Advocating for the MenB vaccine in France

An alliance of organisations has successfully raised awareness about vaccination in France and advocated for the MenB vaccine.

Méningites France Association Audrey and Association Petit Ange Ensemble contre la méningite joined forces in 2012 as Ensemble contre les méningites (Together against Meningitis), working to promote vaccination against infectious diseases, particularly meningitis.

"Before the COVID pandemic, public confidence in vaccines in France was probably among the lowest in the world," explains Patricia Merchant-Sorel, President of Association Petit Ange. "As a result, immunisation coverage had declined alarmingly. This paved the way for the reemergence of certain infectious diseases that had been largely eradicated, and of local epidemics such as the meningitis cluster in 2003 in which I sadly lost my own daughter aged four."

Ensemble contre les méningites (ECLM) has drawn on the experience of members to encourage vaccine uptake and persuade the health authorities to communicate more effectively about vaccination to the public. Their numerous activities include sharing personal experiences in a variety of forums, distributing awareness raising materials across France, and providing evidence to public consultations on vaccination.

The alliance has strong relationships with the Ministry of Health and other health agencies, as well as with medical and scientific experts, and has participated in various initiatives to promote vaccination and awareness.

Organisation: Ensemble contre les méningites (Together against Meningitis)
Location: France
Background: Ensemble contre les méningites is a collective of patient groups advocating on meningitis
Contact: Patricia Merchant-Sorel for Association Petit Ange ensemble contre la méningite, Jimmy Voisine for Méningites France Association Audrey
Change objective: Encouraging vaccine uptake and introducing the MenB vaccine in France
Advocating on MenB

Since 2018, the French vaccination schedule has included three mandatory meningitis vaccinations (HiB, MenC and pneumococcus) but not that against MenB. “The authorities saw MenB as a rare disease with limited impact in comparison to other infectious diseases,” explains Patricia. “But I knew from my own experience how swift and devastating it can be and put the case for the vaccine in any forum where I had the opportunity.”

In spring 2021, the Haute Autorité de Santé (HAS), the French National Authority for Health, opened a consultation to review the status of the MenB vaccine, partly in response to calls from ECLM. “The initial consultation was based around an online questionnaire, but it wasn’t open to the public or to patient groups in general. We were invited to participate because of our high-profile on vaccination and our existing relationships with the health authorities,” explains Patricia.

Evidence from the CoMO network was crucial in enabling ECLM to make the case for the MenB vaccine. “Being able to show that other European countries such as Spain, The Netherlands, and the UK had adopted the vaccine was really useful,” explains Patricia. “The Confederation of Meningitis Organisations (CoMO) network is a great resource of evidence and expertise to draw on.”

ECLM’s submission was so powerful that the Technical Committee on Vaccination then requested a further hearing, consisting of virtual meetings and presentations. Jimmy Voisine of Association Audrey comments: “We approached the hearing like a legal trial, arguing that the health authorities would be directly responsible for cases, deaths, and impairments if they didn’t introduce the vaccine.

“We put the case with all the passion and conviction we bring to the issue as families with personal experience.” Patricia Merhant-Sorel, Association Petit Ange

Results and impact

In June 2021, ECLM were delighted that the HAS ruled the MenB vaccine should be ‘recommended’ on the basis of evidence from the Technical Committee. But Patricia Merhant-Sorel comments: “We have won the battle but not yet the war. COVID has helped build public confidence in vaccines but there are still barriers to MenB, including deciding who will pay for it and who should receive it.”

“The HAS will be looking at these issues over the coming months. Meanwhile we are still calling for the vaccination to be made mandatory and included in the national immunisation schedule – not only for infants but for children, adolescents, and young adults. It’s worth remembering that achieving a policy or piece of legislation may be one hurdle to overcome in advocacy. Ensuring things change in practice may take further campaigning, hard work, and determination!”

Key learning

• **Work in partnership.** Combining forces made ECLM stronger than the individual organisations within it. Consider working in alliance with other health organisations or patient groups.

• **Use the CoMO network.** The network is a fantastic support and resource, bringing together the experience, expertise, and evidence of nearly 100 members from all over the world. Make the most of it.

• **Build your relationships.** The opportunity to participate in the consultation came about because ECLM had built relationships with the health authorities over many years.

• **Believe change is possible.** A positive mindset helps campaigning. Patricia comments: “If we can change the mind of the French authorities, who are very stubborn, believe me – anything is possible.”

Further resources:

• Association Petit Ange Ensemble contre la méningite

• Meningites France Association Audrey

• Ensemble contre les méningites

Advocacy tip

Bring your passion and emotion into advocacy. Campaigning takes planning and organisation. But add in your passion and emotion to the mix. It will make all the difference.

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