

Podcast 'We Are Visible' Transcript

Dr. Bluestein Introduction

Karina:

Hi. Thanks so much for having me.

Dr. Bluestein:

When did you first hear of EDS?

Karina:

I first heard about EDS way back in around 2012 or so.

I accidentally stumbled upon the term while I was researching my severe neurological issues that had started in 2010.

In the end of 2010, I suddenly became severely ill and disabled and was diagnosed with cervical spine instabilities shortly after.

But it took another four years until I was diagnosed with EDS - again, accidentally.

Back then, I couldn't find any help for my neck instability in Germany. I had seen all sorts of specialists but nobody knew what was going on with me and others did not believe me.

So I decided to travel to the US. I saw a world renowned neurosurgeon. I didn't know that he also was an EDS specialist.

He then diagnosed me with EDS, dysautonomia, and mast cell activation.

This was the second time I heard of EDS but the first time someone actually explained to me what the condition really meant.

Dr. Bluestein:

You have written a lot about EDS (in both German and English) to spread awareness in some great places like the Mighty. What can you tell us about these projects?

Karina:

I got into journalism because writing was always a passion, but it became even more important after I got sick.

Before I became ill in 2010, I was a research associate. I worked in a German research lab that mainly published academic articles.

So I kind of had a research background and already knew medical terminology.

Then I got sick, and had all of sudden lost everything that had defined my life, like my job, my apartment, my financial independence and more.

I fell into a hole and for a while I didn't quite know who I was anymore.

Then I started to write. First, just to cope with my feelings.

Then, I began to combine my medical background with my personal experiences and published medical articles about EDS and related conditions, personal essays, I created a German blog, and all of a sudden, I was writing journalistic articles with a focus on medicine, science, chronic illness and disability.

Generally, Media representation of people with especially invisible disabilities is often not very accurate, and I wanted to change that. I felt that the best way to do this is by becoming a journalist that is affected by a chronic condition and disability herself.

I then applied for a journalism program and since 2018, I have been studying in a MA degree program in Edinburgh, Scotland. This program has completely transformed my life, because it gave me the tools to take on some great awareness projects, like my documentary about Ehlers-Danlos syndrome.

Dr. Bluestein:

Tell us about your journey to making the film, We are Visible.

Karina:

Ha, yeah, journey is the right word!

This film has probably been the toughest project I have ever taken on.

It started out as a small student project that was meant to be part of my MA thesis, but it became so much more.

When I received the letter from the university that I was allowed to take part in the program, I already knew I wanted to produce a documentary about EDS for my thesis.

I had never filmed in my life and had no idea about documentary filmmaking, but I knew this is what I needed to do, because film as a medium is

great to finally make our struggles visible for an audience that can't understand our invisible condition.

Overall, I worked on this film for 14 months and travelled to six different countries.

I filmed families with EDS in Germany, Malta, the UK, the US, the Netherlands, and Belgium.

I spend around four days with every family and we focussed on a specific challenge in each country.

All those families are one piece in a larger puzzle, which is the whole film in the end.

Dr. Bluestein:

What were the most challenging aspects of making the film?

Karina:

Honestly, there were more challenges than I could have ever imagined.

The first challenge was to find people that wanted to be involved in the film. I only had a limited amount of time, almost no funds, and restricted access to countries depending on my budget and my own health.

The next problem was logistics - like cancelled flights, taxis that didn't pick me up as planned, missed trains, disability services at airports not working out, and many more.

Or the physical limitations of myself but also of the people I filmed. For instance, one day, I couldn't walk much because I was in so much pain, so I used an office chair to move around one families living room and filmed like that.

Another time, one of the children I wanted to film throughout her daily routine became acutely sick with complications of EDS and had to go to the hospital. So we had to film there spontaneously.

Then there was the tight budget for the film. I didn't have any funding and paid everything out of pocket using my disability benefits.

And the exhaustion from filming has caused me to be in a pretty bad place physically at the moment.

And of course typical filmmaking challenges arise like ethical questions I had to consider, camera equipment spontaneously not working, events that didn't work as planned, and more.

So overall, there was always a problem to be fixed but I do not regret any second of it, because every one of the people I filmed gave me so much. I wouldn't change a thing if I could.

Dr. Bluestein:

What future plans do you have?

Karina:

My future plans for myself are to make more films about chronic illness and disability to teach the people around us more about these topics and also to improve representation of people with disabilities in media. Right now, I am not sure if I really can do this because my body isn't in agreement with the physical strain of filming.

I also want to produce more multi-media stories in German and English that combine the patient's perspective with educational content based on recent studies. And a big dream of mine is to get my work published by the New Yorker and to win a journalism award!

Other than that, I don't really know where my journey leads me. After my Master's, I want to take a bit of a break and try to recover from the last months. Then I might look into the possibility to get into a disability studies PhD program since this seems to combine my research background with my personal experiences quite well. And it would be a good position to gain some important background knowledge as an advocate for the community.

In terms of the film, I hope to get it into a film festival in 2020. It has won some small prizes but I would love to actually win a film festival competition. I also hope the film is going to be shown all around the world. We are in the process of setting up screenings in several countries at the moment,

and by the end of the 2020, the film should be on a video on demand platform too, so everyone can access it.

Dr. Bluestein:

Where can people find out about future showings of the film and more projects you are working on?

Karina:

People can find out more about the film and all the events we are planning on the film's official website

www.we-are-visible-film.com

(All with dashes)

We actually have a larger screening in Orange, California in January and some smaller screenings Northern California, Boulder, Colorado, and two in Netherlands and some more.

It is also on IMDb.

My journalistic work, my film, and all my ongoing projects, I share on a bilingual website:

www.karina-sturm.com

Or on my Facebook page @KarinaSturm86 or Twitter @KarinaSturm

I also have a German Blog where I talk about my life with EDS and a couple of other social media accounts which are all linked from my websites.