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| MALE | | Meningitis Research Foundation | | |
| Surname Brown | Forenames Peter | National Health Service Number | | |
| Date of Birth 14/01/00 | | | | |
| Address | Doctor's Name Anthony's Cipher and Stamp | | | |
| Tel No | | | | |
| Subsequent Addresses | | | | |
| Tel No | | | | |
| Tel No | | | | |
| Tel No | | | | |
| Occupation None | | Year None | Occupation None | Year None |
| (Date changes and most recent year of change) | | | | |
| SURNAMES | | | | |
| Date of Death None | | | | |
| Cause of Death None | | | | |
| Doctor's Signature None | | | | |

CONFIDENTIAL

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

“By the time we got to hospital, the few bruise-like marks I had seen turned into a septicemic blood-clotting condition, starved of oxygen and turned black in front of our eyes. He was barely recognizable, pumped full of fluid, his whole body swollen 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 control his blood pressure, 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. He was in hospital for six months.

His heart stopped twice, he had anasarca (swelling of the body), and starved of oxygen and turned black. 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 grafts and dressing changes under anaesthesia. He also underwent various skin grafting operations.

Total acute costs **£151,651**



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 vaccination.

"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.

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