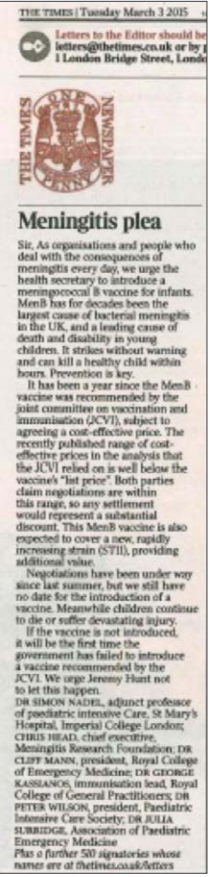


516 leading doctors & scientists and **02** Royal Colleges wrote to UK Health Secretary



#Where'sOurVaccine:
Hundreds of letters and tweets to the UK Health Secretary from people affected



05
public petitions

100,000
signatures

MRF evidence to Joint Committee on Vaccination Letters to medical journals

'Counting the Cost' of meningitis

Meningitis Research Foundation (MRF) worked with meningitis patients and health professionals to calculate the life-time cost of meningitis-induced health conditions and has used the information to campaign for vaccination and improving diagnosis and care.

The true cost of contracting meningitis is difficult to calculate and often not fully accounted for in assessing the costs and benefits of policies such as vaccination. But meningitis-related infections can lead to serious impairment, including limb loss, deafness, and behavioural and neurological difficulties. Survivors may require life-time specialist medical care, as well as educational and financial support.

In 2011, MRF wanted to gather evidence to demonstrate the true cost of severe impairment following meningitis. Methods then used by government to calculate

the cost-effectiveness of vaccines were reliant on limited data on impairment following meningitis – often drastically underestimating the cost of the disease to the government, as well as to individuals and their families. MRF therefore decided to calculate the costs of severe disability over a person's lifetime to provide a more accurate picture and make the case for vaccination.

Initially MRF interviewed multiple people affected by meningitis of different ages about their care and support needs at their life stage. They then interviewed health

Organisation:

Meningitis Research Foundation (MRF)

Location:

UK

Background:

MRF is one of the largest civil society meningitis organisations in the UK

Contact:

Claire Wright, Evidence and Policy Manager, MRF

Change objective:

To ensure the widest and earliest implementation of vaccines against meningitis

MALE

Surname Brown **Forenames** Peter

Date of Birth 14/01/00 **National Health Service Number**

Address **Doctor's Name** **Authority's Officer and Street**

Title No. **Title No.**

Title No. **Title No.**

Title No. **Title No.**

Title No. **Title No.**

Title No. **Title No.**

Title No. **Title No.**

Title No. **Title No.**

Occupation **Yes** **Occupation** **Yes**

Date of Death 30

Case of Death 30

Doctor's Signature

CONFIDENTIAL

We remember being so helpless and could only sit and watch our baby battle for his life as a small army of doctors and nurses rushed around.

Peter was 12 months old when his mum took him to the GP with a fever and rash. He had been very sick and she knew something was terribly wrong. He was rushed to hospital by ambulance with suspected meningococcal disease, then transferred to a Paediatric Intensive Care Unit (PICU) by a mobile intensive care team.

“By the time we got to hospital, the few bruise-like marks I had seen now covered him completely – his skin was turning black in front of our eyes. He was barely recognisable, pumped full of fluid, his whole body swelled grotesquely. We felt so helpless and could only sit and watch our baby battle for his life as a small army of doctors and nurses rushed around.**”**

Peter's mother

In PICU he was aggressively managed to combat multiple organ failure, and spent the next month fighting for his life. He had severe septic shock, acute respiratory distress syndrome and was on dialysis for kidney failure.

His heart stopped twice, he had catastrophic blood clotting and, starved of oxygen-laden blood, Peter's legs and one arm turned black as the tissue died, resulting in gangrene. It also destroyed 60% of his skin.

Finally Peter was transferred to a paediatric ward where he spent five months.

Both legs were amputated above the knee and one arm below the elbow and he returned to theatre continually for removal of dead skin, bone trimming and dressing changes under anaesthetic. He also underwent various skin grafting operations.

He was in hospital for six months.

Total acute costs
£151,651

One side of Emma's brain had absorbed away post-meningitis. At age 10 she had an operation to disconnect the damaged part of her brain to reduce the severity of seizures.

Shunt revision surgery

Emma developed hydrocephalus (water on the brain) due to her illness. For the rest of her life, she needed a shunt to drain away excess fluid. Like any other piece of equipment, shunts can break down. They can also become blocked, or infected. Throughout her lifetime, Emma had numerous operations for shunt revision, and twice needed intensive care after emergencies due to shunt blockage.

Emma age 8

Shunt revision surgery lifelong costs
£30,919

professionals from different specialisms about the interventions that would be offered in these scenarios, and care and benefits experts about the additional support that would be provided. From this MRF developed two fictional scenarios focused on ‘Peter’ and ‘Emma’, costing their projected care into later life.

- ‘Peter’ was 18 months old when he was struck down with septicaemia which left him with multiple amputations and behavioural difficulties. The total lifelong costs of supporting Peter to age 70 were calculated as £2,833,374.
- ‘Emma’ was three years old when she became ill with meningitis which left her brain damaged, deaf and partially blind. The total lifelong costs of supporting Emma to age 50 were calculated as £3,507,664.

Building on the research, MRF organised a series of campaign activities. Robbie Jones, a boy who had suffered amputations due to meningococcal B infection, delivered a public petition to Number 10 Downing Street. A ‘Meningitis Matters’ lobby day saw people affected by meningitis visiting their MPs at the House of Commons, garnering support from media and politicians. Letters to *The Times* signed by hundreds of doctors, and in the BMJ authored by MRF, called for the widest and earliest implementation of vaccines against meningitis.

Findings from the *Counting the Cost* research¹, published in 2013, were also submitted to the Joint Committee on Vaccination and Immunisation (JCVI) which had put out a call for evidence on the case for the Meningitis B vaccinator.

“The original report helped establish us as a trusted source. This started a dialogue with the Committee who have frequently come back to MRF since then, seeking evidence on meningitis-related issues.”
Claire Wright, MRF

Results and impact

MRF continues to call for the widest possible vaccination against meningitis, but progress has been made since the original Counting the Cost campaign. The MenB vaccine is now routinely administered to infants in the UK, and MenACWY is offered to teenagers in school and as a catch up for those going to university. This is partly as a result of MRF’s continuing dialogue with policy makers – and the sharing of research evidence, and the personal stories from survivors, to make the case for vaccination.

Key learning

- **Respond to opportunities.** Responding to the JCVI’s call for evidence was a great opportunity to build a relationship with them and with the researchers the JCVI were consulting. Look out for consultations or information requests from local or national government departments or other public bodies.
- **Involving those affected is key** All MRF campaigns have relied on very close involvement of with families affected by meningitis, as well as medical and scientific contacts.
- **It’s a process.** Counting the Cost was the first piece of work done by MRF on cost-benefit analysis and increased its confidence and expertise in this area.

- **One thing leads to another.** Interviewing those affected by meningitis and health experts helped MRF identify the need for survivors to meet others in the same position. This led to its ‘pushing the boundaries’ events, which bring those affected by limb loss together to share experience.

- **The research is replicable.** MRF have helped other organisations to cost cases of severe meningitis in their own countries which have been used to highlight the need for prevention through vaccination elsewhere.

Further resources:

- **Counting the cost of meningococcal disease.** Academic paper on PubMed.
- **Counting the Cost.** Article on MRF website

Advocacy tip

Evidence plus! The combination of robust evidence, a high-profile campaign stunt, and garnering public opinion through the petition helped make the case for vaccination. Journalists loved having a clear, compelling statistic on cost and the story got wide media coverage.

Contact details:

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¹Counting the cost of meningococcal disease: scenarios of severe meningitis and septicemia. Claire Wright Rebecca Wordsworth, Linda Glennie. Paediatric Drugs 2013