

# I am UNIQUE

**SMA Europe, creating a better world for people living with SMA**

We are delighted to be able to share some insights and imagery from SMA-Europe's very successful #WeAreUnique campaign.

SMA Europe are a brilliant example of what can be achieved when organisations and individuals come together to work towards a shared common goal; 'together, through greater understanding, we will create a better world for all those living with SMA.'

Spinal muscular atrophy (SMA) is a rare progressive neuromuscular condition that can affect both children and adults. There is no cure for SMA, so for those living with it treatment is centred on stabilising disease progression, and treating and managing day-to-day symptoms. Of course, what this looks like, or indeed whether or not you can access different medication and/or treatment protocols will differ substantially depending on where you live as there are very real differences across Europe in the way individual countries fund and structure health and social care.

SMA Europe is a non-profit, umbrella organisation that works with, and supports 26 patient organisations from across Europe, as well as working closely with several international partner organisations. Their core mission is to 'bring effective treatments and optimal care to everyone living

with SMA.' The organisation works in exciting and innovative ways, and through their broad membership of patient-led organisations, they represent a diverse mix of nationalities. This enables them to gain a true insight and country-based perspective of the different experiences and lived realities for those with SMA. As well as their members, SMA Europe have a Board, a small staff team, a few working committees and significantly, a brilliant and committed team of volunteers that act as delegates. Together they work tirelessly to promote their shared mission, united by their motto 'all together. One goal'

'All together' does not mean the same. In SMA the wide spectrum of how individuals are affected is classified into different clinical types, and symptoms can further vary within this framework. SMA Europe's new awareness campaign for 2023, #WeAreUnique, was designed hand in hand with their community to show the different faces of SMA, and to introduce some of the diverse and unique individuals from the European community.

The campaign featured 11 individuals, and each person was introduced using a striking theme that put them at the centre of their story. The initial image featured a portrait photograph captioned with their name, and the description of who they are, for example, 'I AM NADYA. I LOVE TRAVELLING.' Later images shared were emblazoned with the simple yet powerful words 'My name is Nadya, I am a passionate traveller' followed by 'I live with SMA. My condition is rare, I am unique.' We met with two of the participants, Nadya and Stefan, and share their stories below.

*Photograph by Daria Dyadkina  
Taken as part of SMA-Europe, #WeAreUnique campaign*



SMA  
EUROPEI am  
Nadya.  
I love  
travelling.All together.  
One goal.

Photograph courtesy of SMA-Europe, #WeAreUnique campaign

## In conversation with NADYA

*"I travel a lot with my mum, we've visited so many countries. There are so many interesting places that you can visit. You can feel and understand a country and culture through the language and atmosphere."*

Throughout our conversation what shone through most was Nadya's vibrant and bubbly personality, as well as her deep love of languages and curiosity about the world. Now thirty-seven years old, Nadya was born in a city called Rostov-on-Don in Southern Russia but moved with her family to Belgorod at around two years old. The move followed Nadya's SMA diagnosis and was made mainly so that her grandparents could help care for her, whilst her parents worked. *"We moved because my parents needed help, especially my mum, she was afraid of the disease I have, so we moved because my grandparents could help my parents with me."*

Nadya remembers her childhood as a happy and sociable one, being cared for by her grandparents in the countryside and playing with her friends whilst her parents worked

and her older brother went to school. *"I stopped walking when I was five years old, I couldn't walk as a normal child, so I needed some help, but I remember that I had the flu and after that I stopped walking, I couldn't stand up anymore and I started to use a wheelchair."*

Growing up in Russia some thirty odd years ago very few buildings were accessible or adapted to include disabled facilities, but her family were determined that Nadya should have the same opportunities as everyone else. So, when she was seven years old, she was enrolled in a local kindergarten for a year before she started school. Again, Nadya has happy memories of those days, which was clear to see on her face. School too was an overwhelmingly positive experience, with the school working hard to meet her needs as much as possible within the space they had.

*"At that time it was very difficult to attend school because the schools were not accessible... but they decided I should attend and that was also a very nice period of my life because I attended every day."*

*"My parents took me to the school and my brother also helped because he was also there. I was in one classroom and had all the lessons there. My fellow students were very nice and the teacher we had was just an amazing woman."*



Photograph by Daria Dyadkina  
Taken as part of SMA-Europe, #WeAreUnique campaign



Nadya's mum was determined her daughter would have the best life she could, and even changed her career to become a teacher, going on to work in each of the settings her daughter attended over the years, including university, so that she could meet her physical needs.

Primary school unlocked Nadya's lifelong love of learning, and she blossomed, thriving both socially and academically. When it was time to leave primary school the reality of what it meant to be disabled in Russia became much more real, as she was unable to find a secondary school she could attend and had to continue her education at home. *"I had to stay at home and all the teachers came to me and taught me at home because there was no opportunity, or no accessibility after primary school."*

The teachers came when they could, but it was far from easy. However, her innate curiosity about the world around her and her dedication to learning meant that she was still able to do well in her exams, and she graduated with honours. This ensured that she had the qualifications she needed to be able to attend university, where she chose to study linguistics and economics.

*"That was, I think, the best period of my life because that was the life that I always dreamed off. I was at university, I was young,*

*I had a lot of friends, I was like all the girls and boys I started with."*

The reality of living with SMA is a hard one, as it is a degenerative disease, the progression of which can be difficult both physically and mentally. Over the years Nadya has undergone painful surgeries, and has had to accept and adapt to a loss of mobility and function resulting in increased reliance on those around her for care and support. Recently she has lost both her beloved dad and brother, two of her biggest champions in life, who had always been there to make things as easy as possible for her.

*"Step by step, my SMA became worse and worse of course, as this is the disease. It is what I have and I can't do anything about that... The period from finishing school and studying in the university was I guess the strongest period of my life. I couldn't walk of course. I couldn't always help myself, just going to the toilet I couldn't do, and there were things I was not able to do and I'm still not able to do. But I managed with everything that life could give me."*

Nadya is a determined and positive person, who worked hard after graduating from university to carve her place in the world; going on to work as both a language teacher and translator. Her curiosity in the world remains undiminished; she has travelled far and wide with her mum, exploring



*Photograph by Olga Markova*



faraway countries and immersing herself in local cultures and languages. Her work as a delegate for SMA Europe along with her involvement in the SMA Family Foundation Russia have also introduced her to the global SMA community, bringing opportunities for travel as well as deep and meaningful interpersonal connections that few of us could have imagined in the pre-internet world.

Alongside digital advancement, recent drug development has meant that the progression of her SMA has slowed, and even improved in some small but important ways. As she explains *"I have been treated with a new drug for almost three years now and I feel much better. I am not so tired after the working day."* She continues by explaining that although the improvements she has seen are gradual, the small increased level of independent function they offer is hugely important. As too is the slowing of the disease progression and her overall increased resilience. *"It is easier to take a cup full of coffee or tea because it is easier to hold it in my hands, it is also easier to take a telephone call. And, when I go*

*outside when it is cold it is easier for me to bear the weather conditions. So, I think it's great result and at least I don't feel I am getting worse and that's the best result, that the progression is at least stopped."*

Like so many of us Nadya dreams of finding her person, of getting married, of having children, and of living a happy and fulfilled life. Underpinning it all is her hope that she can remain well. *"I want to make progress in my profession, I want to improve my skills, my teaching abilities. I want to help my pupils, to make them understand how important it is to know foreign languages and to improve themselves, to realise their dreams. Because teaching is not only about giving them the information I know, it's much more than that, it is trying to make sure that your students will become great personalities, great people. I feel that that's my duty to make them good people in life."*



*Photograph courtesy of Nadya*

**SMA  
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My name is **Nadya**.  
I am a passionate traveller.

I live with SMA.  
My condition is rare,  
**I am unique.**

#IamUnique

#SpinalMuscularAtrophy

[www.sma-europe.eu](http://www.sma-europe.eu)



*Image courtesy of SMA-Europe, #WeAreUnique campaign*



SMA  
EUROPEI am  
Stefan.  
I am an  
SMA Super  
Explorer.All together.  
One goal.

Image courtesy of SMA-Europe, #WeAreUnique campaign

## In conversation with STEFAN

Stefan lives in Assen in the Northeast of the Netherlands, in an adapted studio adjacent to the house that is still shared by his mum and younger brother Kevin. His dad moved away following his parent's divorce, although they remain a close family. Reflecting on his childhood Stefan explains that he was raised to understand that he was just like everyone else, "I was always told 'you're normal, the only thing that's different is that you have a wheelchair and the other people walk.' That was the only difference. I never went to a special school, I just did the normal things in life."

It is well documented that the environments and experiences of our formative years are hugely important in shaping who we are, and as well as having parents who refused to see him as anything other than himself

Stefan also had an older sister with SMA, who like him used a wheelchair to navigate the world. So although his disability might have singled him out as 'different' in some ways, he was far from alone and instead had an older sister whose experiences matched his own. Indeed, because of the shared diagnosis with his older sister his parents knew almost immediately that he had SMA, although the official diagnosis of SMA Type 2 was not made until he was around six months old.

"I had an older sister, she was two years older than me and she also had SMA Type 2. They diagnosed her with SMA when my mum was about five or six months pregnant with me. And when I was born my parents almost immediately knew that something was wrong, that it was the same thing that my sister had. Because there are certain symptoms in children with SMA that you can recognise. For

example, if you lift a baby up above your head they cannot keep their own head up, the head falls forward. Or they have very shaky tongue, so if they stick their tongue out it's wobbling. So those are things that my parents noticed in my sister and later on noticed in me." Family photographs from that time show Stefan and his sister side by side in their wheelchairs, their shared experience of how they moved in the world making it simply their normal, in a very real and tangible way.

Devastatingly his sister died following an accident when he was just five years old. Although this meant that he then grew up without his sister there to continue to guide him, he was, according to his parents, determined he was not going to grow up without a sibling.

Photograph  
courtesy  
of Stefan

*"We are more than the wheelchair and the disability that we have."*



*"After my sister passed away my parents told me that I said 'I want a new brother or sister because I'm already in a wheelchair, and everyone pities me. And now my sister has passed away and everyone has even more pity for me. And I don't want to be alone, I want another sibling.' So, then my brother came along, he doesn't have SMA and I'm really happy for him, and for that."*

Stefan is positive, confident and outgoing, now thirty-four years old he runs a successful web design company and loves to travel. His dark sense of humour means that he is often to be found making jokes that most people wouldn't dare to make. Having grown up in a supportive family who dealt with the additional physical support and care he required in such a matter-of-fact way he is comfortable in his own skin, able to ask for help, and can navigate the world independently within the context of the physical support he needs.

Until recently he didn't feel any particular connection to other people with disabilities, indeed he often actively avoided them, because his impression had been that *"a lot of people complain, and say 'I can't do this and I can't do that' and that's not my point of view, that's not the way I was raised."* However, everything changed for Stefan just under three years ago when he began

taking a new medication that had been approved for the treatment of all forms of SMA.

This new treatment had been shown, during multiple clinical trials, to have the potential to significantly slow the disease's progression and, in many cases, improve the strength of individuals with SMA. As Stefan explains *"when I was younger, I could pick up a football, I could write my homework with a pen on a piece of paper. Now I can move one index finger and I use eye control to control my computer. So, the progression of the SMA is really shown there, I can't do the same things anymore that I could do when I was younger. But since I started getting my treatments, I've noticed that my hands are getting a bit stronger, my voice is getting better... but the biggest difference that I'm feeling for myself is that my eating is getting better and more safe because my food doesn't get caught and I don't choke as often as I did. So, I'm really happy with that!"*

The other big change in his life has been Stefan's introduction to both the local and the global SMA community. He explains that after he started treatment his mindset began to change. *"I was really interested in how it worked, and how everything to do with SMA worked. I had never really looked at it before, I just accepted the fact that I had SMA."* First Stefan



became involved with the national SMA organization in Holland, the Vereniging Spierziekten Nederland, and was eventually invited to become a delegate for SMA Europe when it was suggested that he might be a good fit for the role of a volunteer delegate, *“because you like to talk a lot and you have an opinion, so maybe you can do something with that.”* He didn't have to think it over for long because it felt like the perfect fit, combining his love of travel and speaking in different languages. Reflecting back he is clear; *“I think it was the best decision I ever made.”*

Although he is an innately positive person, and one who is determined to find the best in any situation, this does not mean that he travels through life unscathed, the very real issues that many people with a wide range of different disabilities face are ones he too faces. He recounts the story of how, on a recent trip to the US to attend a global SMA conference, unexpected delays to the journey, caused in large part by the airline forgetting his wheelchair in the airport he transited through, ultimately led to him being admitted to intensive care. Despite the tireless work of disability rights campaigners over the years, there are currently no airlines which have made proper adaptations for disabled passengers. *“I was sitting in the airplane not being able to eat and drink because I can't go to*

*the bathroom on board. So, my whole body went into shutdown mode, my blood sugar dropped and my potassium dropped and my whole body just shut down.”*

The changes and experiences of the last few years have marked the beginning of a very new and different journey for Stefan, leading ultimately to his transformation from someone who was determined not to be defined by their disability to someone who has become a passionate disability campaigner and advocate. He is committed to helping to bring about changes in the world that will help ensure that no-one is unfairly limited by

their disabilities, or by their immediate environment. *“I was looking at it from my point of view, and like I said before my point of view is that I'm not disabled. It was really easy to look at life like that, but I can understand now that if you live in a country where nothing is adapted then you can't go outside. Or, if you don't have a proper wheelchair then I can understand that you feel disabled in that moment.”*

In joining SMA Europe Stefan has found a way in which he can actively campaign for the world to see what he has always known, *“we are more than the wheelchair and the disability that we have.”*



*Photograph courtesy of Stefan*

**SMA  
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My name is **Stefan**.  
I am an SMA Super Explorer  
and SMA Europe Delegate,  
all rolled into one  
adventure-loving package!

I live with SMA.  
My condition is rare,  
**I am an explorer.**

#IamUnique

#SpinalMuscularAtrophy

[www.sma-europe.eu](http://www.sma-europe.eu)



*Image courtesy of SMA-Europe, #WeAreUnique campaign*



### About SMA

Spinal Muscular Atrophy (SMA) is a rare genetic and progressive neuromuscular condition which is characterised by the gradual degeneration of nerve cells in the spinal cord (motoneurons). SMA leads to progressive muscle weakness and atrophy, left untreated it can result in a very poor outcome. There is a wide spectrum of how children and adults are affected and the symptoms vary from person to person, but SMA may affect crucial activities such as breathing or eating through to more minor motor function issues.

\*Information based on the 'About SMA' section of the SMA Europe website

Click [here](#) to access SMA-Europe's tool, OdySMA which overviews country-based access to different SMA treatments.

### Contact Information

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