

Sharing the experience of families to achieve better diagnosis and treatment

MRF and Meningitis Now worked in partnership to bring families affected by meningitis together with decision makers to share their stories and advocate for more effective diagnosis and treatment.

Meningitis strikes quickly, so rapid diagnosis and treatment is key. Sometimes, however, meningitis is missed with devastating consequences. Many countries could make improvements in the way meningitis cases are handled by health services.

Both MRF and Meningitis Now offer direct support to families affected by meningitis and often families are keen to share their stories to help others. In 2017, the organisations supported three families to talk to decision makers about their experiences, with the objective of improving future diagnosis and treatment.

Initially the organisations helped each family set up meetings with their local MPs. This involved advising families on how to present their stories, providing background briefings about wider meningitis issues, and accompanying them to meetings. Ongoing support was also provided as sharing stories can be challenging for families.

All the MPs were receptive to the issue, and the organisations then asked them to each contact senior ministers with their concerns about meningitis diagnosis or raise a parliamentary question in the House of Commons. The questions

Organisation:

Meningitis Research Foundation (MRF) and Meningitis Now

Location:

UK

Background:

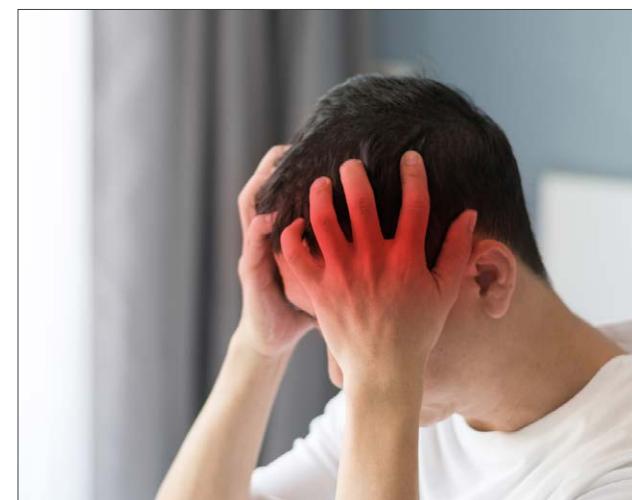
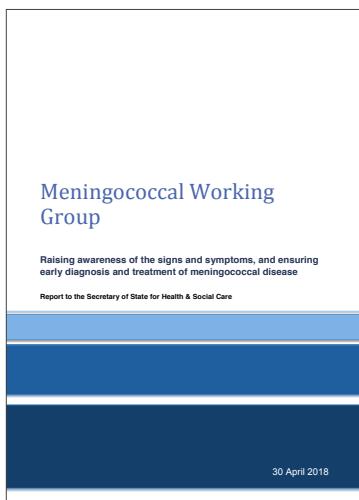
MRF and Meningitis Now are the largest UK-based civil society organisations working on meningitis

Contact:

Brian Davies at MRF or Tom Nutt at Meningitis Now

Change objective:

Better treatment and diagnosis for meningitis patients



caught the interest of then Prime Minister Teresa May, who asked Health Secretary, Jeremy Hunt to follow up and meet the families.

At the meeting (November 2017), the families spoke of their devastation at losing their loved ones, and the missed opportunities for diagnosis and treatment which might have saved them. Kirsty Ermenekli explained what happened to her daughter Layla-Rose who died aged six when health professionals misdiagnosed a purple mark and failed to treat her quickly for meningitis. Nicole Zographou also shared the story of her brother George who died aged 18 and Paul Gentry spoke about his daughter Izzy who died aged 16.

The families' testimonies were very powerful, and the health secretary was notably affected by the interaction. With two major civil society organisations also calling for action, this combined voice helped to drive action. The government agreed to establish a working group – including affected families, meningitis charities, and experts – with a view to improving early diagnosis and treatment.

Result and impact

The working group met through the early months of 2018 and published its report in July, which included 12 recommendations on sepsis and meningococcal disease. A key recommendation included routine provision of 'safe-netting' information for those sent home by their hospital or GP without a diagnosis, to ensure they seek further help if their symptoms worsen and that meningitis is not missed.

The meningitis charities continued to work with the families throughout the process, including on publicising the report. Progress against the recommendations has been monitored by all organisations involved and published in July 2019.

"The families were very open about their experiences, mistakes that had been made, and how their loss had affected them. This clearly made an impression on Jeremy Hunt and helped inspire the decision to set up the working group to explore how to do things better in future"
Rob Dawson, former Advocacy Director, MRF

Key learning

- Sharing their stories is hard for families.** All the families really wanted to share their experiences to help others but talking about the death of their loved ones to politicians was demanding and emotional. Effective support for those sharing stories is vital.
- Families will have other demands.** Families will need to work and may have other caring responsibilities. It can be difficult for them to find time to prepare for and attend meetings.
- Data, evidence, and analysis are also important.** The meningitis organisations also provided technical briefings for the MPs. Stories can engage decision makers and sway opinions; giving them the evidence to make a case for new policies to senior leaders and budget holders is also important.
- Working with local MPs can help influence national policy.** All the families initially engaged with their local constituency MPs, with a view to improving local meningitis care. The MPs then raised questions in parliament, giving the issue a national profile.

Further resources:

- Meningococcal Working Group Report**, Department of Health and Social Care, 2 July 2018
- Summary of Responses** to the Recommendations of the Meningococcal Working Group, Department of Health and Social Care, 15 July 2019
- Article on MRF [website](#)

Advocacy tips!

- Working in partnership can strengthen your campaign.** MRF and Meningitis Now are the largest and most experienced UK organisations working on meningitis. By combining forces, they strengthened their voices and gained access to high-level decision makers.
- Being pragmatic helps.** The families had originally wanted to advocate for top-up MenB vaccines for children who had not been offered them at birth (universal vaccination for infants was introduced in 2015). Government analysis indicated, however, that this would not be cost-effective. Instead, the organisations and families agreed to focus on the equally important issue of improving diagnosis and treatment to improve outcomes.

Contact details:

Meningitis Research Foundation (MRF) www.meningitis.org

Meningitis Now www.meningitisnow.org

Confederation of Meningitis Organisations (CoMO) www.comomeningitis.org