

Quarterly Newsletter

NOVEMBER 2020 ISSUE 04



**NCUK
VIRTUAL
SUMMIT!**

CONTINUOUS SUPPORT

Zoom Natters, Nurse helpline,
and News Pages
- we got you covered!

WORKING TOGETHER CHANGING ATTITUDES DRIVING CHANGE



**NET CANCER DAY
10TH NOVEMBER**

FACES OF NCUK

Jessica Howell and her
wonderful team of Zebras
share their story with us

OFFICE CLOSURE

Sadly our office will be
closed during lockdown -
for the next four weeks



**Neuroendocrine
Cancer UK**

Supporting the Neuroendocrine Cancer community

CONTENTS

1. WELCOME FROM THE CEO
2. LATEST NEWS
3. PARTNER NEWS
- 4-5. NCUK VIRTUAL SUMMIT
- 6-7. FACES OF NCUK SUPPORTER STORY
- 8-9. NCUK NATTERS
- 10-11. OUR WONDERFUL FUNDRAISERS

**THANK YOU FOR ALL YOUR
CONTINUED SUPPORT
DURING THIS DIFFICULT
YEAR**

- THE NCUK TEAM

WELCOME FROM THE CEO



Catherine Bouvier, CEO, Neuroendocrine Cancer UK

Hello!

Welcome to our Autumn newsletter. What a year it's been to date. So much more uncertainty thrust upon so many, but even with all the demands on physical and mental well being, the Neuroendocrine Cancer community spirit has been strong, and we are blown away by the support people are giving to each other, and giving to us. Thank you all for your time, energy and care. A huge thank you also to those who have completed surveys and polls and to those that have fundraised in the most remarkable way over the last few months.

There really are quite a few projects ongoing, and the funds we have received will support those projects directly. For example:

- 'Challenging Barriers to Diagnosis' project,
- MIND The Gap report and recommendations publication,
- NCUK Research campaign
- Commissioning of national Neuroendocrine Cancer services campaign
- New patient materials, videos and podcasts..... and so much more.

Please do visit our [website](#) for further information.

We were so looking forward to holding our first national summit face to face this year, but like so many other plans, we have had to cancel and adapt the meeting to a virtual setting. I truly hope that you find a presentation that is of interest to you. I am fully aware that we have not covered every topic, and have plans to repeat this classroom format in the Spring of 2021, where we can cover such topics as: Carcinoid Heart Disease, Surgery for Lung Neuroendocrine Cancer, Merkel Cell Carcinoma, Pheochromocytoma's and Paragangliomas, High Grade and Neuroendocrine Carcinomas & rarer Neuroendocrine Cancers.

I want to sincerely thank everyone who has taken the time to be part of these virtual classrooms and very much hope that the content can provide some direction in these uncertain times!

Please please do not forget World **Neuroendocrine Cancer Day** on the **10th November**. Share the posts if you are on social media, or just talk about Neuroendocrine Cancer if you are not! Help us all globally to change attitudes towards this disease, get patients the expertise deserved, challenge the continued late diagnosis for so many, and keep the conversation going. November 10th is every day for all those living with these complex neoplasms, and although we only have one day dedicated to awareness, advocacy organisations around the world are raising awareness every day, so please help support if you can.

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.

NEWS

The latest Neuroendocrine Cancer news and updates.



Office Closure

We are really sorry to share that our office will be closed again during this winter lockdown. Our landlords have taken the decision to close the building to keep us all safe so we will be working from home for the next 4 weeks.

We are especially disappointed as our shop was due to reopen with all sorts of new and amazing items, including our new Christmas cards.

This has come as a bit of a blow to us but we must do the most sensible thing and keep everyone home and well.



We would like to ask that if you decide to give to a charity instead of sending Christmas cards this year, please consider NCUK.

Thank you for your support.



Keep checking our **NEWS** page for all the latest updates from NCUK!

As we all know, 2020 has been quite the year, with government announcements, regional lockdowns, and new rules almost every week.

We have been curating our Virtual Summit and creating a NET Cancer Day video, and UKINETS and INCA have also been working on their campaigns for NET Cancer Day.

We continually share any updates we have for our community so please keep checking our news page!

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](#).

PARTNER NEWS

#NETCancerDay

This NET Cancer Day, help INCA to 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.

Follow @NETCancerDay on Facebook, Twitter and Instagram so be part of this amazing campaign, and to do your bit to raise awareness this #NETCancerDay2020

#UKINETS2020

To mark 20 years since the Society's inception, the UKI NETS National conference will be taking place online from 30 November – 3 December 2020. The educational content will be available on demand and free of charge to all UKI NETS members.

Join **UKI NETS** for their 18th National Conference, to increase your understanding of NET therapy, and listen to featured talks by experts from across the NET community!

Register [here](#).



Join in by adding the NET Cancer Day 2020 frame to your profile picture [here](#).



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.

bequeathed

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.

NCUK VIRTUAL SUMMIT

NOVEMBER 2020

6th and 7th NOVEMBER
NCQT 10th NOVEMBER

NCUK FIRST EVER VIRTUAL SUMMIT - THIS WEEKEND!!!

We are so excited to present a weekend-long schedule full of passionate Neuroendocrine Cancer experts, specialists and members of the community, sharing their experience and knowledge through our virtual classrooms!

You can watch all of the sessions or just dip in and out as you please... and all from the comfort of your own home.

This innovative programme will culminate in your very own Neuroendocrine Cancer Question Time (NCQT) - a live event on the 10th November, where you will be able to take part in a dynamic Q&A session - submitting your questions, in advance or on the day, to our expert panel.

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

REGISTER NOW!!

NEUROENDOCRINE CANCER UK

NCUK Virtual Summit 2020

Our virtual classrooms will include the following talks:

- **KEYNOTE SPEAKER:** Professor Martyn Caplin - "Research and Clinical Trials in the UK & Across the Global Community".
- Professor Andrea Frilling "SIRT – Where does this fit into the treatment pathway".
- Amy Eccles - "Treatments Across the Neuroendocrine Cancer Spectrum – Advances and Options in Radioligand Therapy".
- Professor Chrissie Thirlwell - "Genomic Advances in Neuroendocrine Cancer Research".
- Craig Spears - "Working well with your team - dealing with a complex condition and trying to maintain a normal life".
- Dr Christos Toumpanakis - "The Latest Innovations in Diagnostic Tools".
- Professor John Newell-Price - "Hormones, Syndromes and You".
- Professor John Ramage - "Updates on Neuroendocrine Cancer Terminology & Classification – what does this mean for my care".
- Professor Juan Valle - "Treatments Across the Neuroendocrine Cancer Spectrum - Advances in Chemotherapy & Targeted Therapies".
- Kate Quirk - "Understanding Research - reporting back from Bootcamp".
- Kym Winter - "Living with the Uncertainty of It All".
- Professor Mark Pritchard "Spotlight on Gastric Neuroendocrine Tumours/Cancers".
- Mike Tadman "Spotlight on Pancreatic Neuroendocrine Cancers".
- Ronny Allan - "Becoming Your Own Expert".
- Dr Ros Taylor - "Pain Management".
- Philippa Hand - "NET Care in a District General Hospital".
- Dr Raj Srirajaskanthan - "Spotlight on Small and Large Bowel Neuroendocrine Cancers".
- Ryan Barron "Options, Influences and Progress in Surgical Options for Pancreatic Neuroendocrine Cancers".
- Tara Whyand "Myth Busting and Research Needs in Nutritional Care".
- Teodora Kolorova "INCA- The International Approach to Patient Advocacy".
- Professor Was Mansoor "Spotlight on Lung Neuroendocrine Cancers".

FACES OF NCUK

SUPPORTER STORY [Jessica Howell](#)

Notice something different?

12 months have passed and my life has changed in extraordinary ways.

In October 2019 I was diagnosed with cancer. Not a sexy and curable cancer but a crappy and incurable cancer.

It took time but I now take pride in the rarity of my disease. Diagnosed with a paraganglioma (what is that I hear you ask?), a large mass was discovered in my abdomen originating from my adrenal glands. Growing slowly over a number of years the tumour had opportunity to spread and take up home in my lungs, liver and bone.

I'm extremely lucky to sit here writing this today. It turns out the tumour was pumping life threatening levels of adrenaline throughout my body and if left undiscovered a stroke or heart attack was likely on the cards.

Having been told towards the end of 2019 that surgery was off the table and palliative care would begin, I tried to get my head around what this meant for me and those closest around me.

What happened next?

In January 2020 everything changed.

One phone call and what we thought was a routine visit to King's College Hospital later, I was told there was a surgical team willing to try and remove the tumour. There was a chance they would open me up and be unable to do anything. There was a 30% chance of complication (think eating/secretory through a tube or general organ failure) and 10% chance of death.

On January 15th 2020 the surgical theatre was cleared with just one name on the board, mine.

They predicted a complicated surgery, lasting approximately 15 hours. Loved ones were told to go home and wait for the call.

7 hours later they receive the call- the tumour is gone! Turns out it was living in its own sack- there were some challenging aorta cuts but we managed to get it out!

The days that follow are a bit of a blur for me, nearly a week was spent in hospital recovering whilst high on all sorts of painkillers (NOT fun to come off of kids!). Big shout out to the nurses of Copcoat Ward!

Phase 1 complete, I moved into the next stage of treatment- targeted radiation therapy.

A radioactive drug called MIBG is given as an infusion and it's job is to hunt down the cancer and set up

The side effects are rough. You spend 5-6 nights locked in an isolation room in hospital as you're too radioactive to hang with the masses. The nausea slaps you in the face hard, your appetite disappears and I particularly despised the sensitivity to smells. Long term, fatigue is a real thing and my hair has definitely taken a hit- apparently these two side effects will improve over time. There's been a few more but I'll spare you the details.

Treatment 1 took place in March (just before lockdown) and 2 took place in June. I'm thankful Covid-19 did not slow us down. Treatment 3 is scheduled for the middle of November, fingers crossed this can still take place.

Scan anxiety is a thing, each treatment involves a discharge scan to check uptake and between T1 & T2 you can see if any changes have occurred.

For now, they've interpreted the results as stable. My cancer cells are always reproducing which means being told there's no growth is an epic outcome. The MIBG is killing the new cells!

How does the future look?

The radiation kills your white blood cells which are useful for fighting infection- hence why you haven't seen me much during the pandemic! They will slowly restore but the damage to my bone marrow is permanent which means the number of therapies I can have is limited.

I'm in a new phase now and I'm starting to live my life again. With the help of the amazing TYAC Unit at Royal Surrey and the team at King's College London I'll be here today and for many more years to come.

Despite the treatments and lockdown, I've returned to work and even got married in September! The cancer isn't going anywhere but I certainly am!

I was introduced to Neuroendocrine Cancer UK, a charity dedicated to creating awareness and support for those diagnosed with a disease that represents just 2% of the cancer population.

Myself and a group of friends ran the Great South Run in October to mark 1 year since my diagnosis, and help raise funds for this amazing charity. Team Zebra are amazing, a combination of friends, family and work colleagues I was honestly so surprised by how many were willing to sign up and take part with me. Really helped with the fundraising too!

To read Jess' amazing Fundraising story, click [here](#)



A NEW WAY OF NATTERING

This year there have been restrictions on social gatherings, including the ability to hold our Natter groups face to face – so, to maintain ongoing support through our groups, we have been, and will continue, to hold our Natter Groups through zoom*, until further notice.

*with zoom you can join online - through pc, laptop, tablet or smartphone - or by phone... yes even landline!

Find out more about zoom and our Natters - click [here](#)

Joining a support group for the first time can be a bit nerve-wrecking, you may not know what to expect or be worried about being asked to share personal issues with people you don't know. - please don't be worried - the groups are welcoming - and do not expect you to reveal anything you're not comfortable with - it really is a very informal chat with others going through similar experiences - you can speak to Nikie ahead of time by calling the helpline number.

You may find it helpful at the start to simply listen – if you feel comfortable to share your own ideas and experiences please do – but you should never feel coerced or uncomfortable.

Please note : confidentiality and respect for each other's privacy and time to talk or just listen, is an absolute requirement of attendance and continued participation.

Our 'Natter' Support Groups are local community based and 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.

talk feeling listen Care Friends kindness advice
knowing support Learning information
knowledge Help informative
understanding Relief sharing reassurance
People comfort experience friendship

“Because there's nothing more comforting than someone who actually gets it. Really gets it”.

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

In accordance with NCUK's guidance – each group agrees its own format and frequency – and is run as informally or formally as group members agree.

All group members have free access to all NCUK resources and support services

To receive the link or phone number to join your Natter group - visit our Natter Calendar [here](#)

Scroll through the calendar list to find the group you'd like to join and click on 'View Details ' - and you will be able to self-register.

If you are unsure how to join - or would rather join by phone - contact Nikie by email: nikie@nc-uk.org or through our freephone number 0800 434 6476.

If you cannot find a group near you - you can join the one nearest to you and / or the regional group ... as no travel required.

Once we restart face to face meetings we will continue with the regional zoom Natters - and can base any new groups near to where people are.

If you have joined a group and it doesn't feel like a good fit for you, consider joining a different group or a different group format e.g. join us online in one of [Facebook groups](#).

If you don't think a face-to-face support group is appropriate for you, but need support in coping with your condition or situation, you can talk to your specialist team or us about counselling or other types of [help that may be available](#).

It's been an unusual year - but we are still here to help, in whatever way we can - to keep our community connected and support you.

Natter Matters!



#NCUKNatters
#GoodtoTalk



“This group is so friendly and so genuinely caring that people are prepared to talk openly about things they may not have said to anyone else... and I just think that's a wonderful atmosphere that's produced here in the group.”

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.

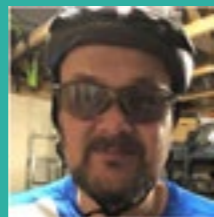


Your donations, no matter how big or small, will help us to get one step closer to reaching our vision of a world in which people know how to recognise, diagnose, treat, care for and ultimately cure patients with Neuroendocrine Cancer.

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.



A HUGE Thank You to Martin Tetlaw for completing the ultimate 'Tour de Garage' cycling challenge for the 2.6 Challenge this year! No mean feat when facing health complications and rearranged events! We salute you Martin!

We want to say a huge Thank you to Emma O'Neill who has chosed NCUK for her Birthday Fundraiser on Facebook this year, in memory of her dear beloved fiance, Enda.

Emma says: "As much as saddens me that we won't make any more new memories, I am eternally grateful for all the ones that we had made so far. It's been his outlook on life that's given me the strength to go on and to continue to do good things in this world.

I don't want Enda's story to be remembered as one of sadness but one of inspiration and determination. To inspire others to be able to face anything that life throws at them with courage and hope no matter the circumstances

I hope this money will go to towards finding quicker diagnosis of NET's and provide better treatments for those livings with it. So if you haven't already please support and share my [page](#)"



A huge thank you to Mike who ran the 2020 London Marathon in memory of his good friend, Phil. Mike raised almost £3500 for NCUK!! Although the official event in London was cancelled, Mike still wanted to complete the challenge so ran the marathon where him and Phil grew up.

"I ran through 5 hours of rain, wind and cold from Watford to Fulham. I set off at 7 am and did continuous running for 5 hours and 3 mins, with exception of puddles (lakes in some places!), kerbs, traffic, traffic lights, people etc. A person was never going to achieve a good time with all these obstacles in the way, plus the weather. For me it was not about time, but finishing and hitting my goal to show my gratitude to those kind sponsors."

Sending the biggest thank you to Heidi, who ran the Edinburgh Marathon (in London) despite it being postponed due to COVID-19. Heidi has raised over £4000 for NCUK!

"Just over a year ago, at what I thought was a routine post operation check up following appendicitis, I got told they had found a cancerous tumour on my appendix, a NET. I was 27 & prior to this, fit & healthy or so I thought. Fast forward many more hospital appointments, tests & tears, in April I underwent a major operation to remove the right side of my bowel. It went well and I made an amazing recovery over a period of months. And then after what felt like a lifetime of waiting, I got the best possible news, a clear PET/CT scan in August! Talking about the race Heidi said:

"I loved it! Well, most of it. From about 34km onwards I wanted to cry!! But I managed it in 3hr59. So I am over the moon! Haven't stopped smiling!"



We cannot thank Kath and her Rambling Potters enough for their continuous fundraising. Every year the Rambling Potters embark on a rambling adventure, usually around Christmas and New Year. The group have raised thousands for NCUK. Here's what Kath had to say about their recent ramble:

"Yes we did it, it was a great day and a great turn out. We did 6.5miles (10.5km), there were a couple of steep bits for me, but I did it! £642 raised, + £153 gift aid, not bad for a nice stroll"

No matter how small, a monthly donation can make a HUGE difference!

Check out our other amazing fundraisers [here!](#)