2018 Campaign Toolkit

Join us in 2018
#LetstalkaboutNets

www.incalliance.org
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**THINK ZEBRA**
If you don’t suspect it, you can’t detect it.
**BACKGROUND**

**Who is behind World NeuroEndocrine (NET) Cancer Day?**

World NET Cancer Day is coordinated by the International Neuroendocrine Cancer Alliance (INCA).

INCA is the global voice for Neuroendocrine cancer (NET) patients and carers with a mission 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 20 member organisations from 17 countries located around the globe.

**Why World NET Cancer Day matters**

NET Cancers are frequently misdiagnosed and early detection is key. In a recent survey conducted by INCA/Novartis* it was found that 58% of patients have advanced stage neuroendocrine cancer by the time they are correctly diagnosed. There is currently no cure for the majority of patients.

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

**What is World NET Cancer Day?**

World NET Cancer Day is an annual event held on the 10th of November, created to increase awareness of Neuroendocrine (NET) cancers and to provide a voice to the NET community for improved diagnostics, treatments, information, care and research.

World NET Cancer Day is about drawing attention to this uncommon form of cancer and starting a global conversation amongst communities, medical professionals and governments - #LetsTalkAboutNets.

On November 10, INCA members from around the globe partner with local cafes and communities to promote the ‘Let’s Talk About NETs’ branded cups to increase community awareness about this often-misdiagnosed form of cancer.

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*The Global Survey of Patients With NETs is a collaborative effort between the International Neuroendocrine Cancer Alliance (INCA) and Novartis.*
HOW CAN YOU SUPPORT WORLD NET CANCER DAY?

Help INCA spread the word further than ever before on November 10 by making #LetsTalkAboutNets a global conversation - both online and throughout all communities.

Whether you are an individual or an organisation there are many ways you can help spread the word on World NET Cancer Day, from asking local cafés to serve hot drinks in specially branded ‘Lets Talk About NETs’ cups, to simply spreading the word on social media, the possibilities are endless.

The aim of World NET Cancer Day is to:

- Raise awareness of NET cancers among decision makers, health professionals and the general public to improve quality of life and prognosis for NET cancer patients and decrease misdiagnosis.
- Help the voice of NET cancer patients be heard by more people.
- Focus on NET cancers for a day to bring hope and information to people living with NET cancers, their caregivers and families.
- Ensure equity in access to care and treatment for NET cancer patients around the world.
- Encourage more funds for research, treatments, patient support and resources for NET cancers.
Consistency is important to help raise awareness on World NET Cancer Day. Please feel free to use these messages and adapt for your local campaigns.

**Key campaign messages for 2018 fall into 4 categories:**

- **Symptom awareness**
  Informing the wider community about NET symptoms

- **Unmet needs**
  Highlighting the need for more resources and information

- **Access to care and treatment**
  Stressing the importance of quality care and treatment for all NET patients

- **Research and funding messages**
  More research and funding is required to find a cure for NETs
World NET Cancer Day – raising awareness of neuroendocrine cancers around the worlds

NETs are most often found in lungs, pancreas and gastrointestinal system, but can arise anywhere in the neuroendocrine system

NET cancers are on the rise effecting men, women and children at various stages in their life

7 in 100,000 people are diagnosed each year, with diagnoses on the rise

Neuroendocrine cancer symptoms are wide and varied - Irritable Bowel Syndrome (IBS), asthma-like symptoms, flushing and unexplained anxiety
SYMPTOM AWARENESS MESSAGES

Diagnosis of 1 genetic NET syndrome patient often results in the diagnosis of multiple family members

Children of a parent with Multiple Endocrine Neoplasia (MEN) have a 50% or 1 in 2 risk of inheriting the condition

NET Cancer can be sporadic or result from inherited conditions including Multiple Endocrine Neoplasia (MEN), Succinate Dehydrogenase (SDH) or Von Hippel Lindau (VHL) disorders and affect men, women and children at various stages in their life

THINK ZEBRA
If you don’t suspect it, you can’t detect it.
Over 50% of NET patients are not receiving access to the information that they need at the time of diagnosis.

Up to a third of patients diagnosed are not provided with enough information on how to manage the condition.

Psychological care – over half of NET patients interviewed have not had access to the psychological care that they required.

Greater access and promotion of resources by medical experts in partnership with patient organisations are vital – 70% of patients access information from NET patients organisations online.

REMEMBER: All infographics used in the key messages can be downloaded via the website www.incalliance.org.
ACCESS TO CARE & TREATMENT MESSAGES

45% of patients are not correctly diagnosed at first diagnosis

Almost 50% of patients visit a doctor 5 or more times before receiving their diagnosis

Many patients are travelling over 300km/186 miles to receive treatment, creating a huge financial and psychological strain on patients and families

Patient access to gold standard diagnostics and treatment on a global scale is vital

Neuroendocrine cancers are complex and unpredictable and require an expert and experienced multidisciplinary team, working alongside community advocacy groups, to ensure the best outcomes for all patients
The rising incidence rate of NETs means more research is needed.

For things to change medical professionals need a basic understanding of the unmet needs of NET patients, as well as understanding NET related symptoms and syndromes.

NET patients need more involvement in research, including drug trial design.

Patient and medical communities should support each other to ensure: global clinical trials, international registries and increased funding for research and education on NETs.

TIP: All campaign messages are adaptable. Modify these messages to suit your local campaign.
World 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

Below is material to help you spread the word

**Campaign poster**
Share this with participating cafes and businesses to spread the word amongst your community

**Campaign Infographics**
Utilise on social media to help raise awareness and drive the key messages home

**Campaign World NET Day Facebook frame**
Last year over 2,000 people updated their profile picture with the NET Cancer Day frame... let’s do it all again!

**Campaign Cover Letter**
Help cafes understand why their participation is so important and let them know what they need to do on the day with this info cover letter
GET INVOLVED

Last year over 100,000 ‘Let’s Talk About NETs’ cups were distributed in cafes, hospitals and special events around the world. 8.2 million people saw the hashtag #LetsTalkAboutNets and over 2,000 people updated their Facebook profile picture. In 2018 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 / organise a fundraiser with the local community. The earlier you start asking your community for help the better. Refer to social media messages and timeline within this document for more information

GET SOCIAL

Promote and support World 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 #INCAliance

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 Meet the Press section of this document for more information and download a template media release from our website: www.incalliance.org
GET INVOLVED

USE THE LOGO

Wherever possible use the World NET Cancer Day logo - on your website, social media and any promotions. The NCD logo and brand guidelines can be downloaded directly from our website: www.incalliance.org

ASK FOR HELP

Ask local cafes and businesses to show their support and serve coffees in 'LetsTalk About NETs' branded cups. Ask local politicians, influencers and celebrities in your network to support the cause, ask businesses to provide sponsorship. Head to: www.incalliance.org for more template letters

PROMOTE

In exchange for supporting NCD offer to promote local cafes and businesses: on your website, across social media and to the press (when appropriate). The more promotion you can offer the better.
GET INVOLVED

CREATE A BLOG

Promote NET Cancer Day by uploading related blog articles and newsletters onto your website and then promote them via social media. It’s a great way to direct traffic back to your website with new and engaging content. Include case studies that link back to your key messages and news on NCD events.

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!
On World NET Cancer Day last year the hashtag #LetsTalkAboutNETs reached millions around the globe with the campaign reporting its highest reach so far.

Over 8.2 million impressions were gained on Twitter and thousands edited their Facebook profile pictures with the NET Cancer Day frame to show support.

#LetsTalkAboutNets
#NetCancerDay
#NetCancer
#IncAlliance
SOCIAL MEDIA STEPS

Social media is an effective tool to increase the exposure of World NET Cancer Day messages and promote any events on the day. Follow these steps below and utilise the top tips within this document to help spread the word in 2018.

STEP 1: CONNECT

Connect with us and stay up to date:
Like us on Facebook: @netcancerday
Follow us on Twitter: @netcancerday
Follow us on Instagram: @netcancerday

STEP 2: SPREAD THE WORD

Spread the message far and wide. Tweet, post and hashtag #LetsTalkAboutNets on and around November 10. Top tips are included in this document - use them!

STEP 3: USE THE NET CANCER DAY RIBBON

Download the NET Cancer Day ribbon from our website and use as a temporary profile picture on Facebook and other social media platforms #LetsTalkAboutNets
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 Ribbon

Encourage followers to change their profile picture to our NET CANCER ribbon, available for download via our website.

### 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 the pre-generated messages within this document and download the infographics available via our website.

### Take a Selfie

Encourage patients and stakeholders to upload pics of themselves sipping from a “Let's Talk About Nets” cup and upload it to the NET Cancer Day Facebook page.
Use twitter to be a part of the conversation in the lead up to World 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 #IncAlliance

**Follow, Like & Retweet each other**
Follow other NET and cancer organisations that support your work and will share your message to their followers. The more shares the better
Instagram is the perfect platform to personalise 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 Instagram**

**Feature Patients**
Tell your patient 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

**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.
Below are ready-made messages for World NET Cancer Day. Copy and paste these onto your social pages and compliment with a great image or use one of the infographics available at www.incalliance.org

**Symptom awareness messages**

November 10 is #NetCancerDay – let’s raise awareness about neuroendocrine cancer around the world
#LetsTalkAboutNets

Did you know that #NetCancer is most often found in the lungs, pancreas and the gastrointestinal system? If you don’t suspect it, you can’t detect it
#LetsTalkAboutNets #NetCancerDay

#NetCancer is on the rise affecting men, women and children at various stages in their life #LetsTalkAboutNets #NetCancerDay

Fact: 7 in 100,000 people are diagnosed each year with #NetCancer, and diagnoses are on the rise. Help spread the word #LetsTalkAboutNets #NetCancerDay

#NetCancer symptoms are wide and varied – IBS, asthma-like symptoms, flushing and unexplained anxiety.
#LetsTalkAboutNets #NetCancerDay

**Unmet needs messages**

Fact: Over 50% of NET patients are not receiving access to the information that they need at the time of diagnosis. Let’s change that #LetsTalkAboutNets #NetCancerDay

Did you know over half of NET patients interviewed have not had access to the psychological care that they require? Help us change that
#LetsTalkAboutNets #NetCancerDay

Up to a third of patients diagnosed with #NetCancer are not provided with the right information on how to manage their condition. Together we can change that #LetsTalkAboutNets #NetCancerDay

#NetCancer patients need access to more resources from medical institutions. Help us to find ways to build more resources
#LetsTalkAboutNets #NetCancerDay

Did you know children of a parent with Multiple Endocrine Neoplasia (MEN) have a 50% or 1 in 2 risk of inheriting the condition?#LetsTalkAboutNets
Ready Made Messages

Access to care & treatment messages

Did you know 45% of #NetCancer patients are not correctly diagnosed at first diagnosis? Help us change that #LetsTalkAboutNets #NetCancerDay

Almost 50% of patients visit a doctor 5 or more times before receiving their #NetCancer diagnosis. Help us raise awareness #LetsTalkAboutNets #NetCancerDay

Some #NetCancer patients travel up to 300km/186 miles to receive treatment. More resources are needed #LetsTalkAboutNets #NetCancerDay

#NetCancer is complicated - centres of excellence and multidisciplinary teams are needed globally #LetsTalkAboutNets #NetCancerDay

Research & funding messages

The rising rate of #NetCancer means more research is needed. Help us spread the word #LetsTalkAboutNets #NetCancerDay

Medical professionals need a basic understanding of the unmet needs of #NetCancer patients and NET symptoms #LetsTalkAboutNets #NetCancerDay

Patient and medical communities should support each other to ensure: global clinical trials, international registries and funding for #NetCancer #LetsTalkAboutNets #NetCancerDay

Remember: Messages have the most impact when paired with an image. All infographics can be downloaded via the website: www.incalliance.org
Patient/Membership engagement message

"We are seeking member support, referrals and commitment via social media in July/August.

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 this NET Coffee Day campaign to key decision makers.

INCA and (INSERT YOUR ORGANISATION 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.
STOP THE PRESS

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

A template press release will be available for your use and adaptation on our website from early September 2018. Personalise it with your key messages and any local campaign information and use it to reach out to 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
TIMELINE

Below are key dates and suggested timelines to assist local campaigns in obtaining equal success

**JUL**
- Decide and define primary and secondary campaign messages for your organisation – Symptom Awareness? Earlier diagnosis? Unmet needs?
- Most importantly though KEEP TO MESSAGE throughout the campaign.
- Need inspiration? Refer to the Key Messages within this document.
- Develop your localised NCD communication campaign. Include: social media, media and think about possible NCD involvement benefits to commercial sponsors
- Create an Excel Spreadsheet of possible sponsors and media targets
- Place orders for NCD coffee cups

**AUG**
- Start posting patient membership engagement messages (refer p.21 of this document)
- Utilise and leverage patient referral and involvement – ask for their help/referrals/contacts
- Contact potential sponsors via initial campaign letter – provide an email & telephone contact

**SEP**
- Identify and qualify a list of QUALITY supporters committed to a high level of support and determine if support is financial or promotional
- Issue letters detailing agreement and timelines
- Agree to any commercial arrangements, e.g. Co-branding & sponsorship, funding levels (10 Cents per cup?), venues, supporting NCD marketing tools (poster campaign, literature in downloadable, printable PDF form, coffee cups)
- Finalise marketing support package for each sponsor on the day (A media pack and a commercial sponsor pack – posters, cups, leaflets, etc.)
Set reminders in your calendar to ensure you remember key dates in the lead up to NCD.

**OCT**

- Spread the word online - INCA are releasing teaser video snippets that will be about 30 seconds long. The "talking heads" video montage, produced by some of our INCA members will be available for use within the campaign. Messages will include – I lost my sister, partner, friend, daughter – I have sarcoma, GIST, Para MEN, VHL – I was undiagnosed for 5 years/10 doctors/Cancer had spread/Equal funding is all we ask.
# OCTOBER / NOVEMBER TIMELINE

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

#LetsTalkAboutNets

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<th>WEEKS OUT</th>
<th>Tasks</th>
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| **3**     | • Send out all promotional material to supporting cafes, businesses and sponsors  
            • Reach out to patients and stakeholders via newsletter/database and ask them to show their support/come forward with their stories |
| **2**     | • Prepare your media release, use patient stories, include stats and use quotes from experts  
            • Reach out to local media and share local stories |
| **1**     | • Update all social media accounts with the official World NET Cancer Day banner  
            • 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 on behalf of local cafes and businesses  
            • 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

THANK YOU TO ALL OF OUR MEMBERSHIP ORGANIZATIONS
#LetsTalkAboutNets
www.incalliance.org