

MEN2B and Me: Kristina

Multiple endocrine neoplasia type 2B (MEN2B) is a genetic disease in which more than one endocrine gland forms a tumour that can make too much hormone.

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“No one explained MEN2B to me and I just felt really negative about the whole experience, even as a patient there was no information being given to me.”

Kristina

Well, at nine days old I had bowel problems. My whole large bowel was removed, and then, at two and a half I was diagnosed with medullary thyroid cancer, so they put two and two together and they came up with this multiple endocrine neoplasia type 2B. So, without that early diagnosis at two and a half, I probably wouldn't be here right now.

They removed my thyroid completely so that it didn't spread to various other parts of my body. With the early diagnosis they were able to remove it and help me in my early days to have as much as a normal life as possible, as such.

I've had blepharitis and I'm recovering from malignant melanoma. I have thyroid issues and have got an upper GI issue with GERD. I've got a stomach issue where I had my large bowel removed. I have bone and joint pain and I suffer with fatigue. There's always something to look at. There's always something to get checked.

There's never been a whole complete year where there's not been something to worry about. It's tiring but I suppose as you get older it gets easier in some cases. Recently I've had my adrenalectomy on my right hand side. That was quite difficult for me because it was my first major operation that I had since my malignant melanoma on my face in 2008. So it's quite a lot to take in when you just think that things have just calmed down, and then it's something else that crops up so you're always adapting to what's coming at you.

Growing up, having such a rare disorder, I did grow up thinking I was the only one with it. There wasn't any information out there. We was all on our own, so we only had the support of each other.

“It was only recently that I found out about AMEND, and now I know that there are others just like me.”

It makes me feel quite lucky to have found AMEND who's offering this support and help that I need. 'Cos I think back to say a year ago when I didn't even know that AMEND was around, feeling I was so alone in this, that you know the doctors don't quite know how to deal with me. I don't know how to deal with myself; what am I looking for? And I am now happy to say that I'm hopefully going to get the right care that I deserve. Especially who will now know about my condition, so I'll get the best care now and not just be a guessing game. To have someone

now out there who knows a bit about my condition. The support is really quite fundamental to how things will now progress in the future for me.

Edna (Kristina's mum)

The doctors said that they didn't expect her to live past the age of five because she was such a poorly baby. They just didn't know and they just thought that she probably wouldn't get to school age. She's exceeded all the expectations of what the have hospitals said that, she wouldn't make it this far. She's proved them all wrong and we're very proud of her.

End

AMEND provides support to patients and their families and friends. Providing information and promoting a wider knowledge of MEN among the medical profession to assist in early and accurate diagnosis, and assisting in future MEN research.

We are here to break the isolation so often felt by those with these rare diseases.

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