Neuroendocrine Cancer UK



One of the biggest lifelines has been discovering NCUK.
Living with neuroendocrine cancer can feel isolating, especially when many healthcare professionals don't fully understand it. The charity community has been lifesaving.

Impact Report.

For the period 2020-2025

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Welcomes.



Chief Executive
Lisa Walker

This impact report captures the real difference NCUK has made for those affected by neuroendocrine cancer over the last five years – progress that has been directly shaped by patient voices.

We have worked to ensure lived experience drives everything we do, amplifying real experiences, responding to real needs, and keeping our focus firmly on what matters most to those affected. Alongside this, we have strengthened our educational offerings, built meaningful partnerships across the UK and globally, and made better use of our data.

Supporting our community is central to everything we do. Building on strong foundations, we are committed to delivering lasting impact – improving outcomes, experiences, and understanding of neuroendocrine cancer, both now and in the future.

I want to recognise our teams and wider community for their commitment and strength as we have navigated considerable change in the years since Covid. With our new five-year strategy in place, we are now well positioned to go further – driving greater awareness, influence and understanding of neuroendocrine cancer across the NHS, government, and the wider healthcare system.

Having recently stepped into the role of Chief Executive, and after three years with NCUK, I have seen first-hand the dedication and impact that defines this organisation. I am proud of what we have achieved together and excited for what comes next.

Lisa Walker

“Patient voices have directly shaped the progress we have made over the last five years.



Chair of the Board of Trustees
Peter Gwilliam

As demand grows and diagnosis rates rise, charities like NCUK are increasingly called upon to fill critical gaps in awareness, care, coordination and patient support. This comes as the NHS begins to deliver its new 10-Year Plan, and NCUK is ready to play its part.

The progress outlined in this report shows what can be achieved through partnerships, with the potential to do more. We aim to be a dependable ally, focused on practical solutions, while remaining a clear and credible voice when gaps emerge or patient experience shows systems are not working as they should.

We are committed to working collaboratively with the NHS to reduce time to diagnosis, improve treatment pathways and deliver better outcomes for patients. Generous support from our donors has made this progress possible, but rising demand means we must build a more sustainable financial model for the future.

With a clear strategy and shared purpose, we are well placed to meet the challenges and opportunities ahead. Having co-founded the organisation in 2000, I am proud of how far we have come. Today, NCUK is the leading voice for neuroendocrine cancer in the UK and remains committed to making a meaningful difference for those affected.



Patient Support Team and NCUK Ambassador
Kate Quirk

When I was first diagnosed with neuroendocrine cancer over 20 years ago, there was little support and even less reliable information available. That gap allowed fear and misunderstanding to grow. Today, the landscape looks very different.

Our work raises awareness and connects patients and healthcare professionals to a wide range of services offered by NCUK – many shaped and delivered by volunteers with lived experience. These include counselling and group therapy to help people navigate the emotional impact of diagnosis, as well as online and in-person support groups, spaces for loved ones, monthly educational webinars, and active online communities.

Our podcast and helpline provide trusted, accessible information when it's needed most. The impact is significant: people report feeling more informed, more confident, and far less alone.

Together, volunteers and patients have helped turn a fragmented landscape into a connected, supportive community. We're proud to support this diverse community and that so much of this work is powered by their insight and experience.



Patron
Professor Martyn Caplin

The progress set out in this report reflects years of careful, determined work and research across our community, showing what's possible when patients and clinicians work together.

NCUK's achievements demonstrate the impact already made and the potential for further progress in the years ahead. Meeting this challenge will require a secure foundation for discovery and the use of emerging technologies, including AI, to accelerate breakthroughs and carry out deeper, faster research.

When work started on The Invisible Cancer report in early 2026 (see more on page 15), it became immediately clear that this was an important platform for patient voices and reminded us why research matters.

Behind every data point is a person waiting for answers and better treatments, reinforcing the need for continued investment in research and for the Centres of Excellence around the UK to be used to their full potential.

I am proud to be part of an organisation that continues to advance the field and champion the work that will make a difference for patients and their families.

About this Impact Report.

This report explains how we have used funding and support over the past five years to deliver meaningful change for people affected by neuroendocrine cancer.

It brings together evidence, outcomes, and lived experience to illustrate the difference our work makes in practice. It also reflects our commitment to transparency and accountability to our supporters, partners, and wider community, offering a clear view of our progress and impact over time.





Who we are and what we do.

We are Neuroendocrine Cancer UK (NCUK), the leading voice for neuroendocrine cancer in the UK.

- Co-founded 26 years ago by patients, families and healthcare professionals, we were built by the community we serve.
- We are dedicated to supporting people affected by neuroendocrine cancer, whether it's a neuroendocrine tumour (NET) or a neuroendocrine carcinoma (NEC), putting patients, families and carers at the heart of everything we do.
- We provide compassionate support and trusted information, raise awareness and fund vital research.
- We are a small team, but with the support of our community we deliver real impact.
- Our community voices are not just part of the conversation, they are the conversation, guiding our strategy and shaping our future.
- We do not receive any funding from the government, NHS or larger cancer charities. Our work is made possible almost entirely by the generosity of our community, individuals and organisations who give their own time and money to support our mission.

Advocacy and partnerships

As an evidence-based advocacy group, we work with our partners in the UK and globally to gather real-world data from the neuroendocrine cancer community. These insights shape our efforts to influence access to treatment, clinical practice, and policy.

Advocacy is a vital but often unseen part of our day-to-day work. It's how we raise awareness, open doors to better care, and create lasting change within a broader community, and within systems that may not fully understand the unique needs of people living with neuroendocrine cancer.

Our partners

UKI NETS · UK and Ireland Neuroendocrine Tumour Society · Royal College of Surgeons of England · INCA International Neuroendocrine Cancer Alliance · cancer52 · AMEND · RareCan. · Society for Endocrinology

The challenge in numbers.

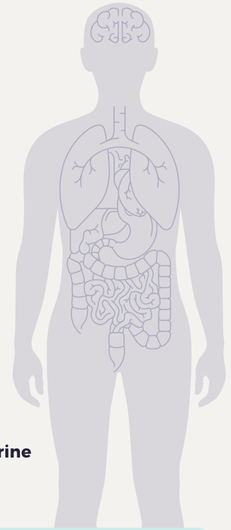
371% increase in the incidence of neuroendocrine cancer between 1995 and 2018

More than 36,000 people in the UK are living with neuroendocrine cancer at any one time, making it more common than those living with stomach cancer or pancreatic cancer

4.5 years average time from first symptoms to diagnosis

1 person every 90 minutes is diagnosed with neuroendocrine cancer – that's approximately 6,000 people every year

What this means for patients.



- **People visit their GPs 11 times on average before receiving a diagnosis** (those with NETs)
- **More than half of patients are diagnosed at Stage 3 or 4** when treatment options are limited
- **Neuroendocrine cancer can occur anywhere in the body,** making it difficult to recognise and easy to misdiagnose
- **Symptoms often mimic common conditions such as IBS, menopause, asthma and anxiety,** leading to further delays
- **There is no national diagnostic pathway for neuroendocrine cancer,** resulting in inconsistent experiences and outcomes across the UK

Behind these statistics are people living with uncertainty, repeated appointments and unanswered questions.

Earlier recognition and clearer pathways could significantly improve experiences and outcomes for people living with neuroendocrine cancer.

What our community says:

"You are an amazing charity and **have helped me immensely from the start of the hardest journey of my life**. You assisted in understanding the diagnosis and supported me emotionally throughout the months waiting for scans and answers and treatments. I am forever thankful!

"I found the time between initial diagnosis and first treatment, and proper contact with a Centre of Excellence, really stressful. The helpline at **NCUK was an emotional lifeline**.

"We cannot thank you and the Helpline enough. The support and email links and signposting you have offered me have been fantastic. **My wife also feels reassured** that she can call back at any time for your expert help.

"Your NCUK online handbook is one of the best uses of internet technology I have ever seen... the way it links to videos and stories... the way content is available in different formats... **it really is superb**.

Our impact.

Everything we do has to make a measurable difference for people living with neuroendocrine cancer, and this section sets out what that looks like in practice.

We look at the outcomes that matter to the people within our community, where we are adding value and where we need to concentrate ongoing and further work.

Support & Care.

We provide vital support and care to improve the quality of life for everyone affected by neuroendocrine cancer.

We help people navigate their diagnosis with clarity, strength and hope, always finding better ways to meet their needs.

“I wasn’t very optimistic starting the [mindfulness] course to be honest, as I didn’t think I would achieve much from it. But wow, I am totally shocked! I have completely changed my approach to everything, not just pain, anxiety and fatigue. **I can manage my body, my mind and everyday situations that pop up. I am truly a changed man.**

Progress with this priority.

Emotional support

- Improved our helpline service, answering more than **1,000 queries per year**, with demand rising 30% year on year.
- **Funded 500 counselling sessions per year** for those with the disease as well as their families, ensuring access to specialist emotional support.
- **Launched three dedicated group therapy programmes**, delivered twice yearly, tailored for those newly diagnosed, those living with the disease and for family and friends.



Information and education

- Introduced a **virtual handbook** for patients and supporters, designed for diverse learning styles. Accessed **85,000+ times by 15,000 unique users** since July 2024.
- Set up **monthly patient and family educational webinars,** hosted by clinical experts, covering different aspects of neuroendocrine cancer, with some sessions co-developed and led by patients.

System-level advocacy

- **Took active roles in working groups with key membership organisations** including the British Nuclear Medicine Society and the UK Molecular Radiotherapy Consortium, to ensure patient voices are represented.
- **Helped shape national policy** by establishing strategic collaborations with the NHS, contributing to consultations to shape the new NHS 10 Year Plan and the Rare Cancers Bill.
- **Designed a new evidence-based neuroendocrine cancer ideal patient pathway** with our Centres of Excellence to standardise high quality care across the UK.

Community connection

- **Supported 1,300 people per year** via our 40 Patient Support Groups across the UK, creating safe spaces for discussions and practical advice.
- **Launched our Hero Awards** – an annual programme recognising people making a difference across the neuroendocrine cancer community and healthcare sector, attracting hundreds of applications each year for those living with neuroendocrine cancer, supporting loved ones, or delivering frontline care.

The Neuroendocrine Cancer UK HERO AWARDS
Celebrating outstanding individuals in the neuroendocrine cancer community



- **Launched a podcast** to raise awareness of this little-known cancer, sharing real-life stories, expert insights, and practical advice to support and connect those affected.



Patient case study.

Finding strength and support through our community



When Melanie Lucas was diagnosed with neuroendocrine cancer in her lung, she learned that surgery wasn’t an option and her cancer was not curative.

Her doctors believe she may have been living with the tumour for up to 10 years before it was discovered.

Like many other patients, Melanie had to adjust to a new rhythm of life, shaped by cycles of tests, treatment and waiting for results. The uncertainty has been one of the most difficult aspects of living with neuroendocrine cancer.

The impact on her life was significant – she returned to self-employment because being in employment and living with cancer and all that it entails was too hard. For Melanie, support and understanding have been vital in helping her navigate this new reality.

Melanie said: *“Being supported, listened to and treated as a person, not just as a diagnosis, has helped me focus on living well for as long as possible.*

“One of the biggest lifelines has been discovering NCUK.

“Living with neuroendocrine cancer can feel isolating, especially when many healthcare professionals don’t fully understand it.

“The charity community has been lifesaving.

“It’s a safe space where people truly understand the fear and uncertainty. We share experiences, information and reassurance. When treatment options are limited and funding is scarce, having trusted support makes all the difference.”

Through support and connection, Melanie is finding strength and reassurance that she is not facing neuroendocrine cancer alone.

Stories like Melanie’s show why long-term, specialist support is essential for people living with neuroendocrine cancer.

Awareness & Education.

One of our biggest challenges is the lack of awareness and understanding of neuroendocrine cancer among healthcare professionals, policymakers, and the public.

This gap has led to delayed diagnoses, inconsistent care, and limited access to reliable information.

Over the past five years, we've made progress in providing accurate, data-driven information to increase recognition and understanding of the disease.



Progress with this priority.

- **Launched our Spotlight on Neuroendocrine Cancer campaign**, in partnership with the UK and Ireland Neuroendocrine Tumour Society (UKINETS) to increase awareness of the disease among non-specialist health care practitioners (see more on page 11).
- **Commissioned a report** in collaboration with mental health charity, Rareminds, **on the mental health of neuroendocrine cancer patients**. This led to the Open Conversation initiative, providing healthcare professionals with practical communication strategies to navigate discussions about mental health.
- **Funded a dedicated cancer analyst to map and better understand the neuroendocrine cancer population across the UK**, leading to the publication of a significant report: *Incidence and survival of neuroendocrine neoplasia in England 1995–2018: A retrospective, population-based study.* This study was crucial in evaluating the epidemiology of neuroendocrine cancer in England and examining changes in survival over time.
- **Created a comprehensive nursing competency framework, earning Royal College of Nursing Accreditation**, that is now shaping future learning for nurses working with neuroendocrine cancer patients.
- **Created the Neuroendocrine Life Alliance** with the AMEND charity to strengthen advocacy, raise awareness and enable a stronger UK voice for neuroendocrine communities.
- **Strengthened global patient advocacy** by working with 37 neuroendocrine cancer patient organisations worldwide through our position on the International Neuroendocrine Cancer Association Advisory Board.

Case study.

Strengthening care and support through collaborative education

Through our *Spotlight on Neuroendocrine Cancer* campaign, launched in partnership with the healthcare professional organisation the UK & Ireland Neuroendocrine Tumour Society (UKINETS), we set out to improve awareness of neuroendocrine cancer among non-specialist healthcare professionals.

The campaign was shaped through conversations with clinicians, who identified the need for practical, confidence-building resources to help healthcare professionals better recognise and understand the disease, and offer improved guidance and support to patients.

Central to this work was Dr Alia Munir, a Consultant Endocrinologist, Training Programme Director, and Head of the UKINETS Education and Training Committee. Dr Munir worked closely with our team to develop the materials for this campaign.

Through this collaboration, we developed disease overviews tailored to six healthcare disciplines, highlighting the key information each profession needs in everyday practice as well as patient case study videos to demonstrate people's experiences.



These resources were shared at conferences, across social media and through established professional platforms.

The campaign also featured on three GP podcasts and key insights were presented at two national conferences. Practical guidance was circulated through a dedicated primary care digital channel, reaching more than 45,000 GPs and other clinicians.

Working alongside these clinicians, educators and patients, and being championed by Dr Munir, ensured the resources were relevant and accessible. Clinicians are reporting greater clarity thanks to this coordinated, collaborative approach.

"NCUK continues to demonstrate exceptional impact through its commitment to collaborative practice.

Their development of education packages for healthcare professionals and patients has strengthened understanding of neuroendocrine tumours across the care pathway.



Dr Alia Munir
Consultant Endocrinologist and Training Programme Director

Research & Innovation.

We are working to progress understanding, develop better treatments and ultimately find a cure through targeted research and innovation. We have launched our own research grants and supported studies that have generated valuable insights.

Despite rising incidence and significant unmet need, we receive little to no dedicated funding from major UK cancer research funders. This makes NCUK's role in supporting early-stage and practice-changing research essential to progress.

While our research is making a difference, it also highlights a serious gap. Cases are rising year-on-year, yet investment remains far below what's needed to improve diagnosis, treatment and prevention. The generosity of our community has brought us this far, but it cannot meet growing demand.

Much of the research we fund begins as pilot projects, enabling researchers to test new ideas and deepen understanding of the disease. These early studies generate the evidence needed to attract larger funding and drive further breakthroughs.

Progress with this priority.

- **Committed £100,000 to fund five research projects in 2025**, comprising three pump-priming grants and two practice-changing grants. This builds on a further £270,000 invested over five years to improve patient outcomes.
- **Began a project to identify key research priorities, shaped by people living with neuroendocrine cancer, their carers and clinicians**, by supporting the James Lind Alliance Priority Setting Partnership.
- **Enabled the routine publication of accurate neuroendocrine cancer data** by partnering with the National Disease Registration Service's 'Get Data Out' project.
- **Partnered with the Royal College of Surgeons on a £30,000, three-year project**, to fund the first neuroendocrine cancer Surgical Speciality Lead. This funding is enabling research into the value of surgery in advanced neuroendocrine tumours (NETs), where evidence is currently limited (see more opposite).

ADVANCING NEUROENDOCRINE CANCER RESEARCH



Case study.

Building momentum in research

When Consultant NET Surgeon, Professor Samuel Ford, began exploring neuroendocrine cancer, opportunities to build meaningful research in this field were scarce. There was no established network and limited recognition of the growing impact of the disease. A £30,000 research grant from NCUK changed that.

That support became a turning point as it allowed him to grow his research and take on the role of Surgical Speciality Lead for neuroendocrine cancer at the Royal College of Surgeons. This gave him a platform to bring together clinicians, scientists and patients, forming both national and international networks working to improve patient outcomes.

NCUK also supported the development of a national registry. This resource will gather high-quality clinical data for the first time, giving researchers a clear picture of how the condition progresses and where interventions make the greatest difference. We also helped advance work in promoting liver transplantation for those with neuroendocrine cancer and creating a sustainable platform for efficient, cost-effective prospective clinical trials.

"Support from NCUK has been instrumental in helping me grow my research career and take on the role of Surgical Specialty Lead for neuroendocrine cancer at the Royal College of Surgeons.

This role has enabled the development of both national and international NET research networks and supported the James Lind Alliance to prioritise research, with feedback from patients, their families and healthcare practitioners.

With NCUK's backing, we are building the UKINETS Registry to collect high-quality data that will ultimately improve outcomes for people living with NETs.

Professor Samuel Ford
Consultant NET Surgeon
Surgical Speciality Lead for neuroendocrine cancer
Royal College of Surgeons



Income Generation & Sustainability.

Over 95% of our income is entirely funded by our community's generosity – we receive no government or NHS support. Every donation drives better care, improved patient outcomes, and world-leading research.

With cases of neuroendocrine cancer increasing year-on-year and people facing a much tougher economic climate, we recognised the need to adapt how we generate income and run the organisation.

In 2025, we introduced an income and sustainability strand to our new five-year strategy. This focuses on strengthening governance, refining our operations and organisational structure, investing in robust systems and processes and building capacity to grow our income by 50% over the life of the strategy. Together, these investments will enable us to respond more quickly and effectively to rising demand for support from our community.

In the last five years we have:

- **Integrated with the Ann Edgar Charitable Trust in Scotland** (January 2023) with the aim of ensuring continuity of support, maximising resources, and pledging ongoing support to improve outcomes for those affected by neuroendocrine cancer in Scotland.
- **Increased our fundraising capacity by recruiting two new fundraisers** to focus on community and individual giving.
- **Ensured continuity in leadership with the appointment of a new Chief Executive from within the organisation,** demonstrating strong succession planning.
- **Invested in our customer relationship management system** (CRM) to improve data insights and communicate with our supporters, helping us build stronger relationships.



Fundraisers at a tough mudder event raised £1,750



Our new Chief Executive Lisa Walker with NCUK colleagues

Case study.

Walking in Mum's Footsteps – community-led fundraising

Katia Crolla describes how her family is carrying forward a lasting fundraising legacy

"When I was asked to share some words about NCUK, I realised just how much their support shaped the journey my mum, Diana Pacitti, my sisters, and I walked together. From Mum's diagnosis with neuroendocrine cancer in November 2019, the charity became a constant source of guidance, reassurance, and community.

"Their support became woven into Mum's life, especially through her monthly patient support group, which quickly became a lifeline. In those meetings she found friendship, understanding, and a sense of belonging that no one else could give her. She connected with fellow NET warriors who truly understood what she was facing, and the compassion she received brought her comfort when it was needed most. As a family, we were welcomed with open arms, receiving information, encouragement, kindness, and even shared laughter during some of our darkest days.

"Inspired by Mum's strength and her deep gratitude for the charity, we joined her for the Kiltwalk in 2023 and completed the 'Mighty Stride' in 2025 in her memory, raising £6,410 for NCUK – an event she had proudly signed us up for.



Left to Right: Luciana Boyle, Katia Crolla, Diana Pacitti, Silvana Pacitti, Marilena Pacitti and Stefania McAnea

"Walking the Mighty Stride was incredibly tough for us. We had just lost Mum, and mentally it was so hard because she should have been waiting at the finish line with her amazing smile and her words of "that's my girls". Although we lost our beloved Mum on 18 February 2025, her love for this community and her determination to raise awareness live on in us. We will continue fundraising and advocating in her memory, knowing how vital this support network is not just for those fighting neuroendocrine cancer, but for the families who walk that journey alongside them."

> **"...her love for this community and her determination to raise awareness live on in us.**

Future focus.



Work is well under way to deliver our new **five-year strategy**, continuing to focus on our four priority areas and the outcomes we want to achieve for the people we support.

We started 2026 strongly, with the publication of our *Invisible Cancer* report to coincide with World Cancer Day (4 Feb 2026). The report aims to increase awareness of neuroendocrine cancer which is too often misdiagnosed and misunderstood.

It generated extensive regional, national and international media coverage, reaching millions of people. But its real impact has been the conversations it sparked and the response from our community, many of whom told us they finally feel seen and heard.

Alongside this work, we have made key appointments to strengthen our services and build a more sustainable organisation. In January, we welcomed a new Director of Operations, along with two new nurses who will join our support team and help us meet rising demand.

There is still more to do, but the first months of 2026 have given us strong momentum to move forward with confidence.

We will continue fundraising and advocating in [my mum's] memory, knowing how vital this support network is, not just for those fighting neuroendocrine cancer, but for the families who walk that journey alongside them.

Katia Crolla, community fundraiser

Neuroendocrine Cancer UK

www.neuroendocrinecancer.org.uk

Support our vital work today:
www.neuroendocrinecancer.org.uk/donate

@neuroendocrinecanceruk