

Retina International Newsletter

Winter 2021



Retina
International

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Letter from the Chief Executive Officer of Retina International, Ms. Avril Daly

Welcome to the Retina International Winter 2021 Newsletter.



As we reach the end of 2021, the team at Retina International (RI) reflect on a year of global challenges, learnings and opportunities.

When writing the RI newsletter this time last year, we looked forward to 2021 and getting 'back to normal'. While this did not happen to the degree we all would have liked, ground-breaking medical research resulted in society moving closer to normality with the accelerated development of vaccines and therapies for COVID-19. Despite the inevitable emergence of variants, we are hoping that these new interventions will keep us safe as the international research effort continues.

The members of RI will be familiar with so much of the scientific terms having spent decades funding and fostering retinal research. Throughout the pandemic these terms became common place in society. There is a growing interest in science, genetics and innovative therapeutic approaches to tackling disease and we hope that this will result in a better understanding of the need to support medical research as well as innovation in the delivery of care among decision makers in governments at a regional, national and international level.

Some regions have pledged to commit to greater funding for health and health research as a priority. There has also been a greater understanding of the role of those who live with health-related conditions, the patients and caregivers in the development of research and innovative approaches to health care delivery. In the 22 months of the pandemic, it is the generation of data to underscore the unmet needs of our community, the impact of retinal disease and the importance of patient and public involvement in research that we at RI have focused on.

Through our RI Education Hub, the organisation has demonstrated its commitment to building capacity among our membership to advocate on behalf of their local communities on every aspect of the research journey, from bench to bedside. The eleven globally representative students who enrolled truly embodied the course philosophy of Listen, Learn, Lead and this was demonstrated in the inspiring and considered final projects presented by them on December 7th. We look forward to working with the

course alumni in our communications and policy actions going forward and are very excited to lay the groundwork for our 2022 course.

Another highlight of our year was the facilitation of the Genetic Testing Landscape Study, a two phased approach to generating data on the process of genetic testing in Europe and Australia as well as a global patient perspective on access. The results of this study demonstrated clearly the challenges faced by patients in accessing genetic testing, the gaps in process, lack of genetic counsellors and specialists and a general lack of awareness about the importance of genetic testing among Health Care Providers. In late 2021 RI has formed a globally representative task force of patient representatives to review the results of this study and work towards the development of global policy actions on genetic testing. We are very encouraged by the number of member organisations represented in this group. Thank you for answering our call for engagement, we are looking forward to beginning this work with you in January.

RI also undertook a study to understand the impact of Geographic Atrophy (GA) and Age-related Macular Degeneration (AMD) among those affected and those who provide their care. This initial study is examining the experience of Bulgaria, Germany and the United States. We are looking forward to sharing the results of this important study in early 2022 and working with our membership and stakeholders to turn our learnings into action that will result in early detection of these conditions and improved access to care, treatment and support.

The team at RI were all excited to work with so many of our members on the rebranding of the organisation in 2021. Changing branding is a huge task for any organisation and particularly so for one that has such great history, diversity and also serves a community where accessibility is the most important aspect of all that it does. It is fair to say that a lot was learned during this process and very special thanks must go to our Retina Youth Council who really engaged on this activity bringing a fresh and empowered approach to the design. I must also thank our Communications and Outreach subcommittee for really pushing this project all the way to completion with great advice and enthusiasm.

I would like to take this opportunity to thank our dedicated and resourceful team, Operations Manager, Kelly McVicker, Education and Engagement Manager, Fiona Waters, Policy Manager, Dr. Petia Stratieva MD., and Communications Officer, Dana Hufe. Orla Galvin PhD left us in November after over three years on the team and her position has now been filled. I look forward to introducing you to our new Research and Innovation Manager in January. I would also like to sincerely thank Christina Fasser and Daniela Capelli who continued to manage our finances from Retina Suisse as we continue our transition to registration in Ireland. Thanks also to CEO of Retina Suisse, Stephan Huesler for all his support during this period.

I sincerely thank our chair, Franz Badura, for his leadership this year as we navigated a very time-consuming process of registration in Ireland. The NEC made up of Franz, our Vice Chair Martin Smedstad, Treasurer, Jeremy D'Souza, Company Secretary, Ronan Holahan as well as Claudette Medefindt, Jason Menzo, Saburo Morita, Caisa Ramshage, Marina Sutter and David Sanchez, have been exemplary in their commitment to RI and support of our team. Each taking on more than one responsibility in our various committees. They have given up a lot of Saturday's and evenings this year.

Time is one of the most important things that we possess, and to give our time is one of our greatest gifts to bestow. We thank you, our SMAB, our partners and stakeholders for all of your time in 2021. We especially thank our members for your time, the time you give us but also the time you give to your local organisations throughout the year. Because of you giving so much of your time, 2021 was positive, despite the challenges of an ongoing global pandemic. We had the opportunity to really collaborate using accessible online tools, we learned a lot about technology through necessity and we definitely all had our moments of frustration with that technology! It is our great hope that we can leave the screens behind and meet again in Iceland at the RIWC in 2022.

We are looking forward to Meeting in the Middle in June 2022

Season's Greetings and Happy New Year!

Avril Daly

CEO

A Year in Review: The Retina International Executive Team

Dr. Petia Stratieva MD PhD., Policy Manager

This year, I continued to facilitate the Genetic Testing Landscape study, broadening the geographic scope of the study and adding the patient experience perspective. We were delighted to have received over 419 responses from IRD patients and caregivers on our survey, which was conducted in eight languages. The results are now under preparation for publication. They are providing the groundwork for building an effective advocacy strategy for equitable, affordable, accessible and timely genetic testing for IRDs.



Petia Stratieva

I also facilitated our Cost of Illness study on the impact of Geographic Atrophy (GA) and wet Age-related Macular Degeneration (AMD) along with my former colleague, Dr. Orla Galvin. The data generated from this project will support access to care pathways, therapeutic intervention, and research, as well as reflect the current burden and impact of AMD at all stages. Furthermore, data from this study will also be of use to support the identification of the most “at risk” groups who would benefit most from early diagnosis.

I am also pleased to say I will be representing RI as an ePAG with the ERN-EYE for the duration of the next five-year term!

Fiona Waters, Education and Engagement Manager

Despite the challenges this year has brought, there have been numerous innovative developments within our Education and Engagement outputs in 2021.

In Spring of this year, I had the great pleasure of curating the Retina International Advocacy Toolkit - a comprehensive resource that has been designed to provide a framework for creating and implementing advocacy strategies.

Over the Summer, I was delighted to lead the launch of RI’s new branding and updated websites, reflecting our evolution and growth as a pioneering, global patient organisation. In addition, I took great delight in conducting the recruitment and establishment of our first official RI Youth Council.



Fiona Waters

The latter half of this year for me was marked by the launch of the RI Education Hub Pilot Programme. I thoroughly enjoyed working closely with subject matter experts from across the community in designing the curriculum and creating the content for the

programme. We welcomed eleven trainees from around the world to learn about patient advocacy in the policy and research space, and design their own advocacy strategy throughout their student project. In the final quarter of the year, I have been reviewing our membership structures and procedures, and imagining new ways of engaging with our community going in to 2022.

Next year, I look forward to our World Congress in Iceland, and further developing our education and engagement projects.

I would like to sincerely thank the rest of the Executive Team, the NEC, the Outreach and Engagement Subcommittee, and the membership at large for your continued enthusiastic support of our work. See you all next year!

Kelly McVicker, Operations Manager

It has been a busy year for the RI team and we are all still adapting to the changes during the worldwide pandemic. This has not been without its challenges, but it has allowed the team to grow in many other ways.

From an operational perspective there have been a number of exciting new changes; we are now fully up on a new server with new systems and processes in place. We have furthered our registration with the Charities Regulator in Ireland to allow us to show we are fully compliant and transparent as a charity organization, and we have been reviewing all our current policies to comply with the governance code. For 2022 I hope to streamline these further, including implementing a project management system, setting up a new database system, as well as improving current procedures.



Kelly McVicker

Dana Hufe, Communications Officer

I had the pleasure of joining the Retina International team in July, just in time to assist with RIs rebrand! I've received a very warm welcome since then, and have very much enjoyed working closely with the RI team, the Retina Youth Council, and our members.

Although it's been an interesting and challenging experience getting situated with this position remotely during the global pandemic, I've taken on a number of exciting tasks. I've assisted with the planning and execution of our Virtual Youth Conference in August, which was a very inspiring event. I've had the pleasure of preparing our members bulletins and quarterly newsletters, as well as running our social media—including an exciting campaign for World Retina Day. I'm very excited for the work to come in 2022, which will include the promotion of the results of our Genetic Testing Landscape study as well as getting our Retina Youth website up and running.



Dana Hufe

January: Retina Action Call to Action Launch and Webinar



Retina Action is a global coalition of civil society organisations, including non-governmental organisations and professional associations, concerned with vision health, ageing, caregiving, medical research, and the delivery of appropriate and timely treatment options to patients affected by conditions of the ageing retina.

On **January 12th, 2021**, the Retina Action coalition launched a **Call to Action** for the ageing eye on the theme of **Inclusion & Wellbeing**. We called upon governments around the world to collaborate with patient and advocacy organisations to address the inclusion and access of older visually impaired citizens as equal members of society. This call to action included:

- Develop and where developed, implement screening programs for Age-related Macular Degeneration and Diabetes-related Retinopathy.
- Sustain and prioritise screening programs for Age-related Macular Degeneration and Diabetes-related Retinopathy during times of crisis;
- Improve awareness on the issues of digital poverty in the development of remote screening and eye healthcare programs;
- Prioritise the vaccination of the already vulnerable vision loss community against COVID-19; and
- Promote the inclusion and wellbeing of the ageing vision loss community.

To mark the launch of this call to action, Retina International hosted a panel discussion on the wellbeing and inclusion of the ageing community living with low vision in our society. RI Director of Research Policy, Dr. Orla Galvin moderated the event, which took place on January 12th at 2 pm CET. Panellists included:

- Dr. Keith Gordon – Chair of Retina Action, and Senior Research Officer of the Canadian Council of the Blind (CCB)
- Karen Denton – AMD Ambassador for Retina South Africa,
- Mike Smith – President of Retina New Zealand
- Daniela Brohlburg – Counsellor & Retinal Dystrophy patient advocate, PRO RETINA Deutschland e.V.
- Dr. Juliana Sallum – Board Certified Ophthalmologist and Geneticist, UNIFESP, Brasil

April: Launch of the Retina International Advocacy Toolkit



Advocacy Toolkit Launch

Retina International was delighted to announce the launch of our [Advocacy Toolkit](#) in April. This toolkit is a comprehensive resource that has been designed to provide a framework for creating and implementing advocacy strategies – from picking your particular battle, gathering and generating the information (data) to support it, to deciding on the most effective lobbying avenues available to you. The toolkit was created to support our membership in developing practical, structured advocacy strategies that empower you to be active and involved agents of policy change.

The Retina community is diverse; as are the issues it tackles. As such, the framework described in this toolkit can be applied to many different kinds of advocacy, including research, access to therapies, supports, and more. The toolkit launch was celebrated with a webinar titled “Advocacy: who, what, when, and why?” on April 22nd. In the webinar, we explored what the toolkit has to offer, and discussed with our panel some practical tips and advice for getting advocacy initiatives off the ground.

June: Retina International Continuous Education Programme

Retina International held its Continuous Education Programme (CEP) virtually on June 24th and June 25th. The theme was “**Working to Meet the Challenge: Taking Action in a COVID-19 World.**” The subthemes of the meeting were the topics “innovations for engagement: adapting the delivery of a service or initiative during the COVID-19 restrictions”, as well as “advocacy and local policy actions: describing an advocacy campaign or policy action your organisation has been involved in during the COVID-19 pandemic.”

The goals of the CEP are to provide insights into RI projects and activities, share activities and initiatives with RI membership, and provide a platform for members to share experiences and learnings with each other. On June 24th, the Retina International team shared our own projects, including information on our Genetic Testing Landscape study and our new Education Hub. We also heard from Clara Hervas from Rare Disease International about the UN Resolution for Rare Disease, and from Marina Sutter-Penz, who shared the work of the RI Youth Council.

On June 25th, our membership spoke about their work, with discussions and presentations from the Swedish RP Association, Retina South Africa, Retina Brasil, JRPS (Japan), and Fighting Blindness Canada. As always, we enjoyed hearing from our global membership about their projects and achievements, and very much look forward to the next CEP meeting, scheduled to take place in Iceland in June 2022.

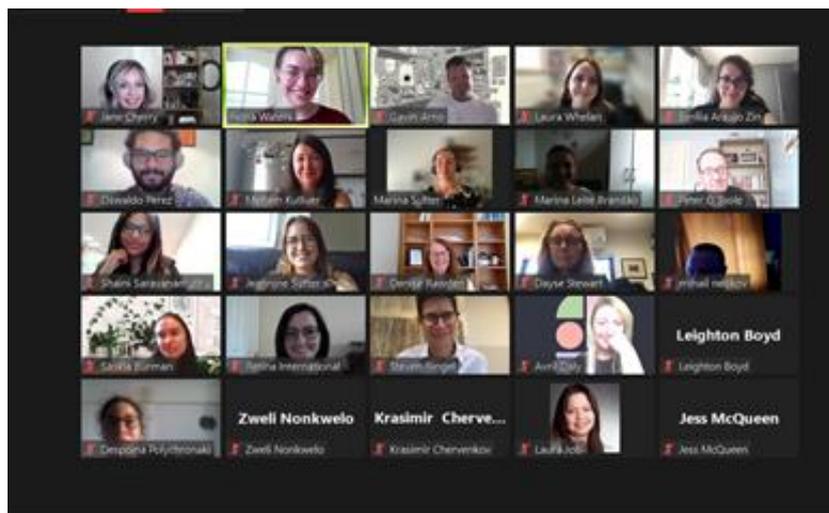
July: Retina International Rebrand



Retina International launched our new brand in July! After five years of growing and evolving through the support of our global membership and stakeholders, we were delighted to reflect this growth in our striking new design system.

This new logo and branding system details primary shapes including squares, circles, and triangles in a variety of colours coming together to form a creative “RI” emblem. The words “Retina International” are located to the right of the emblem, and are in branded font. This new logo symbolizes our future as a pioneering, global patient organisation and we are delighted with the transformation.

August: Retina International Youth Council and Conference



The RI Youth Council is made up of young adults and parents of minors affected by retinal degenerative conditions. The participants, who come from all over the globe, have continued to amaze us with their leadership, motivation, and creativity. Retina International very proudly conducted our

second annual **Virtual Youth Conference** on **August 12th and 13th 2021**, via Zoom. The conference showcased an incredible panel of speakers and the discussion centered around hope for the future.

Day 1 consisted of two sessions: **Genetic Testing** and **Access and Enablement**. First, we heard from Michelle Glaze, Associate Director of Professional Outreach for the Foundation Fighting Blindness, on the importance of genetic testing. Next up was Kari Branham, Director of Ophthalmic Genetic Counselling for the University of Michigan's Kellogg Eye Centre, who spoke on the process of genetic testing and the role of a genetic counsellor. Then, our very own Youth Council member in Canada, Shaini Saravanamuthu, along with Russia's patient advocate Kirill Baybarin, shared their personal experiences with genetic testing.

The **Access and Enablement** session started with Doug Goist, Program Manager of Workforce Development at NSITE, who talked about the importance of technology in aiding independence, and shared some helpful apps and gadgets such as [WayAround tags](#) and the [PenFriend 2](#). Dr. Karen Wolffe, owner of Career Counselling & Consultation, LLC in Austin, Texas, spoke next about career searching and goal setting. Finally, Dr. Kirk Adams, President and CEO of the American Foundation for the Blind (AFB), shared his personal experience as a blind job seeker and offered advice for those beginning their careers.

The second day of the conference, on August 13th, began with four interactive break-out rooms revolving around different areas of **Personal Interest**: dating, career, family and parenting, and mental health. Participants joined the rooms of their choosing to have in-depth and open conversations with their peers and the leaders of the Youth Council.

We ended the conference with the **Research and Innovation** session. Ben Shaberman, Senior Director of Scientific Outreach at the Foundation Fighting Blindness, gave a thorough presentation on emerging therapies for retinal degenerative diseases that are in, or approaching, clinical trials. Then we heard from five young researchers,

Meltem Kutluer, Laura Whelan, Dr. Emilia Zin, Oswaldo Perez, and Dr. Gavin Arno, who discussed the projects they're working on and the importance of patient involvement in research.

The virtual conference was a great success, and we would again like to thank the organisers of the Youth Conference for coming together to help others learn, network, ask questions, and join a community. Another sincere thank you goes out to all our speakers and our very engaged participants. We look forward to the next Retina International Youth Conference, set to take place during the Retina International World Congress, scheduled for June 2022 in Iceland.

If you would like to learn more about the conference, you can visit the post on our website [here](#). You can also see below to learn more about the Youth Council from the personal perspective of our Youth Council member in Canada, Shaini Saravanamuthu.



Shaini Saravanamuthu

Happy Holidays everyone! My name is Shaini Saravanamuthu, and I'm from Montreal, Canada. Earlier this year I was super excited when I found out that I would be representing Canada on the Retinal International Youth Council. Knowing that I can do what I do on the national level for our community, but this time on a global level, was super exciting!

Our international youth council is made up of so many amazing young individuals that have different types of visual impairments. It's been so amazing learning from one another from so many different parts of the world, even if it's only been virtual.

In August we had our Retina International Virtual Youth Conference, and I was so proud of our team for putting together such an informative and fun program for the two days. We had so many attendees from all over the world and everyone was so engaged, especially in our Personal Interest Discussion Rooms. People really got involved and open about different topics like dating, parenting, technology, and coping with Covid. No one will understand our struggles like our own community, and it's great when people from all over the world get to meet, as we get to learn things that we may not have known about.

I'm looking forward to Iceland 2022 to be able to meet some of these people in person and have more conversations, learn and help each other grow, help break stigmas, and raise awareness about our community together!

September: Retina International Education Hub Launch

In September, RI launched our Education Hub pilot programme! This three-month course is designed to equip patient advocates with the knowledge and skills to be effective agents of change in the retina community and beyond. See the reviews below from participants Jane Cherry and Robin Skeates to learn more:



Jane Cherry

“I was lucky enough to be accepted into Retina International’s pilot programme.

I was diagnosed with Retinitis Pigmentosa in 2019 and since then I have been keen to learn as much as I can about IRDs, but I also wanted to get a view of the bigger picture in terms of research, the patient experience and ways to get patients a seat at the table for the important conversations.

The programme spanned three months covering a huge range of topics including genetic testing, ethics, policy, patient registries and regulatory bodies. For each topic we were given access to reading materials to brief us ahead of a seminar and each seminar we were treated to a really fantastic presenter. They were engaging, passionate about their topics, and really injected that enthusiasm into their presentations and our discussions.

Running in parallel to the seminars, we were given a project to build up and develop along the way. The project broke down the process on how to effectively craft an advocacy strategy. The steps aligned with the progress of our course and pulled from our newly acquired knowledge.

I learned so much from the programme. It’s increased my knowledge level on the relevant topics, given me the ability to speak confidently on them and armed me with tools to push forward to address the issues that impact most on the IRD community.

I met so many great people, both locally and internationally through the programme and it’s really nice to be connected with a passionate community all striving for the same end goal.”

-Jane Cherry, Retina Australia

“I was asked by Fighting Blindness Canada (FBC) if I would like to engage in Retina International’s first ever Education Programme for Patient Advocacy. As a member of the Retina Community, I felt it was important to be as well informed as I could be so that I could provide a more fulsome and impactful patient advocacy role in any future endeavours I would participate in.

This programme was comprised of 11 patient advocates from across the world and from all walks of life, ie. different age groups, academic backgrounds, etc. Although some of the time differences did make the learning a little challenging due to early morning or late-night participation simultaneously, we all benefited immensely. This made for a dynamic virtual class.

The nine session training program that included extensive pre-reading and ongoing weekly and bi-weekly sessions culminated in a broad but vitally important array of topics which included basic understanding of genetics, ethical evolution of clinical trial processes, data gathering and analyses, the importance of genetic testing and genetic counseling as a pairing, patient advocacy boards, policy/program and regulation development, government approval authorities (e.g. FDA, EMU, Health Canada and many others), the role of Health Technical Assessments (HTAs), Communication Strategies, etc.

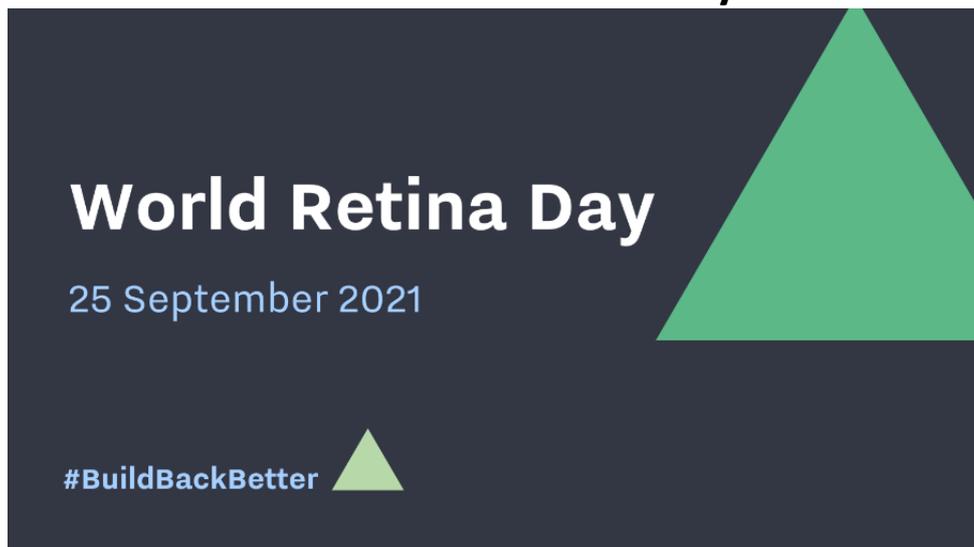
The world class experts that Retina International invited to speak throughout the programme were informative, engaging, open and positive. This included representatives from the genetic counseling community, EURORDIS reps (both from the main body and the Community Action Board), Retina International experts and many others including one from the clinical trial for Luxturna. All RI students received a wealth of information that enables and establishes a very strong foundation for building a global patient advocacy representation.

I want to extend my sincere gratitude to the RI Team, especially Avril Daly, CEO of RI, and Fiona Waters Education and Engagement Manager, for their enthusiastic and tireless input to the programme. I would also like to thank my project partners Shari Shaw (Manager, Health Information at FBC) and Rick Henson (Life/Motivational Coach) for their ongoing participation into our project survey and presentation. Lastly, I would like to thank Ann Morrison, Director of Philanthropy at FBC for putting my name forward for this first ever education programme for patient advocacy by RI.”

-Robin Skeates, P.Eng.

Toronto, Ontario Canada

September: World Retina Day 2021- Highlighting the Impact of the COVID-19 Pandemic on the Retina Community



World Retina Day took place this year on **September 25th, 2021** and the theme was centered around how we can “Build Back Better” from the pandemic. To honour this day, Retina International highlighted the impacts of the COVID-19 Pandemic on the inclusion and wellbeing of its global patient community. We shared some of the statistics from our 2020 study on the impacts of Covid-19, and made graphics in five different languages (English, Spanish, Portuguese, French, and German) for others in our community to share.

The consequences of COVID-19 have greatly impacted the lives of those affected by inherited, age-related, and diabetes-related retinal dystrophies through its effects on:

- safe, accessible mobility and inclusion in society and the workforce;
- migration of services online, furthering the digital divide;
- delays in access to healthcare and support services; and
- slowing the progress of research and innovation which supports the development of potential treatments for retinal conditions.

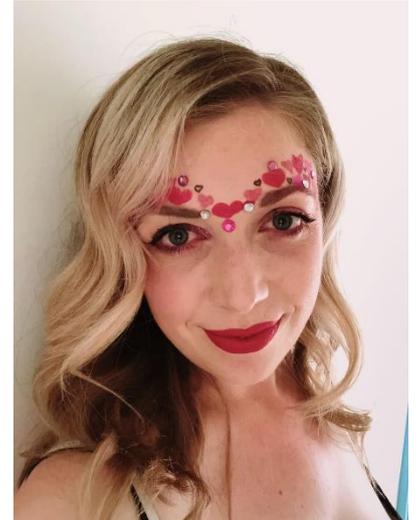
In light of these consequences, we called on governments to prioritise and protect the wellbeing and inclusion of those affected by retinal disease. We were delighted with the collaboration and outputs we saw on World Retina Day from our digital community, and appreciate everyone who helped raise awareness for this important day.

October: World Sight Day 2021- Love Your Eyes



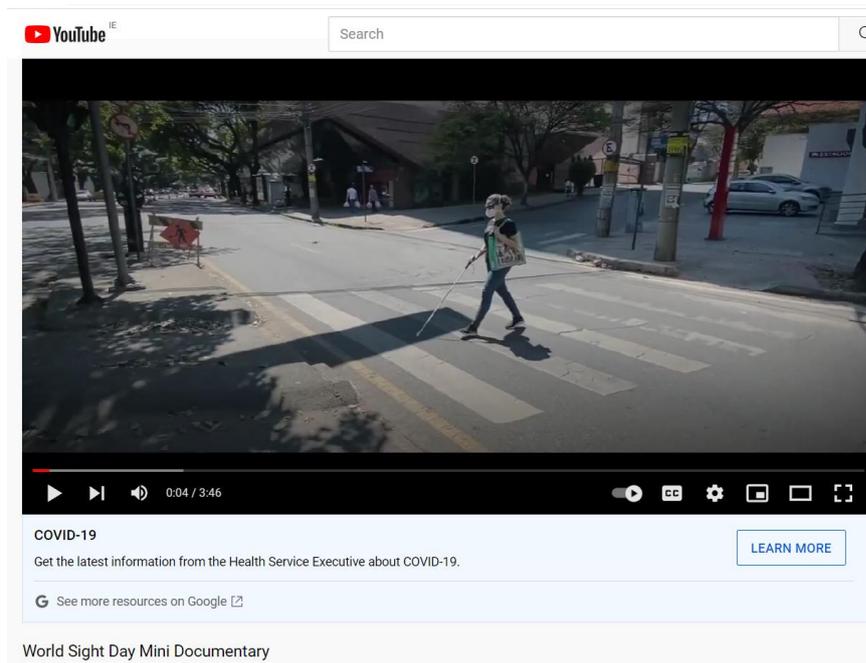
Marina Leite

World Sight Day took place on **October 14th, 2021** and the theme was **Love Your Eyes**. This was a day to encourage prioritizing and protecting your eyes, and to bring attention to the visually impaired community. Members of the community showed they loved their eyes by demonstrating their creativity in the **RI Makeup Challenge!** They used makeup to



Jane Cherry

create hearts around their eyes and shared their photos across social media. Thank you to those who participated in the challenge!



Another way we honoured this day was with the release of the RI **mini documentary**. In the film, we sat down with members of the retina community from all over the globe to hear how the Covid-19 pandemic has affected their lives. We'd like to extend a big thank you to everyone who took the time to share their experiences with us. The video was shared on our social channels and is now up on our [YouTube channel](#).

December: UN Resolution Adoption

On **Thursday 16 December 2021**, the UN General Assembly (UNGA) will formally adopt the first-ever UNGA Resolution on “**Addressing the Challenges of Persons Living with a Rare Disease and their Families**”.

The text recognises the over **300 million persons living with a rare disease (PLWRD)**, their families and loved ones and calls for action from the countries of the United Nations. In November, the Resolution was adopted by consensus by the UN Third Committee. However, for the final text to be an official UN Resolution it must be formally accepted by the UN General Assembly.

Formal adoption of the Resolution is scheduled to take place at a meeting of the 76th UN General Assembly which will start at 15.00 (New York Time)/21.00 (Europe Time).

Avril Daly, Retina International CEO tells us what this means for the retina community:

“Over 300 million people are living with a rare disease globally. People who live with a Rare Disease are often affected by disabling conditions as a result of a chronic or life-limiting condition and it is estimated that only 5% of those living with a rare disease have access to a treatment. This constitutes a significant unmet need.

There are over 300 different genes responsible for Inherited Retinal Degenerations (IRDs), most of these conditions are ultra-rare and the needs of this community must be considered beyond health care. The right to access education and employment are tied to the aims of the Sustainable Development Goal (SDGs), beyond healthcare, and these demand the attention of the United Nations as a whole. With the passing of this resolution our IRD community is empowered to act at a global and national level to ensure our needs are considered by all governments.

Retina International has been actively involved in this process from the outset and as part of Rare Disease International has presented the needs of our retina community to the UN Committee of NGOs and to national missions since 2016. We were honoured to have been part of the journey to this resolution and look forward to working with our community in the IRD space and beyond to ensure that no one living with a rare disease is left behind!”

You can learn more about the resolution by visiting rarediseaseinternational.org and share the news on social media with the hashtag #Resolution4Rare.



In Focus Podcast Series 2

In Focus Podcast Series

This year, we began the second series of our [In Focus Podcast](#), sitting down each month to speak with an important figure in the retina community. In our first episode, we spoke with **Laura Whelan**, a third year PhD candidate in Professor Jane Farrar's lab in Trinity College Dublin. Laura discussed her research, what motivated it, and how she shares her experiences with others through her very popular Instagram and Twitter accounts ([@phdwithlaura](#)).

Next we talked with **Martin Sigsworth**, Senior Employment Manager at [Thomas Pocklington Trust](#), about career development for people with low vision. He discussed the resources Thomas Pocklington Trust offers and laid out some guiding advice for job-seekers. Episode 3 starred **Mary Mammoliti**, a culinary expert living with Retinitis Pigmentosa. Mary runs a popular cooking blog and Instagram account, both titled [Kitchen Confession](#) and has recently debuted her television show [Dish with Mary](#).

In the fourth episode, we spoke with Claudette Medefindt and Karen Denton from Retina South Africa about the impacts of the Covid-19 pandemic on the retina community—on eye health, daily living, and the progress of retinal research. The last episode of this year's In Focus Podcast was in honour of [World Diabetes Day](#). RI CEO Avril Daly spoke with consultant ophthalmologist Professor David Keegan. They discussed how diabetes affects the eyes and why early detection is so important in preventing sight loss.

We were very happy to have such an interesting and inspiring lineup of interviewees this year. We were also delighted to publish the podcast not only on the media section of our website, but also on Spotify, Google Podcasts, and more!

Key Awareness Dates for 2022

The year has flown by, and we look forward to continuing to raise awareness and advocate for the rights of the retina community in 2022! Below are some important awareness dates for our community that you may want to know:

January 4th: World Braille Day

February 11th: International Day of Women and Girls in Science

February 18th: National Caregivers Day

February 28th: Rare Disease Day

March 1st: Zero Discrimination Day

March 8th: International Women's Day

April 7th: World Health Day

April 27th: International Guide Dog Day

September 24th: World Retina Day

October 1st: International Day of Older Persons

October 13th: World Sight Day

October 15th: White Cane Day

November 14th: World Diabetes Day

December 3rd: International Day of Persons with Disabilities

December 12th: Universal Health Coverage Day

Looking to the Future: Plans for 2022

We are very much looking forward to the coming year as we already have a lot planned for 2022! We'll have a new team member joining us in January and we'll also be completing the process to become a registered charity in Ireland.

In the first quarter of the year, we will be sharing the results from our Genetic Testing Landscape study, and we'll have the first meetings of our new Genetic Testing Taskforce. This dedicated group of members and invited patient experts will review the outputs from the study. They'll then develop global indicators on process and access to genetic testing services and work to identify local legislators who may support the action and be our ambassadors.

We're also very excited about the launch of the Visionaries project! For this project, we've partnered with Roche to capture the daily realities of both people living with diabetic retinopathy and people living with diabetic macular edema (DME), as well as their loved ones.

In May, we'll attend the Association for Research in Vision and Ophthalmology (ARVO) meeting in Denver, Colorado, the theme of which is "Accelerating Discovery Through Team Science."

Retina International World Congress 2022



A very exciting event coming up in 2022 is the next Retina International World Congress (RIWC)! It is scheduled to take place in person from **Thursday, June 9th to Saturday, June 11th 2022** in **Reykjavík, Iceland**. The programme for members will be from Wednesday, June 8th to Sunday, June 12th, and the Youth Programme will take place from Tuesday, June 7th to Sunday, June 12th.

This exciting event will bring together some of the world's leading retinal scientists and clinicians as well as global leaders in patient advocacy.

You can register for the event [here](#)!



A Year in Review:

Retina International Member Highlights

2021 has been a year of settling into a Covid-19 world, adjusting to a new normal. The retina community has continued to face challenges posed by the pandemic, including limited access to health and support services, social isolation, the migration of activities online, and many more.

Our membership has worked hard to adapt to these changes and not only provide support to our community through these uncertain times, but also strive to accomplish the goals they set. We would like to take this opportunity to thank our members for their dedication and showcase some of the outstanding highlights submitted from our membership this past year.

Choroideremia Research Foundation



Choroideremia Research Foundation (CRF) has worked for over 20 years to support our global community and fund research leading to a treatment and cure for choroideremia (CHM), a rare degenerative x-linked inherited eye disorder (IRD). Up to 70% of CHM patients are initially diagnosed with Retinitis Pigmentosa (RP), which has similar symptoms to CHM. The CRF continues to advocate for genetic testing to confirm a diagnosis along with genetic counseling for patient support.

In 2021, CRF funded eight grants in six countries, several of which were provided in collaboration with CRF Canada as well as one with the Penn Orphan Disease Center. Projects include the development of four new CHM iPSC lines, the development of a CHM pig model, female carrier research, and more.

CRF also recently launched the International Choroideremia Research Network (ICRN) to stimulate multidisciplinary research collaborations and encourage professional education about CHM. To date, over 90 members have joined the network from 26 countries. Five working groups have been created including International Data Collection, Female Carriers, Industry Collaboration, Clinical and Preclinical Trials, and Pathophysiology.

Over the past year, CRF hosted ten educational webinars on topics such as gene therapy, stem cell therapy, wearable technology, and genetics and the “Meet a CHM Family Member” video series offers a glimpse of how patients and family members are thriving while living with CHM (view at: [YouTube.com/curechm/](https://www.youtube.com/curechm/)). Regularly scheduled virtual socials were held for CHM Patients, 18-35-Year-Old CHM Patients, Spouses/Partners of Patients, and Moms of CHMers, along with other fun, theme-based online gatherings.



This year CRF was able to attend the ISGER conference in Switzerland and present at both AA-Opt in Boston and the annual meeting of Dansk Blindesamfund in Denmark. CRF has also continued ongoing collaborative participation with the rare and ultra-rare disease communities via Global Genes and NORD EURORDIS. Genetic testing remains a priority through our participation in the UK Eye Genetics Group, US Ophthalmic Genetics Study Club and the International Society of Gene and Cell Therapy.

CRF looks forward to hosting its next International Conference, June 16-18, 2022, in Rochester, NY. Save the date! We hope you can join us.

For more information, visit <https://www.curechm.org> or email info@curechm.org.

Fighting Blindness Canada



FIGHTING
BLINDNESS
CANADA

The Impact of the COVID-19 pandemic on eye health in Canada estimates 1,437 Canadians experienced vision loss due to delayed eye examinations and delayed treatment in 2020. [Our cost of vision loss and blindness report](#) further explains implications of the pandemic on the eye health of Canadians.

[https://www.fightingblindness.ca/wp-content/uploads/2021/11/FBC Impact Report VF Digital.pdf](https://www.fightingblindness.ca/wp-content/uploads/2021/11/FBC_Impact_Report_VF_Digital.pdf)

In mid-November, Fighting Blindness Canada partnered with FYidoctors to launch the inaugural ***Eye on the Cure Awards***. Early career researchers battled head-to-head in front of a panel of judges for awards to further their vision research projects.

Learn more about the event here:

[Fighting Blindness Canada's Eye on the Cure presented by FYidoctors](#)

Fighting Blindness Ireland



Fighting Blindness held their 22nd annual Retina conference on 5/6 November 2021. The event stayed online again this year following the success of virtual Retina 2020 which won the 'Educational Meeting of the Year- Webinar Award' at the Irish Healthcare Awards this year.

The first day of Retina 2021, the Scientific Day, brought together leading clinicians and scientists at the vanguard of ophthalmology research to share their insights. This year the aim was to showcase the latest research in gene therapy underway to address certain conditions of vision impairment; and included input from two patients – one who is awaiting gene therapy and another who was the first person in the UK to receive voretigene neparvovec [Luxturna] - who reported that his vision had significantly improved.

Highlights from the Scientific Day include the talks from keynote speakers with experience both in clinical practice and research. One of the keynote speakers was Professor of Molecular Ophthalmology at UCL Institute of Ophthalmology, Mariya Moosajee, who talked about non-viral therapeutic approaches for inherited retinal diseases. These alternative DNA plasmid delivery vehicles can hold genes of any size and have the capacity to reduce the immune response.

The Scientific Day also included early investigators presentations, as well as posters and sizzlers. The winners of the Geraldine Duggan Early Investigator Award and Poster Sizzler Award were the PhD students Laura Whelan (TCD) and Ailis Moran (UCD), accordingly.

Talks were given on the role of the PPI in research, from the keynote speaker Edel Murphy who is the national Programme Manager for the PPI Ignite Network, and Dr Orla Galvin, the Director of Research Policy with Retina International (RI) spoke about research into the patient experience of accessing genetic testing internationally.

The second day of Retina 2021, the Public Engagement Day, focused exclusively on people living with sight loss and their families and was aimed at bringing the latest developments in eye treatments, alongside motivational talks on living our best lives in the face of adversity.

The Scientific Day is available on demand and can be viewed www.retina.ie; while the public engagement day is available to view at www.fightingblindness.ie. Retina 2021 was sponsored by Novartis, Janssen, Roche, AbbVie and Specsavers.



Foundation Fighting Blindness

Fighting RP on the Foundation's Front Line

Michelle Glaze, the Foundation's associate director of professional outreach, shared her personal story of being diagnosed with retinitis pigmentosa (RP) in the film '[Decoding Disease.](#)' In her own words, Michelle also describes her journey with genetic testing and the Foundation Fighting Blindness' impact on her life.

By Michelle Glaze

My vision loss journey started long before I was aware that I had a retinal disease. I grew up in a small town in California. My days were full of exploration and excitement. A tomboy at heart, I was always outside, active and engaged in sports. My first glimpse of any visual challenges surfaced in my early 20s after a long day of co-ed softball. My eyes took a long time to adjust to the change in light from outside to indoors. Shortly thereafter, I went to the optometrist for a checkup and learned that something was atypical with my retinas. The physician recommended that I see a retina specialist for further testing.

About a year later, in 2004, I was clinically diagnosed with an inherited retinal disease. As one can imagine, this is a devastating moment, one that I will never forget. I would lose my vision over time and there was not a treatment. Over the next several years, I did my best to ignore the diagnosis. I was in complete denial, determined that my vision would not worsen. As I noticed changes in my sight, I did everything possible to hide the signs. I was embarrassed, angry, and afraid.

Four years after my diagnosis, my beautiful son was brought into this world and that changed everything. He inspired me to push forward, adjust, and take control of my visual challenges. I wanted to DO SOMETHING – fight to save my vision. This deep desire led me to the Foundation Fighting Blindness. In 2011, I shared my story for the first time and formed a VisionWalk team. It was empowering to be part of the mission to drive research in hope of finding treatments and cures for blinding retinal diseases. My son was by my side during that VisionWalk and has been with me every step of the way ever since.

After being encouraged by my retina specialist to do so, I sought genetic testing in 2013. I was very concerned that my son may have the same genetic disorder as mine. Additionally, I wanted to know my genetic mutation so that I could find and follow any research that may be underway. Genetic testing results indicated mutations in RP1 to be the likely cause of my retinal disease, retinitis pigmentosa. Through genetic testing and genetic counseling, I learned that my disease is recessive. This was a huge relief, as it meant that my son has little to no risk of having retinitis pigmentosa. I felt like a weight was lifted from my shoulders the moment that I heard this wonderful news.

In 2019, an opportunity to join the Foundation as an employee surfaced, and I was excited to be considered. I would have never believed that one day, I would join the team at the Foundation. After many tears of joy and gratitude, I embraced that reality and gift when I was offered the position of associate director of professional outreach. For over two years, I have been helping eye care professionals around the U.S. learn about all the wonderful resources available for individuals with an inherited retinal disease.

My work with the Foundation has helped me accept my vision loss, while providing a tremendous amount of optimism for the future. The research and clinical trials underway give me hope. My dream is to see my son's face clearly one day. However, if my remaining vision is simply preserved, that would have a huge impact and I would be extremely grateful. Thus, I will continue to move forward towards a future where there is a treatment, a cure, with my son by my side every step of the way.

Learn more about the Foundation's Open Access Genetic Testing Program [here](#).

Retina Australia



In 2021 Retina Australia continued to expand its fundraising program, developed strategic partnerships, updated information services on our website, and continued to provide support to our members as the pandemic continued.

In March, a new fundraiser was launched called 'Do it in the Dark'. This campaign gave people the opportunity to host an everyday activity with their friends, family, or colleagues with a twist – custom glasses simulating tunnel vision were worn by participants, providing an insight into the experience of those living with an inherited retinal dystrophy (IRD). A variety of events were held, including an easter egg hunt, dinner parties, and playing video games.

Our popular webinar program continued with three events throughout the year covering:

- Assistive technology for those with low vision
- Research update from Retina Australia grant recipients
- Clinical Genetics Services helping with genetic information, counselling and access to clinical therapy, trials, and research for IRDs

All webinars are now available on the Retina Australia YouTube channel.

The quarterly newsletter was also an important resource providing key updates in the low vision & blindness sector. This was distributed to members through print, audio CD and email.

We successfully launched our first 'Giving Day' fundraiser in June with all donations doubled for 24 hours only. Stories from our members and supporters were featured during the month and promotion was widespread across social media & email. The generosity of our matchers, members and the community resulted in raising over \$78,000 in 24 hours – an incredible achievement that exceeded our original goal.

We also hosted online trivia events in August & October, that provided members and friends an opportunity to get together during lockdown and raise money for Retina Australia at the same time.

In partnership with Novartis Australia, the Discover IRD awareness campaign was launched in September. Discover IRD aims to provide the newly diagnosed and their loved ones with answers to a myriad of questions they may have about inherited retinal dystrophy and genetic testing. Learn more: www.retinaaustralia.com.au/discover-ird/

The 2022 recipients of the Retina Australia medical research grants were announced in November, with a combined total value of \$120,000. Further details can be found at: <https://www.retinaaustralia.com.au/news/>

Retina Brasil

GENETIC TEST FOR IRDs AND THE ENGAGEMENT OF RETINA BRASIL IN 2021



Retina Brasil acknowledges the importance of genetic testing for its community of patients with inherited retinal diseases for a conclusive diagnosis of the disease, as well as for a good prognosis. Hence, since a recent offer from a private laboratory to make available free genetic tests to Brazilians with IRDs, Retina Brasil launched in 2021 a big effort to inform and motivate its members to enroll in consultation and testing.

With the support of its Scientific Committee and other ophthalmologists linked to its regional associations, spread across the country, Retina Brasil contributed to enlarging the number of patients genotyped, as well as to disseminate information about the genetic causes of the retinal dystrophies in Brazilian Society. Free genetic testing allowed people who have no access to eye care to be examined by an ophthalmologist and have clinical and genetic information about their eye disease.

In parallel, Retina Brasil is seeking to introduce genetic testing for IRDs as part of public policy for eye health, incorporating it in the National Health Service which has a coverage of 80% of Brazilian population (170 million inhabitants). For this goal our organization has been active towards the Ministry of Health and the representatives at the National Congress in order to have free genetic tests for all types of inherited retinal diseases.

Retina Bulgaria



In 2021 we, Retina Bulgaria www.retinabulgaria.bg, have continued to expand our activities in our mission to support people living with blinding retinal conditions through the implementation of our projects.

Some of our achievements include:

- a. [“What should I expect from the genetic diagnostic of rare eye diseases”](#) – an educational material for patients, eye care professionals, general practitioners providing basic information about rare eye diseases – the leading cause for blindness among children and young people in Europe; the benefits of genetic diagnostics and of genetic counselling; where and how genetic services can be found in Bulgaria; other practical information.
- b. [“How to welcome visually impaired people in hospitals”](#) – an educational video, promoted by the European Reference Network for Rare Eye Diseases (ERN-EYE), translated to Bulgarian and distributed through the social networks aiming to support VI people in their access to healthcare in the COVID situation.
- c. [Monthly e-bulletin](#) providing updates about research developments, assistive technological achievements, successful stories of people living with retinal degenerations or of those who are taking care of them.
- d. [“Vision portal”](#) – a web-based platform for people with visual impairments providing a variety of practical information about diseases, rehabilitation centers, associated regulations and pathways, educational centers, books for VI people, etc.
- e. [Regional meetings](#) in 5 of the 6 main regions of the country organized jointly with the municipalities and dedicated to increasing the knowledge among the VI communities in these regions about the prevention and treatment of eye diseases, low vision rehabilitation and one for people with blindness, the role of the optometrists, the genetic services, the opportunities for networking.
- f. Participation in public consultations on strategies or regulations related to our community
- g. Presenting the results of the Genetic Testing Landscape Study of Retina International at the National Congress of the Bulgarian Ophthalmological Society.
- h. Our Bulgarian Speaking Online Community (Our Facebook Group) „Пигментен ретинит – група за взаимопомощ“ was created in 2021 and has over 100 patients and family members already.

Retina Finland

Merja Regnér Vice Chairman, Retina Finland.

Virtual Retina Day Event in Finland 18th of September

This year's World Retina Day was on Saturday, September 25th, 2021, but due to the impact of Covid-19 Retina Finland organized its annual Retina Day event as a virtual event on Saturday September 18th. The event was hosted and recorded through Microsoft Teams. The recording is available on YouTube and can be found through Retina Finland's website www.retina.fi.

The agenda of the event included lectures from experts and time for questions. **Outi Lehtinen**, Retina Finland's Communications Officer, did a great job and got once again some of the best experts in Finland to join and speak at the event.

This year's event was again very popular with 55 people attending live and the recording has been watched by 68 people so far. The feedback from the attendees, speakers and organizers of this event is always very positive, which means that this type of an event is very much in demand.

Below you can find the topics and speakers of the event.

- The importance of vision for individuals and the society. **Professor Hannu Uusitalo, Tampere University Hospital Eye Center**
- National health research in Finland on the importance of vision in different eye diseases. **Doctoral researcher Petri Purola, M.Sc., University of Tampere and the Finnish Register of Visual Impairment**
- A vision game in the brain - Five dimensions of vision. **MD Markku Leinonen, Ocuspecto Oy, Turku**
- Measuring the field of vision and predicting its change using VR glasses. **Tuukka Vainio, Tampere**
- Usher Syndrome - From Gene Discovery to Clinical trials. **MD Eeva-Marja Sankila, HUS Retinal Outpatient Clinic**
- Good life of a deafblind. **Experience specialists Sanna Nuutinen and PhD. Riitta Lahtinen, Finnish Deafblind Association**

Advancements in Stem Cell Research. **Professor Heli Skottman, Faculty of Medicine and Health Technology, University of Tampere**

Retina New Zealand



In a year full of twists and lockdowns, Retina New Zealand have managed to launch an exciting new endeavour: the Pathways Project.

The Pathways Project is an initiative that has been created to encourage those with low vision to follow their interests into study or work. This multifaceted project aims to assist those in our community who may need extra support in achieving their goals.

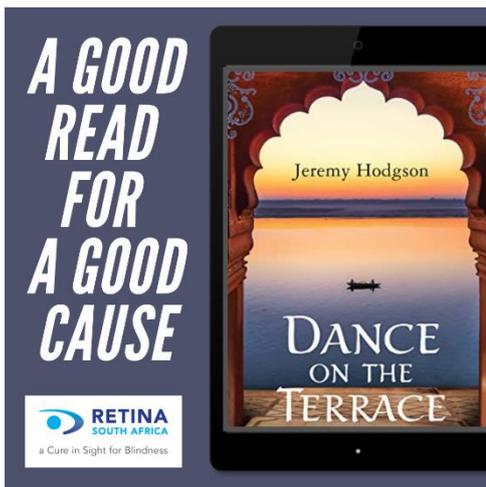
This year, Retina NZ kicked off the Pathways Project by bringing together six individuals from around the country. These inspiring people were filmed sharing their experiences of entering tertiary study and finding work. Discussions included

- the importance of social inclusion;
- becoming a successful self-advocate;
- what works for you and meets your needs;
- advocating for your community;
- building social networks to support each other

A survey was sent out to current and past low vision students in November this year to find out the areas in which they would have liked more support. 75% of those who responded would have liked to have an online social group, and 88% wanted in person meet ups.

The Pathways Project will continue to develop in 2022 as a programme to be used within Universities and other tertiary institutions in New Zealand. Blind and low vision students will have support in ways that meet their needs, such as the development of social groups, help when navigating around campus, and so much more!

The videos are now live on the Retina NZ website: www.retina.org.nz/youth/pathways-project, and are just the gateway into what is to come.



A Good read for a good Cause.

A Dance on the Terrace by Jeremy Hodgson is an intriguing glimpse of the life in India in the early 1980's.

The story is one man's search for a new love and a young woman's search for her family roots. Miriam finds her answers through the newly developed DNA technology.

The Author Jeremy Hodgson is kindly donating 1 Euro for every e-book purchased and downloaded from Amazon. <https://amzn.to/3jbNRa5>

All the monies raised will go towards an extremely important search for mutations causing genetic retinal vision loss in young South Africans.

Diabetes Alert

WORLD DIABETES DAY – 14 NOVEMBER 2021



by Karen Denton

The theme for World Diabetes Day (WDD) 2021 was "Access to Diabetes Care". The year 2021 is significant for the diabetes world, as it is the centenary of the discovery of insulin by Banting and Best in a small laboratory in Toronto.

It is notable that a hundred years after this life saving discovery, there are millions around the world who do not receive adequate care.

As many as 20% of people who are diagnosed with Type 2 Diabetes for the first time already have eye damage that they are usually unaware of.

This is of such significance that in 2007 the UN General Assembly adopted a resolution to recognise November 14th as World Diabetes Day (WDD) to highlight 'the urgent need to pursue multilateral efforts to promote and improve human health and provide access to treatment and health-care education.'

People with type 1 or type 2 diabetes need ongoing care, support, and education to live a fulfilling, meaningful life and to delay or prevent the complications that impact the individual, the family, and society.

One of the questions that we are frequently asked at Retina SA is 'which is more dangerous, Type 1 or Type 2? The answer surprises many - because it doesn't depend on the type of Diabetes. People who are given the tools to care for themselves, know what to do and how to do it, can live a long, healthy life. However, Diabetes is dangerous and can precipitate short- and long-term problems when there is insufficient care. Sadly, as stated above, many people do not have access to adequate care, and face complications such as heart attacks, strokes, amputations, kidney failure and blindness.

The International Council of Ophthalmology states that " ... one-third of people with diabetes have some form of diabetic eye disease that can lead to vision impairment and blindness. With effective diabetes management and early detection through regular eye exams and timely treatment, almost all vision impairment and blindness from diabetic eye disease can be prevented.

If you already have a retinal condition you need to ensure that you protect yourself against the further loss of vision that Diabetes causes. Prevention strategies include:

- Regular exercise
- Healthy food choices
- No smoking
- Control of BMI, BP, and Cholesterol
- Get regular eye checks

Retina South Africa did intensive training of councillors to improve public education on Diabetic related vision loss.

Pic of Claudette Medefindt, Lindiwe Maredi, Victoria Musimbo and trainer Karen Denton.

Retina UK



The last 12 months have been increasingly challenging for our community as the effects of the pandemic continue to disrupt day to day life.

Conferences

The charity held its very first online Professionals' and Annual Conferences in April. More than 400 people registered for the Annual Conference and 200 registered for the Professionals' Conference. The theme for 2021 was 'genetics' and the Conferences saw the launch of the new Unlock Genetics website.

Unlock Genetics

This new resource was developed in response to Retina UK's Sight Loss Survey in 2019. Of the 1,000 people who responded, 43% said they were 'not aware' of genetic testing or that they were 'aware of it but it is not available to me'. It is estimated that 85% of the Retina UK community do not have a current genetic diagnosis.

The new website (www.RetinaUK.org.uk/genetics) aims to increase the level of awareness of genetic testing and genetic counselling, empowering our community to make fully informed decisions about their lives, healthcare and family planning. It has been developed with significant input from experts in the field and also those who live with inherited sight loss.

Webinar series

Our webinar series has so far featured three different research scientists undertaking research into different areas of inherited retinal dystrophy causes and treatments. They included Optogenetics, DNA and RNA base editing tools and inflammation and retinal degeneration in RP. We plan to hold one a month in 2022. All of the webinars have been recorded and are available on the Retina UK website: www.RetinaUK.org.uk/recordings.

Talking about wellbeing

Another outcome from our Sight Loss Survey in 2019 was that 92% of respondents told us they experienced psychological effects, with the most common being loss of confidence, anxiety and stress. The pandemic has sadly made these existing feelings worse as can be demonstrated in the volume and length of calls to the Retina UK Helpline.

Working with Arthur Ellis Mental Health Support, Retina UK has provided our volunteers with a series of online training modules to help them identify and deal with issues surrounding their own wellbeing. This was a vital part of enabling them to better support our community.

In 2022 we will further develop this work to provide additional training for volunteers and create accessible wellbeing resources for our community.

NEWS FROM STARGARDT APNES-RETINA ARGENTINA



Stargardt APNES-Retina Argentina is a non-profit association which began in 2010 and includes patients and family members with inherited retinal and optic nerve dystrophies (IRDs). They

affect children, youth and adults and hinder effective school and work inclusion and often cause exclusion and poverty as well as isolation and depression in patients. They have especially high impact in low middle-income countries (LMIC).

Stargardt APNES-Retina Argentina is a member of FADEPOF (Federación Argentina de Enfermedades Poco Frecuentes), RETINA INTERNATIONAL, RETINA IBEROAMÉRICA, FAICA (Federación Argentina de Ciegos y Amblíopes) and the Argentine Network of Patients for Advanced Therapies (RedAPTA), which is a network developed by the Ministry of Science and Technology that brings together associations of patients whose pathologies will require advanced therapies such as gene therapy, gene editing and others to reach a cure, protecting them because by their desire for a cure, patients and their families could be vulnerable to inappropriate offers of unapproved treatments.

In Argentina, public and private health systems do not cover genetic diagnosis, generating great inequality between patients who can and cannot afford them.

Stargardt APNES-Retina Argentina sought to impact this domain in a few ways. Since 2013, we started by taking clinical and genetic data of IRD patients in a database registered with the Ministry of Justice of Argentina, with full support of and consent by the patient community. So far, we have more than 700 IRD patients with complete clinical and genetic results obtained through different agreements signed with the Ministry of Science and Technology (MINCYT) who sponsored the molecular diagnostic test for one specific IRD for patients without resources, thus equalizing access to genetic testing for the poor. We also signed an agreement with the University of Barcelona, Spain, to do adequate genetic tests to identify the genetic variants which cause all IRDs, along with other free genetic tests to help people who cannot obtain them. In all the cases the database is completely anonymized, according to the personal data protection law (25326) and all patients and families receive free and adequate genetic counselling by experts from PANIRD (Panamerican Inherited Retinal Diseases Group) who are volunteers in our organization.

This work allowed us to include in 2018, the first 10 Latinoamerican LHON patients in a clinical trial for ND4 gene therapy with great success. The correct and fluid articulation between all the actors involved: association of patients, local and foreign researchers, and the state through which the commissions of MINCYT supported and accompanied all the instances of this project, allowed patients with low resources to have equal opportunities to access to the gene therapy, preserving their safety at all times.

During the COVID-19 pandemic, we continue all of our activities with IRD families, working topics such as special care for low vision or blind people during the pandemic, vaccines, and advancing learning about IRD diagnosis, therapies, care of vision, and patient rights according to la Convención Internacional sobre los Derechos de las Personas con Discapacidad through virtual webinars, webpages, and notes. In the same way, we collaborated with other Iberoamerican associations in the organization of the 1st International Congress of Retina Iberoamerica last October 2021. This Congress had the participation of researchers from the USA, Latin America and Spain, (members of PANIRD) explaining in their own language advances and challenges in IRDs, which could be directly followed by thousands of patients and families in Spanish, Portuguese, and English in all Iberoamerica.

Genetic sequencing and advanced therapies as a whole are invaluable tools to better understand genetic diseases and address the solutions for IRDs.

The Stargardt APNES- Retina Argentina focus is centred on patients who are the origin and destination of these scientific developments. The researchers' job must be to find the cure, and patient organizations must provide information, act as a link, instruct patients and disseminate the correct operations, avoiding unnecessary risks that may worsen their condition. Our work is to link with the role of the state to safeguard citizens and their data, encourage research, support organizations by providing expert evaluation and equalizing opportunities, fix the inequity that prevents access to diagnosis and therapies to many of the citizens living in LMIC countries.

Usher Syndrome Coalition

The USH Ambassador Program

The Usher Syndrome Coalition is a small nonprofit with a big mission - to find and support every individual living with Usher syndrome and their families. With an estimated 400,000 individuals worldwide living with this rare syndrome, we knew that we would need to be creative. In the Spring of 2018, a small board committee met to discuss ways in which we could grow our outreach efforts. From this discussion, the USH Ambassador program was born.

An USH Ambassador is a volunteer who is knowledgeable about Usher syndrome and the community, and is willing to be a point of contact in their state for individuals and families. Candidates for this volunteer position must either have Usher syndrome or have a family member with Usher syndrome. Ambassadors educate their community about Usher syndrome and the USH Trust Registry; provide information and resources; connect with others in their state/country; and may represent the Coalition on committees, at workshops, and conferences. All ambassadors are provided training, and can participate in monthly meetings with other ambassadors.

What started as a committee of 5 has now grown to almost 40 members, with representation in 8 countries. Ambassadors play a key role in growing our community. Each has an "official" ambassador email address and a webpage on the Coalition's website. Within their states or countries, they are reaching out to agencies and organizations that work with or serve children and adults with Usher, and their families. They are also reaching out to individuals living with Usher and building the Usher community worldwide, one person at a time. They may do this in a variety of ways including email, social media, and/or video calls.

There is strength and hope in numbers. If you'd like to learn more about becoming an USH Ambassador, please fill out a volunteer application.

Usher Community

Conferences relevant for the Usher Community in 2021 – News from the Usher Community for the Usher Community

by Dominique Sturz, Patient Advocate Usher Syndrome & Rare Diseases

This year we have seen several high quality conferences on Usher Syndrome despite the impacts of the pandemic.

USH2021 Usher Connections Conference 12-15 May 2021

This year's USH2020 Connections Conference organised by the US based Usher Syndrome Coalition was a virtual event from 6-11 July. It was a joint event with the Usher 1F Collaborative hosting a two day Scientific Workshop, supported by the Chan Zuckerberg Initiative, on Therapeutic Strategies for Large Protein Coding Genes in Usher Syndrome.

USH2022: Next year's **Usher Connections Conference** is planned as a hybrid event (in person and live-streamed) in Austin, Texas, **9-10 July 2022**, registration will open in January 2022.

FFB USH1B Scientific Workshop

The Workshop, hosted by the Foundation Fighting Blindness and supported by Save Sight Now, was held virtually on September 13, 2021. This full day meeting was co-chaired by Dr. Shannon Boye and Professor José-Alain Sahel, leaders in the USH1B field and brought together leading experts from academia and industry, to discuss openly, and in detail, what is known about Usher 1B disease pathology, disease models, clinical characteristics, and therapeutic approaches. Presentation slides can be accessed here:

<https://www.fightingblindness.org/usher1b-workshop#presenters-1009>

Usher Info Scientific Symposium 6-8 Oct 2021, 15.00pm-18.30 CET each day online

The symposium was co-chaired by Prof. José-Alain Sahel and Prof. Christine Petit and gathered outstanding experts (ENTs, ophthalmologists, residents, young scientists, students, patient associations) in the field of sensory disorders. The recordings are available here: <http://pro.usherinfo.fr/usher-info-symposium-2021/replay-vod/scientific-symposium/>

Usher Info Patient Symposium, 9 Oct 2021, 14.00-18.00 CET, online

The goal of this afternoon was to inform patients with Usher Syndrome and their families about recent breakthroughs in the scientific field, including social and human sciences and lived experiences. Conference language French, French simultaneous transcription & French sign language were offered. Translated-captioning into 23 languages was kindly provided by the [Usher Syndrome Coalition](#)

Acknowledgements

Retina International would like to thank again our members, and various collaborators over the course of 2021. We would also like to make a special mention of the Retina International Network of Partners, of whom without their support our work would not be possible.

With your continued support, we look forward to continuing our mission to foster research, and ensure universal access to diagnosis, treatment and care for people affected by Retinal Degenerative conditions in 2022.



Retina International Network of Partners



Photo: Retina International Network of Partner logos - AGTC, Apellis, Biogen, Boehringer Ingelheim, Editas, Janssen Global, Novartis Pharma AG, ProQR Therapeutics, Roche, Spark Therapeutics, and Sparing Vision