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LATEST NEWS AND ACTIVITIES



Merry Christmas and a Happy 2026!

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Members conference 2025, 24-26 October

Some remarks of the participants: "The members' conference was an inspiring experience. The combination of in-depth content, open conversations, and a warm atmosphere made it a valuable gathering."

"I gained new insights and feel strengthened in my role as a parent. Thanks to the organisers! It was once again wonderful to meet all the other families and enjoy a fun weekend together. Excellent content sessions, with relevant topics presented by expert professionals. Very valuable!"

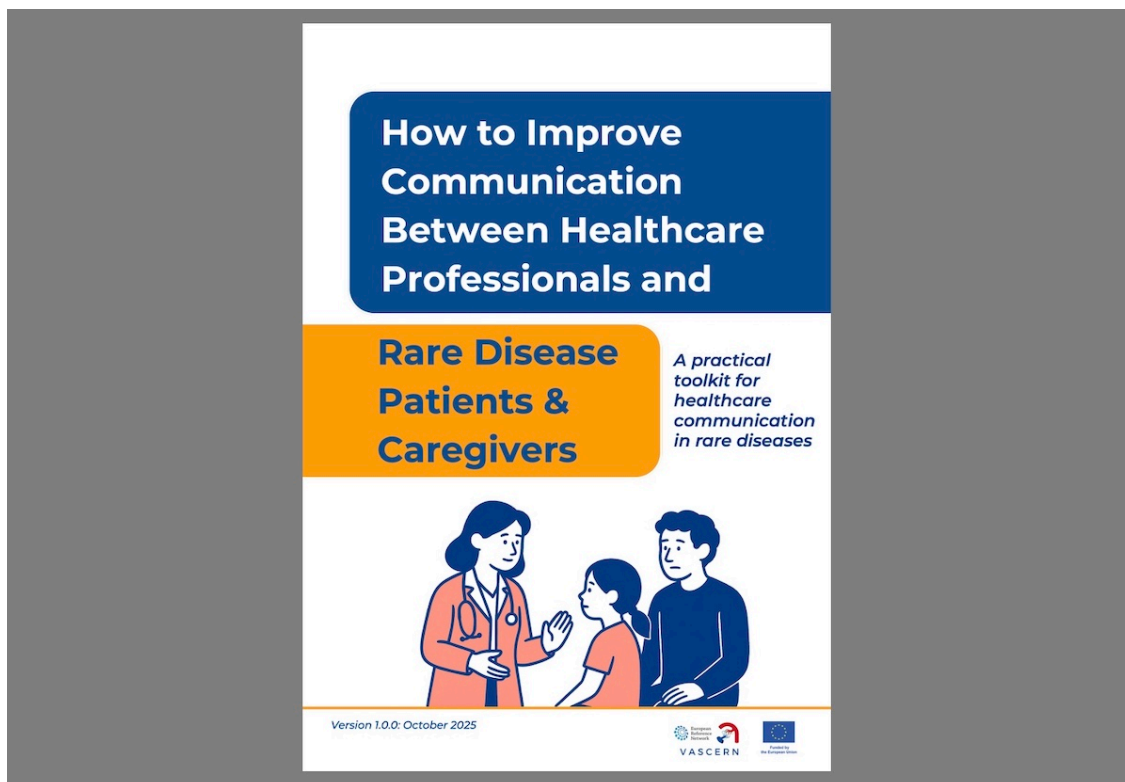
[Read the report](#)



Two new board members and a social media specialist!

expand our support for the patient community. From left to right: Tari de Jong- Secretary, Erik Kloosterman- Treasurer, Mirjam Puijs-Social Media specialist.

[Read more](#)



A practical toolkit for healthcare communication in rare diseases

Good communication, especially about difficult topics such as serious illness and death, can increase trust and strengthen the bond between people in the roles of patient, caregiver, and healthcare professional. The Transversal Psychology Working Group of ERN VASCERN, of which we are also a member, has therefore developed a brochure to improve communication between healthcare professionals and patients and caregivers. Here is the result. Feedback and suggestions for further improvements are welcome.

[Read more about the booklet](#)

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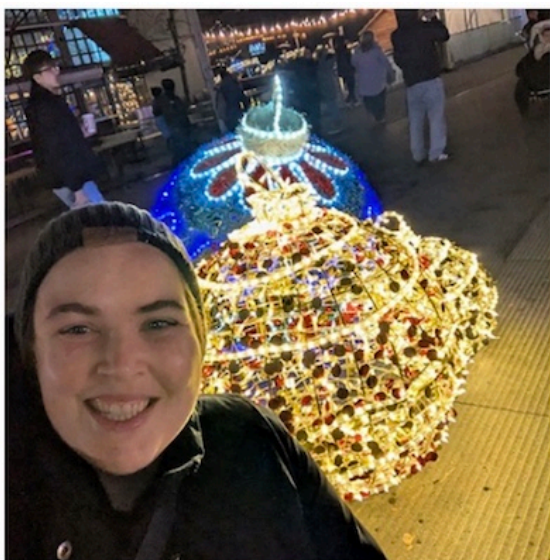
Activities 2026

[Family day Efteling: 4 July 2026](#)

[Family weekend: 23-24 May 2026](#)

[Members Conference: 6-8 November 2026](#)

Don't forget to put these dates in your calendar!



Blogs Katie Allen and Arianna Faro 2025

Read the blogs of Katie Allen (Canada) and Arianna Faro (USA).

[Blog Katie Allen \(Dec 2025\)](#)

[Blog Arianna Faro \(Aug 2025\)](#)



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