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Welcome from Avril Daly, CEO of Retina International

In June 2022, the Retina International World Congress (RIWC) took place in Reykjavik, Iceland. It was an incredible experience to have so many people in the retina community come together from around the globe, after months of virtual meetings.

The members of RI originally voted in 2016 to hold the 2020 congress in Iceland. Looking forward four years, we anticipated a treatment for an IRD being a reality by then, great advancement in research being made, and our community meeting in a place and time where the sun didn’t set.

We were correct in some of our assumptions. There is now a therapy for an IRD available and a strong pipeline at clinical trial phase. We are learning more about the mechanism of retinal diseases both rare and inherited, as well as the aging retina. Our community is growing in number, stature, and confidence. We have reasons to be hopeful. However, the only treatment for an IRD is still not available to all those who are eligible, and access to a genetic test for an IRD is challenging for most, which in turn challenges not only the progress of research but also impacts those living with these conditions.

We could not have anticipated in 2016 when Iceland was selected as the venue for the 2020 RIWC that it would be six years before we would meet there, as a global pandemic separated us. Nor could we have understood then that the challenges presented by the pandemic would facilitate a new way of working, of reaching out and engaging with our members across the globe in a way that would allow us to address the aforementioned challenges and many more in a truly collaborative way and with a strong commitment to leave no one behind. After two years of getting to know each other in a virtual world behind us, we finally met in-person in Iceland for four days of discussion, learning, and exchanging views and fond memories.

The RIWC started with two days of engagement with the Retina International Youth Council. Twenty-three young people gathered to discuss how the RI
strategy could address their specific priorities. Next was the Continuous Education Programme – CEP – which brought delegates together to present and exchange experiences, share learnings and discuss the future path of RI. The scientific session at the CEP set the scene for a great weekend of hearing about the developments and trends in the retinal research space. While not all members were in a position to travel due to the continuing effects of the pandemic, virtual streaming meant that members around the globe could still participate in the discussion. We were also delighted for RI’s new Board of Directors to convene in person for the first time.

We were then treated to two days of excellent presentations on research developments at both the scientific and lay sessions of the congress. For the first time, members of the RI executive team presented the results of our own in-house research. The opportunity to listen to and speak directly to world leading researchers and clinicians face-to-face to ask the burning questions was a highlight of the congress for many delegates.

In keeping with tradition, Franz Badura, Chair of Retina International closed the RIWC 2022 with music. While we look forward to the next RIWC in Dublin, Ireland in 2024, we look back at where we have come from and respect and recognise the huge efforts taken by Christina Fasser, Claudette Medefindt, and so many volunteers over the decades to plant the seeds and establish RI for all those who live with retinal degenerations, the rare and inherited and age-related. Without this work we would not have such a hopeful future or a strong community.

We’d also like to thank the team at SENA, for their professional help in the logistics and planning of the conference, which we are delighted to say was a great success. Finally, we thank Kristinn Halldór and all the team at the Blindrafelagid, Icelandic Association for the Blind for six years of planning and re-planning. Thank you also for coping with the challenges faced by the onset of the pandemic three months before the RIWC was due to take place in 2020. Thank you for keeping going and for ensuring that we had an unforgettable event in 2022.

The team at RI and many of our new board members were immensely motivated by this opportunity to be together with our membership and we’d like to thank all our members and RIWC participants for your engagement and commitment to this cause.

Avril Daly
Retina International Youth Programme 2022

Written by Marina Leite

The Retina International Youth Programme is an event that takes place before the Retina International World Congress. It is organised by Retina International Youth Council members in collaboration with Retina International staff and the hosted association. This year, in 2022, the event occurred in Reykjavik at the Icelandic Association of the Visually Impaired.

The event started with a dinner, followed by one and a half days of activities. Part of the event was hybrid, allowing online participation and making it more accessible for youth participants around the world. There were about 40 participants in total, from many countries and continents, with the majority being from Europe. In-person, there were people from Australia, Brazil, Bulgaria, Canada, Chile, Finland, Germany, the Netherlands and Switzerland. The event was organised by a group of young women living with inherited retinal diseases (IRDs) and their fellow Retina International Youth Council (RIYC) members. These brave women are Marina Sutter, Jane Cherry, Shaini Saravanamuthu, Jeannine Sutter and myself (Marina Leite). We organised the event with the great support of Fiona Waters from Retina International and Marjakaisa Matthiasson from Retina Iceland.

Day 1: Tuesday, 7 June

The Retina International Youth Programme started with an informal dinner on Tuesday, the 7th of June. Some icebreaker activities helped to create a safe, friendly environment for all the participants, followed by excellent pizza and refreshments. As some of the youth stated during the evening, everyone there
was "awesome and cool". The dinner was a great way to start off the busy programme.

**Day 2: Wednesday, 8 June**

On Wednesday, the schedule was intense. The programme consisted of yoga, scientific and daily life themes, career support, and an outdoors activity. Yoga class was delivered in the early morning, helping participants to balance and centre themselves for the day. Following that, the first session was presented in a hybrid mode by RIYC members. They talked about the objectives and vision of the Council. It was a shared conversation where the above-mentioned young women showed their passion for engaging with the organisation.

After that, there was another hybrid session about Genetic Testing. The session started with a formal presentation on the topic given by Steven Ringel, a member of the RIYC and a patient advocate. The emphasis was on the importance of genetic diagnoses for IRDs and related topics such as genetic counselling, understanding your code, and coping with the diagnosis. To involve the participants, the session moderator, Jane Cherry, facilitated a True and False game, where she read statements about genetic testing for IRDs. Participants judged its veracity and discussed related ideas.

Wednesday morning ended with two simultaneous sessions: career and personal development, moderated by Steven Ringel, as well as a supporters' roundtable moderated by Avril Daly. The career session aimed to present practical skills for young people living with an IRD to thrive in the workplace. The supporters' roundtable aimed to understand the challenges faced by family and friends of those with a retinal condition.

The afternoon session was very interactive. Just after lunch, Fiona Waters conducted a brainstorming activity on the strategic planning for the future of the RIYC. Participants collaborated, sharing lived experiences, reflections and aspirations. The session ended with a direction for the future of the RIYC, and a conviction that all young people involved are energetic and brave.
To finish the agenda, participants were separated into groups and engaged in an Amazing Race. This was the most fun part of the Youth Programme. The Race had several goals, which each group executed in different parts of Reykjavik. The purpose of the activity was to get the visually impaired people out, challenge them to find unknown places, and perform everyday and unexpected tasks. Some tasks included taking photos with birds, buying local chocolate, and finding specific locations. It was encouraged to use assistive technology. The final destination was a restaurant where everyone could have dinner and relax.

**Day 3: Thursday, 9 June**

On Thursday, the final day, the Youth programme agenda occurred in the morning and attendees were invited to join the Continuous Education Programme (CEP) in the afternoon. The morning covered essential topics for patient advocates and those living with IRDs. There were three speakers: Fiona Waters, Avril Daly and Prof. Elise Heon from the Hospital for Sick Children, Toronto. The topics discussed included emerging therapies, challenges in securing health access for all, and how to demonstrate the value of IRD therapies to decision makers. There was also a pleasant conversation about how youth patients can improve communication with ophthalmologists, geneticists and researchers. To conclude the Youth Programme, people were encouraged to share final thoughts and recap what was discussed before. The Youth Council closed by stating its purpose of being the voice of the youth today, building leadership and capacity for the future.

**Personal takeaway**

It was a unique experience to prepare and participate in the Retina International Youth Programme. For me, it was the first time I had the chance to share on an equal basis with a group of young people in my age group, my experience living with an IRD. Furthermore, acknowledging how the youth are capable, clever, skilled and energetically engaged is fundamental to keeping everyone willing to work on the mission for a better future.

Over the event, we created personal connections, starting friendships that I hope will remain for many years. Travelling to Iceland was also exciting. Informally we visited warm pools and beaches in the evenings. On Sunday, a day trip showed us some of the beautiful Icelandic landscapes. Besides the inspiring and fun social aspect, the scientific sessions were crucial to ensure everyone had the same knowledge base. The strategic planning helped with trust and consensus building for the future of the RIYC. Now, the Council members should enjoy this momentum and continue to work for the future.
Personally, it was an unforgettable experience, and I wish to see this Programme in future years with even more brave youths.
Continuous Education Programme (CEP)

Session 1: Members Presentations
Written by Dana Hufe

The Continuous Education Programme (CEP) took place at the Retina International World Congress in Reykjavik, Iceland on June 9th, 2022. The first session of the CEP began with presentations from RI members. Full members had the opportunity to apply to make a 10-minute presentation during the Membership Information Session. The theme for this year’s programme was “Forward Vision; Preparing for Tomorrow, Today.”

Stephan Hüsler, Retina Suisse
The first presentation came from Stephan Hüsler of Retina Suisse presenting on the Retina Suisse database for rare eye diseases. The database aims to record all patients residing in Switzerland affected by retinal diseases and fosters collaboration between patients, patient organisations, and clinicians. It provides patients with targeted information around clinical trials and therapies, and provides clinicians and researchers with anonymized information the help with the planning of studies. Hüsler also gave an overview of the process for patients to be registered in the database, the statistics around health insurance reimbursement, and the general genetic landscape of IRDs in Switzerland.

Gustavo Serrano and Arturo Landaeta, FUNDALURP
The following presentation was from Gustavo Serrano and Arturo Landaeta from FUNDALURP, more recently renamed Retina Chile. They presented on the Redbee App, which aims to connect patients and patient organisations. It involves a variety of diseases, such as arthritis and psoriasis, but Serrano and Landaeta discussed how it could be helpful for the retina community.

Efstratios Chatzicharalambous, Hellenic Retina Society

After that we heard from Efstratios Chatzicharalambous of the Hellenic Retina Society, Greece on Greek Patient Society Opportunities and Limitations. He
discussed how the pandemic has limited people in the community, causing issues with remote working, isolation, and reduced independence, particularly for people who don’t have the technology to maintain communication. He discussed how patient societies like the Hellenic Retina Society collaborate with the European Reference Networks (ERN) and companies to provide support. To conclude, Chatzicharakalambous explained how the pandemic has made patient societies have to adapt in the way they work and communicate, and the importance of collaborating with other communities to reach a common goal.

**Doug Earle, Fighting Blindness Canada**

Doug Earle from Fighting Blindness Canada (FBC) presented on using Facebook to reach and educate the retina community. He discussed how FBC used targeted Facebook advertisements to raise awareness on eye diseases and encourage Canadians to show their interest in FBC’s work. With the help of these marketing efforts, their IRD registry has doubled, and the FBC Facebook page has grown from 4,000 followers in 2019 to over 61,200 followers. The foundation has also used Facebook ads to garner support for their Approve Luxturna campaign to get Luxturna, a treatment for certain forms of inherited retinal degeneration, publicly funded. They also have used Facebook to promote their webinars, fundraising events, and advocacy campaigns.

**Dr. Frank Brunsmann, PRO Retina Germany**

Dr. Frank Brunsmann from PRO Retina Germany had a presentation titled “Checkheft: Preparing for Tomorrow’ Coping, Today.” He discussed what determines quality of life for people with low vision, and of primary importance is to have an accurate diagnosis. Beyond that, he mentioned availability of treatment and support for coping. Checkheft is a collection of well-tested coping strategies available in both paper and electronic version. It aims to help IRD patients protect and regain daily living skills. These skills revolve around areas such as mobility, money and shopping, housekeeping, and many more. Checkheft helps provide a clear structured way to scan for weaknesses in patients’ coping strategies.

**David Sanchez, FARPE**

Next, David Sanchez from FARPE in Spain talked about the formation of FARPE in 1990 and how they work to provide a better quality of life for those living with retinal degeneration. He discussed the Foundation Fight Against Blindness (FUNDALUCE), which aims to help Spanish researchers with an annual funding grant. The foundation has donated more than 600,000 euros to sight-saving research. The foundation is also dedicated to involving patients more in the
healthcare system, collaborating with researchers, and registering people on the national patient registry for rare eye diseases.

**Marina Leite, Retina Brasil**
Retina International Youth Council member Marina Leite had a presentation titled, “Looking Back and Preparing for the Future: Retina Brasil at 20 Years.” Marina spoke of how the 2006 Congress in Brazil helped to boost medical involvement in the international retina community, and incentivized doctors to come to the World Congresses. She spoke about recent advancements in therapies for eye diseases and innovation in communication such as Whatsapp groups that help connect patients in different regions. She talked about the current advocacy objectives for Retina Brasil, including making genetic testing available for all patients with IRDs in the healthcare system and enhancing the patient voice in government agencies.

**Andres Mayor, Retina Iberoamérica**
Lastly, Andres Mayor from Spain spoke about Retina Iberoamérica. The organisation combines different associations from Argentina, Brazil, Spain, and Chile. They organise events online to bring the community together and provide support to patients and families. He also spoke about the importance of providing information in different languages like Spanish and Portuguese.

The Continuous Education Programme encourages collaboration among our global membership and provides a platform for members to share ideas, experiences, and future plans in the community. We were delighted for our members to finally be able to engage in-person this year. It was overall a day of hope and inspiration, and we are very much looking forward to the next one.
Session 2: Scientific Session
Written by Nabin Paudel

The scientific session of the CEP programme included four speakers – Dr. Nabin Paudel and Dr. Petia Stratieva from Retina international, Prof. John Flannery from UC Berkeley and Dr. Daniel Chung from Sparing Vision.

Drs. Paudel and Stratieva, Retina International
Drs. Paudel and Stratieva presented the results on the Retina International Genetic Testing Landscape Survey that was conducted in two phases. The findings from the two studies implied that patients with IRDs do not have equitable access to genetic services. It also demonstrated that greater awareness regarding the availability and importance of genetic services for IRDs is needed among health care professionals, as is a best practice model on access to genetic testing and counselling for IRDs.

Dr. Daniel Chung, Sparing Vision
Dr. Daniel Chung from Sparing Vision presented on Gene Independent approaches to therapies for IRDs. Dr. Chung provided details about a suit of interesting therapeutic approaches that are currently in development from Sparing Vision. The target of these therapeutic interventions was to act on cone metabolism and function (SPVN06 – cone metabolism, SPVN20 – cone functionality, SPVN30-both cone metabolism and cone function) and to slow down the degeneration of cone photoreceptors.

Prof. John Flannery, University of California, Berkeley
Prof. John Flannery from the University of California, Berkeley then presented on the optogenetic method to restore high sensitivity object and pattern vision in motion. Prof. Flannery discussed several encouraging results in animal models where they successfully demonstrated improved object recognition and pattern vision in mice after optogenetics therapy.
It was a pleasure for our members to be able to hear about the exciting advancements in the retina space and be able to ask questions. The scientific session of the CEP was a wonderful opportunity to bring our members together to learn and discuss, and an excellent prelude to the rest of the Congress.
Session 3: Members Discussion
Written by Fiona Waters

Education and Engagement activities
Fiona Waters, Education and Engagement Manager, summarised the Education and Engagement activities of Retina International over the past two years, highlighting key developments such as the organisation’s rebranding, provision of translated social media and a commitment to increase availability of translated content, executing the pilot of the RI Education Hub, the Genetic Testing Members Taskforce, Data Generation Studies, and establishment of the Retina Youth Council.

RIWC future directions
CEO of RI, Avril Daly, highlighted the unique opportunity the RI World Congress posed to the community, but also the importance of coming together as a community to reimagine the congress and make it more accessible for attendees and organisers alike. We look forward to the RIWC Dublin in 2024, and collaborating with our hosts, Fighting Blindness (Ireland).

RI Youth Council; the journey so far
Members of the RI Youth Council, Marina Sutter (Retina NZ), Marina Leite (Retina Brasil), Jane Cherry (Retina Australia), Shaini Saravanamuthu (Fighting Blindness Canada) and Jeannine Sutter (Retina Suisse) shared the progress and visions of the Retina Youth Council in its first two years of establishment. This promising and energetic council poses an incredible opportunity to elevate young voices in the retina community at a global platform.
EU Projects and opportunities – Ms. Christina Fasser
Former President of RI, Ms. Christina Fasser, highlighted the opportunities for RI members within the EU to take advantage of grants available through EU funded programmes, making them aware of specific grants, and considerations when applying for them.

Future of Membership – Plenary Discussion
The final session of the CEP was dedicated to RI members coming together in active discussion about the future of RI and its membership, and strengthening our global community. This session was chaired by Ms. Claudette Medefindt (Retina SA). A number of our community volunteered to take part in a member’s taskforce to enact the recommendations and discussion points that emerged from these critical conversations.
Launch of Universal Policy Indicators on Genetic Testing
Written by Fiona Waters

RIWC 2022 marked the launch of the Retina International Universal Policy Indicators for Access to and Delivery of Genetic Diagnostic Services for IRDs, which were developed by the RI Genetic Testing Patient Taskforce.

RI Education and Engagement Manager Fiona Waters presented the findings of the taskforce and the proposed indicators during the RI Global Challenges session of the RIWC on Saturday June 11th. Click here to download that PowerPoint presentation.

These indicators provide an essential tool for effective consensus building within the retina community, networking of our IRD community with experts beyond the IRD space, centers of expertise, and patient organisations with similar needs in order to foster health care systems strengthening.

They are presented and scored in a format that is transferrable for use at international, national, and regional levels, reflecting the reach and needs of the diverse RI membership and wider community. This tool will enable the community to advocate for effective policies that provide equitable access to genetic services with a consistent and unified voice.
A report of the taskforce findings, and an overview of the indicators is available for download on the Know Your Code website.

If you have any feedback or questions, please contact Fiona.waters@retina-international.org.
RIWC

RI Activities
Written by Fiona Waters

Over the course of the World Congress on June 10th and 11th, Retina International contributed in a number of ways, highlighting its broad scope of work in the areas of education, data generation, and policy action.

Visionaries Booth with Roche
Written by the team at HavasSO

Last month, we had the honour of exhibiting Visionaries at the 21st Retina International World Congress in Reykjavik, Iceland. Over three days, around 100 people visited the physical installation, including 41 patient advocacy group members. Importantly, we had the invaluable opportunity to speak directly to many members of the low vision community to gain further feedback on the Visionaries Hub. This is an absolutely vital part of the continued co-creation of the Hub, and we thank everyone who we had the pleasure to speak with.

“Vision impairment and retinal conditions are invisible most of the time. Resources like the ones available on the Visionaries Hub are important because they will make people more aware of this and our needs.”

-Patient advocate from Germany
RI hosted an open session targeted towards our industry partners and colleagues present in Reykjavík. Mr. Jason Menzo, CEO and President of Foundation Fighting Blindness moderated this session and Mr. Franz Badura, Chair of Retina International opened the floor, discussing the critical importance of active engagement between the industry and patient community. CEO of RI, Ms Avril Daly, spoke to the Patient Public Involvement (PPI) in research life cycle, and called for clinicians, scientists, and industry partners to work together to achieve the common goal of proving equitable and timely access to innovative diagnostic and therapeutic services for people with age related and inherited forms of retinal diseases.

Dr. Nabin Paudel, Research and Innovation Manager at RI delivered preliminary insights into “Understanding the Economic Burden and Societal impact of Age related Macular Degeneration and Geographic Atrophy”; and the unmet needs faced by this community. The next presentation was on IRDs: Counting the Cost, Understanding the Impact.

Ms. Fiona Waters, Education and Engagement Manager highlighted the journey so far with RI’s IRDCOUNTS Studies – which measured the socioeconomic burden of IRDs, in addition to their impact on wellbeing and mental health. Also highlighted were RI’s two studies on the global genetic testing landscape, and the work being undertaken by RI to work towards universal access to these essential diagnostic
services. Information about this body of work is available on the RI Know Your Code website.

Prof. Dr. Elise Heon, from The Hospital for Sick Children, Toronto, Canada spoke to the Challenges of Outcome Measures in Retinal Degeneration, and their impact on clinical trials for therapies in this space. Dr. Heon highlighted the urgent need to come together as a community to critically appraise and address questions about the Outcome Measures, specifically in relation to the end points and patient reported outcome measures (PROMs).

Measuring the Socioeconomic Burden of AMD in the USA, Germany, and Bulgaria
RI’s Research and Innovation Manager Dr. Nabin Paudel presented the preliminary findings of the Economic Burden of AMD in the USA, Germany, and Bulgaria study conducted by Retina International, which demonstrated that the majority of the economic cost attributable to AMD was due to the productivity loss and well-being of the patients. This finding was consistent across the three countries. RI looks forward to publishing a report including these data the coming months.

Access to Genetic Testing and Diagnoses for IRDs – A multiphase initiative by Retina International
Fiona Waters, Education and Engagement Manager discussed “Access to Genetic Testing and Diagnoses for IRDs – A multiphase initiative by Retina International” at the lay session on Friday of the RIWC. This presentation highlighted RI’s journey so far from generating data on the processes and patient experience of undergoing genetic testing in Phase one and two, to the activities of its global genetic testing taskforce in phase 3, which resulted in the development of Universal Policy Indicators for Genetic Testing.

Global Genetic Testing Landscape – Results from a two-phase study
Fiona Waters, Education and Engagement presented on RI’s “Global Genetic Testing Landscape – Results from a two-phase study”. These preliminary data demonstrated key issues such as: receiving a genetic diagnosis is a fundamental step in the patient journey, a best practice model on access to genetic testing and counselling services for IRDs is needed urgently, greater awareness and training is needed for HCPs, patients, and their families on the benefits of genetic testing and counselling for IRDs, and finally that the burden is on the patient and families to navigate (often complex) care pathways. RI looks forward to publishing these data in a peer reviewed journal in the coming months.
The Retina International Global Challenges session focused on the targeted policy actions being undertaken by RI in two specific areas: the ageing eye, and genetic testing for inherited retinal diseases. The ageing eye panel discussion was chaired by Avril Daly, CEO of Retina International, during which Dr. Nabin Paudel introduced the two key aging eye diseases that Retina International is focusing on - AMD and Diabetic Retinopathy, and discussed the importance of generating real world evidence for decision and policy making purposes. The panel members, Dr. Petia Stratieva (RI, Retina Bulgaria) Doug Earle (Fighting Blindness Canada), and Daniella Brohlburg (PRORETINA Deutschland) shared their experiences and actions in the aging eye space at various levels.
The inherited retinal diseases panel discussion was chaired by Jason Menzo, CEO of Foundation Fighting Blindness, USA. Fiona Waters, RI Education and Engagement Manager, presented on the genetic testing landscape taskforce results, the Global Universal Policy Indicators developed by the group, and future steps of multistakeholder engagement. This was followed by a panel discussion with Ms. Claudette Medefindt (Retina SA), and Ms Marina Leite Brandao (Retina Brasil) on the theme of providing equitable access to innovative diagnostic and therapeutic services for patients with IRDs.

**Poster Presentations**
RI proudly presented two posters at the RIWC:

1. Retina International Education Hub - Educate. Participate. Innovate: Training and empowering patients living with rare, degenerative retinal diseases as active stakeholders in medicines research & development, Author: Fiona Waters, Education and Engagement Manager, Retina International

2. Universal Indicators for Equitable Access to a Genetic Diagnosis: Outputs of a Retina International Patient Taskforce, Author: Fiona Waters, Education and Engagement Manager, Retina International
Scientific Highlights
Written by Nabin Paudel

The 21st Retina International World Congress was jointly organised by the Icelandic Association of the visually impaired (BIAVI) and the Nordic Ophthalmic Society in Reykjavik, Iceland from the 9th of June to the 11th of June, 2022. The congress convened a diverse group of audience members that included clinical scientists, researchers, patient advocates, industry partners and lay public from all around the globe.

During the scientific programme, leading experts in the field of inherited and age-related retinal diseases provided latest research updates. Key research themes of this years’ conference were the importance of genetic diagnoses for patients with inherited retinal disorders (IRDs), innovative therapies such as gene therapy and stem cell therapy for IRDs, assessment of end points in clinical studies in IRDs and cell and gene-based therapies for Age Related Macular Degeneration. Notable speakers in the congress included Prof. Bart Leroy, Ghent University, Belgium, Prof. emeritus Friðbert Jónasson, University of Iceland, Iceland, Prof. Elise Heon, The Hospital for Sick Children, Toronto, Canada, Dr. Daniel Chung, DO, MA, Sparing Vision, USA, Dr. Masayo Takahashi, Vision Care Inc., Kobe, Japan, Christina Fasser, past president of Retina International, Dr. Kapil Bharti, National Eye Institute, USA, Prof. Dominik Fischer, Oxford Eye Hospital, UK, Prof. Robert Koenekoop, Montreal Children’s Hospital, Montreal, Canada, Prof. Mark S Humayun, University of Southern California, Los Angeles, USA and Prof. Artur Cideciyan, University of Pennsylvania, Philadelphia, USA.

Research Related to Inherited Retinal Disorders (IRDs):
Prof. Bart Leroy delivered an inaugural keynote speech on the importance of genetic diagnoses for IRD patients. Prof. LeRoy highlighted that given the emergence of innovative therapies for IRDs, a genetic diagnosis is the fundamental requirement for IRD patients to be enrolled in clinical trials and to access novel therapies.

Prof. Elise Heon discussed several important considerations and issues in conducting paediatric clinical trials. She mentioned that 12% of all clinical trials are paediatric clinical trials while the group carries 60% of the disease burden. Furthermore, Prof. Heon highlighted that current assessment protocols are not adapted to children which may affect the interpretation of results. Recruiting children in clinician trials is also a challenge as they have limited attention span, they fear missing school, parents have to take leave from their work and so on.
Dr. Daniel Chung from Sparing Vision spoke on the development of patient relevant outcomes in gene therapy trials where he discussed the development of a novel functional vision endpoint measure – the Multi-luminance Mobility Test (MLMT). Dr. Chung described the validity of the test and how a novel outcome measure can be accepted by the regulatory agencies if the value of the test for patients can be clearly demonstrated.

Prof. Masayo Takahashi discussed about her research in developing cell and gene therapies for outer retinal layer diseases for over 10 years. Past president of Retina International, Christina Fasser delivered a keynote speech sharing her experience on engaging with researchers, scientists, and patient advocates from around the globe and motivated youth advocates by emphasizing why we should never give up hope on scientific research despite some frustrations along the way.

Prof. Dominick Fischer from the University of Oxford presented on the Real-world safety and effectiveness of voretigene neparvovec (the PERCEIVE study). The study demonstrated that the most common adverse event due to the therapy was chorioretinal atrophic changes (13%). However, these changes did not affect the visual function of the patients at least up until two years post therapy.

Prof. Rob Koenekoop delivered a presentation on medical therapies for IRDs. Prof. Koenekoop presented four exciting new therapies that are currently in clinical trials. Three therapies are targeted for Stargardt’s (STGD) diseases and one for retinitis pigmentosa. Prof. Artur Cideciyan delivered a keynote address wherein he offered his perspective on two gene-based therapies for IRDs (RPE65-LCA and the CEP290-LCA). Prof. Cideciyan emphasized that while it is good be hopeful about the potential treatments for IRDs by looking at the bigger picture, it is also recommended to understand the practicalities of the research process which is far more complex than it is thought.

**Research Related to Age Related Macular Degeneration (AMD):**
Prof. Friðbert Jónasson from the University of Iceland presented some interesting findings on the risk factors for AMD. One remarkable finding was that AMD patients with higher HDL cholesterol level had higher odds (2.3X) of developing Geographic Atrophy (late-stage dry AMD). Similarly, Prof. Jonasson stated that they have identified a new serum protein biomarker that predicts if a patient with an early/intermediate AMD will develop late-stage AMD in 5 years. Furthermore, it also predicts if the patient is going to develop Geographic Atrophy or neovascular AMD. They hope that this novel finding could help in the management of AMD in the future.
Prof. Mark S Humayun from the University of Southern California, Los Angeles delivered a keynote lecture virtually on the theme of vision restoration. Prof. Humayun particularly reported the safety findings of the two novel therapies: a) the 256-channel intelligent micro implant eye (IMIE256) and b) Allogeneic RPE Cell Bioengineered Implant for Advanced Dry Age-Related Macular Degeneration. At a one year follow up, both therapies were considered safe.

Dr. Kapil Bharti from National Eye Institute presented their work on autologous induced pluripotent stem cell therapy for age related macular degeneration (autologous cells are preferred to allogenic cells because they do not require immune-suppressive agents after transplant).

Dr. Bharti described the safety and efficacy of the therapy in animal models and stated that a phase 1 clinical trial is scheduled in 12 advanced AMD patients at the NIH facility.

Overall, the scientific programme of RIWC 2022 was excellent with a lot of exciting research being presented. These research advances certainly offered some hope for patients with inherited and age-related forms of retinal diseases.
Special Recognitions and Awards
Written by Avril Daly

No World Congress is complete without its Speakers and Gala dinners. These provide a great opportunity to engage informally and continue the discussions and exchanges.

Professor Hélène Dollfus, ERN-EYE Coordinator
This year at the Speakers Dinner, RI presented Prof. Hélène Dollfus with a Special Recognition Award for not only the work she continues to undertake as Coordinator of the European Reference For Rare Eye Diseases (ERN-EYE), but also her work on promoting the eye in important policy actions that resonate globally. RI particularly wished to recognise Prof. Dollfus for the work she undertook to support patients living with Rare Diseases in Ukraine through the European Reference Networks, work that is both lifesaving and life-changing.

Claudette Medefindt, National Secretary and Head of Science at Retina South Africa
We also recognised the retirement of Claudette Medefindt from the Board of RI at the recent AGM. Claudette has been an advocate for all people living with retinal dystrophies for over forty years. Her tireless determination to ensure access to diagnosis and foster research has ensured that Retina South Africa continues to be one of the most creative and impactful national charities. Her work in RI ensured that the membership structure and engagement was always prioritised and it was an honour to thank her for being an example of true volunteerism.
**Christina Fasser, Former President of Retina International**

The executive and board of RI finally had the chance to say thank you to our fearless leader for so long, Christina Fasser. The pandemic prevented the community from acknowledging the personal commitment to the promotion of retinal research and innovation that Christina gave for over three decades. The Chair of the RI Board of Directors, Franz Badura presented her with a token of the appreciation of the community, thanked Christina for laying the foundations and fostering the grassroots of RI and for all she brought to RI in her tenure as president from 1992 to 2020. The members and many researchers and clinicians whose work she has tirelessly supported, honoured Franz’ words with a standing ovation.

**Prof. Frans Cremers, Radboud University, and Dr. Frank Brunsmann, Pro Retina**

At the Gala dinner, Prof. Frans Cremers and Dr. Frank Brunsmann were finally presented with their lifetime achievement awards originally presented virtually in 2021 to mark Rare Disease Day. Their work on Choroideremia as a then patient and scientist is one of the most compelling examples of true collaboration between patients and researchers.
Online Engagement
Written by Dana Hufe

We were delighted to see so many people in the retina community join us in Reykjavik, Iceland for the Congress and engage not only in-person, but also online by tagging @retina_int and using the hashtag #RIWC2022. We loved seeing photos of the presentations, informational snippets, and of course a few fun selfies from our global members!

Twitter
Twitter was perhaps the most-used platform at the Congress, as it facilitates short posts in rapid succession, an easy way to keep others updated on the happenings of the event. We saw huge growth on the Retina International Twitter account, with our mentions growing by over 785% the first two weeks of June compared to the previous month. Our tweet impressions grew by 117% and our profile visits spiked up by over 58%.

“It’s awesome to finally meet people in person that I have spent hours talking with over Zoom,” tweeted Doug Earle of Fighting Blindness Canada along with a selfie of himself, former RI president Christina Fasser, and Roche’s Iris Van den Brande.
“I am currently blessed to be in beautiful Iceland for the inspirational @Retina_Int #RIWC2022 - head is exploding with excitement!” tweeted Prof. Lauren Ayton, who flew all the way from Australia for the Conference.

LinkedIn
On LinkedIn, our shares increased by 366%, our reactions by 600%, and our new followers increased by 225% in the first two weeks of June. “What an honour and experience to be here in Iceland, representing Canada on the Retina International Youth Council!” posted RI Youth Council member Shaini Saravanamuthu on LinkedIn. “Patient advocacy is so important to better the lives of those of us living with a rare inherited retinal disease. Thank you Fighting Blindness Canada & Retina International for this amazing experience and platform!”

We also saw wonderful engagement on Instagram and Facebook, particularly on our stories. We were delighted to see such active participation across all of our platforms from our global supporters and encourage you to follow us on social media for continuing updates.
RIm on Tour - The Golden Circle
Written by Fiona Waters

Photo: Group picture of RI community on guided tour of Thingvellir National Park.

On Sunday, June 12th, the Retina International community enjoyed an accessible guided tour exploring the “Golden Circle” of Iceland. We were delighted to experience the natural wonders of the Icelandic countryside on a sunny day, and enjoy the beautiful Thingvellir National Park, Geysir Geothermal Area, and the Gullfoss Waterfall. A special way to end an immensely rewarding week!