



Strategy

2017-2020

Defeating meningitis

“In just 24 hours my life changed forever. Now I’m helping Meningitis Research Foundation to raise awareness.”

- Sophie Royce



We are a leading UK and international meningitis charity that brings together people and expertise to defeat meningitis and septicaemia wherever it exists.



Imagine a better world...

We want a world that promises more for people and families at risk of meningitis and septicaemia, and for those already living with the after effects of the disease.

In that world, research we have funded is used in the development of new vaccines. Existing vaccines are used more effectively. Everyone has a better understanding of the impact of this dreadful disease on people and families.

We have helped improve the rules governing vaccine access so that they are fairer. This means that more people get the vaccines they need. More people are protected as populations develop community 'herd' protection. Better access in turn leads to improved uptake of meningitis vaccines.

We've helped the world come together to create a global plan to defeat meningitis by 2030 because we really do believe, for the first time in history, it is within reach to do it.

To enable this, we've helped improve global and country level data so that the policy implications are clearer and key stakeholders and decision makers can make more informed choices about tackling the disease.

In clinics and hospitals, improved diagnosis and treatment recommendations and methods are being used as a result of research we have funded.

Amongst the general population, we have helped ensure better meningitis awareness, meaning more people seek out help more often when they need to thanks to better understanding of the symptoms and the actions they can take.

With our support, increased numbers of healthcare workers are suitably trained and supported with tools to prioritise meningitis cases for diagnosis and treatment. They are an integral part of improving data capture to benefit meningitis diagnosis and treatment.

Our funding and support will mean communities are more involved in demanding better services resulting in better pathways of care. We will be learning from an extensive network of patient groups around the world leading to increased effectiveness of information available to patients and families.

This is the world we want to see.

“Now we no longer have cases of children dying while waiting to receive treatment.”

- Health worker, Malawi



Leaving no one behind

Every day we hear from individuals and families affected by or at risk of meningitis and septicaemia. By listening to their stories, and with nearly 30 years of experience, we have developed a good understanding of what they need to be protected, treated and supported. This strategy is written for them, from their perspective, so that no one is left behind.

Between 2017 and 2020 we will bring together people and expertise to meet the challenges of meningitis and septicaemia wherever they exist in the world – we are driven to defeat a disease that does not respect people or national boundaries.

We have three major goals:



To see fewer people get meningitis and septicaemia in the first place.



To see more people survive with a better quality of life and reduced disability.



To have more engaged, informed and supported patients and communities.

We believe that these three developments can help deliver protection for everyone. More people can survive and with less disability. Families can be cared for whilst ensuring their 'patient voice' is included in all considerations about sustainable services that meet their needs.

This is what we have been delivering for nearly 30 years in the UK and Republic of Ireland. Between now and 2030 we believe they are within reach around the world.

To achieve this, over the next three years we continue our work that has been successful in the past. At the same time we will use our expertise, build new partnerships, attract new funding and undertake new activities towards a world free from meningitis and septicaemia.

We will support research as a bedrock of an evidence-led approach to defeating meningitis wherever it exists. We will support healthcare professionals in the UK and Republic of Ireland by developing information and tools they need to do their jobs better. We will keep supporting our wonderful members and supporters who rely on our help and information. And we will keep advocating on their behalf for better services and vaccines for those affected and most at risk.

We will also undertake more international work at both a global and country level, especially in Sub-Saharan Africa. We will bring together the most influential decision makers in global health in a conversation about how to eliminate meningitis. We will work to strengthen the patient healthcare pathway at a country level so

sick children, including those with meningitis and septicaemia, are prioritised for treatment according to need. We will ensure that communities have their voice heard and that patient need is at the heart of sustainable change.

Being committed to an evidence-led approach to defeating meningitis wherever it exists means we will use and advocate for better data on meningitis at all levels. Our commitment to partnership working means we will work with others to effect change. And a commitment to thinking about sustainability from the outset so that people see long lasting benefits and our work delivers change that stays in place.

Above all, this strategy is driven by a desire to ensure that the people we have lost are not forgotten, that their families and close connections know we care, and that others do not have to go through what they have.

This work will take place at global, regional and national levels. It will involve scientists and researchers, health professionals and health workers, patient groups, public and private sectors, policymakers, funders and public. It represents our collective efforts to bring about change and make a difference to the lives of people around the world.

Strategy summary

Vision

A world free from meningitis and septicaemia.

Mission

To defeat meningitis and septicaemia wherever they exist.

Role

To support research into, advocate for and take action towards the defeat of meningitis and septicaemia.

Foundations

To defeat meningitis wherever it exists our work will be built on three foundations. These cut across all our work and are commitments we make in everything we do.

1.

Evidence

We will ensure robust data is available in order to implement effective, sustainable solutions for a world free from meningitis and septicaemia.

2.

Partnership

We will bring together experts and coordinate knowledge to advocate for change.

3.

Sustainability

We will think long term from the start.



PROGRAMME 1

Prevention

Goal

To see fewer people get meningitis and septicaemia.

By 2030 this means

Effective vaccines for epidemics and routine schedules in place to protect people most at risk within populations.

Key objectives in this strategy

- To support ongoing research into better ways to improve prevention of meningitis.
- To secure a global commitment and plan to eliminate meningitis with vaccines at its core.

Our activity

To fund, promote and undertake research into vaccines and advocate for effective vaccine policy and financing in the UK and Republic of Ireland, as well as at a global and country level.



PROGRAMME 2

Diagnosis and treatment

Goal

To see more people survive with a better quality of life and reduced disability.

By 2030 this means

Patient pathways, health systems and appropriate tools exist that enable accurate, rapid diagnosis and appropriate treatment of meningitis and septicaemia.

Key objectives in this strategy

- To be working with partners in the UK, Republic of Ireland and 3-5 countries in Sub-Saharan Africa on strengthening the patient healthcare pathway.
- To maintain and develop our work in Malawi.

Our activity

To fund, promote and undertake research into effective diagnosis and treatment as well as carry out targeted projects with suitable partners to strengthen patient pathways, and access, in countries with high burden of disease.



PROGRAMME 3

Engagement, information and support

Goal

To have more engaged, informed and supported patients and communities.

By 2030 this means

People and communities are cared for and have their voice heard within the health system to make it responsive to their needs.

Key objectives in this strategy

- To maintain our strong UK and Republic of Ireland patient voice.
- To have established new partnerships at both a global level and country level directly with at least 10 patient representatives or groups in Sub-Saharan Africa.

Our activity

We will help our members and supporters and ensure their voice is heard in the UK and Republic of Ireland policy process. We will reach out to other like-minded patient groups in settings where burden of disease is high to help ensure their communities play an active role in the fight against the disease and after effects.

Why our work matters

In 2015 it is estimated

380,000
people died of
meningitis

and over **1 million** are likely to have survived who now have to live with the after effects.

The most severely affected survivors have such **profound damage** that they are never able to lead independent lives - no other illness produces such mutilating injuries.



India is the country with the **most cases of meningitis.**



For decades parents in the UK have named meningitis as the **disease they most fear.**



Pneumonia is the largest infectious cause of death of under-5s globally (killing approximately **920,000** under-5s in 2015), and the 2nd overall killer of under-5s. The leading cause of pneumonia in children is one of the leading causes of meningitis (Streptococcus pneumoniae).



Sub-Saharan Africa remains the area in the world where the **risk of catching meningitis is highest** and countries have the least resources to respond.



Meningitis strikes without warning, affecting mainly healthy children. The disease acts at lightning speed and **can kill within 12 hours.**

Symptoms are difficult to spot and can be mistaken for milder illness.

Despite major progress over the last 20 years, meningitis is still the world's

6th largest infectious disease killer.

If you survive, the effects can last a lifetime for you and your family.

The UK has seen a fall in rates over the past 20 years due to successful vaccination programmes, but we know it is still a

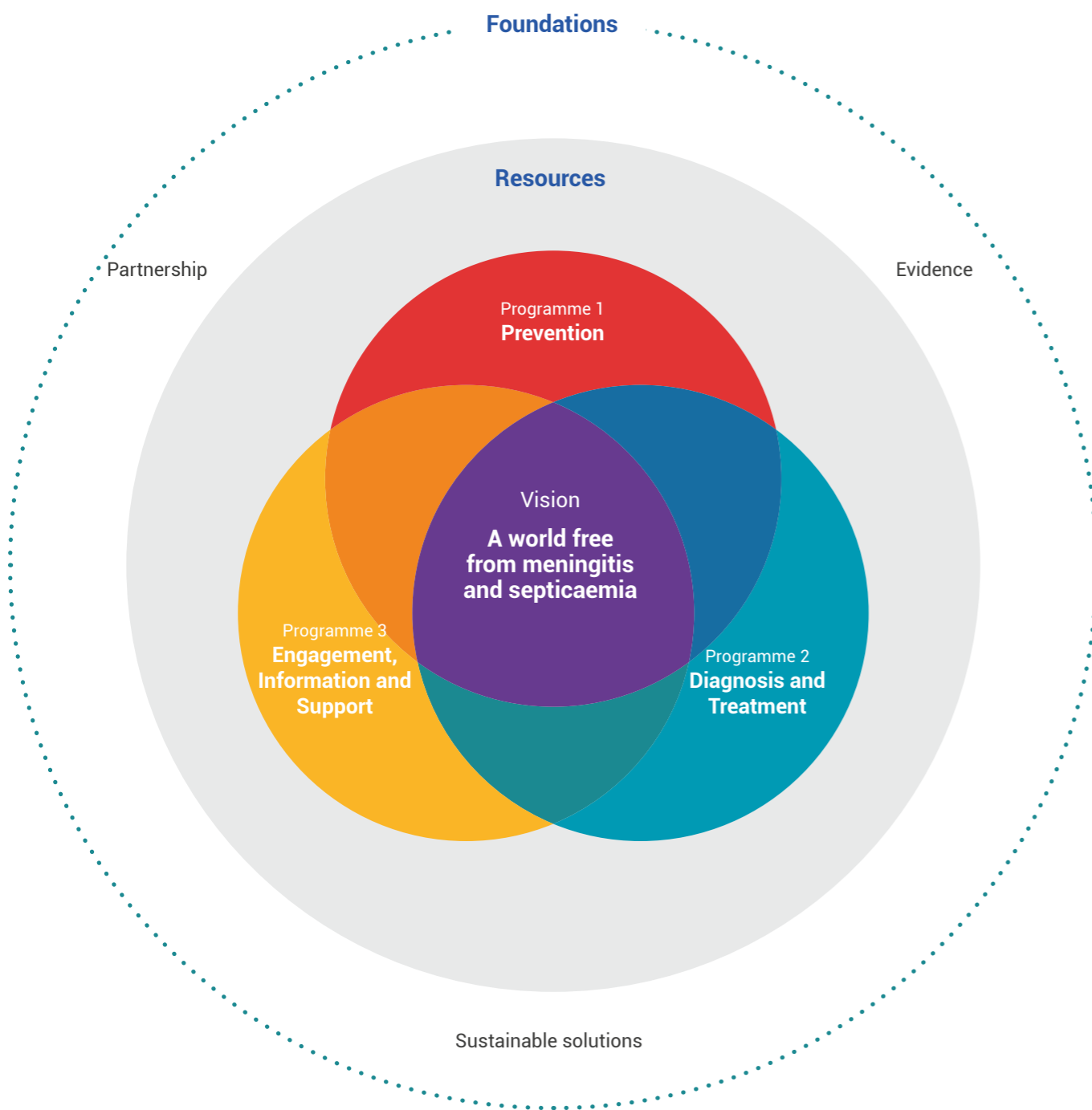
leading cause of infant death.

In the UK, children under 3 months of age are

70 times more likely

to get the disease than other children.

Our Approach



Foundations

To defeat meningitis wherever it exists our work will be built on three foundations. These come from our insights about the challenges we face today. They cut across all of our work and are commitments we make in everything we do.

- 1. Evidence**

Available data on meningitis is often partial or poor. Because of this we do not have a true picture of the disease. Poor or inconsistent data collection and surveillance systems are a major contributory factor. We need to ensure robust data is available in order to implement effective, sustainable solutions for a world free from meningitis. Because of this we will ensure that all of our actions are based on the best possible evidence so that robust solutions can make real progress towards defeating meningitis.
- 2. Partnership**

Many experts and organisations are working on meningitis but none achieve the transformation we are looking for on their own. MRF, with our unique history, can play a key role in connecting the right people to bring about change. By convening others, bringing together experts, and coordinating knowledge we can advocate for change. Forming new partnerships will also give us a stronger voice of influence. Because of this we will work in partnership with others to combine expertise, skills, and experience, bringing together knowledge needed to deliver our goals.
- 3. Sustainable solutions**

To defeat meningitis we need sustainable long-term solutions. While we continue to be innovative, we do this in order to find solutions that last. The United Nation Sustainable Development Goals (SDGs) provide a clear framework for long-term priorities and we will work to align global meningitis action with these goals. Because of this we will work towards a long-term, sustainable programme of work to ensure continued effort to defeat meningitis.



Our 3 programmes



PROGRAMME 1

Prevention

Goal: Fewer people get meningitis and septicaemia



PROGRAMME 2

Diagnosis and Treatment

Goal: More people survive with a better quality of life and reduced disability



PROGRAMME 3

Engagement, Information and Support

Goal: More engaged, informed and supported patients and communities

Turning hope into reality



PROGRAMME 1

Prevention

Fewer people get meningitis and septicaemia

Stopping people from getting meningitis or septicaemia is what everyone wants. Achieving this means ensuring that people have access to, and receive, effective vaccines. Vaccinations need to directly protect the most at risk groups as well as providing indirect protection for the whole population by knocking out the bugs from circulation amongst those who carry them.

Why we should act

Despite major progress against the disease over the past 20 years in the UK and Republic of Ireland, major challenges remain.

The UK and Ireland now have vaccination programmes against the main types of meningitis: meningococcal, pneumococcal and Hib, and yet there was an increase in meningitis cases in the UK in 2015.

Cases of MenW have been rising steeply and doubled between 2014 and 2015. The resulting emergency MenACWY vaccine campaign has reduced cases in teenagers, but MenW continues to rise in other age groups as vaccine uptake has not yet been sufficient to stop transmission of the infection and create population protection.

MenB vaccination has now been successfully introduced to protect infants but will have negligible impact on population protection, since teenagers are the key age group for transmission.

Group B streptococcus (GBS), the leading cause of meningitis in newborns, is increasing in numbers of cases and as a proportion of all cases. There is a rise in the number of cases of pneumococcal infection including meningitis that are not covered by the current vaccine.

The decision making framework used for the introduction of new vaccines disadvantages conditions that affect children and produce life-long disabilities.

On a global level there has also been major progress in the last 20 years, including mass vaccination of nearly 270 million people in Africa against Meningitis A since 2010 and the introduction of Hib and pneumococcal vaccines. However, massive problems persist.

60% of the world's children do not get vaccinated against pneumococcal infection - one of the most important causes of bacterial meningitis. Although 45 of 55 African countries have introduced pneumococcal vaccine, uptake is below 80% in more than half of them. Even with high uptake, pneumococcal outbreaks can occur as Ghana experienced in 2016.

Nearly one in five children misses out on their routine vaccinations for preventable diseases.

In the African Meningitis Belt, there are outbreaks of MenW, MenX and even MenC, which had not been seen in the region since the 1970s. MenC reached epidemic levels in 2013 killing 800 of those affected.

The MenA vaccination campaign has eliminated MenA epidemics for now, but the vaccine has only been introduced into routine schedules in three countries so far. MenA bacteria still circulate, and to maintain control the vaccine must be routinely introduced across the meningitis belt.

There is an unclear financing framework for new Men ACWYX vaccine due by 2022.

There is a particularly high burden in Sub-Saharan Africa which still faces high numbers of deaths due to meningitis.

Implementing epidemic plans takes resources and capacity that are often not there.

We do not yet have vaccines against all infections that are major causes of meningitis and septicaemia. Many countries do not have meningococcal or pneumococcal vaccines that need them.

Highlights so far

We have awarded around

£5 million

to research projects investigating meningitis prevention and surveillance since 1995.



The UK's meningococcal genome library was funded by MRF, a world first for a human disease. It enabled the correct identification of the MenW strain originating from South America and led to the vaccination of UK teenagers from 2015.

In 2014 we were instrumental in achieving a decision to introduce the

MenB

vaccine in the UK.



We have campaigned for the early introduction of vaccines to obtain rapid and comprehensive protection against meningitis.

We have promoted vaccination to the public and health professionals with information and awareness campaigns to ensure that those eligible for vaccines are able to access them.

What needs to happen next

In the UK we want to see a definitive study to show whether MenB vaccine can prevent teenagers from acquiring and spreading the infection, resulting in population protection. If the results are positive, MenB vaccination for teenagers will need to be implemented.

The MenACWY vaccine programme for teenagers needs to continue to achieve and maintain population protection against both MenW and MenC. There have also been increases in MenW in other countries where the MenACWY vaccine should be considered.

The decision making framework used for the introduction of vaccines needs to be made fairer for severe childhood illness with life long after effects.

Further evidence needs gathering to enable a Group B streptococcus (GBS) vaccine. Research into the development of pneumococcal vaccines – covering strains not covered by current vaccines – must be undertaken as a priority.

At a global level we want to see a new plan to defeat meningitis, with protection for all through a comprehensive vaccine plan at its core.

To support this we want to create a global, synthesised, user-friendly, 'single-source' of the latest available information on meningitis and septicaemia using and not replicating existing available sources.

We need quality analysis and policy advice on the implications of the existing available data.

Research and evidence needs to be gathered, analysed and shared into why children do not get vaccinated against pneumococcal infection; into why outbreaks occur even in countries with routine vaccination programmes; and on the barriers to effective emergency response at a country level.

We want to see a clear plan and financing in place for MenA vaccine to be included in routine schedules across the meningitis belt. And to see a clear plan and financing for new Men ACWYX vaccine due online in 2021.

How we will do it

MRF will play a key role in making this happen by combining three approaches: funding research; advocating for change; taking action to get results.

Research

We will seek grant funding and directly fund and support research into:

- Enabling the development and implementation of new vaccines.
- Optimising the use of existing vaccines.
- The global and local burden of meningitis.
- Strengthening the patient pathway.

Advocacy

We will advocate for:

- Fairer rules that govern vaccine access.
- A global plan for meningitis.
- The introduction of new and effective vaccines.
- Maximum possible protection from available vaccines.
- Maintenance of beneficial vaccine programmes.
- High quality studies into the burden of meningitis and impact of vaccines.
- Increased vaccine research and development for new and improved vaccines.

Action

We will carry out:

- Analysis of the decision making frameworks influencing access to vaccines.
- Synthesis and communication of latest available data on disease burden.
- Communication campaigns to increase uptake of available vaccines.
- Making available data on global burden of the disease easier to access and use.
- Making the potential policy implications of the available data useful for decision makers.
- Sharing evidence on barriers to vaccine uptake, why outbreaks occur even in countries with routine vaccination programmes, and barriers to effective emergency response at a country level.

How we will measure success

We will measure and report on our success in each of these three areas. We want to see:

- Use of research we have funded used to positively inform the development of new vaccines, optimisation of use of existing vaccines, and improved understanding of disease burden.
- A change in the rules governing vaccine access that increases protection for people from meningitis.
- Improved uptake rates of meningitis vaccines.
- The creation of a global plan to defeat meningitis by 2030.
- Use of global and country level data and policy implications by key stakeholders.



PROGRAMME 2

Diagnosis and Treatment

More people survive with a better quality of life and reduced disability

Whilst prevention through vaccines is the only way to protect everyone, good protection for everyone is a long way off. This means people will keep getting the disease for the foreseeable future making effective diagnosis and treatment essential parts of the meningitis transformation. Ensuring effective diagnosis and treatment will also have major implications for getting good data on the burden of disease which underpins decisions about introducing vaccines.

Why we should act

We have made huge inroads in improving diagnosis and treatment in the UK but key challenges still remain.

While most parents in the UK have heard of meningitis, knowledge of many of the symptoms remains low. This means that people may not seek help when they need to.

When people do seek help, health professionals frequently do not identify the disease on first presentation. Of the children with meningitis seen by a GP in the UK only 51% were sent to hospital after the first consultation.

When people are sent home, they are often not clear what to do if symptoms worsen. Presenting at A&E when the patient is in a critical condition is a likely consequence.

In resource poor settings such as Sub-Saharan Africa, even when people are aware of their sickness, they may lack transport, good roads, money or good enough health to get to a health service.

The health system can lack resources, capacity, skills and knowledge needed for effective diagnosis and treatment. There is often a lack of training and tools in place for healthcare workers to enable them to prioritise treatment for the sickest patients.

This in turn can compound – with some good reason – a lack of faith in the health service providers to have the ability to respond effectively.

Highlights so far

We have invested over

£3 million

in research on meningitis detection, treatment and pathogenesis between 1995 and 2016.

Research funded by MRF has shown that of the children with meningitis seen by a GP in the UK only

51%

were sent to hospital after the first consultation.



Our research underpins widely used, national algorithms for treatment of childhood meningitis and septicaemia produced by MRF since 1999, validated by NICE in 2010 and endorsed by Royal Colleges and specialist medical associations.

In 2016 we launched a major new national guideline for the treatment of meningitis in adults called the "Joint UK Specialist Societies Guideline",

partnering with 5 of the country's leading medical bodies,

and published in the Journal of Infection.

We share the latest information and guidelines throughout the year with a wide range of health professionals. We developed a protocol based on the guideline which we sent to all UK hospitals.

With support from the Scottish Government and in partnership with the Malawi-Liverpool-Wellcome Trust in Malawi we have been working since 2012 to encourage the adoption of an Emergency Triage and Treatment Protocol (ETAT) into Government policy in the country. So far the system has triaged over

200,000 cases

of sick children, including those with meningitis and septicaemia.

What needs to happen next

Treatment of meningitis starts with symptom recognition, prioritisation and diagnosis.

We need to ensure that people who do get meningitis can and do seek out diagnosis and treatment because they are aware of the symptoms and have the full capacity to access services they trust.

When people get seen by a health worker they need to be rapidly prioritised for stabilisation and they need access to rapid diagnosis of the disease.

Treatment needs to be provided by informed health care workers that are equipped with the knowledge and tools to respond.

We need to ensure that primary level health systems are strong enough to improve diagnosis and treatment of cases where they occur when people do seek help.

We need to see healthcare workers with knowledge, skills and suitable tools so that they can routinely identify symptoms and prioritise treatment based on the need of the patient.

Primary healthcare workers need to be supported by trained medical professionals and reference laboratories with the knowledge and capacity to take samples and deliver appropriate treatments in suitable conditions.

The system needs to support evidence-based, sustainable policy, making maximum use of mHealth technologies to support training, capture data and enable analysis that optimises cost-effective interventions.

We need to ensure that those who live with the after effects of meningitis have appropriate care and treatment.

How we will do it

MRF will play a key role in making this happen by combining three approaches: funding research; advocating for change; taking action to get results.

Research

We will seek grant funding and directly fund and support research and gather evidence into:

- New technologies supporting rapid diagnosis, treatment and evidence gathering.
- Effective diagnosis and treatment.
- Meningitis awareness.
- Improving health-seeking behaviour.
- Improving healthcare-worker recognition and prioritisation of meningitis symptoms.
- Strengthening the patient care pathway for severe illness and infection.

Advocacy

We will advocate for:

- Improving the patient pathway.
- Rapid diagnostics.
- Better 'safety netting' for people sent home on first presentation.
- Improved training of health workers.
- Improved tools for health workers to use for prioritisation of meningitis.
- Improved data to provide a clearer picture of meningitis so that meningitis diagnosis and treatment efforts can be improved.
- Research into new antibiotics.
- Better aftercare and services for people affected.

Action

We will:

- Undertake communication campaigns to make people aware of signs and symptoms and encourage them to seek medical help.
- Partner with other effective health awareness raising organisations.
- Provide effective information and tools for healthcare workers.
- Share and promote the latest evidence for improving diagnosis and treatment to key stakeholders and policy makers.
- Support healthcare worker training on effective recognition, prioritisation, diagnosis and treatment of suspected meningitis cases with national research partners.
- Establish new partnerships to develop innovative projects, such as mobile health technologies.
- Collect data and share the evidence base of what works in health systems that effectively optimise meningitis treatment.

How we will measure success

- Improved diagnosis and treatment recommendations and methods as a result of research we have funded.
- Better meningitis awareness and appropriate health seeker behaviour in general populations.
- Increased numbers of healthcare workers who are suitably trained and supported with tools to prioritise meningitis cases for diagnosis and treatment.
- Improved data capture to benefit meningitis diagnosis and treatment.



PROGRAMME 3

Engagement, Information and Support

More engaged, informed
and supported patients and
communities

It is vital that those affected by meningitis – survivors, families and communities – are supported to live with the often very challenging consequences of the disease. It is also vital that solutions are sustainably implemented in each country and this means ensuring patient voice is at the heart of that process.

Why we should act

Meningitis kills 1 in 10 and three times that number are likely to experience significant after effects. Every person, every family, every friendship and community are impacted.

Today, survivors and their families often cannot access information or receive the support they need to improve their quality of life as they are experiencing the disease or afterwards

As children grow up, their support and aids need to grow with them. Lifelong costs can be as high as £3 million and that does not include emotional distress or loss of earnings to carers.

Ongoing treatments are often expensive and health services struggle to prioritise specialist care. Health services and social services needed to support them are under financial constraints.

Patients and families can feel that services are a struggle to access; that they have to fight for their care; each new phase of managing the experience is a struggle. Equally, they are the most qualified people to know what good services should look like. Today, this voice is often not heard.

There is a gap between the demand for support and information to people and families to help them manage the impact of the disease on their lives

Together, this experience can needlessly compound the negative experiences of the disease.

Highlights so far:

We have funded over

£500,000

into understanding the after effects of meningitis since 1995.



We provide a telephone and email support service that includes bereavement support, befriending and an invitation to become a member of the charity. Membership is free and open-ended, and offers a variety of opportunities to fight back against meningitis and septicaemia.

We have a network of

over 100

ambassadors who reached out to people and communities across the UK and Ireland.

We provide tailored support for people affected by meningitis that includes in-depth information about the diseases and after effects.

What we want to happen next

We want to see patients, families and communities have access to reliable, high quality and useful information about their conditions.

We want to see people receive high quality aftercare tailored to their needs.

We want to see networks of people and families affected who can provide peer-to-peer support.

We want to see health providers adequately trained and resourced to provide patient-centred services.

We want to see patients involved in designing services around their needs.

We want to see communities engaged in expressing their demands from their health services to prioritise an effective meningitis response.

How we will do it

MRF will play a key role in making this happen by combining three approaches: funding research; advocating for change; taking action to get results.

Research

We will seek grant funding and directly fund and support research and gather evidence into:

- Effectiveness of information provided for patients and families.
- Lifetime impact of meningitis and septicaemia and the management of after effects.
- The role of community involvement and engagement in improving the healthcare pathway.
- The role of community involvement and engagement in improving long term support for people living with the after effects of meningitis.

Advocacy

We will advocate for:

- Improving the patient pathway.
- Better patient and family information and support services.
- Patient and community involvement in defining the healthcare pathway that meets their needs.

Action

We will:

- Provide personal support to the public in the UK and Ireland who need it in times of crisis.
- Provide ongoing personal help to our members and supporters as they live with the after effects of the disease.
- Reach out to civil society patient groups, primarily in meningitis belt countries, to establish new partnerships for knowledge sharing.
- Continue to ensure that survivors, their families and communities can access the information and the support they need.
- In the meningitis belt, we will set up information and best-practice sharing partnerships with patient groups.

How we will measure success

- Improved community engagement in health pathways as a result of our research.
- Use of our website and helpline service.
- Partnerships established with other patient groups.
- Increased effectiveness of information available to patients and families.

Making it happen

This is an ambitious strategy and MRF cannot achieve it alone. We need supporters, members, partners and potential partners to join us on this journey. At the same time, we will adapt to become the organisation that can help deliver these transformative goals.



The first of our three years will see us implementing reviews undertaken to prepare this strategy; a programme of tactical investment in new fundraising; creation of a new International Projects department; the formation of a new Communication, Advocacy and Support team; expansion of our Corporate, Trusts and Major Gift team; and a new way of managing our finance processes and budgeting.

The first year of this strategy will see MRF update our brand to better reflect the range of work we do. We will also launch a new website using our updated brand that will help us communicate with and on behalf of our many supporters and stakeholders more effectively. Both of these initiatives have only been possible due to pro bono work carried out by very generous corporate donations of time and expertise for which we are incredibly grateful.

During the first year of this plan we will also be developing detailed budgets and operating plans by department aligned to the three programmes set out here.

At the same time as implementing these changes we will be developing four new sub-strategies to this paper; research; communications, advocacy and support; international programmes; and income generation.

Regardless of the outcomes of these new strategies, some things are known and clear today.

For almost 30 years MRF has relied on the generosity of supporters in the UK and Republic of Ireland for the majority of our income. This in turn has been the mainstay of our investment in research, as well as our awareness raising and support work.

This strategy continues to rely on this support and looks to build this further, especially by encouraging regular donations, as we demonstrate our ongoing commitment to the best outcomes for patients and families.

At the same time, we will invest more in building stronger relationships with corporate partners, foundations, trusts and with individuals who are motivated to invest strategically in our programme of change. We need even more catalytic investment to realise the goals set out here.

With an ambitious global programme, we will look to recruit more international development knowledge and skills enabled by significant new investment from grant funding sources. As we build this programme we will ensure the quality of our work and investments are maintained and strengthened by ensuring suitable quality assurance processes are in place for our research investments and international development projects.

In the next three years we also need to become more nimble as an organisation that works across the globe. To do this we will maintain our head office in Bristol, UK, as well as continue to support

our regional presence in Scotland, Northern Ireland and the Republic of Ireland. At the same time, we will invest in technologies that enable more distance working, remote access to cloud-based infrastructure and collective sharing of information and expertise so that location is no barrier to collaboration.

We will rely on our incredible staff team to deliver this ambitious programme. To support them, we will strengthen management practices to ensure they are developed and supported to achieve their best. This will include a review of our HR practices, including appraisals, reviews and rewards.

Underpinning all of this work are our values.



Values

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.

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 20 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.

Programme summary

Prevention

Goal: Fewer people get meningitis and septicaemia



Research

- Enabling the development and implementation of new vaccines.
- Optimising the use of existing vaccines.
- The global and local burden of meningitis.
- Strengthening the patient pathway.



Advocacy

- Fairer rules that govern vaccine access.
- A global plan for meningitis.
- The introduction of new and effective vaccines.
- Maximum possible protection from available vaccines.
- Maintenance of beneficial vaccine programmes.
- High quality studies into the burden of meningitis and impact of vaccines.
- Increased vaccine research and development for new and improved vaccines.



Action

- Analysis of the decision making frameworks influencing access to vaccines.
- Synthesis and communication of latest available data on disease burden.
- Communication campaigns to increase uptake of available vaccines.
- Making available data on global burden of the disease easier to access and use.
- Making the potential policy implications of the available data useful for decision makers.
- Sharing evidence on barriers to vaccine uptake, why outbreaks occur even in countries with routine vaccination programmes, and barriers to effective emergency response at a country level.

Diagnosis and Treatment

Goal: More people survive and with reduced disability



Research

- New technologies supporting rapid diagnosis, treatment and evidence gathering.
- Effective diagnosis and treatment.
- Meningitis awareness.
- Improving health-seeking behaviour.
- Improving healthcare-worker recognition and prioritisation of meningitis symptoms.
- Strengthening the patient care pathway for severe illness and infection.



Advocacy

- Improving the patient pathway.
- Rapid diagnostics.
- Better 'safety netting' for people sent home on first presentation.
- Improved training of health workers.
- Improved tools for health workers to use for the prioritisation of meningitis.
- Improved data to provide a clearer picture of meningitis so that meningitis diagnosis and treatment efforts can be improved.
- Research into new antibiotics.
- Better aftercare and services for people affected.



Action

- Communication campaigns to make people aware of signs and symptoms and encourage them to seek medical help.
- Partner with effective health awareness raising organisations.
- Provide effective information and tools for healthcare workers.
- Share and promote the latest evidence for improving diagnosis and treatment.
- Support healthcare worker training with national research partners.
- Establish new partnerships to develop innovative projects, such as mobile health technologies.
- Collect data and share the evidence base of what works in health systems that effectively optimise meningitis treatment.

Engagement, Information and Support



Goal: People get the support and information they need



Research

- Effectiveness of information provided for patients and families.
- Lifetime impact of meningitis and septicaemia and the management of after effects.
- The role of community involvement and engagement in improving the healthcare pathway.
- The role of community involvement and engagement in improving long term support for people living with the after effects of meningitis.



Advocacy

- Improving the patient pathway.
- Better patient and family information and support services.
- Patient and community involvement in defining the healthcare pathway that meets their needs.



Action

- Provide personal support to the public in the UK and Ireland who need it in times of crisis.
- Provide ongoing personal help to our members and supporters as they live with the after effects of the disease.
- Reach out to civil society patient groups, primarily in meningitis belt countries, to establish new partnerships for knowledge sharing.
- Continue to ensure that survivors, their families and communities can access the information and the support they need.
- In the meningitis belt, we will set up information and best-practice sharing partnerships with patient groups.

Images:

Page 4: A mother and baby outside a health post in Oromia Region. Nena Terrell, USAID Ethiopia

Page 14: A child with a vaccination card, Mali. Adrian Brooks

Free helpline 080 8800 3344

+44 (0)333 405 6262

info@meningitis.org

www.meningitis.org

Offices: Belfast, Bristol, Dublin, Edinburgh.

A charity registered in England and Wales no 1091105, in Ireland 20034368 and in Scotland no SC037586.

A company limited by guarantee.

Registered in England no 4367866. Registered office: Newminster House, Baldwin Street, Bristol BS1 1LT.

If you no longer wish to receive communications from us please contact us at the above address.

