



Stephanie Ernst

TAPS Nerd | Speaker | Writer |
Twinfluencer | Content Marketing

Speaking Topics

- Multiple births and the Neonatal Unit - what are the considerations?
- Creating online communities
- Patient-centric research and advocacy groups
- Patient perspective on a rare disease diagnosis (multiple births)
- Parenting twins
- Communication with patients and patient organisations

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About

Stephanie Ernst is an Australian-born, Dutch-by-choice writer, speaker, and patient advocate, living in the Netherlands.

Her daughters, born at 31 weeks, are the faces of Twin Anemia Polycythemia Sequence (TAPS). After struggling to find quality information on TAPS, Stephanie created a Facebook community that evolved into the charity TAPS Support.

Her aim is to promote research into the complications of monochorionic twins, raise funds for research projects, and support future researchers. She emphasizes the importance of parents being active members of their care teams by providing clear, accessible information and breaking down medical jargon.

Stephanie actively publishes research with other TTTS mothers, and frequently writes and speaks on twin-related topics. She works in marketing for companies involved in clinical research, training, and coaching. In her spare time, she enjoys spending time with her twins and patient husband, drinking coffee, and occasionally indulging in a G&T.

Stephanie's passion for myth-busting twin complications and building rare disease communities drives her continued advocacy and research efforts.