

Name: Marou Schenk

Age: 26

Country: Netherlands

Name of the Organization

EGAN/FSIGN

About my Organization:

- EGAN is an alliance for organizations with a special interest in genetics, genomics and biotechnology.
- EGAN is working for a voice in research and health policy.
- EGAN is working from the patient perspective on biomedical research and therapy development.
- FSIGN is a Dutch organization that's specific for patients with Fabry's disease
- FSIGN is mostly working on peer support

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About me:

My name is Marlou Schenk, I am one of the founding members of the EPF youth group. I have a disease that's called 'Fabry'. My disease is pretty rare, I was searching for a group that could help me overcome the things I didn't like about my life. My mother was at that time vice president of FIN a international organization for Fabry. She met someone from EPF and that's how I became part of the youth group in 2011(?). I really like to make people aware of things in life in general.