

SMA Support UK & The SMA Trust Potential Merger

Questions and Answers

Q1. Why are you considering merging? Why not just carry on cooperating closely?

A. Discussions about a possible merger have been ongoing for some years, but in the current climate make greater sense than ever before:

- The existence of two national SMA charities has led to confusion for donors as to where their support will have greatest impact and the differences between the two organisations.
- Combining our priorities, to support research/clinical trials with offering services and support, will enable us to take a 'joined-up' more powerful approach to the issues that matter to the SMA Community.
- Access to care and support provision from health and social services is becoming ever tighter and with more treatments on the horizon the need to advocate for access and better services will be more important. Also, with a greater number of people living longer lives with SMA, research has never been more important. All of these areas of work will be more effectively and efficiently carried out by one unified entity.
- It makes good financial sense - with operational savings meaning significant additional frontline funds for the benefit of the Community.
- The ability to fundraise e.g. bidding for grants, will be strengthened as one united, national organisation supporting the SMA Community, through both support and research.

Q2. When you say you would be more powerful as one charity, please can you give an example?

A. We believe that by being a single, united force we will be better able to advocate for people with SMA to access new treatments and therapies, especially when interacting with the NHS and funding approval bodies. We have already seen this with the arrival of nusinersen, where we have shared information and worked closely together. Another good example is our international impact. Here, a single voice will be powerful – we are already two influential members of SMA Europe and we are confident that as a single organisation we would be one of the top three SMA-dedicated charities, in global terms.

Q3. How quickly would the planned merger take place?

A. Subject to feedback from supporters and stakeholders of both charities, we hope to confirm an intended merger in the Autumn. There is, inevitably, a lot to do practically to bring two organisations together in the right way and many practicalities and work involved has already been explored at Trustee and Management level to ensure that if a merger decision was made, operationally this would be a quick transition and there would be minimal distraction from day-to-day priorities and operations.

Q4. At such a critical time for the SMA Community, with access to nusinersen being at the forefront for many, why consider a merger now?

A. Both sets of Trustees are convinced that the benefits to the community are sufficiently large that there is no better time to merge. Clearly the changed landscape of SMA – where treatments are available and need to be lobbied for NOW - has focussed our minds even more. Advocating for access

to nusinersen for everyone who may benefit, has been a focus and priority since the global Expanded Access Programme (EAP) for those with SMA Type 1 was announced in Autumn 2016. We have worked together to make access to the EAP possible across the UK. We have made submissions to both bodies that recommend NHS funding (The Scottish Medicines Consortium and NICE), and are committed to ongoing campaigning until everyone who may benefit has access. This will remain our priority, for nusinersen and the future treatments that are on the horizon.

With more people living longer with SMA, the ongoing delivery of information and support services and advocating for better services becomes increasingly important. Additionally, accelerating research is fundamental to understand more about SMA and inform the next generation of treatments and progress towards a cure. Work on a merger will not distract us from these priorities.

Q5. What would The SMA Trust bring to the combined charity?

A. The SMA Trust has funded over £4 million in SMA research, over 80% of non-government funding in the past decade. This has had a tangible impact on research development. Their focus and expertise is in research and working with the SMA scientific community in the UK, as well as in Europe and the US. All applications for its research grants are carefully reviewed by its Scientific and Clinical Advisory Group (SCAG) who are both UK and international experts in their fields:

- Professor Tom Gillingwater, BSC, MBA, PHD, FRMS, FAS, Professor of Neuroanatomy, Edinburgh University, UK
- Professor Richard Finkel, MD. Paediatric Neurologist and Director of Neuromuscular Programme, Children's Hospital, Philadelphia, USA
- Dr Michael Sendtner, Professor at the University of Würzburg, Germany
- Professor Linda Greensmith, Professor of Neuroscience, UCL, London, UK
- Dr Martine Barkats, Team Leader at the Institut de Myologie, Paris, France
- Professor Chris Lorson, Professor at the Bond Life Sciences Centre at the University of Missouri with specialties in neurodegeneration, molecular genetics & Spinal Muscular Atrophy
- Dr Ewout Groen, Wellcome Trust Postdoctoral Fellow, University of Edinburgh

SMA research is still vitally important, even with the current treatment and advanced clinical trials in other potential therapies. While the search for a cure continues, we must focus on the growing numbers of people living longer with SMA, so there is a need to address the gaps that still exist in SMA research. We will be bringing together The SMA Trust's SCAG, along with other experts, to evaluate priorities and develop a new strategy that maximises our contribution to SMA research and the development of future treatments.

The SMA Trust also has a great track record of connecting the SMA Community with high-level patrons and trustees which has meant they are able to create a number of high profile and profitable events. If the merger is confirmed, The SMA Trust would bring its patron base (led by Keira Knightley) to the new charity. The SMA Trust has also had a leadership position within SMA Europe, holding the Chair of that group for over 5 years in the past.

Q6. Why is SMA research still an important mission for the merged charity?

A. The current advances in SMA therapy have only been possible through a concerted international effort. UK researchers funded and supported by The SMA Trust and other charities have played a significant part in many areas, both in the laboratory and in the clinic. UK paediatric neurologists are leaders in clinical research to measure outcomes, which are vital for clinical trials. We believe that this is the beginning of the story of SMA therapy, not the end. There are many unanswered questions which have to be resolved before SMA is fully treatable and our work in supporting research is not over. The number of people living with SMA will increase as a result of new treatments given in infancy. For these children, the journey into adulthood will require new therapies to maintain their strength. In SMA Trust-funded research, UK researchers are leading the way in developing novel therapies to maintain muscle strength, which can be combined with drugs like nusinersen or with gene therapy.

Supporting the best research gives a charity access to the international SMA Community and a stake in shaping the research agenda. It ensures that people living with SMA can be 'partners' in research and their voice can be heard. The UK is still seen by the pharmaceutical industry as at the forefront of research in rare diseases like SMA. Research support from the new charity will ensure that the UK SMA research community can flourish and continue to attract funding from other sources.

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Q7. So changing the name, will that mean a rebrand – and if so isn't that a waste of money?

A. We think that we will need a new name and brand to make it clear that this is a new merged and united charity. SMA Support UK rebranded successfully in April 2014 and kept these costs to a minimum. Our current thinking is that if we go ahead in the autumn, we won't make lots of instant changes as there are so many more important things going on in the SMA Community but we will gradually work towards a new brand which we would look to take effect in April 2019. This will mean we won't waste the resources we already have such as any stationery and any merchandise.

Q8. What relationship would you have with wider organisations like Muscular Dystrophy UK and other patient support and advocacy groups?

A. We will continue to collaborate with these important partners in the interests of the SMA Community, where it is beneficial to do so. We feel we will be able to do so more easily as one united organisation.

Q9. Would you still work with SMA Europe?

A. Absolutely. We are already two influential members of SMA Europe which is doing more and more work pushing for research, access to treatments and other issues. We see our ongoing work with SMA Europe as a vital part of our future plans, whether in relation to joint research funding or these patient advocacy initiatives. The small size of the international SMA Community means that there are many situations where a bigger voice is more powerful.

Q10. We know families who have Angel, Tribute, SMArt or Inspiration Funds that are really important to them. Will they be able to continue raising money in this way?

A. Absolutely. Both charities believe we would be acting in the best interests of our supporters and the SMA Community by merging, but we have only been able to make the progress we have made over a combined 45 years, because of all these families. The proposed new charity would similarly be dependent on their continued loyalty and support. We are committed to ensuring that individuals and Teams will be able to continue to support the new organisation, in a similar way. The new organisation would assign a key staff member to link to Fund Holders and with The SMA Trust Teams that would come across and continue to provide fundraising support.

Q11. What about staffing and management?

A. Joanna Mitchell has worked hard for the SMA Community in her role as CEO of The SMA Trust and decided in late 2017 that she would like to step back and pursue a different work / life balance. We are grateful to her for the contribution she has made to the SMA Community during her years in post.

The two organisations will therefore unite with Doug Henderson, current Managing Director of SMA Support UK, in the lead role. There would be no changes to the Support Services Team. The Fundraising Teams would be streamlined and come together efficiently, as would administrative and communications support.

Overall, staffing and management costs in one united organisation would be lower than they currently are with two organisations.

Q12. Would there be other savings?

A. Yes, with one office and one database as examples, we estimate achieving savings of around £113,000 annually. That's more money to spend on what matters to the SMA Community.

Q13. How would you spend that money? Would you give equal weight to support and research?

A. We will remain 100% committed to providing and developing SMA Support UK's information and support services for as long as they are needed and would continue to advocate for better services (e.g. equipment provision, care and support packages, psychological and emotional support) and access to treatments. We would also look at options to develop services further as well as research funding needs when considering future funding priorities. You can see how we would plan to do this below.

Q14. Would the new organisation still have a membership structure with trustees? How would trustees be chosen in future?

A. Just as for SMA Support UK now, a merged charity would be a membership driven organisation governed by a board of trustees. Anyone could be a member and membership would be free. It would not, though, be necessary to be a member to access our information, support or any other services. We would continue with SMA Support UK's pattern of membership communications 2-3 times per year, including sending audited accounts and an annual activity report as part of the September AGM process.

The new charity would be governed by a board of trustees with equal representation of current trustees from both SMA Support UK and The SMA Trust boards working together as one. Jonathon Griffith, current Chair of SMA Support UK, and Hugo van Vredenburg, current Chair of The SMA Trust, would lead the Board for the first year as Chair and Vice Chair respectively.

Our trustees would prioritise where we spend our funds, depending on where there is the most need at any given time. By having an equal balance of trustees from both The SMA Trust and SMA Support UK on the board, as well as staff from both charities running the new organisation, we would bring together expertise in both areas and have a good, balanced approach. We would need to be flexible so that we can respond to any changing needs and challenges ahead.

In the future, the new charity would have trustee elections. Members would have the opportunity to read about people who wish to serve as a trustee and vote for them by post or at the AGM. As now, trustees would serve for up to two, three-year terms of office. To ensure continuity, only a third of trustees would 'retire' each year at the September AGM. We imagine we may advertise in due course that we are looking for people with specific skills / experience, but anyone who wished to serve as a trustee would be able to offer their services.

Q15. Where will the new organisation be based?

A. The organisation will be based at the current SMA Support UK office, in Stratford-upon-Avon.

If you have any more questions, please don't hesitate to phone SMA Support UK on 01789 267520, or email doug.henderson@smasupportuk.org.uk

The SMA Trust's letter and Q and As can be found at: www.smatrust.org/merger-proposal and please if you have time, we would love to hear what you think. Our survey is open until July 15th here: www.surveymonkey.co.uk/r/Mergerview