Meningitis
Research
Foundation

CONFEDERATION OF MENINGITIS ORGANISATIONS
CoMO
ESTABLISHED 2004

Fuelling innovation to defeat meningitis

Our research strategy, 2025 - 2030

We want a world free from meningitis.

So we’re working towards defeating meningitis, wherever it exists.

This is how our research programme will achieve this over the next five years.

Contents

Foreword

As the world's leading meningitis research charity, we have made significant strides towards our vision of a world free from meningitis. However, with an estimated 2.3 million cases of meningitis[1] still occurring each year, our work is far from over.

As we developed this ambitious strategy, our supporters told us that research is what they value the most, while the research community urged us to continue supporting vital research with more focus than ever before.

In response, we have set out our commitment to research, focusing on optimising the use of, and access to, meningitis vaccines; reducing the lifelong impacts of a meningitis diagnosis; and enhancing equitable access to vital pathogen genomics.

We will act as a catalyst for change, building on and harnessing our experience as a funder, enabler and research partner.

We will remain driven by all of those who have been affected by the devastating consequences of meningitis.

We will not stop until we defeat meningitis and, with your support, we are confident that together we will see this realised.

Vinny Smith, Chief Executive & Claire Leigh, Chair of Trustees
Meningitis Research Foundation and the
Confederation of Meningitis Organisations

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[1] Meningitis Progress Tracker, Meningitis Research Foundation, 2025.

Executive summary

In our charity strategy, we have pledged our commitment to work towards a world free from meningitis. To deliver this, we plan to invest £1 million in research, bringing more focus to this area of our work than ever before.

Since we were founded in 1989, we have invested more than £19.5 million in vital research – investment that has supported major advances in meningitis prevention, recognition, diagnosis, treatment and care. We have supported the establishment of pioneering resources for genomic research and built effective partnerships in the UK and internationally, to ensure we could deliver our goals.

Over the next five years, we will continue **to fund and enable high-quality research**. In order to continue to deliver meaningful change, we have been called on to focus on the areas of research that we are uniquely placed to fund, enable and partner on. That is why we will be harnessing our efforts and investment on three research goals – areas where we can, and must, make a difference.

Beyond facilitating scientific advancements, our **catalyst grant schemes will support future leaders and leverage further funding for research on meningitis**.

Our flagship conferences will continue to bring together the world's leading minds, **fostering knowledge exchange** to accelerate research on meningitis.

Above all, we will ensure that **people with lived experience inform and shape the future of research** on meningitis.

Addressing inequity

The impacts of meningitis are far reaching, not only transforming the lives of those directly affected but also the lives of their families, caregivers and communities.

The availability of vaccines has led to significant advances in preventing people from getting bacterial meningitis. Yet progress in defeating meningitis lags behind that of other vaccine-preventable diseases.

Not all causes of meningitis are vaccine-preventable and access to existing vaccines is inequitable.

There is still an urgent need for novel, rapid diagnostic tests that can speed up the accurate diagnosis of meningitis and, for many, access to vital care and support is lacking.

Such inequities are echoed throughout the research funding environment. Our recent review of global meningitis research spend revealed that in 2022, over £88 million was estimated to have been spent on research into meningitis. Yet, whilst research was funded across 40 countries, it was disproportionately allocated, with high-income settings estimated to have received over 85% of the total research spend.

In our charity strategy, we have set out our commitment to equity. In funding and enabling research, our commitment will address existing inequities, ensuring that research efforts reach those most affected and those who are often the least served.

Our research goals

1 Optimising use of, and access to, meningitis vaccines

We will fund research that will optimise access to meningitis vaccines, to ensure that in the UK and globally there is equitable use and uptake of the vaccines that prevent meningitis.

2 Understanding and reducing the lifelong impacts of meningitis

We will fund, enable and partner on research to transform understanding of the lifelong impacts of meningitis due to any cause, improving the quality of life for all those who are affected by the consequences of a meningitis diagnosis.

3 Enhancing equitable access to pathogen genomics

We will partner on research that strives to improve the accessibility of pathogen genomics, globally. We will enable the development of data standards to promote equitable sharing of genomic and associated metadata.

Looking beyond our three research goals

While we will focus our efforts and resources towards tackling our three research goals, we will continue to support and champion research that contributes towards our wider vision of a world free from meningitis.

This includes:

- Research that aims to develop and evaluate safe, effective and affordable new meningitis vaccines.
- Research that aims to improve diagnosis of meningitis so that it can be detected and treated sooner.
- Research that is designed to tackle the growing threat of antimicrobial resistance through ensuring appropriate use of existing treatments and making a concerted effort to develop new ones.
- Research that is committed to improving the surveillance of meningitis.
- Research exploring how the burden of meningitis may be affected by a changing climate.

This support will be delivered in a range of formats, including harnessing the experiences of our diverse network of Ambassadors and supporters to ensure that research is designed and delivered to meet the needs of those with lived experience.

We will showcase progress, and the need for action, across the full landscape of research on meningitis at our flagship conferences and virtual spotlight sessions.

Key to achieving our vision of a world free from meningitis is maintaining a strong understanding of where science and technology is at any point in time. To do this, we will maintain a watching brief on emerging and escalating threats, retaining flexibility so we can pivot our focus to respond to urgent, unmet needs.

Research goal 1:
Optimising use of, and access to, meningitis vaccines

Vaccines against three of the leading causes of meningitis have dramatically reduced cases, deaths and disability caused by meningococcal, pneumococcal and haemophilus influenzae type B bacteria. Despite remarkable progress, not all causes of meningitis are yet vaccine-preventable, and in some parts of the world, there are barriers to accessing and maintaining uptake of licensed meningitis vaccines.

To defeat meningitis, we need new and improved vaccines that are effective, affordable and accessible. In response to this demand, many government, industry and philanthropic foundations are investing in vaccine research and development.

Our analysis of global spend has shown that, in 2022, more than £44 million was spent on research into preventing meningitis. Since we were founded more than thirty years ago, we have invested over £5 million funding vital meningitis vaccine research. Our investment has supported important advances, including:

- Investigating the markers of protection against MenB, supporting MenB vaccine development.
- Assessing the duration of protection afforded by various meningococcal vaccines.
- Assessing the cost effectiveness of meningitis vaccines.
- Supporting the discovery of a GBS vaccine candidate (that has since progressed into the late stages of development).

We are proud to have made contributions that have paved the way for the development and introduction of meningitis vaccines in use today. But we have now been called upon by the research community to ensure our efforts can make the greatest difference.

That is why over the next five years, we will continue to support the meningitis vaccine landscape but, in meeting the call for focus, we will be directing our resources towards research that will optimise and enhance equitable use of licensed meningitis vaccines.

Additionally, with vaccine hesitancy threatening hard-fought gains, we will support attitudinal research to better understand public perceptions toward vaccination, to maintain and strengthen vaccine confidence.

Through research, we will:

- Enable optimal use of existing and newly licensed meningitis vaccines.
- Enhance equitable access and uptake of meningitis vaccines.
- Improve our understanding of perceptions, attitudes and beliefs towards meningitis vaccines and the effect on vaccine confidence.

Generating evidence to support the future introduction of a Group B Strep vaccine

Impact case study

Across the world, Group B Streptococcus (GBS) is a leading cause of neonatal meningitis. Vaccines offering protection against GBS are not currently available but are in late-stage development. To ensure future readiness once GBS vaccines are licensed, in 2014, we funded a research team at the University of Cambridge (led by Professor Caroline Trotter) to develop a mathematical model to assess the potential impact of future GBS vaccines.

Through discovering that a GBS vaccine would be cost-effective to use in the UK, this important research could speed up introduction of a GBS vaccine once licensed for use, providing much-needed protection to pregnant women and their newborn babies.

Following this research, Professor Caroline Trotter was subsequently invited to work with the World Health Organization (WHO) to expand this work and assess the full value of GBS vaccines at a global scale.

> I was naive to the possibility that this pregnancy would be any different. At 24 weeks pregnant with my fifth child, my waters broke spontaneously and I was told that my daughter would be born and wouldn't survive. The day after I was admitted, Meah-Angel arrived and she was beautiful. She passed after one hour of being alive.
>
> *Cat Shehu*

Read Cat's *Meningitis in your words* story

Research goal 2:
Understanding and reducing the lifelong impacts of meningitis

Whilst we know that one in five people who survive bacterial meningitis may experience long-term after-effects, the true cost of meningitis has not been quantified or humanised.

We still do not understand, nor have the tools to measure, the lifelong impacts of meningitis, including the implications on families, caregivers and communities, especially in resource-limited settings.

As a result, community awareness and healthcare worker recognition of the range of disabling after-effects caused by meningitis is limited, and access to support to manage meningitis sequelae is lacking.

Not only are the lifelong consequences of meningitis poorly understood, diagnosed, treated and managed, the research needed to remedy this remains critically under-funded.

Our analysis of global funding for meningitis research found that, in 2022, **less than 1% (0.56%) of funding was estimated to have been spent on research into the lifelong impacts of meningitis**, which is almost 100 times less than spend on vaccine research.

As a result, research has scarcely assessed the long-term impacts of meningitis, including emotional and behavioural after-effects which may be delayed in presentation. Few studies have also evaluated the devastating impacts of bereavement that arise from the death of a loved one from meningitis.

This is why, in setting our goals for the next five years, we are committing to fund and enable research that will accelerate global understanding and reduce the devastating consequences of all those affected by a meningitis diagnosis, at any age, due to any cause.

Through research we will:

- Explore community perceptions of meningitis sequelae and strengthen awareness to reduce stigma and discrimination.
- Understand the knowledge, attitudes and practices amongst healthcare workers, to strengthen recognition, diagnosis and management of meningitis sequalae.
- Develop and validate new and improved methods to assess health-related quality of life, including context-appropriate assessment tools that can accurately measure health losses after meningitis in infants, children and adults.
- Explore and evidence the inequity associated with the impacts of meningitis, including for women and girls (who are disproportionally caregivers).
- Provide data on the catastrophic costs and socio-economic impacts of meningitis and meningococcal sepsis on those affected and their families, caregivers and communities.
- Explore the impacts of meningitis in those with weakened immune systems, who are at greater risk of developing cryptococcal meningitis and tuberculosis meningitis.
- Investigate the psychological, behavioural and emotional sequelae that are poorly understood.
- Evaluate the impacts of bereavement on parents, families and caregivers following a death from meningitis.
- Improve understanding of outcomes and long-term after-effects following neonatal meningitis.
- Identify and enhance understanding of risk factors for poor outcomes after meningitis.
- Develop and evaluate novel interventions that will reduce the lifelong impacts of meningitis on those affected, their families and communities, especially in limited-resource settings.

Preventing post-traumatic stress disorder in children diagnosed with meningitis and meningococcal disease

Impact case study

In the late 1990s, we awarded funding to Dr Simon Nadel (a consultant in paediatric intensive care at Imperial College Healthcare NHS Trust) to investigate the psychological outcomes and post-traumatic stress disorder (PTSD) in children admitted to hospital with meningitis and meningococcal disease.

The study found surprisingly high rates of psychiatric problems following meningococcal disease in children and following admission to paediatric intensive care. An intervention was developed and piloted to help families manage the psychological sequelae of intensive care admissions and showed promise in helping achieve this.

Following this discovery, the team secured further funding to apply their findings from meningitis and meningococcal disease more broadly, to children with very serious illness. An intervention to prevent PTSD is now being prepared for rollout, to benefit families and children after intensive care.

Our funding played a critical role in kickstarting a programme of research which has spanned more than thirty years, one that has improved the outcomes of children and families affected by meningitis.

> I am more confident now than I used to be because I've learnt that, if people stare, you can just explain to them what has happened and suddenly they become very supportive and understanding. I think lack of knowledge is predominantly an issue.
>
> *Ella Bailey, Meningitis Research Foundation Ambassador*

Read Ella's *Meningitis in your words* story

Research goal 3: Enhancing equitable access to pathogen genomics

Whole genome sequencing is a cutting-edge technology that can be used to study the genetic make-up of the bacteria that cause meningitis. Genomic information can tell us how closely related different strains of meningitis bacteria are, which is crucial when tracking and tracing meningitis outbreaks. Importantly, it can also determine whether strains are covered by available vaccines and whether they are resistant to antibiotics.

By enabling emerging threats to be identified and tracked, genomics is a powerful tool in the fight against meningitis.

However, few countries have access to, and allocate the resources to, perform whole genome sequencing. This limits our understanding of the evolution and spread of meningitis across the globe.

With the impact of these gaps particularly acute in low- and middle-income countries, where more than 80% of the world's meningitis cases and deaths occur, there is an urgent need to expand genomic surveillance globally.

> Setting up the library was a global first. It used whole genome sequencing, a technology that was not commonly available at the time, to decode the DNA from all samples of meningococcal bacteria isolated as a cause of meningitis and sepsis in England, Wales and Northern Ireland over a three-year period from 2010 to 2013. Data from Scotland was later included. This work led to the formation of the Meningitis Research Foundation - Meningococcal Genome Library, which we continue to feed into on a routine basis.
>
> *Professor Ray Borrow, UK Health Security Agency (UKHSA)*

We have established a strong history of supporting pathogen genomics research. In 2011, we funded the University of Oxford to establish a UK meningococcal genome library in collaboration with UKHSA (formerly the Health Protection Agency) and the Wellcome Sanger Institute.

Over the last decade, this has proven to be a life-saving resource, bringing to light links between cases in outbreaks and promoting understanding of how the bacteria can spread between people and evolve over time.

We take pride in having been an early and innovative funder of pathogen genomics research and remain committed to supporting enhanced, equitable access. Yet with funding now being made available by other major grant-giving foundations, we have now been called on by the research community to strengthen our role as an enabler.

While we will not prioritise investment of our own funding in pathogen genomics research, we will continue to enable research to understand disease epidemiology and for public health benefit, by:

- Partnering in an international research collaboration designed to validate and pilot the **Meningitis Value Chain Framework**. This will help identify where investments are most needed to improve genomic capacity in low- and middle-income countries, to enable better disease tracking, outbreak response and targeting of vaccines.
- Supporting the **development and implementation of data standards** to provide vital context to genome data. This includes factors such as the country the sample was derived from and anonymised patient characteristics, such as their vaccination status.
- Continuing to support the **Global Meningitis Genome Partnership** steering group: a collaborative group of infectious disease, laboratory and public health experts from across the world, who came together to establish a co-ordinated approach to collecting and sharing global genomic data for four of the leading causes of bacterial meningitis.
- Advocating for the role of pathogen genomics research in the fight against meningitis, through our active membership in initiatives such as the International Pathogen Surveillance Network (IPSN).

Using pathogen genomics to identify and halt spread of a deadly MenW strain

Impact case study

The Meningitis Research Foundation - Meningococcal Genome Library was launched just in time to investigate a sharp rise in deadly cases of meningococcal group W (MenW) disease in England and Wales. With the power of whole genome sequencing, researchers were able to identify that the MenW strain originated in South America and then spread to Europe and beyond.

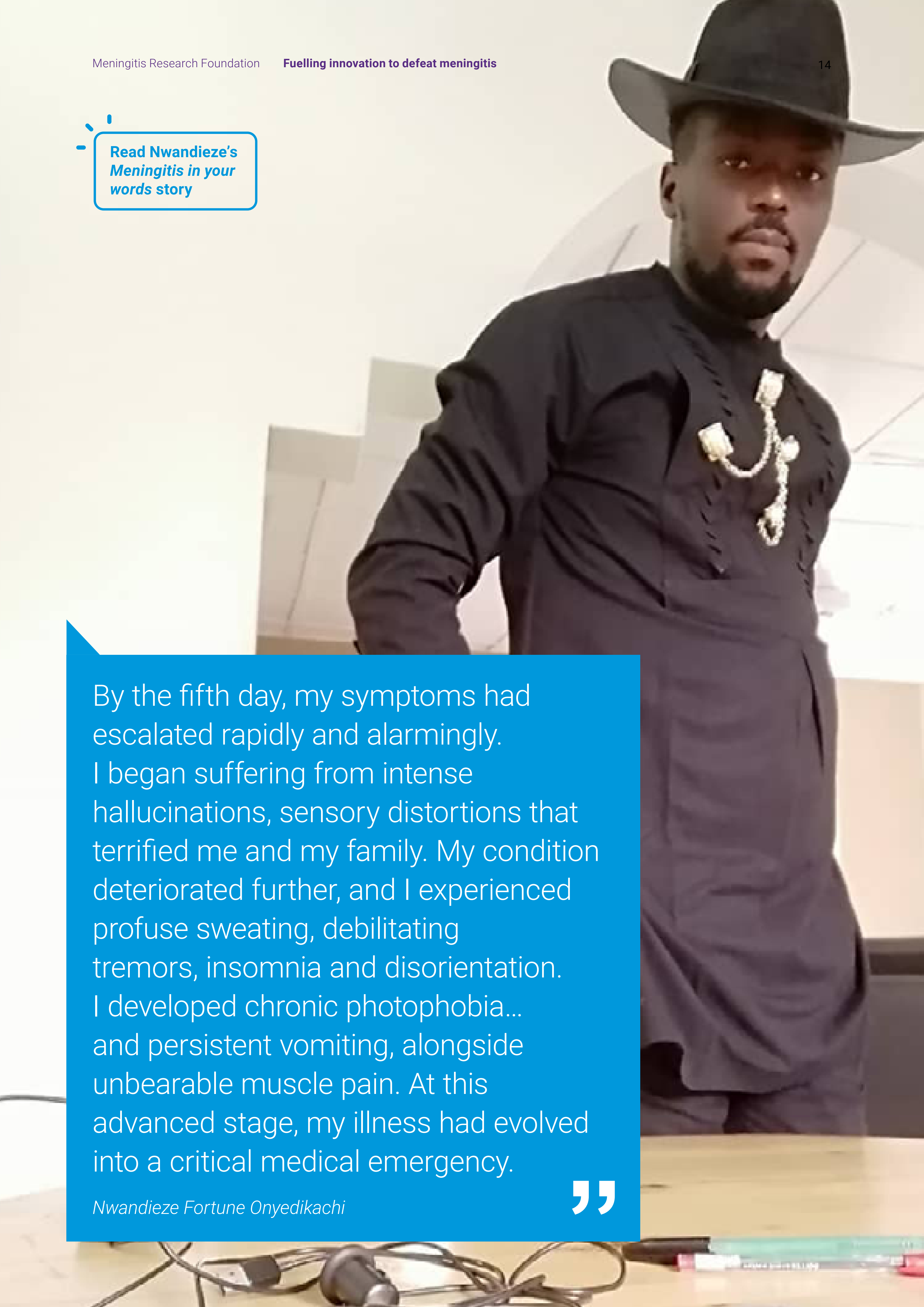
This enabled the team to provide vital evidence to the UK’s Joint Committee on Vaccination and Immunisation (JCVI) government advisors on vaccination. In 2015, through explaining that this meningococcal strain was on the rise, where it had originated and what to expect, this led to the JCVI instigating a MenACWY vaccine programme for teenagers in the UK.

MenACWY vaccination programmes have since been introduced in many other parts of the world, stopping this deadly strain in its tracks and reducing its further spread.

Following the success of the Meningitis Research Foundation - Meningococcal Genome Library, and in recognition that meningitis is a global issue that urgently needs addressing, we subsequently funded the establishment of a Global Meningitis Genome Library to provide data on four of the leading causes of bacterial meningitis, on a global scale.

> PubMLST.org, and the Global Meningitis Genome Library within it, has become the premier tool used globally by researchers and practitioners to exploit molecular and genomic data for meningitis pathogens. It is extensively used in the academic, industrial, clinical and public health fields with thousands of regular users.
>
> *Professor Martin Maiden, University of Oxford*

Read Nwandieze's *Meningitis in your words* story



> By the fifth day, my symptoms had escalated rapidly and alarmingly. I began suffering from intense hallucinations, sensory distortions that terrified me and my family. My condition deteriorated further, and I experienced profuse sweating, debilitating tremors, insomnia and disorientation. I developed chronic photophobia… and persistent vomiting, alongside unbearable muscle pain. At this advanced stage, my illness had evolved into a critical medical emergency. ”
>
> *Nwandieze Fortune Onyedikachi*

Our route to impact

We will accelerate change globally and in the UK, through funding, enabling, partnering and connecting the research community. At the centre of our approach will be ensuring that meningitis research is shaped and informed by those with lived experience.

> The grant funding that I received from Meningitis Research Foundation when I was a lecturer helped me to kickstart my senior academic career.
>
> *Professor Saul Faust, University of Southampton, UK*

Funding

We will award funding to members of the global research community to carry out innovative projects that address our research goals 1 and 2. Our funding mechanisms will be designed to attract and support the brightest minds to tackle some of the most significant challenges on meningitis. The projects that we fund will need to be focused on outcomes that are relevant, deliverable and make a tangible difference to people affected by meningitis.

To reflect our commitment to **support and nurture the next generation of research leaders**, our funding approach will be centred around catalytic grants - accessible to those early in their career and intended to enable early-stage projects or feasibility studies, generating preliminary data to support subsequent, larger grant applications. This will **build on our strong history of catalysing research**, with our £19.5 million investment in research having helped train a generation of researchers. Our investment has enabling recipients of our research grants to go on to secure more than £60 million in follow-on funding.

Successful grant applications will be selected through open competition in response to funding calls aligned to our research goals. With the expertise of our Scientific Advisory Panel and robust peer review systems, we will fund research that is most likely to deliver improved outcomes for people affected by or at risk of meningitis.

By adhering to the Association of Medical Research Charities’ principle of diversity, we will consult reviewers with diverse backgrounds and experiences to ensure that **funding decisions are informed by a varied set of ideas, beliefs, skills and knowledge**.

The research projects that we fund will be monitored to ensure that they are on track to deliver their goals. Grant applicants will be asked to describe in their proposals how their **study findings will benefit people affected by meningitis**. Grant holders will be required to describe the outputs and outcomes of the research that we have funded, which has been made possible through the generosity of our supporters.

Enabling and partnering to accelerate the pace of research

We will strengthen our role as an enabler and partner to support and accelerate the pace of research on meningitis.

We will seek to **support, establish and participate in innovative partnerships** that bring together a diverse range of expertise, in recognition that together we can achieve more.

We will build on our reputation as a neutral broker to create meaningful opportunities for collaboration to address our research priorities.

For research goal 3, this will be delivered through:

- Continuing to support the work of the Global Meningitis Genome Partnership, by co-delivering international research designed to explore barriers and opportunities for wider use of whole genome sequencing.
- Participating in multi-disciplinary networks to support the cross-fertilisation of ideas.

For research goal 2, we will identify more partnerships and funding opportunities that enable us to drive meaningful change. This includes addressing areas of unmet need that require investment more substantial than the catalytic grants we have the resources to award.

Better outcomes for babies after bacterial meningitis (BOBBie)

Impact case study

Even with antibiotic treatment, around 1 in 20 babies affected by bacterial meningitis will die, while 1 in 3 will have serious lifelong after effects. In older children, giving steroids with antibiotics can reduce serious after effects. But it is not yet known whether steroids could help improve outcomes in young babies.

To address this, the UK's National Institute for Health and Care Research (NIHR) awarded funding to a multi-disciplinary research team led by Professors Paul Heath and Chris Gale. Over the next four and a half years, the 'BOBBie' trial aims to recruit almost 1,000 babies, across sixty UK hospitals, to determine whether or not steroids can improve outcomes following a diagnosis of bacterial meningitis in babies under three months.

To ensure that the research design was shaped by the experiences of those affected by meningitis, we supported the recruitment of parents and caregivers to a series of focus groups. This enabled families to share their experiences and make meaningful contributions to the study design, including the most important outcomes to measure at the two-year follow-up and the best way to ask for consent.

We are delighted to be partnering on this research and continuing to support the active involvement of families in it. As part of our role, we will co-lead a study advisory group, working with families to advise on all aspects of the research cycle.

Connecting the research community

Defeating meningitis is an international endeavour, requiring the engagement of researchers, healthcare professionals, funding agencies and people with lived experience of meningitis from all over the world.

For more than 30 years we have hosted the **world's leading research conference dedicated to meningitis**, bringing together thousands of experts in infectious disease, paediatrics, vaccinology, public health and tropical medicine to share the latest advances and challenges for meningitis.

Through our international conferences and virtual spotlight sessions we will continue to support the international research community to meet, share information and develop new ideas and ambitious plans to tackle meningitis.

We will offer **equitable access to our programme of medical-research events**, with reduced rates for trainees and bursary schemes to support attendance of delegates from low- and middle-income countries.

In the intervening years to our conference, we will continue to deliver virtual meningitis spotlight sessions, which are free to attend and accessible to researchers and clinicians across the world.

> Attending the Meningitis Research Foundation Conference in 2023 was a significant milestone in my career. Participating in the conference broadened my perspective on meningitis research, giving me a much better overview of the vast research landscape and even helping me identify potential PhD topics.
>
> I feel more strongly now that I want to focus on meningitis in my work, within the wider domain of infectious diseases. The networking opportunities have also been amazing – the chance to meet people from organisations working directly on the WHO Global Road Map to Defeat Meningitis by 2030 and people from different universities around the world was invaluable. Perhaps one of the people I have met could even be my future PhD supervisor!
>
> *Jeannièrre Manegab, Panzi General Hospital, Bakavu, Democratic Republic of the Congo*

Ensuring that people affected by meningitis inform and shape the future of research

People affected by, and at risk of, meningitis lie at the very heart of our work. They are the ultimate beneficiaries of the work that we do and, in many cases, they make our work possible through their generosity. We are therefore committed to ensuring that the research we fund is relevant to, and informed by, people with lived experience of meningitis.

We will build and develop a network of people affected by meningitis, ensuring that they form an integral part of informing and shaping the research that we fund and the wider research environment. We will continue to open our medical research events with an individual with lived experience sharing their personal story of meningitis, which is a stark reminder of why the time for action is now.

> For me personally, the support and relationship we had with the charity was instrumental in my career. I took my first steps into how to do research with support from Meningitis Research Foundation.
>
> Through the charity, we spoke regularly to parents who had lost children from the disease. This was a very big inspiration to everyone in the team, as we all felt we were doing research that was needed because of the terrible illness that was affecting so many children.
>
> *Professor Mike Levin, Professor of Paediatrics and International Child Health, Imperial College, London*

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Established 2004

Thank you

We are immensely grateful to everyone who has given their time and insight to help shape this research strategy, including members of our Scientific Advisory Panel, people from across the research community who participated in our surveys and interviews, our supporters and our Ambassadors.

Support our work to defeat meningitis

Our vision is a world free from meningitis.

Your donation could help us realise this ambition, enabling groundbreaking research, transforming lives and bringing us closer to defeating this disease.

Every contribution makes a difference, so donate to defeat meningitis at meningitis.org/shop/donate.

meningitis.org
#DefeatMeningitis

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