# **Defeating meningitis**

Our strategy | 2021-2025



meningitis.org

### Introduction

### "Make sure no family goes through what we have."

is what the families we support ask us to make happen on their behalf. They want to see a world free from meningitis and septicaemia.

# This strategy sets out how we will help make that happen between 2021 and 2025.

It has been developed by listening to what those families told us are their priorities. Researchers, funders and policy makers have also given their time and expertise to focus it on what we do best and where we can make the biggest difference. It could not have been written without them and I am extremely grateful for their kind support and expert guidance.

By 2030 we want to see meningitis defeated. In 2020 the World Health Assembly supported by members from all six World Health Organization (WHO) regions passed a new resolution with that single goal as its focus. This means reducing new cases of meningitis by 50%. Reducing deaths by 70%. Ending epidemics. Ensuring people get the support and aftercare they need. It is a highly ambitious aim, but one that we and our partners in this work think is achievable.

We are confident it can happen because we have achieved so much already. Meningitis deaths have fallen around the world over the past 20 years. We have campaigned for and seen the introduction of several new vaccines that have stopped people dying or becoming disabled. We have helped people feel less alone in their experience by being on a call, email or webchat to listen and support them

Our 'golden thread' is simple and has never changed. We connect people, evidence and action for change to defeat meningitis, wherever it exists.

In this strategy we set out two ways we will make this happen. By enabling research and evidence for better policy and by transforming engagement in meningitis. If we are successful, we will make a significant contribution to the goals of the new global Road Map and make the Meningitis Research Foundation the leading meningitis charity in the world. There is absolutely no way we will achieve this on our own. Our partnerships around the world, including through the network of members we represent in more than 40 countries worldwide, are essential. Further strengthening our ability to work flexibly and efficiently will be crucial so we use every drop of our resources to maximum effect.

### This strategy is about improving our lives together, wherever we live.

On behalf of people everywhere, we will recognise advances and be impatient that progress against meningitis lags behind other infectious diseases.

We will celebrate new vaccines and be impatient that even existing vaccines do not yet reach everyone who needs them.

We will applaud new research and be impatient to fill in gaps in our knowledge.

By 2025 we will only have five years left to meet our global goal. That is why this strategy is ambitious. We have a lot to achieve in the next 5 years and we are ready to deliver for the families we are here to represent.

**Vinny Smith** 

Chief Executive, Meningitis Research Foundation & Confederation of Meningitis Organisations (CoMO)



Vinny speaking at the Meningitis Research Foundation conference

# Our vision

A world free from meningitis and septicaemia.

# Our mission

To defeat meningitis and septicaemia wherever they exist.

# Our role

Supporting and connecting people and research to drive action and save lives.

# **Our history**

1980s-1999

9

#### Late 1980s - 1990s

High rates of meningitis B and C lead to student deaths and ensure meningitis-related disease is a public health issue in the UK.

0

### 1990s: Keeping meningitis at the UK public health forefront

Cases of meningitis remain high throughout the 90s, so we keep meningitis at the forefront of the public health agenda, working with survivors to highlight cases in the media, with health professionals to ensure people have the information they need during outbreaks, and with the UK government to develop public health guidelines.

9

### 1994: Funding scientifically robust research

Made up of international scientists who volunteer their time and expertise, our Scientific Advisory Panel is established. It ensures we fund scientifically robust research, in line with our research strategy.

9

# 1995: Funding research into how genes influence disease risk

We begin funding research into how people's genes influence their meningitis disease risk informing patient care and laying the groundwork for new approaches to diagnostics.

9

## 1999: MenC vaccine campaigning for introduction and uptake

Following high rates of meningitis C and campaigning from MRF, other organisations and the public, the MenC vaccine is introduced in the UK to the student-aged population. Having campaigned for its introduction, we switch to supporting the uptake, reassuring people about vaccine safety and publicising the importance of getting vaccinated.

1985



#### 1989: Our journey begins

The Meningitis Research Foundation is founded, bringing together people and scientific evidence to defeat meningitis and septicaemia. Since 1989, we have awarded 162 research grants in 24 countries and invested over £19.3 million in vital research into meningitis and septicaemia prevention, treatment and aftercare.

1990

### 1992: Hib vaccine introduction; our helpline launches

We raise awareness of the UK introduction of a vaccine to prevent Haemophilus influenzae type b (Hib) infection, reducing cases of meningitis in babies and children. Alongside this progress, we continue to highlight other types of non-vaccine-preventable bacterial meningitis, raising public health understanding and knowledge.

Our helpline, offering one-to-one advice to anyone on signs, symptoms and treatment, as well as expert support for those affected by meningitis, is established. Today our helpline has supported many thousands of people and is at the very heart of what we do.

1995

# 1998: Expanding our patient and carers Support Services

Our Befriending Network launches, reflecting a clear patient need evidenced by our helpline. A call from people affected by meningitis wanting to speak with others who had been through a similar experience leads to today, where many hundreds of befrienders have now been paired with people affected by meningitis, offering a listening ear and support to one another.

9

### 2000-2014

2001: Campaigning for the MenC vaccine rollout for under 20s

Our campaigning continues as the UK government responds to calls by MRF and other charities for the rapid roll-out of MenC vaccine to all babies, children, and young people. As a result, rates of meningitis C rapidly drop from 1,300 cases a year in the UK to far fewer cases each year.

2006: UK introduction of the pneumococcal vaccine (PCV)

The PCV vaccine is introduced into the UK routine vaccination schedule; we write to the Irish Taoiseach, Bertie Ahern, urging Ireland to follow the UK in its adoption.

2011: Counting the Cost, the world's first Meningococcal Genome Library, Kilimanjaro

the widest and earliest implementation of vaccines against meningitis. Meningitis survivor Robbie Jones delivers a petition to Downing Street; a 'Meningitis Matters' day sees people affected by meningitis at the House of Common; MPs sign the Counting the Cost petition; and letters are published in the media calling for extended vaccination.

are submitted to the Joint Committee on Vaccination and Immunisation (JCVI), as evidence on the MenB vaccination.

We commission the world's first Meningococcal Genome Library, helping scientists develop and test vaccines for meningococcal infections. This is a ground-breaking resource, holding the complete genetic blueprint of bacteria

> isolated as a cause of meningococcal disease in the UK.

Our very first Challenge trip to Kilimanjaro launches, now one of many challenge events that help to fund our research. advocacy and support activities.



#### 2001-8: Raising awareness of pneumococcal meningitis

2000

2005

2010

We focus on raising awareness of the high burden of pneumococcal meningitis in the UK and globally, joining initiatives calling for low income countries to have access to the pneumococcal vaccine (PCV).

2008: Advocating for global pneumococcal disease funding

Alongside meningitis survivor Laura Mittelman, we give evidence to the UK's All-Party Parliamentary Group for Pneumococcal Disease Prevention in the Developing World, encouraging the UK to support GAVI (the Vaccine Alliance) in making pneumococcal vaccination available in low income countries. The UK government becomes one of the major donors behind a GAVI US\$1.5 billion pneumococcal vaccination fund.



2014: Ensuring clinical best practice

Our Medical Advisory Group is formally established, to ensure clinical best practice in the support we provide. To this day, they play a vital role in developing clinically sound information for policy makers, health professionals, and the public on meningitis.



Our Counting the Cost campaign calls for

Findings from Counting the Cost research1



<sup>1</sup>Counting the cost of meningococcal disease: scenarios of severe meningitis and septicaemia. Claire Wright Rebecca Wordsworth, Linda Glennie. Paediatric Drugs 2013

### 2015-2018

2015: The UK paves the way on MenB vaccine introduction; our Genome Library paves the way to MenACWY vaccination; introducing Pushing the Boundaries

Building on work on cost-effectiveness by MRF and others, the UK government and pharmaceutical companies agree on a price that leads to the introduction of the MenB vaccine for infants. The UK is one of the first countries in the world to introduce MenB into its routine vaccination schedule, paving the way for many other countries.

The Meningococcal Genome library highlights the sudden increase of meningitis W in the UK, due to a particularly virulent strain of the disease, providing vital analysis to support the routine introduction of MenACWY vaccination in the UK.

Our Support Services expand again with *Pushing the Boundaries*, bringing together families who have a child with limb loss due to meningitis or septicemia. A whole family event, children and their siblings enjoy activities, while parents and carers share experiences and get support from our specialist team.



# 2018: Pushing for safe-netting and One Life, One Shot

We participate in the improving diagnosis and treatment working group, resulting in the recommendation for routine provision of 'safe-netting' information for those sent home by their hospital or GP without a diagnosis.

We win the Third Sector's 'Communication Campaign of the Year' for *One Life, One Shot,* raising awareness and increasing uptake of MenACWY vaccine among teenagers, particularly those starting university.



## 2016: beginning a Global Plan and advocating for MenB vaccination

Despite global efforts to tackle meningitis, progress is still behind other infectious diseases. MRF and other organisations join the World Health Organisation (WHO) discussions on developing a global plan to defeat meningitis.

As we see continued cases and deaths among those who had missed out on the MenB vaccine as infants in the UK, there are public calls for catch-up vaccinations. MRF advocate for this for all under-fives.

2017

2018

2015

2016



### 2017: Consensus and commitment to a Global Plan

In collaboration with the WHO, we organise a meeting bringing together more than 50 stakeholders to discuss the need for a global plan to tackle meningitis. This results in a broad consensus and WHO commitment to take this forward.

We work with Meningitis Now to call for improved diagnosis and treatment in the UK, including supporting families affected by meningitis to meet the Secretary of State for Health. This results in the UK government agreeing to establish a working group to investigate the issue.

9

6

### 2019-2022



2019: From patient voice to WHO global strategy; data for change with the Meningitis Progress Tracker; Support Services drive for inclusion

We support a major civil society consultation, asking people affected by meningitis what they want to see in the WHO's global strategy to defeat meningitis. The consultation receives over 3,000 responses, including from members of the Confederation of Meningitis Organisations (CoMO).

We launch the Meningitis Progress Tracker (MPT), enabling policymakers, researchers, and health activists to access global data about meningitis in one tool.

We introduce live chat to our helpline services, enabling people affected by hearing loss, and those not ready to speak over the phone, to access our support for the first time.

2021: Welcoming CoMO, celebrating the Road Map and joining a global taskforce

We strengthen our long-standing collaboration with the global network Confederation of Meningitis Organisations (CoMO) and its members, becoming one so we can work even more closely together to defeat meningitis.

The WHO Global Road Map launches in Geneva, with an address by Dr Tedros Adhanom Ghebreyesus, WHO Director-General. We re-join the WHO Technical Task Force for the next phase, working alongside many partners on Road Map implementation.

2019

2020

2020: A Global Road Map to defeat Meningitis; Global Meningitis Genome Partnership; Meningitis and Me

WHO member states approve the **Global Road Map to Defeat Meningitis by 2030** with a clear plan in place on prevention and epidemic control; diagnosis and treatment; disease surveillance; support and care for people affected by meningitis, and advocacy and engagement.

We begin working with international experts to establish a **Global Meningitis Genome Partnership**, linking resources for the four leading causes of bacterial meningitis to help identify and monitor strains, control epidemics, and support vaccine evaluation and development.

Meningitis and Me launches, our National Lottery funded video series of peer-to-peer support, sharing experiences, tips and advice by and for those affected by meningitis.

2021

#### 2022: Our work continues

And to today, as we continue our work with survivors and their families, the global research community, and national and international policy makers to defeat meningitis and septicaemia through an evidence-based advocacy, research and support program.

2022

2023

2024

**Our strategy |** 2021 – 2025





Meningitis and neonatal sepsis together are the world's second biggest infectious diseases killers of children under 5.

But meningitis lags behind other diseases in progress and funding.

Defeating meningitis matters.

# Our strategy | overview

### **Our strengths**

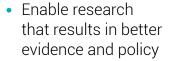


#### Our strategy builds on our strengths.

- We have a unique role in linking science and research with people and their experiences.
- We run an international network of patient groups through the Confederation of Meningitis Organisations (CoMO).
- We have an international research network and reputation for being evidence-led.
- Our national and international partnerships and relationships enable us to act as a 'neutral broker'.
- We have a reputation for grass roots advocacy and long-standing evidence of success
- We bring global data together and make it accessible for policymakers and the public.

# Our strategic objectives, 2021-2025





- Transform engagement in meningitis
- Secure funds and profile to deliver our goals
- Grow our capacity to deliver at scale

# Our vision & mission



- To see a world free from meningitis and septicaemia.
- To defeat meningitis and septicaemia wherever they exist

# Our guiding principles



- Be evidence-led
- Operate with integrity
- Pursue our goals with determination
- Be a passionate advocate
- Collaborate to make progress
- Act with compassion

# How our work brings change

Global health issues Meningitis and neonatal sepsis Meningitis and neonatal together are the second biggest sepsis cause a wide range killers of under 5's globally of impairments **Funding & Fundraising Organisational Development**  Active supporter base High-quality teams with the right expertise Flexible and sufficient funding Effective procedures, processes and systems Research, Evidence and Policy **Engagement** Our output Meningitis Progress Tracker, Global partnerships & advocacy, Support Services, Global Meningitis Genome Partnership, campaigning (awareness and policy), Research Conference, expert advice CoMO network Research and better evidence and Public and policy engagement in meningitis is transformed policy are enabled Our outcomes Scientists, researchers and public Meningitis will be a global health priority. health practitioners will better understand More people will be aware of signs and symptoms. meningitis, its impact on people's lives, More people will seek help when they need to. and what to do to defeat it. Patient groups will be stronger and better supported to advocate for meningitis. 1. Prevention: 2. Diagnosis & Treatment: 3. Support and Aftercare: Fewer people get More people survive with More people have access meningitis reduced disability to support and care Global health outcomes 4. Surveillance: 5. Advocacy and Engagement: Better data is used for policy and decision making Policies are implemented and people involved Meningitis is defeated by 2030: A world free from meningitis and septicaemia

# 4 strategic goals

**Goal 1** | To enable research for better evidence and policy

#### **Outcome 1:**

Scientists, researchers and public health practitioners will better understand meningitis, its impact on people's lives, and what to

#### Outcome 2.1:

Meningitis will be a global health priority.
More people will be aware of signs and symptoms. More people will seek help when they need to.

**Goal 2** | To transform public and policy engagement with meningitis

Outcome 2.2
Patient groups
will be stronger
and better supported
to advocate for
meningitis.

**Goal 3** | To secure profile and funds to deliver our goals

Outcome 3:
We will have
the funds and
relationships
needed to support
our work.

#### **Outcome 4:**

We can deliver on our promises and potential as an organisation.

**Goal 4** | To grow our capacity to deliver at scale



Why our work matters

12 reasons



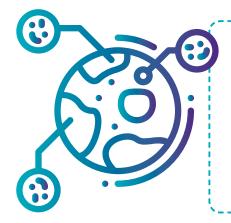
In 2019, it is estimated that over 230,000 people died of meningitis globally. Over 2.2 million people survived the disease but approximately 1 in 5 of those survivors have been left with an impairment, whether physical, behavioural or neurological.



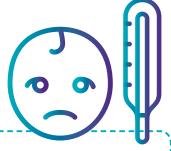
Globally, over 1 in 10 people who contract bacterial meningitis will die.







In 2019, India was the country with the most cases, Nigeria had the most deaths, and Somalia, Chad, Mali and Niger were the countries with some of the highest mortality rates per 100,000 of population. **Meningitis affects all countries** and communities in the world.



The most severely affected survivors have such profound damage that they cannot lead independent lives again. No other illness produces such mutilating injuries. We calculate that between 1990 and 2019 over 11 million people have been left with a disability caused by meningitis.



Approximately half of all meningitis deaths are in children under 5 years old. Meningitis and neonatal sepsis kill more under 5's than malaria, measles and tetanus combined. Collectively, meningitis and neonatal sepsis are the world's biggest infectious disease killers of newborn babies.



For those that survive, meningitis and neonatal sepsis are the world's leading cause of severe intellectual disability. Meningitis is also the leading infectious disease cause of severe hearing loss.

Meningitis disproportionately affects the poorest communities. 93% of healthy life lost to meningitis in 2019 was in low and lower middle income countries.

ies.

Meningitis impacts hardest on women: women share the largest burden of care for relatives with disabilities that can include limb loss, hearing loss, and neurological dysfunction.

Sub-Saharan Africa is the area of the world where the risk of getting meningitis is highest. People living in Sub-Saharan Africa are over

three times more likely to get meningitis and over 3.5 times more likely to die from it compared to the global average. It is the area of the world where countries have the least resources to respond.



Meningitis can return to areas where people assume it has disappeared – in 2015 Nigeria and Niger experienced outbreaks of MenC, something which had not happened since the 1970s. In 2021, the UK saw growing MenB cases in teenagers, as the country emerged from cycles of COVID lockdowns and school closures.

Despite major progress over the last 20 years, meningitis is still the world's 6th largest infectious disease killer.



Data sources: Global Burden of Disease Study 2019, Institute for Health Metrics and Evaluation, WHO Global Health Estimates 2019. (collated using the Meningitis Research Foundation Meningitis Progress Tracker), UKHSA. All data accurate as of February 2022.

Further references: Debbie Budlender, Time Use Studies and Unpaid Care Work (New York, Routledge, 2010); Marzia Fontana, "Gender dimensions of rural and agricultural employment", in Gender Dimensions of Agricultural and Rural Employment: Differentiated Pathways out of Poverty —Status, Trends and Gaps (Rome, Food and Agriculture Organization of the United Nations, 2010); United Nations General Assembly Report of the Special Rapporteur on extreme poverty and human rights; Stephen Clark, Helen Campbell, Anna A. Mensah, Aiswarya Lekshmi, Andrew Walker, Sonia Ribeiro, Lloyd Walsh, Laura Willerton, Xilian Bai, Jay Lucidarme, Mary E. Ramsay, Shamez Ladhani, and Ray Borrow ,An Increase in Group B Invasive Meningococcal Disease Among Adolescents and Young Adults in England Following Easing of COVID-19 Containment Measures (SSRN, December 16, 2021): dx.doi.org/10.2139/ssrn.3998164.

To enable research for better evidence and policy

### We will ...

- a) Create and share the best available data and evidence on progress being made against meningitis around the world.
- b) Support the research ecosystem by convening people and expertise through conferences, meetings and the Global Meningitis Genome Partnership.
- c) Fund and partner on research into genomics and the lifetime impact of meningitis on people's lives.
- d) Strengthen clinical practice by participating in expert advisory groups.

### So that ...

- a) We become the source of the best data on meningitis in the world.
- b) We forge a reputation as a centre of excellence for the promotion and support of genomics research for meningitis, and understanding of the lifetime impact of meningitis.
- c) We deliver the world's most highly regarded meningitis research conference.
- d) Clinical practice uses the latest evidence.

#### **Outcome 1:**

Scientists, researchers and public health practitioners will better understand meningitis, its impact on people's lives, and what to do to defeat it.

### By ...

- a) Updating the Meningitis Progress Tracker each year.
- b) Meeting the Global Genome Partnership aims.
- c) Supporting new research through funding and partnerships into genomics and the lifetime impact of meningitis on people's lives.
- d) Hosting world-leading research conferences in 2021, 2023 and 2025.
- e) Launching a research webinar series.
- f) Advocating for the research agenda in the WHO Global Road Map to be adopted and integrated into major funder programmes.
- g) Participating in expert advisory groups (e.g. NICE, DIAMONDS and GMI).

To transform public and policy engagement in meningitis

### We will...

- a) Ensure policy prioritisation of meningitis at a global level.
- b) Enable increased global awareness of meningitis.
- c) Support countries to have messages and tools to raise awareness of meningitis.
- d) Support organisations and citizens to be engaged in national policies and plans.
- e) Ensure people get the support they need.

### So that...

- a) Meningitis will be a global health priority. More people will be aware of the signs and symptoms, seeking help when they need to.
- b) Meningitis is included in WHO plans and funding.
- c) There is a global communications framework of messaging for regional adoption.
- d) Meningitis and sepsis awareness campaigns are conducted in >80% of priority countries.
- e) Awareness is raised on International Day of Persons with Disabilities in >80% of countries.
- f) There is a dedicated support service based in the UK that responds to need.

Outcome 2.1:

Meningitis will be a global health priority.

More people will be aware of signs and symptoms. More people will seek help when they need to.

### **By...**

- a) Advocating for improved awareness of meningitis as a national and global health issue; for better policies for vaccines, for better diagnosis and treatment, and for better support for people and families affected.
- b) Raise awareness of the signs and symptoms of meningitis so that people can seek medical help when they need it.
- c) Directly support people and families affected via our support services, social media and world-class website.



# To transform public and policy engagement in meningitis



### We will...

- a) Support and develop the CoMO network and its impact.
- b) Ensure network members voices are represented at a global level.
- c) Link CoMO members to global developments in public health related to meningitis.
- d) Connect members to each other and their experience.
- e) Support CoMO members, so they can be engaged in national policies and plans.

Outcome 2.2
Patient groups
will be stronger
and better supported
to advocate for
meningitis.

### **By...**

- a) Running the CoMO network, including a website with tools for use in multiple languages.
- b) Leading on World Meningitis Day awareness raising activity globally.
- c) Holding an annual conference of CoMO members.
- d) Holding regular remote meetings of members and advisors.
- e) Providing training and capacity building support for CoMO members.
- f) Represent CoMO at external global meetings and events.
- g) Linking and involving CoMO members and work to country awareness raising activities.

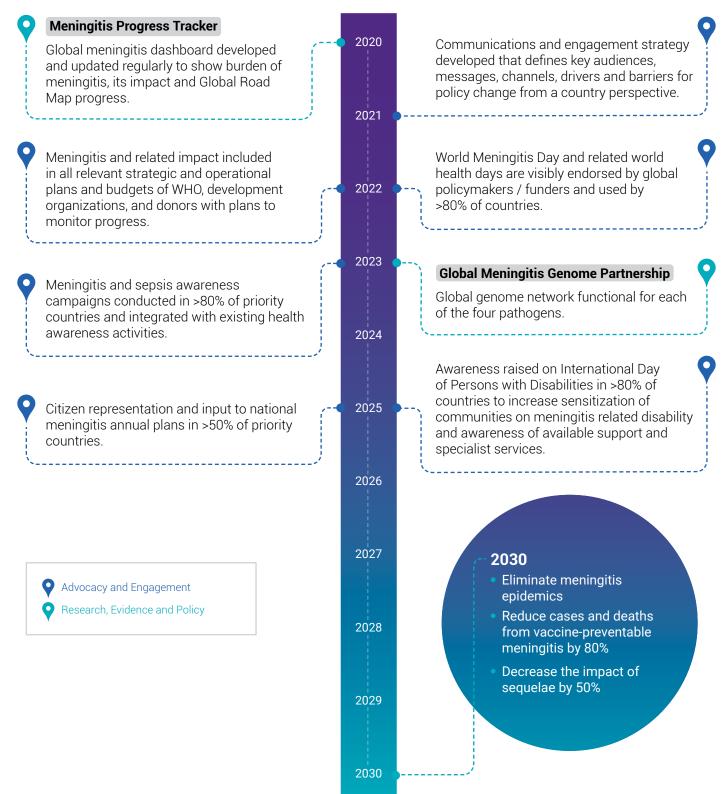
### So that...

- a) CoMO maintains and grows our reputation as the main international representative network of meningitis organisations and individuals globally.
- b) World Meningitis Day and related global health dates are visibly endorsed by global policy makers/funders and used by >80% of countries.
- c) CoMO members are represented and input to national meningitis annual plans in >30% of priority countries.
- d) CoMO grows, with new members in 20 countries.

# Participating in WHO Global Road Map milestones

# the next 5 years

# World Health Organization (WHO) Global Road Map agreed



To secure profile and funds to deliver our goals

Outcome 3:
We will have
the funds and
relationships
needed to support
our work.

### We will...

- a) Raise awareness of our work amongst funders.
- b) Identify and apply for grants from Trusts and Foundations.
- c) Gain corporate donations, grants and sponsorship.
- d) Support volunteer fundraising.
- e) Support people to take part in fundraising events of their own.
- f) Fundraising places available at e.g. London Marathon and Mount Kilimanjaro Treks.
- g) Support and promote regular giving.

### **By...**

- a) Focusing on multi-year grants to secure funds for our priority projects such as Meningitis Progress Tracker, global advocacy and engagement work and capacity building for patient groups / the CoMO network.
- b) Maximising events and student fundraising, including London Marathon and Treks, to support our core activity.
- c) Supporting community and volunteer-led fundraising.

### So that...

- a) We grow income.
- b) We attract multi-year grants.
- c) We explore new funds for community engagement.
- d) We continue to balance our historical UK focus with our international profile.

### To grow our capacity to deliver at scale

### We will...

- a) Make sure we plan for success with the resource available.
- b) Attract and keep great people by retaining and developing our teams and attracting the best new recruits.
- c) Ensure our infrastructure enables our work.
- d) Ensure good governance of MRF and CoMO, including Board and sub-committees.
- e) Ensure legal, regulatory and financial compliance and reporting.

#### **Outcome 4:**

We can deliver on our promises and potential as an organisation.

### **By...**

- a) Retain high-performing team members.
- b) Successfully recruit high-quality and diverse people, as funding becomes available.
- c) Support remote working and a dedicated office.
- d) Deliver transparent project reporting, demonstrating effective use of funds.

### So that we...

- a) Ensure our high-quality team have the support they need to develop.
- b) Make the most use of our supporters' funding for the reasons they give.
- c) Recruit and retain high-quality people to fill the gaps in our capacity, in line with funding.
- d) Ensure we have an ethnically, geographically and disability-diverse Board and team.
- e) Review and update the composition of our Scientific Advisory Panel and Medical Advisory Group to align to our research strategy.

# In their own words: the meningitis experience

"He was a year old when he was affected with meningitis. We were in a rural area so we couldn't get a proper treatment for him in time. He showed the common symptoms as diarrhoea, high fever, vomiting ... He is now 25 years old and he is mute and deaf and also gets seizures (from) time to time."

Resha Sedhai | bacterial meningitis | Nepal

"Ryan was two years old when he was diagnosed with viral meningitis. It took longer for the doctors to identify the disease. He went through three scans, two CTs and an MRI ... (He) lost his eyesight, can't do anything that he could do before. No movement, no speech just nothing except eating."

Calisto Ochieng | viral meningitis | Kenya



Thank you to our community of patients, survivors, families and friends who share their experiences so others can understand the true impact of meningitis and septicaemia.

"... my sister called out 'Em I'm cold can you get me a blanket', 'bloody cheek', I thought, 'get your own blanket'. If only I had known at that point that my 19-year-old little sister Jolene would be dead in 24 hours. The next morning, she woke and was displaying all the classic signs of flu. She had vomited and complained of her eyesight going funny, cold legs and feet ... It was from this point that Jolene rapidly went downhill. The rash took over her body and was even present in her eyes. Jolene was put on kidney dialysis and life support machine as her organs were starting to fail but she sadly lost her fight at four am just a little over 24 hours from the first symptoms appearing."

Jolene Mccardle | meningococcal meningitis | UK

Taken from our Book of Experience, where those affected by meningitis and septicaemia tell their story, in their words:

meningitis.org/the-book-of-experience

# **Our principles**

### We are evidence-led

We pride ourselves on being grounded in facts. Research and evidence are at our core and remain essential to our work today – guided by our panel of scientific advisors and disease specialists. This approach ensures we provide considered responses to the challenges brought about by the disease, wherever they may be found.

### We operate with integrity

To the people we support and work with, we are a trusted source of information and learning. We weigh all of the evidence and operate with openness and transparency to exceed expectations and deliver the best services and responses - be that helping a family, or working with health organisations around the world.

# We pursue our goals with determination

We will not stop until we defeat meningitis. We will relentlessly seek answers, work tirelessly with purpose and are driven by those we help. Our dedication enables the best modern science, research and on-the-ground learning to work in the positive interests of individuals, families and communities impacted by meningitis and septicaemia, both here in the UK/ROI and in communities around the world.

### Join our community

# We are a passionate advocate

We are a united voice against meningitis and septicaemia and a dedicated champion for those it affects. We exist to ensure that the voices of our members, supporters and those impacted by meningitis and septicaemia in the UK, ROI and around the world, are heard and not forgotten. We are highly focused in our work and inform and advise health policy and practice, driven to make a contribution to reducing the burden of the disease and its aftermath.

# We collaborate to make progress

We believe in partnership and collaboration. Whether we are supporting individuals and families who have been impacted by the disease, working with international funding partners or supporting on-the-ground health teams working in challenging environments, we combine resources and expertise to deliver the very best results. We share the knowledge we've gained through more than 30 years of work in the UK and ROI to support and enable those impacted by or battling to defeat the disease.

### We act with compassion

We are driven by the stories of those we work for and with. We care deeply, listen and take the best action for each unique circumstance. Whether it's providing direct support, finding the right information, or campaigning for the change that will make a real difference.

