

QUARTERLY NEWSLETTER

SUMMER 2023 - AUGUST

21 YEARS OF SUPPORTING
THE NEUROENDOCRINE
CANCER COMMUNITY



Neuroendocrine Cancer UK

Incorporating The Ann Edgar Trust 

INSIDE THIS ISSUE...



SPOTLIGHT...
READ DAVID'S STORY
INSIDE THIS ISSUE



PATIENT PATHWAY
GOES TO
PARLIAMENT!



READ ABOUT ADVANCING
NEUROENDOCRINE
CANCER RESEARCH

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Our quarterly newsletters include information and updates on the key pillars of work that Neuroendocrine Cancer UK focuses on. These include: **ADVOCACY AND AWARENESS, RESEARCH, EDUCATION, SUPPORT AND FUNDRAISING.**

We'd like to take this opportunity to thank our generous community for their ongoing donations and fundraising. Please do continue to support us in whatever way you can so we can keep offering our services and supporting the neuroendocrine community, we are so grateful to all the donations we receive as without them we wouldn't be here! Please remember, we're always here to offer guidance and support so please do get in touch:

Fundraising Support: hello@nc-uk.org
Helpline: 0800 434 6476
General Enquiries: 01926 883 487

All other contact details and opening times can be found on our website here:

<https://www.neuroendocrinecancer.org.uk/contact-us/>

DONATE



WELCOME TO OUR SUMMER NEWSLETTER

2023 has been a very special, if not challenging, year for Neuroendocrine Cancer UK - this newsletter covers some of the core activities and special campaign work we have undertaken - thanks to your support.

It's a special year because, 21 years ago, on the 11th of June 2002 we first registered with the Charity Commission as "Living With Carcinoid" - a 'kitchen-table' organisation - made up of a small group of like-minded individuals, all affected in some way by Neuroendocrine Cancer. All determined to help and support others facing the challenges this diagnosis can bring. All coming together to raise Awareness, promote Research, Educate, Advocate and Support. These 5 pillars - or areas - of activity we continue to work on.

Over the last 2 decades, despite no central or government funding, we have raised our collective voice, collaborated, communicated, challenged and campaigned... culminating, this year, in our most ambitious, challenging, but achievable, target-setting ever :

- **a UK wide implemented pathway for those with Neuroendocrine Cancer**
- **a £50k Fundraiser to Advance Research in this field**

Our grass roots activities remain true to those 2002 aims - our Support & Information Services, remain available to anyone affected by Neuroendocrine Cancer - and remain free to access.

Our new group therapy programmes have started and preparations are already underway for this year's World Neuroendocrine Cancer Day.

...THANKS TO YOU...

whether you have donated, fundraised, shared your expertise or experience, taken part in a working group, survey, information review, or given us a grant! **Thank You.**

And to our co-founder and CEO Catherine Bouvier-Ellis - from inspiration to action, from kitchen table to now - tirelessly continuing to push, strive and advocate for anyone and everyone affected by Neuroendocrine Cancer - **Thank You**

Beth, Clare, Famida, Jackie, Kate, Leanne, Lex, Lisa, Nikie and Olivia.

P.S do keep an eye on the website and/or our social media platforms, to find out more about what we're up to and how YOU can get involved.



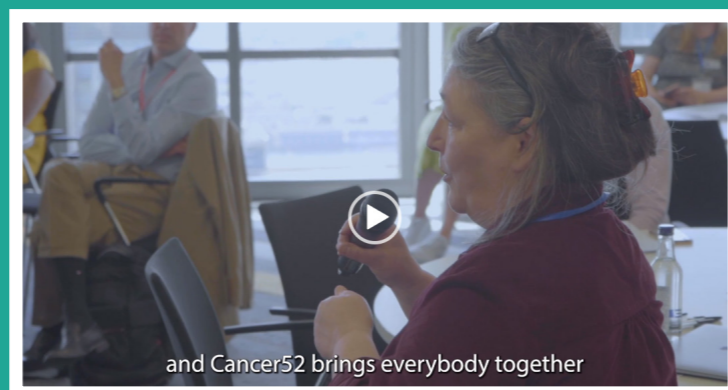
Recently the team has been involved in a number of initiatives and activities - with several more planned to take place before the end of the year. Read on for a peek 'behind the scenes!'

NET MASTERCLASS

In May, Nikie, our senior nurse (Support Service & Education Lead) took part in a NET Masterclass in London, where she spoke about the "Patient journey to diagnosis and treatment" - and at Cancer 52 all members meeting, she was invited to talk about "Radioligand Therapy" - the implications not just for those with neuroendocrine cancer, but how it is also being trialed for use in other cancers. She gave the opening talk "NCUK and patient perspective" at UKINETs "NETs for Newcomers" programme - a one-day course, run annually, for trainee Doctors, Consultants, and specialist Allied Health Professionals in all disciplines, wishing to gain confidence in the diagnosis, investigation, and management of patients with neuroendocrine tumours (NETs), in a multidisciplinary setting.



The Big Cancer52 Conversation on Wednesday 14th June brought together leaders from the charity, healthcare and pharmaceutical sectors, to share best practices, exchange ideas and explore collaborations, with the ultimate aim of improving outcomes for people with rare and less common cancers. The day was structured around three 'big conversations'; sessions geared towards finding solutions to challenges faced by people affected by rare and less common cancers. Critical to the day were the networking sessions, to connect with peers and potential partners. As a member of Cancer52, Nikie (our Support Services Lead) from Neuroendocrine Cancer UK, attended: "a chance to both contribute and learn". **Click the image below to watch the Cancer52 video: the eagle eyed amongst you may spot Nikie, asking questions, taking notes but also jotting down suggestions to add to the 'working' boards!**



and Cancer52 brings everybody together

NEUROENDOCRINE CANCER UK TURNS 21!

Over two decades ago, our journey began with a humble helpline operating from Catherine's kitchen table. On 11th June 2023, we continue to stand tall as a beacon of support for thousands of patients and their families across the UK who are affected by neuroendocrine cancer. We want to express our deepest gratitude to our CEO, Catherine Bouvier, who has been our organisation's driving force from the beginning. Alongside co-founders, Peter Gwilliam, Liddy Oldroyd, Andy Geach, and Cathy Kalamis, Catherine's visionary leadership has transformed their dream of making a difference into a reality. In honour of this remarkable milestone, Catherine has recorded a heartfelt video that takes us on a reflective journey through the past 21 years. Her words beautifully capture the passion, dedication, and unwavering commitment that has propelled Neuroendocrine Cancer UK to where we stand today. **Click the image below to watch on the Neuroendocrine Cancer UK website.**





NCUK NEWS



SOUTH WALES NET SERVICE

On Monday 17th June, Nikie visited Cardiff, to take part in the South Wales 'NET' Service Stakeholder meeting: another great collaboration between patients, healthcare professionals and service management to support the drive to excellence in care, led by Dr Mo Khan, across Mid & South Wales, for those affected by neuroendocrine cancer.



UK MRT CONSORTIUM

In July, Nikie caught up with fellow members of the MRT Consortium Steering Committee. The MRT Consortium is an alliance of clinicians and patient advocates formed with an overarching aim:

'To support equitable patient access to and safe delivery of evidence-based theranostic MRT across the UK and provide a multidisciplinary forum for all relevant stakeholders engaged in MRT to advance research, knowledge and policy engagement on MRT across the UK.'

MRT = Molecular Radiotherapy: this includes both diagnostics e.g., PET scans (both FDG and Gallium68Dotatate) and treatments e.g., Lutetium177, Yttrium90, MiBG therapy and SIRT (Selective Internal Radiotherapy). MRT may be used in other cancers

Previous projects worked on with members of the MRT Consortium, BNMS, and Royal College of Radiologists, alongside the Health Policy Partnership, include addressing system readiness for Radioligand Therapy, in the UK - and with an International perspective.

[CLICK HERE for further information](#)



Neuroendocrine Cancer UK is excited to announce a partnership with RareCan to help grow cohorts of people with neuroendocrine cancer, empowering them to share data and information about their cancer, and in turn, help drive research to enable improvements to treatment and outcomes in the future.

RareCan is a digital health company, building a community of members who are willing to share information about their cancer. It gives power to patients building cohorts, so that researchers can find them in a keystroke. Established in 2020, RareCan also offers a suite of tools, co-designed by its members, to help support them and manage their lives as they live with their rare cancer.

RareCan makes it much easier for researchers to find people who are diagnosed with neuroendocrine cancer each year and gives this community the opportunity to say they are ready and willing to take part in research.

[CLICK HERE for further information about RareCan](#)

You can hear Andy Hall, Chief Scientific Officer at RareCan speak to our Campaigns Lead, Lisa in our latest 'Not Just NE Cancer Takeover Podcast' which is part of the Advancing Neuroendocrine Cancer Research campaign. [Click here to listen](#)

To read about the Advancing Research Campaign, [click here](#)

FIFE SPECIALIST NURSES GROUP

As we head towards August, NCUK 'Talked Neuroendocrine Cancer', with the Fife Specialist Nurses Group, coordinated by Kerry Russell, Upper GI Cancer Nurse Specialist NHS Fife & QNIS 2023 selected candidate.

The group includes specialist nurses working in a variety of settings including **NHS Fife's Rapid Cancer Diagnostic Service (RCDS)**.

"It was a great opportunity to discuss Neuroendocrine Cancer with dedicated healthcare professionals outside of specialist centres who are starting to see, diagnose and treat more and more people with a NET or NEC and who want to know more, to further develop their practice and support strategies for their patients"

UKONS AOS EDUCATIONAL WEBINAR

On Wednesday, 12th July, NCUK presented at the UKONS AOS Educational webinar 'Acute Oncology - the rarer cases part 2: "Neuroendocrine Neoplasms - not just NE Cancer". UKONS members can watch the full webinar by logging into the [website here](#)

FOR ALL THE LATEST NEUROENDOCRINE CANCER NEWS AND UPDATES, CLICK HERE TO VISIT OUR WEBSITE

NEUROENDOCRINE CANCER: AN IDEAL PATIENT CARE PATHWAY



Addressing inequities in diagnosis, care and support.

Neuroendocrine cancers, also known as neuroendocrine neoplasms (NENs), are a diverse group of cancers that have been increasing in incidence and prevalence across the world.

Despite this increase, and the presence of **14 accredited Centres of Excellence across the UK**, there are barriers in accessing faster accurate diagnosis and expert informed specialist care, treatment and follow up.

Our National Health Service is devolved: each nation has it's own population priorities and healthcare needs, and each nation has it's own Health and/or Cancer Plan.

We have started our journey to implement the Ideal Pathway, across the UK, with NHS England. Our next steps include not only incorporating each devolved nation's cancer plans into the pathway to meet each nation's specific requirements but also piloting the pathway in a number of Integrated Care Boards across England: to support UK wide implementation.

[READ MORE ABOUT THE PATHWAY HERE](#)



Neuroendocrine Cancer: patient pathway goes to Parliament!

On 14th June 2023, Neuroendocrine Cancer UK, alongside The Health Policy Partnership and a group of dedicated supporters, travelled to Parliament to share the neuroendocrine cancer: ideal patient care pathway with MPs.

The day was commenced by Rt Hon Justin Madders MP who spoke about the frustrations and struggles of living with Neuroendocrine Cancer in a 'pathless world', given the experience one of his employees and Neuroendocrine Cancer patient Kerie, had shared with him.

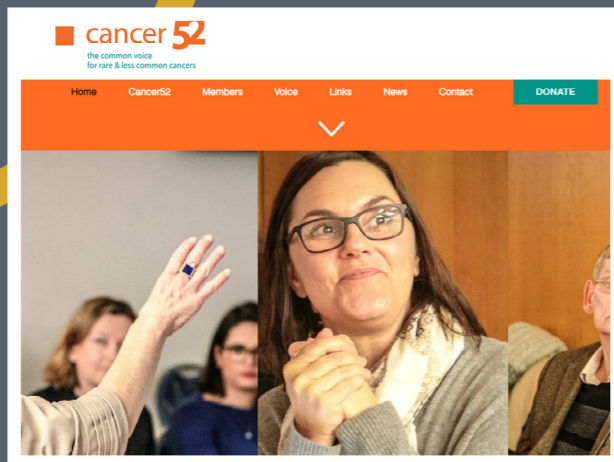
Catherine Bouvier shared an overview of neuroendocrine cancer, various treatment options and the challenges faced by those living with neuroendocrine cancer. She spoke passionately about the pathway, highlighting that 'the time to act is now'.

Actor Olivia Williams gave a personal account of her struggles in obtaining a correct diagnosis, and the difficulties in accessing appropriate care.

Consultant Endocrinologist and UKINETS Education and Training Committee Chair Dr Alia Munir discussed how establishing a standard care pathway for neuroendocrine cancer could benefit everyone living with the condition while still supporting the NHS's current ambitions and practices.

Throughout the event, MPs were able to prompt change by signing a pledge to support people with neuroendocrine cancer and push for the implementation of the ideal care pathway in their constituencies. A total of 11 MPs pledged their support. We thank each and every one of you!

[CLICK HERE TO READ THE FULL ARTICLE ABOUT THIS IMPORTANT DAY](#)



CANCER 52

Represents over 100 predominantly small patient support group cancer charities, including NCUK, united by their vision of seeing a better future for everyone affected by the rare and less common cancers, which account for more than half of all cancer deaths in the UK. Its aim is to promote improved diagnosis, treatment, and support for those affected by rare and less common cancers.

Catherine (pictured) is a member of Cancer 52's Charity CEO working group and Nikie is involved in 2 of Cancer 52's current working groups addressing specific issues that run across rare/uncommon cancer diagnoses: the "IBS" labelling of symptoms and the impact of menopause - alongside or due to cancer and its treatments.

UKINETs

UK and Ireland Neuroendocrine Tumour Society came about in the year 2000 with a meeting of UK and Ireland neuroendocrine experts. At the time there was little interaction amongst the specialists, with people working within their own small teams to manage these incredibly complex conditions. The UK-NETwork was created to meet these challenges, evolving into professional society we see today - leading on research and clinical practice development to improve the lives and outcomes of those affected by neuroendocrine cancer.

Neuroendocrine Cancer UK works closely with UKINETs, with many members graciously giving their time and expertise to sit on our Multidisciplinary Expert Advisory Board. We, along with patient community members, also collaborate in reviewing and co-producing patient information: for research and innovative practice initiatives, for example, the Liver Transplant in Neuroendocrine Tumour Pilot Programme. Catherine and Lisa, sit on committees within UKINETs - and work on cross-reaching projects.



MAJOR CONDITIONS STRATEGY

June was rounded off by a submission to the UK Government, in response to their 'Call for Evidence' to inform their Major Conditions Strategy : we also supported and collaborated in the submission, as a collective, by Cancer 52.



FACES & VOICES OF NCUK SILVER LINING FOR LUNG NET PATIENT

David

Diagnosed in 2016, Lung NET patient, David Wright, reports back on successfully starting PRRT (Peptide Receptor Radio Nuclide Therapy) in June 2023:

‘So far, I’m feeling well, after my first cycle of PRRT. The bouts of tiredness, usually one a day, have receded to the point that I now just take a short break if I feel tired, rather than a nap. There have been no other side effects to the treatment. No nausea at all (which I had been prewarned about). I understand this can also be a result of the amino acid drip to protect my kidneys. My only other reaction was to the steroid tablets which I stopped after one day of a five day course as I simply did not need them.

I am so glad I managed to access this treatment and am immensely grateful to the team at Guy’s for their highly professional approach



Background:

Following a right sided lobectomy in 2016, and annual surveillance (CT scans with contrast), I showed recurrence in 2019 at several sites including liver, bones and some lymph nodes but not in my lungs. Four weekly injections of Lanreotide kept this under control for a further 3 years but slight progression was then noticed following a Gallium-68 Dotatate PET scan. I was offered Everolimus (Afinitor) but also discussed with my oncologist the possibility of PRRT, after learning more about this treatment option at ‘Natters’ (patient support groups). He wrote to Guy’s Hospital London, and the ball started rolling.

“Because of licensing issues, Guy’s only treat 3 or 4 Lung NET patients a year with PRRT. Also, they are extremely cautious in selecting patients who are able to withstand the treatment. So I underwent a kidney function test using a radio tracer and some radiotherapy to my spine to reduce the effects of “flare”, which is when the tumours swell as the Lutetium 177 starts to attack them.

“The whole process of getting started with PRRT took over 9 months, mainly because of the highly cautious approach. But I am so glad I managed to access this treatment and am immensely grateful to the team at Guy’s for their highly professional approach. Five weeks after the treatment I feel well and am not at all anxious about the next cycle which is in September 2023. Incidentally, my Lanreotide injections have continued, with care taken that they followed the PRRT so as not to interfere with its action.

“Silver lining ... this picture was taken the day before my PRRT started - pre-assessment day. I took the opportunity to visit the Royal Arsenal at Woolwich in the morning. I’m still smiling!”



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

Our ‘Not Just NE Cancer’ stories and experiences page is a safe space for those who wish to share their story and a place for anyone affected by Neuroendocrine Cancer to access real-life experiences and advice from those who have experienced it first-hand.

Each year in the UK, around 6,000 people are diagnosed with a Neuroendocrine Cancer – and the incidence is rising. Despite this increase, in a recent survey of more than 200 people with Neuroendocrine Cancer, less than 5% had heard of it... until they were directly affected by it.

You may be one of those people who have never heard of Neuroendocrine Cancer... you may have been told it is rare. You may feel isolated and afraid.

Here you will learn that you are not alone.

Continue reading to browse and watch stories by Neuroendocrine Cancer patients, who have bravely shared their experiences of how they became ill, their treatment, and their road to recovery. Many of the blogs offer support and handy hints and tips about topics such as; preparing for treatment, or how to care for a loved one with Neuroendocrine Cancer.

We warmly invite you to join our community by sharing your own story, as your experiences can inspire and support others on their pathway with Neuroendocrine Cancer.

[Click here to read stories from our community](#)
[Click here to share your story](#)

ADVANCING NEUROENDOCRINE CANCER RESEARCH



Research is the cornerstone of progress in the medical field, and the Advancing Neuroendocrine Cancer Research campaign aims to address the unique challenges neuroendocrine cancer patients face. Due to the rarity of the disease and low awareness, patients often miss out on crucial funding opportunities, hindering the development of innovative treatments and care options.

“We at NCUK are so excited about the possibilities of this campaign,” said Campaigns Lead Lisa Walker. “We are determined to make a meaningful impact on the lives of neuroendocrine cancer patients by supporting quality research that will enhance their well-being and provide hope for the future.”

Our ambitious two-pronged approach will be the driving force behind the campaign’s success. Firstly, we aim to fund at least three practice-changing grants each year. These grants, open to healthcare professionals, seek to discover practical solutions that can make a tangible difference in the lives of neuroendocrine cancer patients within 12 months. These grants will address critical needs and improve patient experiences, from group therapies to post-surgery protocols.

Furthermore, the campaign will allocate resources to “big question” research, tackling fundamental issues surrounding neuroendocrine cancer. This research will focus on unravelling the causes of the disease, genetic implications, reducing delays in diagnosis, and exploring innovative treatments and management options. By working with larger research organisations, we aim to unlock significant breakthroughs in understanding and treating neuroendocrine cancer.

To support this campaign we are using our ‘Not just NE Cancer Takeover podcast’ to explore more about research by interviewing the researchers and organisations that are involved in research to understand why it’s done, the different types and why it’s so important to progress of any condition.

LISTEN TO OUR EPISODES HERE

To support the Advancing Neuroendocrine Cancer Research campaign, you can donate by texting **NCRESEARCH** followed by your donation amount (NCRESEARCH10) to 70085. Text NCUK followed by your donation amount to 70450 to support the work that we do and our services.

For those passionate about the cause and eager to get involved, Neuroendocrine Cancer UK encourages you to reach out to campaigns@nc-uk.org. Your support, ideas, and resources drive the campaign’s success and foster a vibrant community of advocates.

Stay updated with the latest developments, inspiring stories, podcasts, and ways to support the Advancing Neuroendocrine Cancer Research campaign by visiting the official webpage. Follow Neuroendocrine Cancer UK on social media for exciting updates and join the conversation using the hashtag **#AdvancingNeuroendocrineCancerResearch**

Let’s make history in the fight against neuroendocrine cancer and create a brighter future for those affected. Join us in Advancing Neuroendocrine Cancer Research today!

Neuroendocrine Cancer UK is thrilled to announce the official launch of our campaign, “**Advancing Neuroendocrine Cancer Research.**” This campaign aims to improve the understanding, management options, and outcomes for individuals with this complex cancer. Read on for more details...





CLINICAL TRIALS & RESEARCH: THE IMPORTANCE OF THE PATIENT'S PERSPECTIVE

Last year, Neuroendocrine Cancer UK's Patient Support Co-ordinator, and neuroendocrine cancer patient, Kate, gave a presentation to Ipsen, the manufacturer of Lanreotide, a monthly Somatostatin Analogue prescribed to many members of our patient community. The presentation emphasised the significance of involving patients in future clinical trials and research design.

Subsequently, Kate recently delivered a presentation to Neuroendocrine Cancer patients at the Midsummers Eve WebiNatter*, highlighting the importance of patient involvement in clinical trials and research design. During her presentation, Kate explained the numerous roles patients can play, such as setting research priorities, serving on Trial Steering Committees, reviewing Patient Information Leaflets (including the language used), meeting with researchers, contributing to protocol synopsis, assisting with recruitment, discussing practical considerations (such as mobility, travel, and home care for participants), fundraising, participating in study reporting, ethical reviews, and more. She emphasised that it is crucial for patients to have a seat at the table.

According to Kate, **“As patients, if we don't speak up, clearly express our needs, engage, advocate, and, above all, persist, we run the risk of not being included in the design of that one Clinical Trial that might just deliver the breakthrough that the Neuroendocrine Cancer community desperately needs.”**



[CLICK HERE TO WATCH THE VIDEO](#)



[VISIT THE NEUROENDOCRINE CANCER UK WEBSITE TO LEARN MORE ABOUT RESEARCH](#)

NATTER SUPPORT GROUPS:

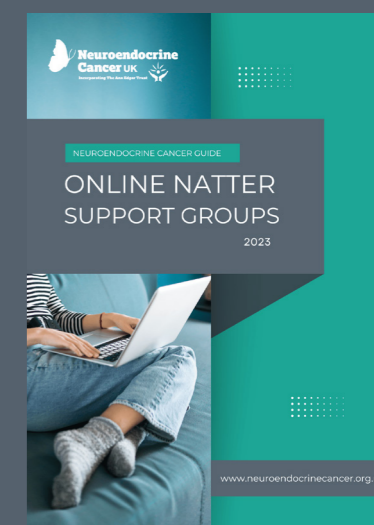


[VIEW OUR
NATTER
CALENDAR](#)

***WebiNatters are online Natter meetings that have an invited guest speaker: the guest speaker talk is recorded to be made available for all via the website/YouTube channel - the Q&A session is not recorded but a summary of questions asked and answered is available after the event.**

In addition to these online Natters we also run face to face meetings which are facilitated by a fellow patient or family member, Neuroendocrine Cancer UK staff or ambassador, Clinical Nurse Specialist and / or cancer support centre staff member (the latter dependent on venue).

[CLICK HERE TO READ MORE ABOUT NATTER SUPPORT GROUPS ON THE NEUROENDOCRINE CANCER UK WEBSITE](#)



SOME FACTS & FIGURES...

If you, or someone close to you, has been diagnosed with Neuroendocrine Cancer, you might be finding it's harder than ever to get the vital support you need right now. Being diagnosed with a rare or uncommon cancer can have additional consequences, not least in terms of awareness, early diagnosis and access to expertise. Feelings of isolation, fear, uncertainty and anxiety are not uncommon. But during this time of increased uncertainty and isolation, we're here for you, whatever your question. There are a range of ways we can help you from clear, easy to understand information to emotional support when you need to talk.



In the year to date, our Counselling Service has provided more than 200 counselling sessions:

- 100% found the counselling 'very helpful'
- 83% felt it 'very helpful / important' to have a Counsellor who had an awareness of their condition
- 83% feel less isolated
- 67% feel more resilient
- 100% feel better equipped to manage their condition

You can arrange to speak to one of our counsellors by emailing: ncuk-counselling@rareminds.org

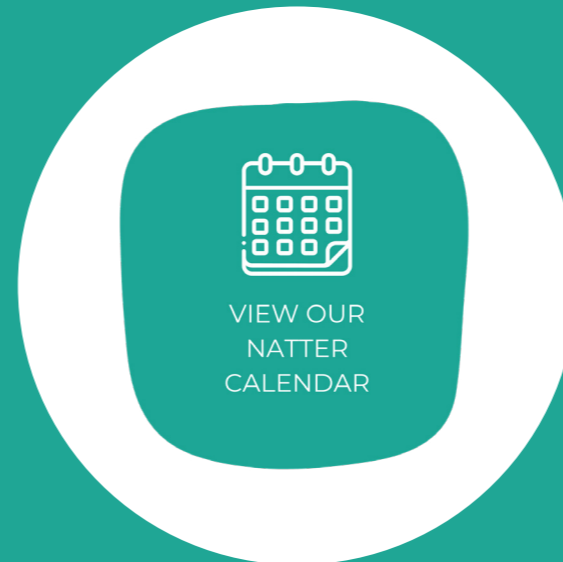
Our Counselling FAQ guide is available to download [here](#)

Our free and confidential Helpline has fielded ~ 500 calls

You can call us and speak to one of our Support Team members:

Tuesdays / Wednesdays / Thursdays 10am-4pm.

The Helpline is Closed Mondays / Fridays / Weekends
0800 434 6476



Over the past 3 months, Neuroendocrine Cancer UK has run and/or supported more than 50 Natter group meetings online or face-to-face, 35 of which took place, outside of the 9-5 day, in the evenings or weekends.

To find a Natter to suit you, visit our [Natter Calendar](#)



In partnership with the Counselling Team at RareMinds, Neuroendocrine Cancer UK, are committed to scheduling a series of group therapy programmes - following the success of our pilot programme "Living Well with Neuroendocrine Cancer", completed earlier this year. This 8-week programme included discussions that explored themes around:

- Living with the uncertainty
- Invisibility
- HCP- lack of time, knowledge and understanding
- Family "You look better"
- Difficulty asking for help
- 'Rollercoaster'

After completing the 8-week programme - attendees said they:

- felt better equipped to manage their mental health and wellbeing following the programme (100%).
- felt that the Group Facilitator understood the experience of living with neuroendocrine cancer 'very well' (100%)
- felt less isolated (100%), more resilient (85%)

WHERE TO FIND US...

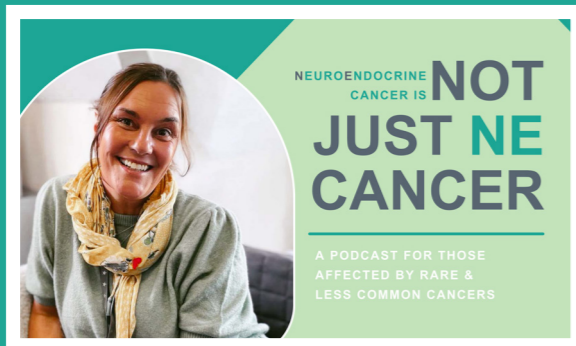
As a way of supporting those living with neuroendocrine cancer and their loved ones, we regularly produce educational content in the form of videos, podcasts and social media posts as well as run support groups such as 'Natters' and Facebook groups. It's vitally important for us as a charity to engage with you, the neuroendocrine cancer community in multiple ways so please visit the links below where you can like, subscribe and leave feedback.



YOUTUBE

The Neuroendocrine Cancer UK Youtube channel features content from medical professionals, campaign updates, expert videos from patient education events and members of the Neuroendocrine Cancer community sharing their stories.

[CLICK HERE TO WATCH](#)



PODCASTS

Real life experiences, practical advice and everything in between. Whether you are diagnosed with Neuroendocrine Cancer or another rare or less common cancer, our podcast series cover topics from initial diagnosis, treatments and follow up, looking after your mental health and the professional perspectives from those involved in your care. Hosted by Catherine Bouvier and produced by Neuroendocrine Cancer UK. We hope this series answers some of your questions or provides a source of support – or both, after all, this NeuroEndocrine Cancer is not just NE cancer.

[CLICK HERE TO LISTEN](#)



FACEBOOK GROUPS

Neuroendocrine Cancer UK currently runs 6 distinct Facebook groups:

- **Neuroendocrine Cancer UK Support Group** - this group runs alongside our local & regional Natter Groups and is open to all affected by Neuroendocrine Cancer here in the UK.
- **Neuroendocrine Cancer Family & Friends Support Group** - this group runs alongside the friends and friends Natter Group and is open to all family & friends of someone diagnosed with Neuroendocrine Cancer.
- **Friends of Neuroendocrine Cancer UK** - this group is open all affected by Neuroendocrine Cancer – wherever you may live.
- **High-Grade (G3 NET/NEC) Group** - this group runs alongside our HGNC Natter Group and is open to all family & friends of someone diagnosed with High-Grade (Grade 3) Neuroendocrine Cancer.
- **Merkel Cell Carcinoma Group** - this group runs alongside our MCC Natter Group and is open to all family & friends of someone diagnosed with Neuroendocrine Cancer of the Skin (MCC).
- **Lung / DIPNECH Group** - this group runs alongside our Lung Natter Group and is open to all family & friends of someone diagnosed with Neuroendocrine Cancer of the Lung and/or DIPNECH.

IGNITE YOUR PASSION FOR A CAUSE: JOIN THE FIREWALK CHALLENGE

Neuroendocrine Cancer UK is thrilled to announce the upcoming Firewalk Challenge, a heart-pounding event that aims to raise vital funds for Neuroendocrine Cancer UK. This exhilarating challenge will take place on November 10, coinciding with World Neuroendocrine Cancer Day, at the Johnstone Bowling Club, Johnstone PA5 8LR.

Led by the indomitable spirit of Craig Speirs, our esteemed Neuroendocrine Cancer UK Ambassador, this event promises to be a testament to courage and determination. Having battled neuroendocrine cancer for a decade, Craig has already made a significant impact by raising an incredible £54,000 through various charity initiatives, including two Kiltwalks.

Now, Craig invites you to be a part of this extraordinary journey. Step out of your comfort zone, embrace the thrill, and experience the awe-inspiring sensation of walking across scorching hot coals, all in the name of raising awareness and funds for Neuroendocrine Cancer UK. By taking part in the Firewalk Challenge, you'll play an integral role in helping us reach our ambitious goal of £100,000.

This unique event offers you an opportunity to stand alongside Craig and his supportive friends, as they fearlessly face the glowing embers. Not only will you contribute to a worthy cause, but you'll also be part of an international movement, united in our mission to eradicate the challenges posed by neuroendocrine cancer.

By participating in the Firewalk Challenge, you'll not only raise much-needed funds but also help us shed light on this rare form of cancer, ensuring that individuals and their families receive the support and resources they deserve.

Don't miss this incredible opportunity to make a tangible difference. Rally your bravery, gather your friends, and sign up for the Firewalk Challenge today!

[Click here to read Craig's Article](#)

[Click here to donate to Craig's fundraiser](#)

Email us to join the challenge: hello@nc-uk.org

Please note: We acknowledge that there is an inherent risk in any activity involving fire. This activity has been arranged with an officially recognised, experienced and reputable company - where activity training, environmental considerations and all necessary safety measures are in place.



THANK YOU! The activities and vital support services that Neuroendocrine Cancer UK provide are only possible because of your generosity and support: from awareness raising to taking part in discussions to completing our surveys from fundraising to donations generously made - as one-off or by monthly direct debit.

NEUROENDOCRINE CANCER UK'S 2023 VIRTUAL FUNDRAISING CHALLENGE



SIGN UP TODAY!

Welcome to Neuroendocrine Cancer UK's 2023 virtual challenge! We're thrilled that you're considering joining us in this exciting and meaningful journey. By participating in this challenge, you'll be helping to raise essential funds dedicated to **advancing neuroendocrine cancer research**.

Our challenge will take you on a virtual journey along the neuroendocrine cancer pathway from Aberdeen to Leamington Spa, stopping off at all the Neuroendocrine Cancer Centres along the way. You can choose to run, walk, trek, or cycle – the choice is yours! This is an opportunity to be part of something truly special, a nationwide community dedicated to achieving neuroendocrine cancer excellence.

Together, let's make history and create a brighter future for those impacted by neuroendocrine cancer. Join the Pathway Virtual Challenge today and help us make a real difference! **CLICK HERE TO READ MORE**

OVERVIEW:

- The challenge is open to everyone of all ages, fitness levels, and abilities.
- You can support the challenge as a fundraiser, participant or a donor.
- You choose your own activity, such as walking, running, or cycling, and your own distance.
- Funds raised will support our 'Advancing Neuroendocrine Cancer Research' Campaign.
- Our target is to raise £50,000.
- The challenge started in June and ends on November 10th, World Neuroendocrine Cancer Day.



Text NCRESEARCH followed by your donation amount to 70085 to give that amount.

Texts will cost the donation amount plus one standard network rate message.



OUR AMAZING FUNDRAISERS!

Some of your incredible fundraising undertaken in 2023!



DONATE



MULTIPLE RACES THROUGH 2023!

Neil, Richard and Charlotte, a.k.a, The N.E.T. Nerds are a Father, daughter and son trio. The trio have designed a personal fundraising challenge, 'The Lovely Linda 2023 Runathon'. The challenge will see them take on multiple races throughout the year, including:

- The Lap, Lake Windermere – A 50 mile ultra marathon
- Wright Hassall Regency Leamington 10k
- Oxford Half Marathon

Here is Richard, who ran the first of the six events earlier in the year, The Leamington Regency 10k – NCUK's home territory!!



"OUR WELL-LOVED INSTRUCTOR".

Thanks to Carol, Carolyn, Dave and friends at the Hutton Moor Leisure Centre for raising £808.00! A fitness day held in memory of Ann Beakes, "Our well-loved Instructor".



'A CHARITY CLOSE TO OUR HEARTS'

Molly & friends at York St John University Cabaret evening. A total of £538.40 was raised on the evening. Here's why Molly chose to fundraise for us: "My mum was diagnosed in 2021, so I decided to fundraise for the charity close to our hearts and to give back to her. It's a time for all family and friends to get together to celebrate what a wonderfully strong woman she is".

Prepare to dive headfirst into an awe-inspiring world of fundraising possibilities, where challenges become triumphs, adventures become memories, and silly antics become heroic acts of generosity. Join us on this extraordinary journey as we make a profound difference together!



For more information about fundraising or other ways to support Neuroendocrine Cancer UK, click here to visit our website

Spotlight on Neuroendocrine cancer is our new campaign to support Healthcare Professionals (HCPs)

We want to use Spotlight on Neuroendocrine Cancer (NC) to support non-NC specialist HCPs by increasing awareness of this complex cancer and providing bite-size and relevant education about NC, ultimately to improve the patient experience. This education will include what Neuroendocrine Cancer is, clinical presentation, symptoms and common differentials to look out for, useful investigations to diagnose NC and the psychosocial impact and how to support patients with this aspect of the disease.

We want all Neuroendocrine Cancer patients to be able to access the same, all-inclusive, joined-up care – to see the right person at the right place and at the right time.

This month an overview of Neuroendocrine Cancer for Gastroenterologists was created to support them to identify the symptoms of neuroendocrine cancer and useful investigations for its diagnosis. **It can be seen on the HCP section of the website.**

Objectives of Spotlight on Neuroendocrine Cancer:

- To raise awareness and knowledge about NC among non-NC specialist HCPs, commissioners (who are responsible for planning and prioritising health services locally) and policy makers (those who define specific healthcare goals for the UK). In the first year we will focus on Gastroenterologists & General Surgeons, GPs and Clinical Nurse Specialists. Our vision is a world in which people know how to recognise, diagnose, treat, care for, and ultimately, cure patients with Neuroendocrine Cancer.
- To achieve more equal and equitable care we are working to ensure that NC is included in national cancer plans and has its own dedicated NC Care pathway integrated into the NHS system.
- To empower patients to feel more in control of the management and treatment of their disease and support them to work with their healthcare team, to be at the heart of the decision-making process and to ensure prioritisation of what matters most to them.

Spotlight on Neuroendocrine Cancer Plans:

- We will continue to collaborate closely with HCPs to deliver relevant NC information to support the diagnosis of NC.
- We will develop a new HCP dedicated website.
- We are developing the first national NC care pathway to help HCPs diagnose and manage their patients and ensure that all patients across England are treated in the same and optimal way. We are working with HCPs, patients, NHS England, Industry and policy makers on this to make sure it is fit for purpose for those who will use it when it is launched in 2023. It will provide a framework for the ideal management pathway of a patient with NC which will make the journey easier and better for both HCPs and patients.
- We have collaborated with a number of GP organisations who will deliver more topline, practical education via different platforms to a wider GP audience in 2023.
- We will hold top line educational meetings that support non-NC specialist Gastroenterologists, General Surgeons and Clinical Nurse Specialists (other HCP specialities will be supported in following years).

Spotlight on Neuroendocrine Cancer Achievements:

- This campaign was created at the end of 2022 after collaboration with NC-specialist and non-NC specialist HCPs to understand how we could best raise awareness and support in a way that is relevant for them.
- We have worked closely with HCPs to develop a practical overview of Neuroendocrine Cancer to support HCPs to recognise and consider NC as a potential diagnosis. We have also created a practical overview specifically aimed at supporting General Practice.
- We have worked with the Primary Care Society of Gastroenterology to deliver an educational talk on Neuroendocrine Cancer to support GPs on how to recognise the disease.
- Additional materials that have been developed for GPs include an early symptoms awareness card and training modules that were developed with the Royal College of GPs to target the issues around late and misdiagnosis, and provide useful information around symptoms, diagnosis and referrals into expertise.
- Other educational initiatives we have include the Neuroendocrine Cancer Nurse Competencies for the UK, (endorsed by the Royal College of Nursing to ensure the right skill set is obtained by nurses caring for people affected by NC) and the NCUK training academy which is an educational website for nurses and allied HCPs. We will continue to develop the NCUK academy.

If you would like to make a donation to support us with this campaign, please text NCUK followed by your donation amount to 70450 to support the work that we do and our services. Please note that texts will cost the donation amount plus one standard network rate message.



COMING UP SOON



SOCIETY FOR ENDOCRINOLOGY (SfE) BES 2023

This annual conference will be held in Glasgow, 13-15th November, bringing together “the largest gathering of endocrine professionals in the UK”.

The SfE has a long history of **supporting patient organisations** and related charities, including them not only to take part in the exhibition arena, but also to present and/or attend conference sessions.

Health care professionals wishing to find out more about the conference or wanting to **register can do so here**.

UKONS 2023



This year UKONS is bringing their annual cancer nursing conference to the newly developed ICC Wales in Newport. This year's theme is 'Let's integrate cancer care' - this allows the academic programme to explore a wide range of subjects, including nurse education, workforce planning and promoting the delivery of the best cancer care across a wide range of settings, as well as working across boundaries. We are delighted to have an abstract accepted for poster presentation.

UKINETS 2023

The UKI NETS 21st Annual conference will be held in person in Sheffield, on Monday the 4th of December, where “We continue to support our NET community and to promote collaborations, education and advancement of practice in the field of neuroendocrine neoplasms (NENs).” For further information and registration details, **visit UKINETS event page here**

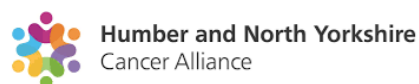
UKINETS will also be hosting the 3rd International Symposium on Carcinoid Heart Disease, the day after their annual conference, on Tuesday 5th of December.

The symposium is aimed at clinicians, cardiologists, cardio-thoracic surgeons, anaesthetists, nurses, neuroendocrine cancer specialists, and allied health professionals who have an interest in the care of patients with carcinoid heart disease. Further event information is available here.

NCUK staff members will be attending both events and will report back!

HUMBER & NORTH YORKSHIRE CANCER ALLIANCE 2023

Humber and North Yorkshire Cancer Alliance Annual Conference, September: During the conference NCUK will have a stall to discuss Neuroendocrine Cancer and raise awareness of the disease and the patient care pathway, with the clinicians and staff who work for organisations which make up the cancer alliance.



COMING UP SOON

World Mental Health Day 10th October 2023

The World Health Organisation (WHO) recognises World Mental Health Day on 10 October each year.

It's a day dedicated to raising awareness about mental health issues and advocating for better mental health support, understanding, and treatment. The goal is to promote open conversations, reduce stigma surrounding mental illnesses, and encourage individuals to prioritize their mental well-being.

For over 70 years, the **Mental Health Foundation** has been working to make sure that mental health is treated equally with physical health.

Mental health affects various aspects of our lives, spanning from our personal well-being to our interactions with others, our ability to perform at work or in school, and our overall quality of life. There is a need to call on national and local governments to prioritise reducing the factors known to pose a risk to people's mental health, enhancing those known to protect it and creating the conditions needed for people to thrive.

It's important to remember that mental health is complex and varies from person to person. While some individuals may face mental health challenges, others may not. However, promoting awareness, understanding, and access to support services is essential for everyone, regardless of their current mental health status. World Mental Health Day is also a chance to talk about mental health in general, how we need to look after it, and how important it is to talk about things and how/where you can find help when its needed.

*Newly Diagnosed Programme

At Neuroendocrine Cancer UK, working with our colleagues at RareMinds, we have developed a series of Group Therapy programmes - to run alongside our well-established one-to-one counselling services. Our new programmes aim to help address some of the factors that can affect mental health well-being - especially for those living with a rare / uncommon cancer diagnosis - such as uncertainty, isolation and invisibility.

SPACES STILL AVAILABLE

Our new 8 week 'Newly Diagnosed' programme will be commencing 7th September 2023 and is for those who have received their diagnoses 6 months to 2 years ago. This programme will be delivered online via Zoom from 19:30-21:00 over 8 consecutive weeks. The programme is free to attend and applicants will be asked if they are able to attend all 8 sessions. For more information contact rebecca@rareminds.org or **APPLY HERE**.



*Newly Diagnosed includes those who received their diagnosis 6 months to 2 years ago. If less than 6 months, we recommend 1:1 session with our counselling team. If more than 2 years ago, we recommend our "Living Well With" programme - date TBC.

Click here for more information on counselling support available.

World Neuroendocrine Cancer Day - 10th November 2023

World Neuroendocrine Cancer Day is held on 10th November each year and is coordinated by the **International Neuroendocrine Cancer Alliance (INCA)**.

It's a day dedicated to raising awareness about neuroendocrine cancers, educating the public, and supporting individuals affected by this uncommon form of cancer.

There will be various events and activities taking place on the day itself so **keep an eye on our website and social media** for further updates on how you can get involved.

World Neuroendocrine Cancer Day will also mark the launch of our "N.E.W.S" webinar series and the end of our Virtual Fundraising Challenge which **you can read more about here**.

