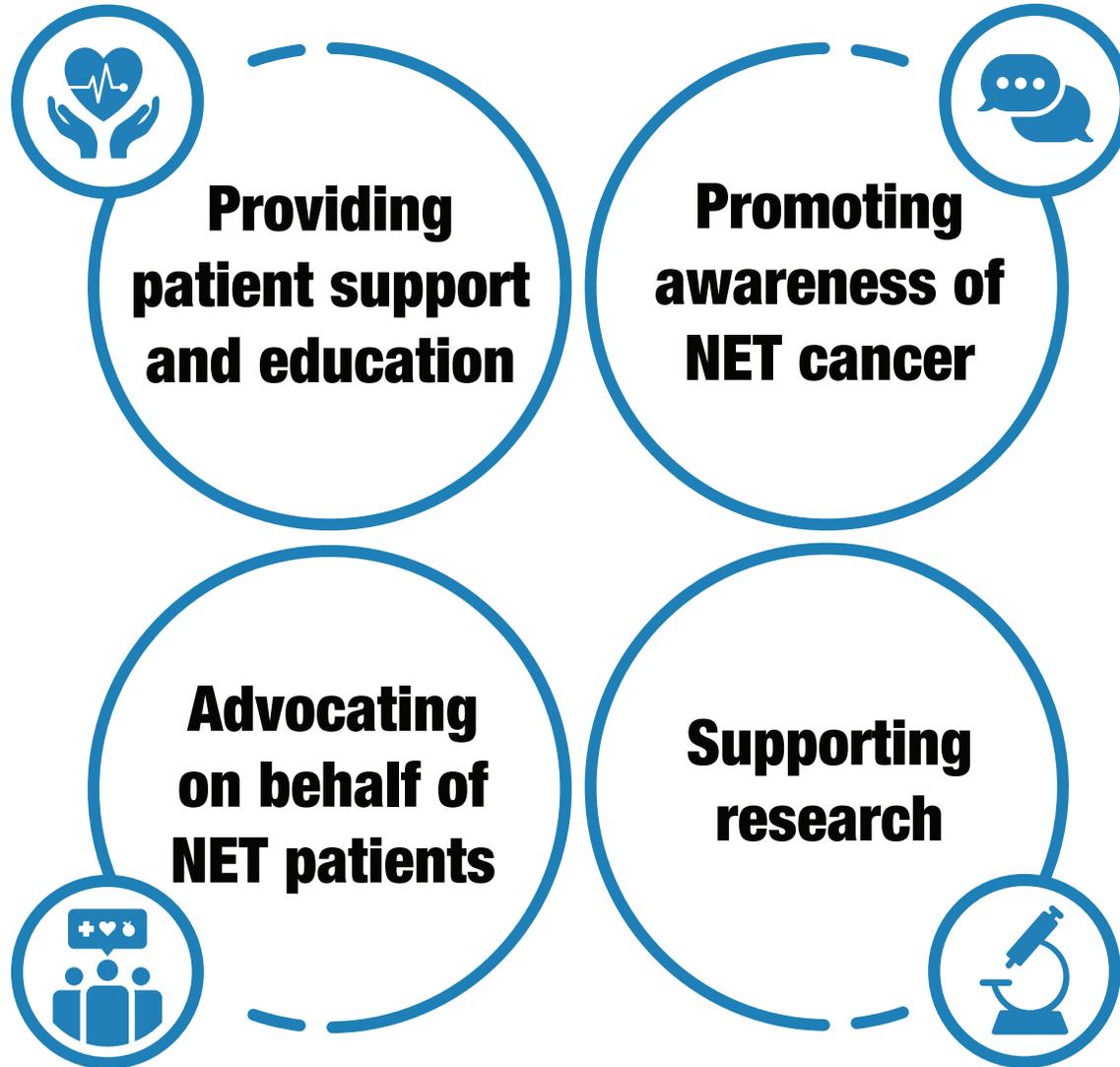
I donate to CNETS Canada because we need more research. The more people give, the more opportunities there are for research and a cure. You don't think about it until you are affected.

As a caregiver, I attended a CNETS Canada support group meeting. The support group is a place where everyone understands what you and your loved ones are going through. I always know who to contact to get questions answered and I will never be alone. The group is such a resource, I can't imagine not having it.

”

- **Jane Brennan of Ottawa, ON with her fiancé Jim**

# CNETS Canada's Priorities



## How We Help



**Donated to NET  
cancer research**

**\$380,000**



**Annual visitors to  
online resources**

**25,000+**



**Patients +  
caregivers attend  
support groups annually**

**350+**



**Patient + caregiver  
education sessions and  
conferences**

**70+**



**Annual patient + caregiver  
email/phone enquiries**

**500+**



**NET reference  
guides distributed  
across Canada**

**3000+**

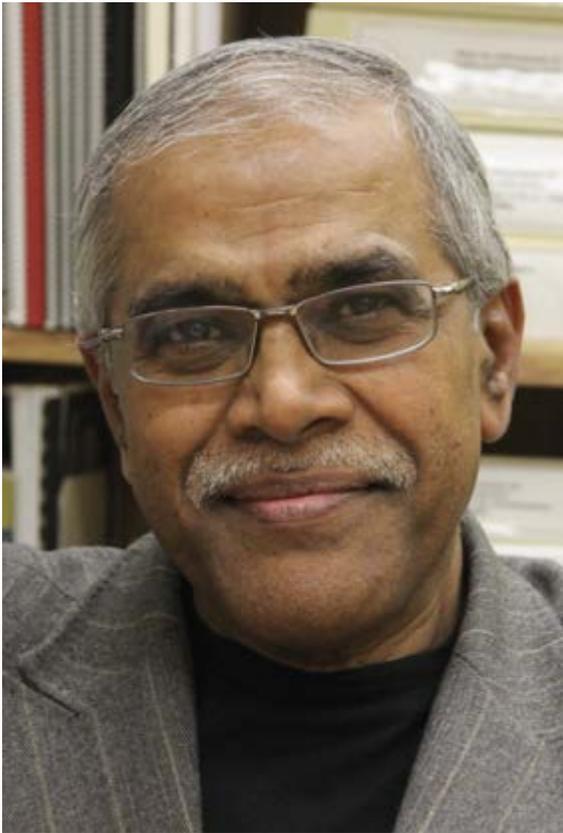
# Our Aspiration



**Research is the game changer. Without it, we will never understand the causes of NET cancer, nor will we be able to expedite diagnosis and develop state-of-the-art treatments.**

**Research is the only thing that will make a difference.**

# Research is the Game Changer



“

Today's neuroendocrine (NET) cancer therapy was yesterday's research.

If we want cutting-edge therapy for NET cancer tomorrow, we need to be ready to strongly support today's research.

”

- **Dr. Girish Shah**

Chair, CNETS Canada's Scientific & Medical Advisory Board

## Meet Sharon Needham



“

I think the calibre of what CNETS Canada offers is what makes me have confidence. It's so professional; information is timely and responses and support are there when you need them.

CNETS Canada has made a difference to me as a patient by leading me to a top notch team of doctors which resulted in a better outcome for my NET cancer treatment.

”

- Sharon Needham of Saint John, NB

# Research Dollars Provide Key Support



“

The CNETS Canada grant provided key support to answer the question of how Gallium 68 PET CT is best used for patients with NETs in Canada. With the introduction of Gallium PET, Canada is now at the forefront of NET therapy. The PET NET will allow patients from all over British Columbia to benefit from PET imaging to accurately find their cancer and treat it.

”

**- Dr. Hagen Kennecke**

Medical Oncologist and Professional Practice Leader  
Medical Oncology, BC Cancer Agency

**Dr. Kennecke was one of two successful recipients of CNETS Canada's 2016 research grant.**

# Research is our Highest Priority



## OUR FOCUS

High priority research projects that will lead to improved quality of life and survival for NET cancer patients in Canada. Our goal is to target our research support towards state-of-the-art personalized care for NET cancer.



## BUILDING ON SUCCESS

From 2010-2016, CNETS Canada has awarded \$380,000 to fund NET cancer research projects. From 2010-2015, our funds were matched by the Cancer Research Society. In 2016, CNETS Canada's Scientific and Medical Advisory Board guided the process for the development of its own research framework with input from NET cancer patients and stakeholders. As a result, two \$40,000 research grants were awarded in 2016. These funds will be leveraged by each applicant to accomplish a much larger project that will benefit NET cancer patients from coast to coast.



## WHY NOW?

NET cancer patients are dying with an average life span of five to seven years from time of diagnosis. By 2025, with an investment of 5 million dollars, we will be able to develop better diagnostic tools for early detection of NETs, and state-of-the-art personalized therapies. More importantly, future research directions will help us understand the causes (genetic, cellular, environmental) that turn our body's normal neuroendocrine cells into a cancerous (NET) cell. Understanding the causes will allow us to focus on prevention of NET cancer.

# New Way to Improve Treatment



“

Thanks to CNETS Canada's support, we will study a novel way to improve the treatment of neuroendocrine tumours with radionuclides (known as PRRT). Our goal is to combine PRRT with a drug able to make these tumours more vulnerable to radiation. If our results are positive, this new combination could rapidly be offered to patients, since we already administer PRRT. The research that we are conducting thanks to all CNETS Canada donors has the potential to make a difference for patients with neuroendocrine tumours in the near future.

”

- **Dr. Jean-Mathieu Beauregard**  
CHU de Québec, Université Laval, Quebec City

**Dr. Beauregard was one of two successful recipients of CNETS Canada's 2016 research grant.**

## CNETS Canada Saves Lives



“

CNETS Canada's funds are used wisely and not wasted. I am fortunate to know where the money goes because I am in control. I know the good that we are doing - research, support groups and all the rest. To be blunt, if CNETS Canada did not exist, many people would no longer be with us today. The factors that go into my **personal** decisions about giving are that as much as possible, my money goes where I am led to believe it will go. That's paramount. And it has to be a cause that's very worthwhile like CNETS Canada. ”

- **Vernon Holt**

**Director of Finance and Secretary-Treasurer, CNETS Canada**

# Support CNETS Canada

Be a founding member of the monthly Zebra Club

Be a volunteer

Donate annually as part of our Loyalty Club

Fundraise for us

Make a bequest through the Maureen Coleman Legacy Society

Shop at our zebra store

Contribute a major gift of \$5,000 or more and join the Tip Top Club

Tell everyone about CNETS Canada

**HOW MANY BOXES CAN YOU TICK?**

## The Needs and Interests of our Patients are our Top Priority



“

I was Chief and Chair of Nuclear Medicine in London, Ontario from 2003 until 2008. At the time the London Hospitals were one of the only two centers across Canada to have a nuclear medicine program for the diagnosis and treatment of neuroendocrine tumors. We were seeing patients from all over the country. Around 2006, we were asked by one of our hospital administrators to stop the program. Realizing that there was a major disconnect between the health care system and the patients, I decided to join the only Canadian patient advocacy group that represented the interests and needs of patients dealing with NETs. I have been part of CNETS Canada since 2007 and enjoy every minute of it.

”

**- Dr. Jean-Luc Urbain**  
**Vice-President of CNETS Canada**

**With your help, there is hope!**



“

The future for neuroendocrine (NET) cancer patients hinges on the development of cutting edge diagnostics and treatments.

”

**- Dr. Shereen Ezzat**  
Professor of Medicine & Oncology  
University of Toronto

**REACH  
FOR  
THE** **NET**  
Finding A Cure For Neuroendocrine (NET) Cancer

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TUMOUR SOCIETY CANADA