



NET Cancer Day

November 10



NET Cancer Day

INCA

International
Neuroendocrine
Cancer Alliance



2020 CAMPAIGN TOOLKIT

#LetsTalkAboutNETs

www.incalliance.org



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BACKGROUND

Who is behind NET Cancer Day?

NET Cancer Day is coordinated by the International Neuroendocrine Cancer Alliance (INCA) – the home of NET Cancer Day. INCA is the global voice in support of patients with neuroendocrine cancer and multiple endocrine neoplasia syndromes.

INCA's mission is to: raise awareness about all types of NETs; push for scientific advancements with a focus on identified unmet needs; and to provide a platform for global collaboration to address the many challenges NET patients and the medical community face, in securing a timely diagnosis and accessing optimal treatment, support and care.

INCA represents 26 patient advocacy organizations from 22 countries around the globe.

What is NET Cancer Day?

NET Cancer Day is an annual event held on the 10th of November, created to increase awareness of neuroendocrine tumors.

NET Cancer Day is about drawing attention to a group of less common cancers with increasing numbers being diagnosed and starting a global conversation amongst communities, medical professionals and governments.

#LetsTalkAboutNETs

Why NET Cancer Day matters?

Neuroendocrine tumors are frequently misdiagnosed and early detection is key. In a survey conducted by INCA at the end of 2019, it was found that 46% of patients have advanced stage neuroendocrine cancer by the time they are correctly diagnosed. For many of these patients a cure is not possible.

Frequently misdiagnosed with conditions such as: anxiety, menopause, Irritable Bowel Syndrome (IBS), asthma or diabetes, a greater awareness of NETs amongst the community and medical profession is needed.



SUPPORT

How can you support NET Cancer Day this year?

Help INCA,

the home of NET Cancer Day, spread the word further than ever before on November 10 by making #LetsTalkAboutNETs a global conversation - both online and throughout all communities.

The focus of this year's campaign is to highlight the challenges patients and clinicians face around Early Diagnosis. This toolkit will provide you with all of the information you need to help spread the word on

November 10



#LetsTalkAboutNETs

THE AIM OF NET CANCER DAY IS TO:



Raise awareness of NETs among key decision makers, health professionals and the general public, to improve quality of life and prognosis for NET patients and decrease misdiagnosis.



Help the voice of NET patients be heard by more people.



Focus on NETs for a day to bring hope and information to people living with NETs, their caregivers and families.



Ensure equity in access to care and treatment for NET patients around the world.



Encourage more funds for research, treatments, patient support and resources for NET.



KEY CAMPAIGN MESSAGES 2020

Consistency is important to help raise awareness on NET Cancer Day. The focus of this year's campaign is around Early Diagnosis and below are key Early Diagnosis challenges that we have identified to help get you started.

Key campaign messages for 2020 fall into 4 categories:



Misdiagnosis & Time to Correct Diagnosis

NET patients are often misdiagnosed for years, and require multiple consultations prior to receiving the correct diagnosis. Sometimes they are diagnosed by pure chance.

Awareness of Symptoms and Availability of Diagnostic Tools

Highlighting the need for greater awareness of NET symptoms among all healthcare professionals



Access to NET specialists and healthcare centers, specialized in NETs

Better access to NET specialists and medical centers specialized in NETs is crucial for improving diagnosis and saving lives.

Healthcare professionals involved in diagnosing NETs

More healthcare professionals knowledgeable in NETs is key to improving early diagnosis of NETs





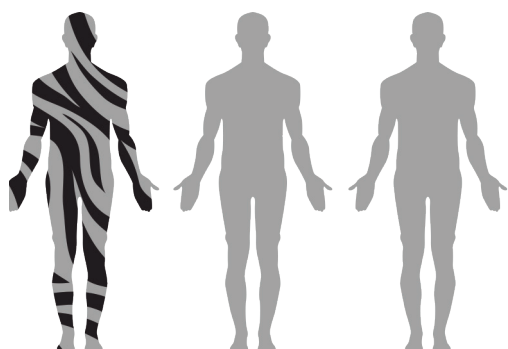
MISDIAGNOSIS

& TIME TO CORRECT DIAGNOSIS

Neuroendocrine tumors (NETs) are a group of less common cancers with increasing numbers being diagnosed and more people living with this disease due to improving detection methods and raising awareness among healthcare professionals (HCPs).

SCAN

Survey of **C**hallenges in **A**ccess to Diagnostics and Treatments for **NET** patients (SCAN) results will help drive forward optimal care and referral pathways to achieve the goal of earlier diagnosis.

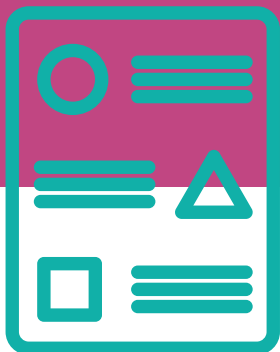


- Among the NET patients who responded to the Survey of Challenges in Access to Diagnostics and Treatments for NET patients (SCAN) **only 27% (1/3) were diagnosed first time**, while:

- **Misdiagnosed for years: 44% on average**, in Oceania (54%), North America (47%), Europe (43%), Asia (33%)

- Diagnosed by chance: incidental diagnosis 26%
- Globally, it takes 5 years on average from initial symptoms to actual diagnosis: North America – 6 years; Oceania – 5 years; Europe – 4; Asia – 2 years. Best results on early diagnosis are registered in Asia
- Four out of five misdiagnosed patients globally (81%) failed to receive a correct diagnosis within 1 year (North America (86%); Oceania (82%); Europe (80%); Asia (72%))
- Almost half of patients (46%) were diagnosed with stage IV NETs or had metastases at time of diagnosis

**EARLY DETECTION IS VITAL TO IMPROVE PATIENT OUTCOMES
DELAYED NET DIAGNOSIS REMAINS A GLOBAL CHALLENGE.**



AWARENESS OF SYMPTOMS AND AVAILABILITY OF DIAGNOSTIC TOOLS

NETs are a complex disease because their symptoms may mirror more common ailments such as gastritis, irritable bowel syndrome, menopause, stomach and bowel ulcers, anxiety and asthma.

- Healthcare professionals at all levels of care should be equipped with the skills to identify neuroendocrine cancer symptoms and perform or refer for appropriate diagnostic tests.
- **Biopsy** (59%) and **CT** (45%) most commonly led to NET diagnosis.
- Limited understanding of the disease and financial constraints mean current availability of diagnostic and treatment tools for NET patients vary considerably within and across healthcare systems, with many patients experiencing suboptimal care.
- **Gallium 68-DOTA PET CT**, an advanced and more precise diagnostic tool, had significantly lower usage vs more common diagnostic tools globally and locally (Global: 18%).



- *Incorrect diagnoses prior to NET diagnosis were most often:*
 - **gastritis (36%),**
 - **irritable bowel syndrome (34%),**
 - **anxiety (22%),**
 - **menopause (12%),**
 - **stomach and bowel ulcers (12%),**
 - **and asthma (10%).**

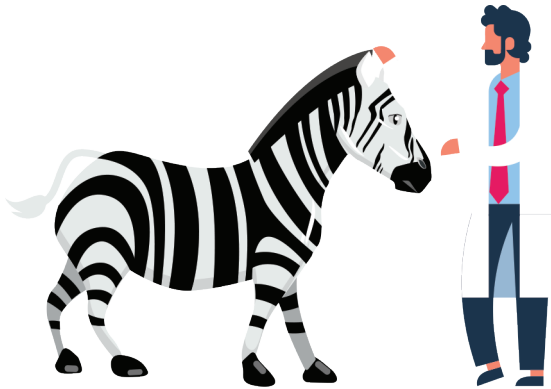


IMPROVEMENTS IN THE USAGE OF MORE ADVANCED
DIAGNOSTIC TOOLS IS NEEDED.



ACCESS TO NET SPECIALISTS

AND HEALTHCARE CENTERS, SPECIALIZED IN NETS



Better access to NET specialists and medical centers specialized in NETs is crucial for improving access to relevant diagnostics, promoting equality in cancer care and saving lives, according to 53% of NET patients and 63% of HCPs who participated in SCAN.

- A quarter (24%) of patients had not heard of NET specialist
- In 41% of cases, the diagnosis is received in a hospital without a specialist in NETs.

HCP INVOLVED IN DIAGNOSING NETS

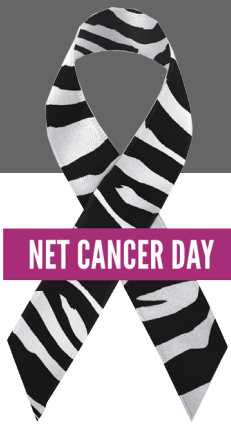


- Neuroendocrine tumors are difficult to diagnose, and most commonly, NET patients had more than one healthcare specialist involved in their diagnosis.
 - NET patients commonly had **more than one HCP involved** in their diagnosis: 11% - one HCP, 39% - two HCPs, 23% - three HCPs, 22% - four or more HCPs.
 - The HCPs most often involved in NET diagnosis were **gastroenterologists (20%)** and **GPs (19%)**
- A key recommendation to improve NET diagnosis: More HCPs knowledgeable in NETs (NET patients: 62%; HCPs: 50%)

AWARENESS AND ACCESS TO NET SPECIALISTS AND EXPERT CENTERS REQUIRES IMPROVEMENT

CAMPAIGN MATERIAL

TO HELP YOU SPREAD THE WORD



NET Cancer Day has been designed to start a conversation about NETs with medical professionals, key decision makers and local communities in order to raise awareness about the key issues faced by NET patients.

Download via www.incalliance.org

1. CAMPAIGN POSTERS



Take a selfie with this poster - the more creative the better - and share across all your social media channels using the #LetsTalkAboutNETs hashtag on November 10th.
#LetsTalkAboutNETs

My Route to my NET Diagnosis

Misdiagnosed with: _____

Number of doctors seen: _____

NET Diagnosis: _____

Type of Doctor: _____

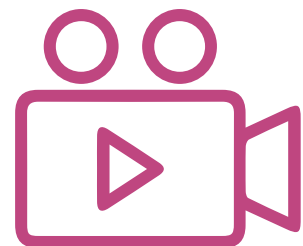
Thank you for diagnosing my NET!

Dr. Name: _____

Institution/Country: _____

2. NET CANCER DAY VIDEO

Share the INCA Early Diagnosis video, available in 10 languages. Videos will be available at www.incalliance.org



3. NET CANCER DAY LOGO

Wherever possible use the new NET Cancer Day and INCA logo - on your website, social media and any promotions.

4. 2020 CAMPAIGN INFOGRAPHICS

Utilize on social media to help raise awareness and drive the key messages.



The infographics will be made available in 10 languages on the INCA website.

SHARE YOUR ROUTE TO DIAGNOSIS

This year's campaign is focusing on the challenges patients and clinicians face around early diagnosis of NETs. Have you had multiple consultations prior to receiving your NET diagnosis? Or have you been diagnosed at first visit? You can help make a difference by snapping a selfie to capture your experience.

TAKE A SELFIE WITH YOUR COMPLETED TEMPLATE(S) AND UPLOAD IT HERE. PLEASE, MAKE SURE TO SHARE YOUR SELFIE WITH US BY OCTOBER 20TH.



Thank you for snapping a selfie – it's that easy to help make the world talk about early diagnosis of NETs!
We look forward to receiving your photos!



#LetsTalkAboutNETs



My Route to my NET Diagnosis

Misdiagnosed with: _____

Number of doctors seen: _____

NET Diagnosis: _____

Type of Doctor: _____



Thank you for diagnosing my NET!

Dr. Name: _____

Institution/Country: _____



The posters can be downloaded from <https://incalliance.org/net-cancer-day-2020/>

INCA will share your photos along with all those coming from NET patients around the world on our social media platforms **@NETCancerDay** to raise awareness around NET Cancer Day, November 10th.



GET INVOLVED

Last year over 12 million people saw the hashtag #LetsTalkAboutNETs and thousands of people updated their Facebook profile picture. In 2020 let's aim even higher!

REACH OUT

Reach out to patients and social networks and ask them to share their stories / connect you with potential sponsors / organize a fundraiser with the local community. Refer to social media messages and timeline within this document for more information

GET SOCIAL

Promote and support NET Cancer Day via all social media platforms. Refer to the social media guide within this document for some great ideas and inspiration

#LetsTalkAboutNETs #NetCancerDay

START A CONVERSATION

Find your unique local angle and let the media know what's happening. Conversations don't always have to be over the phone, send a tweet or email a media release. Refer to the Stop the Press section of this document for more information and download a template media release from our website: www.incalliance.org

GET INVOLVED



Patient/Membership engagement message

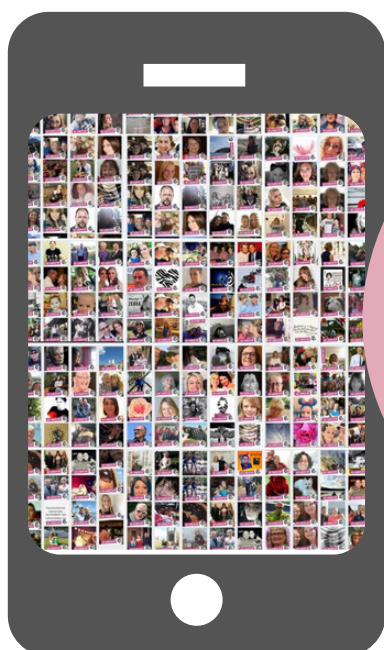
We are seeking member support, referrals and commitment via social media.

NET Cancer Day is on the 10th of November

We need your help as a NET patient, friend or family member to achieve an improved outcome for our friends and relatives by helping us promote NET Cancer Day and the concerns patients face around timely diagnosis of NETs

INCA and (INSERT YOUR ORGANIZATION NAME HERE) intend to make this NCD campaign grow to create awareness of our underfunded and underrepresented group of diseases and our patients' unmet needs.

Inbox us if you can help.



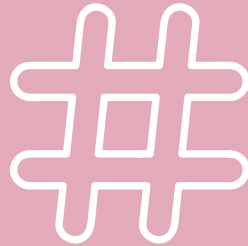
TIP: Don't leave things to the last minute. Use this patient/membership message early to gain support from your local community.



SOCIAL MEDIA STEPS

On NET Cancer Day last year, the hashtag #LetsTalkAboutNETs reached millions around the globe with the campaign reporting its highest reach so far. Over 12 million impressions were gained on social media and more than 200 000 people watched the INCA Members videos addressing the key access issues that our NET community faces today.

One of the fastest ways to spread the word on NET Cancer Day is via social media.



**NET CANCER DAY
OFFICIAL HASHTAGS:**
#LetsTalkAboutNETs
#NetCancerDay

1

STEP 1: CONNECT

FOLLOW US



@netcancerday



@netcancerday



@netcancerday



@inca-alliance

STEP 2: SPREAD THE WORD

Spread the message far and wide. Tweet, post and hashtag your Route to Diagnosis #LetsTalkAboutNETs on and around November 10.

2

3

STEP 3: USE THE NET CANCER DAY FRAME

Use the NET Cancer Day frame on your profile to show your support



FACEBOOK



Facebook is a great platform to reach out to your local NET community and ask for their support. Share their stories, connect with supporting businesses and promote any local NET Cancer Day events.

Top Tips for Facebook

NET Cancer Day Frame

Encourage followers to use our NET Cancer Day frame on their profile pictures



Spread the word

Ask your followers to spread the word and reach more people by sharing your messages and posts

Key Messages and Images

Use your personal Route to Diagnosis story or the pregenerated messages within this document with the posters available via our website



Included in this document is just a handful of ways you can get involved and spread the word on NET Cancer Day. Don't think you have to stop here - if you can think of more great ways to promote NCD please do!



TWITTER



Use Twitter to be a part of the conversation in the lead up to NET Cancer Day and to reach out to local politicians, pharmaceuticals and the media in your country.

Top Tips for Twitter

Tag influencers to get their attention

Search for politicians, celebrities, pharmaceutical and media contacts to tag @ in your tweets.

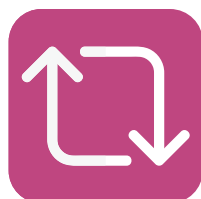
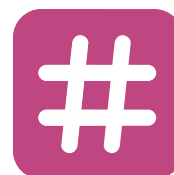


Stay current

Twitter is all about present time – provide real time updates on your events to your followers

#Hashtag, #Hashtag, #Hashtag

Use the hashtags so that we can find you:
#LetsTalkAboutNETs #NetCancerDay #NetCancer



Follow, Like & Retweet each other

Follow other NET and cancer organizations that support your work and will share your message to their followers. The more shares the better



INSTAGRAM



Instagram is the perfect platform to personalize your stories. As the saying goes 'a picture tells a thousand words' and Instagram is just the place to share these images.

Top Tips for Twitter

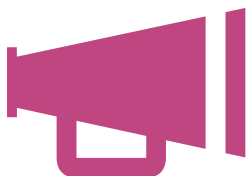
Feature Patients

Tell your Route to Diagnosis stories with a bold image and a great back story



Cross Promote

Link Facebook with Instagram so content uploaded onto Instagram is shared on Facebook



Instagram Stories and IGTV

Increase reach and a wider audiences by utilising Instagram stories and use IGTV to upload longer video content



TIP: People respond best to real life experiences. Encourage your patients to submit case studies that you can share across all digital platforms - website and social media.



LINKEDIN

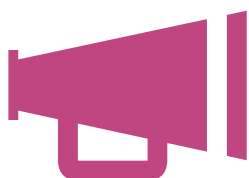
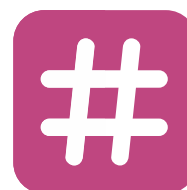


LinkedIn is the perfect platform to reach out to your professional networks and to share your NET Cancer Day messages to a targeted group of specialists and professionals.

Top Tips for LinkedIn

Link your content & posts to trending hashtags

In addition to the hashtag LetsTalkAboutNETs try linking your posts about NET Cancer Day to a hashtag that is trending on the day - this will help increase your reach



Share NET articles with your professional network

Upload NET articles that you can easily find at <https://incalliance.org/abstracts-articles/>

Tag INCA in your post

Help increase our LinkedIn presence and raise awareness around our global brand by tagging International Neuroendocrine Cancer Alliance (INCA) in all of your posts





STOP THE PRESS

One of the most influential ways to reach out to your community is via your local media.

TIPS AND IDEAS TO GAIN MEDIA ATTENTION:



Create an eye-catching title that will make the journalist want to open your email



Always include the who, what, where, why, how information in the first two paragraphs. Journalists are busy and they want to grasp the idea of your message as quickly as possible



Include a striking image. Press releases with a great image are more likely to be opened



Keep it punchy and get straight to the point – include links to the INCA website for more details on statistics and facts. Journalists will always ask you for more information if they want it



Be consistent with your chosen key message and find local case studies to support it. How do NETs affect your community/ country?



Link your story back to current events. If NETs somehow relate to a current affair within your country, leverage it.



Include quotes from experts and have them available for interview

A template press release will be available for your use and adaptation on our website. Personalise it with your key messages and any local campaign information and use it to reach out to your local media.

www.incalliance.org



TIMELINE

Below is a checklist of items to consider throughout October and more detailed steps for the weeks leading up to November 10

TIPS AND IDEAS TO GAIN MEDIA ATTENTION:

- Decide and define primary Early Diagnosis campaign messages for your organization – Most importantly though KEEP TO MESSAGE throughout the campaign. Need inspiration? Refer to the Key Messages within this document
- Develop your localized NCD communication campaign. Include: social media and media strategies
- NCD involvement benefits to commercial sponsors
- Start posting patient membership engagement messages
- Utilize and leverage patient referral and involvement – ask for their help/referrals/contacts
- Identify and qualify a list of QUALITY supporters committed to a high level of support that you can leverage in the lead up to NET Cancer Day
- Qualify PRECISE level of support (financial or promotional)

OCTOBER 1-20

Call to action for My Route to Diagnosis campaign – mobilize your communities to send INCA selfies capturing their experience with diagnosing NETs

OCTOBER 20 – NOVEMBER 9

building up to
NET Cancer Day

NOVEMBER 10 NET Cancer Day



OCT / NOV TIMELINE

It's time to hit it hard! Let's spread the message far and wide

#LetsTalkAboutNETs

3 WEEKS OUT

- Reach out to patients and stakeholders via newsletter/database and ask them to show their support/come forward with their stories

- Prepare your media release, use patient stories, include stats and use quotes from experts
- Reach out to local media and share local stories

2 WEEKS OUT

1 WEEK OUT

- Start sharing key messages daily via social platforms. And ask your followers to do the same
- Send out reminder newsletter to all patients/stakeholders
- Promote any upcoming events/fundraisers
- Follow up with any media that were interested



ON NET CANCER DAY NOVEMBER 10

**Share any events
and fundraiser
images as they
come to light**

**Re-engage with
any media that
showed interest,
offer interviews
and images**

**Get social!
And ask your
followers to
share your
messages**

**Use the NCD frame
on your profile
picture. Share your
Route to Diagnosis
stories across
social media.**



#LetsTalkAboutNETs



THANK YOU TO ALL OF OUR MEMBERSHIP ORGANIZATIONS

