

Quarterly Newsletter

JUNE 2021 ISSUE

A BIG THANK YOU TO ALL OUR FUNDRAISERS!



REACH NEW HEIGHTS

Sign up to the NCUK Skydive Fundraiser!

NEW PATIENT & HCP RESOURCES

Site-specific factsheets now available on our website and to order

NCUK ACADEMY NURSE COURSE

CPD accredited course, 'by nurses, for nurses'



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To keep up to date with NCUK news, please visit [our website](https://www.neuroendocrinecancer.org.uk)

A special thank you to all our donors, past and present!

Every donation helps us to continue supporting anyone affected by Neuroendocrine Cancer from diagnosis, throughout treatment and beyond.

For more information on how you can support NCUK, please visit our [website](https://www.neuroendocrinecancer.org.uk)



WELCOME FROM THE CEO

Hello!

I need to start with a huge thank you to our amazing community for all of their support, not only through the challenging times of lockdown, but also as this year is progressing. Some fantastic fundraising initiatives have taken place or are being planned, and all of the money raised, supports not only our major projects but our services too. We only exist because of your generosity and efforts.

For 2021/22 our two biggest projects are focused on 2 of our pillars; advocacy and education. Our education project is an NCUK Academy that we hope to launch in July 'by nurses, for nurses', and our GP training modules, in collaboration with the Royal College of GPs (RCGP), is to be launched later this year. Our advocacy pathway project is a multi-stakeholder project with contributions from patients, healthcare professionals, supporters, industry and (we hope) the NHS, to develop of a clear pathway for the Neuroendocrine Cancer patient, following their unique path and highlighting points of vulnerability, because there is no doubt that pathways matter.

This month's newsletter covers lots of other activity too, from our Voices and Faces of NCUK Campaign, the launch of the new My NETs App, spotlights on research and patient stories. It is a powerful tool in our armoury to highlight the experience of the Neuroendocrine Cancer community, so a sincere thanks to all of those who have taken the time to share. We also say hello to 3 new Ambassadors in the newsletter – Welcome! Our Ambassadors are really remarkable individuals who are pushing for change and raising awareness of this complex cancer. This week is actually 'volunteers week' so it is a great opportunity to acknowledge their unwavering contribution, alongside our trustees, natter coordinators and medical advisory board, who have all helped drive us in the right direction.

As always, do feedback any comments you have and remember your voice is at the heart of our work.

Cathy



If you have any news you'd like to share with us, please let us know by [emailing us](#).



NCUK SHOP

We're pleased to announce that the NCUK online shop is now open and stocked full of amazing new products!

We have carefully chosen products that are useful in everyday life or simply beautiful and fun to wear whilst promoting your support for NCUK.

Visit our shop [here](#)



NEW RESOURCES

In order to provide further support to those affected by Neuroendocrine Cancer we have been working hard on producing a range of factsheets which provide in depth information about NENs, from Duodenal to Thymus.

Our patient information packs will also be available again with updated Neuroendocrine Cancer UK branding and these will be free to order.

Please visit either our [patient information page](#) or [HCP page](#) to order.



'MY NETS' APP

'My NETs' is a new disease-specific App that can be utilised by anyone affected by Neuroendocrine cancer.

It can be used for day to day information gathering such as symptom tracking, managing and storing health details, (such as blood and other test results, diet and medications, appointments, etc.)

Visit our website, [here](#) for further information and to download.



TRAVEL GRANT

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](#)



NCUK ACADEMY NURSE COURSE

We are thrilled to announce that Neuroendocrine Cancer UK will be launching a CPD accredited NCUK Academy Nurse Course; 'by nurses, for nurses' in July 2021.

Nurses can register their interest [here](#)



STAFF UPDATES

We are pleased to introduce our new administrator, Beth Chesser who is covering Famida's maternity leave. She will be working alongside Leanne, Cathy, Nikie and Kate during what is turning out to be a very busy year for NCUK!

In other staff news, congratulations to Clare and Famida for giving birth to beautiful baby boys!



SPOTLIGHT ON PARAGANGLIOMA FACES OF NCUK

[CLICK HERE TO READ MORE STORIES FROM THE NCUK COMMUNITY](#)

'PURSUING A PARAGANGLIOMA'

Looking back now, all the pieces fit together. However, at the time it was entirely a different story.

Initially, I noticed a distinct whooshing sound in my left ear. But I hadn't had any previous ear problems before so wasn't overly worried.

But I did have an anxiety issue and this was accompanied by facial and neck flushing.

My symptoms continued for a couple of months and initial thoughts were a possible cold or congestion so I just let it play out. But when this continued I decided to visit my GP Surgery.

They assured me it was just a build up of wax and I should have my ears syringed, which they arranged. And they said facial flushing due to anxiety was common amongst many people.



At the time I felt both relief and distress, it was a very strange concoction of emotions.



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 visit our ['Faces of NCUK' page](#) where you can 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.

#FacesofNCUK #LetsTalkAboutNETs

Although the syringing improved my hearing, the whooshing noise continued albeit at a slightly lower frequency – with the wax build up potentially causing the whooshing to appear louder.

And the flushing continued. I repeatedly sought medical advice via my GP on numerous occasions, to be told the same thing time and time again. But after several months my partner convinced me that I should request a transfer to another GP Surgery, which I did. And I booked an appointment almost straight away to get a second opinion on the noises and sensations in my ear.

After discussing my situation, the new GP referred me to a specialist at my local hospital. I had an examination and discussed my symptoms, and although the doctor wasn't concerned he had picked up on my anxiety and facial flushing issue which I was displaying.

He offered me an MRI to rule anything sinister out and in his words: to "put my mind at ease." But he also mentioned a particular word which I wasn't familiar with. It sounded like he'd said "shwannoma."

Obviously I was curious and anxious so did what many of us do, some online investigating!

I wanted to be prepared for anything that could be confirmed as I mentioned I have suffered from anxiety from a young age and I just had a gut feeling that something was being overlooked.

I had an MRI in December which came back inconclusive. They then repeated the scan in late January. A week or so later, I received an appointment with an ENT specialist.

This for me was a red flag. I knew something had been found and I prepared myself by researching everything I had experienced and words I had heard along the way.

The ENT specialist confirmed that a 'Paraganglioma' had been identified in my neck skull/base area on the left side. By now, I was already pretty toiled-up with knowledge! In fact, the doctor was slightly taken a back at how I knew what a Paraganglioma was.

At the time I felt both relief and distress, it was a very strange concoction of emotions.

I left the appointment feeling overwhelmed and frightened as to what this meant from every aspect of my life going forward and after telling my family, I felt very alone.

I've got lots of friends but this was something I couldn't discuss with them as my diagnosis is so rare and unheard of.

I also asked my hospital team if there were any groups or support services and they provided me with a leaflet. This enabled me to seek some counselling

services and it was from this I learnt about online communities, forums and social media pages.

I'm quite savvy with technology but I'd not been on Facebook due to personal reasons. I decided that in order to access the support group, I need to set myself up with an account and get talking about my experience and diagnosis to seek ongoing support.

It was from this that I found Neuroendocrine Cancer UK's Facebook page and I applied to become a member. I was accepted and instantly felt a rush of relief, I had found a place where I could talk openly.

Since then, I have chatted with people from all backgrounds with various different stories to mine which are both interesting and helpful. This was what I needed: a space to freely discuss symptoms, feelings and worries without having the anxiety attached to seeing people face-to-face.

Neuroendocrine Cancer UK's support group is an incredible source of advice and sense of belonging to me. I am extremely grateful that this was available at a time where I felt at a loss with my place in the world.

Christina



VOICES OF NCUK



'YOU ARE STILL YOU'

BY KATH LEWIS



Being diagnosed with neuroendocrine cancer tips life upside down (as will any type of cancer diagnosis). It can take a long time to come to terms with, and not only is it a confusing and complex cancer, few seem to have heard of it either.

Furthermore, its a cancer that you know is probably incurable, which can in turn can have a big impact on your mental health; it can leave you feeling very alone and isolated, and you may even question if You are still You anymore?

When word gets round, you may notice that some people look at you and treat you differently, mainly I think because they are unsure of how to react,. It scares them too.

But what do you see when you look at yourself? What do they see when they look at you? You haven't changed as a person, you may have lost some weight, you may have gained some; you may have had surgery, you may not; you may be taking a whole medicine cabinet of drugs everyday, you may not. Nevertheless, one of the most important things to remember in all this is that You are still You.

There are good days and bad days that can take many forms both physically and emotionally, and which can arrive quite unannounced with their own additional challenges. Still, the person having to deal with these challenges is essentially the same person you were before diagnosis, dealing with everything that life throws at you in its own inevitable way, and often you will need additional help to do this; and if you do don't be afraid to ask for it either.

Through it all though remember, You are still You, and yes some people will fall by the wayside as you travel on this part of your life's journey, but those who stay also see that essentially You are still You too.

In the words of Brené Brown – "Owning our story and loving ourselves through that process is the bravest thing we'll ever do."

Kath Lewis

We always want to hear from people who have a story to share.

[Click here to join the campaign!](#)



REACH NEW HEIGHTS!

NCUK SKYDIVING 2021 CHALLENGE

On the 12th & 26th September 2021 we will be taking on our biggest challenge yet, and we'd love for you to be a part of it.

Our aim is to raise £100,000, so we need as many people as possible to take on the ultimate skydiving challenge! Knowing our community and your bravery, we are sure that we can reach easily reach our target.

For more details including how to sign up, **[please visit our website.](#)**



RUN FOR NCUK

Looking for a running challenge? Why not run for Neuroendocrine Cancer UK?

NCUK have places in the following races, so what are you waiting for! For more information and to register your interest, please **[visit our website.](#)**

LONDON MARATHON

3RD OCTOBER 2021

ASICS LONDON 10K

25TH JULY 2021

GREAT BIRMINGHAM RUN

10TH OCTOBER 2021



NATTER News Updates

Our patient Natter Meetings continue to be held on Zoom and we hope to resume face-to-face meetings in the Autumn (subject to Government guidelines, venue regulations and, importantly, group attendee preferences).

We have also started supra-regional Natters - these have started and will remain on-line - and are for all, anyone and everyone affected by Neuroendocrine Cancer, especially those who may not have a local group or have difficulty attending one - [see Natter Calendar](#) for all group meeting listings.

Have you ever wondered what gets talked about at a Natter Support Group?

Parrots, PRRT, Flushing, Specialist Centres, Hormones, Knitting, Emotions, Toilets, Anxiety, Humour, Diabetes, Scans, Loss, Fatigue, Happiness, Clinical Trials, SIBO, Work, Nature, Specialist Care, Exercise, PERT, and...

Whether you're newly diagnosed or have been living with Neuroendocrine Cancer for some time, do come along to our friendly supportive meetings. You may learn something new and it's not always about Neuroendocrine Cancer - it's about you.

It's an opportunity to chat with others, those who 'get it' and build your own network of support and friendship.

[Visit the calendar](#) to see which date and time suits you best - click "View Details" and follow the link to self-register - we hope to see you there.



It gives you the control back... that's one thing you lose when you're diagnosed.

You try and get back the self confidence you lose, you think 'I'm sick' then you get into a group like this and you start to gain a bit of self-management back.



A few highlights...



One of the most striking things has been the laughter...yes we've cried, talked about all manner of things, but...yes laughter has been a big part...some of my friends don't get that...that we laugh at these groups...

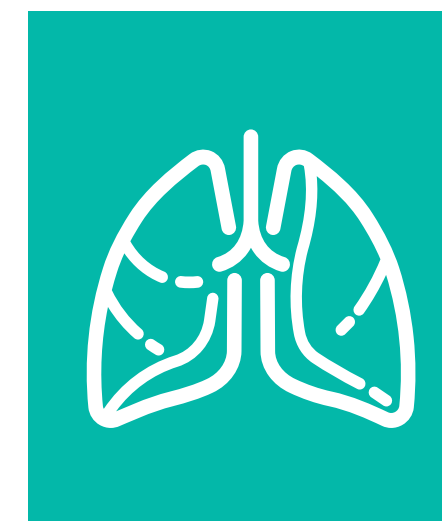


Online Support Group Goes From Strength to Strength

Did you know we now have more than 800 members on our Facebook Neuroendocrine Cancer UK Support Group? It's a truly supportive (and private) environment for all to share tips, experiences and knowledge.

If you'd like to join our online community - visit us [here](#) for further details.

We also have a group just for Friends & Family and one for our wider International Neuroendocrine Cancer Community - Friends of NCUK.



NEW Lung Neuroendocrine Cancer Natter, launched June 1st

If you have been diagnosed with Lung Neuroendocrine Cancer or DIPNECH, why not come along to our Lung Specific Natter. The next scheduled date is on 20th August at 6pm on Zoom.

Visit the [Natter Calendar](#) and "View details" to self-register.



Monthly Injections - Sandostatin LAR / Olutaton

Recently those previously on [Sandostatin LAR](#) have noticed they are now getting [Olutaton](#).

[Olutaton](#) is equivalent to [Sandostatin LAR](#), both are long-acting Octreotide, but [Olutaton](#) is produced by generics company TEVA. So same drug - with same effectiveness, with [Olutaton](#) proving to be more cost-effective.



NCUK Grant Awardee Update

Each year, Neuroendocrine Cancer UK offer a research grant to the UK's medical research community, and we publish an update on the work undertaken and projects achieved by our Grant Awardees. This month, we're featuring an update by Mark Pritchard – Professor of Gastroenterology at the University of Liverpool and Head of the Department of Cellular and Molecular Physiology. Prof Pritchard is also a great supporter of NCUK and you will often see him taking part in our Educational Events for patients.

Understanding How Type I Gastric Neuroendocrine Tumours Develop Prof Mark Pritchard, University of Liverpool. Research Grant 2014 & 2019 Awardee Project Update

There are three main types of neuroendocrine tumour (NET) that develop in the stomach. The commonest type (type 1) develops in patients who have an autoimmune condition that results in destruction of the acid producing (parietal) cells in the stomach. Many type 1 gastric NET patients also have pernicious anaemia and require regular vitamin B12 injections. As a result of their stomachs producing little or no acid, these patients have very high levels of a hormone called gastrin in their bloodstream and it is this hormone that is believed to be responsible for the development of type 1 gastric NETs.

The long term outlook for most patients who have type 1 gastric NETs is very good. The majority of patients have small tumours and don't actually need any type of active treatment. However a minority of patients have larger tumours and these may need to be removed either via an endoscope or by surgery. In 2010-4 we conducted a clinical trial involving eight patients in Liverpool and eight in Norway to test a potential new tablet treatment for type I gastric NETs (funded by Trio Medicines Ltd). If successful, this might mean that in future some type I gastric NET patients might be able to avoid surgery. The new drug (Netazepide) blocks the effects of gastrin. The trial showed promising results with a shrinkage in the size and number of the tumours in many patients and the treatment also resulted in no serious side effects^{1,2}. Trio medicines Ltd are still working on the development of this drug, so at the moment it is not available for general prescription.

In 2014, we were awarded a research grant by Neuroendocrine Cancer UK to investigate how Netazepide was exerting its effects in these patients. We used stomach biopsy samples that had been taken before, during and after the patients on this trial were being treated with Netazepide. We found that only 12 genes showed significantly decreased expression when the patients were taking Netazepide. One of these genes called pappalysin or PAPP-A2 was particularly interesting. This gene encodes a protein which is an enzyme that regulates how much of a growth factor called insulin-like growth factor is present in the stomach. We performed several additional experiments which demonstrated that this signalling pathway appears to both be important during gastric NET development and in determining how these tumours respond to Netazepide treatment. As well as increasing our scientific understanding about type I gastric NETs, our research has at least partially explained how Netazepide works and it also provides opportunities to design other potential new drug treatments for type I gastric NETs in the future.

The results of our study were published in the scientific journal 'Cellular and Molecular Gastroenterology and Hepatology' in 2020 and are available online to read by anyone who is interested³

In 2019 we were awarded another grant by Neuroendocrine Cancer UK to try to grow gastric NET cells in the laboratory in order to be able to test the effects of potential new treatments before actually giving these drugs to patients within a clinical trial. This research is still ongoing and we hope to provide an update about our findings in due course.

For information about Neuroendocrine Cancers of the Stomach - [click here](#)



Research update ↴

1. Moore AR, Boyce M, Steele IA, Campbell F, Varro A, Pritchard DM. Netazepide, a gastrin receptor antagonist, normalises tumour biomarkers and causes regression of type 1 gastric neuroendocrine tumours in a nonrandomised trial of patients with chronic atrophic gastritis. PLoS One. 2013;8(10):e76462.
2. Boyce M, Moore AR, Sagatun L, et al. Netazepide, a gastrin/cholecystokinin-2 receptor antagonist, can eradicate gastric neuroendocrine tumours in patients with autoimmune chronic atrophic gastritis. Br J Clin Pharmacol. 2017;83(3):466-475.
3. Lloyd KA, Parsons BN, Burkitt MD, et al. Netazepide Inhibits Expression of Pappalysin 2 in Type 1 Gastric Neuroendocrine Tumors. Cell Mol Gastroenterol Hepatol. 2020;10(1):113-132.

We have participated in a number of educational webinars and initiatives over recent months - as a result we have re-formatted the [research section of our website](#) and will shortly be adding a list of current UK, European and Global trials - a testament to the drive and commitment towards better understanding of Neuroendocrine Cancers - their accurate diagnosis, treatments and improvements in care.

An emerging topic, that has been simmering in the background for a while, is that of the impact advances in Genomics

"Genomics is the study of all of a person's genes (the genome), including interactions of those genes with each other and with the person's environment."

For an explanation of the difference between DNA, gene, chromosome and genome and how they fit together - [this great article by Gabriella Beer helps explain.](#)

In April we provided an update on Genomics : [100,000 Genomes Project – and beyond!](#)

In June we will be looking at "Terminology and Real World application" of what has been learned to date

For now 2 key findings are already influencing care : DPD deficiency and gene-fusions.

Gene fusion occurs when a piece of the chromosome containing a gene breaks off and joins with a gene on another chromosome.

In **NTRK gene fusion** - the (TRK) proteins associated with this gene are involved in cell growth, behaviour and cell survival. NTRK gene fusion can disrupt the normal protein processes and lead to uncontrolled growth of cancer cells.

NTRK gene fusions are uncommon but have been found in more than 25 different types of cancer - including neuroendocrine.

In those positive for NTRK gene fusion there may be benefit from NTRK gene fusion targeted therapy - no matter what type of cancer they have.

"The development of specific fusion protein inhibitors, such as larotrectinib and entrectinib, could revolutionise the diagnostic and treatment pathway of those with these kind of gene fusion alterations."

Garrido et al (2021) Clinical and Translational Oncology - [the scientific consensus paper can be found here](#)

One current trial utilising gene-fusion targeting therapy is STARTRK-2 - A study of **Entrectinib** (RXDX-101) for the treatment of patients with solid tumours that harbour an **NTRK1/2/3**, ROS1, or ALK **gene fusion**. [NCT02568267](#) (Global) - click link for more trial information.



WELCOME TO OUR NEW AMBASSADORS!

PUBLICATIONS



MAXINE

Maxine is the newest addition to the NCUK Ambassador team.

Maxine is 74 and previously a Deputy Head Teacher, but her first love is teaching English.

When Maxine retired, she became involved in the U3A in her local area where she established two Book Groups, a Creative Writing Group and a Photography Group!

We're so happy to have Maxine on-board as our Ambassador and look forward to her creative input into our work.

To read Maxine's story, [please visit our website.](#)



MARTIN

Martin has recently joined NCUK as an Ambassador and we are so glad to welcome him to the team.

Martin has over 30 years of consultancy experience and is looking forward to utilising these skills to assist with the various reviews and projects planned for the team.

Also keep an eye out for Blogs / Vlogs where Martin plans to share his experiences as a long-term Pancreatic Neuroendocrine Cancer patient.



SIMON

Simon joined NCUK as an Ambassador in April and we are so pleased that he has joined the NCUK team.

Simon is 38, husband to Amy and father to three girls.

Previously a Senior Vice Principle in secondary education, Simon was diagnosed with Pancreatic Neuroendocrine tumours in 2018.

We're grateful to have Simon's expertise and experience in the NCUK Ambassador's team.

To read Simon's story, [please visit our website.](#)

We're delighted to highlight some very important publications discussing various aspects of Neuroendocrine Cancer.

The first of which, we are proud to say is written by NCUK's very own, Cathy and Nikie.

'Patient perspectives, from diagnosis through treatments and beyond'

The purpose of this review is to reflect on the current patient experience of Neuroendocrine Cancer (NC) from the prediagnosis stage to identify recommendations that will provide quality care through patient centred decision-making.

[CLICK HERE TO READ THE FULL PUBLICATION](#)

'The Role of Patient Support Groups in Neuroendocrine'

The purpose of this review is to establish the role patient support groups play in NENs.

[CLICK HERE TO READ THE FULL PUBLICATION](#)

'Neuroendocrine liver metastasis from the small intestine: Is surgery beneficial for survival?'

The aim of this study is to evaluate and compare the overall long-term survival of patients with siNENs with and without liver metastasis at initial diagnosis and the possible benefit of surgical treatment as compared to active surveillance of metastases.

[CLICK HERE TO READ THE FULL PUBLICATION](#)

'Lung carcinoid tumors with Diffuse Idiopathic Pulmonary NeuroEndocrine Cell Hyperplasia (DIPNECH) exhibit pejorative pathological features'

Diffuse Idiopathic Pulmonary NeuroEndocrine Cell Hyperplasia (DIPNECH) is a rare disease often associated with carcinoid tumors. We aimed at evaluating the impact of DIPNECH on characteristics and prognosis of patients who underwent radical treatment of pulmonary carcinoid tumors.

[CLICK HERE TO READ THE FULL PUBLICATION](#)

DID YOU KNOW?

The NCUK was co-founded by patients, for patients. Our ambassadors work with us on a variety of projects maintaining the patient-centric ethos that underpins everything we do.

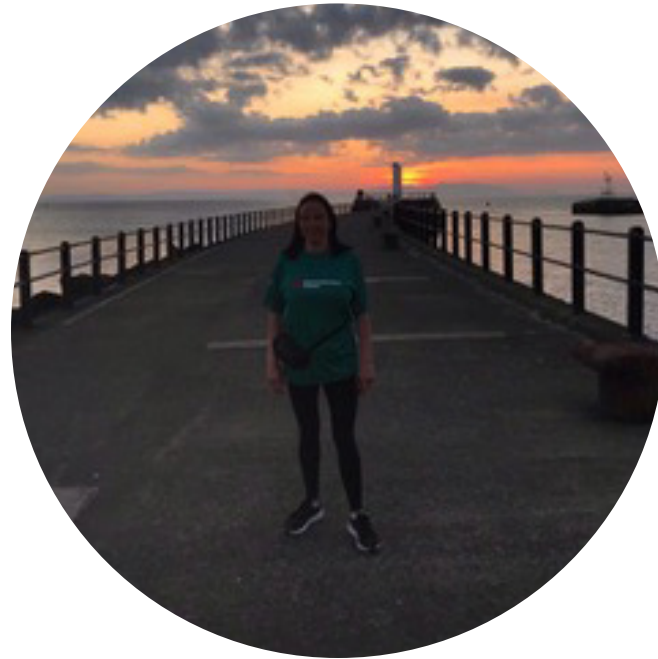
You can read more about all of our Ambassadors [here](#) and if you would like to express your interest in becoming an NCUK Ambassador, please complete [this application form](#).

SPOTLIGHT ON FUNDRAISING

Although we are only half way through 2021 we have already had some amazing fundraising efforts from our supporters.

We'd like to take this opportunity to highlight the amazing fundraising work that our community undertakes in support of all those affected by Neuroendocrine Cancer.

Highlighted here are just a few of our amazing fundraisers but to see all of those who have fundraised for us in the past, please visit our [website here](#)



Shona - 26 mile Scottish Kiltwalk

Please join us in thanking Shona who in April, took on The Scottish Kiltwalk and 26 miles in one day. Shona took on this challenge for her dad who was diagnosed with a Neuroendocrine tumour at the end of last year.

Shona raised over £800 for NCUK!

Thank you Shona, you are amazing!

In Memory of Darrel

NCUK would like to take this opportunity to acknowledge the incredible fundraising and awareness raised by Darrel Amrani-Roshier who sadly passed away in April 2021.

Over the past year Darrel has been tirelessly raising awareness of Neuroendocrine Cancer, even featuring in Vogue Magazine. He has supported other patients through his Instagram page, and during March Darrel organised a nationwide fundraising event which raised over £14,000 for NCUK.

Our thoughts are with Darrel's friends and family at this time.



Lily - cycling 100 miles for NCUK

Lily is cycling 100 miles in May and has already raised over £1000 for NCUK!

Here's why Lily is fundraising for us:

'Just over 5 years ago my nan was diagnosed with a rare form of cancer - Neuroendocrine cancer. This has been stable until recently and she is now under going treatment.

Even with treatment my nan's cancer will never be cured. This affects her daily life in so many ways but she just keeps fighting.



Not only does she suffer from this but she also suffers from carcinoid syndrome which only 30% of people with neuroendocrine cancer have.

My nan is my best friend and a true inspiration to me. Which is why I have decided to cycle 100 miles through May to help fund the research that is needed to help fight this rare cancer but also give cancer patients the support and information they need.'

[Click here to visit Lily's fundraising page](#)

Thank you Lily - You are amazing!!



Moira and Arthur - 10,000 steps

Moira and Arthur raised over £1400 for NCUK by walking 10,000 steps during March this year.

**Thank you Moira and Arthur
You are amazing!**

**THANK YOU
TO ALL OUR**

**AMAZING
FUNDRAISERS!**