

NET NEWS

JANUARY 2019 ISSUE 01



**TRAINEE
GP'S LEARN
ABOUT NETS**

PROFESSOR CAPLIN

"I have only given a flavour of what is happening but it is so exciting"

MIND THE GAP

Putting Quality of Life first

MOLECULAR GENETICS IN PNETS

Generating new drugs

RESEARCH ROAD TRIP

Encouraging researchers to focus on projects with greater impact on patient benefit



SUPPORTING THE NEUROENDOCRINE CANCER COMMUNITY

GLOSSARY

KEYWORDS:

- AAA - Advanced Accelerator Applications (A Novartis Company)
 - ACC - Adrenocortical Carcinoma
 - AMEND - Association for Multiple Endocrine Neoplasia Disorders
 - BTOG - British Thoracic Oncology Group
 - ENETs - European Neuroendocrine Tumor Society
 - EORTC - European Organisation for Research and Treatment of Cancer
 - ESE - European Society of Endocrinology
 - ESMO - European Society of Medical Oncology
 - EURACAN - European Network for Rare Adult Solid Cancers
 - INCA - International Neuroendocrine Cancer Alliance
 - MCC - Merkel Cell Carcinoma
 - MEN - Multiple Endocrine Neoplasia
 - NPF - NET Patient Foundation
 - NCRI - National Cancer Research Institute
 - NECs - Neuroendocrine Carcinomas
 - NENs - Neuroendocrine Neoplasms
 - NETs - Neuroendocrine Tumours
 - NETRF - NET Research Foundation (USA)
 - NICE - National Institute for Health and Care Excellence
 - NLCNF - National Lung Cancer Nurse Forum
 - PHE - Public Health England
 - pNETs - Pancreatic NETs
 - PROMs - Patient Reported Outcome Measures
 - QoL - Quality of Life
 - SFE - Society for Endocrinology
 - SSA - Somatostatin Analogues
 - UKONS - UK Oncology Nursing Society
 - UKINETs - UK and Ireland Neuroendocrine Tumour Society
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WELCOME FROM THE CEO



Catherine Bouvier, CEO, and the NET Patient Foundation Trustees

Hello!

As you read through this magazine, you will see that there are multiple components to running a patient organisation. We are a ‘small but vital charity’ doing a wide range of activities, ensuring that the message we are shouting gets heard across many platforms, with the ultimate goal of working in a truly collaborative way, with compassion, and providing the best care for all affected by Neuroendocrine Neoplasms (NEN). Yes you read it - a change of name! The World Health Organisation, in 2017, changed the classification of what we know as NETs. Now the umbrella term for all neuroendocrine tumours and neuroendocrine carcinomas is Neuroendocrine Neoplasms. We are still using NETs, it’s in our name! We will be updating our materials.

You will read about our main pillars of work and the interesting work of many of our partners and supporters. One of our key outcomes is to ensure that all the cogs in the NEN pathway are listening to the patient’s perspective and focusing conversations on Quality of Life: how we can all best help patients manage and live with their illness. We have undertaken work this year looking at the overriding emotions of a NEN diagnosis and have seen clearly that Quality of Life is a personal perception, that differs between people even with the same clinical condition. We need to feed this work, time and time, again into the inboxes of those treating NEN patients. Advocacy organisations have an essential role to play, working in partnership with the medical community to identify issues and improve diagnosis, care and research. The quality of communication between the patient and the medical team has an enormous impact on the quality of care. Understanding each other’s perspective is the key.

We couldn’t progress our work without the support of our volunteers, our dedicated trustees, our Patron, Professor Martyn Caplin, our advisory board, our fundraisers, and sponsors. A heartfelt thanks to them all, and we hope to keep developing strong relationships with the key stakeholders in NENs, keep pushing an agenda for change and improving our organisation to meet the needs of our community.

We have only included a snapshot of our work and the work of others, but do hope it is a valuable read!

Catherine Bouvier
CEO, NET Patient Foundation

#LETSTALKABOUTNETS



NET PATIENT FOUNDATION
SUPPORTING THE NEUROENDOCRINE CANCER COMMUNITY

Working with Experts

Raising Awareness



SERVICES THAT WE PROVIDE



Specialist NET Nurse Helpline



Information Guides & Videos



NET Natter Support Groups



Research Grants



Counselling Service



Patient Education Events



Facebook Support Groups



Handy Wallet Cards



netpatientfoundation



netpatientfound



netpatientfoundation

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SOME OF OUR PLANS FOR 2019

RESEARCH

We cannot put services into place for a community without understanding the unmet needs of that community, and our in house research projects are a valuable way to obtain important data. Thank you so much if you have contributed to questionnaires and surveys. Working alongside pharmaceutical companies and researchers, is also vital, collaborating to give patients improved access to optimal, kinder and quicker treatments that are personalised to their disease. Below are some examples of this years projects:

- Publishing the first ever UK wide epidemiology and survival statistics data
- Publishing data on secondary cancers and NETs
- Increasing funds to boost our research grant fund to support more projects
- Engaging with researchers to encourage patient involvement at a much earlier phase
- Publishing results of the research surveys and Research Road Trip experience.

EDUCATION

- Developing a dedicated healthcare professional section on our website
- Producing 17 updated fact-sheets
- Producing new Lung NET patient information
- Holding 4 patient education events, including the first Merkel Cell Carcinoma patient event
- Promoting education about NETs within the medical school curriculum
- Development of healthcare professional resources
- Driving the development of competencies for nurses caring for NET patients.

AWARENESS

- Forming a new patient media panel and expand our patient involvement group
- Promoting NPF Coffee Mornings and Walk for NETs
- Launching the Faces of NETs campaign
- Attending critical conferences
- Continuing our awareness programme within medical schools around the UK
- Increasing our reach and engagement with the NET community.

SUPPORT

- Developing our NET Natter support groups in collaboration with Maggie's Centres across the UK
- Hosting Facebook live chats covering specific areas of concern
- Launching a new mobile self management tool in the form of an App
- Initiating the 'MIND the Gap' project. This will be a primary focus of our support work. For many people the 'what comes next' is the hardest part and for NET patients living with uncertainty is a consistent and persistent challenge. The reality of cancer long term can be an anxiety ridden place, and we have to help patients carry, not only the physical but also the psychological burden of disease.

ADVOCACY

- Continuing our work with INCA and Cancer52 on issues around policy, research, access and information
- Working with Professor John Ramage and ENETs, to produce a patient experience questionnaire that can be used throughout the specialist NET Centres across Europe
- Lobbying for Telotristat to be commissioned in the UK
- Ensuring that NET information is updated and clear on the NHS website
- Liaising with NHS England, to encourage inclusion of a non-specific pathway, that will be support earlier diagnosis for NET patients through the Rapid Diagnostic Centres.

In 2018, our helpline was a lifeline to hundreds of people affected by NETs, who needed personalised information and emotional support from our specialist nurses at a difficult time. Hundreds of email and telephone enquires were handled by our nurses, ranging from questions about diagnosis, support management, symptom advice, treatment options and practical support.

We have other services which may be of interest to those who do not feel the need to use our helpline services, including video guides, which can be found on our YouTube channel: [NET Patient Foundation](#)



We are a small but vital charity and rely on the generosity and kindness of people like you to continue supporting the Neuroendocrine Cancer community.

Please visit www.netpatientfoundation.org to make a donation and help us to be there for more patients and their loved ones.

THANK YOU!

LUNG NETS (NENS)

We are about to embark on some really important work relating to the support of patients with Lung NETs. This will include a patient survey to understand the unmet needs in this patient group, a new information pack for patients diagnosed with a Lung NET and working towards the first patient education day dedicated to patients living with a Lung NET.

CAN YOU HELP?

We are looking for patients to get involved with this project to ensure the information is fit for purpose and to share their experiences of living with a Lung NET. Please email Catherine, if interested: catherine@netpatientfoundation.org

“WHERE WE ARE WITH NETS TODAY”

*Professor Martyn Caplin, Professor of
Gastroenterology and Neuroendocrine Tumour Biology
at the Royal Free Hospital London and University College London.*



Twenty years ago Cathy Bouvier, our NET Nurse at the Royal Free Hospital at that time, with patients including the late highly acclaimed Liddy Gwilliam (nee Oldroyd) and her husband Peter started the first NET Patient Support group “Living with Carcinoid”. We all loved that name as it encompassed the concept that if you could not be cured by surgery then we would endeavour to optimise living with the NET and trying to get on with a normal life as much as possible. Terminology changed so carcinoid was replaced by neuroendocrine tumour (now neoplasm) and Cathy, through her success as a NET nurse and with the patient support group went on to found, with Peter and wonderful patients Andy Geach and Cathy Kalamis, the NET Patient Foundation. Under Cathy’s outstanding leadership, NET Patient Foundation has grown into perhaps the most important as well as leading national NET patient support group in Europe. I like to look back because it is a chance to remember so many patients (too many to mention) and their families and the contribution so many have made in different ways. Sometimes in medicine it is easy to highlight technological and medical advances and forget that the patient is the “reason why”. Additionally those technological and medical advances need to include not only optimising patient outcomes from therapy but also optimise Quality of Life. That should also include optimising the experience of the patient’s family or carers who are an integral part of this journey “living with NET”.

The NET Patient Foundation not only supports patients and families, provides top quality information and enables appropriate referrals, it also funds and coordinates research into NETs and collaborates with the UK & Ireland NET Society as well as International Patient Groups and Societies. What a fantastic job Nikie, Lindsey, Leanne, Kulli, Bal and the team of trustees do. NET Patient Foundation truly advocates for patients at local as well as national and international level including UK and European

Parliamentary levels. These are exciting times. The last 10 years has seen crucial trials demonstrating the benefit of Somatostatin Analogues (Octreotide and Lanreotide) for symptomatic and tumour control; the benefit of molecular targeted agents such as Everolimus and Sunitinib in Pancreatic NETs and the former also in Gastrointestinal and Bronchial NETs; and most recently the benefit of PRRT with Lutetium-177 DOTA Octreotate for gastrointestinal NET. NET Patient Foundation is important because the pharmaceutical companies need patient support in promoting and endorsing such clinical trials from the earliest developmental times as well as the crucial role, for example, the NET Patient Foundation played in getting Lutetium-177 DOTA Octreotate approved by NICE. NHS England and NICE are currently reviewing the drug Xermelo which is a tablet for controlling the diarrhoea of Carcinoid Syndrome. The political role of NET Patient Foundation cannot be underestimated. There are other randomised clinical trials ongoing, for example, looking at a new form of Lutetium-177 therapy with Lu-177 Edotreotide vs Everolimus; and another study assessing the best order to give therapy in Pancreatic NET (SEQTOR study) with chemotherapy first then Everolimus or vice versa. There are a whole host of smaller phase II studies with many new agents targeting specific molecular sites within the tumour. Of course, you will all be aware of immunotherapies and certainly, there are encouraging results in specific groups of NET patients, often those with more aggressive tumours. There are many types of immunotherapy, the question is which type works best, and could immunotherapy be better in combination than alone.

Such clinical trials are crucial but when the drugs are so expensive, perhaps as important, is the research to determine which patients are going to be most suitable for a specific treatment. The future is moving in this direction, whereby understanding the genome of patients with NETs may be able to predict which

treatment might work best. However the genetic and epigenetic (i.e. other outside factors and chemicals affecting the DNA) changes associated with a NET, can change with treatment as well as environmental factors. I am sure that the microbiome (billions of bacteria) within the gut will be an important source of understanding not only its effects on gastrointestinal NETs, but also the impact on the functioning of the immune system. The advances in blood tests related to circulating DNA or RNA and even circulating tumour cells are all incredibly important to determine which type of blood test could be the most helpful in predicting growth of tumour or relapse as well as perhaps response to therapy. Currently the new NETest® is being advocated as a prognostic and predictive marker in NETs and may be a better tumour marker than the current chromogranin A. It is undergoing a number of clinical trials to see how accurate it is. The advances in imaging especially PET imaging with Gallium-68 Octreotate PET, particularly for the lower grade NETs, has already transformed management and of course, there are experimental advances for identifying insulinomas with Gallium-68 Exendin imaging. The quality of CT and MRI has continued to improve as well as endoscopic techniques.

I have only given a flavour of what is happening but it is so exciting. The importance of being able to demonstrate that each advance is worthwhile in terms of diagnosing and treating patients is a challenge and one needs to take into account the impact on Quality of Life. There is also only so much money within the NHS, thus being able to demonstrate cost-effectiveness is also important, and choosing the most appropriate patients for the most appropriate treatment at the right time is key. Multidisciplinary collaboration continues to have to be the way forward between different medical and surgical specialties but also to involve for example dietitians/nutritionists and also specialties such as psychologists. The specialist NET nurse is central not only often to coordinate but also to act as the interface between patients and their medical teams.

NET Patient Foundation is a source of information and help to patients and doctors, but perhaps most of all, it is a strong and loud voice for the patient so that the NET patient is heard at the highest levels, within the medical services and within government. It is a privilege for me to play a part in the NET journey and a privilege for me to be a patron of NET Patient Foundation.

Best wishes to patients and carers for good health and good support and continued progress as we try to beat this cancer.

Martyn Caplin

WHO WE WORK WITH

We are a small organisation and to achieve our aims we must work collaboratively with other key organisations.

Our closest collaborators are:

AMEND
Cancer 52
ENETs
INCA
Maggie’s
UKINETs
Victory NETs

Other organisations we work with are:

AAA (A Novartis Company)
ESE
ESMO
IPSEN
MERCK
NOVARTIS
ONO
SFE
UKONS



Catherine and Teodora (INCA) picking up best poster prize at ESMO

NET PATIENT FOUNDATION RESEARCH

The NET Patient Foundation undertakes in-house research as well as supporting external clinical trials. We recognise the patient voice in research is vital. This voice is a hugely underused expertise in research and we thank every one who has contributed to any of the research that we have undertaken or supported. Advocacy groups are working globally to increase the patient contribution in research.

Examples of NET Patient Foundation's research projects:

1. We understand that being a NET patient often involves intermittent visits to hospital. But most of the time you are at home, managing your condition in the community. In 2017 we started a project looking at the support needs of NET patients and their families in the community, outside of the hospital setting. Several focus groups were held to discuss what the issues are and to give us an idea of what questions we should be asking. We presented these in a poster at UKINETs in December 2017 and won best poster in the category **'Living With and Beyond NETs'**. This year we invited NET patients to take part in an online survey about support, the feedback has been absolutely invaluable and we are very grateful to anyone who took the time to complete the survey or take part in the focus group.

2. 'MIND the Gap' - this is a 2 year project, undertaken with our psychotherapy service. The main aim is to raise awareness and to fill the gap (or huge void for some) in terms of the reality of cancer long term. This can be an anxiety ridden place, and we have to help patients carry, not only the physical, but also the psychological burden of disease. There are 9 major themes within this project, ranging from living with uncertainty to managing communication with your medical team.

3. Development of an **EORTC Quality of Life** questionnaire for patients with **Pancreatic Neuroendocrine Tumours**. This international study aims to create a Quality of Life questionnaire for patients with Pancreatic Neuroendocrine Tumours (pNETs). This study is funded by the EORTC, the NET Patient Foundation and Pfizer. The lead site for this project is Hampshire Hospitals, Professor John Ramage. There are 7 UK sites set up and 7 International sites.

4. PanDA | Pancreatic Cancer Dietary Assessment - Prospective study to assess the impact of embedding a dietician into the pancreatic cancer clinic; pro-active identification and treatment of pancreatic enzyme insufficiency to improve outcomes for patients with pancreatic malignancies.

The main aims of the study are:

- The early identification of those "at risk" of malnutrition
- Early and appropriate intervention
- Promotion of Quality of Life (QoL)
- Improve treatment tolerance and positively influence treatment outcomes.

This study is funded by the NET Patient Foundation and Pancreatic Cancer UK.

The lead site is the Christies Manchester, Professor Juan Valle.

5. PHE Partnership Project - this has been a huge project for us and work has finished on the initial interrogation of Public Health England Dataset on NET patients, along with registries in Northern Ireland, Wales and Scotland. We are hugely grateful to all the contributors from each registry, and to our medical working group for their commitment to this project. To date UK information about incidence, prevalence and survival of persons with Neuroendocrine Neoplasms (NENs) has been lacking. From our completed work, this information is now available for the first time and our finalised paper has been sent for publication.

Other 2018 collaborative publications are:

- Delays and Routes to Diagnosis of Neuroendocrine Tumours - R Basuroy, C Bouvier, J Ramage, M Sissons and R Srirajaskanthan BMC Cancer (2018)18:1122
- Prevalence of Self-Reported Side Effects in Neuroendocrine Tumour Patients Prescribed Somatostatin Analogues - T Whyand, C Bouvier, P Davies, Br J Nurs. (2018) Jul

55% of all cancer deaths are caused by rare of less common cancers. Despite this, these cancers remain severely under represented and under funded across all areas, including policy services and especially research

WANT TO FIND OUT ABOUT CLINICAL TRIALS FOR NETS CURRENTLY RUNNING IN THE UK?

VISIT THE RESEARCH SECTION ON OUR WEBSITE

The NCRI Clinical Studies Groups (CSGs) have been in existence for more than 10 years, and are a central part of the UK's cancer research infrastructure. There are 18 CSGs that bring together clinicians, scientists, statisticians and lay representatives to coordinate development of a strategic portfolio of trials within their field. All CSGs interact with clinical research networks, funders and researchers to develop studies aimed at improving outcomes for patients. In addition to the 18 CSGs, there are also 3 Advisory Groups that provide ad hoc advice to the CSGs, and others, on developing clinical trials.

Lindsey, NPF's Research Nurse, and Paul, a patient representative, sits on the NET NCRI Group. Lindsey also sits on the MCC NCRI Group.

NET PATIENT FOUNDATION/ UKINETS RESEARCH GRANTS

The NET Patient Foundation and UKINETS had two £25,000 grants to award in 2018 and we are delighted to share with you details of the two winners.

The TRACERx

TRACKing Cancer Evolution through therapy (Rx)

One of the winners of the UKINETS / NET Patient Foundation grants is a member of the TRACERx team. Further information about the TRACERx project can be found below. This project gained our support through its inclusion of all lung cancer variants specifically Lung NETs.

The TRACERx (TRACKing Cancer Evolution through therapy (Rx)) lung study is a multi-million pound research project taking place over nine years, which will transform our understanding of non-small cell Lung Cancer (NSCLC) and its variants, now to include Lung NETs, take a practical step towards an era of precision medicine. The study will uncover mechanisms of cancer evolution by analysing the intratumour heterogeneity in lung tumours from approximately 850 patients and tracking its evolutionary trajectory from diagnosis through to relapse. At £14 million, it's the biggest single investment in lung cancer research by Cancer Research UK, and the start of a strategic UK-wide focus on the disease, aimed at making real progress for patients.

Led by Professor Charles Swanton at UCL, the study will bring together a network of experts from different disciplines to help integrate clinical and genomic data and identify patients who could benefit from trials of new, targeted treatments. In addition, it will use a whole suite of cutting edge analytical techniques on these patients' tumour samples, giving unprecedented insight into the genomic landscape of primary and metastatic tumours and the impact of treatment upon this landscape.

In future, TRACERx will enable us to define how intratumour heterogeneity impacts upon cancer immunity throughout tumour evolution and therapy. Such studies will help define how the clinical evaluation of intratumour heterogeneity can inform patient stratification and the development of combinational therapies incorporating conventional, targeted and immune based therapeutics.

Intratumour heterogeneity is increasingly recognised as a major hurdle to achieve improvements in therapeutic outcome and biomarker validation. Intratumour genetic diversity provides a substrate for tumour adaptation and evolution. However, the evolutionary genomic landscape of non-small cell lung cancer (NSCLC) and how it changes through the disease course has not been studied in detail.



Molecular Genetics in PNETs

The other worthy winner is Kate Lines, a PostDoctoral Researcher, who works at the Radcliffe Department of Medicine in Oxford, alongside Professor Raj Thakker. She is continuing her work on molecular genetics in Pancreatic Neuroendocrine Tumours.

"I am delighted and very grateful to have been awarded NET Patient Foundation award at this years UKINETS meeting. I am very much looking forward to beginning the study. As an early career scientist this grant is especially important as the data generated from the project will help form the basis of my future NET research career".

"The aim of the project is to develop a new drug for the treatment of Pancreatic Neuroendocrine Tumours (PNETs). We have previously shown that a drug called JQ1, which inhibits the function of a family of proteins called the BET family, could reduce the number of PNET cells in the laboratory. This family of proteins help to control the expression of genes that promote tumour cell growth and prevent tumour cell death, by binding to chemical marks in specific DNA regions, also known as epigenetic regulation. Therefore, by inhibiting the activity of the BET proteins we were able to prevent the cell growth and increase cell death.

Although JQ1 has shown promising results in PNETs, similar to a chemotherapy, it can act on any cell that expresses the BET proteins, and therefore may have side effects. The focus of this study is therefore to generate a new drug that specifically targets JQ1 only to NET cells or tissues. To do this we are using a man made version of the hormone Somatostatin,

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

called a Somatostatin Analogue. Receptors that Somatostatin binds to are only expressed in certain endocrine tissues, and are seen in high levels in PNETs. Therefore by making a drug with a Somatostatin Analogue joined to JQ1, we plan to target JQ1 only to the PNET cells. We will test the ability of this new Somatostatin-JQ1 drug to reduce the number of PNET cells. If successful, the ultimate aim is to use this data to plan a clinical trial of the Somatostatin-JQ1 drug in PNET patients."

NET PATIENT FOUNDATION CLINICAL FUND

The NET Patient Foundation clinical fund supports:

- Research into patient focused issues related to patient experience and equality of care
- Vital basic clinical research in the UK with our partners at UKINETS
- Nurse and dietetic research
- Quality of Life research
- Psychosocial research
- Epidemiology research.

AN INTERESTING PIECE OF RESEARCH IN NETS!

Will the ability of a Dutch molecular geneticist to build miniature human organs in a Petri dish solve a decade old problem in NET research? How the tiniest laboratory replicas of your small intestine might help scientists run a dress rehearsal to see if your next treatment will work.

THE BIRTH OF THE ORGANOID

A little more than a decade ago, Hans Clevers, MD, PhD, Hubrecht Institute, the Netherlands, made an important discovery. He invented a way to activate the adult stem cell in the small intestine. Using a protein called Lgr5, Dr. Clevers' laboratory jump-started the stem cell into performing its essential function of repairing and regenerating lost cells. With this finding, Dr. Clevers' team started growing human organs in a dish to serve as a platform for testing.

They isolate a single stem cell from a tissue sample (healthy or cancerous) and put it in a dish with a gel containing growth factors. The cells replicate and generate new cells. As they expand, they self-organise into the structure of a mini-organ or organoid.

THE QUEST FOR A NET LABORATORY MODEL

Researchers use laboratory models to understand cancer cells and to test new treatments. But it has been difficult to produce laboratory models for Neuroendocrine Tumours. One reason is that the tumours are widely different from one another (called heterogeneous). The slow growth of these cells also serves as a major obstacle in conducting efficient and accurate laboratory experiments. For these reasons, there are only a few preclinical models available to study NET treatments.

NETRF has been involved in the quest to develop a reliable laboratory model for more than a decade. This void is a major obstacle in moving research forward, and it sets NETs apart from other cancer types in being able to achieve progress.

"Being able to create stable and reliable intestinal NET organoids from tumor tissues, that are able to expand indefinitely, will be a major breakthrough in the field of Neuroendocrine Cancers," said Effie Tzamelis, PhD, NETRF Director of Research. "For the first time, we will have a precious laboratory tool to use for different types of experimentation."

THE POTENTIAL OF THE ORGANOID

NETRF awarded Dr. Hans Clevers a 2017 Accelerator Award, the largest and longest research grant, providing funding for three years to test organoids in NETs. Dr. Clevers will study organoids made from healthy and NET cells to understand how cancer cells develop. He and his team will try to isolate what genomic mutations or cellular communication errors occur. If they identify what goes wrong they will then try to recreate that error using a gene-editing technique called CRISPR/Cas9. Reproducing the formation of NET cancer cells will help confirm the exact path of the disease.

Once the cancer cell development process has been mapped, researchers will look for an opportunity to interrupt this incorrect cellular cycle. They call this an actionable target. Therapies have been developed to act upon specific targets or genomic mutations, for example, by turning cell signaling on or off, that is, sending the incorrect instruction to create cancer cells.

Organoids can serve as an efficient way to test various therapies in the laboratory (preclinical testing) for large-scale drug testing. The technology could also be used to advance precision therapies. An individual's tumor tissue, obtained from a biopsy, could be used to grow a person's own organoid. Researchers could then test a therapy on the person's organoid first to see if it works. That could help improve the safety, efficiency, and precision of care for individual NET patients.

AIM

To identify outstanding research needs for the benefit of patients with neuroendocrine tumours and neuroendocrine tumour syndromes and to devise a research strategy for the same.

BACKGROUND

Jo Grey (AMEND) and Cathy Bouvier (NET Patient Foundation) discovered that 85% of research currently undertaken is useless and wastes around \$85 billion per year.

THE ASSOCIATION OF MEDICAL RESEARCH CHARITIES (AMRC) STATE

AMRC members funded over £1.6 billion of medical research across the UK in 2016, the biggest proportion of public funding, compared to £1.04 billion from the National Institute for Health Research, and £0.93 billion from the Medical Research Council.

This funding stimulated more than £500 million in further investment during 2016 from international funders, government funders, industry, universities and other charities, including donations from members of AMEND and the NET Patient Foundation Community - THANK YOU. Aisling Burnand MBE, Chief Executive at AMRC commented: *"At a time when there is uncertainty about the potential impact of Brexit on the UK's medical research sector, it is vital that charitable funding can continue to have such impact. Small and medium sized medical research charities are struggling with the challenges they now face in a time of changes to fundraising practices and uncertainty about the future of research when the UK exits the EU."*

The NET Patient Foundation and AMEND realised that they had no clear research strategies, and no clear understanding of all the research in NETs taking place across the UK. We read about the work of Myeloma UK, which changed from a grant-giving patient advocacy charity, to one that commissions its own research based on patient need. They built a clinical trials network, which is more focussed on patient need; prioritising research according to their strategy.

AMEND and the NET Patient Foundation would like to emulate this work, to a degree, by visiting clinical researchers around the UK. This fact-finding exercise will help to identify what different types of research is being undertaken, with a view to prioritising funding to those projects that show a likely higher benefit to patients. Understanding what our patients felt were research priorities is a key mission.

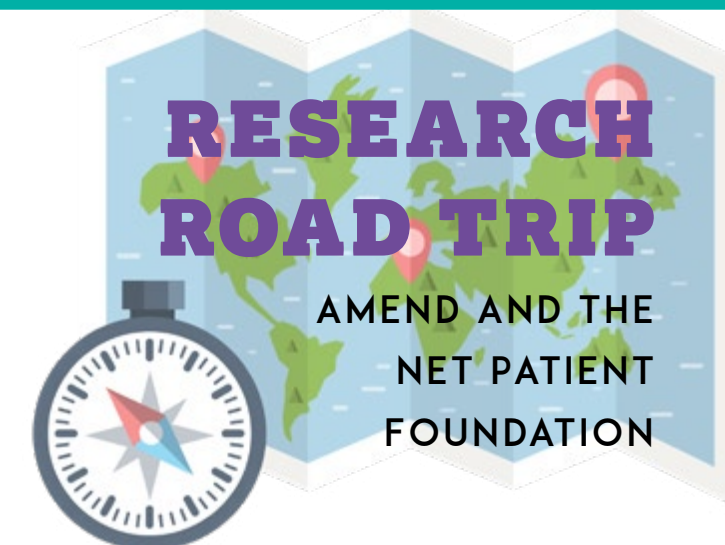
ACTIVITIES

There are 3 key activities that need to be undertaken in order to produce a research strategy for NETs, NECs, MEN, ACC and MCC:

1. Survey of patient need and perceptions of priorities in NET research
2. Survey of researchers perceptions of priorities in NET research
3. Development of a research network for NETS.

OUTCOMES

1. Understand the needs of the patient community with regard to research
2. Gain a complete understanding of the research landscape in the UK
3. Understand whether or not current research is in line with patient expectation
4. Encourage researchers to focus on projects with greater impact on patient benefit with regard to NETs, NECs, MEN, ACC and MCC
5. Set up an independent research network/organisation/charity to act as an independent decision-maker with regard to research focus.



We are half way through this project and the survey is now live on our website. So please HAVE YOUR SAY!

NEW MEDICINES

The NET community had success in gaining access to new medicines, and this provided a huge relief for all. However, there is still much work to be done to improve the development, access and commissioning of new innovative medicines for NET patients.

Here is a summary of medicines approved in 2018:

SCOTLAND

The Scottish Medicines Consortium have approved lutetium 177Lu oxodotreotide (Lutathera) for patients in NHS Scotland.

The Scottish Medicines Consortium (SMC) kindly thanked NET Patient Foundation and all the NET patients who got involved and shared their experiences.

SMC: "We would like to thank you for the time and effort taken to produce your submission. Capturing the views and experiences of patients and carers is an important part of the SMC process and plays a key role in helping our Committee reach its decisions. We hope that your patient group will welcome this decision".

ENGLAND

The National Institute for Health and Care Excellence (NICE) has recommended Lutetium (177Lu) oxodotreotide, within its marketing authorisation, as an option for treating unresectable or metastatic, progressive, well-differentiated (grade 1 or grade 2), Somatostatin receptor-positive gastroenteropancreatic neuroendocrine tumours (NETs) in adults. Issued by NICE, as guidance, on the 29th August.

Thank you to all the patients, medical professionals and industry groups who fought so hard for this.

WALES

The All Wales Medicines Strategy Group has recommend Telotristat ethyl (Xermelo®) as an option for restricted use in NHS Wales to treat Carcinoid Syndrome diarrhoea in combination with Somatostatin analogue (SSA) therapy in adults inadequately controlled by SSA therapy.

95% of all clinical trials result in failure. We need to focus on new approaches to clinical trials in rare and uncommon cancers. Re-purposing drugs and the use of real world - time data to test drugs should be used to speed up the adoption of new treatments and discount those who do not work



TOWN HALL PASSES MOTION TO TACKLE RARE CANCERS

Hackney Council has unanimously resolved to work with local GPs and local NHS Trusts to do more to tackle neuroendocrine tumours (NETs) and other rare cancers.

In moving scenes at a full council meeting in October 2018, councillors were asked to raise their hands if someone in their life had received a cancer diagnosis, and keep them up if they had lost someone to the disease.

The vast majority of the chamber kept their hands in the air.

Cllr Rebecca Rennison (Lab, Kings Park), cabinet member for finance and housing needs, who made the motion, spoke of the need to raise awareness around NETs and other rare and uncommon cancers, which make up almost half of all cancer diagnoses. Cllr Rennison said:

"Cancer is something that affects all of us, but people rarely seem to talk about it.

I had two family members diagnosed with cancer a couple of years ago, almost at the same time. This is something that touches all of us, it is so important to raise awareness and to save lives.

We see lots of talk of the Big Four of Breast, Lung, Bowel and Prostate Cancers, but all too often rare or less common cancers come as an afterthought. That can't be the case anymore."

Her motion to the council was seconded by Cllr Yvonne Maxwell (Lab, Hoxton West), who added:

"Aretha Franklin was Queen of Soul and Steve Jobs, King of Apple Macs. Their deaths made headlines everywhere, but few people know they both died from NETs".



Nikie, NPF nurse and Hackney Councillors

**Can you help us raise awareness with your local council?
Do you know a local councillor?
If so, please email
catherine@netpatientfoundation.org**

WHAT ELSE HAVE WE BEEN UP TO?

BTORG

January 2018

Presenting patient experience of living with a Lung NET and highlighting the significant differences in cancer types.

Kent NET Education

February 2018

Regional pharmaceutical sponsored education event for Healthcare Professionals. Covering all aspects of NETs, including a patient support talk from our NET Patient Foundation nurses.

ENETs Barcelona

March 2018

Annual European NET conference providing an opportunity to network with our European colleagues and share information and clinical updates about advances in NET care.

Society for Endocrinology: Clinical / Nurse Update

April 2018

Information and education stand to raise awareness and educational opportunities to learn more about NETs.

Adrenocortical Carcinoma (ACC) Day

May 2018

Joint initiative between the NET Patient Foundation and AMEND to support those living with ACC.

EURACAN

June 2018

Attending annual meeting as advocates for NET patients throughout Europe and driving the EURACAN initiative forward

Facilitators Day

August 2018

An opportunity for our wonderful NET Natter Facilitators to get together, share stories and receive training on the challenges of running a support group.

ESMO

October 2018

Large European cancer conference with an advocacy focus. We presented a poster with International NET Cancer Alliance (INCA) on unmet needs in NETs, using data from the 2016 survey that many patients contributed to. We were delighted that our poster had won the Best Poster prize for its category.

Nurse Training Day

October 2018

Annual training day supported by IPSEN to share experience and knowledge with nurses and dieticians to improve outcomes for NET patients.

NLCNF

November 2018

Presenting an overview of Lung NETs to lung cancer nurses from across the UK.

NETs Masterclass Berlin

November 2018

Presenting initial data from our 'MIND the Gap' project to medics from across Europe.

Newcastle NET Cancer Day Event

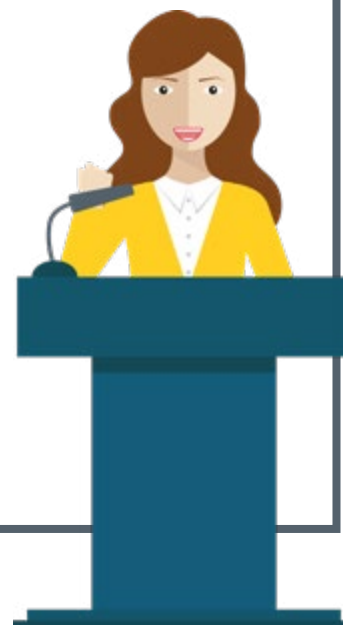
November 2018

Regional pharmaceutical sponsored event for Healthcare professionals, organised by Angie Williamson (Newcastle NET Clinical Nurse Specialist). This event was well attended by both primary and secondary care staff.

UKINETs

December 2018

We attended the 16th UKINETs annual conference. This included dedicated sessions on Lung NETs, personalised medicine and nutritional issues for patients from diagnosis, through treatment to follow up. Our Research Nurse, Lindsay, presented her work on MCCs in poster format.



NET NATTER SUPPORT GROUPS



NET Natter Support Groups are local community based meetings that offer an opportunity to meet others in your area, who are also affected by Neuroendocrine Cancer; patients, family, friends and supporters.

They are run by nurse specialists, fellow NET patients and/or local volunteers. Each group agrees its own format, in accordance with the NET Patient Foundation's guidance, and are run as informally or formally as the group is comfortable with.

All groups offer refreshments and are free to attend - some meet monthly, others 6-8 weekly or quarterly, once/twice a year.

Those who attend the meetings tell us how important these groups are to them - how meeting others in a similar situation, with the same or similar diagnosis, symptoms, treatment plan or follow up, helps to reduce feelings of anxiety or isolation, improves understanding and creates new friendships and support.

"I have been working, as a Clinical Nurse Specialist, with people diagnosed with malignant Neuroendocrine Tumours (Neuroendocrine Cancer) since 1999.

During that time, and since joining the NET Patient Foundation in 2015, I have seen how this group of cancers impacts on all aspects of everyday life - from the shock of diagnosis to the uncertainty of the future, from managing symptoms to dealing with long term follow up - from feeling alone to becoming part of a community.

Many people have told me how isolating they feel their diagnosis is, how misunderstood it is by others. The NET Natter Groups provide a safe place to meet others - kindred spirits, who "get it" and who understand.

My ambition is to try to ensure that every NET patient, new or old, has that opportunity - knows that they have somewhere they can turn to for information, advice and support. Our joint hope and aim is to make sure that everyone here in the UK has access to support - by phone, on-line or face-to-face through our fabulous NET Natter Groups".



Nikie Jervis,
Patient Support Manager (RGN, PGDip)

Details of our groups, venues and contact details can be found on our website: www.netpatientfoundation.org

To find out more, please contact our NET Nurse Specialist Team:
Nikie and Lindsey:
Helpline: 0800 434 6476
nurses@netpatientfoundation.org

"We had our NET Natter meeting today. I really must say, it was one of the best meetings we have had. It was so easy to chat, we all came away with so much information, all questions were answered, and we are all looking forward to the next meeting"



INFORMATION PACK FOR NEWLY DIAGNOSED PATIENTS

Have you, or a loved one, recently been diagnosed with a NET? If so, our resources provide clear, up-to-date and accurate information, which can help patients make informed decisions and know what to expect.

Our patient pack for newly diagnosed patients contains a USB wristband which includes informative videos and a comprehensive guide to life with a Neuroendocrine Cancer. It also contains details of how we can support patients including: details of our local NET Natter Support Groups and of our Specialist NET Nurse Team. We are working on other valuable materials to add to this pack.

MERKEL CELL CARCINOMA

7% of all NETs are Skin NETs, more commonly known as Merkel Cell Carcinoma or MCC. To add to the distress of being diagnosed with this rare cancer, MCCs are aggressive with explosive growth rates, and both the tumour and treatments can be physically disfiguring.

One of the biggest challenges for those with rare or less common cancers is finding support and consistent, reliable, accurate information. The NET Patient Foundation worked closely with the MCC medical community and patients to produce a dedicated MCC patient information guide which is available via the NET Patient Foundation website and has been distributed to centres around the UK.

You can download the guide on our website
www.netpatientfoundation.org

In 2018, the NET Patient Foundation conducted a global survey to establish what support needs this group of patients have. The survey was live on the NET Patient Foundation website from March 2018 - May 2018 and publicised via social media. Results showed that many patients were not getting written information and their main source of support was other MCC patients via online forums. It was a concern to us that MCC patients at their most vulnerable feel they can only turn to social media for advice and support.

If you would like to order our free patient information, please visit our website and complete an order form

To receive more information on the launch of this App, then please subscribe to our newsletter by 'Joining our Community' on our website

LOOK OUT FOR OUR NEW MOBILE PHONE APP IN APRIL 2019

Throughout 2018, the NET Patient Foundation, UKINETs, patients and a group of NET Consultants and Clinical Nurse Specialists have been designing and developing a 'free-at-the-point-of-use' novel patient centred Neuroendocrine Tumour mobile phone application ('App') to help patients manage their disease and record Quality of Life.

The App will be 'life-useful' and will simplify day-to-day administrative management, providing a resource for information about the disease, the patients' NET care team and their medications. In addition it will be a powerful, accurate repository of information specific to the patient, one that they are likely to always have with them in case of emergency admissions or contact with healthcare professionals. In this way patients own their disease information and can be empowered to better self-manage, without being specifically required to undertake behaviour modification.

The second aspect of the App will be to enable clinical teams to capture Quality of Life (QoL) data and Patient Reported Outcome Measures (PROMS) to review, monitor and develop care and NET service. Over time with uptake of the App by all centres in the UK, we could hope to obtain PROMS data and QoL for the whole disease cohort. This would be valuable for assessing health impact of NETs in patients and giving healthcare professionals a better understanding of the long term impact of being diagnosed and living with NETs.

Along with our partners at UKINETs, the NET Patient Foundation aims to launch the App in April this year.

"This is a great idea and i think the patients will love it! It will be excellent to engage the patients in Quality of Life and symptom reporting".



"This would be brilliant and incredibly useful, especially for those who are being monitored on a 6 monthly basis, as its not always easy to remember all your symptoms".

QUALITY OF LIFE - LET'S OWN IT!

Mark Zwanziger, Patient Diplomat



On 29 August 2018, The National Institute for Health and Care Excellence (NICE) published their first “positive” guidance on Peptide Receptor Radionuclide Therapy (PRRT) in England. On this day, thousands of NHS England patients now had access to this fantastic treatment. The main weapon in fighting the disease that has become inoperable. On that day, Catherine Bouvier met with Mark Zwanziger over lunch to discuss lessons learned from the NICE appraisal of Neuroendocrine cancer treatments (Lanreotide, Sunitib, Everolimus, and Lu-177 Lutathera PRRT (now being called Oxodotreotide).

This was a very long lunch! There were dozens of lessons learned from this appraisal process that at times looked like an impossible task. Mark's comments started with, “isn't this great? Even with today's climate of political stalemates, fiscal challenges of the NHS, health care challenges of pathways, and the rising rates of cancers (including NET cancer) the government, drug companies, charities, research groups, doctors, and patients can come together to get things done. This proves it! It isn't perfect or all-inclusive yet, but it is a long way from 2015 when the treatments were cut from the NHS England.”

The team consisted of AAA (A Novartis Company), NET Patient Foundation, NET Cancer Consultants and Mark as “the patient expert”. The NET Patient Foundation plans to do a series of interviews from these players, and provide their story of how they got here and where they are going next. Since he was here for lunch, I'll start with Mark Zwanziger our patient rep on the appraisal team.

BACKGROUND

Mark is originally from Nashua, Iowa in the US. He joined the US Air Force at 18. Having served in America for the majority of his career, he was posted to the UK (Dec 1998) and spent his last 4 years

of active duty stationed at RAF Molesworth in Cambridgeshire. After meeting his wife, Lesley, he settled in the UK, continuing to work at RAF Molesworth as a defence contractor (2002-2012). Mark now lives in Oundle, Northamptonshire with his wife, and has two daughters in the US, a stepson and a step-daughter in the UK. He's very proud that all four children have completed post-secondary school degrees: the youngest is a junior doctor who graduated from Kings College in London.

PATIENT HISTORY

Mark started to notice a series of symptoms prior to his diagnosis including diarrhoea, night sweats, unexplained rashes, panic attacks, inability to concentrate, pain in his right side and tiredness. These symptoms went on for at least 10 years and eventually a diagnosis of a well differentiated neuroendocrine tumour with liver metastasis was made in 2007.

After 70% liver resection surgery in 2008, along with surgery to remove the primary tumour, and monthly Lanreotide (Somatostatin), Mark was relatively stable until 2011 when scans revealed the cancer had progressed and was now inoperable. He was referred to the Royal Free Hospital, London for treatment options.

While waiting to hear from the Royal Free he searched the United States for options, and met with Dr. O'Dorisio at the University of Iowa. It was there he learned that the treatment he needed (PRRT) was not available in the US yet, but that Europe had it. “You need to get the wizard's attention”.

Shortly after meeting with Dr O'Dorisio, Mark was contacted by the Royal Free in London as a “private patient”, and received three Y-90 treatments. (Unbeknown to him, slots had opened up during the “postcode lottery” period for the NHS).

When he learned of how the slots opened up, he vowed to himself that somehow, he would do his best to make this right.

His health insurance through the whole illness has been complicated. For example, his time in the UK up to May 2012 was under a “Status of Forces” VISA, and this meant he was not covered by NHS, but had international corporate insurance. Since 2012, he has been in the UK under sponsored dependent status VISA, and has paid the NHS surcharge. But, since his treatment wasn't authorised by NHS, his care is currently paid for by USAF retired military TRICARE insurance and his life savings.

He acknowledges, he is in a very fortunate position to have received the healthcare he has, and sincerely believes he is here today because of his treatment with a form of PRRT. He also believes in the UK health system (NHS & private), and that America can learn a lot from the UK and vice versa. All of this insurance experience has come in very handy as it has provided him with cost data the normal NHS patient never sees. This would prove crucial during the NICE appraisal.

THE APPRAISAL HISTORY

The conditions of NHS fiscal troubles deteriorated further in 2015 when Lu-177 therapy was removed from the Cancer Drugs Fund, and was no longer available to any NHS England patients. This was quite a blow to the entire NET community, as Lu-177 was at a crucial evaluation point with both the US Food and Drug Administration and European Medicines Agency process. It would not look good if, the UK as a world leader in this treatment deemed it too expensive. The main weapon in managing “incurable/inoperable” NET cancer was being eliminated. You either needed private insurance or a lot of cash. It was possibly only a matter of time before insurance companies could also declare the treatment too costly as well.

This news came in the middle of Mark's Lu-177 treatments in 2015. Mark felt this just couldn't be right. His Quality of Life on the PRRT was exceptional. Especially since discovering a lot of what he thought was treatment related radiation sickness or effects of the cancer, was actually diabetes. “They all feel very similar”. It was also at this point the nuclear pharmacist administering the treatment told him, “Mark, I've just given a NET patient his 13th round of PRRT”. To Mark, “this could mean, approximately 10 years before I need a treatment that hasn't been

invented yet”. This was where his mindset changed from “exit strategy” to “extremely active”.

The desire to explain QoL developed when Mark started working with the NET Patient Foundation on how to rectify this decision. He had a strong belief that there would come a day for an appraisal, and somebody needed to be ready to demonstrate the potential benefits of the treatment. This was well before he'd ever heard of NICE.

To do that, he needed to raise his profile in the patient community. So, despite having had knee surgery 4 times and hating running - Mark ran - he ran 10Ks, a half-marathon, and the London Marathon (2016) for the NET Patient Foundation. Now he had proof. 3 hours 150 minutes of proof of QoL improvement.

Later in 2016, NICE announced a combined appraisal of Lanreotide, Sunitib, Everolimus and Lutathera (Lu-177) for Neuroendocrine Cancer patients. Mark applied to be the patient expert on the NICE panel, and was nominated by the NET Patient Foundation on the back of the demonstrated improved QoL of running the London Marathon. Mark understood the decisions NICE had to make, and he compares this to the commanders and senior government officials he has worked for in the US military, watching them make tough decisions (some right and some wrong), but knowing that the right data was vital to inform them and send them down the right path. But, this was the first NICE appraisal for the NET cancer community, and we were quite unprepared for the complexity and time the process would take.

“I think the biggest lesson for patients in the NICE process is a basic understanding of the ICER (Incremental Cost Effectiveness Ratio)”. This takes the emotion out of the equation, and provides a fair way of approving treatments without bankrupting the NHS. Here are six very basic points of the ICER:

- 1-QALY = Quality of Life Year
(Progression Free Time x QoL)
- 2-ICER = QALY/Cost
- 3-<£10K Doesn't need to meet NICE board
- 4-<£20K Almost automatic approval
- 5-£20K-£30K Approved if revolutionary
(which PRRT is)
- 6->£30K RARELY Approved.
- Just look at petitions with 115,000 breast cancer patients unable to budge.
- This line is “seriously” firm!



Catherine Bouvier, NPF CEO & Mark

WE LOST THE FIRST BATTLE

The “unfair” part of this ICER is what is included in the treatment. For example; room, imagery, the treatment, blood work, Lanreotide or Octreotide, etcetera. The drug companies submitted their ICERs and “assessment group” submitted their estimates against the “scope” of the appraisal stated by NICE. Sometimes these ICERS weren’t even close. This “scope” was complicated, and without a NET cancer specialist on the NICE board it was a situation where the panel had to side with their assessment group. It is quite a frustrating fact of life in government evaluations, and it resulted in a “negative” ruling on Lu-177. The other drugs (Lanreotide, Sunitib, and Everolimus) were subsequently approved through separate evaluations.

To Mark, “the NET cancer appraisal looked like we had missed our opportunity, and it felt like we had missed a two-foot putt. As a team and a NET community we were devastated. It was horrible, really horrible. We had failed!”

Mark wants to be clear, “NICE is not the enemy”. It is amazing to him, that every NHS person he talked to seemed to believe in NICE, and their word was the “circle of trust” of the entire system. This doesn’t feel like a “willful blindness” situation. It really is at the core of what makes the NHS great! And, this ICER formula may be called other things in other countries, but the issues are the same for insurance companies or personal finance.

THE 2ND BATTLE

Fortunately, NICE recognised the value of Lu-177 and instead of a “hard no” ruling (which would have meant a three year wait to meet NICE again), they split Lutathera off the combined appraisal, and

reevaluated in 2017. “But, we knew the ICERs were still too high, and somehow, we needed to get that down”. Mark’s theory is, “This was basically a two-part solution. First, the drug companies and NICE negotiated price. With Novartis’s help, AAA worked it out with NICE.

The second part was the “Quality of Life” index used in the ratio. Lu-177 was not getting the credit it deserved in having a higher Quality of Life than chemotherapy. Something everybody knew, but was very difficult to quantify. NETTER-1 trial data was excellent, but even it is getting old. “We’ve learned a lot of lessons since. So, there was a rush behind the scenes to get up-to-date Quality of Life data “published”. To do that, it first had to be briefed a major conference, and it was. I don’t know exactly the whole story of how this happened, but this was a heck of an effort to get this data published in June 2018”. Please note: the 2nd appraisal had a NET cancer expert (Endocrinologist) on the panel (this is something Cathy and Nikie took as a key action from the start – this was a “big win” for NETs). “In fact, he is the one that asked for “up to date” QoL data. We managed to get it close enough”. As a layman’s guess, Mark knew “this was a very close decision to the £30K cutoff published by NICE”. His computations of his own ICER based on his insurance costs was almost double this cost. “Every tidbit of information on QoL was going to count”. Even the patient testimony. For example, the side effects of treatment, such as requiring insulin to manage the high blood sugars caused by steroids. A review with his consultant led to him doing the last four rounds of Lu-177 with only Ibuprofen for pain relief.

How would this lesson affect NETTER-1 trial data on QoL? This could be the difference. Meanwhile leaders in NET research looked for other trials that better defined QoL, and they did through a combination of studies like ERASMUS and the new QoL data published on the control of diarrhoea. Some of the actions to find the right data seemed “right out of a court room drama.” This was the eye opener to Mark, “As patients, we need to own the Quality of Life (QoL) index used in the NICE ICER formula. Just as the drug company is responsible for the cost and the research and trial researchers own the data of progression free survival data and hazard/risk ratios. This is our power as patients. The ICER is a ratio that is fair, but is a bit ambiguous. A QoL index changed by a couple of tenths of a point

can drop the ICER by thousands of pounds and this can change a decision very quickly. I’ve done some research into the NICE recommended measurement of QoL, ‘EQ-5D-3L’ appears to be very simple. We could do this every month we take our Sandostatin LAR shot for example. We can and need to own this data, and we need to make sure the patients know this is more than another checklist. We have to ensure their buy-in.”

For Mark’s NICE submission, he shared what he had mapped out as ‘my own QoL profile’, with the Lutathera treatment has received, and what he believes is possible for his life. He didn’t know that ‘retreats’ weren’t part of the appraisal. “So, we have more work to do! But, the seed has been planted.”

LESSONS LEARNED

Mark believes “This fight is all about proving treatment worthiness, staying focused on cancer as the enemy. The enemy isn’t other types of cancers, patients or the NHS or government or drug companies. That is what the military calls “blue on blue”. We need to bring the patient community together, be proactive and make sure that Quality of Life is visualised. So, each and every individual can focus on living with this cancer to the highest ‘quality’ as possible. As patients, we do have power. The appraisal was a tough, but a valuable lesson for us. Not just for NHS patients, but all patients. Insurance companies use ICERS. What could the impact be for all cancer patients if their QoL index is not accurate? This is big!”

POWER OF THE PATIENT

Mark also wants to state, “An eye opener to the patient community should be; there were only two people in the appraisal room that could make points to anyone. One was the head of the panel, and the other was the patient. The patient that meets this board in the future needs to be trained and advised on this power and the skills of diplomacy. When the decisions are this close, everything counts.

This process works. Researchers, charities, administrators, government, drug companies, assessment groups, and patients can work together to get things done. This proves it! The connections I made through this process have been unreal, and I intend to keep them strong. I’ve talked to Cancer Research UK policy advisors, NET Research

Foundation, Breast Cancer Now, friends in the NHS, medics, medical students, faith healers, mind-control gurus, Church of England vicars, patient expert handlers from NICE, and the drug companies themselves. It is amazing what you can learn when you take off a self-label of victim.”

“This NICE decision was one of the greatest experiences in my life”, says Mark. “I made mistakes, almost every player in the appraisal did. But, humility and humanity did come through in the end. Maybe the biggest mistake I made was thinking I would be done when it was finished. I see now, we are only getting started! We need to educate patients on the QoL index, and it is surprisingly simple. We need to look at owning this data from trial through approved treatments. More hard decisions are surely on their way. Surely new drugs will face the same scrutiny, and justifications will be constant in tightening budgets. We cannot become complacent.”

This vision is a long way from the time his Carcinoid Syndrome kept him on the toilet for hours and panic attacks had him questioning his own mortality and sanity. But, he capitalised on his positive outlook to take advantage of the time, and taught himself to play the guitar! Now he plays in his rock band ‘The Acoustic Supper Club’ (Fleetwood Mac inspired), and his latest QoL demonstration was at the Oxford NET Cancer Ball on 10 Nov 2018.



Lindsey Devlin, NPF Nurse & Mark



FACES OF NETS

Over 40,000 people are affected by Neuroendocrine Cancer in the UK, with over 5,000 people newly diagnosed each year. That is more than 13 people a day. For many the first time they will have heard about Neuroendocrine Cancer will be the day they receive their diagnosis.

WE NEED TO CHANGE THAT

Whoever you are - a Neuroendocrine Cancer patient, a carer, a friend, healthcare professional or a loved one - you have the power to take action and make your voice count. It's time to spark a new conversation about NETs so that all of our voices can be heard and amplified.

WE NEED YOUR HELP

The power of social media means that each of us have the opportunity to connect with more people which can help carry our messages to get more people talking about NETs! Faces of NETs is here for you to share your own thoughts, stories and opinions on social media to help create a wider and deeper conversation about NETs across the UK.

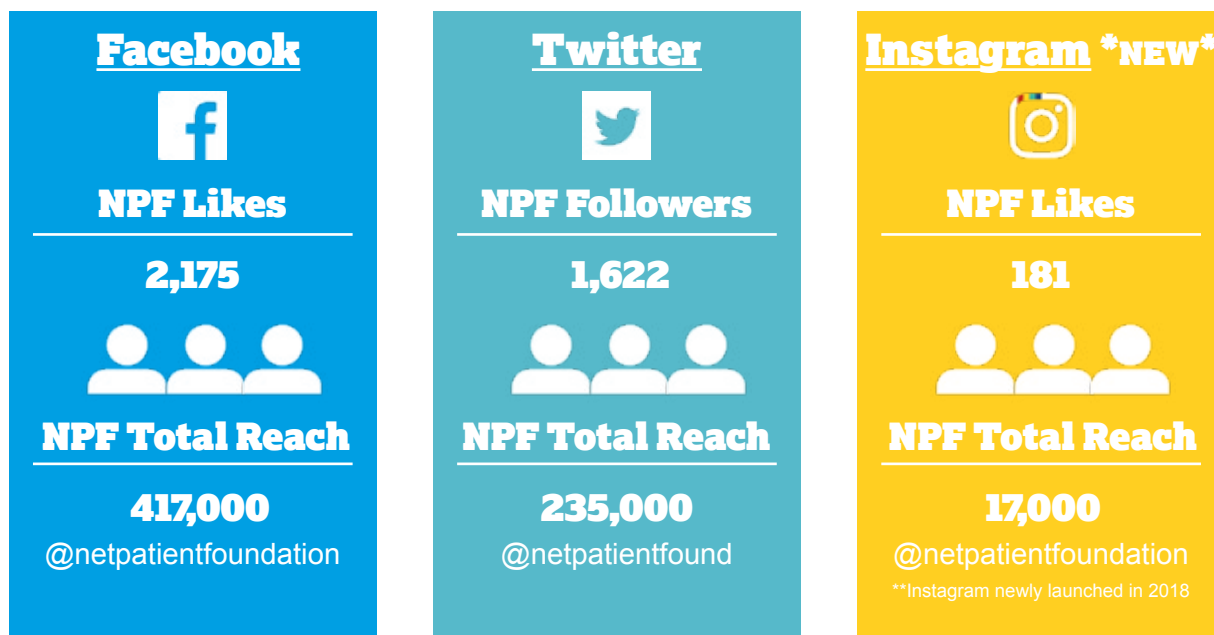
MAKE YOUR VOICE COUNT

Join our Faces of NETs campaign by sharing your thoughts and a picture of yourself, or something meaningful to you, on social media using the hashtag **#FacesOfNETs**. All posts using **#FacesOfNETs** will be collated into our virtual gallery on our website - www.netpatientfoundation.org. By uniting online and tagging your posts with our official hashtag we hope to continue building understanding around this uncommon cancer and help others know they are not alone.

NOT ON SOCIAL MEDIA?

Don't worry, you can make your voice count! You can either upload your picture and your Faces of NETs story directly to our virtual gallery on our website or send us an email (hello@netpatientfoundation.org) and we will upload it for you.

How are we doing on social media?



NET CANCER DAY 2018

GLOBAL AWARENESS CAMPAIGN

NET Cancer Day is an annual, awareness-raising event coordinated by The International Neuroendocrine Cancer Alliance (INCA) and comprises of representatives from 20 countries.

NEUROENDOCRINOLOGISTS OF THE FUTURE As part of our NET Cancer Day activities in 2018 we reached out to the 'Neuroendocrine Doctors of the Future' by inviting medical schools across the UK to get involved! This campaign was inspired by one of our patients, Brian. Here's what Brian had to say: *"This is a great opportunity to get our message across to the people who need more understanding about this form of cancer. The level of interest I received was amazing, as was the level of ignorance about the condition. Please volunteer to help us to help ourselves. Thank you and stay strong"*.



Carol, Chris, Angela and Bill manned a stand at The University of Cambridge School of Clinical Medicine

Throughout the month of November our patient and supporter volunteers manned stands across the UK sharing their stories and raising awareness of NETs to medics and aspiring new medical students. Perhaps inspiring future career pathway choices leading to the speciality of NETs.

Thank you to all those who were involved in the 2018 amazing campaign! To all who would like to repeat or get involved this year then please let us know.



The NPF and Oxford NET Natter Team at the Oxford Black & White Ball

OXFORD NET NATTER PATIENT EDUCATION EVENT & BALL

Over 100 patients and supporters attended a patient education event, arranged by our NET Natter Oxford Group, learning more about new treatments, surgery, genetics and the psychology behind NETs. After the event we had an evening of dancing, raffle prize winning and a silent auction at a Black and White Ball where £10,000 was raised for the NET Patient Foundation and Maggie's. A massive thank you to all those who donated and attended this wonderful event.



Janet's coffee morning

NET PATIENT FOUNDATION COFFEE MORNINGS

We also asked our supporters to hold a coffee morning to help raise awareness of Neuroendocrine Cancer and help us to continue providing community support to anyone affected by NETs. We had a phenomenal response. A huge thank you to all who got involved. Check out our website for more details on our 2019 coffee morning.



PATIENT EDUCATION EVENTS

We hold patient education events across the UK, which are open to anyone affected by a NETs. These events are free to attend and include talks from NET experts. The events provide an opportunity to meet other patients / supporters who are in a similar situation.

"Today my partner and I attended the patient education meeting at Prospero House which provided a generous amount of information relating to NETs.

As someone fairly newly diagnosed, I was impressed by the amount of technical information given, while extremely grateful that the top specialists were willing to come and explain so many issues involved in the treatment of NETs."

Topics covered can include: Diet and nutrition, the psychological aspects of NETs, new treatments, current research and of course, general information about NET types, grading, staging and most importantly time to ask questions to an expert panel.

We cannot run these meetings without the support of the wonderful healthcare professionals, who give up their time to share their knowledge and expertise.

EVENTS TAKING PLACE IN 2019

MANCHESTER

January 2019

LONDON

May 2019

CORNWALL

September 2019

LEEDS

November 2019

EVENTS THAT
TOOK PLACE IN 2018

NORTHERN IRELAND
LONDON
OXFORD
NEWCASTLE

**To be notified
of upcoming events,
subscribe to our
newsletter**

AWARENESS SESSIONS FOR HEALTHCARE PROFESSIONALS AND PROVIDERS

Did you know there are over 20 cancer site specific learning outcomes for junior doctors and over 65 cancer sub types. Neuroendocrine cancers are not on that list!

One of the NET Patient Foundation's key pillars and aims is to increase national awareness of NETs and positively influence improvements in support and outcomes.

We are strongly committed to providing and encouraging educational awareness initiatives that target audiences from all aspects of health and social welfare provision - from primary care to councils, to specialist expert centres and research units.

In December, following our medical school initiative, we were invited to deliver a "NET training session" to a group of (about 40) Yr2 GP trainees at the Big C Centre, Norfolk and Norwich.

This gave us an amazing opportunity to not only raise awareness of Neuroendocrine Cancer with the next generation of primary care physicians, but also gain a better understanding of their perspective and informational needs.

We not only received very positive feedback, but also an invitation to come back in 2019!

"Very interesting and frightening to think of the times we may have missed a diagnosis!"

We look forward to building and further developing this training initiative, including the formation of an education team to help deliver sessions across the UK. We already have FY1 and FY2 Junior Doctor sessions in the diary for the Autumn, with further activities in discussion and development.



FUNDRAISING

The NET Patient Foundation is dedicated to providing support and information to anyone affected by NETs. From diagnosis, throughout treatment and beyond, our team and our services are here to offer patients, and their loved ones, with guidance, support, education and information.

We are here every step of the way - whether it's over the phone, on our website or a chat in person. But we couldn't be here without your support. We rely on the generosity and kindness of people like you to provide our vital services to the NET community.

There are over 5,000 people diagnosed with NETs each year in the UK. It costs us approximately £1,000 to provide all of our support services to one patient for one year. We receive no government funding - all of our services are funded by donations from people like you, through grants and corporate support.

We want to be there for more patients and their loved ones so we know we need to do more, but we can't do this alone.



Andy has been fundraising for the NET Patient Foundation since his mum was diagnosed with a NET in 2014

Your donations, no matter how big or small, will help us to get one step closer to reaching our vision of a world in which people know how to recognise, diagnose, treat, care for and ultimately cure patients with Neuroendocrine Cancer.

MAKE A DONATION

Last year we helped more than 3,000 people. By supporting the NET Patient Foundation with a monthly donation, you can help us to be there for more patients at their time of need. Together, we can make sure that no one faces Neuroendocrine Cancer alone.

**Please set up
a monthly
donation
today. Visit
our website
for more
details**

"I didn't know anything about this type of cancer so I reached out to the charity to learn more. It took my mum almost two years from the first symptoms to being diagnosed with Neuroendocrine Cancer, and it opened my eyes that this could happen to anyone. I don't want anyone to be in the same position. Since 2014, I have been partaking in a number of fundraising events and hope to continue in the future to do whatever I can to get NET Patient Foundation and NETs the funding and coverage they deserve".

CORPORATE SUPPORT

Does your company have a Charity of the Year scheme? Could you hold a bake sale, dress down day or an NPF Coffee Morning in your office to help raise funds for the NET Patient Foundation?

As a small charity, we need your help to secure support from companies as these partnerships make a big difference and help us to support more people affected by NETs.

Any company, regardless of size, can choose to support the NET Patient Foundation and there are lots of ways that your company can get involved. Please get in touch with Bal, our Communications and Fundraising Officer to find out more. Email bal@netpatientfoundation.org.



F1 Real Estate Management take on the 3 Peaks Challenge in memory of their colleague, Alison

THANK YOU!

Last year our supporters went above and beyond to help raise funds for the charity. Holding danceathons, sponsored walks, hikes, skydives, mudruns, discos, craft stalls and so much more! We are immensely grateful for all of the support.

Our fantastic fundraisers also put on their walking boots and took part in our Walk for NETs 2018 campaign. Sponsored walks were held all across the UK and collectively raised an incredible £10,000!

A huge thank you also to everyone who took part in NPF's Coffee Morning 2018. The amazing array of delicious treats raised over £8,000 for the NET Patient Foundation!

Want to take part in the NPF Coffee Morning or Walk for NETs 2019? Sign up to our newsletter to receive updates and more information about all of our fundraising events.

GET INVOLVED

There are so many other ways that you can support NPF from running a marathon, skydiving or simply asking your local shop to put one of our donation tins on their counter.

Our fundraising pack is filled with ideas on how you can get involved and tips to make your fundraising a huge success.

Email bal@netpatientfoundation.org to get your free fundraising pack or visit www.netpatientfoundation.org

NEWS FROM AROUND THE GLOBE

INCA International
Neuroendocrine
Cancer Alliance

2018 has been a year of growth and success for the International Neuroendocrine Cancer Alliance (INCA), as we strive for better research, standards of care, treatment and outcomes for NET patients around the world. Collaboration is the key principle underlying INCA work. Being an umbrella organisation of 20 patient advocacy and research groups from around the world, it is only by employing its network and effective partnerships with its constituents, that INCA can truly represent the global NET patient voice. As one of the INCA founding members, NET Patient Foundation UK has contributed massively with its knowledge, experience and commitment, to asserting INCA's role over the years.

World NET Cancer Day 2018 reached an even larger audience than ever before through more translations and reinvigorated website, and provided a fantastic platform for patients and carers from around the globe to get involved and talk about NETs. #Letstalkaboutnets, which has built significant momentum over the 3 years of consistent effort, generated over 12 million impressions across Facebook, Twitter and Instagram in the 2 weeks leading to NET Cancer Day.

GLOBAL PATIENT RESOURCES

Bringing the findings of this research closer to all relevant stakeholders is a key priority, with a focus on reinforcing collaboration with the expert medical communities, INCA has committed to improve information for patients and education about NETs for healthcare professionals, as well as encouraging more support for research with a stronger patient voice and more funding to

help patients be active partners in the treatment process. To overcome the language barrier and spread the messages to as wide audience as possible, INCA has undertaken translating of the White Paper and all visual collateral including infographics and videos into 7 languages, on top of English. The resources are now available in Chinese (Mandarin), German, English, French, Italian, Japanese, Spanish and Russian to ensure further reach of INCA Unmet Needs Initiative. This assessment was supported through a grant from the Neuroendocrine Tumor Research Foundation (NETRF), a non-profit charitable organisation and INCA member, and the translations of all unmet needs materials were funded through the NETRF grant, as well as grants from Novartis, Ipsen and Pfizer.

This year INCA has been represented at all major medical society meetings, to voice the patient perspective.

PUBLICATIONS/PRESENTATIONS:

- ESMO – Best Poster Award
- NANETS – e-poster presentation
- APNETS – oral presentation
- ENETS Conference 2019 – abstract submitted
- European Society of Endocrinology Newsletter (Autumn edition 2018) – published feature article by INCA on the significance of collaboration with the medical experts in the context of the unmet needs survey findings.

MEETINGS AND PRESENTATIONS:

First Global NETs Leadership Workshop – INCA Unmet Needs Initiative highlights – Simone Leyden, Palma de Mallorca, 29 November.

ENETS Advisory Board 2018 – INCA 2018 Achievements Update – Teodora Kolarova, Palma de Mallorca, 29 November.

2nd International Conference for Organisations Representing People with Chronic Lymphocytic Leukemia (CLL)–CLL Horizons & the 3rd International Conference for Organisations Representing People with Myeloproliferative Neoplasms.

(MPN) – MPN Horizons in Prague on September 2nd, attended by about 80 patient advocates from around the globe – Teodora Kolarova presented the INCA Unmet Needs initiative and its impact on evidence-based advocacy.

European School of Oncology (ESO) Masterclass in Cancer Patient Advocacy 2018 – 56 patient advocacy leaders representing 23 European cancer patient networks gathered in Lisbon at the end of February 2018 for the 3rd edition of the ESO Masterclass “Working Towards Stronger and More Effective Advocacy in Europe”. Teodora Kolarova showcased the results of the INCA Survey on Unmet Needs at the Evidence-based advocacy: how to increase impact session on February 25, 2018. The audience was impressed by the scope of the project and the huge potential for further reach, with the translations of all resources into 7 languages.

Joint ENETS/INCA Symposium – March 9, 2018, Barcelona, Spain - At the second Patient-Physician Symposium, INCA and medical leaders discussed a roadmap of actions to address unmet needs of NET Patients. Over 150 conference participants, including some of the thought-leaders in the NET medical community were in attendance, which clearly indicated the growing appreciation of the role patients can play. The focus was on unmet needs in the “Patient Pathway” - the patient information gap, ways to improve the information delivered to patients throughout the treatment journey, as well as access to appropriate care. Another key topic was engaging patients in research from trial design to clinical trials. INCA and ENETS leaders have pledged to form task forces to identify concrete steps that can be taken to address the issues that impede optimal care and research, and to invite the other NET medical societies (NANETS, COMNETS, APNETS) to join INCA.

INCA AGM and Summit – March 5-6, 2018, Barcelona, Spain - The Annual INCA General Membership Meeting and Members Summit gathered 16 member organizations from 14 countries around the globe in Barcelona on March 5-6, just two days before the start of the 15th ENETS Conference. In addition to a review of NET Cancer Day 2017 and the Unmet Needs initiative, as well as draft plans for 2018, a significant review of the INCA strategic plan was carried out by way of a facilitated discussion and breakout group work leading to consensus on potential 2018-2022 objectives. Initial action plans to meet patients' information needs and engage patients in the design and support of research will be developed by two task forces. The excitement sparked by the feeling of bonding and the recognition of the power we have as a community was palpable during the meeting.

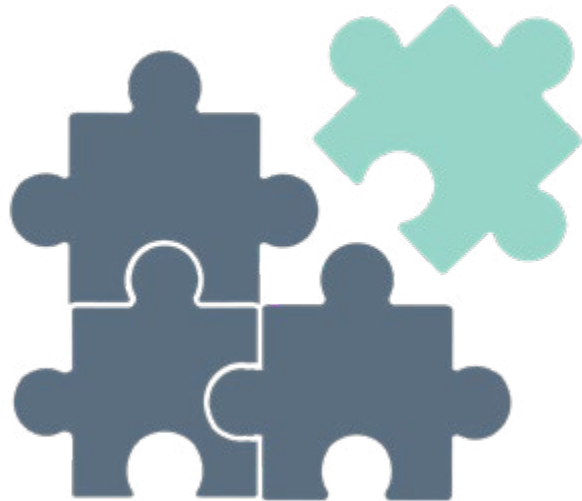
First Global NET Leadership Workshop – November 29, Palma de Mallorca, Spain - INCA, represented by its current President, Simone Leyden, had an instrumental role at the First Global NETs Leadership Workshop, whose key objective was to provide a platform to work together and identify common and unmet needs from a global perspective as well as potential joint initiatives to overcome these. All major NET medical societies were keen to collaborate with INCA in addressing patients' unmet needs: APNETS, COMNETS, CSNETS, CNETS, JNETS, NANETS, NET Initiatives in South America.

Teodora Kolarova, Executive Director, INCA



INCA 2018 Executive Board

NEWS FROM OUR MEDICAL PARTNERS



UKINETs is a truly multidisciplinary Society founded nearly 20 years ago with the express intent of improving the diagnosis and management of patients with NETs, and to promote and foster research aimed to better patient care. UKINETs has world-renowned expertise in all areas of NET science and practice and works collaboratively with the NET Patient Foundation and others within the UK and abroad, to pursue these ends.

Here are a few words from the current UKINETS Chair, Professor John Newell Price:

"I am delighted that UKINETS and the NET Patient Foundation continue to work closely together for the betterment of patient care. There has been a long history of the two organisations working collaboratively. This joint working has included grant schemes for research work to progress care for patients, that have been generously funded by the NET Patient Foundation. These projects have led to new data that has allowed further major project funding, whilst all the while keeping the end game in focus – better treatments and care for patients. Quite often such projects may take considerable time to reach a point where there is direct impact on patient care, but it is exactly such projects that can lead to major breakthroughs in the future.

Now, in a new partnership UKINETs and the NET Patient Foundation are working on a joint project that will have an immediate impact for patients and clinicians. This is in the form of an App for mobile devices that will allow patients to record important details and outcomes and be used by them to enhance their interaction with the clinicians that they see. Such Apps are being used in a wide variety of different medical disciplines and the aim is that this new development will be tested and rolled out within the next two years. It is only by working in such a joined up way that UKINETs and the NET Patient Foundation are able to bring together the patient voice and the medical expertise."



NEWS

2ND NETS BASICS DAY - A GREAT SUCCESS!

On the 13th September, we held our second NET Basics Day - a one-day course in London for trainees and consultants wishing to gain confidence in the investigation and management of patients with neuroendocrine tumours in a multidisciplinary setting.

The course was organised by UKINETs and leads to CPD accreditation from the Royal College of Physicians. The course was well attended, and the feedback was really positive.

A huge thank you to the faculty, and everyone who helped to make this course a success. Next year we hope to build on this success and bring NET Basics to more trainees around the country.

"Excellent course and teaching. Flawless and an absolute must to attend for gastro trainees".

“One of the best and most relevant courses I have attended”.

UKINETS NET DIETICIAN GROUP FORMED

This year we welcomed a group of specialist dieticians to the UKINETs family. This group will be working on guidelines for the nutritional management of NETs, and other pieces of Bitesize Guidance to add to our library.

There was great turnout of allied healthcare professionals at the 2018 year's annual conference - with the nurse forum welcoming dietitians into the fold for the first time.

Over 30 nurses and almost a dozen dieticians, with a specialist interest in NETs, got together to share information and network.

BITESIZE GUIDANCE

We are delighted to launch our new Bitesize Guidance Library. We will be adding further pieces of guidance, however, if you would like to comment on existing guidance, or help with creating new items, please email ukinets@endocrinology.org.
3 Bitesize Guides are already available.



www.ukinets.org



Our vision

Our vision is of a world in which people know how to recognise, diagnose, treat, care for, and ultimately, cure patients with Neuroendocrine Cancer.

Our mission

Our purpose is to support and inform patients and families from diagnosis, enabling access to the best care and treatment, whilst stimulating Neuroendocrine Cancer research, increasing national awareness and influencing improvements in outcomes.

Our values

- Equality of care for all Neuroendocrine Cancer patients in the UK
- Excellence in support, care, treatment and research
- Fair allocation of national resources and inclusion in national policies and strategies for all cancer types
- Collaborative working and building an accessible, approachable fraternity
- Honesty, transparency and integrity to promote confidence and trust in the charity.



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