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Speaker bio



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My name is Ellen Vrieze, just turned 40 years, married and mom of three children. Living in the Netherlands. Our medical journey starts when our second child is born, way too early.

In his first year his medical condition is pretty worse, but no doctor can find anything that causes the problems. Before he turns two our third child, a girl, is born. She walks almost the same medical path and the doctors also have concerns about her health issues.

After all, it will take another 4 years before the doctors finally take my concerns for real and start more research. After 5 years we have a diagnosis, and through DNA research we found out that our 2 children, as well myself, have a very rare genetic disease which involves kidneys, pancreas, lungs, liver and intestines.

It has been a bumpy road the last 10 years. Every time we think we know everything or find a solution, something new pops up. But it's so joyful to join and share our knowledge within the patient needs.