Neuroendocrine Cancer UK

OUR STRATEGY TO 2030

INTRODUCTION

NO MORE BLIND SPOTS: IT IS TIME TO SEE NEUROENDOCRINE CANCER **CLEARLY**

Catherine Bouvier Ellis
Chief Executive
Neuroendocrine
Cancer UK

At Neuroendocrine Cancer UK, we stand with every person facing a diagnosis of neuroendocrine cancer — a disease that, despite being the tenth most prevalent cancer in the UK, often slips under the radar. It is misunderstood, frequently misdiagnosed and struggles for the recognition and awareness it urgently needs. Right now, it is a blind spot.

We are here to change that.

Our hope is for a world where neuroendocrine cancer is no longer overlooked. A world where people can recognise the signs, get swift diagnoses, access the best treatments and feel supported every step of the way. And where care and cures are within reach for everyone affected.

Together we can transform lives. Through awareness, research, better funding and support, we can give our community the attention it deserves.

Our new five-year strategy is designed to make this happen, ensuring we can respond to the challenges facing our NHS and advancements in technology while staying true to our mission.

Building on the outstanding work of the last five years, we are determined to drive forward the ambitions of our community.

Our team is committed to working alongside patients and their families, healthcare professionals, our partners and dedicated supporters to achieve these priorities. By uniting our efforts, we can raise awareness, deepen understanding, attract more funding and drive better outcomes for everyone affected by neuroendocrine cancer.

It is time for neuroendocrine cancer to be seen more clearly. Let's work together to remove this blind spot.

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CONTENTS

STRATEGY AT A GLANCE

Our vision

A world in which people know how to recognise, diagnose, treat, care for, and cure patients with neuroendocrine cancer.

Our mission

Support and inform patients and families from diagnosis, enable access to the best care and treatment, advance neuroendocrine cancer research, increase national awareness, and influence improvements in outcomes.

Our four priorities

1. Continue to provide support and care for our community
2. Increase awareness and educate a wider audience
3. Increase investment in research and innovation
4. Continue to increase income and be a sustainable organisation

Our values

EQUITY

We champion equal care for all neuroendocrine cancer patients in the UK.

EXCELLENCE

We strive for excellence across our support, care, treatment, and research.

COLLABORATION

We collaborate with our colleagues, community and partners to build an accessible, approachable community.

HONESTY, TRANSPARENCY AND INTEGRITY

We act with integrity and promote openness, honesty and transparency to build confidence and trust in our organisation.

ADVOCACY AND PARTNERSHIPS

As an evidence-based advocacy group, we work tirelessly 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
INCA – International Neuroendocrine Cancer Alliance
AMEND
cancer52 – the common voice for rare and less common cancers
Royal College of Surgeons of England – Advancing Surgical Care
RareCan. – Together we Can
Society for Endocrinology

OUR STORY

Neuroendocrine Cancer UK was founded by a small group of patients, families and healthcare professionals to support, raise awareness, and drive research for neuroendocrine cancer patients.

They saw firsthand how this often misdiagnosed cancer left people feeling isolated and unsure of where to turn. They galvanised support through their shared experiences, frustrations, hopes and determination.

What started around kitchen tables has blossomed into a national charity that advocates for patients and their families across the UK. Along the way, we have built a community where people affected by neuroendocrine cancer can find information, support and a sense of belonging to help them deal with the physical and emotional impact of this cancer. We have championed critical research, launched educational programmes for healthcare professionals and fought for earlier diagnoses and better treatment options.

While we are proud of these achievements, we have some way to go to achieve our goals. That is why we will continue to work with our community, healthcare professionals and other partners to drive improvements and bring about lasting change.

THE NEXT STAGE OF OUR STORY

We want neuroendocrine cancer to be a higher priority within the NHS, in government and across the wider healthcare system. We want to have a seat at every table where decisions about cancer are made, allowing the voices of our community to be heard, understood and acted upon.

We will continue to listen. Every step we take is shaped by the experiences of those affected by neuroendocrine cancer. Their voices are not just part of the conversation – they **are** the conversation. They will continue to be at the core of every decision, guiding our strategy and shaping our future initiatives.

2001

Living with Carcinoid

The foundation of what would eventually become Neuroendocrine Cancer UK launched, offering local support and guidance for those affected by neuroendocrine cancer.

2006

NET Patient Foundation

We evolved into the NET Patient Foundation, providing resources, support, and advocacy for individuals living with neuroendocrine tumours (NETs) across the UK.

2020

Rebranded to Neuroendocrine Cancer UK

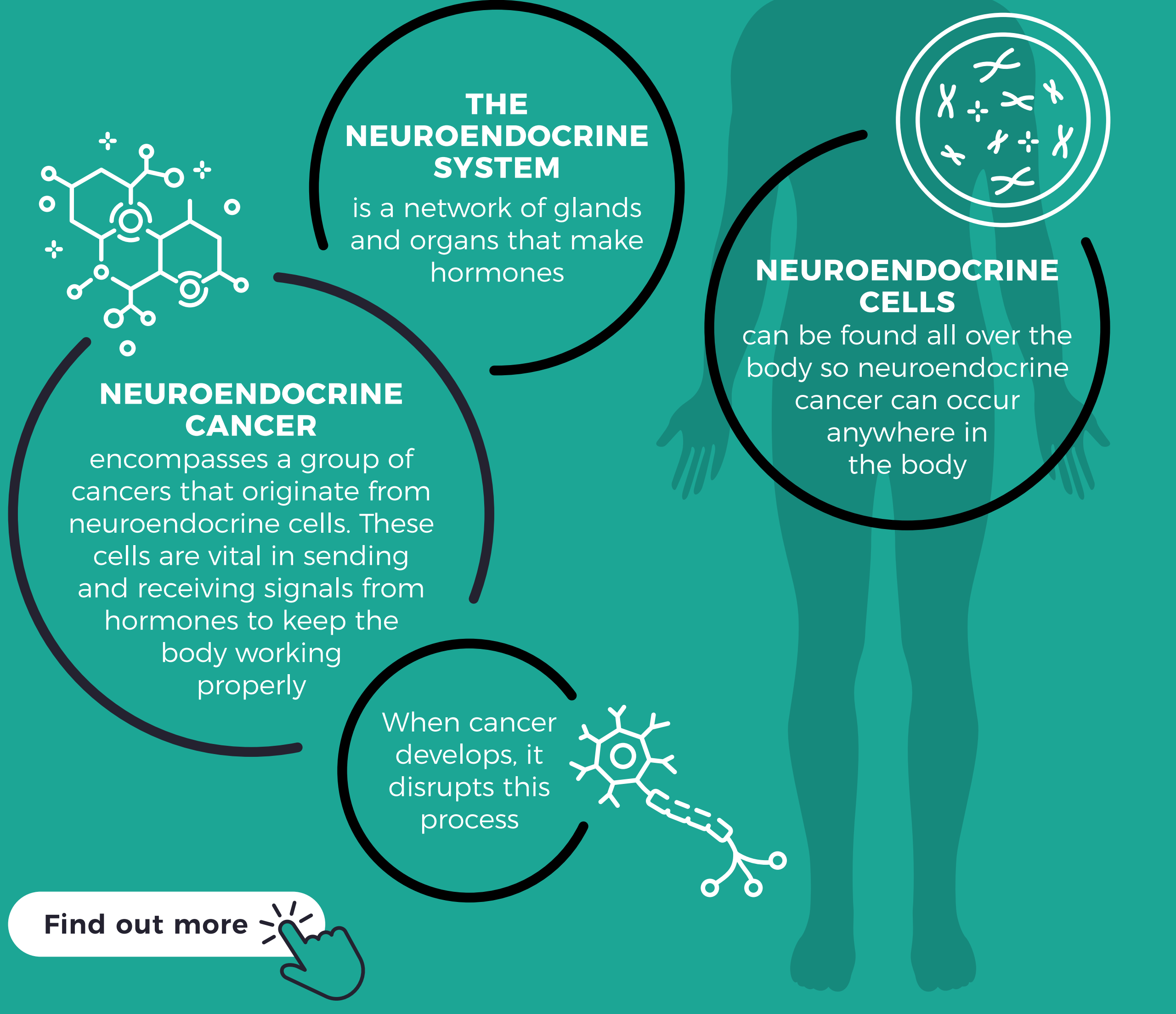
We rebranded to better reflect our community, reduce confusion around neuroendocrine cancers, and raise awareness, marking a key milestone in our mission to support those affected by NETs and NECs (neuroendocrine carcinomas).

2023

Integration with The Ann Edgar Charitable Trust

We incorporated The Ann Edgar Charitable Trust, which supported neuroendocrine cancer groups in Scotland for over a decade, enhancing our reach and resources in the country.

WHAT IS NEUROENDOCRINE CANCER?



THE NEUROENDOCRINE SYSTEM is a network of glands and organs that make hormones

NEUROENDOCRINE CELLS can be found all over the body so neuroendocrine cancer can occur anywhere in the body

NEUROENDOCRINE CANCER encompasses a group of cancers that originate from neuroendocrine cells. These cells are vital in sending and receiving signals from hormones to keep the body working properly

When cancer develops, it disrupts this process

Find out more

OUR IMPACT OVER THE LAST FIVE YEARS

> “Thank you so very much for supporting us all: your neuroendocrine tumour patients. **You have been there for us** to hold our hand, offer expert knowledge, advise and answer every question. I am extremely grateful to you. I have been on this journey for five years now. You have made it bearable.
>
> **Community member**

In 2022 we ran a survey of 880 patients which showed

48%

were not diagnosed after their first referral

Many had to visit their GP multiple times

29% returned **1-2** times

17% returned **3-5** times

7.5% returned **6-8** times

5% returned **8-10** times

16% returned **>10** times

The past five years have been shaped by unprecedented challenges – from the pandemic to ongoing economic uncertainty. Yet, through it all, our teams and community have sustained and strengthened our work, ensuring that vital support reaches those who need it most.

Some of this vital work has been visible through our services and initiatives, while other efforts have happened behind the scenes – shaping policies, building partnerships, and strengthening foundations to ensure everything we do is connected and impactful.

2019 – 2024 HIGHLIGHTS INCLUDE:

Provided vital support to over 6,000 people through our improved helpline and grew our network of support groups to 39 locations across the UK.

Funded 2,500 **counselling sessions**.

Developed and launched a centralised, interactive learning experience for neuroendocrine cancer patients and supporters – a **virtual handbook** designed for diverse learning styles – which was accessed 44,000+ times by 15,000 unique users in just 18 months.

Created a comprehensive competency framework for nurses, **earning Royal College of Nursing Accreditation**, that is now shaping future learning for nurses working with neuroendocrine cancer patients.

Developed a dedicated GP module on neuroendocrine cancer with The Royal College of General Practitioners.

Developed the first stage of an **NHS-integrated patient pathway**, improving access to care.

Funded a dedicated cancer analyst to map and understand the neuroendocrine cancer population across the UK.

Pioneered first-of-its-kind research on the incidence and prevalence of neuroendocrine cancer across the UK.

Provided £300,000 in seed funding to **help researchers** prove new concepts.

Increased social media engagement by

196%

and **grew our followers by**

221% across four platforms, significantly expanding our reach.

This included engaging

25,000+ **GPs**

through our **dedicated podcast** to raise awareness of neuroendocrine cancer.

WHAT WE WANT TO ACHIEVE BY 2030

PRIORITY 1

Support and care

A cancer diagnosis is one of life's greatest challenges, but for those diagnosed with a rare or uncommon cancer, the journey can be even more complex.

Neuroendocrine cancer patients face particularly tough realities: the chances of remission or cure are often limited, and unlike many other cancers, recurrence is highly likely, even when no visible signs of the disease remain after treatment. This makes long-term support essential.

From the beginning, we have provided vital support, guidance and care to the neuroendocrine cancer community. As we move forward, we will continue to do this while finding even more effective ways to help people navigate their diagnosis and live with strength and hope.

OVER THE NEXT FIVE YEARS, WE WILL

Continue to improve the quality of life for everyone affected by neuroendocrine cancer through enhanced support and care.

HOW WE WILL ACHIEVE THIS

- Expand our support by recruiting a third specialist nurse and increase mental health provision with our partners, Rareminds.
- Build a strong and sustainable Medical Advisory Board to guide our support team, ensuring they are fully up-to-date with the latest knowledge and skills in neuroendocrine cancer.
- Strengthen our community through online forums, patient support groups and our new Loop newsletter, building inclusivity and connection.
- Increase confidence in patients and empower them to understand and manage their healthcare pathway through webinars, improved support groups and an annual in-person event.
- Work with our patient ambassadors and wider community to gather insights on the most pressing needs of patients and their families.

DESIRED OUTCOMES

- All newly diagnosed patients feel informed and welcomed and know how we can support them from day one.
- Healthcare practitioners confidently signpost all neuroendocrine cancer patients to our services.
- Patients feel heard, supported and empowered to take control of their healthcare and wellbeing, leading to a better quality of life.
- Feelings of isolation and loneliness are reduced, replaced by a strong sense of belonging.
- A fully functioning support service where our helpline team is equipped with expert knowledge, ensuring patients receive the care, information and reassurance they need.

> I honestly wouldn't be here if it wasn't for the counselling, as I had no one to turn to …my counsellor saved me to be honest and I will be **forever grateful** to him and to NCUK.
>
> **Counselling and Psychotherapy Service feedback**

Today, neuroendocrine cancer is the 10th most prevalent cancer in England and the 2nd most prevalent gastrointestinal cancer

Neuroendocrine cancer patients often grapple with emotional distress due to delayed diagnosis, misdiagnosis, and the **unpredictable nature** of their illness

Accessing mental health support can be challenging, compounded by **low disease awareness** and misconceptions about the condition

We provide a wide range of **support services** including:

- Counselling and mental health
- Peer support groups
- Specialist nurse helpline
- Educational materials
- Welfare grants
- Patient educational events
- Monthly educational webinars and podcasts

PRIORITY 2

Education and awareness

One of our biggest challenges is the lack of awareness and understanding of neuroendocrine cancer among healthcare professionals, policymakers, and the public. This gap leads 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. But there is much more to do.

To drive lasting change, we'll increase our efforts with a focus on two key areas:

- Providing healthcare professionals with the knowledge and tools to recognise, diagnose, and manage neuroendocrine cancer effectively.
- Empowering patients with trusted information to make informed decisions, advocate for themselves, and engage in their care, while capturing their experiences to influence policy and improve outcomes.

By educating, informing, and influencing our community, healthcare professionals, and policymakers, we will close the gap and build a future where everyone affected by neuroendocrine cancer feels informed and empowered to access the care they need.

OVER THE NEXT FIVE YEARS, WE WILL

Increase engagement activities with key audiences to drive awareness, action and improved access to care.

HOW WE WILL ACHIEVE THIS

- Publish a State of the Nation Report to drive improvements in treatment and reduce disparities in care.
- Launch a new tool to gather real-world insights from our community, strengthening our campaigns and advocacy with lived experience data.
- Launch an outreach programme to better connect with hospital teams and GPs.
- Work with our community to redesign and launch a new user-friendly website ensuring patients and families can find accurate and evidenced-based information quickly.
- Forge partnerships that increase impact and reduce duplication.
- Expand resources for healthcare professionals and our community through campaigns, outreach, and a new online Education Hub.
- Run a targeted PR and marketing campaign to reach those who need to hear from and understand us the most.
- Define and champion five key policy priorities to drive long-term change.

DESIRED OUTCOMES

- Neuroendocrine cancer is officially recognised by the NHS as a distinct cancer type by 2030.
- Relevant healthcare professionals are equipped with the knowledge and tools to deliver the best care.
- Faster diagnoses meet NHS early diagnosis timelines, supported by a standardised care pathway.
- There is greater collaboration and less duplication – all focused on the best patient outcomes UK-wide.
- The NHS invests in centres of expertise, offering world-class, centralised care.
- Patients report having easier access to information, feel their voices are heard and are confident with managing their treatment.

Nationally, there is a **lack of awareness** and understanding of neuroendocrine cancer among medical professionals and the wider public, leading to later diagnosis

Diagnosing this cancer is challenging
it can affect almost any part of the body, show no symptoms or mimic common conditions such as IBS, asthma, menopause, or anxiety

> …and can I just say that your NCUK book online 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 …better than many commercial sites who have whole teams, departments and budgets for that kind of thing …**it really is superb**.
>
> **TH – living with neuroendocrine cancer**

It takes an average of **4.5 YEARS** for someone to be diagnosed with neuroendocrine cancer from the first symptom

More than **50%** of people are diagnosed at an **advanced stage** (Stage 3 or 4)

PRIORITY 3

Research and innovation

We are proud of the progress we have made through our research programme, including the creation of our own research grants. This has been achieved without funding from the government, NHS, or major cancer research charities. Currently, no national cancer research charities fund research into neuroendocrine cancer. We are determined to change this.

All our research activities have been entirely funded by the generosity of our community and supporters. But with cases of neuroendocrine cancer rising, the need for greater investment has never been clearer.

We are committed to increasing investment in research, embracing technologies such as AI to revolutionise diagnosis, and working to secure funding from national bodies.

Over the next five years, our focus will be on building our own research capabilities while creating a fairer and more sustainable future for neuroendocrine cancer research in the UK.

OVER THE NEXT FIVE YEARS, WE WILL

Increase investment in research by 100% to help us explore how new technologies and innovations can accelerate progress and bring us closer to our goals.

HOW WE WILL ACHIEVE THIS

- Develop a new research strategy that explores the potential of technologies like AI.
- Set up an internal research panel to build our research capabilities.
- Increase research collaborations with relevant organisations such as the Royal College of Surgeons.
- Launch a new fundraising campaign to drive research excellence. (See more under Income and Financial Sustainability).
- Plan and launch a research project to support the implementation of the Patient Pathway.
- Increase the reach of our published research to highlight the unmet needs of our community.
- Develop a tool to collect real-world data from our community which will shape clinical decision making.
- Carry out a survey to understand the research priorities of our patient community.

DESIRED OUTCOMES

- An independent neuroendocrine cancer UK research advisory board is established.
- Investment in research increases by 100% which prioritises community need over research preference, giving us greater influence over how research funding is used.
- New technologies are adopted to improve diagnosis and treatment.
- A more equitable share of national funding is made available to us.
- Collaboration increases and duplication decreases.
- Research priorities are shaped by the lived experiences, insights and needs of patients and their families.

Cases have **increased** by

371%

between 1995 and 2018

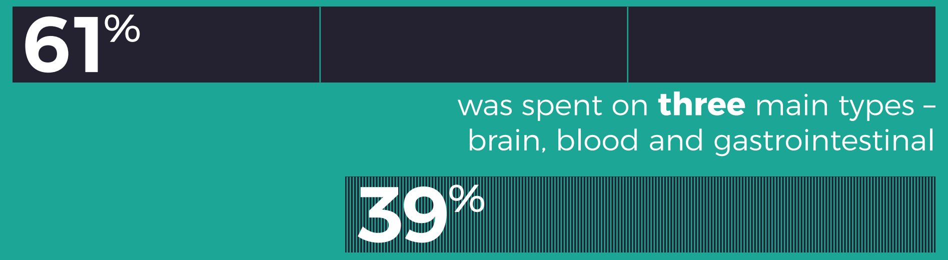
> I found the time between initial diagnosis and first treatment, and proper contact with a Centre of excellence, really really stressful. The helpline at NCUK was an **emotional lifeline**.”
>
> **RW living with neuroendocrine cancer**

Despite the **rise in cases** no additional research funding has been allocated to neuroendocrine cancer

In 2021

£179m

was spent on **research into rare** and less common cancers in the UK



was spent on **three** main types – brain, blood and gastrointestinal

was spent on **190+** other rare and less common cancer types

Neuroendocrine cancer is **not a priority** for the main cancer research charities

PRIORITY 4

Income generation and sustainability

Our work 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. Despite the challenges of the past five years, we've sustained our efforts through resilience and hard work. Now, we must go further.

To meet growing needs and maximise impact, we must expand and diversify our income. This requires a strong foundation for short-, medium-, and long-term planning, strengthening governance, improving efficiency, and investing in technology and expertise. By refining our strategy and operations, we can amplify our impact, enhance care, and drive groundbreaking research.

We must also find new ways to engage donors, supporters, and partners, strengthening relationships, inspiring generosity, and securing the funding needed to achieve our goals.

OVER THE NEXT FIVE YEARS, WE WILL

Increase income by 50% while improving efficiency and governance to secure long-term sustainability.

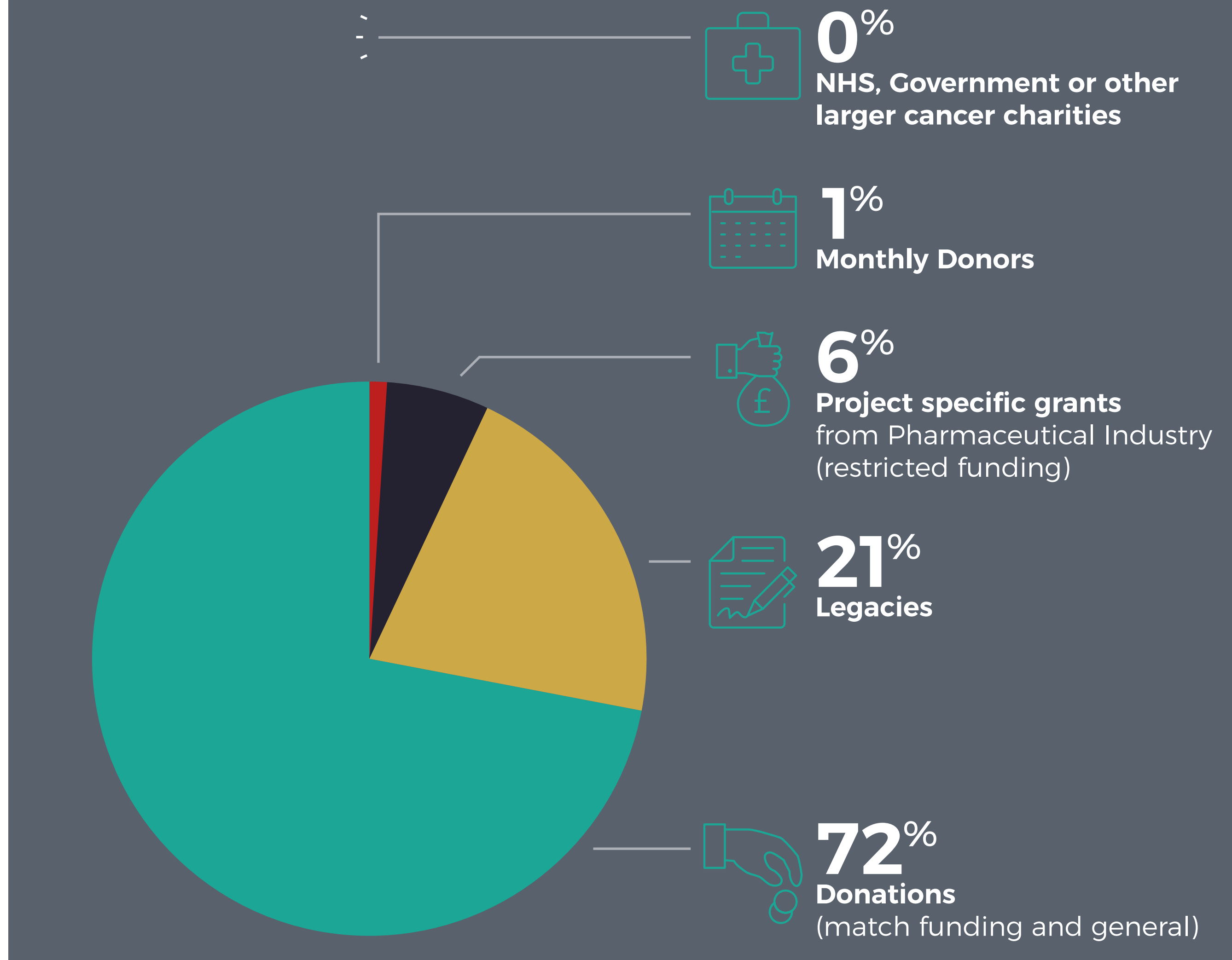
HOW WE WILL ACHIEVE THIS

- Strengthen governance, systems and processes to support our teams and mission.
- Future-proof the organisation through sustainable growth and clear succession planning.
- Maintain transparency by publishing annual reports and financial statements.
- Strengthen our fundraising team to grow our income by diversifying our funding base.
- Broaden corporate partnerships and adopt a more sustainable sponsorship model.
- Prioritise donor recognition to build lasting relationships.
- Integrate systems to enhance donor management and engagement.

DESIRED OUTCOMES

- Continue to be a financially sustainable organisation, providing support, education, and community to those affected by neuroendocrine cancer.
- Our research investment increases by 50%.
- We have the right expertise to deliver services, raise awareness and engage stakeholders.
- Our Board of Trustees grows by 40%, bringing in the skills needed to deliver this strategy.
- Financial reporting and succession planning are stronger and more strategic.
- We are a trusted and respected organisation that inspires confidence and generosity, encouraging people to support our work through regular donations.

WHERE OUR FUNDING COMES FROM



A FINAL WORD FROM OUR CHAIR

For approaching 25 years we have provided care and support for the neuroendocrine community. We have achieved so much – beyond the wildest dreams of the co-founders. We now look forward to addressing our refreshed priorities over the next five years.

Our CEO and Co-Founder, Cathy Bouvier-Ellis, has built a strong, focused, and dedicated team, backed by an experienced board of trustees, which is equipped to develop and deliver for our community. I am confident that with the continuing support of the neuroendocrine community – patients, supporters, healthcare professionals, partners, staff, and trustees – we can continue to transform lives. Please continue to support our mission. Your involvement truly makes a difference.

Thank you.

Peter Gwilliam
Chair of Trustees
and Co-Founder,
Neuroendocrine
Cancer UK

Neuroendocrine Cancer UK

Picture courtesy of totalwarrior.co.uk

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