Chair of Trustees

Thank you for your interest in applying for the position of Chair of Trustees for the Meningitis Research Foundation. This is an extraordinary opportunity to lead a dynamic and impactful organisation committed to defeating meningitis and improving the lives of those affected by this life-threatening disease. We are at the forefront of advocacy, research, and provision of resources to ensure that no one suffers unnecessarily from meningitis and its devastating consequences.

As Chair of Trustees, you will play a pivotal role in shaping our strategic direction, fostering key partnerships, and ensuring that our governance supports sustainable growth and robust outcomes. It is an opportunity to amplify our voice globally, mobilising action and resources to combat meningitis, especially in regions and among populations most vulnerable to the disease.

Our Trustees bring a wealth of expertise and passion to guide our mission, and as the Chair, you will lead this team with vision and integrity. Your leadership will be instrumental in driving forward initiatives that align with our values of collaboration, innovation, and impact. Together, we aim to reach the ambitious goals outlined in our mission to defeat meningitis within a generation.

This candidate pack contains important information about the role, including responsibilities, requirements, and what we hope you can bring to this position. We invite you to explore it in detail and consider joining us in this vital fight to defeat meningitis.

Kind regards,

Vinny Smith
CEO, Meningitis Research Foundation

About meningitis

Meningitis is the swelling of the lining around the brain and spinal cord (the meninges) and is usually caused by a bacterial, fungal or viral infection. It can be life-threatening.

1. Every year, there are around 2.3 million cases of bacterial and viral meningitis around the world. 1 in 10 people who get meningitis will die *(1,2)*.

2. Meningitis can strike anyone at any time, but some people are particularly at risk because of age, living in crowded conditions and immune deficiencies such as HIV. Babies, children and young adults are some of the groups most at risk of meningitis *(4)*.

3. 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 *(1,2,3)*.

4. Bacterial meningitis is one of the deadliest forms of meningitis, with the World Health Organization estimating that around 1 in 6 people who get it will die *(4)*.

5. Across the world, bacterial meningitis leaves 1 in 5 people with lifelong disabilities. These include hearing loss, brain damage, limb loss and epilepsy *(4, 5)*.

6. Most meningitis deaths can be prevented but progress is behind other infectious diseases. Between 2000 and 2021, meningitis deaths fell by 45%, while deaths from measles fell by 89% and tetanus by 79% *(1,2)*.

7. People living in a region of sub-Saharan Africa known as the "Meningitis Belt" are at the highest risk of getting meningitis globally: they are over 14 times more likely to get meningitis in their lifetime than people living in Europe *(2)*.

References

1. Meningitis Progress Tracker, Meningitis Research Foundation, 2025.
2. Global Burden of Disease Study 2021, Global Burden of Disease Collaborative Network, Institute for Health Metrics and Evaluation, 2024, , Seattle, United States (accessed February 2025).
3. Global Health Estimates (who.int): Deaths by Cause, Age, Sex, by Country and by Region, 2000-2021. Geneva, World Health Organization; 2024 (accessed February 2025)
4. Meningitis: key facts, World Health Organization, Geneva, April 2023 (accessed February 2025).
5. Edmond K, Clark A, Korczak VS, Sanderson C, Griffiths UK, Rudan I. Global and regional risk of disabling sequelae from bacterial meningitis: a systematic review and meta-analysis. Lancet Infect Dis. 2010;10(5):317–28.
6. Investing to defeat meningitis and beyond, World Health Organization (accessed February 2025).
7. Global, regional, and national burden of disorders affecting the nervous system, 1990-2021: a systematic analysis for the Global Burden of Disease Study 2021, GBD 2021 Nervous System Disorders Collaborators (2024), The Lancet. Neurology, 23(4), 344–381.

About us

Meningitis Research Foundation is an international health charity headquartered in the UK, driven by a passionate mission to prevent the devastating impact of meningitis.

Founded by individuals whose lives were profoundly affected by meningitis, we are dedicated to enabling positive change by uniting people and knowledge to save lives.

The Confederation of Meningitis Organisations (CoMO) is our worldwide network of people and groups who are driven by a shared purpose to defeat meningitis. By coming together to share their diverse experience and expertise, they are a formidable global force against this life-threatening condition.

We support research because it is the evidence needed for decisive action. We fund research projects to drive the breakthrough science that will help defeat meningitis. We are a catalyst for genomics research, so we understand the origins and evolution of meningitis pathogens. We bring together the leading minds from around the world to fuel collaboration and innovation at our events. And we use the insights gained from the latest science to influence policy and practice.

Our campaigns make sure people know meningitis is a threat, so communities worldwide can be safe from harm. We put the voices of people affected by meningitis in front of those who make decisions about the healthcare available to us all, to ensure meningitis is a global health priority that cannot be ignored. We make sure like-minded people and groups have the tools and evidence they need, enabling collaboration to drive change in communities across the world.

Fundraising is the glue that holds together our work to defeat meningitis. Our fundraising activities support people to not feel helpless in the face of tragedy and heartache, so they can leave a legacy for those they have lost.

Our work is trusted and supported by some of the world's leading science and health organisations.

Through adventures and experiences, we create a community, so people can be passionate advocates and connect with others, whether they have been through a similar life-changing experience because of meningitis or simply want to support our cause.

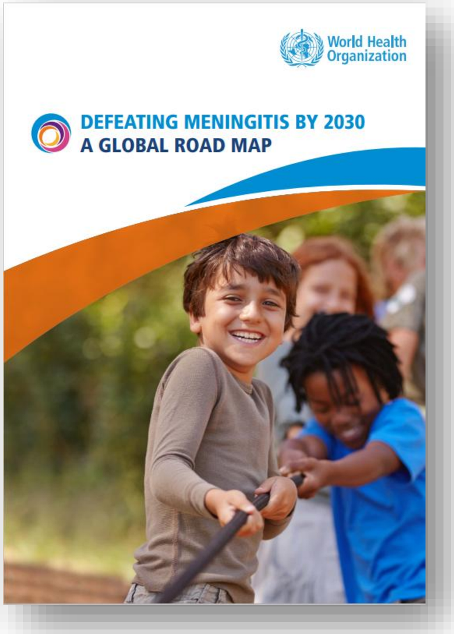
We take seriously our responsibility to invest the funds raised for us where they will have the biggest impact. Why? Because our supporters enable everything we do.

Find out more about who we are here:
meningitis.org/about-us

Read about the people who inspire us:
meningitis.org/meningitis-in-your-words

Activity highlights

- We are a member of the World Health Organization Technical Task Force to defeat meningitis by 2030.
- We run the Confederation of Meningitis Organisations which represents over 150 like-minded members in more than 50 countries.
- We hosting a one-stop-shop for the best data for modelled estimates on burden of meningitis called the Meningitis Progress Tracker , a critical tracking mechanism for the new global roadmap. This has now been used more than 50,000 times in over 100 countries.
- We provide a secretariat support function for the Global Meningitis Genome Partnership building on the establishment of the Global Meningitis Genome Library.
- We deliver an internationally renowned research conference every 2 years showcasing latest cutting-edge research on meningitis from around the world.
- We fund research into meningitis, especially related to genomics and the lifetime impact of meningitis.
- We provide a world class website and support service that has over 2 million uses each year.
- We've led research on the lifelong impact of meningitis. Our "Counting the costs" analysis revealed the lifelong financial burden of surviving meningitis, giving health policymakers in the UK the evidence needed to support wide and early implementation of vaccines.
- We have developed a group of Ambassadors who have a genuine connection to meningitis. They are living testaments of our support ethos, sharing their individual experiences through talks, presentations and media interviews to help society understand why defeating meningitis matters.


World Health Organization

DEFEATING MENINGITIS BY 2030
A GLOBAL ROAD MAP

Our values

Our values are extremely important to us and mean far more to us than words on a page.

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 and in communities around the world

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 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 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.

If you have read and understand these values and they appeal to you they are a good indicator of what it is like to volunteer for MRF.

Our strategy 2025-30

In the next 5 years we will build on the success of our strategy 2021-2025. This strategy sees us picking up the pace of progress needed to defeat meningitis by 2030 and equipping ourselves as an organisation ready for the 2030's.

We renew our commitment to research as the bedrock of our work on behalf of people and families affected. We will amplify their voice to build greater understanding of the disease and the change that needs to happen on their behalf.

Our vision is a world free from meningitis.

Our mission is to defeat meningitis wherever it exists.

Our strategic direction is to accelerate progress globally and in the UK whilst strengthening our foundations.

We are a UK-based organisation with global ambition

We are driven by the personal impact and scale of meningitis

People ask us to *'Make sure no family goes through what we have'*. This drives our mission - to defeat meningitis wherever it exists.

In 2019 there were 2.5 million meningitis cases causing 240,000 deaths with 1 in 5 acquiring a disability. Every number is a person.

To address this we have three goals

Goal 1
Research
For better evidence

We will fund, deliver and partner on research.

Goal 2
Understand
For better policy

We will share research and implications for public health policy.

Goal 3
Act
For better lives

We will raise awareness and advocate for change.

And our Foundations will underpin everything we do

Listening
For learning from lived experience

We will listen to & learn from & with people and families affected to address their priorities.

Support
For people affected

We will support people and families affected

Sustainability
For the future

We will put in place high quality, sustainable, and diverse teams, capabilities and resources to act.

Equity
For fairness

We will apply an equity lens to everything we do.

So that we can work towards our vision of

A world free from meningitis

Our new strategy is currently being designed and a full copy is available to interested candidates

Our goals this year

By January 2026 to **launch a new £300k research funding round** to support improved use of **available vaccines and improving quality of life after meningitis**.

By March 2026, to scope the research question/s and policy landscape we want to address on the **Lifetime Impact of Meningitis**.

By March 2026, MRF has a vision and well defined approach for capturing data on **'all-cause meningitis'** in the **Meningitis Progress Tracker**.

By the end June 2025 to have hosted a successful **CoMO Member Conference** and by the end of November to have hosted a successful **Research Conference.**

By March 2026, to maintain **156 members in 58 countries** and continue to support organic member growth.

By December 2025 to see **75 countries engage in World Meningitis Day** around the world.

By March 2026 at least five **advocates use project resources** to call on their government to develop or publish a **national plan** and at least five advocates use project resources to request involvement in **national plan development**.

By January 2026, we will have developed a **policy position** on the introduction of a **MenB protective vaccine in the UK**.

By December 2025, to agree a set of **metadata standards** for genome sequencing data sharing at the GMGP Steering Group.

By March 2026, to deliver **£3.1million of new income**.

Role Description

This is a great opportunity to join an inspirational Board of Trustees.

You will drive the Board to thrive so it can support and challenge the senior executive to lead the organisation well, and to achieve more impact for people suffering from meningitis.

Core duties and responsibilities will include:

- Supporting the creation of clear strategic objectives linked to our vision and mission.
- Working with the Board and team to protect the charity’s financial sustainability.
- Act as principal liaison between Board and the CEO, taking all reasonable steps to ensure that the expectations of the Board towards management are clearly expressed, understood and respected.
- Introducing new networks to MRF to aid its strategic objectives and impact.
- Ensuring compliance with the charity’s governing document and regulatory requirements.
- Planning board meeting agendas and ensuring robust governance review mechanisms are in place;
- Building a diverse, effective Board with a mix of skills and lived experience relevant to MRF;
- Establishing and building a strong, effective and constructive working relationship with the MRF team, ensuring it held to account for achieving agreed strategic objectives.

The Chair is expected to be based in the UK or have significant presence in the UK for extended periods of time within the year.

Person Specification

The successful candidate will be expected to demonstrate evidence of the following skills, capabilities and experience:

- Evidence of effective Chairing skills.
- An inclusive style of leadership and ability to adapt to circumstances that may change rapidly.
- International health/research experience involving policy with global bodies e.g. World Health Organization.
- Knowledge of global south advocacy and funding landscape.
- Strong network of potential to support the goals of the organisation.
- International low/middle income country experience
- Significant advocacy experience.

In addition, the below experience is particularly welcomed:

- Experience of running or Chairing a non-profit as a CEO or equivalent.
- Infectious disease research.
- Biosciences.
- Epidemiology.
- Social value strategy/planning and delivery.
- Charity law.

The role of Trustees

Our trustees play a vital role in making sure we achieve our core purpose.

They oversee the overall management and administration of the charity.

They also ensure we have a clear strategy and that our work and goals are in line with our vision.

Just as importantly, they support and challenge the executive team to enable us to grow and thrive, and through this, defeat meningitis wherever it exists.

Board members have a collective responsibility. This means that trustees always act as a group and not as individuals.

The duties of a trustee are:

- Ensuring that the organisation pursues its stated objects (purposes), as defined in its governing document, by developing and agreeing a long-term strategy.
- Ensuring that the organisation complies with our Articles of Association, charity law, company law and any other relevant legislation or regulations.
- Ensuring that the organisation applies its resources exclusively in pursuance of its charitable objects (i.e. the charity must not spend money on activities that are not included in its own objects, however worthwhile or charitable those activities are) for the benefit of the public.
- Ensuring that the organisation defines its goals and evaluates performance against agreed targets.
- Safeguarding the good name and values of the organisation.
- Ensuring the effective and efficient administration of the organisation, including having appropriate policies and procedures in place.
- Ensuring the financial stability of the organisation.
- Protecting and managing the property of the charity and ensuring the proper investment of the charity's funds.
- Following proper and formal arrangements for the appointment, supervision, support, appraisal and remuneration of the chief executive (if the charity employs staff).
- In addition to the above statutory duties, each trustee should use any specific skills, knowledge or experience they have to help the Board of Trustees reach sound decisions. This may involve scrutinising board papers, leading discussions, focusing on key issues, providing advice and guidance on new initiatives, or other issues in which the trustee has special expertise.

Commitment

The MRF Board meets four times each year (usually February, May, October and November/December) at a four-hour meeting that takes place during UK working hours, typically 10am-2pm.

Board Meetings are held remotely.

We also have one annual Strategy Day in person at the Charity's Bristol head office (usually in November/December each year).

Papers for meetings are distributed one week in advance and take approximately two hours to read and prepare for each meeting.

Trustees are requested to attend all Board meetings. Where this is not possible, Trustees are asked not to miss more than two meetings consecutively.

For Trustees outside the UK, or for those who may have difficulty travelling, remote attendance at all meetings is possible (via MS Teams or similar) and this can be arranged in advance.

The MRF Board is supported by four committees:

- Finance and Risk
- Confederation of Meningitis Organisations Advisory Council
- Remunerations Committee.
- Audit Committee.

Committees are made up of a smaller group of Trustees.

Committee meetings take place two weeks before each full Board meeting and last 2 hours each, except for the Audit and Remunerations Committees, which meet annually.

Papers are circulated in advance where possible no later than 48 hours before meeting. Committee meetings take place by MS Teams to reduce time and cost on travel.

Where necessary, travel expenses for UK participants to meetings are covered by the Charity, including to the Strategy Day.

If Trustees are based outside the UK, the charity is unable to cover travel expenses for international travel.

The Chair is responsible for maintaining regular contact with the CEO between meetings to stay up to date with latest developments within the charity and sector. In addition, the Chair commits to being available at short notice to advise the CEO on developments requiring attention.

Over the course of a year, the Chair time commitment is approximately half a day a week though this is not uniform.

Find out more about our Board here:
meningitis.org/meet-the-trustees

How to apply

If you are interested in this exciting position, please apply by providing:

1. A concise covering letter (ideally no longer than two pages), setting out why you are interested in being Chair and how you experience matches the person specification.
2. An up-to-date curriculum vitae.
3. Names and contact details of three referees (although referees will only be approached at the final stage of the process, and only with your express permission).

Applications sent without a covering letter will not be considered.

Please do not use Artificial Intelligence (AI) tools to create your application.

Letters and CV's to be sent to: Kateg@meningitis.org

If you would welcome an informal conversation to gather more information before applying, please liaise with Kate Gill Kateg@meningitis.org who will help set up a call with Vinny Smith.

The deadline for receipt of applications is 5 pm on Friday, 4 July 2025..

Shortlisted candidates will be invited to interview with a panel of current Trustees on Wednesday, 16 July, in person in central London.

An appointment will be made subject to receipt of satisfactory references.

We are committed to ensuring that anyone can access our application processes. This includes people with hearing, sight, mobility, and cognitive impairments.

Should you require access to this document in an alternative format, wish to apply in a different format, or need any other reasonable adjustments made for you (including at interview), please contact us at kateg@meningitis.org.

We also welcome suggestions or comments about any more general access improvements we should consider.