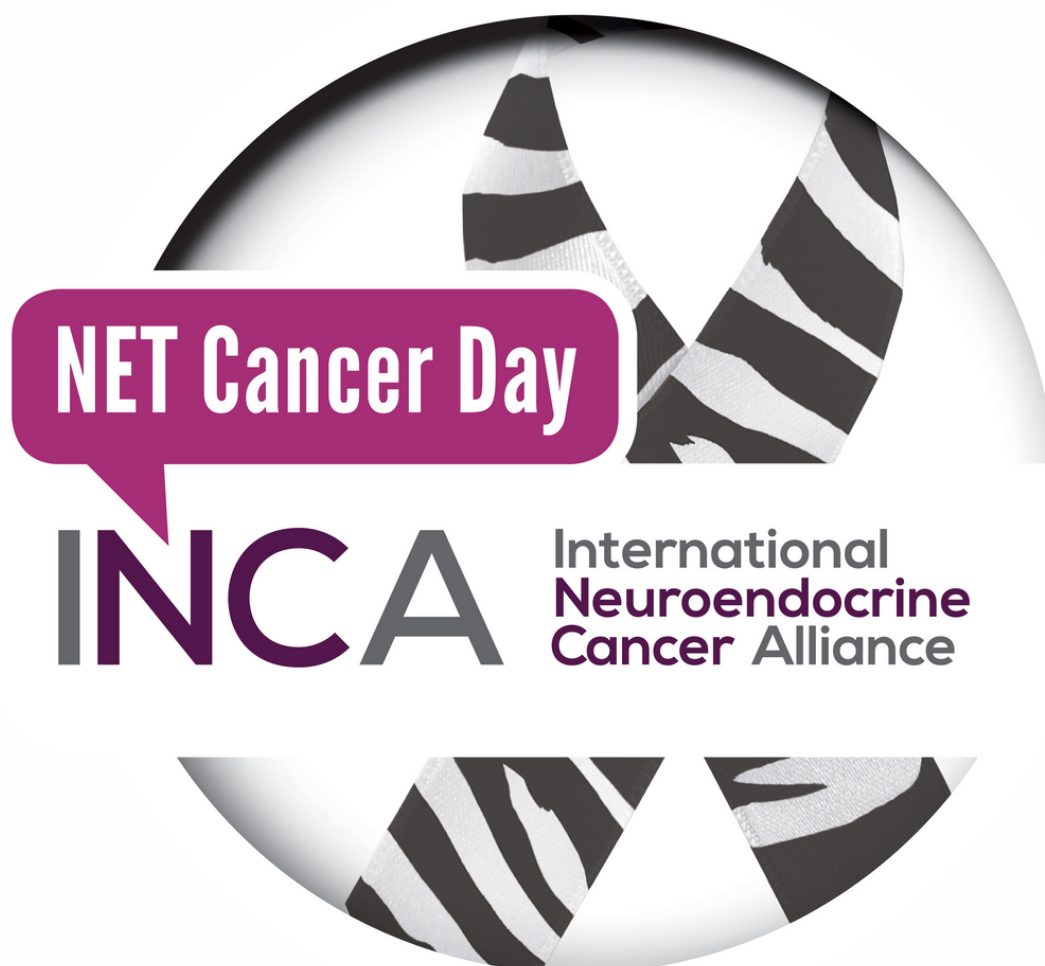


NET CANCER DAY, NOVEMBER 10



2019 CAMPAIGN TOOLKIT

JOIN US IN 2019

#LETSTALKABOUTNETS

www.incalliance.org

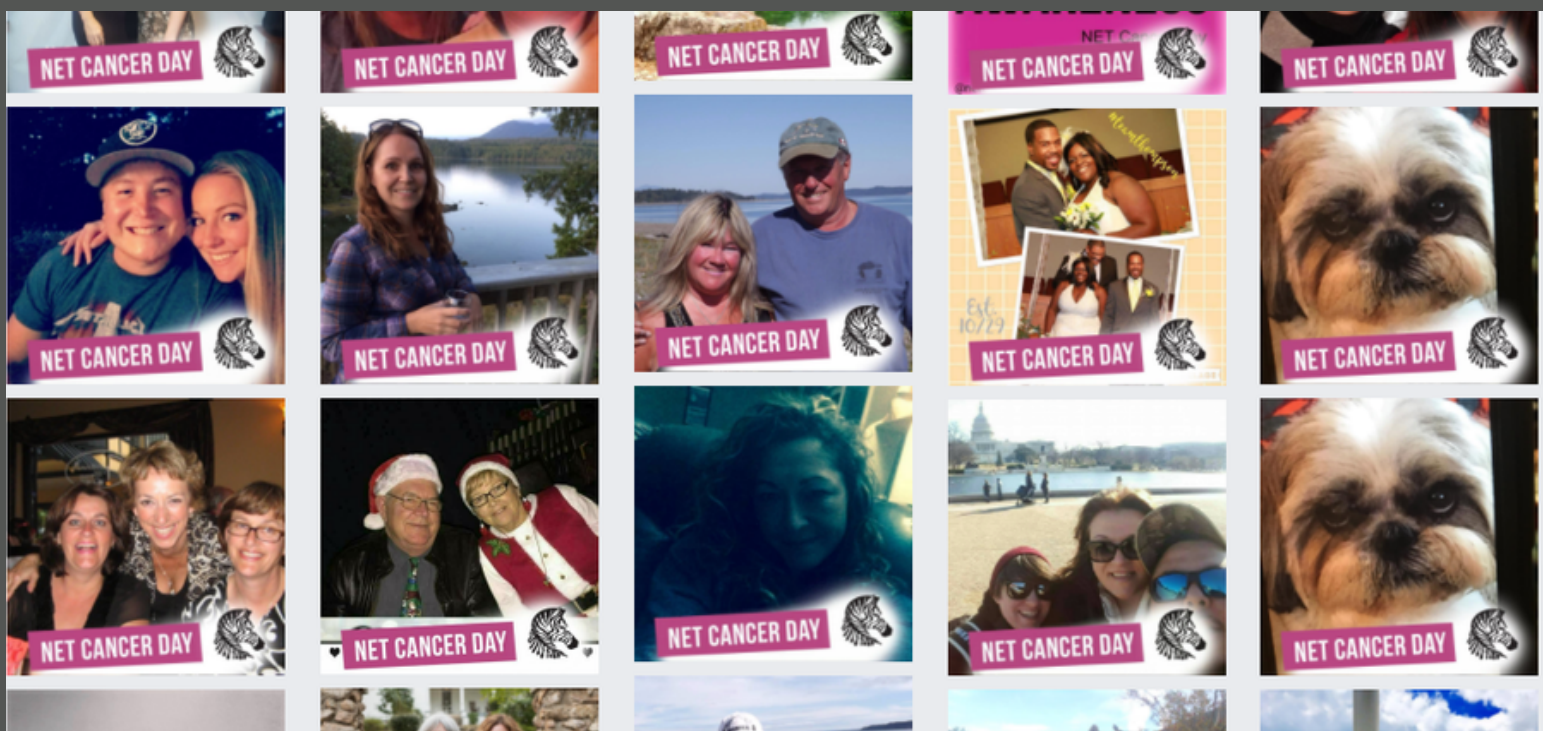
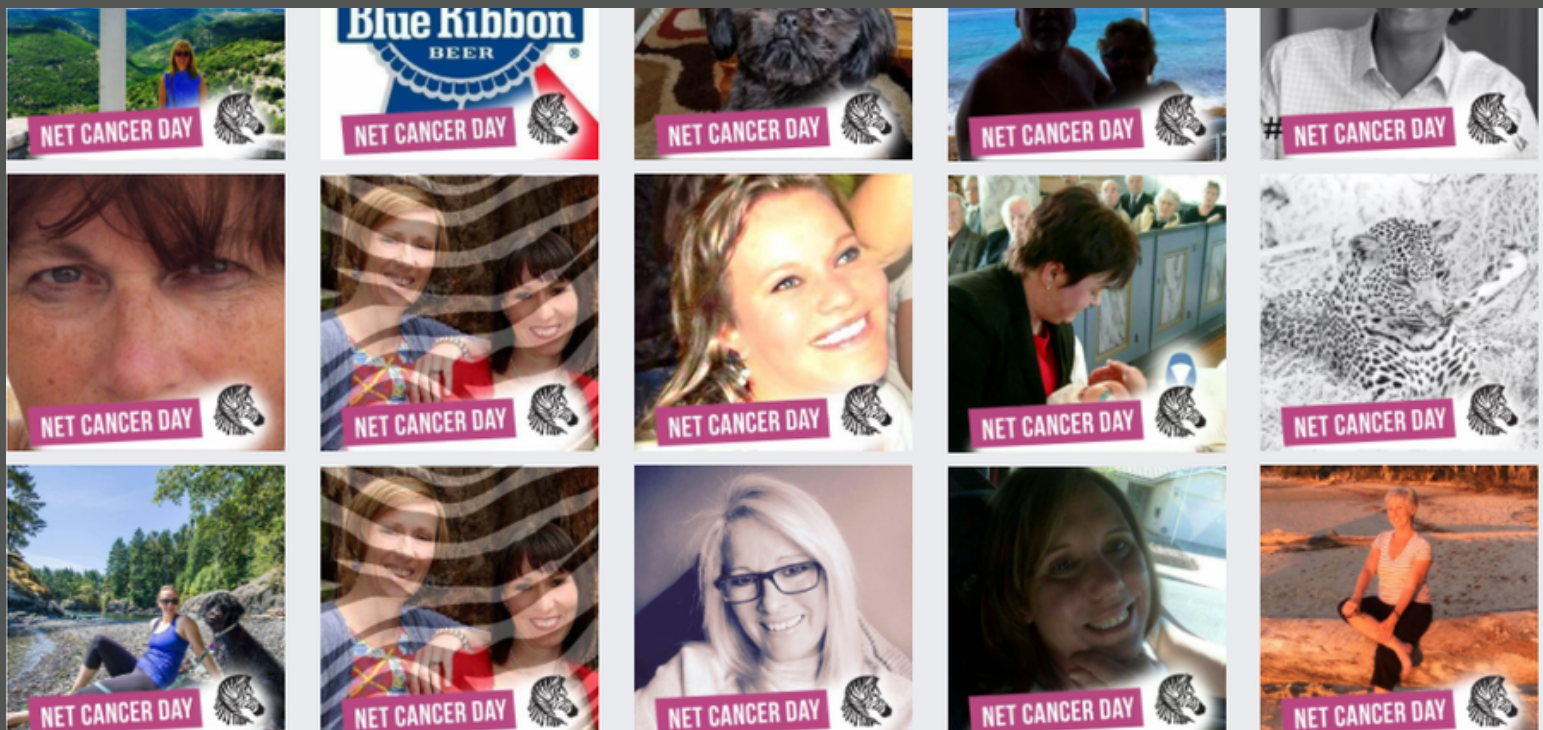
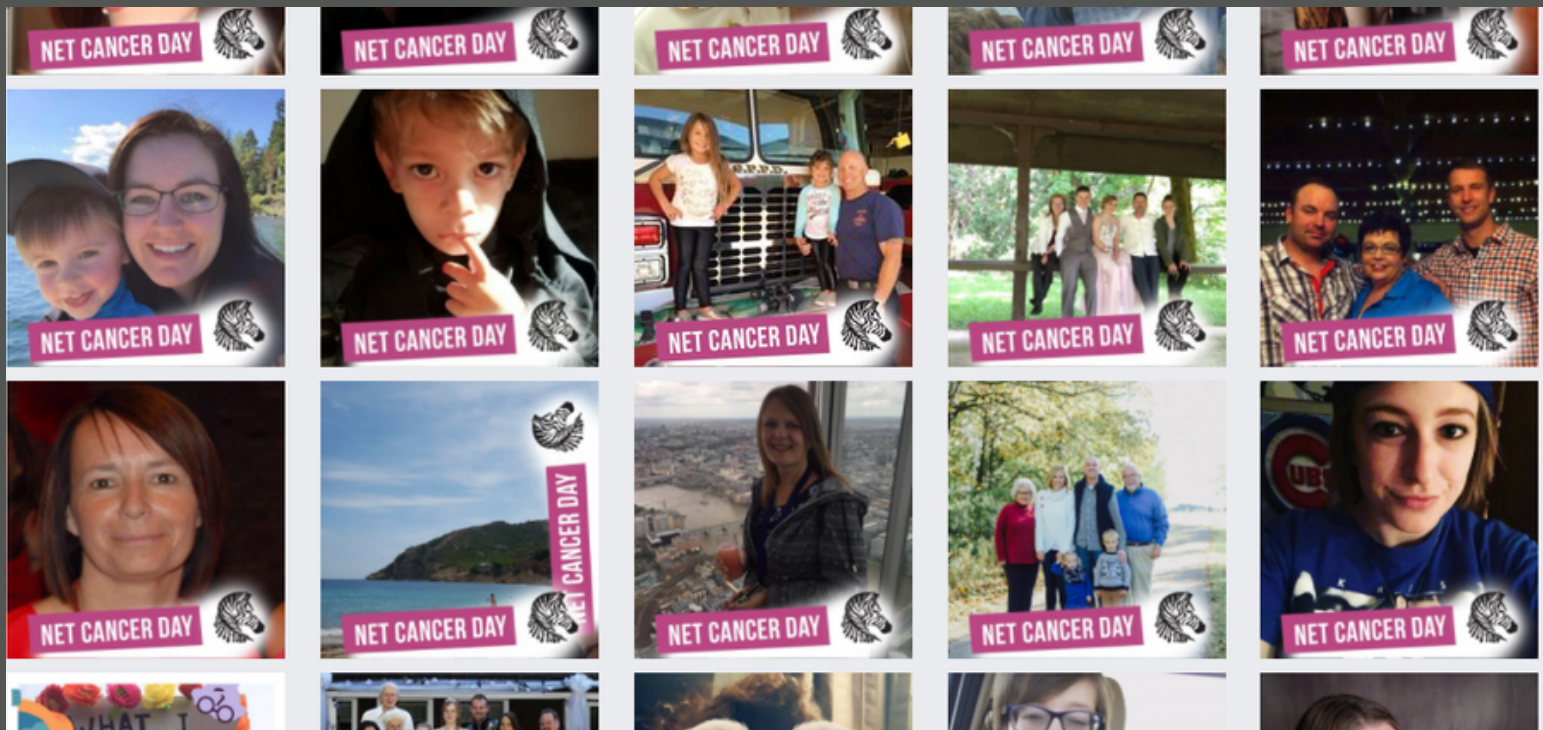




TABLE OF CONTENTS

02 BACKGROUND

- Who?
- What?
- Why?

03 HOW CAN YOU SUPPORT NET CANCER DAY THIS YEAR?

- Key campaign messages
- Campaign material
- Share your ACCESS stories

11 GET INVOLVED

- Simple ideas to show support around the day

13 SOCIAL MEDIA GUIDE

- Facebook
- Twitter
- Instagram
- LinkedIn
- Ready made messages

24 STOP THE PRESS

- How to get local media attention

25 TIMELINE

- Key dates for NET Cancer Day

THINK ZEBRA

If you don't suspect it,
you can't detect it.





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 organisations 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 Tumours.

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.

Why NET Cancer Day matters

Neuroendocrine Tumours are frequently misdiagnosed and early detection is key. SCAN global survey interim results show that 44% of patients are initially misdiagnosed. The disease has spread to other organs by the time 53% of patients receive the correct diagnosis. For many patients a cure is not possible.

SCAN global survey interim results show that patients are frequently misdiagnosed with conditions such as: gastritis, Irritable Bowel Syndrome (IBS) or other digestive disorders, unexplained anxiety. More awareness about NETs is needed among healthcare professionals and the wider NET community.

**Need a soft copy?
All campaign material can
be downloaded at
www.incalliance.org**





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 ACCESS - access to information, access to care & treatment, access to research and access to support. This toolkit will provide you with all of the information you need to help spread the word on NOVEMBER 10.

Whether you are an individual or an organisation there are many ways you can help raise awareness on NET Cancer Day #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 2019

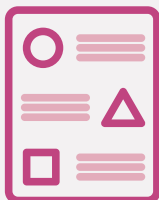
Consistency is important to help raise awareness on NET Cancer Day. The focus of this year's campaign is around ACCESS and below are key ACCESS challenges that we have identified to help get you started.

Key campaign messages for 2019 fall into 4 categories:

ACCESS to information

Patients and clinicians need greater ACCESS to information in order to understand NET symptoms and ACCESS more timely diagnosis

.....



ACCESS to support

Highlighting the need for greater patient ACCESS to resources and information in order to receive the support they need

.....

ACCESS to care and treatment

Stressing the importance of ACCESS to quality care and treatment for all NET patients.

.....



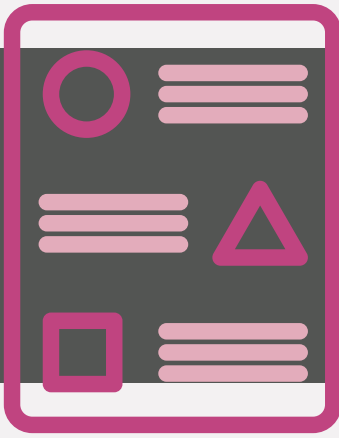
ACCESS to research and funding

ACCESS to more research and funding is required to find a cure for NETs



ACCESS TO INFORMATION MESSAGES

- ACCESS to information in local language is important - NETs are on the rise globally affecting men, women and children at various stages in their life
- ACCESS to media – speaking about a “forgotten cancer” - 7 in 100,000 people are diagnosed each year, with diagnoses on the rise
- ACCESS to innovative solutions - NET symptoms are wide ranging and varied – e.g Gastritis, Irritable Bowel Syndrome (IBS), unexplained anxiety, flushing and asthma-like symptoms
- NET Cancer Day – raising awareness of NETs around the world and highlighting the challenges faced by patients and clinicians around ACCESS
- ACCESS to basic facts - NETs are most often found in lungs, pancreas and gastrointestinal system
- NETs 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
- Children of a parent with Multiple Endocrine Neoplasia (MEN) have a 50% or 1 in 2 risk of inheriting the condition
- Diagnosis of 1 genetic NET syndrome patient often results in the diagnosis of multiple family members



ACCESS TO SUPPORT MESSAGES

- ACCESS to support – the INCA SCAN global survey interim data shows 68% of patients don't have access to a patient support group, 94% don't receive any palliative care, and just 11% get help from a consultant for their psychological needs. Only 33% have a multidisciplinary team.
- ACCESS is about ensuring every NET patient can receive psychological support - over half of NET patients interviewed have not had access to the psychological care that they required
- ACCESS to patient organisations and peer support - greater access to information and promotion of resources by medical experts in partnership with patient organisations are vital

THINK ZEBRA

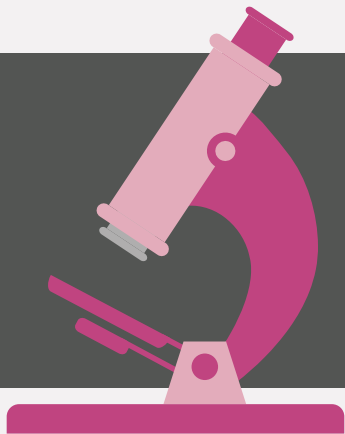
*If you don't suspect it,
you can't detect it.*





ACCESS TO CARE & TREATMENT MESSAGES

- Patients need ACCESS to earlier diagnosis - according to the SCAN global survey interim data, 44% of patients are initially misdiagnosed.
- ACCESS is about having appropriate diagnostic tools available to all patients - almost 50% of patients visit a doctor 5 or more times before receiving their diagnosis
- ACCESS to financial support - many patients are travelling over 300km/186 miles to receive treatment, creating a huge financial and psychological strain on patients and families
- Every GenNET patient needs ACCESS to a centre of expertise - patient access to gold standard diagnostics and treatment on a global scale is vital
- ACCESS is ensuring every NET Centre of Excellence has a dietician as part of their MDT – NETs is complicated, it needs specialist NET clinics and multidisciplinary teams globally
- Patients and clinicians need ACCESS to emerging treatment options
- Patients need ACCESS to a multidisciplinary team
- Patients need ACCESS to a NET specialist
- Patients and clinicians need ACCESS to timely and regular consultations



ACCESS TO RESEARCH & FUNDING MESSAGES

- ACCESS to timely and regular consultations - for the current situation to change, medical professionals need a basic understanding of the unmet needs of NET patients as well as NET symptoms
- ACCESS to new treatments - NET patients need more involvement in research including drug trial design
- ACCESS to clinical trials in NETs - patient and medical communities should support each other to ensure global clinical trials, international registries and increased funding for research and education on NETs
- ACCESS is about proportionate access to research - the rising incidence rate of NETs means more research is needed
- ACCESS to decision-makers to secure more attention to NETs
- ACCESS is ensuring distribution and allocation of research funds to be fair, equal and proportional across all cancer types
- ACCESS to bio-banking by patients for donating blood and tissue

TIP: All campaign messages are adaptable. Modify these messages to suit your local campaign or personal story.



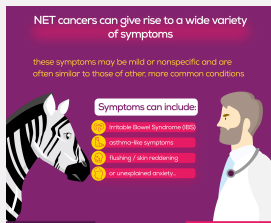
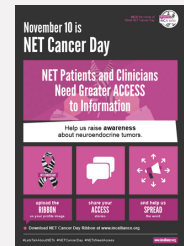
CAMPAIGN MATERIAL

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 posters

Use these posters to help drive home your personal ACCESS messages on social media
#LetsTalkAboutNets



Campaign Infographics

Utilise on social media to help raise awareness and drive the key messages home #LetsTalkAboutNets

NET Cancer Day Ribbon

Download the NET Cancer Day ribbon from our website and set as your profile picture from the 1st of November to help raise NET awareness



Campaign Pins

Make sure you wear your campaign pins on NET Cancer Day and share images of yourself across social media
#LetsTalkAboutNets



SHARE YOUR ACCESS STORIES

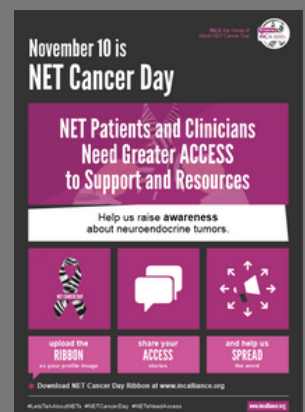
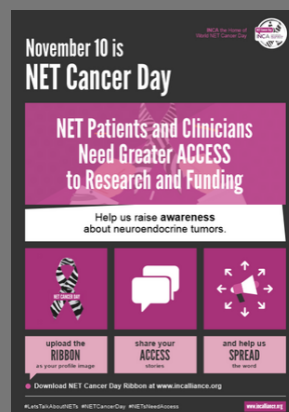
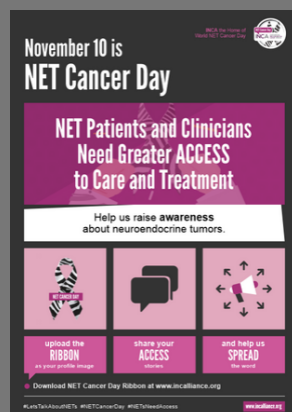
This year we are asking patients and clinicians to share their ACCESS stories across social media.

You can print off one of our downloadable ACCESS posters and take a picture of yourself holding the poster or upload the poster directly onto social media along with your ACCESS story.

"My name is John, I am a NET patient and today I am supporting NET Cancer Day. I believe NET patients need more ACCESS to information so that they feel educated and supported on their NET journey"
#LetsTalkAboutNets



All ACCESS posters can be downloaded via our website:
www.incalliance.org





GET INVOLVED

Last year over 12 million people saw the hashtag #LetsTalkAboutNets and thousands of people updated their Facebook profile picture. In 2019 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. 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 #INCAAlliance

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



CAMPAIGN MATERIAL

NET Cancer Day has been designed to start a conversation about NETs in order to raise awareness about the key issues faced by NET patients. Use the information on pg. 9 of this document to help spread the message far and wide.

USE THE LOGO

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

ASK FOR HELP

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 templates

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.



SOCIAL MEDIA GUIDE

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 thousands edited their Facebook profile pictures with the NET Cancer Day frame to show support.

NET CANCER OFFICIAL HASHTAGS



#LetsTalkAboutNets
#NetCancerDay
#NetCancer
#IncAlliance

FOLLOW US



@netcancerday



@netcancerday



@netcancerday



@inca-alliance

THE MESSAGE HERE: one of the fastest ways to spread the word on NET Cancer Day is via social media.



SOCIAL MEDIA STEPS

Social media is an effective tool to increase the exposure of 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 2019.

1

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
Follow us on LinkedIn: @inca-alliance

STEP 2: SPREAD THE WORD & SHARE YOUR ACCESS STORY

Spread the message far and wide. Tweet, post and hashtag your ACCESS stories #LetsTalkAboutNets on and around November 10.

2

3

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



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 DAY 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 your personal ACCESS story or the pre-generated 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

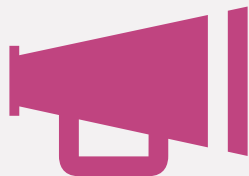


Use twitter to be a part of the conversation in the lead up to NET Cancer Day and to reach out to local politicians, pharmaceuticals and the media in your country.

Top Tips for Twitter

Tag influencers to get their attention

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

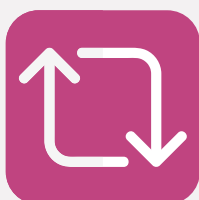
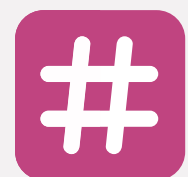


Stay current

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 #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



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 ACCESS 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 audience 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.

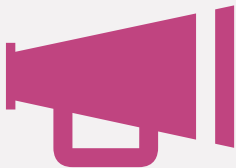
Top Tips for LinkedIn

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 related to NET Cancer Day - such as the INCA unmet needs research and link it back to the key messages

Tag inca-alliance in your post

Help increase our LinkedIn presence and raise awareness around our global brand by tagging @inca-alliance in all of your posts





READY MADE MESSAGES

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

ACCESS to Information Messages

#NETCancer patients and clinicians need greater ACCESS to information in their native language - NETs are on the rise globally affecting men, women and children and information is limited
#LetsTalkAboutNets

Did you know #arethafranklin and #stevejobs died from #NETCancer? #Neuroendocrinecancers need more coverage In the media. We need to speak about this 'forgotten cancer'
#LetsTalkAboutNets

Patients and clinicians need ACCESS to innovative solutions: #NETCancer symptoms are wide and varied and call for better treatments
#LetsTalkAboutNets

#NETCancer 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 #LetsTalkAboutNets

Children of a parent with Multiple Endocrine Neoplasia (MEN) have a 50% or 1 in 2 risk of inheriting the condition. #NETCancer patients need ACCESS to information
#LetsTalkAboutNets

Did you know the diagnosis of 1 genetic NET syndrome patient often results in the diagnosis of multiple family members? NETs need greater ACCESS to information #LetsTalkAboutNets





READY MADE MESSAGES

ACCESS to Support Messages

Fact: Preliminary SCAN results reveal that 68% of patients don't have ACCESS to a patient support group, 94% don't receive any palliative care, and just 11% get help from a consultant for their psychological needs.
#LetsTalkAboutNets

Did you know over half of NET patients interviewed have not had access to the psychological care that they require? ACCESS is about ensuring every #NetCancer patient receives psychological support
#LetsTalkAboutNets #NetCancerDay

Up to a third of patients diagnosed with #NetCancer are not provided with the right information on how to manage their condition. ACCESS means ensuring every NET patient has access to a specialist nurse #LetsTalkAboutNets
#NetCancerDay

#NetCancer patients need ACCESS to more resources from medical institutions, more patient organisations and more peer support. Help us to find ways to build more resources
#LetsTalkAboutNets #NetCancerDay

#NET patients and clinicians require greater #ACCESS to timely and regular consultations #LetsTalkAboutNets
#NetCancerDay

**REMEMBER: Messages have the most impact when paired with an image. All posters and infographics can be downloaded via the website:
www.incalliance.org**





READY MADE MESSAGES

ACCESS to Care & Treatment Messages

Did you know 44% of #NETCancer patients are not correctly diagnosed at first diagnosis? Patients need ACCESS to earlier diagnosis #LetsTalkAboutNets #NetCancerDay

ACCESS is about having appropriate diagnostic tools available to all patients - almost 50% of #NETCancer patients visit a doctor 5 or more times before receiving their diagnosis #LetsTalkAboutNets

Did you know many NET patients are travelling over 300km/186 miles to receive treatment? This creates a huge financial and psychological strain on patients and families – NET patients need ACCESS to financial support #LetsTalkAboutNets

NET patient access to gold standard diagnostics and treatment on a global scale is vital - Every #GenNET patient needs ACCESS to a centre of expertise #LetsTalkAboutNets #NetCancerDay

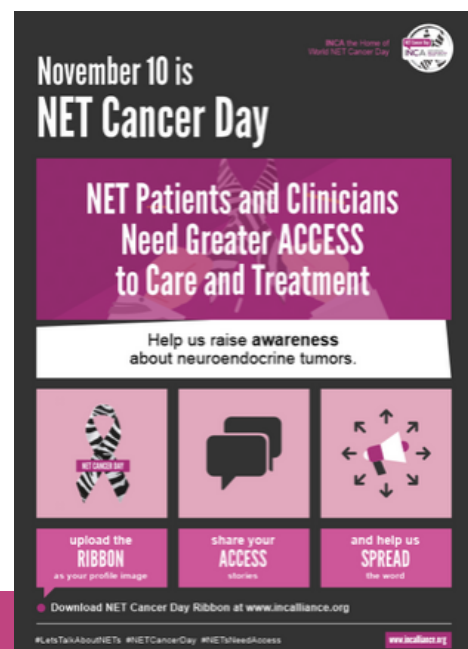
#NETCancer patients need ACCESS to a NET specialist #LetsTalkAboutNets

ACCESS is ensuring every NET Centre of Excellence has a dietician as part of their MDT – #NETs is complicated, it needs specialist NET clinics and multidisciplinary teams globally #LetsTalkAboutNets

#NET patients and clinicians need greater ACCESS to emerging treatment options #LetsTalkAboutNets #NetCancerDay

#NeuroendocrineCancer patients require ACCESS to a multidisciplinary team #LetsTalkAboutNets

#NETcancer patients need ACCESS to palliative care #LetsTalkAboutNets





READY MADE MESSAGES

ACCESS to Research & Funding Messages

#NET patients require ACCESS to timely and regular consultations and medical professionals need a basic understanding of the unmet needs of NET patients and symptoms
#LetsTalkAboutNets

#NET patients need more involvement in research including drug trial design because #NETCancer patients need ACCESS to new treatments
#LetsTalkAboutNets

Patient and medical communities should support each other to ensure global clinical trials, international registries and increased funding for research and education in NETs – overall we need greater ACCESS to NETs clinical trials
#LetsTalkAboutNets

The rising incidence rate of NETs means more research is needed – ACCESS is about proportionate access to research
#LetsTalkAboutNets

#NETCancer patients and clinicians and advocates need ACCESS to decision-makers to secure more attention for NETs and to help raise awareness
#LetsTalkAboutNets #NetCancerDay

ACCESS is ensuring distribution and allocation of research funds to be fair, equal and proportionate across all cancer types
#LetsTalkAboutNets

#NETCancer patients require ACCESS to bio-banking for donating blood and tissue
#LetsTalkAboutNets
#NetCancerDay





READY MADE MESSAGES

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 ACCESS.

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. 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



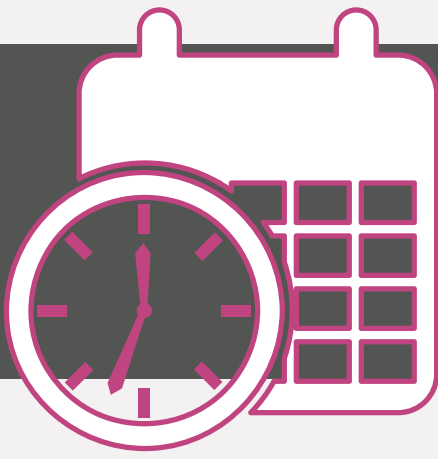
Be consistent with your chosen key message and find local case studies to support it. How do NETs affect your community/country?



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

- Decide and define primary ACCESS campaign messages for your organisation – 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 and media strategies
- NCD involvement benefits to commercial sponsors
- Start posting patient membership engagement messages (refer p.23 of this document)
- Utilise 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)



OCT / NOV TIMELINE

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

#LetsTalkAboutNets

3 WEEKS OUT

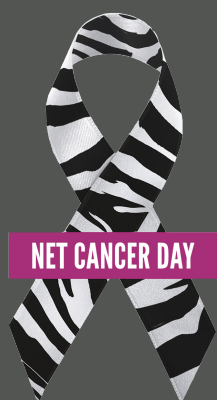
- Reach out to patients and stakeholders via newsletter/database and ask them to show their support/come forward with their stories

- 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

- Update all social media accounts with the official NET Cancer Day ribbon
- Start sharing key messages daily via social platforms. And ask your followers to do the same
- Send out a 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

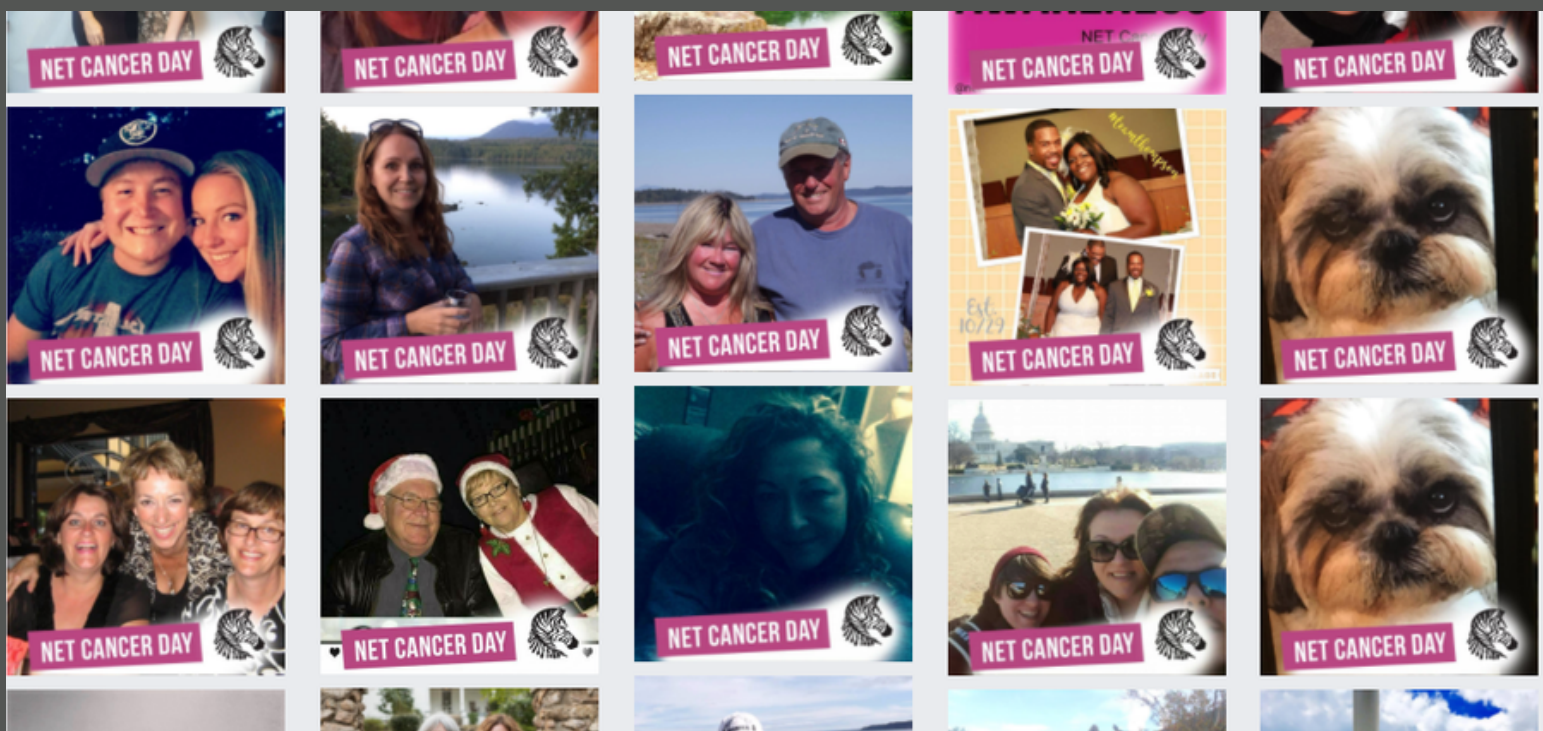
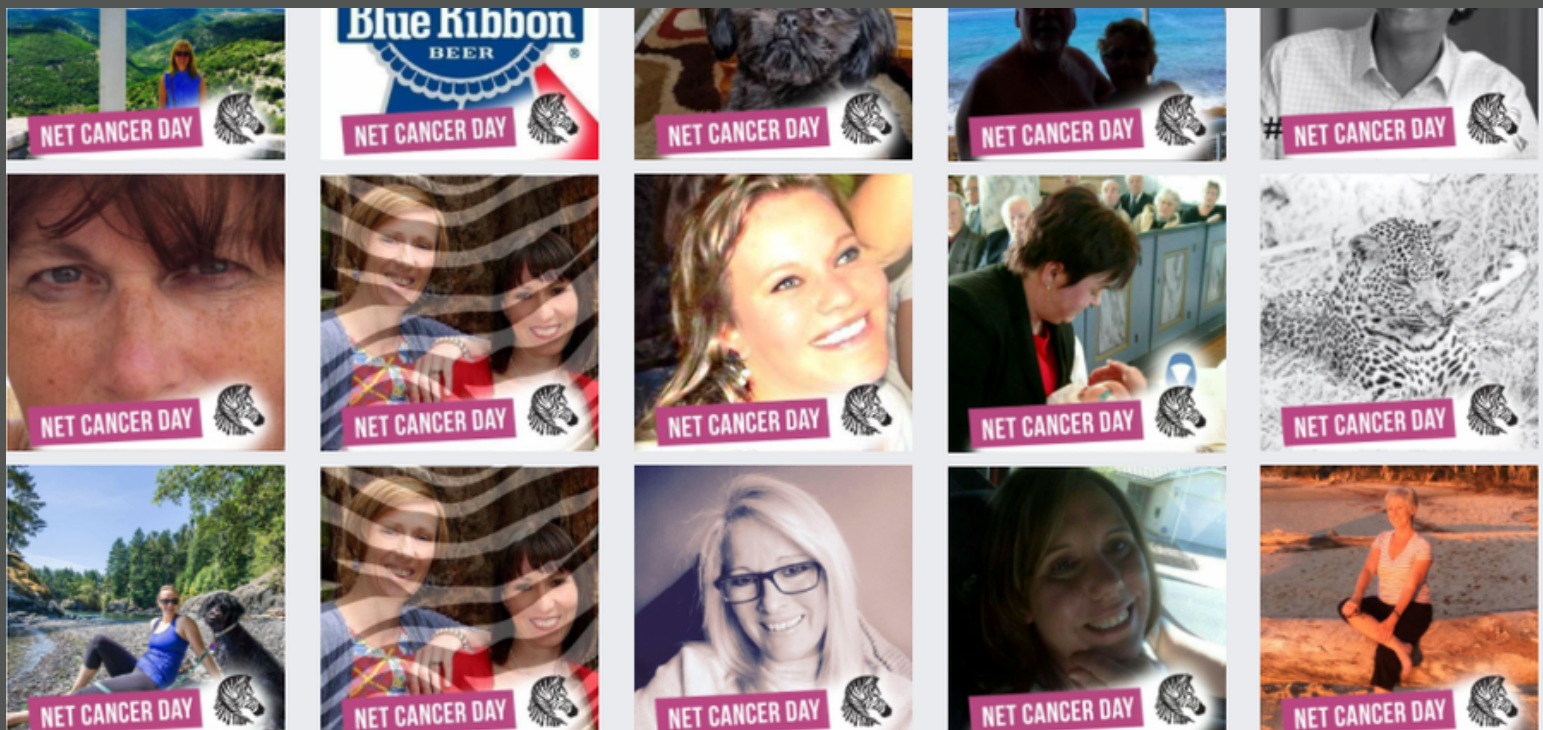
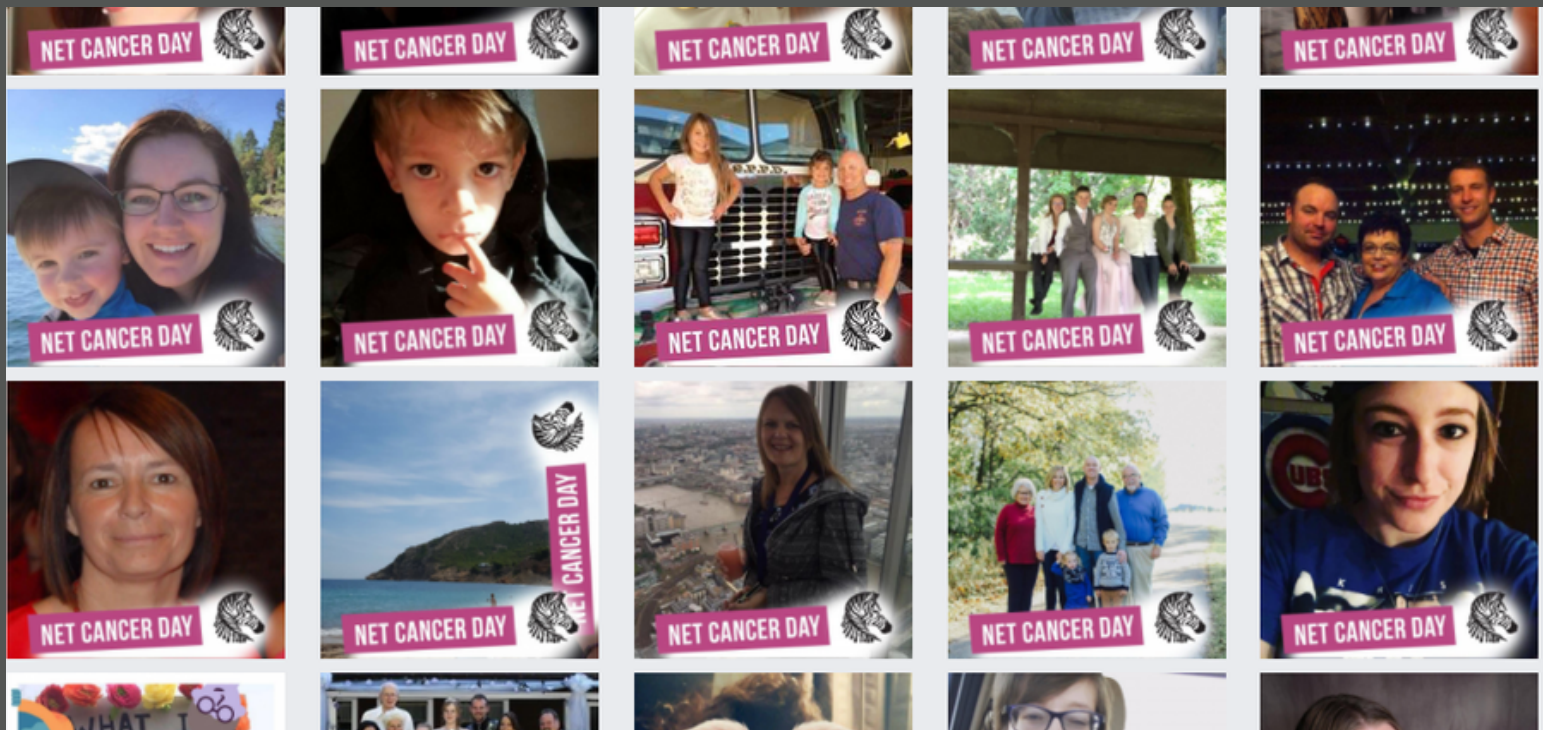
Share any events
and fundraiser
images as they
come to light

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

Get social! And
ask your
followers to
share your
messages

Download the NCD
posters and share
your ACCESS stories
across social media
#LetsTalkAboutNets







THANK YOU TO ALL OF OUR MEMBERSHIP ORGANIZATIONS



#LetsTalkAboutNets www.incalliance.org