

Rare Disease Day 2021, Sunday 28 February (12:00 to 2:00 pm)

Stargardt's Connected Community Meeting on Zoom

Register: <https://us02web.zoom.us/meeting/register/tZEIfuqvz4iEtImXpJIRfFi1w4KaBAmJdWA>

Agenda	
12:00 – 12:15 pm	Welcome Introduction to Rare Disease Day by Bhavna Tailor - Chief Executive, Stargardt's Connected
12:15 – 12:25 pm	UK Strategy for Rare Diseases Introduction to the UK Governments new strategy for rare diseases by Toby Evans - Trustee, Stargardt's Connected
12:30 – 12:50 pm	Time to Focus – Fight for Sight Overview of the Time to Focus report on the personal impact and other costs of sight loss by Tori Griffiths – Philanthropy and Partnership Manager, Fight for Sight
12:50 – 1:00 pm	Letter writing campaign Campaign to call for more Government support for research into Stargardt's disease by Rea Mattocks - Trustee, Stargardt's Connected
1:00 – 1:10 pm	Break
1:10 – 1:55 pm	Small group chats Breakout into small groups to meet other Stargardters from around the world - facilitated by Andi Skilton – Trustee, Stargardt's Connected
1:55 – 2:00 pm	Goodbye By Bhavna Tailor - Chief Executive, Stargardt's Connected