

# Impact of Meningitis Findings and Recommendations from MRF's Member Survey

Laura Clark<sup>a,b</sup>, Chantal Sunter<sup>a</sup>, Arleen Flack<sup>a</sup>, Sandra Spencer<sup>a</sup>, Caroline Trotter<sup>b</sup>, Matthew Hickman<sup>b</sup>, Linda Glennie<sup>a</sup> Meningitis Research Foundation<sup>a</sup> and University of Bristol Department of Social Medicine<sup>b</sup>



### Aims of the survey

To understand MRF members' experiences of meningitis and septicaemia, including:

- Access to urgent acute care
- Access to follow-up care
- Long-term impact on health and well-being





#### People involved

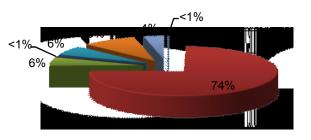
809 members who (themself, their child or other close family)

- survived meningitis/septicaemia between 1988 and 2003
- experience at least 6 months before survey date
- 50% response rate to questionnaire

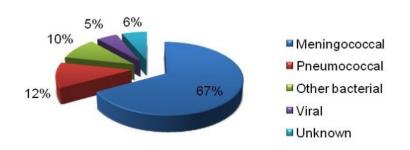




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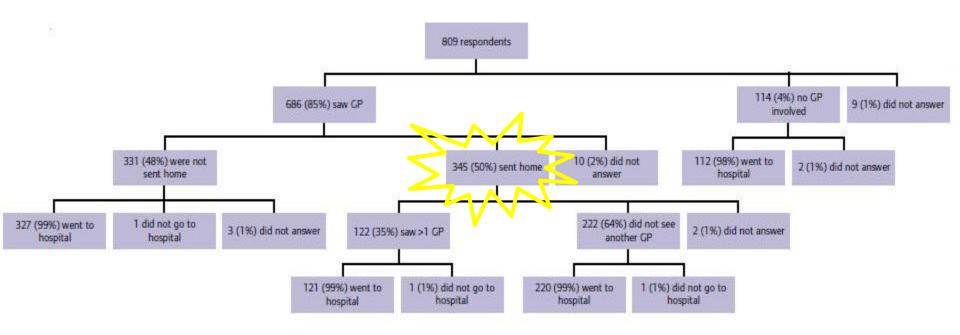




Age distribution of cases similar to national surveillance statistics

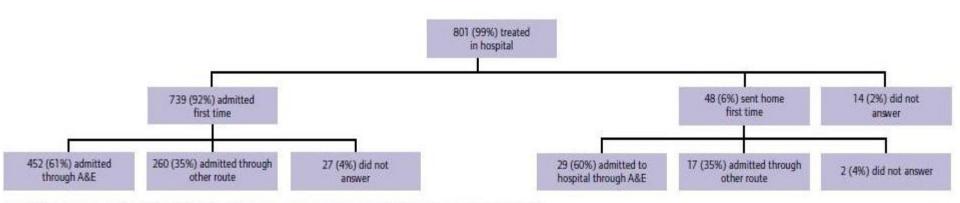


# Patient journey: GP





# Patient journey: Hospital



(8 participants had viral meningitis without hospital treatment or did not provide information, so were excluded)



Most (67%) reported short-term after effects; half had long-term effects

- 22% reported long-term sensory / neurological problems
- including 10% with long-term hearing loss
- •13% reported long-term behavioural / psychological problems
- 44 had severe scarring, 27 had amputations



Those with severe neurological damage usually had multiple disabilities, including problems with hearing, learning ability, and movement.

"S. has been severely brain damaged. He has quadriplegic cerebral palsy, severe learning difficulties, cortical visual impairment and epilepsy. These are permanent and we are using medications to control them as best as possible....We can't communicate with him as we used to and the sense of loss is great both for us and for his brother..."

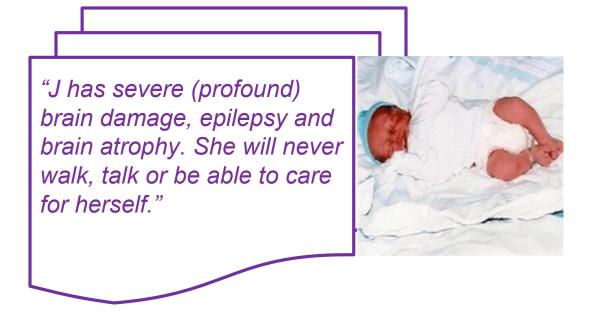




"E. is severely disabled. She has general shrinkage of the brain, spastic quadriplegia, and severe epilepsy. She is unable to sit, stand or walk, unable to speak or understand language."

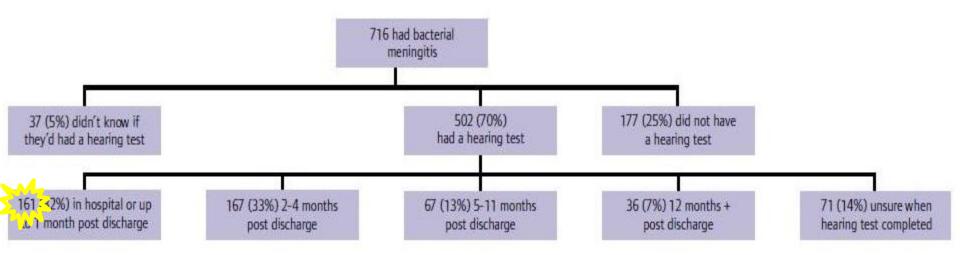








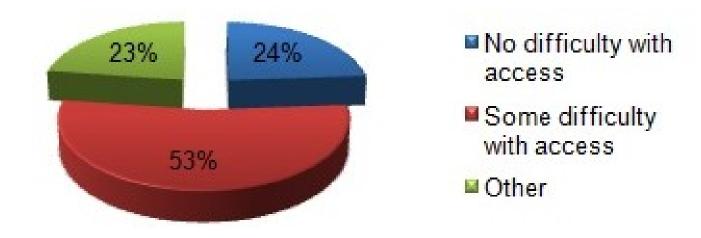
### **Hearing Tests After Meningitis**



Fewer than a quarter of those with bacterial meningitis had a hearing test within the recommended 4 weeks of being well enough to test.



### **Access to Speech & Language Therapy**





# **Access to Speech & Language Therapy**

Obtain as much information about therapeutic need as you can and don't take no folan answer.

Do not listen if this therapy is not given due to so called shortages. Push for what is your child's right and take action if necessary.

This was one area we were very disappointed with. L. needed S&L therapy. We believe if some work/ exercises were done she would not have lost her all of her speech and would not then have developed apraxia which means she still has speech problems 8 years on.

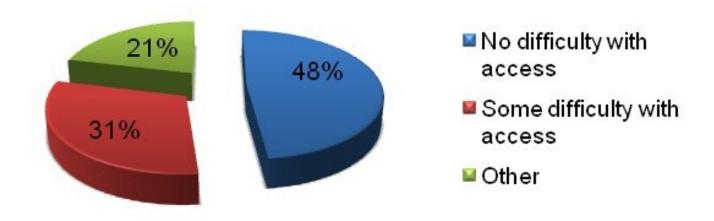
Don't give up, just keep bothering the speech & language department.

It is very frustrating as there is such a shortfall in provision - go private if you can. Seek funding charities, don't give up. Do what you can vourself.

Fight for more help, demand speech appointment. Don't let them walk over you. Find out as much as you can. Don't be scared.

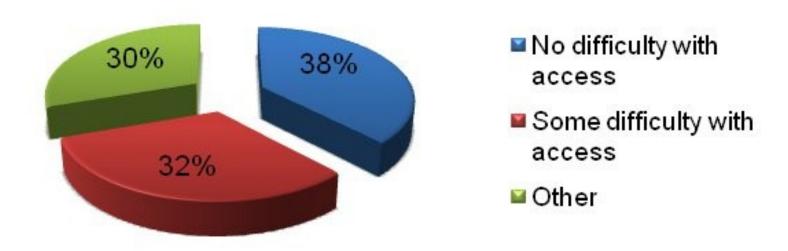


### **Access to Physiotherapy**



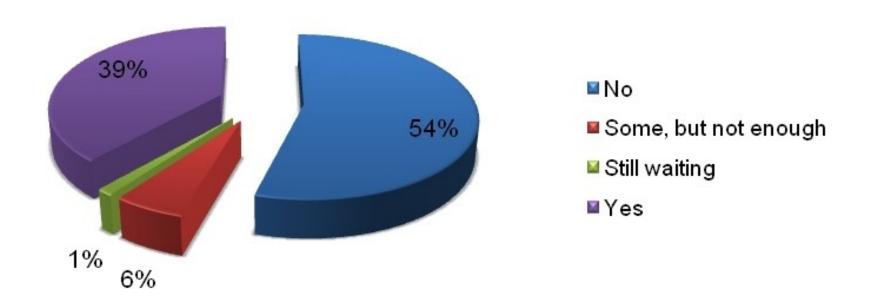


### **Access to Occupational Therapy**



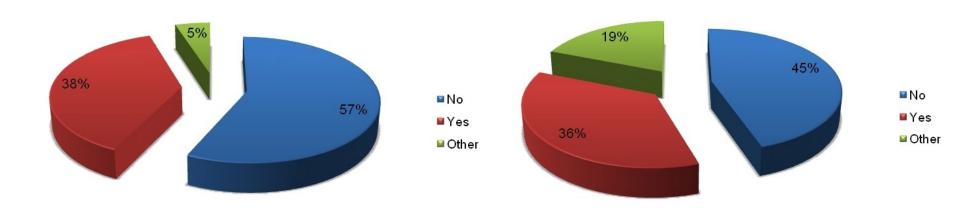


# Support for behavioural / psychological problems





# **Impact on Education and Work**





#### **Conclusions and Recommendations**

- Training for health professionals in recognition of men&sep
- Formal audiological testing ASAP / within 4 wks of fitness
- Improved and equal access to SLT, physio and occ therapy
- Vigilance to need for early referral for psychiatric services
- Better and quicker access to educational support
- Widest and earliest possible implementation of vaccines



# **Acknowledgements**

Part-funded by the Department of Trade and Industry within the Knowledge Transfer Partnership scheme, and by Wyeth Vaccines (now Pfizer).

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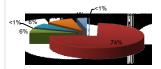
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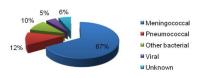
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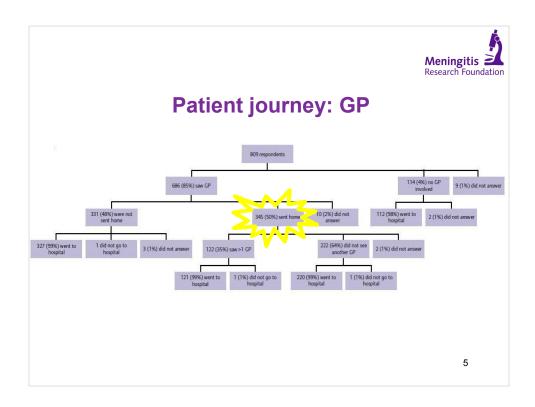






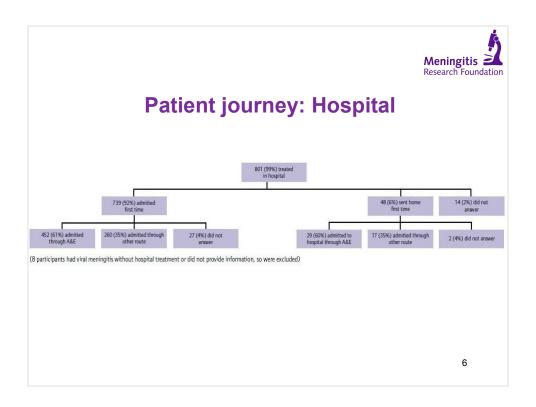
Age distribution of cases similar to national surveillance statistics

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This figure shows how members obtained urgent medical help from their GP. Half of those who went to their GP with meningitis or septicaemia were sent home the first time and this is in line with the findings of a national MRF-funded study of meningococcal disease in children¹. Those who were sent home first time from the GP were 2.4 times more likely to have pneumococcal infection. People with pneumococcal infection were 2.7 times more likely to encounter delay at both the GP and hospital, than people with other infections.

Of those sent home from the GP only 4% remembered having the symptoms of meningitis and septicaemia explained to them, which reinforces the need to educate healthcare professionals and the public about the symptoms of meningitis and septicaemia. Since this survey was conducted, studies and guidelines<sup>1,2,3</sup> have highlighted how crucial it is for healthcare professionals to explain to parents how to recognise serious illnesses, including meningitis, in sick children being sent home. This 'safety net' aims to enable parents to seek help again promptly if their child's illness gets worse.



Most were admitted to hospital the fist time, but two-thirds of the 48 who were not admitted first time were under age 5 and 31% were under age 1.

Thirty-eight per cent of respondents told a health professional that they suspected meningitis, but fewer than half felt that this was acted upon. A number of recent studies and national guidelines<sup>2,4,5</sup> have highlighted the importance of parental perceptions in identifying serious infections, including meningitis and septicaemia, so if their concerns are disregarded, potentially useful diagnostic information is lost.



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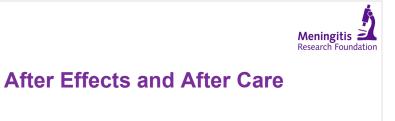
National statistics provide information on the number of people who get meningitis and septicaemia and are hospitalised, and the number of deaths. However, when a patient is discharged, there is no information about whether they leave hospital completely recovered or with disability—we do not know what happens to survivors. With no clear picture of the true impact of disease for those affected, the cost of these diseases may be greatly underestimated and after-care may be far from comprehensive.



Those with severe neurological damage usually had multiple disabilities, including problems with hearing, learning ability, and movement.

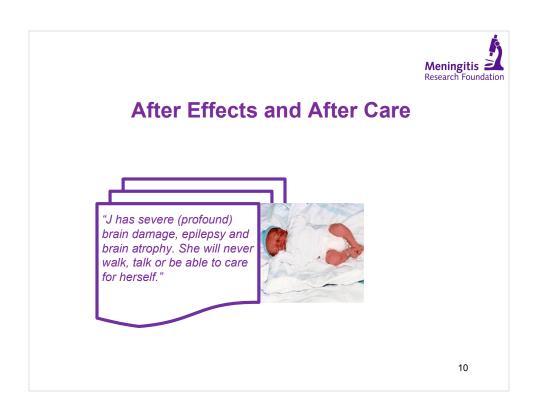


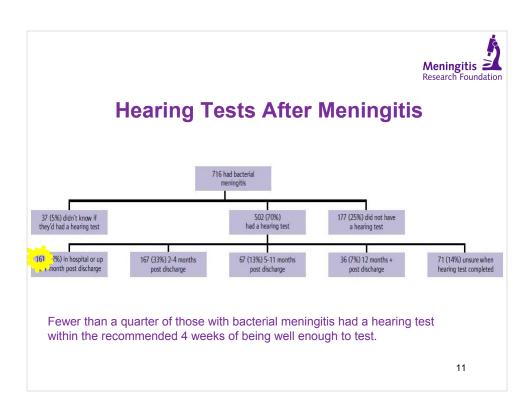
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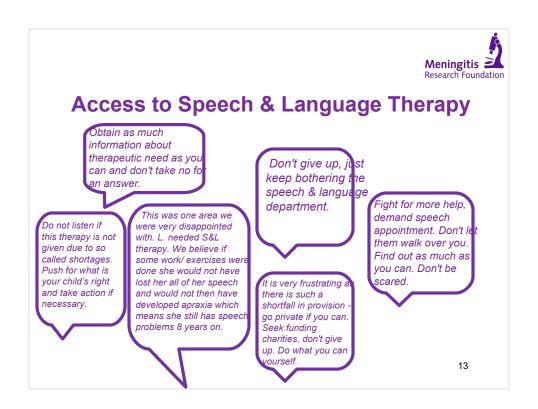




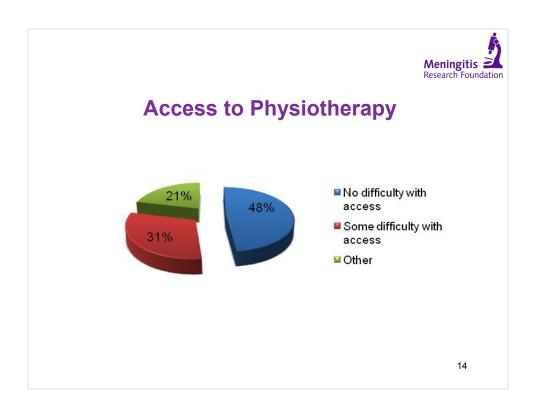




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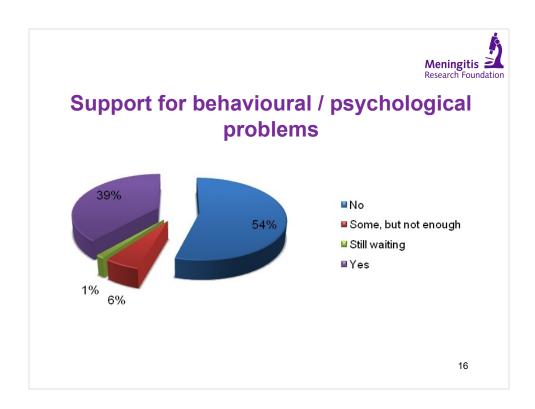


Physiotherapy is important for enabling mobility and developing or regaining the ability to carry out everyday tasks. For the 151 cases where physiotherapy was needed this figure shows the percentage who had difficulty getting access (either did not start soon enough, not often enough or not long enough).

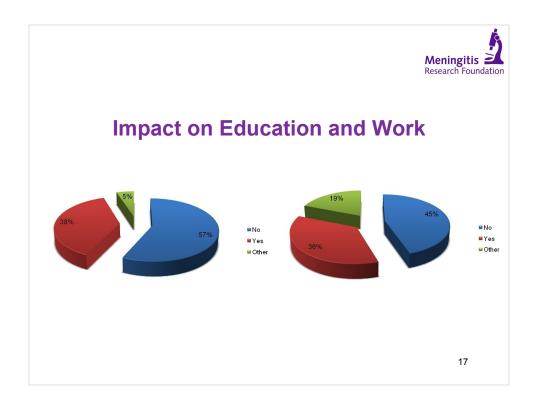


The occupational therapist is often key for access to physical rehabilitation, equipment for daily living, support for learning disabilities, and financial benefits. It is important that the therapist's assessment of need in these areas is timely, as delay is likely to affect a wide range of aspects of the person's rehabilitation.

In 66 cases where occupational therapy was needed the above figure shows the percentage who had difficulty getting access (either did not start soon enough, not often enough or not long enough).



301 members were affected, of whom about one-third (105) reported that the problems were long-term (13% of the total survey). This figure shows the percentage of people with behavioural / psychological problems who received support for those difficulties.



This figure shows the percentage of people reporting an impact on a) education and b) work, if in education at the time or after illness (total 455) or in employment (184) respectively. Seven percent of those in education either at the time of or after the illness (total 455) were given a statement of educational needs. Of the 171 who reported an impact on education, 14% felt that they did not receive enough support.

Long-term after effects had a significant impact on the work and finances of people affected and their families. Nineteen percent of our survey (157) reported an impact on finances and 15 percent (122) reported an impact on a family member's job, sometimes forcing parents to leave jobs in order to become full-time carers.



#### **Conclusions and Recommendations**

- •Training for health professionals in recognition of men&sep
- •Formal audiological testing ASAP / within 4 wks of fitness
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