

Speaker Bio



Stephanie Ernst

TAPS Nerd, Charity Founder
& Raconteuse.



stephanieernst.nl



tapssupportfoundation.com

Speaking Topics: Building Rare Disease Communities, Monochorionic Twins, Twin Anemia Polycythemia Sequence, Patient Advocacy, Raising Twins and Amusing Placenta Stories.

About:

Stephanie Ernst is an Australian-born, Dutch by choice writer, speaker and patient advocate living in the Netherlands. Her daughters are the faces of Twin Anemia Polycythemia Sequence, born at 31 weeks with this rare disease. She draws on her own experience at the challenges of raising rare twins, challenging the system to get them long-term care, and living with a rare disease diagnosis to raise awareness of twin complications. Her passion lies within myth busting twin complications, building recognized rare disease communities, and continuing essential research into the complications faced by multiple birth parents worldwide.

She works as a freelance writer and content curator for several companies, and loves her kids, her husband, and coffee equally. In her spare time, she takes naps and writes the occasional research paper.

Find me online



www.stephanieernst.nl

Phone: +31629841203
(Amsterdam, CET)

Email: stephanie@stephanieernst.nl

Pronouns: She/Her