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PATIENT DRIVEN SOLUTIONS

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Inspiring Anniversary Highlights

The Power of Patient-led Multi-Stakeholder Alliances: The European SMA Newborn Screening Alliance

More than an early test: Why newborn screening matters

For babies born with spinal muscular atrophy (SMA), time lost means motor neurons lost forever. SMA Europe launched the European Alliance for Newborn Screening in SMA on 31 August 2020 to reduce the time to diagnosis and to help patient advocacy groups (namely their Member Organizations) accelerate the identification of children with SMA, grounded in the widely recognized principle that earlier diagnosis and treatment lead to better outcomes.

From the outset, SMA Europe and admedicum as the secretariat viewed the Alliance as a multi-stakeholder effort, bringing together patient organizations, expert networks, academics and industry partners around that shared goal of reducing the time to diagnose SMA. (SMA Europe)

SMA NBS Alliance

The SMA Newborn Screening Alliance: turning urgency into structure

admedicum supported SMA Europe during the Alliance's creation and first three years of implementation. The initial scope already shows how comprehensive the build phase was: Alliance secretariat work, online meetings and reporting, stakeholder correspondence and sponsor support, drafting flyers and the first versions of the full White Paper, and developing both a communication plan and guidance to help national organizations translate and adapt the materials locally.

This mattered because the Alliance did not rely on one single message or one event. It built a practical advocacy architecture: a White Paper, a policy flyer, a dedicated website, a regularly updated European map, translated materials, webinars, conference presentations, and ongoing engagement with stakeholders across countries.

The Alliance's own materials describe these tools as resources both for national patient organizations and for health authorities considering the inclusion of SMA in newborn screening programs. (SMA Screening Alliance)

From launch to momentum across Europe

The results were striking. In 2020, routine nationwide SMA newborn screening was not yet established across Europe: only the Netherlands had validated inclusion of SMA, while Belgium, Germany and Italy were still running local pilots.

At the same time, the Alliance kept widening its reach and credibility. In 2021 the Alliance, driven by admedicum, launched its first Whitepaper, Spinal muscular atrophy: screen at birth, save lives. This White Paper has subsequently been updated in 2024 with new scientific references and publications. (Note: admedicum was not part of the updated version).

By the end of 2022, SMA Europe estimated that 45% of newborns born in Europe were being screened for SMA. Nationwide screening was active in Belgium, Germany, Norway and the Netherlands; nationwide pilots were underway in Austria, the Czech Republic, Hungary, Portugal and Poland; Slovenia announced its national program; and several other countries were running regional pilots. (SMA Screening Alliance)

Also, in 2022 the Alliance joined Screen4Rare, hosted a webinar on SMA newborn screening techniques, took part in more than 17 events, translated the White Paper into Spanish, Portuguese and Romanian, and highlighted cost-effectiveness evidence from the Netherlands. The same year, it received the EURORDIS Black Pearl Company Award for Patient Engagement.

What makes this project such a strong case study is not one single output, but the way the pieces and stakeholders worked together, and we believe were able to enact changer at a faster pace than any individual entity working alone. Shared evidence, structured coordination, practical country-facing tools, and visible tracking of progress via a map gave patient advocates and Alliance partners something concrete to take into national policy conversations.

While it's not possible to quantify exactly how much the Alliance influenced change in newborn screening policy compared to other national, clinical, and advocacy efforts, the timing and scope of its work clearly show that it is playing an important role in driving European progress to include SMA in newborn screening panels.

Looking at how everything unfolded, it's fair to say the Alliance helped spark momentum across many countries. You can view the map of the current status of SMA newborn screening here.

From launch to momentum across Europe (continued)

And importantly, the work proved sustainable. By 2023, SMA Europe was carrying the SMA Newborn Screening Alliance forward within its own project portfolio and expanded team, sufficiently empowered to continue on their own with admedicum taking a step back. It is part of our goals to make patient organizations strong and independent, so this evolution made sense for everyone.

That year, the Alliance was reporting further gains in SMA NBS coverage, a redesign of the Alliance website, and continued support for countries still working towards implementation. admedicum continues to cheer on that mission from the sidelines. That continuity is part of the project's success: the Alliance had moved from launch phase to established advocacy infrastructure with the support of admedicum as a trusted and neutral partner.

"I wish to thank admedicum for the amazing work as the SMA Newborn Screening Alliance Secretariat and for their support to create the Alliance. A special thanks to Robert, he helped us so much in the last years."

- Marie-Christine Ouillade, SMA Europe Board Member

SMA Europe

"From the outset, admedicum's role was to help turn urgency into something practical: a functioning alliance, a credible evidence base, and tools that patient advocates across Europe could use. Watching that foundation support real progress in SMA newborn screening made this one of the most meaningful projects I have had the privilege to work on."

- Robert Pleticha, Project Manager (during the Alliance's Launch phase), admedicum

SINCE 2016

Why we do what we do at admedicum

At admedicum, we believe that patient-led collaboration can move health systems when it is well structured, credible and sustained. Supporting SMA Europe during the creation and early implementation of the SMA Newborn Screening Alliance meant helping turn a clear patient need into a European platform with lasting relevance. This case reminds us that strong project support is not background work alone. Done well, it helps make sustainable, enduring collective action possible.

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