



Raising awareness about Meningitis B in the US

The Meningitis B Action Project (MAP) is raising awareness about meningitis among families, policy makers and health providers in the US.

Patti Wukovits and Alicia Stillman met and bonded in May 2013 through their shared experience of losing their teenage daughters to Meningitis B. Since then, they have worked tirelessly to raise awareness about the importance of the MenB vaccine, and other related issues, among parents, young people and health professionals in the US.

Alicia's daughter Emily was in college when she contracted Meningitis B and sadly died within 36 hours at 19. Patti's daughter Kimberly was in high school when she contracted the disease and died a week before her graduation at 17.

"We started the Foundations (The Kimberly Coffey Foundation and The Emily Stillman Foundation) to keep the memories of our girls alive and try to ensure that no other families needlessly go through what we went through," explains Patti. "Working together has given us a stronger voice and enabled us to advocate more effectively."

"The problem is that parents think their adolescents are protected against Meningitis because they've had the MenACWY vaccine," she continues. "They don't understand that they can still get Meningitis B, and that they need a different vaccine to protect against it."

Organisation:

Meningitis B Action Project (MAP)

Location:

USA

Background:

Meningitis B Action Project has many volunteer advocates and one paid staff member

Contact:

Patti Wukovits and Alicia Stillman:
info@meningitisbactionproject.org

Change objective:

To raise awareness about meningitis, particularly Meningitis B and the vaccines available to prevent it



BACK TO SCHOOL?
IT TAKES TWO
types of meningitis vaccines!

Both the MenACWY and MenB vaccines are necessary to be fully vaccinated against the most common form of bacterial meningitis in young adults.

MenACWY vaccine

MORE HAVE RECEIVED

1st DOSE (11-16 yrs old)

2nd DOSE (16-18 yrs old)

MenB vaccine

FEW HAVE RECEIVED

1st DOSE (16-23 yrs old)

2nd DOSE (16-23 yrs old)

© Meningitis B Action Project

Meningitis B Action Project | @MeningitisBActionProject | #MeningitisBActionProject



One of MAP's objectives is to secure a stronger recommendation from the US Advisory Committee on Immunisation Practices (ACIP) on the MenB vaccine. The current recommendation is that young people should receive the MenACWY vaccine at ages 11 and 16, and that MenB may be offered between ages 16-23. The MenB vaccine is also subject to 'shared clinical decision making' between the clinician and family which can be confusing and has impacted how healthcare providers discuss the vaccine with patients.

From the start, MAP agreed that it was vital to simplify the message about Meningitis B – to make it clear that there are two different meningitis vaccines, and that young people need both. They created visuals to help clarify and emphasise that message and use them consistently across all their communications.

MAP has also developed a team of more than 3,000 meningitis advocates – 'The B Team' – who are taking the message to schools, colleges, and health centres throughout the US. "Our advocates are volunteers who've signed up on the website or through other engagement mechanisms," explains Alicia. "Each quarter we give them a new mission and the resources they need for it. The B Team has turned into a grassroots movement, taking the message into all sorts of spaces which we couldn't get to ourselves."

Patti and Alicia have spoken at numerous meetings, conferences, and other forums – sharing their personal stories and calling for more awareness and stronger policies on MenB vaccination. "Our stories are very powerful and have helped policymakers understand the impact of the disease on individuals and families," says Alicia. "We also want to include other voices such as physicians and scientists, and to collect more evidence and data in order to make the case for the economic and social benefit of the vaccine."

"Time and time again, people tell us... 'we did not know about the two meningitis vaccines'. So we are clearly getting new information out there and increasing understanding."
Patti Wukovits

Results and impact

Highlights from numerous awareness raising activities include:

- Sharing the importance of meningitis vaccination with 44.3 million people through a Radio Media Tour on World Meningitis Day 2021 and with over 43,000 parents through an interview with the Children's Hospital of Philadelphia.
- A Back-to-School Media Tour on the importance of routine vaccines, including the MenB vaccine, reached over 76.6 million people in 2021.
- MenB educational materials have been developed and distributed to 3,250+ doctor's offices and examination rooms, as well as hundreds of schools and colleges across the country.
- MAP conducted their own survey of healthcare providers to determine how the MenB vaccine is being used in clinical practice and used the results to inform their advocacy.

"What we want to do now is more closely engage the ACIP in hopes of strengthening the recommendation on MenB vaccination," finishes Patti. "This is a hard nut to crack, but we'll keep going at this by telling our stories, building evidence, and working closely with physicians and other stakeholders."

Key learnings

- **Keep the message simple and use it consistently.** Narrow down your messages to 1-2 key points and make sure they are easy to understand and use real words people actually say.
- **Use the power of personal stories.** The experience of individuals and families is extremely powerful because they are relatable.
- **Use evidence, data, and experts.** Involve health providers and policy makers in your campaigns where you can. And develop your own evidence through simple surveys, questionnaires or reports.

Further resources:

- Meningitis B Action Project [website](https://www.meningitis.org)
- **Resources** for parents, students, and health providers
- **Social media graphics and videos**

Advocacy tip

If you are a small organisation, work with volunteers to spread the message. They can help take your messages into spaces you cannot reach. To be most effective, give them specific tasks and easy-to-use tools to help them.

Contact details:

Meningitis Research Foundation
[meningitis.org](https://www.meningitis.org)

Confederation of Meningitis Organisations
info@comeningitis.org
[comeningitis.org](https://www.comeningitis.org)

