



# The adventurous side of SWITZERLAND

*by Kim*



**TOGETHER  
IN SMA™**

SHARING THE JOURNEY WITH SMA





# Overcoming mountains with SMA



“ SAY YES to new adventures ”



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The Not a Lonely Journey travel guide is a unique and inspiring collection of life and travel experiences from SMA patients to encourage others who have explored the borders of their disease to go beyond and start exploring a new world of possibilities.

Each chapter features a different SMA traveller, with a new story of navigating the world with SMA. Offering tips and advice on how to find accessible experiences and how to turn challenges into opportunities to experience the best the world has to offer.

This guide celebrates the paths SMA patients can take in improving their quality of life.

*Welcome to Not a Lonely Journey.*



# A journey through Kim's life

## ADVENTUROUS TRAVELS WITH A DISABILITY



I was diagnosed with Spinal Muscular Atrophy (SMA) when I was two years old. Because of this, impulses from my brain don't work properly, and I can't control my muscles and move them the way I want. The doctor told me I'd have 21 years to live, but I'm 36 and I've been travelling the world with SMA for the last 20 years.

There's a view that SMA creates impossible barriers, especially with travel, which is of course all about movement. And I'm not writing to say it's fantastically easy, otherwise, we wouldn't need a guide. But it is possible, and more than that, it's liberating. In a world of appointments and schedules, visiting a new place and not knowing what's around the corner makes sure we're living and not just alive.

I've been travelling the world with  
SMA for the last 20 years.



**BORN:** 1987

**LIVES:** Mannheim, Germany

**TYPE OF SMA:** Type II

**INSTAGRAM FOLLOWERS:** >9,673

**HOBBIES:** Travelling, swimming, thrill-seeking

Traveller's  
Profile







# Swiss Mountain Adventures

## THE ALPS LIKE YOU'VE NEVER SEEN THEM BEFORE

Switzerland is one of my favourite travel destinations in Europe. Not only is it beautiful, action-packed (yes, really!), and stuffed with the most comforting food, but it's also incredibly accessible. From public transport in cities to remote mountain peaks, no wheelchair is left behind.

Don't be afraid to ask activity providers if they can help with accessibility!



In fact, it was on a mountain peak that I got the inspiration to do something a lot of people would think impossible. I was travelling with my long-time friend Miriam between Zurich and the Canton of Valais. En route we visited Rigi Kulm via cable car, an amazing accessible experience. At the summit, which dominates the Swiss landscape, we saw paragliders soaring through the crystal-clear air... and I decided I wanted to fly.



With a little bit of hunting online, we found a company that could help, Flug-Taxi. They specialise in offering flights to wheelchair users, which I of course leaped at the chance to do. Located in the town of Fiesch, this paragliding experience lets you strap into a custom, lightweight wheelchair hooked to a parachute. No training was needed, just a co-pilot and good weather which at first, we didn't have. Clouds shrouded the Fieschalp mountain, our take-off point. Luckily Miriam and I could weather the weather in the scenic village of Fiesch, though we didn't have to wait long. The next day the winds picked up, the skies cleared, and I took to the skies over the ALTESCH Arena, guided by Xandi, my pilot.

“ It's the ultimate example of barrier-free travel ”

What followed were 15 of the best minutes of my life. Soaring over snow-tipped mountains and lush, green valleys; hanging weightless and free in another world. Still, peaceful, but thrilling. The experience felt like a paradox, but I suppose some people might think an SMA patient paragliding a paradox. Still, I proved them wrong, which is what makes this my favourite travel story, because it's the ultimate example of barrier-free travel. Where there's a will, there's a way. My will took me to the skies of Switzerland, which makes anything possible.







## PARAGLIDING AND OTHER SPORTS

If the idea of paragliding fascinates you, but you don't know where to start when organising a sports holiday in Switzerland, the first tip is to have a look at the **PlusSport** website ([plusport.ch/en/plusport](https://plusport.ch/en/plusport)) and **Difference Solidaires** (<https://www.differences-solidaires.ch/en/activities/>), both are specialised in recreational and competitive sports activities for people with disabilities of all ages in Switzerland.



At the **site.schweizmobil.ch**, in the Obstacle free routes section, you will find the most beautiful proposals for accessible hiking in Switzerland, while if you want to try paragliding as Kim did, we suggest agencies that offer tandem flying with special attention to people with disabilities, such as the *Insuperabili association* that organises outdoor activities in the canton of Ticino, including paragliding ([Insuperabili.ch/sport/paragliding](https://insuperabili.ch/sport/paragliding)), skiing, hand biking and many other activities, and *FlybyPara* ([flybypara.com/](https://flybypara.com/)), which specialises in paragliding trips around the world with a focus on the Swiss Alps. Thanks to associations such as *Flyability* (<http://www.flyability.org.uk/>) supported by the *British Hang Gliding & Paragliding Association*, it is possible to attend courses to learn to fly independently!

For equipment rental you can contact *T-Rex Sport* (<https://www.ticino.ch/en/commons/details/Ti-Rex-Sport-Association/149201.html>), which has all the equipment also for people with disabilities. With the association *Velabili* you can take sailing tours on Lake Lugano (<http://cvll.ch/velabili/>).





## GLAMPING, BARRIER-FREE ADVENTURES

To fully enjoy a holiday, comfort is the first requirement. In Switzerland, the **Touring Club Schweiz (TCS)**, in cooperation with the Cerebral Foundation, a private organisation of the Swiss Aid for the Handicapped, has equipped selected campsites with barrier-free bungalows designed for people with mobility impairments and their families. The spaces are designed to allow easy walking and independence with extra-wide doors, well-divided rooms, hospital beds, as well as showers, toilets and kitchens that are easily accessible by wheelchair. The bedrooms have a special kitchen bed that can be comfortably used with a wheelchair. All bungalows have a covered terrace for quiet moments in the open air.



## SOME USEFUL ADDRESSES

### *TCS Camping Bern Eymatt*

Bern and its surroundings satisfy every interest. And the TCS Camping Bern Eymatt campsite located in the heart of the Bremgarten forest near Lake Wohlen makes it easy to reach the city and enjoy contact with nature at the same time.

(<https://www.tcs.ch/de/camping-reisen/camping-insider/campingplaetze/tcs-campingplaetze/campingplatz-bern-eymatt.php>)

### *TCS Camping Bönigen Lake Brienz*

The perfect location for those who love the outdoors and nature trails: TCS Camping Bönigen Lake Brienz enjoys the proximity of the lake of the same name and the breathtaking view of the peaks of the Eiger, Mönch and Jungfrau. And after completing the trail, it will be nice to take a rest by the lake, at the public lido or organise a barbeque in the barbecue area.

(<https://www.tcs.ch/it/camping-viaggi/camping-insider/campeggi/tcs-campeggi/campeggio-boenigen-interlaken.php>)

### *TCS Buochs-Lake Lucerne Campsite*

The TCS Buochs-Lake Lucerne Campsite is located on the shores of Lake Lucerne with direct access to the lake and free use of the nearby lido. In addition, the rowing school Kanuwelt Buochs ([kanuwelt.ch/](http://kanuwelt.ch/)), in cooperation with the Cerebral Foundation, organises kayaking courses and provides special equipment for people with disabilities.

(<https://www.tcs.ch/it/camping-viaggi/camping-insider/campeggi/tcs-campeggi/campeggio-buochs-lago-di-lucerna.php>)







## ORGANISING YOUR TRIP TO SWITZERLAND

First consult the Barrier free travel section on **myswitzerland.com**. There you will find lots of information about facilities at Swiss airports, stations and ports for people with disabilities. In particular, in Switzerland, the **Cerebral Foundation** offers assistance in organising a carefree holiday, from accommodation to finding leisure organisations.

(<https://www.cerebral.ch/de/hilfsangebote/betroffene/erholung-freizeit>)



## SMA CENTRES IN SWITZERLAND

**Children's Hospital of Eastern Switzerland St.Gallen**  
St. Gallen, Svizzera Claudiusstrasse 6, 9000 St. Gallen

**Kinderspital Zürich**  
Steinwiesstrasse 75, 8032 Zürich  
Tel: +41 44 266 82 16, mail: [muskel@kispi.uzh.ch](mailto:muskel@kispi.uzh.ch)

**Universitätsspital Zürich**  
Frauenklinikstrasse 26, 8091 Zürich  
Tel: +41 44 255 55 20, mail: [muskel@usz.ch](mailto:muskel@usz.ch)

**Myosuisse Ticino**  
Via Tesserete 46, 6900 Lugano  
Tel: +41 91 811 69 21, mail: [myosuisse.ticino@eoc.ch](mailto:myosuisse.ticino@eoc.ch)

**Myosuisse Bellinzona**  
Via Ospedale 12, 6500 Bellinzona  
Tel: +41 91 811 66 68, mail: [myosuisse.ticino@eoc.ch](mailto:myosuisse.ticino@eoc.ch)

**CHUV, Centre hospitalier universitaire vaudois**  
Rue du Bugnon 21, 1011 Lausanne  
Tel: +41 21 314 1111







# Ready for anything

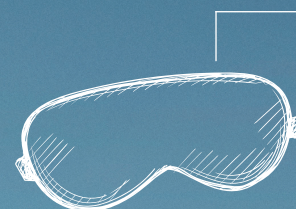
## MUST-HAVE TRAVEL ACCESSORIES

Overpacking is the enemy of travel. If you have two big cases, 40 sets of clothes and those hats you once bought, but never wore, they'll only distract you from the main event; losing yourself in a place you've never been before.

One of my best travel experiences happened in Las Vegas when all my luggage was lost. After an initial panic, my husband and I actually found it liberating to travel light, just absorbing the destination rather than hauling around enough stuff to recreate our apartment back home!



## HOW DID I THRIVE WITH LUGGAGE LOST? BY TAKING 4 MUST-HAVES IN MY CARRY-ON CASE:

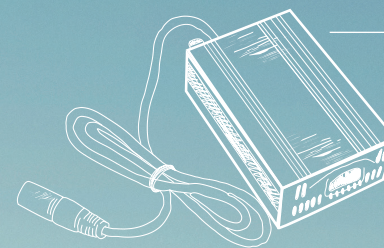


### SLEEPING MASK

This might seem odd, but a sleeping mask is an amazing tool for any traveller. You never know when you might need to sleep in a busy airport terminal or shut out the light in a hotel room with thin blinds. Sleep is essential, so don't forget this!

### SMARTPHONE

This is less odd, this is the connected smartphone age. With a smartphone (and obviously its charger) you can navigate any city, find any amenity, and if something does go wrong, reach anyone to help.

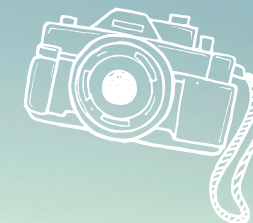


### WHEELCHAIR CHARGER

If like me you have a motorised wheelchair, don't forget to bring the charger! It's a simple mistake that can make the journey a lot less accessible.

### DSLR CAMERA

As a travel blogger this is essential, but it's great advice for everyone. These are precious memories, especially if the journey itself is a huge accomplishment. Don't forget to take a photo to have the moment forever.







## APPS



Before setting off, it can be useful to download a few apps to make the journey easier. Google introduced the **Wheelchair Accessible Routes** function some time ago but it can be useful to combine this with an app for finding toilets and parking spaces such as **WheelMate** (free, iOS and Android), which also offers the possibility of enriching the census network by adding new ones by users, or **Wheelmap** designed to find wheelchair-accessible places and rate them. The app is worldwide and contains details on 30 countries and is available in 32 languages.

## WHERE TO STAY?



Where to stay when travelling? **Bookingbilty** and **Village for all** are portals that bring together accommodation solutions around the world that are accessible for people with disabilities and special needs such as motor, visual, hearing and mental impairments, such as hotels, bed and breakfasts and holiday homes. **Airbnb's** internal search for accessible accommodation can also provide unique places to stay.



## SOME USEFUL GADGETS

Having the right gadget with you can save the day, if not the whole holiday. Here are, in my opinion, some practical items that could do the trick while you are travelling:

- A smartwatch connected with apps
- Pocket translators. Those from Vasco Electronics support 108 world languages
- The folding chair from Flying Tiger is simultaneously a cooler - for medicines that need to be refrigerated
- Rubber band, tennis ball, inflatable pad
- An additional front wheel that can be attached to the wheelchair for less accessible terrain
- Suction cup handles that can be easily removed, transported and used in all bathroom environments
- Telescopic bed rail
- Aids for eating, such as folding cutlery, universal handles for cutlery, pens and other utensils, beakers with spout, sock threader, long-handled bath brush
- Swivel disc for moving from bed to wheelchair
- Universal wheelchair cover



# The top 3 challenging experiences that didn't stop me...

**...AND SHOULDN'T STOP YOU!**

## Challenge #1

Travellers with disabilities know that catching a train means using a ramp to get over the gap between the platform and the rails. New trains often have these built-in, older ones need them to be put in place. To avoid being left behind on the platform, talk with the station employees before you arrive so everything can be ready.



## Challenge #2

Wheelchair breakdown! It happens, whether it's the battery dying or a wheel breaking (which is something that happened to me in Paris!). If you have spare wheels, bring them to store in your hotel. But also search for mobility repair stores in your travel destination and save their details in case you run into trouble.

## Challenge #3

Accommodation surprises, the bad kind! They happen. Barrier-free doesn't always mean accessible. A hotel may have a ramp, but do their bathrooms have grabrails? Is the shower a walk-in with a seat? Is the toilet raised? It can be frustrating to find all this out when you arrive, so always phone ahead and explain your needs.

Sometimes things won't go right,  
but there's always a solution!

Breakdowns and accidents are a basic part of life. Don't let fear of obstacles stop you from experiencing something amazing. Whatever happens, it's manageable, and will make for a great story when you get back home!





# Set up and leave the stress at home

Stress is understandable for anyone travelling while disabled. But, to ensure you have the most relaxing, or exciting, time possible, here are some suggestions.

Advance planning can be key to avoiding stress. Discuss your trip with your doctor, and ask them for advice and recommendation on vaccinations, medications, and other health-related information tailored to your destination.

Consider asking them for a letter describing your health conditions, medications, and any potential complications, in case you need to seek medical care while adventuring.

You should also prepare a travel health kit with difficult-to-find items such as any prescriptions or over-the-counter medications. Depending on your destination, you may also want to pack insect repellent, hand sanitiser, and sunscreen, along with a health insurance card.



With a bit of advance planning, travelling will be even more enjoyable!

“ I spend my money on travel experiences. They mean everything to me. ”

## My World, My Way

1

Don't be afraid to ask for help from people, they're often ready to lend a hand.

2

Always check where the info points are when you reach your destination.

3

Social media can be a huge help to connect with people in the places you'd like to visit.

4

Don't forget to charge up your camera and to take spare batteries if you have a DSLR!

One of the best ways to remember your journeys is by journaling! Sometimes while travelling I'll spend my evenings writing about the day. Not only is this a beautiful memento for years to come, but it helps practice mindfulness, which is a great way to appreciate the good and accept the bad as it comes. I have been gripped by wanderlust for as long as I can remember – the urge to discover new countries and to get to know foreign cultures and people just bubbles up in me!



# Planning the next journey

***DON'T LET DISTANCE BE A BARRIER!***



While I make it a rule to never look too far ahead in the future, I can't help but research my next journey: TOKYO, JAPAN!

Tokyo is really the city that never sleeps, which is perfect if you're a night owl like me. It's a modern metropolis that fuses neon lights with ancient Shinto temples.



Thanks to wheelchair-friendly taxis and public transport systems, you can easily get across this vast city, visiting the Imperial Gardens in the morning, the famous Shinjuku district for lunch all in time for a boat ride on the Sumida River for dinner. It's all there waiting for you!

Far-off destinations can be daunting,  
but it's a modern world out there,  
and it's more accessible than before.  
Think big, do your research,  
and enjoy the world!

“ I'm living for the moment;  
I'm living for the now.  
What I dream about is  
where I'll travel to next. ”





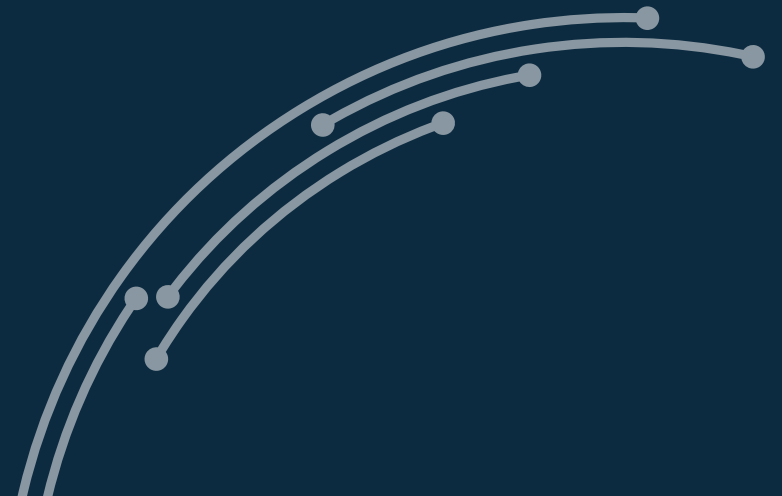


The first travel guide written by travellers with SMA, helping others turn disease journeys into unique travel experiences, and to see there are worlds worth fearlessly discovering.

These are the stories of the places they can go, the goals they can achieve and the barriers they overcome every day.

“ I am proud to be part of a project that aims to change the way to look at people with SMA. ”  
*Kim*

“ Don't let fear of obstacles stop you from experiencing something amazing. ”  
*Kim*







**TOGETHER  
IN SMA™**

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