

SMA Belgium

Belgium



<https://spierziektenvlaanderen.be/>

www.telethon.be



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1. About

Describe to me in a few words what SMA Belgium is? The ABMM & Spierziekten Vlaanderen join forces to ensure better national and international visibility for the disease. SMA Belgium is bilingual. It is a uniform platform that represents all patients living with SMA in Belgium. The objective of the ABMM and the SV is to “fight against neuromuscular diseases and promote the well-being of people affected by them”. ABMM is located in Wallonia, the French-speaking part of Belgium. SV is located in Flanders, the Flemish part of Belgium. The ABMM hosts the “Telethon Belgium” event. The ABMM & SV offer social services, psychological services, patient meeting platforms, scientific advice, thematic conferences, financial aid for research and patients. SMA Belgium’s membership in SMA Europe allows us to create a network of cross-expertise and European lobbying.

2. Mission

The missions of SMA Belgium and SMA Europe are linked since we ultimately have the same objectives. As I volunteer for both organizations, both organizations enrich and strengthen each other. We strive to provide effective treatments and optimal care for all patients living with SMA.

Priorities include promoting relevant SMA research, accelerating advances in diagnosis, treatment and patient care, and improving access to diagnosis and optimal treatment for all patients living with SMA in Europe.

3. Focus

Newborn screening is implemented in Belgium, it was one of the first countries! We are proud of it. We have also created a platform for exchanging good practices, tips and tricks concerning the daily life of people living with SMA and other neuromuscular diseases. We organize events to raise awareness of the SMA in Belgium, including videos. In Belgium, we monitor access and continued access to care and treatment. We must remain vigilant and ensure access for all! Belgium is also focusing on the Belgian Téléthron, raising money to inject into scientific research. SMA Belgium is linked to its two parent associations active in all neuromuscular diseases, we cannot specifically invest the money only for SMA. But SMA is an example of good practice for other types of diseases, thanks to technological and medicinal advances.

4. Coming up

For the future, what would we like? Continued research into treatment, care, and the impact of aging on people with SMA. Access to treatment for all SMA patients in Europe and around the world. Recognition and support. Access to combination therapies and ongoing research to help rebuild nerves and cells and access to regenerative medicine technology. Indeed, the treatment itself are not enough for some people living with SMA. There are still gaps. We hope to improve the care offered to people living with SMA as well as support their autonomy. Etc.





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TOGETHER IN SMA™
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#TogetherInSMA

Kim heeft spinale musculaire atrofie (SMA) en is een zelfstandig ondernemster vol passie

Ontdek haar verhaal

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**C'ETAIT NOTRE ESPOIR,
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**Avec vous, transformons la recherche
sur les maladies neuromusculaires en traitement**

Renseignements :
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Pour aider les personnes : 000-0002323-92

Pour aider la recherche : 000-3252685-81

Une organisation de l'Association Belge contre les Maladies neuro-Musculaires ASBL (RPM 435.150.116) et de
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Avec l'aide de l'Agence Wallonne pour l'Intégration des Personnes Handicapées

Et logo : Jean-Marie HELET, ASBL des Champs de Blé 64 - 7033 MONS

MA MALADIE MUSCULAIRE NE M'ARRÊTERA PAS!

"Ma maladie musculaire limite mes mouvements mais pas mes envies. L'ABMM m'aide à dépasser mes limites." (Kimberly, 17)

ABMM
Maladies neuromusculaires

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En collaboration avec Nema rzw



