

Inspiring Anniversary Highlights

The Power of Information from Patients for Patients

- **More than „from the expert“: Why information from patients to patients is so vital**

Patients and carers are undoubtedly real experts in the chronic conditions they live with. However, when giving information and sharing their knowledge with other patients they are even more than that. They are also sharing a fate, experiences, sharing emotions, sharing concerns and hopes. And they very often share a common way of expressing themselves that may be harder to learn for people who don't live with such condition. That's why the creation of information from patients for patients can make such a difference compared to information created by others for patients. We therefore love co-creating with patients and carers!

„Nothing about us without us!“

SMAlltalk: A space that connects

A compelling example of the power of information from patients for patients is SMAlltalk www.smalltalk-sma.de. Launched five years ago, the SMAlltalk forum* is a digital platform that connects people living with Spinal Muscular Atrophy (SMA) and their loved ones. It offers a safe space where patients and caregivers can openly and honestly share their daily experiences – from hurdles to small and large victories, practical tips, hopes, and deeply personal stories.

Since its inception, the forum has become a valuable point of contact within the SMA community. It now hosts hundreds of articles, blogs and videos that inspire and inform. Regular Life Hacks and Live Events bring people together. Many participants say that SMAlltalk is the first place where they have felt truly understood – because they read and hear from others who know firsthand what it means to live with SMA. Although SMA being a very rare disease, SMAlltalk today sees more than 300 returning visitors every month and has become a go-to place for German-speaking people interested in SMA.

SMAlltalk
Austausch bewegt
www.smalltalk-sma.de

But SMALLtalk's impact goes far beyond individual experiences. The platform creates value on multiple levels: for individual patients and carers, it means improved access to information, practical support and inspiration, stronger networks, even greater self-confidence and much more. For physicians, researchers, other healthcare providers, social workers, industry and many others, it provides authentic insights into the lives of people affected by SMA – insights that inform, challenge assumptions, and drive meaningful improvements. And for the SMA community, it is a trusted space that fosters connection and hope.

"As an editorial team member from the very beginning, I am proud to have contributed to a platform where people with SMA can find useful information and encouragement to approach their daily lives with positivity and self-determination."

– Bastian Krösche, Editorial team member, SMALLtalk forum

Five years ago, the SMALLtalk exchange platform was launched in close collaboration with admedicum as a small project close to our hearts. Since then, the platform, with over 400 posts, and the regular SMA online events have become firmly established in the SMA community. Thanks to the dedicated editorial team and many motivated guest authors and speakers, a space has been created that offers people with SMA and their families a place to exchange ideas, information, and inspiration. Interested people will not only find valuable tips here, but above all authentic and personal insights into life with SMA. As initiators, it fills us with great joy to see how SMALLtalk has become an encouraging resource – by people with SMA, for people with SMA. Thank you to everyone who supports this great project and helps it grow!

– Stephanie Knitt, Senior Manager Patient Advocacy at Biogen

* SMALLtalk has been initiated and fully funded by Biogen GmbH, Munich, Germany. It is designed for people living with SMA as well as their family members and close caregivers. admedicum supports the editorial team of people affected by SMA in developing and publishing their ideas and contributions on SMALLtalk.



SINCE 2016

Why we do what we do at admedicum

At admedicum, we firmly believe that real patient involvement is not only possible but essential. For almost 10 years, we have been bringing together people living with chronic and rare diseases with companies, researchers, and healthcare providers – as equals. Because only together can we create solutions that truly make a difference.

We are deeply grateful to everyone who brings SMALLtalk to life and look forward to many more years of exchange, support, and shared learning.

Contact us!

admedicum® GmbH & Co KG

@ info@admedicum.com

+49 2236 94733 60

www.admedicum.com

admedicum
PATIENT DRIVEN SOLUTIONS