



## **Retina International World Congress 2022**

Session labelling: K= Keynote – L= Lay - P = Professional.

Location: K= Norðurljós – L= Edition – P = Norðurljós

### **Thursday 9th June**

17:00 – 19:00 NOK and RIWC Opening ceremony @ Eldborg Harpa

**The President of Iceland, Mr. Guðni Th. Jóhannesson, will open the congress**

#### **K.1.1 Keynote: Phenotyping and Genotyping in inherited retinal diseases.**

Speaker: Professor dr. Bart Leroy, University of Ghent, Gent, Belgium

Speaker: Dr. Kári Stefánsson, Founder and CEO of deCODE genetics

### **Friday 10th June**

#### **08:30 – 10:00 P.2.1 Age related macular Degeneration.**

Moderators: Dr. Jóhann Ragnar Guðmundsson and Teresa Sandhina F.R.C.S.Ed, MD. St. Pauls Eye University, Liverpool England

08:30 - 08:50

The socioeconomic impact of GA and wAMD in Bulgaria, Germany and the United States

Speaker: Nabin Paudel, Retinal International

08:50 - 09:05 AMD research at Oslo University Hospital: from LUCAS to compounding pharmacy and beyond

Speaker: Professor dr. Morten Carstens Moe, Oslo University Hospital, Oslo, Norway

09:05 - 09:15 Off-label use of Avastin: Scandinavian disparities

Speaker: Tomas Bro, MD, PhD, Högländssjukhuset, Eksjö, Sweden

09:15 - 09:25 The risk of extending AMD treatment

Speaker: David Epstein, MD, PhD. Sankt Erik Eye Hospital, Karolinska Institute, Stockholm, Sweden

09:25 - 09:35 The Swedish Macula Register

Speaker: Inger Westborg, MD, PhD. Uppsala University Hospital, Uppsala, Sweden

09:35 - 09:50 AMD Epidemiology. Genetics & Associated Serum Proteins.

Ocular, Systemic & Lifestyle Risks

Speaker: Professor emeritus dr. Friðbert Jónasson, University of Iceland, Iceland

09:50 - 10:00 QnA

**08:30 – 10:00 L.2.1 Retinal degenerations. Clinical aspects**

Moderator: Professor dr. Elise Heon, The Hospital for Sick Children, Toronto, Canada

08:30 – 08:50 Clinical aspects of IRD

Speaker: Professor dr. Elise Heon. The Hospital for Sick Children, Toronto, Canada

08:50 - 09:10 Clinical aspects of inherited macular degenerations

Speaker: Associated professor dr. Line Kessel, Department of Ophthalmology, Rigshospitalet, Copenhagen, Denmark

09:10 – 09:30 Syndromic forms of IRD

Speaker: Professor dr. Hélène Dollfus, CARGO, Hôpitaux Universitaires de Strasbourg, France

09:30 - 09:50 The genetic testing landscape

Speaker: Fiona Waters, Retina International, Dublin, Ireland

09:50 – 10:00 QnA

**10:00 – 10:30 Coffee break.**

**10:30 – 11:30 P.2.2 Assessment of Endpoints in clinical studies**

Moderators Associate professor dr. Cecilie Bredrup, Bergen, Norway and Professor dr. Sten Kjellström, Lund, Sweden

10:30 – 10:50 Experiences with Luxturna

Speaker: Associate professor dr. Line Kessel, Department of Ophthalmology, Rigshospitalet, Glostrup, Denmark

10:50 – 11:10 Paediatric specificities in trials

Speaker: Professor dr. Elise Heon, MD, The Hospital for Sick Children, Toronto, Canada

11:10 – 11:30 Developing Patient Relevant Outcomes in Gene Therapy Trials: The Novel Functional Vision Endpoint, the Multi-luminance Mobility Test (MLMT)

Speaker: Dr. Daniel Chung, DO, MA, Philadelphia, USA

**10:30 – 11:30 L.2.2 Retinal degenerations - the genetics**

Moderator: Professor dr. Jón Jóhannes Jónsson, National University Hospital, Reykjavík, Iceland

10:30 – 10:50 Pattern of inheritance - easy to understand

Speaker: Dr. Eirný Þórólfsdóttir, National University Hospital, Reykjavík, Iceland

10:50 – 11:10 Understanding the results - a difficult task

Speaker: Professor dr. Jón Jóhannes Jónsson, National University Hospital, Reykjavík, Iceland

11:10 – 11:20 Lessons from Iceland on the diversity of genetic causes

Speaker: Daníel Þorsteinsson

11:20 – 11:30 ABCA4 related IRDs

Speaker: Professor dr. Frans Cremers, Radboud University, Nijmegen, Netherlands

**11:30 – 12:00 K.2.1 Keynote: Stem cell therapy for retinal regenerative diseases**

Speaker: Dr. Masayo Takahashi, Vision Care Inc., Kobe, Japan

**12:15 – 13:30 Lunch symposia: Retina International Network of Partners Meeting**

Moderator: Jason Menzo, President and COO, Foundation Fighting Blindness, USA

12.15 Welcome – Mr. Franz Badura, Chair, Retina International

12.20 Patient Public Involvement in research life cycle: Concept to Delivery – Ms. Avril Daly, CEO, Retina International

12:25\* Understanding the Economic Burden and Societal impact of AMD/GA - Dr. Nabin Paudel, Research and Innovation Manager, Retina International

12:40\* IRDs - Counting the Cost Understanding the Impact – Ms. Fiona Waters, Education and Engagement Manager, Retina International

12:55\* Challenges of Outcome Measures in Retinal Degeneration – Prof. Dr. Elise Heon, The Hospital for Sick Children, Toronto, Canada

13:10 Closing remarks - Martin Smedstad, Oslo, Norway

\* This session includes 5 minutes for Q&A

**13:30 – 14:00 K.2.2**

**Keynote: Scientific results, a rollercoaster between hope and deception**

Speaker: Christina Fasser, former president of the Retina International, Zurich, Switzerland

**14:00 – 15:00 P.2.3 Phenotype-Genotype Correlations in IRD**

Moderators: Josephine Prener Holtan MD, PhD, Oslo University Hospital, Oslo, Norway, and Professor dr. Bart Leroy, Ghent, Belgium

14.00 - 14.10 Natural history and clinical characterization of patients with retinitis pigmentosa caused by mutations in the PRPF31 gene

Speaker: Kristian Lisbjerg, MD, PhD student, Department of Ophthalmology, Copenhagen University Hospital, Denmark

14.10 - 14.20 Genetic basis and phenotypic characterization of Danish patients with Achromatopsia

Speaker: Mette K.G. Andersen, MD, Department of Ophthalmology, Copenhagen University hospital, Rigshospitalet-Glostrup, Denmark

14.20 - 14.35 Whole exome sequencing in the diagnosis of hereditary retinal disorders: A clinical perspective

Speaker: Ragnhild Wivestad Jansson, MD, PhD, Department of Ophthalmology, Haukeland University Hospital, Norway

14.35 - 15.00 ERN-EYE a booster for patients care and research for Rare Eye Diseases in Europe.

Speaker: Professor dr. Helene Dollfuss, Service de Génétique Médicale, Hôpital de Hautepierre, Strasbourg, France

**14:00 – 15:00 L.2.3 Basics of stem cell and gene-based therapies**

Moderator: Professor dr. Kapil Bharti. National Eye Institute, Bethesda, USA

14:00 - 14:20 Overview of on-going clinical trials with stem cells

Speaker: Professor dr. Goran Petrovski

14:20 – 14:35 Stem Cell Based Trials for AMD

Speaker: Professor dr. Kapil Bharti. National Eye Institute, Bethesda, USA

14:35 – 14:50 Clinical trial in opto-genetics

Speaker: Professor dr. Isabelle Audo, INSERM, Paris, France

14:50 – 15:00 How to identify real treatments and good clinical trials as a patient  
Speaker: Martin Smedstad, The Retinitis Pigmentosa Association, Oslo, Norway

**15:00 – 15:30 Coffee break.**

**15:30 – 16:00 K.2.3**

**Keynote: Restoration of vision**

Speaker: Professor dr. Mark S. Humayun. University of Southern California, Los Angeles, USA

**16:00 – 17:00 P.2.4. Innovations in Ophthalmology.**

Moderators: Christina Fasser, Retinal International, and Professor dr. Einar Stefánsson. University of Iceland, Iceland

16:00-16:15 Agnostic gene therapy approaches

Speaker: Dr. Daniel Chung, DO, MA, Philadelphia, USA

16:15-16:30 Eye drops with solubilizing nanoparticle technology in the treatment of Diabetic Macular Edema

Speaker: Þorsteinn Loftsson. University of Iceland, Oculis SA Reykjavik, Iceland

16:30-16:45 The RD Fund, Innovation in Venture Philanthropy

Speaker: Jason Menzo – President and Chief Operating Officer, Foundation Fighting Blindness USA

16:45-17:00 Optogenetics:Next generation strategy for advanced retinal diseases

Speaker: Kamron Khan, Novartis

**16:00 – 17:00 L.2.4 Service and coping with Low Vision**

Moderators: Vala Jóna Garðarsdóttir, National Institute for the blind in Iceland and Rósa María Hjörvar, PhD student, University of Iceland

16:00 - 16:15 National Institute for the blind and visually impaired in Iceland

Speakers: Elva Dögg Jóhannesdóttir Ophthalmologist and Vala Jóna Garðarsdóttir O&M.

16:15 – 16:30 Reading with auxiliary aids

Speaker: Rósa María Hjörvar. PhD student in Literature at the University of Iceland

16:30-16:45 The assistive technology, apps etc.

Speakers: Baldur Snær Sigurðsson and Hlynur Þór Agnarsson

16:45 - 17:00 Coping with visual impairment in live and work

Speakers: Halla Dís Hallfreðsdóttir and Elín Yr Hafdísardóttir Arnardóttir

### **Saturday 11th June.**

#### **08:30–10:00 P.3.1 New Developments in IRD.**

Moderator: Professor dr. Michael Larsen

08:30-08:50 Accessing Genetic Testing for IRDs: The Patient Perspective.

Speaker: Fiona Waters, Retina International, Dublin, Ireland

08:50-09:10 ABCA4 retinal dystrophies

Speaker: Professor dr. Frans Cremers, Radboud University, Nijmegen, Netherlands

09:10- 09:30 PERCEIVE study report: Real-world safety and effectiveness of voretigene neparvovec AND Evaluating a new questionnaire to assess symptoms in RP and LCA

Speaker: Professor dr. Dominik Fischer, Oxford Eye Hospital, University of Oxford, Oxford, United Kingdom

09:30-10:00 Medical therapies in IRD

Speaker: Professor dr. Robert Koeneke, Montreal Childrens Hospital, Montreal, Canada

#### **08:30-10:00 L.3.1 Clinical trials and therapies from a patient's perspective**

Moderator: Martin Smedstad, Oslo, Norway

08:30 – 08:50 Overview and future on on-going clinical trials

Speaker Professor dr. Elise Heon, MD, The Hospital for Sick Children, Toronto, Canada

08:50 – 09:10 RPE65 - the first gene therapy on the market

Speaker: Associate professor dr. Line Kessel, Glostrup, Copenhagen, Denmark

09:10 – 09:30 Oligonucleotides - a hope for all?

Speaker: Professor dr. Bart Leroy, Gent University, Ghent, Belgium

09:30 – 09:50 My personal experience of gene therapy

Speaker: Camilla Jensen, Oslo, Norway

**10:00 – 10.30 Coffee break.**

**10:30 – 12:00 P.3.2 Stem cells and cell-based therapies of retinal diseases.**

Moderator professor dr. Goran Petrovski, Oslo, Norway

10:30 - 12:00 P.3.2 Stem cells and cell-based therapies of retinal diseases

Moderator Dr. Goran Petrovski, Oslo, Norway

10:30 - 10:50 Initiating a Phase I/IIa clinical trial for an autologous iPS cell therapy for macular degeneration: from bench-to-bedside

Speaker: Dr Kapil Bharti (NIH/NEI), Bethesda, USA

10:50 - 11:10 Towards stem cell-based therapy in retinal degeneration.

Speaker: Professor Dr. Anders Kvanta, Stockholm, Sweden

11:10 - 11:30 Genetically corrected iPS-derived RPE cells for cell therapy of hereditary retinal dystrophy.

Speaker: Dr. Slaven Erceg, Valencia, Spain

11:30 - 11:50 Subretinal implantation of primary human RPE cells in minipig eyes.

Speaker: Professor Dr. Goran Petrovski, Oslo, Norway

11:50 - 12:00 Retinal repair by autologous transplantation.

Speaker: Docent Dr. Xhevat Lumi

**10:30 - 12:00 L 3.2 Retina International - the global challenges**

**Global Genetic Testing Landscape**

Moderator: Fiona Waters, Retina International, Ireland

10:30 – 11:15 Impact of age related retinal diseases on society, and calls to action

Speaker: Nabin Paudel, RI, Ireland

Panel Discussion – TBC

11:15 – 12:00 Genetic Testing Landscape – a global policy action to support equitable access.

Speaker: Avril Daly, Retina International, Ireland

Panel Discussion - TBC

**12:00 - 13:00 Lunch.**

**12:30 – 13:00 Poster viewing** - In the area between Norðurljós and Eldborg

**13:00 – 14:00 K.3.1 Keynote: Gene based therapies of retinal diseases**

Speaker: Professor dr. Artur Cideciyan, University of Pennsylvania, Philadelphia, USA

**14:00 – 15:00 P.3.3 Gene based therapies of retinal diseases**

Moderator: Eeva-Marja Sankila, MD, PhD, Helsinki University Hospital, Helsinki, Finland

14:00 – 14:15 CPK850 gene therapy in RLPB1 patients

Speaker: Professor dr. Anders Kvanta, Karolinska Institute, Stockholm, Sweden

14:15 – 14:30 Gene therapy of Choroideraemia and X-linked retinitis pigmentosa -  
Lessons to be learned

Speaker: Professor dr. Robert Koenekoop, Montreal Childrens Hospital, Montreal,  
Canada

14:30 – 14:45 Retinal gene therapy in choroideremia patients - surgical aspects.

Speaker: Professor dr. Ilkka Immonen, Helsinki University Hospital, Helsinki, Finland.

14:45 – 15:00 Gene therapy of Usher syndrome.

Speaker: Professor dr. Isabelle Audo, Institute de la Vision, Paris, France.

**14:00 - 15:00 L.3.4 Programme in Icelandic for the public.**

Stjórnandi: Sigbór U. Hallfreðsson, Félag blindra og sjónskertra, Íslandi

14:00-14:20 Hvað er efst á baugi í rannsóknum og meðferð arfgengra  
sjónhimnusjúkdóma?

Prófessor dr. Ragnheiður Bragadóttir, Oslo universitetssykehus, Osló, Noregi

14:20-14:40 Greining og skráning arfgengra sjónhimnusjúkdóma á Íslandi

Prófessor dr. Jón Jóhannes Jónsson, Landspítalinn, Reykjavík

14:40-15:00 Hvernig getum við með arfgenga sjónhimnusjúkdóma verið með í  
rannsóknum?

Helgi Hjörvar, Félag blindra og sjónskertra, Íslandi

15:00- 15:15 Þjónusta við blinda og sjónskerta á Íslandi: Notendur á Sjónstöð og  
algengustu orsakir sjónskerðingar.

Speaker: Elva Dögg Jóhannesdóttir





**15:30 GRAND FINALE AND FUTURE STEPS @ SILFURBERG**

Speaker: Professor dr. Bart Leroy, University of Ghent, Gent, Belgium Speaker:  
Professor dr. Einar Stefánsson, University of Iceland, Iceland

Introduction of NOK2024