

Quarterly Newsletter

FEBRUARY 2021 ISSUE 05



VOICES OF NCUK

Our patients share their best tips and advice for managing Neuroendocrine Cancer

NCUK GRANT WINNER

We are delighted to award the 2020 NCUK grant to Dr Marc Ooft, Consultant Histopathologist



**Neuroendocrine
Cancer UK**

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



Thank you!

A big thank you to all of you that took part in our COVID & My Care survey and Barriers to Diagnosis survey. Your input is invaluable and shapes so much of what we can achieve.

Also heartfelt thanks for all of your beautiful Star Dedications.

You raised an amazing £3000 for NCUK!

WELCOME FROM THE CEO



Catherine Bouvier, CEO, Neuroendocrine Cancer UK

Welcome!

I think we can all agree that we're happy to see the back of 2020 and look forward to what will hopefully be a brighter and more 'normal' 2021. So while I'll be glad to leave 2020 behind, we should also recognise how much progress there has been despite the challenges all of us faced. COVID-19 did slow us down, cause disruption, loss and fear, and I have never known a period of time like this, but our staff, our Trustees, our supporters, our partners, our colleagues and the whole NCUK community have all shown such strength, it has provided much needed determination and inspiration to keep going.

However difficult this year has already been and however difficult the months ahead may be, this time of recovery is a chance to reshape healthcare, and indeed society. We may never get a better chance. Here at NCUK we will be making use of this time, to look at how the reshaping and recovery of vital NHS services and resources can include a more informed integration of Neuroendocrine Cancer care to meet the needs of our community, through our Bridging The Gap project.

In addition we will launch our MIND The Gap report, launch the NCUK Academy - a training platform for nurses and allied healthcare professional caring for people with Neuroendocrine Cancers. We will also be hosting a mid year educational summit, a wellbeing retreat and maintaining our focus on the founding pillars of NCUK activity: awareness, advocacy, education, research and support - alongside and in collaboration with our colleagues and partners from the UK and around the world.

Make use of our website and visit our News page for updates and further information on all our activities. We work hard to ensure our website is continually updated and welcome ideas for content you would like to see.

New Year, new starts, new beginnings - Clare (NCUK Comms) and Famida (NCUK Admin) will both be going on maternity leave at the end of February. As they take time away - we welcome in Kate, who will be joining us at the beginning of February to support and help coordinate our Natter groups.

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

Catherine

NCUK NEWS

The latest Neuroendocrine Cancer news and updates.



Welcome Kate Quirk!

We are pleased to announce the appointment of Kate Quirk, as Patient Support / Natter Coordinator for the UK, to work alongside our nurse team.

Kate has been an Ambassador for NCUK for the past 18 months, and has also just completed the INCA Advocacy programme.

Kate will be joining our team to help set up and expand our current coordinators network, and will be responsible for helping set up new local groups and networks and recruiting coordinators around the UK. She has lived with Neuroendocrine Cancer for over 15 years and brings a wealth of patient experience to this currently fast moving cancer arena.



Barriers to Diagnosis Survey Results

The purpose of the NCUK Barriers Survey was to consolidate and add to previous national and global Neuroendocrine Cancer (NC)* patient experience surveys and reports, to gain further insights into the patient pathway for those diagnosed with NC.

From initial symptom, through seeking advice to diagnostics and treatments - does current experience of Neuroendocrine Cancer care confirm the influential factors identified in previous cancer care reports?

At Home in Lockdown: Tips from Rareminds

We've all got used to the saying during lockdown that 'we are all in the same storm, but not all in the same boat.' Some of you will be craving space in a house that feels too crowded, some of you will be craving company and coping with loneliness; there are those who have lost jobs or been furloughed whilst some of you will be working harder than ever. And for each one of you feeling relief at having some time off from hospital appointments, there will be another of you worrying about deferred treatments or scans.

Read full article [here](#)



Nutritional Complications & the Management of Patients with Gastroenteropancreatic Neuroendocrine Tumors

Gastroenteropancreatic (GEP) NETs (GEP NET) are a heterogeneous group of rare tumors that have distinct effects on the body due to their tumor location and potential to secrete hormones and peptides. Clinical practice guidelines and consensus guidelines for GEP NETs with regard to best practice for diagnosis, treatment, and medical management are available, but the supportive care needs and optimal nutritional management of patients affected by these unique tumors remain under-researched: evidence to guide clinical practice is lacking.

Read full article [here](#)



Welfare Grant

We are very aware that there are costs associated with getting to and from hospital appointments, especially for investigations and treatments. We really want to be able to support our community, and have therefore developed a compassionate travel welfare fund. The objective of this fund is to provide financial support to Neuroendocrine Cancer patients and, where required, an accompanying family member, clinical advocate or carer, for travel to expert clinical centres to access treatment related scans and treatments. The request for financial support must come from one of your specialist clinical team and there is a form to complete [here](#).

*This grant was made possible through the support of AAA (A Novartis Company).

Clinical teams will be made aware of this fund. We truly hope that this will provide some relief to those who need it.

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](#).

VOICES OF NCUK TIPS AND ADVICE

Again we find ourselves in difficult times. We anxiously wait for vaccines and are all struggling through yet another lockdown.

For Neuroendocrine Cancer patients, life can sometimes be a struggle with managing treatments and explaining their condition to others. From speaking with our community, we often find the best place to turn to, is each other.

For this reason, we have created a support space where you can share any good advice you have received or some of your best tips for managing your condition.

Whether it be learning how to administer your own injections, or things you've found useful when travelling. Valuable lessons you have learned, or the most useful questions to ask your team.

If it's helped you, we'd love to know about it so we can share it with others.

Visit our '[Voices of NCUK](#)' page to share your advice and read about what some of our patients have contributed, or send in your tips to hello@nc-uk.org



[#VoicesofNCUK](#) [#LetsTalkAboutNETs](#)

PATIENT BLOGS



Beauty & The Big C

Irish Gilmore Girl. Aged 33.
Neuroendocrine Cancer patient.
Incurable but treatable?

Trying to take control and learn about healing my body for better quality of life and survive.



Living the Life of a NET Patient - By Craig Speirs

NCUK Ambassador, 39 year old married father of two, who has been living with Neuroendocrine Cancer for 6 years.



Top 10 Tips for Patients – Coping with Sc-Anxiety by Kate Quirk

One way or another, a cancer diagnosis is life changing.

These top tips can help you cope with upcoming appointments and scans.

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 NCUK. Many of you got involved in the 2.6 challenge which raised over £10,000 for NCUK. You also, took on your own 'socially distanced' challenges. 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.

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

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



A huge thank you to Sophie, who did a 6 HOUR WORKOUT on Facebook, in memory of her brilliant Mum, Rosie.

Sophie has raised over £1700 for NCUK!

Please be sure to give Sophie's fitness page a ['follow'](#)

If you missed out and would like to watch back then you can do so [here](#)

If you'd like to donate to Sophie's challenge then you can do so [here](#)

READY, STEADY, RACE!



Finger's crossed, this could be a fantastic year for fundraising and sporting events.

After all of the postponements, cancellations and rescheduling of so many events in 2020, the next 12 months promises to be memorable.

And with that being said, NCUK have the following charity places available for 2021 races - including our second ever place in the **London Marathon!**

As with many of these races, there is huge demand for a place, so do [sign up soon](#) if you can.

We are hugely aware of the effort that goes into taking part in one of these events, so thank you!



1 x London Marathon
3rd October 2021



5 x Great Birmingham Half Marathon
10th October 2021



5 x ASICS London 10K
25th July 2021

ZOOM NATTERS

As we head in to 2021 there are still 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

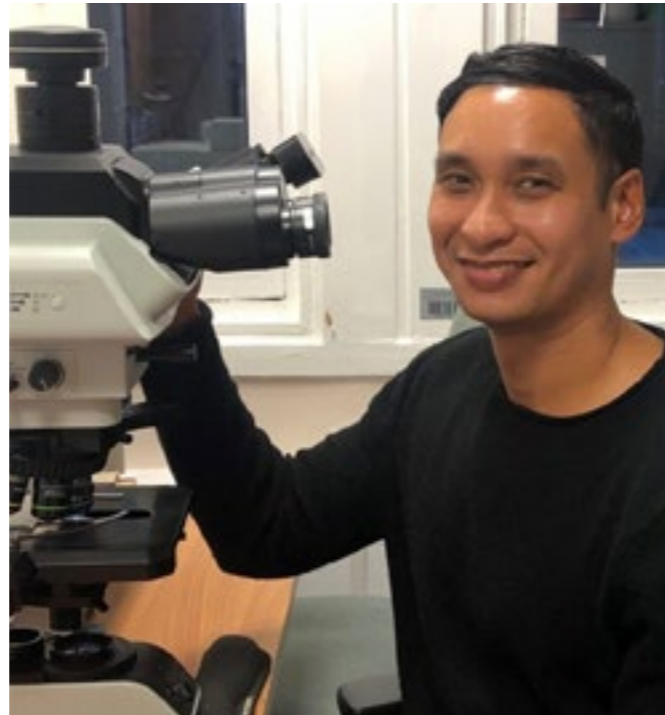


“This group is so friendly and so genuinely caring that people are prepared to talk openly about things they may not have said to anyone else... and I just think that's a wonderful atmosphere that's produced here in the group.”

NEUROENDOCRINE CANCER UK GRANT WINNER

We are delighted to award the 2020 NCUK grant to Dr Marc Ooft, Consultant Histopathologist, Kings College Hospital.

His research alongside the NET GeCIP group is focusing on 'Improving patient stratification through epigenetic and tumour microenvironment analysis of the 100,000 Genomes project Neuroendocrine tumour cohort.'



Dr Marc Ooft, Consultant Histopathologist, Kings College Hospital.

The **100,000 (100K) Genomes Project** was delivered as a transformation project across the NHS and was the largest undertaking of whole genome sequencing (WGS) globally in routine clinical care.

WGS is powerful in that it can identify many genomic aberrations. The NET (neuroendocrine tumour) GeCIP was formed to analyse and interpret WGS data produced from 130 NET cases recruited through the 100K project.

Analysis of the cancer arm of 100K genomes legacy data has identified that whole genome sequencing identified a potential therapeutic target or clinical trial in 50% of cancer cases. We know that NETs have a very low background mutation rate and few mutations which can be actioned upon potential therapy.

However, epigenetic alterations (which are alterations outside of the genome) are significantly more common than mutations in NETs with DNA methylation found in >70% of NETs in different subsites. We therefore set out in this proposal to augment the 100K WGS data by performing epigenetic and tumour microenvironment (alteration in the environment of the tumour itself) analyses in order to improve patient stratification and potentially identify novel therapeutic approaches.

Through the work outlined in this project genetic and epigenetic correlations with histopathological predictors of malignant behaviour will be determined.

Genetics is the study of heritable* changes in phenotype (an individual's observable traits, such as height, eye colour, and blood type), caused by permanent DNA changes within a particular gene.

Epigenetics is the study of heritable* changes in phenotype without permanent change to the DNA of the gene.

The overall aim of this project is to further our understanding of the genetic and epigenetic changes in conjunction with detailed histopathological assessment and clinical annotation.

Elucidating the gaps and inconsistencies in our (epi)genetic knowledge of NETs will help to improve patient selection for treatment (stratification) and prediction of outcomes (prognostication) of said treatment.

This will lead to future work culminating in the development of standardised genetic and epigenetic markers for NETs to aid prognostication and optimise stratification of patients being considered for novel immunotherapy and other targeted therapies.

*Heritability is a measure of how well differences in people's genes account for the differences in their traits.

**To make a
donation to
our clinical
fund, please**



PARTNER NEWS

The Neuroendocrine Tumor Research Foundation (NETRF) announced that a \$1.2 million grant has been awarded to UCL and the Royal Free Hospital (RFH).

The Collaborative Petersen Accelerator Award has been given to our Patron Professor Martyn Caplin, to study mesenteric fibrosis in neuroendocrine tumours originating from the small intestine. Caplin will deliver this project alongside UCL's Professor Krista Rombouts, and in collaboration with Dr Richard Feelders team at Erasmus University Medical Center, Rotterdam.

This collaborative project will explore the underlying molecular cause of mesenteric fibrosis, as well as develop new diagnostic and imaging tools to treat mesenteric fibrosis associated with small intestinal neuroendocrine tumours.



#WorldCancerDay every 4 February is the global uniting initiative led by the Union for International Cancer Control (UICC). By raising worldwide awareness, improving education and catalysing personal, collective and government action, we're working together to reimagine a world where millions of preventable cancer deaths are saved and access to life-saving cancer treatment and care is equal for all - no matter who you are or where you live.

This year's World Cancer Day's theme, 'I Am and I Will', is all about you and your commitment to act. We believe that through our positive actions, together we can reach the target of reducing the number of premature deaths from cancer and noncommunicable diseases by one third by 2030.



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