

autumn 2015 issue 5

news

The magazine for Meningitis Now supporters

Meningitis
now



Battle won...

Fervent fundraising

Love is in the air



Welcome to News



Monumental moment

As this went to print, thousands of UK babies are receiving their lifesaving Men B vaccination via the childhood immunisation programme. Whilst monumental, it is bittersweet for many parents who have felt the disease's devastation, or have babies outside the four-month catch up range. Our commitment continues through Beat it Now! and we pledge to support you wherever possible.

I thank everyone whose determination and support made this possible. Without you there would be no celebrations.

Throughout next year we are commemorating our 30th anniversary, making the most of celebrating our life, but importantly setting our vision for the future. Key to this is launching our five-year Vision 2020 plan. Many of you are helping shape this, either attending CEO Roadshows or doing the critical Meningitis and Me Survey. It was completed by over 1,000 people and

provides valuable insights into challenges faced by those who have experienced meningitis, including those not in touch with us before. This will undoubtedly extend the great research we undertake (pg 10-11) and put a greater focus on fundraising to create a sustainable future.

Inside, we proudly unveil two incredible initiatives - a community-uniting campaign (pg 16) and far-reaching student awareness programme, created to drive Men ACWY uptake and awareness among young people - a difficult to reach group (pg 7). We also celebrate our London Marathon runners (pg 8-9), true love conquering all for TWO couples (pg 13 and 20), our most successful Viral Meningitis Week (pg 14-15), and thank supporters including petite pugs and large lorry firms (pg 18), for every penny raised.

Sue
Sue Davie,
Chief
Executive

Any feedback?
We hope you enjoy News and want to ensure that you continue to. To help, we welcome feedback on this edition, via a quick questionnaire at <https://www.meningitisnow.org/support-us/news-centre/news-magazine/>

Receive more news...

Sign up for our monthly eNewsletter.
Visit www.meningitisnow.org/support-us/news-centre/e-news-sign-up today.

On the front cover

Our cover shows Beat it Now! highlights, from stoic supporters and descending on Downing Street, to awareness trailer tours and petition collecting. We thank everyone who helped to speed up the UK's first Men B vaccine being free to babies on the NHS from September 1.

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Meningitis
now

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Beat it Now!



Another milestone met...

WORLD LEADING: The UK is the first country to protect babies against Men B via a national health programme (from September 1).

A day before Parliament dissolved for the General Election, the Government announced that price negotiations, for vaccine Bexsero to be free to babies on the NHS, concluded successfully with manufacturer GlaxoSmithKline (GSK).

The landmark news came after independent Government advisory body, the Joint Committee on Vaccination and Immunisation (JCVI), initially said Bexsero was not cost-effective for the NHS, before fresh evidence, including Meningitis Now data, saw this retracted over a year ago. It also came over two years after Bexsero received its EU licence, certifying it safe and effective.

The UK has one of the world's highest Men B rates, killing more of our under-fives than any other infectious disease. Bexsero also fights Men W, which has drastically increased in the UK in recent years.

Thanks to supporters' efforts, we funded early research that led to Bexsero. Although historic, it comes too late for some and we remain here to help.

...but my personal battle continues

FATHER of the meningitis movement and Meningitis Now founder Steve Dayman MBE reflects on the news.

Pride of Britain 2014 recipient Steve, who founded the UK's meningitis cause after losing his baby son Spencer to Men B in 1982, said: **"I'm absolutely elated - I've waited 33 years since losing my son to the same strain, to hear this.**

"They were cutting it fine, but so many lives and much misery will be spared.

"I heard the news late on Saturday night whilst attending a ball marking the 20th anniversary of Tracy Cox's son Ashley's death to meningitis.

"I was staggered to hear a deal was done and that babies would be protected from this killer disease.

"Given the importance, I was asked to refrain from too much liquid refreshment as I needed to join Sue in London early the next morning.

"Sue had the same call and travelled from Lancashire to London overnight.

"What followed can only be described as a 'whirlwind' of interviews, questions and probing by journalists, many of whom acknowledged the importance of the occasion.

"Getting from studio to studio was like being part of an air traffic control exercise with Sue and me adopting a holding pattern over London, waiting for the next interview call.



Steve and wife Gloria outside 10 Downing Street

"Whilst fair to say adrenalin, moment and occasion kept me focused, the overwhelming feeling we'd done it prevailed, providing me with the energy and desire to share this great news with anyone who would listen.

"The future? More of the same. My personal battle with meningitis continues for as long as I'm needed and able to help."

Our next fight

Beat it Now!'s next fight is to see more people vaccinated for free, especially high-risk group adolescents. We are pressing the Government for an Adolescent Carriage Study to help inform the vaccine's use within this age group.

Also, we share a top panel seat with health and research charities, to have a bigger voice in future vaccine implementation.

We need your help with these endeavours.



Latest research

UNDERSTANDING Bexsero's impact on bacterial carriage in babies

We are funding a £168,000 project using state-of-the-art DNA technology to discover which bacteria live in healthy babies' noses and throats.

Imperial College London researchers are investigating whether carriage changes when they receive Bexsero.

Results could increase understanding of this vaccine and inform future immunisation strategies and vaccine development.

We have £1.2 million committed to nine research projects and are reviewing our strategy to identify future research priorities.

Our Scientific Medical Advisory Panel guides our programme, focusing on quality, innovative UK-based research.

Forum fantastically filled

SCORES of scientists, clinicians, researchers and experts amassed to ensure our free Research Forum's success. There were discussions on the latest research issues, at the Royal College of Paediatrics & Child Health (RCPC), London, in May.

Our research, information and support officer Rhiannon Conner said: **"We're proud to fund cutting-edge, UK-based research towards eradicating meningitis and related septicaemia."**

"The forum showcased some of the pioneering research we fund and allowed leading experts to enter lively discussions about research possibilities."

"We're delighted by its success."

Speakers included Professors Ray Borrow, Paul Heath and Peter Taylor, and Doctors Mary Ramsay, Jay Lucidarme, Hannah Christensen and Alex McCarthy.

For more on research see pages 10-11



Student awareness drive

THE DEPARTMENT OF HEALTH announced in June that the Men ACWY vaccine will be offered to all 17 and 18-year-olds and all university entrants, aged 19-25, free on the NHS from August this year, to combat the rise in Men W cases in adolescents.

Sue Davie, our Chief Executive, said: **"With the increase in Men W cases among this age group, it is more important than ever for parents to ensure that their children are protected."**

"We have developed a highly-focused campaign designed to reach out to parents, grandparents and legal guardians. The campaign, called 'Off to Uni' consists of resources including information leaflets, new signs and symptoms cards and branded wristbands, all of which can be easily downloaded or ordered from our website."

"The campaign aims to ensure that loved ones heading off to university this autumn are not complacent about meningitis and take the necessary steps to protect themselves, stay vigilant and seek immediate medical help if they suspect the disease."

Over 12% of meningitis cases are in the 14-24 age group. Teens and young people are the second most at risk group after babies. University freshers are particularly susceptible.



Our research shows that four of 10 people aged 18-24 cannot name any symptoms, despite 90% hearing of meningitis, and 25% knowing someone who had it.

To build awareness amongst the hard-to-reach group and ensure high uptake of Men ACWY for 17-18 year olds, we have embarked on a new student programme, comprising three core elements:

- Engage parents pre- and post-A level results, to ensure Men ACWY uptake
- Distribute awareness materials and ACWY reminder to places of study
- Target students to coincide with our first annual Student Awareness Week, from October 19

The programme is part of a larger, ongoing initiative to engage educational establishments and students, from primary school to university/college.

Find out more at <https://www.meningitisnow.org/how-we-help/campaigns/uni/>