



Jose Verstegen

21 years ago Jose and 3 of her 4 (now adult) children were diagnosed with CVID. This made her experience what it is like to live with an immune disorder and how it is growing up with one. Uniquely, in both the role as a mother of a patient and in the role of a patient herself. For over 17 years, she has been a board member of the Immune Diseases Foundation (SAS) and is actively involved in various SAS activities and projects. As of January 2021, she has been proudly chairing the Immune Diseases Foundation of the Netherlands.

The impact of a PID on their family, like the process of diagnosis, research, and acceptance, each in their own way, has been her main motivator to actively work in the Foundation. By offering everyone who has been involved with a PID in their life somehow, being a mom, sister, or brother of a patient or a patient itself, a place to volunteer in the foundation to meet their needs. In her opinion, it is very important to give the patient a voice, and to share the impact of an immune disorder, which leads to more recognition worldwide. By connecting all this knowledge and experience together they keep learning and working together with specialists, researchers, policymakers, and politicians on better care for a patient and a brighter future.

In 2016 she participated in the Patient Ambassador program and took on the opportunity to collaborate with patients from other countries where they learned how to share their personal story. By sharing her personal story at conferences and on



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various media channels, we can put a face to the impact of a PID. With this, she hopes to reach other patients and their families, to strengthen their voice and the overall voice of the patient. The Patient Ambassador program is a great program that she is also committed to in addition to the Immune Diseases Foundation of the Netherlands. Together we can create more awareness and take that extra step that is needed. A home for experiences, perceptions, and future for people with an immune disorder PID.

In addition to all these activities, she also works as a freelance designer, and she is a caregiver for her great-uncle and aunt. As it is clearly a passion to volunteer, she also volunteers at other organisations or associations next to the Immune Diseases Foundation of the Netherlands.

Her motto is ' Life isn't about waiting for the storm to pass – it's about learning how to dance in the rain....'