



## **Retina International World Congress 2020 - Preliminary sessions program.**

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

### **Thursday 4th June**

17:00 – 19:00 Welcoming ceremony

17:30 18:30 **K.1.1.Key note: The development of a bioelectronic implant for sight restoration for retinal degenerations.**

Prof. Mark S. Humayun University of Southern California ,Los Angeles, USA

### **Friday 5th June**

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

Moderator: Dr. Øystein Kalsnes Jørstad, Oslo University

08:30 - 08:50: A systems level investigation on AMD: Insights from the European EYE-RISK project

Speaker: Professor Marius Ueffing, Centre for Ophthalmology, University Medical Center, Tuebingen, Germany

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

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

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

Speaker: Tomas Bro, MD, PhD, Höglandssjukhuset, 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 and Genetics. What is important!

Speaker: Prof. emeritus Friðbert Jónasson, University of Iceland, Iceland:

09:50 - 10:00: QnA

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

Moderator: Dr. Prof. Elise Heon, The Hospital for Sick Children, Toronto, Canada.



08:30 – 08:50: Clinical aspects of IRD

Speaker: Prof. Dr. Elise Heon The Hospital for Sick Children, Toronto, Canada

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

Speaker: Dr. Line Kessel, Department of Ophthalmology, Rigshospitalet, Copenhagen, Denmark.

09:10 - 09:30 Usher syndrome and similar syndromic forms of IRD.

Speaker: prof. Dr. H el ene Dollfus, CARGO, H opitaux Universitaires de Strasbourg, France

09:30 - 09:50: The socio-economic impact of IRDs

Speaker: Dr. Orla Galvin, 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 Dr. Cecilie Bredrup, Bergen, Norway and Prof. Sten Kjellstr om, Lund, Sweden.

10:30 – 10:50: How to measure the effects of gene therapy on meaningful vision for patients

Speaker: Prof. Michael Larsen Department of Ophthalmology, Rigshospitalet, Copenhagen, Denmark:

10:50 – 11:10 Paediatric specificities in trials

Speaker: Prof. 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, Spark Therapeutics, Philadelphia, USA

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

Moderator: Prof. J on J ohannes J onsson, national University Hospital, Reykjav ik, Iceland.

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

Speaker: Dr. Eirn y P or lfsd ttir National University Hospital, Reykjav ik, Iceland.



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

Speaker: Prof. Jón Johannes 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: Accessing Genetic Testing for IRDs: The Patient Perspective.

Speaker: Avril Daly, Retina International, Dublin, Ireland

**11:30 – 12:00 K.2.1 Keynote: Scientific results, a rollercoaster between hope and deception**

Speaker: Christina Fasser, president of Retina International, Zurich (Switzerland)

**12:00 – 13:30 Lunch**

**13:30 – 14:00 K.2.2 Keynote: Phenotyping and Genotyping in inherited retinal diseases.**

Speaker: Prof. Bart Leroy, University of Ghent, Ghent, Belgium

**14:00–15:00 P.2.3 Phenotyping and Genotyping in IRD.**

Moderators: Josephine Prener Holtan MD, Oslo University Hospital, Oslo, Norway, and Prof. 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: Dr. Kristian Lisbjerg, Copenhagen University Hospital, Denmark

14:10 – 14:20: Genetic basis and phenotypic characterization of Danish patients with Achromatopsia. Speaker: Dr. Mette K.G. Andersen, Copenhagen University Hospital, Rigshospitalet-Glostrup, Copenhagen, Denmark

14:20 – 14:30 Whole exome sequencing in the diagnosis of hereditary retinal disorders: A clinical perspective

Speaker: Prof. Ragnhild janson Wives tad, Hauk eland University Hospital, Norway

14:30 – 14:50 ERN-EYE a booster for patients care and research for Rare Eye Diseases in Europe

Speaker: prof. Dr. Hélène Dollfus, CARGO, Hôpitaux Universitaires de Strasbourg, France:

14:50 – 15:00 QnA



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

Moderator: Prof. Kapil Bharti. National Eye Institute, Bethesda, USA

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

Speaker: Prof. Goran Petrovski

14:20 – 14:35 Stem cell trial on Retinitis pigmentosa.

Speaker: Prof. Kapil Bharti. National Eye Institute, Bethesda, USA

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

Speaker: Prof. Isabelle Audo, INSERM, Paris, France

14:50 – 15:00 How to discriminate between real treatments offers and quacks.

Speaker: Martin Smedstad Oslo, Norway.

**15:00 – 15:30 Coffee break.**

**15:30 – 16:00 K.2.3 Keynote: Innovations in Ophthalmology.**

Prof. Eugene De Juan University of California, San Francisco, USA.

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

Moderators: Christina Fasser and Prof. Einar Stefánsson.

Speakers: Dr. Sabri Markabi, MD Senior vice president of Research and Development and Chief Medical Officer of Alcon Laboratories, Inc., a subsidiary of Alcon, Inc., the world's largest eye care company. Prof. Einar Stefánsson, , National University Hospital in Iceland. Kathrine A. High, Emeritus co-founder, president and chief scientific officer of Spark. To be confirmed.

**16:00 – 17:00 L.2.4 Rehabilitation and mobility training.**

Moderators: Vala Jóna Garðarsdóttir and Rosa María Hjörvar Iceland.

16:00 - 16:15: Mobility training and mobility tools

Speaker: Vala Jóna Garðarsdóttir. National institute for the blind in Iceland.

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, aps etc.

Speakers: Baldur Snær Sigurðsson and Hlynur Þór Agnarsson



16:45 - 17:00: Coping with visual and hearing impairment:  
Speakers: Halla Dís Hallfreðsdóttir and Elín Yr. Hafdisardóttir Arnardóttir.

## **Saturday 6th June**

### **08:30–10:00 P.3.1 Preparing for clinical trials in IRD.**

Moderator: Prof. Michael Larsen.

Speakers to be confirmed

### **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 Prof. Dr. Elise Heon, MD, The Hospital for Sick Children, Toronto, Canada

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

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

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

Speaker: Prof. Bart Leroy, Gent University, Ghent, Belgium

09:30 – 09:50 My personal experience with a clinical trial

Speaker: to be confirmed.

### **10:00 – 10.30 Coffee break.**

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

Moderator Dr. Goran Petrovski, Oslo, Norway.

10:30 – 10:45: Initiating a Phase I/IIa clinical trial for an autologous iPS cell therapy for macular degeneration: from bench-to-bedside.

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

10:45 – 11:00 Towards stem cell-based therapies in retinal degenerations

Speaker: Anders Kantar (Stockholm, Sweden)

11:00 – 11:30 Subretinal implantation of primary human RPE cells in minipig eyes.

Speaker: Dr. Goran Petrovski, Oslo, Norway.

11:30 – 12:00 Epigenetic characterization during differentiation from iPS to RPE cells in AMD.

Speaker: Dr. Cristina Zibetti (Oslo, Norway)



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

Moderator: Kristinn Halldor Einarsson ,Iceland

Speakers:Christina Fasser.Avril Daily.

Other speakers to be confirmed.

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

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

Speaker: Prof. Arthur 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: Prof. Anders Kantar, Karolinska Institute, Stockholm, Sweden

14:15 – 14:30 Retinal gene therapy trials - investigators point of view Speaker: Eeva-Marja Sankila, MD, PhD, Helsinki University Hospital, Helsinki, Finland

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

Speaker: Prof. Ilkka Immonen, Helsinki University Hospital, Helsinki, Finland

14:45 – 15:00 Gene therapy of Usher syndrome. Speaker: Prof. Isabelle Audo, Institute de la Vision, Paris, France

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

Moderator: Dr. Sigríður Másdóttir, Reykjavík, Iceland.

**15:00 – 15:30 Coffee break.**

**15:30 – 17:00 K.3.3 What the future holds:**

Panel discussion (AMD, IRD, genetics, Innovation)

**17:00–17:30: K.3.4 What have we learned?**

Speaker: Prof Emeritus Gerald G. Chader, Los Angeles, USA

**17:30 – 18:00 Closing ceremony.**