Meningitis now
saving lives, rebuilding futures

OUR IMPACT
2019-20
“Fantastic to talk to someone today. She was very compassionate and listened. It made me realise, although I am in a very good place at the moment, that I was still emotionally affected by the whole experience of meningitis. The lady I spoke to was amazing, thank you very much indeed.”

“Just to thank you for this really useful and helpful advice. I also wanted to feedback what a great job your organisation does; it is so reassuring and supportive to have someone to turn to for expert guidance at this difficult time.”

“The support has been invaluable for both myself and my family. Meningitis Now’s support makes you feel like you are not alone on this journey. I sometimes wonder how I would have coped without the support of the charity. My family too have benefited, particularly my children. They have built life-long friends with other children who have also been impacted by meningitis and can relate to these children in a way that they can’t with others. Thank you so much.”

“Vital at a time when I was in a pretty dark place. They listened and gave me useful information and most importantly hope.”

“A brilliant website. I found your website useful and helpline fantastically supportive after I had bacterial meningitis last year.”

“We always have a relaxed happy B after one of these days and she can’t wait for the next one. B gets so much from this. She loved the bubbles and slime making. It makes us as a family feel so privileged to be part of the Meningitis Now family.” Family Day 2019

“Reece can now safely travel with us all as a family, he is comfortable and happy with his brothers in the back. It really is the small things that make such a big difference.” Reece’s family received support through the Rebuilding Futures Fund
Saving lives, rebuilding futures – making an impact

Whilst it would be wrong to publish a review of 2019-20 without acknowledging the impact of Covid-19, it would also be wrong to overlook the progress and many achievements of Meningitis Now in the months ahead of the arrival of the Covid-19 pandemic in Spring 2020 - the period when this report finishes.

Indeed, the year saw significant investment and demonstrable progress across all of Meningitis Now’s activities, including research, support and awareness, and a concerted focus on how the Charity makes a difference in its long-standing fight against meningitis.

We invested significant time and money in monitoring and evaluating the impact of our work - in such areas as our Rebuilding Futures Fund, our successful Student and Young People Awareness Campaign and our first-ever residential Forever Weekend, and you can read more on this throughout this report.

The evidence and insight we gain from this activity demonstrates just what a difference Meningitis Now makes in the fight against meningitis and improves the basis upon which we can make future decisions.

Our focus on saving lives and rebuilding futures continues and is resolute. We are determined that Meningitis Now will continue to save lives and rebuild futures for as long as we are needed in the UK.

That 2019-20 was an overwhelmingly positive year in terms of our charitable activities is thanks to the endeavours of the whole Meningitis Now community, including our partner organisations, supporters, donors, volunteers, Ambassadors and staff – everyone who reaches out to the charity and who we, in turn, reach out to.

As always, we remain grateful to everyone who supported us through helping to raise awareness or funds towards our activities over the year.

On the following pages you can read more about the very real difference we have made in the fight against meningitis during 2019-20.

In a 2019 survey of people we have supported, 96 per cent said:

“I would recommend Meningitis Now support to other people who have been affected by meningitis.”

Dr Tom Nutt
Chief Executive

Dr Steve Dayman
Executive Founder

Andrew Fletcher
Chair of Trustees
Our service provision to meet the needs of people whose lives have been affected by meningitis remains at the heart of what we do. We understand how tough life after meningitis is.

Our nurse-led Helpline remains the first point of contact for many people looking for information, reassurance and support. Over 2,500 enquiries ranging from simple requests for information to in-depth support calls were received. Overall callers were positive about the helpline, describing it as “helpful”, “compassionate”, “understanding” and “knowledgeable”.

We were able to offer support to hundreds of individuals and families. This included 179 new referrals, 164 home visits — a significant increase on last year — and over 3,000 calls, texts and emails.

“The person that came out to see me was very supportive and didn’t judge. She was very understanding and had a huge wealth of knowledge.”

Six enjoyable Family Days were delivered across the UK and 74 families, including 187 children under the age of 16, attended these. Children reported having lots of fun, making new friends, feeling more confident and enjoying time with their family.

We also celebrated the 10th anniversary of our Remembrance Garden at our Stroud Head Office with a moving reception attended by over 100 people. We were delighted to place four of the statues from our award-winning Chelsea Flower Show ‘futures’ garden in the Remembrance Garden to mark the occasion.

Now in its third year our Believe and Achieve programme continues to go from strength to strength, this year supporting 90 young people aged 14 to 25 through counselling, life coaching, business mentoring or peer support.

“We listened to feedback and this year we trialled a new venue for our under 18 Believe and Achieve weekend, The Calvert Trust in Exmoor. With fewer guests than at PGL centres, where we held the events previously, the venue offered a calm environment and accessible activities for all abilities. All nine young people attending said that they made new friends, and their confidence noticeably improved during the weekend.”

“The support we have had from Meningitis Now has changed our life. We were struggling to deal with the illness our sons had and the after-effects. Information, family support, referrals to the Child Brain Injury Trust (who have helped with school) and Family Days where we can relax as a family, meet other families and be within a group where people understand, our children can be themselves and nobody stares. Our boys also love chatting to the support staff at the family events, everyone is so friendly.”
At the beginning of the year we launched our Rebuilding Futures Fund, to provide financial support for those who most need it. People of all ages have successfully applied for 82 awards, totalling more than £63,000.

We implemented new evaluation tools to measure the impact of this new programme. This included collecting feedback from people who had awards, using evaluation forms, interviews and a self-assessment outcome tool.

We’re delighted that the evidence from this feedback is very clear – the Rebuilding Futures Fund had a significant positive impact on individuals and families.

- 98% of people said that the award helped them
- 95% of people felt that their award had made a difference to their life

There was evidence of a noticeable improvement to the emotional wellbeing of the award recipients and their family members.

“Having the award for art therapy meant my daughter could explore emotions that she usually chooses to hide from others and gave her a platform in which she can express herself during an extremely difficult time in her life.”

There was also evidence that the issues and concerns negatively affecting people’s lives were alleviated by the award.

People’s feedback about the quality of service they have received from us is also very positive.

“[By] being with others who have lost their children, I felt not so alone. I will take home with me the love I felt from others. I was overwhelmed with the kindness and love I received.”

“The event answered a lot of questions, made us feel we are not alone and realise help is out there.”

“The residential was the best thing we have done together since losing our son. We felt safe to explore our grief with others.”

We will hold more events in the future.

Forever Weekend

In September 2019 we held our first Forever Weekend, a free residential for people who have lost a loved one to meningitis.

The event aimed to provide a safe place for people to share their experiences without judgement, meet others who had lost a family member to meningitis, learn about bereavement and its impact and find out more about how we can help.

Held in a hotel in Nottingham, the event was attended by 15 families, most of them couples who had lost a child to the disease.

Described by its participants as ‘amazing’ and ‘fantastic’, despite its sad and sombre connotations, the event was an undeniable success.

All participants noted that they felt supported and connected to other people as a result of attending the residential. The vast majority reported feeling understood and less alone.

The event also provided its participants with an opportunity to better understand and express their feelings and their grief, in some cases for the first time ever.

We will hold more events in the future.

Help towards a better future

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“It took away the worry of having to find a large sum of money at the hardest time of all.”

“I’m so pleased Meningitis Now has this fund. My life as an amputee is so expensive and having this little bit of help really makes a huge difference to me and my family.”
The grass is greener

The grass is now greener at home for Taylor, thanks to our Rebuilding Futures Fund.

Taylor was eight months old when his life changed dramatically. He fell ill with meningococcal Group W meningitis and septicaemia in April 2016 and Terri, then just 22, watched helplessly as doctors gave her son hours to live.

Luckily, Taylor is a fighter, but the impact of the disease was still life-changing. He needed his fingers and thumbs amputated and both legs through the knee.

Terri applied to our Rebuilding Futures Fund for artificial grass to make their garden safe for Taylor, then aged 5, to play in.

“We moved to a disabled bungalow and the house is perfect for Taylor’s needs,” Terri said. “But the garden was unsafe and not usable. We did a lot to make it better but we needed the grass to finish the job off.

“Taylor loves being outside and before we could use the garden I’d take him to the park, but stares and comments from others because of his prosthetics were getting him down.

“So having a garden he can escape to is his dream come true and I’m so glad I don’t have to say ‘no’ any longer when he asks to go outside - I used to hate that!

“It means Taylor can get back to doing what he enjoys best, which is being an outdoor boy.”

Research

The introduction of a new research strategy saw the Spencer Dayman Research Fund at Meningitis Now invest in a programme of new and exciting research.

New projects covering meningococcal, TB and pneumococcal meningitis were identified and initiated. This expansion of our research portfolio was in line with our strategy, which supports our aim of pursuing lifesaving and life-changing research.

Thanks, in part, to a generous legacy we undertook a successful research grant round in Spring 2019 for projects focusing on the prevention, diagnosis, treatment and outcomes of TB and pneumococcal meningitis.

Generous donations from The Starfish Trust and ‘a Life for a Cure’, funded a project at the Spencer Dayman Meningitis Laboratories at the University of Bristol to bring together a collection of throat swabs and culture samples from the much larger government-funded project called “Be on the TEAM” (‘Teenagers Against Meningitis’) for storage and future analysis.

The year saw the completion of two important scientific research studies at the University of Liverpool and St George’s University of London, valued at £500,000 and it is expected that the results of these will make a significant contribution to the body of knowledge and understanding of meningitis.

At Liverpool the research team successfully carried out the preclinical development of a new vaccine formulation, comprised of three pneumococcal proteins and a novel adjuvant. Results are very encouraging and show that the new vaccine formulation stimulates a strong immune response that is protective against a range of disease-causing pneumococcal strains.
We adopted a strategic approach to raising awareness, which comprised four main aims. These were to inform the UK population about meningitis; to protect groups considered ‘at risk’; to support people with an experience of meningitis; and to influence politicians, policy-makers and health care professionals, including scientists and pharmaceutical organisations.

Our Student and Young People campaign promoted the MenACWY vaccine to eligible young people who missed it either at school or in the catch-up programme. With uptake levels at around 80 per cent and 40 per cent for these programmes, it was estimated that over one million young people missed the vaccine and remained unprotected. The campaign targeted parents, universities and students. This included national syndicated radio and outdoor advertising, student print and social media advertising, and university-based awareness materials.

Key findings included:

- The campaign engaged with two-thirds of UK universities, distributing over 250,000 awareness materials.
- It reached over 1.5 million people through social media.
- Outdoor advertising campaigns in Liverpool reached over half the population of the city.
- In depth interviews carried out with students and staff at four universities in England and Wales gave valuable insight into students’ awareness and attitudes towards meningitis and vaccinations, as well as the effectiveness of our awareness materials and messaging.

Raising awareness and influencing policy

We continued our efforts to maintain and build relationships with key stakeholders including MPs, the Department of Health and Social Care, the Joint Committee on Vaccination and Immunisation (JCVI), the NHS, and public health authorities across the UK, as well as the World Health Organisation and key pharmaceutical organisations.

Building relationships

Meningitis Now has a long-standing and constructive relationship with Public Health England, as well as Public Health Scotland and Wales, and the Public Health Agency, Northern Ireland.

However, many people and families who experience meningitis say that, after their initial engagement with healthcare teams when the disease has struck, there is often only limited information provided about where people can turn to for aftercare or support.

To address this, over 2019 we set out to meet with regional public health teams with the aim of reinforcing and enhancing these teams’ understanding of the role played by Meningitis Now in supporting people after meningitis.

The outcome was that changes are planned in the way that national and regional teams engage and share information with people experiencing meningitis, particularly in relation to the signposting of information about Meningitis Now.
Reaching out to students and young people - Tim’s story

Tim Mason, 21, was attending college and working as an apprentice electrical engineer when he became ill. In just over 21 hours from the first visible symptoms he had lost his life to MenW.

Keen to help prevent other families going through the trauma of losing a child to meningitis, his parents Gavin and Fiona, along with Tim’s brothers Nick and Alex, agreed to feature in our student and young people activity.

The family featured in video and social media content which generated high levels of engagement with students and young people both online and on campus.

In the video Tim’s brothers speak poignantly about how suddenly their youngest brother was taken from them. “My brother first got ill properly at midnight,” Nick says. “He was dead at 9.46 that evening.”

Nick and Alex’s words emphasise how important it is for young people to be fully aware of how quickly meningitis can strike and how deadly it can be when it does.

Gavin and Fiona also helped to launch the parent element of the campaign by giving a series of radio interviews, following the publication of student A-level results.

Fiona said: “In our discussions with friends and family it has proved very difficult to find any awareness of this strain of the disease; indeed people felt they knew about meningitis, and their shock when we described the ferocity of MenW and the difficulty in diagnosis proved incredibly powerful.

“We need to jolt people into action to take up the MenACWY vaccine to combat this strain along with the others.”

In sharing their heart-wrenching story, the Mason family helped us reach over two-thirds of the UK population through our media campaign.

Volunteering

We would not be able to achieve so much without the contribution of our volunteers and Ambassadors, and the tireless work they do in the community and at our Head Office. Their skills, experience, commitment and passion make them an integral part of the Meningitis Now community.

This year, volunteers gave over 4,000 hours of their time to support aspects of our work, including essential awareness raising, important campaigning and fundraising. Contributions included supporting our student and young people’s awareness campaign, major events such as the London Marathon and delivery of the B&A programme for young people.

In addition, volunteers and Ambassadors, most of whom have had an experience of meningitis, made a valuable contribution to raising awareness of meningitis and fundraising in their communities across the UK.

We also understand how important Meningitis Now, and the work it does, is to volunteers and the positive impact volunteering for us has on their lives. Our annual volunteer survey, which received 80 responses, reinforced this.

“I am immensely proud to be involved and to have the chance to give something back to a charity that did so much for my family.”

“To be a face of this wonderful charity is so fulfilling.”

In July we brought together 28 of our Community and Young Ambassadors at our annual ‘Ambassador Day’. This event is one of the highlights of our year, as we get to spend time with those who go above and beyond to support our cause.
Our website, MeningitisNow.org, received 1.8 million visits in 2019-20. That's 3.3 visits every minute.

Of these visits, 80 per cent were unique or first-time visitors, reflecting the important role the site plays in providing important signs and symptoms information to people concerned about the disease.

Our website also provides a vital community of support and reliable information for people who have experienced meningitis, helping people to understand what has happened and access support.

Thanks to support in 2019-20 from Postcode Community Trust, who distribute money raised by the players of People's Postcode Lottery, we have been able to add accessibility software to our website.

Reading content online can be difficult for some people. Using the tools provided through our Recite Me software means it no longer needs to be.

The easy-to-use software lets our website users personalise how the information is presented to suit their own requirements.

For example, it translates information into over 100 languages, changes the font size, typeface or colour, changes the background colour, adds spacing between and around the text and it can read the text out loud. The accessibility toolbar has been accessed more than 5,400 times since we added it to our website, helping people to access our lifesaving awareness and disease information in a way that suits their needs.

"We’re delighted to have this valuable software on our site and really appreciate the generous support from Postcode Community Trust to enable this to happen."

David Clifford, Digital Marketing Manager.

Seema's story

Sports presenter Seema Jaswal contracted bacterial meningitis when she was 16-years-old.

"I was in my first year of college. When I wasn’t studying you would find me on the tennis court, playing netball or at my favourite dance class. I remember life being so busy trying to fit in studying, sport and socialising was a task!"

"It was one particular Saturday that I remember like it was yesterday - this was the day that meningitis struck."

The following morning Seema was rushed to hospital where she stayed for 10 days.

"I recovered fairly quickly but the doctors told me that if it wasn’t for the fact I was extremely sporty the outcome could have been very different."

Seema became a new Celebrity Ambassador for us during the year. She told us: "I have always wanted to support a charity that means something to me and use my profile to make a difference to a cause that is close to my heart - this is more than that."

In 2019 Seema backed our Students and Young People campaign, using her own story as a way to encourage young people and parents of school-aged children to ensure they are protected against the disease with the MenACWY vaccine.

She also helped to promote our New Year New You campaign and maintains an active role in helping us raise awareness.

The financial picture and the future

Our charity relies on donations. Without our supporters, the amazing work that you have read about in this report would not have been possible.

We are extremely grateful to the thousands of individuals, who have supported us through community and events fundraising and in a variety of ways this year.

In addition, DP World London Gateway supported us once again through their annual quiz and we were delighted to receive the continuing support of B&A Group. Caroline Gardner Publishing produced another series of beautifully designed Christmas cards, with a donation made for each pack sold. A range of Caroline Gardner-designed reusable bags were sold in Waitrose (see page 20 for the full story) with a donation to our Charity for each bag sold.

Induced Euphoria Clothing created and sold limited edition sweatshirts in memory of Graham Ward. HSBC kindly hosted a drinks reception at their offices in London, during which supporters heard talks from both HSBC’s CEO Ian Stuart and Meningitis Now Chief Executive, Dr Tom Nutt.

Other companies who have directly supported our work this year include Pfizer, GSK, Boots, Rightmove Group, Transmission Investments, Royds Withy King, Admiral Taverns, GWR, Renishaw, Irwin Mitchell, Leigh Day, Fieldfisher, Enable Law and Anthony Collins.

Thank you also to these companies whose staff selected us as their chosen charity during the year: Caterpillar Northern Ireland, Radwell International, Loxley, Co-Ownership Housing, Computershare, Entanet International, Airbus UK, Dassault Systemes and NM Services.

We are very grateful for the support of 89 grant-making trusts during the year including National Lottery Community Fund, BBC Children in Need, Charles Wolfson Charitable Trust, James Tudor Foundation, The Starfish Trust, Worshipful Company of Butchers, Robert Luff Foundation, The Pixel Fund, Boshier-Hinton Foundation, The Steel Charitable Trust, John Jarrold Trust, Sovereign Health Care Community Programme and the Postcode Community Trust, a grant-giving charity funded entirely by players of People’s Postcode Lottery. See page 16 for how they helped make our website more accessible.
Bags of support

Caroline Gardner has been a significant supporter of our work for more than 16 years now. Founders Caroline and Angus chose us following a personal experience with the disease, when their 18-month-old son Sebastian contracted meningococcal septicaemia. Fortunately, he recovered well.

Caroline Gardner, best known as one of the UK’s leading stationery and gift designers, have now raised well over £235,000 for Meningitis Now. This incredible amount has been raised through sales of their charity Christmas cards and reusable shopping bags, with every one sold supporting our lifesaving and life-changing work.

In 2019 we were delighted to see a second Caroline Gardner range of 100,000 reusable bags go on sale in Waitrose stores across the country. The four colourful and striking designs included two jute shoppers and two foldaway totes made from recycled plastic bottles.

Beth Bottrill, our Director of Fundraising, said: “We’re delighted the bags made an appearance again this year and are really grateful to Caroline Gardner for supporting us in this way – their support makes a huge difference to those who are at risk from meningitis and those whose lives have been changed forever because of it.

“There’s not an easier way to support our work than buying a bag or two and you’re cutting back on plastic bag use too.”

We would like to say a massive thank you to everyone at Caroline Gardner, especially Caroline and Angus, for your long-standing support of our work. It means a great deal to us.

Lucy’s London Marathon challenge

Our supporter Lucy signed up for the London Marathon in 2019, and she’s ready to do it again.

She told us: “My decision to run the London Marathon for Meningitis Now was a simple one. I had bacterial meningitis in 1998, when I was 25. I was seriously ill and spent two months in hospital. I was incredibly lucky as I made a full recovery, with no after-effects.

“The odd coincidence about my meningitis diagnosis was that my dad (former BBC news presenter Andrew Harvey) was the President of what was then the Meningitis Trust and later became Meningitis Now. So, it was an illness I’d been aware of for many years but of course none of my family ever expected that we would experience it directly.

“When I decided to take on the London Marathon it had to be for this wonderful charity who had always been so supportive to me and my family.

“My marathon day was one of highs and lows - but definitely with more highs! The experience of running London really has to be undertaken to be appreciated. The sheer volume of participants and supporters is just incredible. And the enthusiasm of all those lining the route is never-ending.

“Spotting your family amongst the crowds is just wonderful. Their faces shine out like loving beacons.

“I swore to my mum that I wouldn’t do another, but two weeks later I was seriously considering London 2020.

“It was just THE most wonderful experience.”
The arrival of Covid-19 at the beginning of 2020 heralded unprecedented disruption for Meningitis Now, with ‘lockdown’ and the constraints of coronavirus affecting our ability to raise funds and deliver key areas of our work.

In response, we adopted a simple coronavirus strategy with three aims - to survive, to protect knowledge and expertise and to deliver our charitable objectives as far as possible.

Throughout a difficult 2020 we have maintained our nurse-led Helpline; our community support and events; ongoing research projects; financial support through our Rebuilding Futures Fund; peer support; information and support materials; student and young people’s awareness campaign (Don’t assume it’s Covid); the Roundtable project (bringing the NHS, PHE, charities and pharmaceutical companies together); and ongoing support for universities through our Meningitis Aware Recognition Mark (MARM).

Between April and October 2020 over two-thirds of the charity’s staff were on furlough and permanent staffing reductions were unfortunately implemented later in the year.

As a result, a deficit of around £0.3 million is expected for 2020–21 – a prudent position that allows us to begin 2021-22 in a sustainable fashion.

We look forward to launching our new five-year strategy, Making a Difference Every Day, in the spring of 2021.
Meningitis Now is the founder of the meningitis movement and the only charity solely dedicated to fighting meningitis in the UK.

With 35 years’ experience we are working towards a future where no one in the UK loses their life to meningitis and everyone affected gets the support they need.

Meningitis Now fights the disease on all fronts:

• Providing a powerful, united voice for people fighting meningitis.
• Saving lives by funding vaccine and preventative research.
• Reducing the disease’s impact through awareness.
• Rebuilding futures with dedicated support.
• Fundraising to deliver our plans.

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Our cover photo shows Tim Mason. Read his story on page 14.