Meningitis
Research
Foundation

CONFEDERATION OF MENINGITIS ORGANISATIONS
CoMO
ESTABLISHED 2004

Accelerating defeating meningitis

Our 2025 – 2030 strategy

We want a world free from meningitis.

That's why we're working towards defeating meningitis, wherever it exists.

This is the impact we'll have on our vision over the next five years.

Contents

Our priorities

Foreword

Meningitis devastates lives. Every year, there are around 2.3 million cases of bacterial and viral meningitis. In 2021 (the most recent annual estimates), around 214,000 people died from meningitis. Approximately 40% of all deaths from meningitis are in children under five.[1] We can, and must, end this tragedy.

To change this, over the next five years, we will build on our success so we can accelerate progress on defeating meningitis across the world. This includes continuing our work in the UK, Ireland and across the globe.

We will pick up the pace of progress needed to defeat meningitis by 2030 and equip ourselves, so we are ready for the next decade.

We will renew our commitment to research, as the bedrock of our work on behalf of everyone affected by meningitis.

We will amplify the voices of people and families, so others understand meningitis more, and why change must happen to defeat this deadly disease.

We will save lives from meningitis for generations ahead by remaining a UK-based organisation that works locally, nationally, and globally.

Vinny Smith, Chief Executive
Meningitis Research Foundation and the Confederation of Meningitis Organisations

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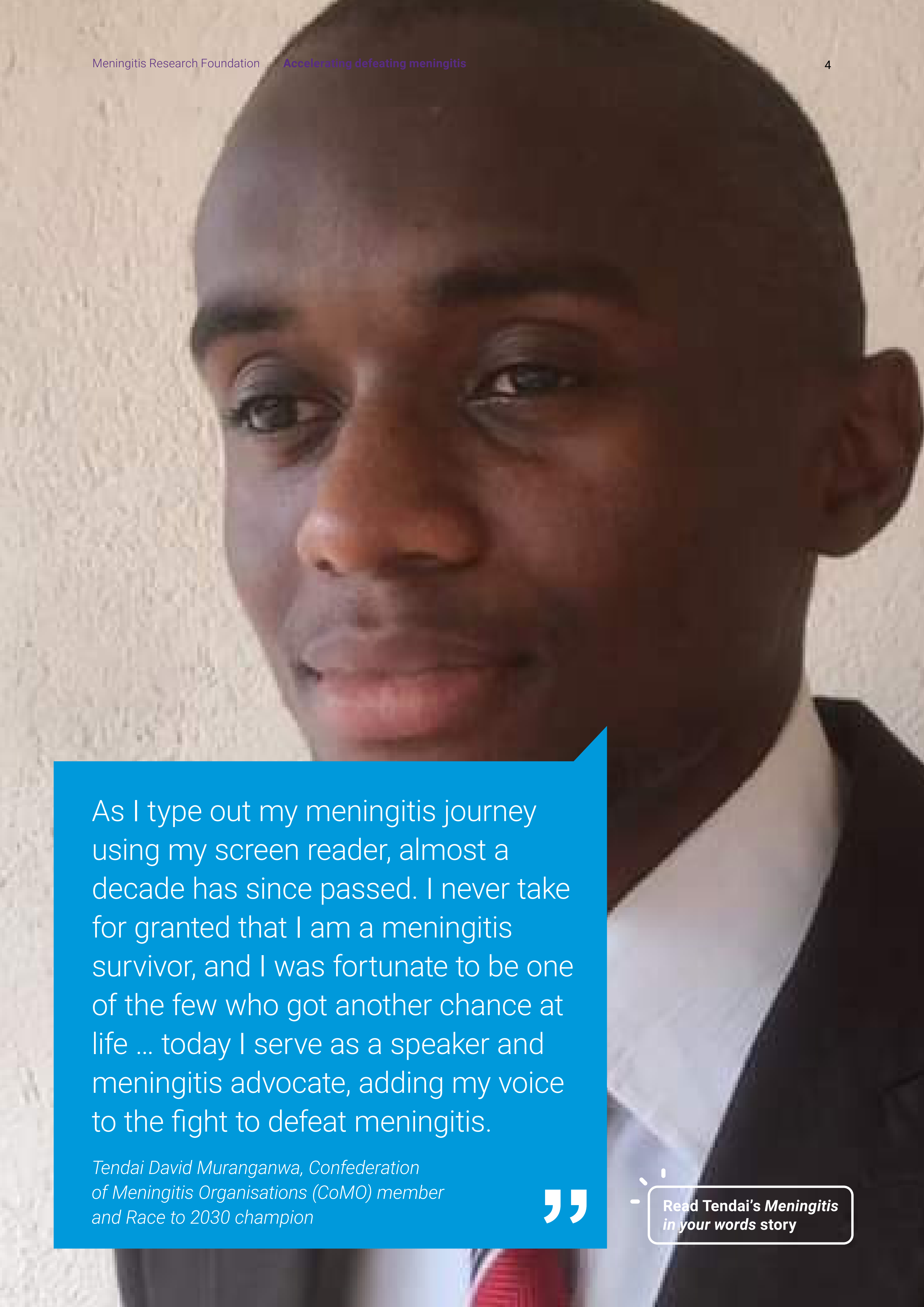
[1] Meningitis Progress Tracker, Meningitis Research Foundation, 2025.



> As I type out my meningitis journey using my screen reader, almost a decade has since passed. I never take for granted that I am a meningitis survivor, and I was fortunate to be one of the few who got another chance at life … today I serve as a speaker and meningitis advocate, adding my voice to the fight to defeat meningitis.
>
> *Tendai David Muranganwa, Confederation of Meningitis Organisations (CoMO) member and Race to 2030 champion*

Read Tendai's *Meningitis in your words* story

Our strategy at a glance

We are driven by the impact and scale of meningitis

'Make sure no family goes through what we have' drives our mission to defeat meningitis wherever it exists.

In 2021, there were 2.3 million cases of meningitis, causing 214,000 deaths and leaving 1 in 5 with a life-changing disability. Behind each number is a person whose life has been changed forever.

How we will accelerate change

Research for better evidence →

We will fund, enable and partner on research.

Understand for better policy →

We will share research and its implications for public health policy.

Act for better lives

We will raise awareness and advocate for change.

Strengthen our foundations

Listening to learn from lived experience

We will listen to, and learn from, people affected by meningitis, so we address their priorities.

Support for everyone affected by meningitis

Every day, we will support people affected by meningitis.

Sustainability for the future

We will put in place high quality, sustainable and diverse teams, capabilities and resources so we can continue to deliver impactful change.

Equity for fairness

We will apply an equity lens to everything we do.

Realising this will ensure we are working towards our vision of a world free from meningitis

> When we were at a point where we felt there was nobody we could relate to or look up to, Meningitis Research Foundation really did provide that support network of people in similar situations. In day-to-day life nobody understands.
>
> *Isabelle Weall, Meningitis Research Foundation supporter*

Read Isabelle's *Meningitis in your words* story

2025–2030: our headline ambitions

Investing in research

Through our research grants programme, we will aim to invest £1 million into the life-long impacts of meningitis and into the use of, and access to, the vaccines that protect against meningitis.

Using data to show the complete burden of meningitis

Adding to our Meningitis Progress Tracker, we will bring together comprehensive data on cryptococcal and tuberculosis meningitis, plus other leading causes, for the first time.

Creating the case for MenB protection

We will increase teen and young adult protection by influencing the policy agenda on the introduction of a MenB vaccine into the UK's routine immunisation schedule.

Using global data standards to drive better surveillance and diagnosis

A new set of interoperable metadata standards for meningitis pathogen sequence sharing, to support surveillance and diagnosis globally, will be agreed.

Funds to defeat meningitis

We will raise over £16 million of new funds to defeat meningitis.

Understanding the life-long impact of meningitis

We will develop and launch a new research and engagement programme to understand and improve the quality of life after meningitis.

Creating the world's leading forums on meningitis

We will deliver international research and CoMO member conferences, as the world's leading forums for knowledge sharing and lived experience learning on all aspects of meningitis.

Strong and vocal global advocacy

We will grow our member network of advocates and survivors to over 60 countries and 300 members, so the voices of those most affected by meningitis are strong, stable and can continue to call for change.

Driving collective action on World Meningitis Day

We will continue to grow the world's largest day of collective action on meningitis, driving activity in 80%+ of countries across the world.

Experience at the centre of national action plans

We will ensure CoMO members are supported to call for, and participate in, the development of national plans on defeating meningitis in 50% of countries where there is a CoMO member.

Priority 1

Research for better evidence

The challenge

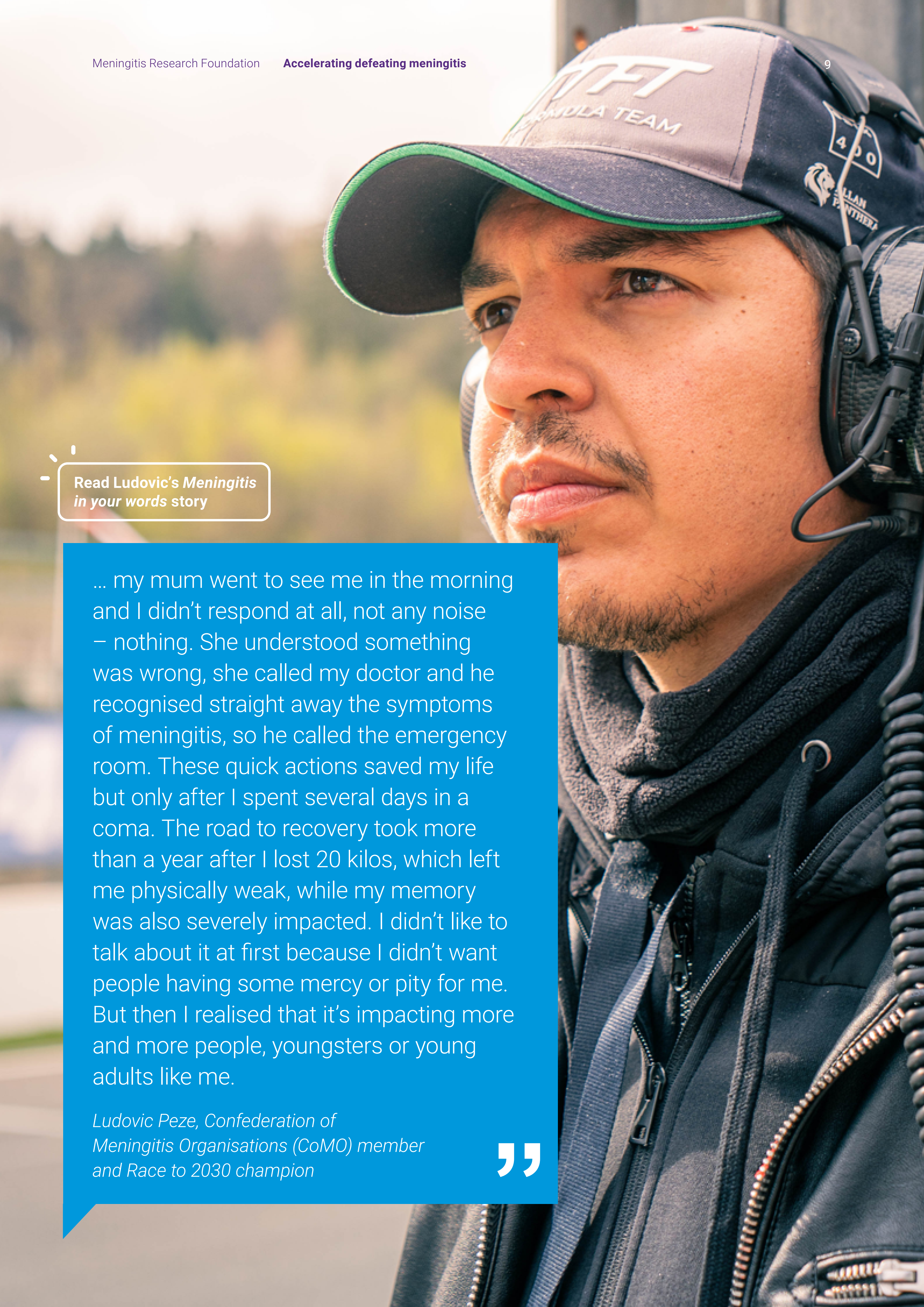
- **Access to, and uptake of, meningitis vaccines is inequitable.** Even when vaccines do exist, they often don't reach the people who need them, in high- and low-income countries. This is even more of a problem in marginalised communities.
- **There is not enough research into understanding people's quality of life after meningitis.** Though funding research into meningitis has grown significantly in the past 20 years, we estimate less than 1% of that funding in 2022 went into understanding the lifetime impact of the disease.
- **Access to pathogen genomics is inequitable.** Pathogen genomics is revolutionising our understanding of pandemics but, as long ago as 2012, we were already investing in the world's first genome library for meningitis pathogens in the UK. Yet today access to this technology and its associated data is centered in high-income countries, even though lower-income countries have the highest burden of meningitis in the world.
- **Opportunities to share the latest scientific research on meningitis are rare.** Experts need forums to focus on meningitis, to better understand the current and developing research agenda, so meningitis isn't left behind in public health advances.

Our ambition

- Invest £1 million in research into the use of, and access to, meningitis vaccines and into understanding and reducing the life-long impacts of meningitis.
- Launch a new integrated research and engagement programme into the life-long impact of meningitis.
- Complete our £1 million, Wellcome-funded research programme into the use of meningitis pathogen genomics for public health.
- Deliver three international research conferences and two research spotlight sessions.
- Continue to support the Global Meningitis Genome Partnership.

What we will achieve

- ✓ More equitable use of, and access to, meningitis vaccines.
- ✓ Improved quality of life for all those affected by the consequences of meningitis.
- ✓ Globally, more equitable access to meningitis pathogen genomics.
- ✓ Improved collaboration and knowledge exchange within the research community.



Read Ludovic's *Meningitis in your words* story

> … my mum went to see me in the morning and I didn't respond at all, not any noise – nothing. She understood something was wrong, she called my doctor and he recognised straight away the symptoms of meningitis, so he called the emergency room. These quick actions saved my life but only after I spent several days in a coma. The road to recovery took more than a year after I lost 20 kilos, which left me physically weak, while my memory was also severely impacted. I didn't like to talk about it at first because I didn't want people having some mercy or pity for me. But then I realised that it's impacting more and more people, youngsters or young adults like me.
>
> *Ludovic Peze, Confederation of Meningitis Organisations (CoMO) member and Race to 2030 champion*

Priority 2

Understand for better policy

The challenge

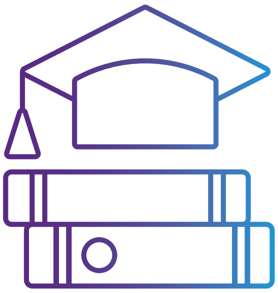
- **Effective policies to support equitable use and access to meningitis vaccines and improved quality of life for those affected by meningitis are not in place.** This is a significant contributing factor to progress against meningitis being behind other vaccine-preventable infectious diseases.
- **Meningitis disease data estimates understate the true burden and life-long impact of meningitis.** The global data for meningitis does not include some of the leading causes of meningitis, meaning it doesn't tell the full story of all the causes of this devastating disease.
- **Civil society advocates do not have access to the data they need for evidence-led advocacy.** Combining powerful personal testimony with national data on meningitis could help change health policy. But only if the data is publicly available, easily accessible and understood.
- **In the UK, there are gaps in the routine protection available to the highest at-risk groups.** Teenagers and young adults still cannot access a MenB vaccine in the UK's routine immunisation schedule. For pregnant women and young babies, there is no vaccine for Group B Strep, the most common cause of bacterial meningitis in babies under three months old in high-income countries.[2]

Our ambition

- Launch new insights and policy papers on the equitable use of, and access to, meningitis vaccines and on improved quality of life for all those affected by the consequences of meningitis.
- Estimate the true burden of meningitis from all causes and include this in the Meningitis Progress Tracker, for the first time.
- Support civil society to use the data in the Meningitis Progress Tracker, so advocacy is evidence-led and enables better policy development.
- Improve protection and care in the UK by advocating for the introduction of a MenB protective vaccine for teenagers and the development of a national plan on meningitis.

What we will achieve

- ✓ An accurate estimation of the full, global burden of meningitis to support better health policy.
- ✓ Insights and policy reports and recommendations that engage, inform and enable change.
- ✓ Fuelling evidence-led advocacy by civil society advocates across the world through personal testimony and easily accessible, verified data.
- ✓ Filling the protection gaps in policies for people at risk of meningitis in the UK.



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[2] Okike IO, Ribeiro S, Ramsay ME, Heath PT, Sharland M, Ladhani SN. Trends in bacterial, mycobacterial, and fungal meningitis in England and Wales 2004-11: an observational study. Lancet Infect Dis. 2014 Apr;14(4):301-7. doi: 10.1016/S1473-3099(13)70332-3. Epub 2014 Feb 7. PMID: 24508198

> My experience was one of fear and confusion but I found resilience I didn't know I had. To others facing meningitis now or in the future, I would say this illness might knock you down, but healing is possible. Surround yourself with care and support and take recovery one step at a time. You are not alone in this battle and there is support there for you. Seeing other people's stories that were similar to my own made me realise that I am not alone
>
> *Eliana Shaw-Lothian,*
> *Meningitis in your words contributor*

Read Eliana's *Meningitis in your words* story

Priority 3

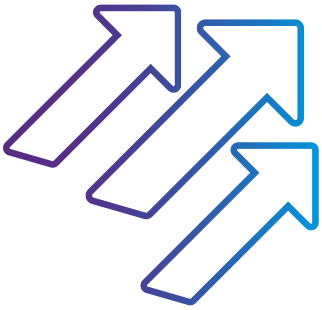
Act for better lives

The challenge

- **Awareness of meningitis is still too low.** People are not routinely aware of the signs and symptoms of meningitis, the vaccines they need and can access, when to seek lifesaving medical help or what the life-long impact of a meningitis diagnosis can be. People are not as well protected or supported as they should be and health policy and funding does not meet their needs.
- **The voice of civil society advocating for change is not as strong as it needs to be because of resources and barriers between institutional processes and civil society**. Whilst CoMO, our global member network, has over 150 members in more than 50 countries, the majority are volunteers operating on no or little funding. The investment case for the World Health Organization's *Global Road Map to Defeat Meningitis by 2030* calls for new funds for civil society, including for their involvement in national plans. Without this, its aims cannot be delivered.
- **People who are affected by meningitis are not listened to or routinely involved in the development of health policy.** CoMO brings together people from over 50 countries who have direct experience of all aspects of meningitis. They are uniquely placed to say what is needed, so we have robust and patient-centered health policies across the world.
- **Countries do not yet have the tools they need to communicate effectively about meningitis.** Our health communication research in sub-Saharan Africa has evidenced the significant gaps in tools and resources needed to communicate effectively about meningitis. Plugging this gap in all regions of the world will accelerate progress in defeating meningitis.

Our ambition

- Increase awareness of meningitis, including maintaining World Meningitis Day as the world's largest day of collective action on meningitis (with over 80% of countries taking action).
- Grow and strengthen our member network, the Confederation of Meningitis Organisations, to over 300 members in more than 60 countries.
- Ensure the voices and needs of people affected by meningitis remain at the heart of our work, reaching over 2,000 *Meningitis in your words* testimonies, hosting five CoMO conferences on the lived experience of meningitis and using this collective, global voice to drive action through our Race to 2030 advocacy programme.
- Develop an evidence-led, meningitis health communication strategy, which is used and adopted in all regions of the world.

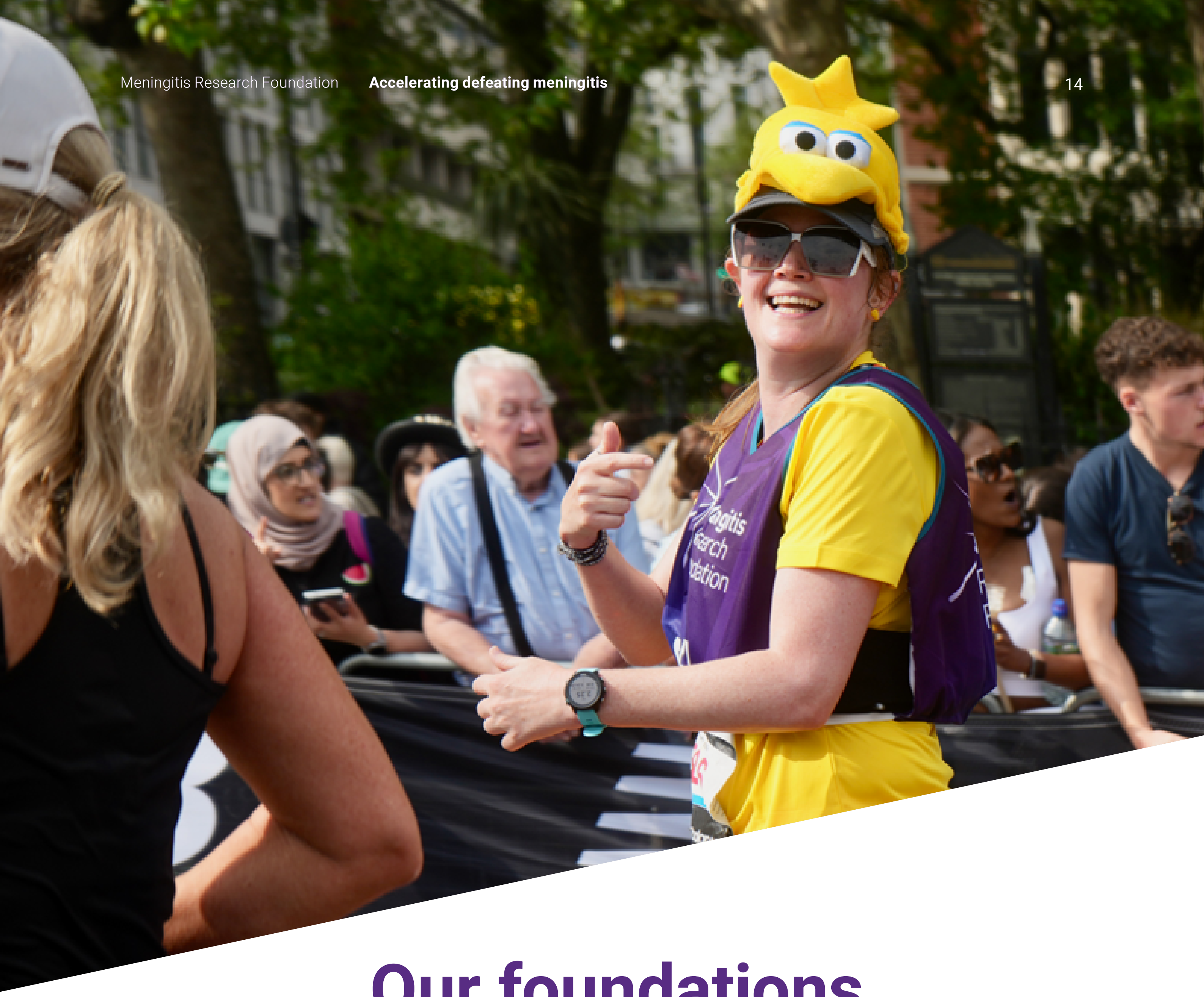


What we will achieve

- ✓ Better health outcomes for people at risk of, and affected by, meningitis globally and in the UK.
- ✓ A stronger civil society voice, equipped to demand the change that is needed.
- ✓ Citizen demand and participation in the development and implementation of national plans on meningitis.
- ✓ A systematic approach to increasing awareness of meningitis at a national level.

Read John's *Meningitis in your words* story

> I've had a lot of wonderful things in my life, like meeting my wife and starting a family. As someone who beat the odds and survived meningitis, I feel compelled to use my story to educate others about this disease.
>
> *John Grimes, Confederation of Advisory Council (CoMO) member and Advisory Council representative for the Americas*



Our foundations

1

We always listen to, and learn from, people affected by meningitis

Listening to, and learning from, people and families affected by meningitis is crucial for developing effective strategies and interventions. Their experiences provide invaluable insight into the realities of meningitis, the challenges faced and the most pressing needs.

By prioritising their voices, we can ensure that our efforts are focused. This fosters trust and collaboration, guaranteeing our work is relevant and impactful.

Our ambition

- Establish a new patient panel for our research programme, to guide our research priorities.
- Reflect the voices of those directly affected by meningitis in all aspects of our insights and health policy work.
- Strengthen our global member network, CoMO, and ensure members have many opportunities for collective global awareness and advocacy.
- Grow our UK and Ireland Ambassador programme, with every Ambassador able to use their lived experience to help reach communities where the need for awareness is greatest.

2

We continue to directly support people affected by meningitis

Supporting people affected by meningitis remains of paramount importance. By providing comprehensive support, we offer a lifeline to those navigating the complexities of diagnosis, recovery and adjustment. This fosters resilience and helps people rebuild their lives, including through opportunities to advocate for meningitis awareness and prevention (which helps to amplify the impact of our work).

Our ambition

- Continue to provide UK and Ireland Support Services, with one-to-one help on the phone, online chat, social media and email.
- Provide global and out-of-hours support through our accurate, comprehensive online health information, developed in collaboration with our Ambassadors and CoMO members.
- Grow our outreach in the UK and Ireland, including to universities, post-16 education and training and into community spaces.

3

We deliver change through high quality, sustainable and diverse teams, capabilities and resources

High quality, sustainable and diverse teams, capabilities and resources are essential for our long-term success and impact. Diverse teams bring a wealth of perspectives, experiences and ideas, which are crucial for innovative problem-solving and adapting to the ever-evolving challenges of meningitis.

By ensuring our teams are equipped with the best resources and capabilities, we can maintain a high standard of care, responsiveness and effectiveness in all our work.

Sustainability ensures that our efforts are not short-lived but continue to grow and adapt to future needs, so we have a lasting positive impact on communities. As a collaborative organisation, we also rely heavily on guidance, expertise and support from many partners, so our work is sustainable.

This is fundamental in building a resilient and forward-thinking organisation, capable of driving meaningful change.

Our ambition

- Raise over £16 million to support our work, maintaining strong events and community income and growing high value, corporate and lifetime giving income.
- Maintain our active membership of the World Health Organization Technical Task Force for the *Global Road Map to Defeat Meningitis by 2030*, One Neurology Partnership, International Pathogenic Surveillance Network and the Global Meningitis Genome Partnership.
- Use the Meningitis Flag as a unifying symbol for meningitis awareness, prevention and support and to build new corporate relationships.
- Develop and launch new digital capabilities (website and CRM), ensuring they are fully accessible and enable responsible use of AI.
- Continue to deliver our environmental sustainability policy.
- Embed continuous learning opportunities for our teams, so we all speak with an expert voice on meningitis.
- Diversify our Medical Advisory Board and staff team and provide tailored training to our Board of Trustees.

4 Equity is embedded in everything we do

Addressing meningitis equitably is crucial because it ensures that all individuals and communities, irrespective of their location or wealth, have better access to prevention, diagnosis, treatment and support.

By embedding equity within our research, policy and community outreach work, we can address the barriers faced by many groups. This will promote fairness and ensure our interventions are effective.

It will empower everyone to participate in, and benefit from, defeating meningitis, amplifying our impact and paving the way for a healthier, more resilient society.

Our ambition

- Ensure our policies and teams support equality, diversity and inclusion.
- Embed equity principles within the terms of reference for our research programme and policy analysis.
- Train, support and recruit Ambassadors who can work with us to reach under-served communities across the UK and Ireland.

Read Onaiza's *Meningitis in your words* story

> Eventually the question came that no parent ever wants to hear - 'do you want us to take your son off the ventilator?'. Before my husband and I could answer, we were informed that Zain had made that decision for us. Our beautiful son stopped breathing and passed away twelve hours after he was admitted to hospital … Since Zain's death, not a day goes by when I don't think about him. His memory lives on through the love that we have for him as a family and the Ambassador role that I have with Meningitis Research Foundation.
>
> *Onaiza Fice, Meningitis Research Foundation Ambassador*

Meningitis: many words, one devastating disease

Every word here represents a life forever changed – a rapidly developing illness, a family deeply affected, a community shaken, a future rewritten.

Meningitis doesn't care about medical names. But we know that behind every one is a person. That's why, whatever the term, whatever the type, we're here. Pushing for better prevention. Supporting survivors. Taking action to save lives.

MenC
Meningococcal disease
Salmonella meningitis
Autoimmune meningitis
Mollaret's meningitis
Cryptococcal meningitis
Viral meningitis
Klebsiella meningitis
Bacterial meningitis
Inflammation of the meninges
MenA
meningitis
MenB
GBS
Chronic meningitis
Septicaemia
Meningococcal septicaemia
Pneumococcal meningitis
Hib meningitis
MenW
Spinal meningitis
E. coli meningitis
Group B Strep
Sepsis
MenY
Aseptic meningitis
Leptomeningeal carcinomatosis
MenX
TB meningitis
Fungal meningitis
Carcinomatous meningitis
Meningococcal meningitis
Listeria meningitis

Meningitis Research Foundation

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ESTABLISHED 2004

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