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## **Meningococcal disease Section 4: Post disease complications, charity support and future perspectives**

Millar, B. C., Banks, L., Bourke, T. W., Cunningham, M., Dooley, J. S. G., Elshibly, S., Goldsmith, C. E., Fairley, D., Jackson, K., Lamont, S., Jessop, L., McCrudden, E., McConnell, D., McAuley, K., McKenna, J. P., Moore, P. J. A., Smithson, R., Stirling, J., Shields, M., & Moore, J. E. (2018). Meningococcal disease Section 4: Post disease complications, charity support and future perspectives. *Ulster Medical Journal*, 87(2), 99-101. Article PMC5974664. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5974664/>

### **Published in:**

Ulster Medical Journal

### **Document Version:**

Publisher's PDF, also known as Version of record

### **Queen's University Belfast - Research Portal:**

[Link to publication record in Queen's University Belfast Research Portal](#)

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Review Article

# Meningococcal Disease Section 4: Post Disease Complications, Charity Support and Future Perspectives

**MeningoNI Forum** (see page 87(2) 83 for full list of authors)

Provenance: externally peer reviewed

Accepted: 5<sup>th</sup> March 2018

## POST DISEASE COMPLICATIONS & MANAGEMENT

Advances in the acute identification and management of meningitis have improved substantially over the last number of years. However, studies have suggested that the improvement in acute care has not been paralleled by comparable developments in post-acute management of the cognitive, emotional and behavioural sequelae of the condition. The implications of this are particularly acute in the case of children, where the meningitic process impacts on the child's rapidly developing brain.

Like any condition impacting on the central nervous system, meningitis can result in direct and indirect impacts on affected person's function. Processes linked with the underlying infective process can directly result in focal areas of damage in the central nervous system, the implications of which can take time to emerge. For this reason, it is vital that children and families have the capacity to re-access community-based support, to assist them in assessing, managing and rehabilitating post-condition difficulties. Equally, the indirect impact of a life-threatening condition on the family should not be underestimated. Viner et al (2012), noted that some of the deficits noted in children post-meningitis could possibly be related to the hospitalisation experience, rather than the underlying condition<sup>1</sup>. In the context of a case-control study of meningococcal serogroup B disease (n=537) Viner et al reported that a tenth of their sample had major sequelae resulting in major physical or neurological disability, including major amputations, very low IQ, seizures, moderately severe bilateral hearing loss and major hearing loss<sup>1</sup>. In addition, over a third of survivors had minor deficits, such as psychological disorders, borderline IQ, digit amputations, minor or unilateral hearing loss and minor communication deficits<sup>1</sup>. Sweeney et al (2013) found that following childhood meningitis, parents desired better education and knowledge from health care professionals, improved access to information about short and long-term sequelae and easier access to follow-up support and advice<sup>2</sup>. Recent local service publications by the Regional Acquired Brain Injury Implementation Group (RABIIG)<sup>3</sup> have highlighted the longer-term, post-acute issues that can impact on children and families post-meningitis and place an onus on all services (acute and community based) to better recognise post-illness difficulties and commission services accordingly, thereby allowing easier and better access to post-injury support.

## THE CHARITIES PERSPECTIVE

*Meningitis Now* and the *Meningitis Research Foundation* are the cornerstone with respect to meningitis awareness and information to all stakeholders with an association with the disease. Equally, their remit extends beyond awareness and information, as highlighted below.

### *Meningitis Now*

*Meningitis Now* ([www.meningitisnow.org](http://www.meningitisnow.org)) was initially established as a local support group based in the South West of England and has grown over the last 32 years, into a national charity covering all of the UK. The charity has been involved in vital research to support the development and introduction of meningitis vaccines, saving lives through awareness campaigns and has supported people as they have rebuilt their lives after meningitis. Their vision is "...a future where no one in the UK loses their life to meningitis and everyone affected gets the support they need to rebuild their lives".

In Northern Ireland, *Meningitis Now* has offered practical, emotional and financial support for all those living with the impact of the disease, through a nurse-led helpline, visiting families in their own homes, offering a range of therapies, including counselling and complementary therapies and providing financial assistance for unexpected costs following meningitis. Family days offer a day of fun and give families the opportunity to meet others who have also been affected by meningitis. *Meningitis Now* is committed to various campaigns, which are driven by their stakeholders' needs and expectations. Such campaigns have been UK-wide and have included; *Beat it Now!*, which successfully supported the recent introduction of the MenB vaccine, the awareness campaign, "*Don't wait for a rash*" and the *Education Campaign*, which aimed to get the hidden impact of meningitis recognised, making sure that children affected get the support they need during their education. In addition, more recently, *Meningitis Now* has created the world's first meningitis aware recognition mark (MARM), comprising of a short online course that will educate and provide free materials and ongoing support for pharmacists and universities.

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As a charity, *Meningitis Now* receives no central government funding and as such, relies on communities to help raise the £4 million needed to support people facing meningitis every year. *Meningitis Now* funds high quality research with the ultimate aim of preventing and eradicating all forms of meningitis and associated disease. In the past, such research has been focused on developing new vaccines and increasing the understanding of how vaccines work. This remains a vital part of the charity's research strategy, as there are still disease-causing organisms/strains, which are not covered by current vaccines. In addition, the charity also funds research that is focused on preventing meningitis through other means.

### ***Meningitis Research Foundation (MRF) in Northern Ireland***

MRF ([www.meningitis.org](http://www.meningitis.org)) has an excellent understanding of the impact of meningitis and septicaemia drawn from members' personal experiences. They support local families affected through their Helpline, website, one-to-one home visits, telephone befriending network, high quality and freely available information leaflets on the diseases and after-effects, online Book of Experience, members' days and Disability Rights and Benefits information. MRF work together with over 400 members and thousands of supporters who reside in NI. MRF's ability to deliver life-saving work for over 25 years has been enhanced through member and supporter fundraising, the signing of petitions for vaccine implementation, sharing personal experiences with media and participation in research projects. The charity works with local communities and supports healthcare professionals in response to incidence of the disease, as well as schools, universities, nurseries, community groups, community healthcare settings and with the NI Public Health Agency. MRF's medical guidelines are endorsed and distributed in A&E departments, critical care and community settings.

The charity receives a DH grant of £14,388 annually for awareness and support activities in NI and supports public awareness media campaigns and provides targeted information talks and information literature for key local health professionals and 'at risk' community groups. Examples include; #*StopTheSpread* (of MenW) campaign for university freshers; *Meningitis BabyWatch* cards, which are distributed to new parents via Council Registrars.

The charity has developed excellent resources to help in the medical training of doctors and nurses in NI, where MRF supports training sessions for QUB Medical and Nursing students. MRF has produced a handbook entitled "*Lessons from research for doctors in training: recognition and early management of meningococcal disease in children and young people*", which has been endorsed by the Royal College of Paediatrics and Child Health and the College of Emergency Medicine. This booklet has been updated in line with NICE guideline CG102 and uses real-life case histories as a learning tool. In addition, there is an interactive e-learning tool version that enables doctors to learn from real cases of meningitis and septicaemia. It is based on a nationwide study, funded by MRF, that highlights where doctors make errors in diagnosis and management. Integrating text, video clips, clinical photos, sound files, charts and illustrations, allows the user to evaluate

steps in the diagnosis and management of each case presented. These resources may be accessed at the following link: [www.meningitis.org/health-professionals/doctors-in-training](http://www.meningitis.org/health-professionals/doctors-in-training)

*Meningitis Research Foundation's* vision is "a world free from meningitis and septicaemia". The charity aims to achieve this by funding research into prevention, detection and treatment of meningitis and associated infections. The research is of the highest merit, in terms of the importance, excellence and probability of success. Since the charity was founded, over £19.1m/Euro24.7m has been invested in 161 research grants in UK, Ireland and globally. Locally, a DNA fingerprinting study at the Northern Ireland Public Health Laboratory, Belfast City Hospital employed partial 16S rDNA PCR and automated sequencing technique to identify non-culturable causal agents of bacterial meningitis from peripheral blood samples and culture-negative CSF specimens in patients with suspected acute meningitis. Overall, this study showed that 16S rRNA broad-range PCR combined with direct DNA sequencing is a valuable molecular tool to aid with the detection as well as identification of non-culturable aetiological agents of acute bacterial meningitis and can augment culture methods in the diagnosis of central nervous system infections in patients who have been treated with antibiotics<sup>4,5</sup>. In addition, MRF has continued to fund further research into improved diagnostics through the development of the rapid diagnostic test, Loop-Mediated Isothermal Amplification (LAMP) molecular assay, in collaboration with BHSCT and QUB<sup>6,7</sup>. There are currently 19 active research projects throughout the UK and overseas, including the MRF-MGL, which was launched in 2012.

### **CONCLUSIONS**

After approximately 160 years since its first report in Northern Ireland, there has been a significant change in the local epidemiology of meningococcal disease, which has been in part due to the development of meningococcal vaccines. Developments in both the diagnosis and management of patients with meningococcal disease have led to a better outcome. However, we must not become complacent, as unlike smallpox, meningococcal disease has not been eradicated and more recently, the evasive nature of this bacterium has allowed for the emergence of new and more aggressive clonal strains (Men cc11). In order to remain vigilant locally in NI to this evolving disease pathophysiology, it is important that we monitor this changing epidemiology, as well as introduce innovations in disease prevention, diagnosis, treatment and management, as highlighted in Table 1. With these aspirations, we look forward to helping to minimise the burden of meningococcal disease in Northern Ireland.

### **ACKNOWLEDGEMENTS**

All authors are members of the Northern Ireland Meningococcal Stakeholders' Forum (MeningoNI). MeningoNI offers a forum for education and discussion of matters with a broad interest to meningococcal disease, allowing key local stakeholders the opportunity to consider recently evolving meningococcal disease in the context of detection and characterisation, microbial pathogenesis, epidemiology, disease prevention and vaccinology. Meningo NI has been supported by an unrestricted educational grant provided by Novartis Vaccines.



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TABLE 1:

Future aspirations with respect to meningococcal disease in Northern Ireland, as highlighted by relevant local stakeholders.

| Discipline                 | Future Aspirations   |
|----------------------------|--|
| Public Health              | In the short term: uptake of Men B vaccine will be as good as other childhood vaccines in NI and a high uptake across NI of all meningococcal vaccines, leading to a fall in the number of cases.<br>In the longer term: a Men B vaccine will be developed that covers all strains of Men B and also protects against carriage of the organism.  |
| Travel vaccination         | The establishment of a body, with the help of the Belfast Islamic Centre, to estimate the number of people going to Hajj in order to facilitate the vaccination and other services needed.   |
| General Practice           | A future where bacterial meningitis is in the same category of measles or even polio and is so unlikely that parents, families and indeed family doctors could rest assured that a sick loved one is not developing this devastating disease.  |
| Laboratory service         | Currently in NI molecular diagnosis of meningococcal disease is fragmented with some local Trusts availing of a 'send away service' provided by Meningococcal Reference Laboratory, Manchester and others employing the services of Belfast Health Trust for meningococcal confirmatory testing and serogroup determination. Ideally in the future, regional microbiology laboratories/ A&E departments/ Health centres should have the option/capacity to rapidly confirm meningococcal disease using appropriate molecular technologies. This would lead to earlier ruling in or out of meningococcal disease cases particularly in early stage disease and increase meningococcal detection in culture negative specimens. Additionally, the facility to type of all meningococcal positives regionally would reduce fragmentation and improve turnaround times for PHA locally.<br>Funding is secured on a rolling basis to ensure that NI meningococcal isolates are analysed via MATS to track local NI coverage of the 4CMenB vaccine against local isolates. |
| Clinical management team   | The host response is extremely complex and variable. Future developments in genomics, proteomics and metabolomics will potentially direct a therapy tailored to the individual.  |
| Antimicrobial therapy      | Rapid real time near patient microbiological analysis of CSF, blood and other samples in the coming years will hopefully maximise the currently conflicting outcomes of optimal patient management and antibiotic stewardship.   |
| Research                   | Ongoing collection of baseline data regarding rates and epidemiology of meningococcal carriage in Northern Ireland would help to inform future decisions about diagnostic testing and vaccination.<br>Enhanced collaboration with public health/clinical microbiology between NI and ROI to tackle meningococcal disease on an "all-island" basis.   |
| Long Term Support Services | Post-acute issues that can impact on children and families post-meningitis place an onus on all services (acute and community based) to better recognise post-illness difficulties and commission services accordingly, thereby allowing easier and better access to post-injury supports.   |
| Charities                  | Perspectives from Charity Partners:<br><i>Meningitis Now</i> - Our vision for Northern Ireland is a future where no one loses their life to meningitis and everyone affected gets the support they need to rebuild their lives.<br><i>Meningitis Research Foundation</i> - We are pleased to have actively contributed towards the success of current vaccines and continued funding for new research including vaccine research is central to our future plans.   |

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