

Quarterly Newsletter

JULY 2020 ISSUE 03



VIRTUAL SUPPORT

Zoom Natters, Nurse helpline, and Mindfulness videos - we got you covered!

**BRAND
NEW
WEBSITE!!!**

FACES OF NCUK LAUNCH!

Patients, Families, Healthcare Professionals - all share their story with us

MY PRUDENTIAL RIDELONDON

Take part in the first ever virtual edition of My Prudential RideLondon to support NCUK!



**Neuroendocrine
Cancer UK**

SUPPORTING THE NEUROENDOCRINE CANCER COMMUNITY

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NEW WEBSITE!!!!



TAKE A LOOK AROUND...

Our website has been completely redesigned and restructured in order to make it more user friendly for our community.

It is a continually evolving space and there are some additions still to be made.

Thank you for your support as always.

WELCOME FROM THE CEO



Catherine Bouvier, CEO, Neuroendocrine Cancer UK

Hello!

Welcome to our newsletter! As you read through, you will see that there are multiple components to running a patient organisation. We are a 'small but vital charity' doing a wide range of activities, ensuring that the message we are shouting gets heard across many platforms, with the ultimate goal of working in a truly collaborative way, with compassion, and providing the best care for all affected by Neuroendocrine Cancer.

It has certainly been a trying and testing time over the last few months but we have not allowed ourselves to be beaten. Our Natters have been moved to Zoom and telephone meetings, and we have all still been working every day, from the safety of our own homes. As well as our patient events and face to face meetings, we have taken a huge hit financially - with almost all of our fundraising events being cancelled. As 90% of our income comes from fundraising, we have been working hard to find virtual challenges and events for our community and their supporters to take part in. We thank you all for your continued support.

While things have slowed down in the outside world, we have been hard at work and busily working on launching our [brand new website!](#) Hopefully you'll have had a chance to take a look around the new site and have found the user experience a little more easy to navigate. The website will be continually evolving and a constant dynamic process. Please share any feedback you may have with us.

We hope you enjoy reading our new quarterly newsletter and finding out about some of the things we've been up to here at Neuroendocrine Cancer UK.

We look forward to seeing you all as soon as it is safe to do so.

Take care, stay safe.

Thanks,
Cathy

NEW FACES OF NCUK LAUNCH #FACESOFNCUK

We are delighted to announce the launch of our new Faces of NCUK campaign, and we would love for all of you to get involved!

Around 36,000 people are affected by Neuroendocrine Cancer (NETs) in the UK, with over 5,000 people newly diagnosed each year. That is more than 13 people a day.

For many the first time they will have heard about Neuroendocrine Cancer will be the day they receive their diagnosis.

Faces of NCUK is here for you to be part of a huge community of like minded people, and to share your own thoughts and feelings about Neuroendocrine Cancer. Whoever you are – a Neuroendocrine Cancer patient, a supporter, a friend, healthcare professional or a loved one – you have the power to take action and make your voice count.

By talking about your experiences, you can help us tell powerful stories that raise awareness and create a wider and deeper conversation about Neuroendocrine Cancer across the UK.

People who've shared their story often find it a really positive experience and an opportunity to make a real difference for people living with Neuroendocrine Cancer, and their families.

Whether you are living with Neuroendocrine Cancer, or supporting a loved one who has been diagnosed, we'd love to hear from you.

How can you get involved?

All you need to do at this stage is click on the 'Share your story' button below and answer some questions, giving us as much information as you can and feel comfortable with.

If we need more details, a member of the Stories team will get in touch to have a chat.

If you'd prefer to send your story via email, you can email Clare at Comms@nc-uk.org

Thank you

The NCUK Team

#FacesofNCUK #Shareyourstory

#Yourvoicematters

[SHARE YOUR STORY](#)

FACES OF NCUK

SUPPORTER STORY

March 19th 2018 – my Dad sat my two big sisters and I down and gave us the devastating news of his diagnosis. He had incurable pancreatic Neuroendocrine Cancer which had also spread to his liver. He told us life was going to be a little different now, that we were to stick together like the strong little team my parents had raised us to be and to try and search for the positives in every scary day. I genuinely thought that right there, life was coming crashing down, but somehow, my Dad still had the strength to hold it up. Heartbreakingly, this illness isn't going to go away – but importantly, my Dad is living with it, not dying with it.

There's been too many scary days to count, but two of the most painful were having to walk out the hospital with my Mum and two sisters, leaving my Dad alone in the hospital the evenings before two life-extending operations, we couldn't be absolutely certain that we would get to see him again, based on how life-threatening these operations were. The operations (between them) saw him have around 70% of his liver removed, his spleen removed, gall bladder removed, pancreas reduced, as well as the removal of various tumours. The operations themselves were of course, traumatic. I cried seeing my Dad cry in pain, but I also smiled – so proud – on his first days out of intensive care, first walks up the hospital corridor and of course, being able to walk back out of the hospital with him – these were the kind of positives that my Dad encouraged us to look for in every day. The small steps to others, which to us – were indescribable.

The last couple of years have been really frightening and I've been learning to cope with the high levels of anxiety, but through every scary day, every scary scan and every scary meeting – my Dad and I sing together. At the top of our lungs every night after dinner, I grab my guitar and we jam to our favourite songs – e.g. "My Girl" by The Temptations – and quite simply, it's my happy place.

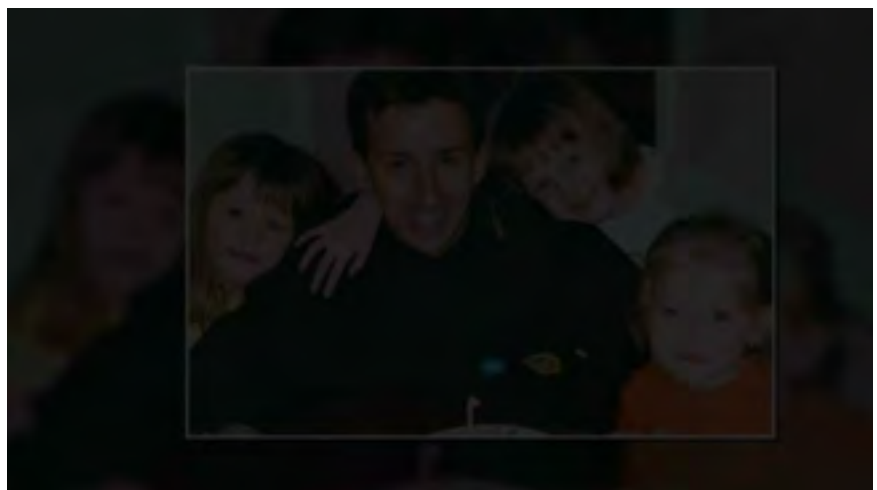
To me, my Dad simply is my hero. To me, he is the strongest man to set foot on earth. He possesses a type of bravery and resilience that I did not know existed, he is positive, fierce and most of all, he has a heart that is made entirely of gold. He listens, he never judges and he stands up for what is right. I wish there were more people like my Dad in this world, so I count myself unbelievably lucky that I get to live life right by his side. He is my source of strength, my widest smile and my loudest laugh. I can only dream of becoming half the wonderful soul that he is, I thank my lucky stars that I get to call him my Dad.

To read Lucy's full story, and other Faces of NCUK stories, visit: [Faces of NCUK](#)

If video doesn't play automatically then please click [HERE](#)



Thank you for sharing
your song with us,
Lucy



"Dad's Song" By Lucy Shaw, daughter and supporter

COVID 19 & MY CARE SURVEY RESULTS



There is a voiced genuine concern regarding the huge impact the Covid-19 Pandemic has had, and will have, on healthcare for patients with cancer.

To understand the impact this has had on the Neuroendocrine Cancer Community, a group often thought of as more chronically than acutely affected, we undertook a survey.

Utilising Survey Monkey, Neuroendocrine Cancer UK's social media platforms, patient database and NCUK website, we sought to obtain a snapshot of the effect this pandemic has had, to date, on patients' healthcare access and psychosocial needs.

The survey offers an insight into healthcare and social impacts of Covid-19 on the Neuroendocrine Cancer Community in the UK.

What is striking is the significant impact in terms of health anxiety and psychosocial well-being that has been felt by this cohort of patients – even for those, who are reasonably well and usually seen less frequently.

Whilst it is reassuring to note that many patients have been able to maintain access to healthcare and contact with their teams, for others there have been delays and cancellations of appointments, investigations and / or treatments – some with no further plans made, leaving them feeling adrift.

[View survey results here:](#)

There are currently around 36,000 people living with Neuroendocrine Cancer in the United Kingdom. It is, therefore, vitally important that in recovering and restoring affected healthcare services, the anxiety and psychological distress that Covid-19 has added to individual's overall psychological burden should not be under-estimated.

MINDFULNESS SESSIONS

AMEND and NCUK Counselling Services have teamed up to offer a series of Mindfulness Sessions.

It can be easy to rush through life without stopping to notice much.

Paying more attention to the present moment – to your own thoughts and feelings, and to the world around you – can improve your mental wellbeing.

Some people call this awareness “mindfulness”. Mindfulness can help us enjoy life more and understand ourselves better. You can take steps to develop it in your own life.

Professor Mark Williams, former director of the Oxford Mindfulness Centre, says that mindfulness means knowing directly what is going on inside and outside ourselves, moment by moment.

“It’s easy to stop noticing the world around us. It’s also easy to lose touch with the way our bodies are feeling and to end up living ‘in our heads’ – caught up in our thoughts without stopping to notice how those thoughts are driving our emotions and behaviour,” he says.

“An important part of mindfulness is reconnecting with our bodies and the sensations they experience. This means waking up to the sights, sounds, smells and tastes of the present moment. That might be something as simple as the feel of a banister as we walk upstairs.

“Another important part of mindfulness is an awareness of our thoughts and feelings as they happen moment to moment.



You can access our full catalogue of Mindful Monday sessions below:

Mindful Monday Session 1 -
Body scan

Mindful Monday Session 2 -
Mindfulness and Sound, what is that?

Mindful Monday Session 3 -
Mindful Habits through everyday activities

Mindful Monday Session 4 -
Mindful Moments - ‘pause and reset’

Mindful Monday Session 5 -
How to Develop Mindful Habits -make time for
yourself

**Many thanks to Mindfulness
Practitioner and Teacher Peter Berry
who recorded these sessions for us
free of charge.**

***“Just remember, it only needs you! Take some time for yourself
and focus on your breathing for mindfulness practice”***

WHATEVER

YOUR WHEELS

REGISTER NOW



The Covid-19 pandemic has had a catastrophic effect on the UK's charities, with the cancellation of thousands of fundraising events and the loss of billions in income.

Many charities have had to reduce or stop services at a time when vulnerable members of society need them most. Thousands of staff have been placed on furlough, and one in 10 charities face bankruptcy, while the sector as a whole faces a funding gap of more than £10 billion in 2020.

Over seven years, the Prudential RideLondon festival of cycling has inspired hundreds of thousands of people to get on their bikes, raising £77 million for thousands of charities in the process.

This year, we can't all ride together, but we can unite for My Prudential RideLondon to celebrate cycling and support Neuroendocrine Cancer UK and the UK's charities.



Get on your bike – or scooter, skateboard, trike, tandem, penny farthing, roller skates, unicycle – to help save the UK’s charities!

The eighth edition of Prudential RideLondon was due to take place on 15 and 16 August 2020, and while the festival can’t go ahead as planned, we want to keep the wheels moving and celebrate the event weekend by encouraging people to get on their bikes – or any other non-motorised wheeled transport! – and help save the UK’s charities in the process.

My Prudential RideLondon is building on the success of The 2.6 Challenge – created following the postponement of the London Marathon – which became the biggest collective fundraising effort in the world, raising more than £11 million and involving nearly 4,000 charities.

My Prudential RideLondon is your chance to take part in the world’s greatest free festival of cycling. Whatever your age or ability, you can join in – wherever you live in the UK and with whoever you like – family, friends or by yourself.

It’s your ride, your way!

Whatever you choose to do for My Prudential RideLondon – cycle 19, 46 or 100 miles, scoot around your local park, or trundle up and down your garden on your trike – help to inspire the nation by sharing pictures or videos of your challenge on social media using the hashtag #MyPRL #NCUK (and please tag us!)

We’d also love it if you could encourage your family and friends to take part too – so why not nominate them to do their own My Prudential RideLondon challenge to support Neuroendocrine Cancer UK?

[**REGISTER NOW!**](#)

[**GET INVOLVED!**](#)



A NEW WAY OF NATTERING



Our 'Natter' Support Groups are local community based or regional online meetings that offer an opportunity to meet others in your area, who are also affected by Neuroendocrine Cancer; you, your family, friends and supporters.

Our groups are facilitated by a fellow patient, NCUK staff or ambassador, Neuroendocrine Cancer Clinical Nurse Specialist and / or local volunteer.

Due to impact of COVID19 pandemic 2020, there have been restrictions on social gatherings – to maintain ongoing support through our groups, we have been, and will continue, to hold our Natter Groups online, until further notice.

If you would like to take part then please contact Nikie for further details - nikie@nc-uk.org

Our Nurse Helpline is still available on 0800 434 6476

If you get our voicemail, please leave your full name and contact details so we can call you back. If urgent or hospital appointment related, please contact your healthcare team or hospital nurse specialist

PARTNER NEWS

INCA is proud to share that the abstract Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) - Usage & Affordability of Nuclear Medicine Tools, a comparative perspective has been accepted as an oral presentation within a featured session for the scientific program of EANM'20, European Association of Nuclear Medicine.

<https://incalliance.org/inca-will-speak-at-eanm20/>

INCA International
Neuroendocrine
Cancer Alliance



Free wills, valuable advice

Make your will with our partners, Bequeathed. Simply follow the steps to create a will online. It's a free service. If you want legal advice at any stage, ask - they'll connect you to a solicitor who'll give you a price to help you complete your will.

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START YOUR WILL



Find out how you can leave a gift in your will to ensure the people and causes you care about are looked after.

Having an up to date Will is the only way to be sure the people and causes you care about are looked after.

With Bequeathed you can make a start on your Will immediately. Simply follow the steps to create a Will online. It's a free service.

Cancer Patients Talk About Their Care

Cancer care was disrupted during the initial days of the Covid-19 pandemic but now services are up and running. But cancer patients are worried about attending. Cancer52 has created a video Cancer patients talk about their care to encourage patients to attend treatments.

The video has been made with the help of Cancer52 member charities who have put forward patients who have had treatment during the pandemic.

You can view the film [here](#)

cancer52
the common voice for
rare and less common cancers

FUNDRAISING

Neuroendocrine Cancer UK is dedicated to providing support and information to anyone affected by Neuroendocrine Cancer. From diagnosis, throughout treatment and beyond, our team and our services are here to offer patients, and their loved ones, with guidance, support, education and information.

We are here every step of the way - whether it's over the phone, on our website or a chat in person. But we couldn't be here without your support. We rely on the generosity and kindness of people like you to provide our vital services to the Neuroendocrine Cancer community.

There are over 5,000 people diagnosed with Neuroendocrine Cancer each year in the UK. It costs us approximately £1,000 to provide all of our support services to one patient for one year. We receive no government funding - all of our services are funded by donations from people like you, through grants and corporate support.

We want to be there for more patients and their loved ones so we know we need to do more, but we can't do this alone.

Your donations, no matter how big or small, will help us to get one step closer to reaching our vision of a world in which people know how to recognise, diagnose, treat, care for and ultimately cure patients with Neuroendocrine Cancer.

Last year our supporters went above and beyond to help raise funds for the charity. Holding danceathons, sponsored walks, hikes, skydives, mudruns, discos, craft stalls and so much more! We are immensely grateful for all of the support.

MAKE A DONATION

Last year we helped more than 3,000 people. By supporting Neuroendocrine Cancer UK with a monthly donation, you can help us to be there for more patients at their time of need. Together, we can make sure that no one faces Neuroendocrine Cancer alone.



Congratulations to Tony who completed the 2.6 challenge. Tony did 400 laps of his front drive, which converted to 6.2 miles!!!! Amazing! We hope you didn't have to replace your front path afterwards!



Thank you Paula and clan for taking part in the 2.6 challenge.

"Yesterday we all took part in the 2.6 'save UK charities' challenge for Neuroendocrine Cancer UK. I'm especially proud of Jack as he not only cycled 5.2 miles with me but he did a further 6 miles with Anthony too! big thanks to all who sponsored us and for all the support"



THANK YOU!

We are thrilled to report that due to your willingness to get involved and the kindness of your friends and family donating to The 2.6 Challenge, we raised over £10,000 for Neuroendocrine Cancer UK!!



"I am running a marathon in my back garden, in ten runs of 2.6m for the #twopointsixchallenge

I have NET cancer, diagnosed in 2012. After a recurrence last year I was no evidence of disease at my last checkup, although my yearly follow up has been postponed due to Covid19.

I'm doing the challenge because I want to help charities, like NCUK, that are supporting cancer patients during these uncertain times. You are needed more than ever now!"

NEWS

The latest Neuroendocrine Cancer news and updates.



A Review of Interventional Radiology techniques in Neuroendocrine Cancer Liver Mets

The purpose of this review is to provide an updated overview of the currently reported intra-arterial embolisation procedures that are used for the treatment of NELM – concluding that whilst benefit has been seen, further studies are needed (to meet the level of evidence/data collation larger randomised controlled trials provide)

[Read full article here](#)



COVID-19 – Shielding Clinical Guidance Explainer

The UK Government has set out a roadmap for the clinically extremely vulnerable on the future of the shielding programme.

For now, the guidance remains the same – stay at home and only go outside to exercise or to spend time outdoors with a member of your household, or with one other person from another household if you live alone – but the guidance will be changed on 1 August, subject to clinical evidence.

[Read full article here](#)



Alternative medicine and thermography: Sean's cancer story

Sean Walsh was 20 when he found out his cancer was back. He'd been in remission for less than two years and was determined that this time round, he would not have conventional treatment. He turned down chemotherapy in the hope that he could cure his Hodgkin's Lymphoma through an alternative approach, including a vegan diet, cannabis oil and coffee enemas.

[Read full article here](#)

If you have any news you'd like to share with us – whether it's about a fundraiser you're organising or Neuroendocrine Cancer in the news, please let us know by [emailing us](#).



**Neuroendocrine
Cancer UK**

(Formerly NET Patient Foundation)

COMING SOON!!!!
([CLICK HERE](#) FOR A SNEAK PREVIEW!)



NCUK VIRTUAL
SUMMIT

NOVEMBER 2020

A free annual event for patients and supporters to learn about all aspects of Neuroendocrine Cancer.