



Retina International CEP 2021 Agenda

Zoom registration Link: https://zoom.us/webinar/register/WN_xJmaoUC-Rr6xOQDOO-44xQ

Theme: Working to meet the challenge - taking action in a COVID-19 world

Subthemes:

- Innovations for engagement: Adapting the delivery of a service or initiative you provided during the COVID-19 restrictions
- Advocacy and local policy actions: Describing an advocacy campaign or policy action your organisation has been involved in during the COVID-19 pandemic.

Goals:

- To provide insights into RI activities and projects
- To share activities and initiatives with the RI membership.
- To provide a platform for members to share experience and learnings with each other.

June 24th 14:00 to 16:00 CET

14:00 Welcome & Introduction – Ms. Avril Daly, CEO

14:10 Keynote: UN Resolution for Rare Diseases – Clara Hervas, Rare Disease International

14: 25 Genetic Testing Landscape Study – Dr. Petia Stratieva, Special Projects Manager

14.40 RI Governance– Ms. Avril Daly, CEO

14: 45 Retina International Youth Council – Mrs. Marina Sutter-Penz, Interim Chair of Retina International Youth Council

14:55 Break

15:10 RI Education Hub – Ms Fiona Waters, Community Engagement & Outreach Officer

15: 25 Communications – Mr. Sean Heagney, Communications Officer

15.40 RI Data Studies – Dr. Orla Galvin, Director of Research Policy



15:55 Closing Remarks – Mr. Franz Badura, Chairperson of Retina International

June 25th 14:00 to 16:00 CET

14:00 Welcome

14:10 Swedish RP Association: Digital meetings for discussion and socializing – giving room for more people to participate - Therese Eriksson

14:25 Retina South Africa: An App a day - Claudette Medefindt
Success of Virtual Outreach project - Karen Denton

14:40 Retina Brasil: Advocacy actions during 2020: Access to treatments - Maria Antonieta Leopoldi

14:55 Break

15:10 JPRS (Japan): JPRS Youth and their activities during COVID-19 - Takayuki Nishikawa

15:25 Fighting Blindness Canada: ApproveLuxturna Advocacy Campaign – Doug Earle
Facebook Patient Education Programme- Doug Earle

15:40 Open Floor

15:55 Closing remarks