



## Steve Dayman Chief Executive, Meningitis UK

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In the desolate days after his 14-month-old son Spencer had died of meningitis and septicaemia, **Steve Dayman** remembers being in the queue for the polio vaccine at a primary school in rural Gloucestershire and wondering why there could not be a single vaccine for meningitis.

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That was back in 1982, when Steve was in the haulage business, rather than the chief executive of Meningitis UK.

Doctors attending to the dying child had known so little about the condition that they had reference books open on the intensive care bed as they tried to save the youngster's life. A specialist told Steve that there would never be a vaccine for any form of meningitis in their lifetime.

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**“Losing a child is the worst thing that can ever happen to anyone. It is not something you ever really get over. There are still days that I am overwhelmed by emotions.”**

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“I describe the loss in terms of shock and emptiness. One minute he was there and the next he was gone. It was like being hit in the chest by a sledgehammer.”

Every parent in his situation blames themselves afterwards and Steve is no exception.

He remembers the GP coming to their house the day Spencer was taken ill and deciding that the child needed to go to

hospital. Steve and his wife Gloria drove their son there together with no sense of urgency, such as their lack of knowledge. The three of them waited for a couple of hours to be seen, with Steve tickling his sick baby's cheek to make him laugh.

“To think that I was tickling his cheek and all the time he was dying,” says Steve. “That is something I will never forget.”

Since then he has seen the whole picture of meningitis change. In 1992 the Hib vaccine was introduced, followed by the meningitis C vaccination in 1999. Steve says: “I am not one to get excited, but I can't believe how things have changed. I believe that in my lifetime there will also be a vaccine covering many of the strains of meningitis B.”

Steve may now be the suited businessman, often seen at conferences alongside world-leading medical experts, but it is clear that the man who has helped to raise millions of pounds towards meningitis research through this charity, is driven by the tragedy that struck him and his wife Gloria 27 years ago. It was a blow that changed the course of their lives forever.

“At the time there was nobody to talk to and not a single leaflet or support group,” recalls Steve. “We felt so alone. It was not until the Stroud meningitis outbreak in the

mid 80s that we met other families that had suffered the way we had. The whole situation when we lost Spencer felt so hopeless.”

The past 10 years since the introduction of the meningitis C vaccine have been particularly inspiring for Steve. He has particular admiration for David Salisbury, Director of Immunisation at the Department of Health, who he initially cast as the enemy for not working fast enough to introduce the vaccine, until he realised the key role the scientist was playing behind the scenes, working with the Government, academic organisations and drug manufacturers.

“I’m full of admiration for David Salisbury,” he says. “The meningitis C vaccine has been a tremendous success. In the early 90s, meningitis C accounted for 18 per cent of cases meningococcal meningitis, and that went up to around 38 per cent. Now the disease has almost been eradicated in this country.”

Following Spencer’s death, Steve gave up the haulage business he ran with his wife and family near Thornbury, although he had left secondary modern school at 14 with no dream other than to drive lorries. His loss drove him to libraries in an angry attempt to find answers to his many questions about the disease that had stolen their son.

He left the business in the hands of his wife and family while he went off around the country to conferences and visiting other families who had lost loved-ones to the disease, trying to drum up support for the meningitis crusade. At one conference in 1991 he came across the then-unknown “tumbler test” for septicaemia, which was being described by a Norwegian scientist. He brought the accompanying literature back to Bristol, had it translated and turned into a leaflet. The tumbler test is now the best-known way parents have to diagnose meningitis.

It soon became clear to Steve that the fact Spencer had died within 24 hours of being admitted to hospital meant little could have been done to save him. The only positive way ahead was to find a vaccine.

In 1986 he became the founding chairman of the Meningitis Trust, which evolved from a support group formed after the meningitis outbreak in Stroud. It is predominantly an awareness-raising organisation which focuses on aftercare and treatment. Steve stayed there for three years but his heart remained set on finding a vaccine – he wanted to eradicate the disease all together. He remained closely involved with the meningitis cause and in 1999 he was asked to become the Chief Executive of Meningitis UK, a new charity with a focus on research.

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In the 10 years since the charity was founded, it has raised £4.7million towards life-saving vaccine research. It funds cutting-edge projects involving leading professors from top universities across the country. It's thanks to their work scientists now predict the illusive vaccine for meningitis B could be a reality in less than a decade.

Steve sees himself as a galvaniser of troops, rallying families that have been devastated by a disease that strikes with lightening rapidity, leaving many children and babies maimed if it does not kill them.

He observes a greater unity in the medical world in the UK than in the eighties, as the pharmaceutical companies and the Health Protection Agency collaborate more to make inroads on meningitis B. He sees many more conferences taking place, making sure scientists are more aware of each other's work.

Steve wants to see more of the kind of collaboration that led to the introduction of the meningitis C vaccine a year earlier than originally anticipated: "I would definitely like to see more of this. The manufacturers are more open than they were. It is the best way. The Department of Health has to know what is going on so that David Salisbury and his colleagues can make the decisions to introduce a national vaccination programme."



Despite the advances, he worries that public confidence in vaccination has been rocked by the MMR controversy and recent attempts to implicate the HPV vaccine in a young girl's death. He feels that his charity has a strong part to play in maintaining public confidence and encouraging the eight per cent of parents who do not have their children vaccinated, to cooperate with programmes.

Says Steve: "If everyone knew what a horrific disease meningitis is – and saw pictures of children overwhelmed by septicaemia – that would close the eight per cent gap even further."

He adds: "I would not have got involved in any of this had it not been for Spencer's death. If he had survived unscathed I would probably have gone back to the person I was and carried on running my haulage business."

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**"It is because of Spencer's death that there is much greater awareness. It's very rewarding to hear from families who have identified the symptoms early enough thanks to our literature highlighting what symptoms to look out for. Sadly, we know that even in the best hands and with the best treatment, it's still not enough to save a life, which is why vaccines are so important."**

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"I was told that there wouldn't be a vaccine in my lifetime. But so much knowledge and research has come out of Spencer's death, including the meningitis C vaccine. We're determined to find a vaccine for meningitis B now that will be Spencer's legacy and redemption for me."

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YEARS