



Meningitis Now Charity Update

July 2021

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Thanks to your support, our Rebuilding Futures Fund continues to make an important difference to people's lives. The fund aims to pay for items and services that people affected by meningitis need to improve their physical and emotional wellbeing, and ultimately their quality of life.

Since the start of our financial year in April 2021 we have awarded £10,175 through our Rebuilding Futures Fund, supporting 13 families. These have been for a range of items including counselling, specialist tricycles, a foot brace, wheelchairs, computer equipment, short breaks, physical therapies, horse riding lessons and a headstone. Below are just a few examples of how your support is helping people affected by meningitis.

Giving hope to a grieving family

Six-year-old Layla-Rose tragically died from meningitis in 2017. Her parents, Kirsty and Ricky, were completely devastated by the loss of their beautiful daughter (pictured) and her family, especially her elder sister Melika, terribly miss Layla-Rose every day.



Mum Kirsty says *"It just all happened so quick, we never had a chance to say goodbye. One minute she was looking at me and giving a little smile, and then she just went. All I can picture from that night is them trying to resuscitate her."*

An inquest into Layla-Rose's death in 2018 found that there was a catalogue of errors in her care at Royal Oldham Hospital and that her death could have been avoided. Knowing this has been incredibly difficult for Kirsty and Ricky to bear. At the conclusion of the inquest Mum Kirsty said:

"I never thought I could be more heartbroken but today has confirmed I can be. I hurt more now knowing she could be here and it could have been prevented."

Meningitis Now has been supporting the family since 2017. Our Founder, Steve Dayman, and Christine Mather (Community Support Officer for the North of England) closely supported the family during the inquest and in their grief. We have funded counselling for Kirsty and Ricky, involved the family in a Department of Health working group to improve diagnosis and care for meningitis patients, and provided access to a peer community through our events and online groups. Their eldest daughter is receiving support through our Believe and Achieve programme.

At our June Rebuilding Futures Fund panel meeting we awarded £1,000 for the family to take a holiday together in North Wales. The family have not been away on holiday together since Layla-Rose's death. Mum Kirsty told us:

"Even though it's been four years, it's still hard to get through each day. We have put off breaks and fun times together as a family due to not having her with us. But I feel we need a family break together and to spend time away from the house where all her memories are surrounding us and do fun things for the children. I feel we need this to heal as a unit together."

Their family income is low and they do not have a car. Making happy family memories together is an essential part of childhood. With this funding in place, we hope that this family can take a step towards rebuilding their lives together.

Helping Seema to regain independence

Seema, from Hertfordshire, contracted meningococcal septicaemia in 2015, a few months before her 60th birthday. The disease led to bilateral amputations below both knees and partial digit amputations on all fingers. Seema also suffered skin scarring and was left immobile and dependent on her family.

Seema told us: “I had difficulty standing from a standard wheelchair and suffered a lack of independence due to my limited range of movement. I needed my children to lift and transfer me, cook for me and pass me anything I needed.”

Our Rebuilding Futures Fund was able to provide £1,000 to help Seema purchase a new powered wheelchair. The new chair has powered seat lift, tilt and recline amongst other features, has brought her greater independence, comfort and ability.

“It allows for a better position for me to attempt to stand from. This same feature allows me easy reach, so I can get things for myself regardless of height – I’m able to make myself a cup of tea, go shopping and cook.

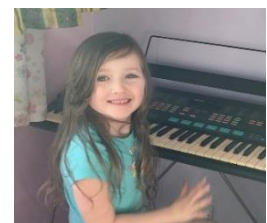


“The shock absorber and suspension helps me greatly. Previously, when traveling in my old wheelchair, bumpy roads would cause me a lot of pain. And because of my mobility issues I am often in my wheelchair in one fixed position - this could become very uncomfortable. The new wheelchair has various positions which give me the comfort lacking in my NHS issued wheelchair.”

Supporting Millie to gain confidence and build her self-esteem

Eight-year-old Millie, from Berkshire, has contracted meningitis twice – at 13 weeks old and when she was six years old. The experience of her second meningitis infection was extremely traumatic for Millie and she has clear memories of being so unwell in hospital and the pain of the four lumbar puncture attempts needed in order to gain a diagnosis of meningitis.

Millie now struggles with memory issues, including processing and retaining information, severe daily headaches, eyesight problems and she has a heart murmur. She has autism and attention deficit hyperactivity disorder.



Millie is struggling at school and her confidence and self-esteem is low. As she is getting older she is becoming more aware of the differences between her and her peers. It makes her feel anxious and her anxiety affects her ability to sleep well. Millie struggles with her co-ordination, balance and dexterity and she is reluctant to take part in sports if they involve running or catching.

Recently Millie started horse riding and she has become more settled, calm and confident. She says being with the horses makes her happy and she is working hard to remember everything she is being taught. There has been a marked improvement in her dexterity and balance. Millie sleeps very well after she has been with the horses, and she is starting to open up more about her issues, and will talk to her mum more about how to manage situations that make her upset.

It is fantastic that Millie has found something that is helping to improve her physical abilities and emotional wellbeing. However, horse riding is expensive, and her mum is a single parent. At our July panel meeting we were able to fund 12 lessons for Millie to enjoy over the coming months.

Thank you for showing your support on social media

Social media plays a vital, and cost-effective, role in how our charity communicates with the public about meningitis awareness and also in galvanising support for our charity. Social media companies are continually changing their algorithms and in recent years these changes have made it more difficult to drive the reach of our organic content on social media – i.e. posts that we do not pay to promote.

We have a very limited budget to spend on paid-for posts on social media. And therefore, the help of our supporters like you to share our content is crucial to helping us to reach as many people as possible through social media, and improve the ranking of our organic content. Thank you so much for your recent shares on social media, for example World Meningitis Day, our Trustee recruitment and our BBC Lifeline Appeal – these small acts make a big difference.

July is Group-B Strep Awareness Month

Group B Strep Awareness Month is an annual campaign to highlight the importance of group B Strep awareness, education and research.

Sadly, many families first hear about group B Strep (GBS) after their baby is seriously ill with GBS meningitis, sepsis or pneumonia. It is the main cause of meningitis in babies but very few adults develop GBS disease. Currently there is no vaccine to protect against GBS disease.

Approximately 43 babies develop early-onset GBS infection in the UK **every month**. Of these 38 will make a full recovery; three survive with long-term physical or mental disabilities and sadly two will die from the infection.



GBS disease is caused by the *Streptococcus agalactiae* bacteria. It is one of the many bacteria that normally live in our bodies and which usually cause no harm. It is estimated that up to 30 per cent of pregnant women carry the GBS bacteria, but the majority of babies born to these mothers will not become ill with GBS disease.

About 60 to 70 per cent of the infection occurs in newborn babies less than seven days after birth and is most likely due to infection being passed on from the mother before or during birth. It is treatable with antibiotics given intravenously during labour to limit the transfer of the bacteria from mother to baby during birth. But there is no national screening programme to routinely check all pregnant women to see if they are carrying GBS bacteria.

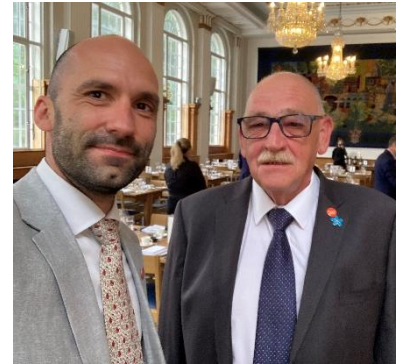
Jane Blewitt, our Information and Assessment Nurse, said, *"All pregnant women should be given information about group B Strep. Knowing about group B Strep when you're pregnant and in the early weeks after birth can make a massive difference – most group B Strep infections in newborn babies can be prevented and early treatment can and does save lives."*

If you are able to, please share our social media posts about Group B Strep Awareness Month and share the guidelines available to pregnant women about GBS - www.rcog.org.uk/en/patients/patient-leaflets/group-b-streptococcus-gbs-infection-pregnancy-newborn-babies/

Meeting your Liverymen

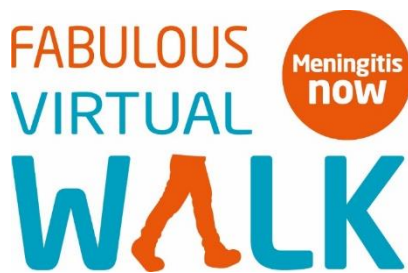
Our CEO Dr Tom Nutt and our London-based Community Ambassador Graeme Burridge were delighted to attend your recent Carvery Lunch at the Butchers Hall. You made them feel extremely welcome and they very much enjoyed getting to know your Liverymen. Thank you so much for your hospitality.

Graeme became a volunteer Community Ambassador after losing his 23-year-old daughter to meningitis in 2016. He talks about his motivation to beat meningitis here: www.meningitisnow.org/support-us/who-we-are/our-team/graeme-burridge/



Support needed for our Fabulous Virtual Walk

The last Sunday of September usually means one thing here at Meningitis Now, and that is our Flagship event, the Five Valleys Walk, which takes in 21 miles of glorious Cotswold countryside. The event has been running since 1987! Sadly due to the uncertainty of the pandemic and our reduced staff capacity, we are unable to deliver this event in 2021, which usually sees more than 2,000 people take part.



But we're determined the spirit of the walk will go on. And so, for the second year, we are running the Fabulous Virtual Walk – a great way to get our boots dirty and raise money to continue the fight against meningitis.

We are asking those taking part to simply walk 21 miles – the length of the Five Valleys route – wherever and whenever they like.

Whether it's walked in a day, a week, or a month. We estimate that 21 people contract meningitis every single day. But by walking 21 miles we can continue to save lives and rebuild futures.

We will start promoting this walking challenge in August and it would be fantastic if the Worshipful Company of Butchers could share our social media posts about the event. We are also seeking corporate sponsors for the event – with Gold (£1,000), Silver (£500) and Bronze (£250) sponsorship packages available. We would be delighted to share more information with any companies in the WCB network who may be interested. Please get in touch if you would like to know more.

Thank you

Your continuing support means so much to our charity and we are extremely grateful for the additional £3,000 donation that you have recently given to Meningitis Now. This is incredibly generous, thank you. With your support our charity is able to make a difference to people's lives, every day. One supporter recently told us:

"When I left hospital, no support was given. Luckily, I found Meningitis Now, and this is where things changed. I sent Meningitis Now a Facebook message and they called me back - and I remember getting off the call thinking 'wow, I'm not alone'."

We rely on donations and without our supporters like you, our charity simply would not be here to offer support to people in what often feels like their darkest hour. Thank you for making this possible.