Retina International Newsletter

Winter 2020
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Letter from the Chief Executive Officer of Retina International, Ms. Avril Daly


The year 2020 has been a year like no other. We at RI started the year with a great sense of optimism; we were excited by the portfolio of work we were undertaking, and were enjoying working with our members to develop our new strategic development plan. Most of all, the team were looking forward to meeting with all of you; our members, scientific community, and partners at the Retina International World Congress that was due to take place in Reykjavik, Iceland in June. We were working with our Retina Youth Council to put together an exciting programme of activities, developing our Continuous Education Programme and of course planning for our General Assembly where important decisions for the future of our organisation would be taken.

Photo: Avril Daly, CEO

As we all know, we did not meet in Iceland as planned, however, we did get the opportunity to fulfil our objectives. With your help we completed our programme of work for the year, we completed our new strategic plan and indeed we hosted an exciting Continuous Education workshop in June, an engaging and motivating Retina Youth Council Meeting in August and in September we hosted our General Assembly.

COVID-19 has changed the way we live now, and will have some impact in how we live in the short to medium term. From the start of the pandemic, the vision impaired community experienced isolation that was unique: in many cases it was difficult to rely on guides due to the need for social distancing, and of course going out alone was difficult for this same reason. Basic things that had been taken for granted, such as being able to hold onto railings or feel your way around the shelves in a grocery shop, were now called into question. The members of Retina International were active from the outset in engaging with their members who were vulnerable and alone. They brought comfort and eased the isolation for many. Retina International hosted a series of podcasts for our members during the summer months to provide information on the virus and how it related to our community, while also having the opportunity to speak to experts about their work in the field of research, care and innovation. As the feedback from you was positive we will continue this series monthly in 2021.

Although COVID-19 kept us far apart, we on the RI team have never felt closer to our membership. We spoke many times across many time zones and learned about you and your work. This was very important for us and particularly for our new team members. You
participated in our surveys designed to understand the impact of the pandemic on your everyday lives. You shared your concerns about access to medical appointments, care and treatment and rehabilitation services. The area of ophthalmology has been severely impacted. The waiting lists for appointments are getting longer and precious time to save sight is being lost. The outputs from our COVID-19 Survey as well as our Cost of Illness Study in the USA and Canada and our study on Attitudes to Treatments of Age-related Macular Degeneration and Diabetic-Related Eye Disease will soon be published, but what we as a community have learnt from them will help us immediately to advocate for better access to early diagnosis, treatment and care, rehabilitation and access to existing and emerging therapies.

Your experience informs our perspective and all that we do. We thank you most sincerely for giving so much of your time to participate and to tell us your reality. It will make a difference.

The surveys highlighted issues around the limitations placed on this community because of lack of online accessibility in work, leisure and practical activities during the pandemic. The points raised will help us to develop better, smarter ways to communicate with you. We will do all that we can to ensure you receive information in a way that is accessible to and hope that you will tell us if something doesn’t work or if you have an idea or suggestion.

Supporting and developing research and innovation that can lead to treatments and cures for retinal dystrophies is the enduring purpose of Retina International, it is the reason we were formed in 1978. This remains our overarching goal, our north star. We will continue to advocate for improved research infrastructures, access to diagnosis and care, and we will work hard to engage with regulators and decision makers to ensure equitable access to emerging therapies. While we do all of this we must take the learnings from 2020: while we wait for treatments, we must be mindful of the inclusion of our community in all aspects of society, in particular as we become more reliant on on-line support and we must consider the wellbeing of this community. With this in mind, our theme for 2021 will be “Inclusion and Wellbeing”, and we look forward to working with you.

Finally, there has been change in leadership in 2020, as Christina Fasser has retired from her role as President and Franz Badura is taking on the role of Chair. I would like to take this opportunity to thank Christina for her leadership, wisdom and great advice throughout the years. It has been a pleasure to be on this journey with you and I look forward to more adventures and laughter in the future. I also would like to welcome Franz and thank him for taking on this task. We enter a new phase in the development of RI and we are delighted to have you as our leader.

On behalf of all at Retina International, I would like to wish you a very happy and restful holiday season, a peaceful and healthy new year. We remain optimistic for 2021 and look forward to working with you as we take a step closer to achieving our goals!

Avril Daly
CEO
A Year in Review: The Retina International Executive Team

Dr. Orla Galvin, PhD.

Director of Research Policy

For me, 2020 had many highlights! Two new triumphs I was delighted to deliver were the first Retina International ARVO Education course on Patient Data, and the first Neurological- Retinal webinar, both available online. Delivering the cost of illness reports of IRDs in the USA and Canada has to be another highlight as I’m excited to see the huge dividends this data provides for advocacy and policy actions, supported through the Know Your Code advocacy tool through 2021 and beyond! Another new 2021 project I’m excited for regards re-evaluating the aging eye. I’m really looking forward to collaborating with you on all of our shared outputs in the new year! Happy holidays!

Photo: Dr. Orla Galvin

Fiona Waters

Community Engagement & Outreach Officer

Since joining the Retina International team in August 2020, I have had the great pleasure of engaging with you all; our innovative and dynamic community of patients, researchers, industry partners, and policy makers on a cohort of exciting projects. Some highlights to date include putting together the “Know Your Code” genetic testing advocacy portal, as well leading Retina International’s collaboration with transMed; training and facilitating Early Stage Researchers in the delivery of our public event “From Bench to Bedside – The journey to creating a sight-saving drug”. In 2021, I am very much looking forward to developing working more with our Special Interest Groups, including Retina Youth, as well as exploring new opportunities to expand the Retina International outreach network. Please don’t hesitate to get in touch at: fiona.waters@retina-international.org.

Photo: Fiona Waters
Kelly McVicker

Administrator

I joined the team in August 2020, and have worked closely with the Executive Team and Board. I have also lead the transfer of the Retina International server, which has been a major step forward for the organisation and has set us up for the amazing growth and projects coming in 2021. I am sincerely grateful for the warm welcomes I have received thus far, and am excited for what’s to come in 2021. Wishing everyone in the Retina International network warm Holiday wishes.

Photo: Kelly McVicker

Dr. Petia Stratieva, MD, PhD

Special Projects Manager

This year, I have been facilitating Retina International’s Genetic Testing Landscape Study—which aims to study of the processes for genetic testing and counselling for inherited retinal dystrophies (IRDs) in Europe. The objective of the study is to identify the barriers and drivers for accessing genetic testing services in Europe so that we may advocate effectively for equitable, affordable, accessible and timely genetic testing for IRDs. In 2021, I look forward to publishing the findings from 18 countries in Europe, and continuing this project into its future stages.

Photo: Dr. Petia Stratieva

Special Thanks to Outgoing Staff

Retina International would like to extend a special thanks and best wishes to outgoing staff members in 2020 Sean Heagney, Science Communications Executive, and Deborah Oshakuade, Research Officer, for their work and commitment to the RI team. Their contributions have been valued across the network, and we wish them the very best of luck in their future endeavours.

We would also like to extend a warm welcome to incoming staff during 2020; Fiona Waters, Community Engagement & Outreach Officer, & Kelly McVicker, Administrator. We are excited to welcome them to the team as Retina International embark on new projects and chapters.
A Year in Review: Retina International 2020 Highlights

Retina Youth Conference

Retina International were delighted to welcome over 100 attendees to our first virtual Retina Youth Conference on August 24th and 25th 2020. Then President of Retina International Ms. Christina Fasser opened the conference expressing a call to action for young people to actively engage in patient organisations and networks; “[The] Youth Council, that’s for you, and you have to make it happen... [it is] extremely important that young people support each other”.

Ophthalmologist Kirk Stephenson from the Mater Misericordiae Hospital in Dublin, Ireland, provided the background to genes, inheritance, and diagnosis of retinal degenerative diseases. Kirk raised issues such as timeliness of genetic testing to facilitate accurate diagnosis and therapeutic intervention. Ben Shaberman Senior Director of Scientific Outreach of Foundation Fighting Blindness (US) shared with us an overview of the current state of therapeutic research, highlighting the 40+ clinical trials presently ongoing to tackle retinal degeneration. He again reiterated the essentiality of genetic testing, which can incur a change of clinical diagnosis, access to clinical trials, and identification of appropriate therapies. Marina Sutter, Interim Chair of the Retina Youth Council, who lives with an IRD, discussed and the role of Public & Patient Involvement (PPI) in research. Marina highlighted the need for a shift in paradigm for research and patient communities, and developing a new, collaborative research journey with patients.

The second day of the Retina Youth Conference followed a theme of patient fulfilment and empowerment. Gilbert Muhumuza from Retina Uganda presented on advances in Assistive Technologies, where innovations such as self-driving cars, 3D-printing, and robotics may all become central features in the near future. Vice President of Retina International & Head of Science at Retina South Africa Claudette Medefindt shared with us her inspirational lived experience of Retinitis Pigmentosa. “The most important assistive device is your family and friends... Know when to ask for help”. Allison Galloway shared with us her experience as a parent of two young children, Logan and Zoe, who both live with Leber’s Congenital Amaurosis. Allison spoke of the emotional journey she felt at her son Logan’s diagnosis, and how engaging with her local organisations helped her find the information and resources to help Logan and Zoe live full lives. The final speaker was Karl Meesters; a personal, career and executive coach, who himself lives with an IRD. Karl implored our young attendees to follow their passion, strategize around their strengths, and focus on the process - not the result. “Don’t wait for others to solve your problems, they will be late. Be the captain of your own ship. Make noise.”

We would like to extend our sincere thanks to the organisers of the Retina Youth Conference, our hosts Sean Heagney and Marina Sutter, all of our attendees, and to our funders; Janssen Global and Novartis Pharma AG for supporting this event and our continued work with the Retina Youth Council.
Retina International General Assembly 2020

Retina International held its 22nd General assembly on September 5th and 6th 2020. Due to the COVID-19 travel restriction it was, for the first time, held as a virtual meeting. The General Assembly was attended by 20 full members and 4 candidate members and the members took some very important decisions including:

- The new constitution was unanimously adopted
- The registration of Retina International in Ireland was formally adopted.
- Franz Badura (Germany) was elected as the incoming chair of Retina International
- A new Board of Directors (formerly known as the Management Committee) were elected to serve RI upon registration with the charity regulator in Ireland. Its members are:

  D’Souza Jeremy (Retina Australia)
  Holahan Ronan (Fighting Blindness Ireland)
  Menzo Jason (Foundation Fighting Blindness USA)
  Medefindt Claudette (Retina South Africa)
  Morita Saburo (Japanese RP society)
  Ramshage Caisa (Svenska RP-Föreningen)
  Sánchez González David (FARPE)
  Smedstad Martin (RP-Föreningen i Norge)
  Sutter Penz Marina (Retina New Zealand)

We wish them every success in their roles!

Photo: Attendees of RI General Assembly 2020 via Zoom
COVID-19 Project

As COVID-19 continued to affect every aspect of our lives, Retina International - with the support of Novartis Pharma AG, embarked on a COVID-19 project to create relevant resources tailored to the unmet needs of the Retina community.

COVID-19 Bulletin

This involved a weekly COVID-19 Bulletin, provided in 5 languages, that communicated up-to-date information from global sources on topics related to research, wellbeing, and accessibility in light of social distancing measures. To review these publicly available bulletins, please click here.

COVID-19 Surveys

We have also undertaken two surveys, with a view to understanding and reporting on the impact of COVID-19 on the retina patient community. We are looking forward to publishing these data in the coming year.

In-Focus Podcast Series

A hugely popular output from this project, and one we will be seeking to continue in 2021, was our “In-Focus” Podcast Series. A total of thirteen podcasts were produced in our pilot series, they were: (Click title to open podcast)

**Episode 1: Christina Fasser**
**Episode 2: Claudette Medefindt & Karen Denton, Retina South Africa**
**Episode 3: Dr. Juliana Sallum, Board Certified Ophthalmologist & Geneticist, Brazil**
**Episode 4: Professor Joe Carroll & Adaptive Optics**
**Episode 5: Michael Griffith, Founder of Fighting Blindness Ireland**
**Episode 6: Marina Sutter, Interim Chair of the Retina Youth Council, Retina International**
**Episode 7: Professor John Flannery & Optogenetics**
**Episode 8: Carol Brill. Usher Syndrome patient advocate**
**Episode 9: Chad Andrews: Senior Advisor on Policy, Equity and Access, FB Canada**
**Episode 10: Dr. Petia Stratieva, Patient Advocate, Retina Bulgaria & Retina International**
**Episode 11: Russell Wheeler & Health Technology Assessments**
**Episode 12: Dr. Brian Mansfield, FFB & the MyRetina Tracker Registry**
**Episode 13: Prof. Jose Carlos Pastor; Ophthalmology & COVID-19**

We would like to thank each of our contributors to this podcast series, and are very much looking forward to continuing with series 2 of the In-Focus Podcast in 2021. If you would like to submit any themes for us to explore, please contact Fiona Waters, Community Engagement & Outreach Officer, at fiona.waters@retina-international.org
COVID-19 Webinar: A Unified Voice for the Ageing Community

On September 3rd, 17:00 CET, Retina International hosted a multi-disciplinary panel exploring the impact of COVID-19 on the ageing patient community, as part of our COVID-19 Project kindly supported by Novartis. This cross-disciplinary panel explored how COVID-19 restrictions and social distancing measures have impacted quality of life, healthcare and access to essential services for patients of the ageing community, in particular those affected by retinal degenerative and neurodegenerative conditions.

Photo: COVID-19 Webinar advertisement

Joining us on the panel was Dr. Keith Gordon (Canada) of the Canadian Council of the Blind and Chair of Retina Action, Dr. Heather Snyder (USA) from the Alzheimer’s Association, Karen Denton (South Africa) from Retina South Africa, and Donna Walsh (Ireland) from the European Federation of Neurological Associations.

Click here to view the full webinar on our YouTube channel.

Repeatedly highlighted in this panel discussion were the challenges faced by those living with retinal degenerative and neurodegenerative conditions in the ageing community during COVID-19. This included the additional burden imparted by the introduction of social distancing measures, resulting in the stymying of clinical trials and lab research, lack of access to supports such as rehabilitation and counselling, and an increase in social isolation and loneliness.

However, COVID-19 has also posed newfound opportunities; increased online events and working from home has improved accessibility for those with low vision and removed the stressful barrier of commuting. COVID-19 has provided the opportunity for us as patients, advocates, clinicians, and researchers to re-evaluate the status quo and create innovative solutions to these obstacles through a fast-tracked digital transformation, and the prioritisation of patient supports and public health.
World Retina Day 2020 – Know Your Code

Retina International announced the launch of a new genetic testing advocacy portal, **Know Your Code** to mark World Retina Day 2020.

Photo: Know Your Code logo.

The portal, supported by an unrestricted educational grant from the Allergan Foundation, was launched as part of a call to action for the Inherited Retinal Degeneration (IRD) community to advocate for accessible and affordable genetic testing to accurately diagnose their conditions.

**Know Your Code** is a go-to web portal for information on genetic testing, designed for patients, clinicians, researchers, and health policy specialists alike. Included in the portal is a comprehensive insight into the genetic testing & counselling process, FAQs from the patient and clinical community, as well as the realities that exist regarding disparities in access to these services, which are often dependent on where a person lives. It is also home to our suite of [IRD COUNTS Cost-of-Illness studies](#), the most recent of which (Canada & US) were published on World Sight Day 2020.

This online platform equips individuals with up-to-date information as well as the context needed to be engaged and informed advocates for affordable and accessible genetic testing services within their own networks.

There are now almost 300 IRD-associated genes, yet this only permits for definitive genetic diagnoses for 2 of every 3 IRD patients. Routine genetic testing will fast-track the discovery of more IRD-associated genes, paving the way for better understanding of disease pathology and potential therapeutic interventions. Genetic testing enables patients to access available treatments, and is a prerequisite to participate in clinical trials.

However, the benefits of genetic testing extend far beyond clinical and therapeutic impact. “Knowing your code”, and the specific inheritance pattern of one’s IRD, empowers patients and their families to make informed life and family planning choices. These choices optimise the continued wellbeing of patients and their families, which can often be severely impacted by progressive vision loss.
World Sight Day 2020 – Cost of Illness of IRD’s in the US & Canada

On World Sight Day, October 8th 2020, Retina International proudly launched the second instalment in our suite of IRDCOUNTS Cost of Illness Studies, which aimed to estimate the societal disease burden, and economic impact of IRDs in the United States of America (USA) and Canada – a cost-of-illness study.

IRDs are rare diseases, and the number of people affected by these conditions, and their impact on the greater population has remained largely undocumented – both at a national and global level. To address the large data gap surrounding the impact and occurrence of IRDs, Deloitte Access Economics was engaged by Retina International, together with a consortium that included patient-led organisations and industry partners. The consortium partners involved in this study were: AGTC, Fighting Blindness Canada, Foundation Fighting Blindness USA, Janssen Global, Novartis Pharma AG, and Retina International.

Here is some key data:

- IRDs in the USA and Canada resulted in a socio-economic burden of up to US $31.7 billion and CAN $1.6 billion respectively in 2019.
- Two thirds of these costs were associated with wellbeing costs; up to US $20 billion (63%) in the US, and CAN$1 billion (66%) in Canada.
- Productivity costs (cost relating to employment) were the second highest burden in both the USA and Canada, amounting to US $4.056 billion (14%), and CAN $205.1 million (13%), respectively.
- The third highest cost was attributed to informal care – 8% of the total cost in the US, and 10% in Canada. This accounts for assistance with domestic tasks such as cooking and cleaning, organising and administering medication, shopping, transport, and monitoring wellbeing.

**Click here to view the full publications on our Know Your Code portal.**
Webinar: IRDCOUNTS: US & Canada Cost-of-Illness study – A Panel Discussion

On Thursday October 22nd Retina International hosted a webinar discussing the key findings and impacts of our ground breaking US & Canada Cost-of-Illness Study. Joining us on the panel was:

Dr. Orla Galvin - Retina International
Mr. Doug Earle - Fighting Blindness Canada
Dr. Todd Durham - Foundation Fighting Blindness
Ms. Allison Galloway - Patient Representative
Dr. Rob Koenekoop - Clinical/Research Representative, Montreal Children’s Hospital

After a presentation of the key data from our suite of IRDCOUNTS studies by Dr. Orla Galvin, Doug Earle discussed the impact of this data and its timeliness with the recent approval of IRD gene therapy Luxturna by Health Canada. Dr. Todd Durham provided insight into the methodology of this survey-based study, before outlining its importance and its wider impact on the retina community as a whole. Allison Galloway joined us to provide her perspective as a mother to two children, Logan and Zoe, who are diagnosed and living with Leber’s Congenital Amaurosis. Allison provided our audience with a powerful personal testimony to the wellbeing and informal care cost to living with an IRD, and emphasised the impact these studies have on patient advocacy, by highlighting the everyday realities and unmet needs. Finally, Dr. Rob Koenekoop from the Montreal Children’s Hospital concluded the panel with a clinical perspective, outlining the key role genetic testing has to play in the next stage of advances for Inherited Retinal Degeneration research and supports, and mitigating the staggering economic cost of these conditions.

Click here to watch the full IRDCOUNTS webinar on our YouTube Channel.
Retina International & transMed: From Bench to Bedside - The journey to creating a sight-saving drug

Retina International were delighted to collaborate with transMed, a research consortium and innovative programme that aims to educate “translational researchers” that focus on the bench-to-bedside development of treatments for Retinal Degenerations. Fiona Waters, Community Engagement and Outreach Officer for Retina International, collaborated with a cohort of thirteen Early Stage Researchers (ESRs) from all over the world, carrying out their research across Europe.

This project involved Retina International training this group of young researchers in science communication, and in presenting to a lay audience with low vision. In addition, Retina International facilitated this cohort of ESRs in presenting a series of bite-size talks exploring the step-by-step process of drug development, clinical trials, and beyond. The event was tailored for those living with a Retinal Degeneration, or who are simply curious about learning the start-to-finish process of translational medicine and the story of life-changing research.

Our first group of speakers provided our audience into how the eye works, a background to retinal degenerative conditions, and why it is so challenging to create therapies for them. Our later speakers then took us through the process of finding drug targets, designing drugs, making & testing them, and then finally carrying out clinical trials.

[Click here to view the full event on our YouTube channel.]

![Retina International & transMed event advertisement]

Photo: From Bench to Bedside event advertisement
Retina Action

Retina Action is a global coalition of non-governmental agencies, charities and patient-led groups concerned with vision loss and committed to improving the lives of those affected in our ageing population. The goal of Retina Action is to raise awareness around the importance of regular screening, early diagnosis and timely intervention to mitigate retinal disease onset and progression. With this in mind, a series of toolkits have been established as an educational resource for clinicians, patients and stakeholders enabling access to a comprehensive set of guidelines and coping measures that aid patients in managing complex retinal diseases, including Age-Related Macular Degeneration (AMD) and Diabetes-related Eye Diseases (DED).

Over the course of 2020, we have been gathering data on the lived experience of these conditions. These data are informing our universal call to action for the ageing eye, which will follow the theme of Inclusion and Wellbeing. This call to action is set to be launched on January 12th 2021; and at 2pm CET, we are delighted to be hosting a launch webinar, which will include a panel discussion and Q&A. Joining us on the panel will be:

- 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, ProRetina Deutschland
- Dr. Juliana Sallum - Board Certified Ophthalmologist and Geneticist, UNIFESP, Brasil

Click here to register for the Retina Action Webinar.

Photo: Retina Action Webinar advertisement
Later in 2021, we are excited to share with our community a series of short films demonstrating the lived experience of AMD and DED, with a view to increasing public and patient awareness around these actionable conditions.

We are looking forward to further engaging with the global vision and aging community to reframe the aging eye, and working together to promote early detection of these conditions in order to eliminate avoidable blindness in at-risk groups.

We would like to thank Novartis Pharma AG, Roche, and Janssen Global for their continued support of the Retina Action initiative.
ARVO: CME-accredited Education Course

Retina International CEO Avril Daly, and Director of Research Policy Dr. Orla Galvin, curated a Continuous Medical Education (CME) accredited online education course entitled “Patient data: Recognition, evaluation, incorporation and practice”, which was proudly hosted by the Association for Research in Vision and Ophthalmology (ARVO).

This course highlighted the importance of a patient-centred approach to research and clinical practice, public patient involvement (PPI), understanding the full scope and potential of patient data and the patient voice, and provided practical guidance on why and how people living with sight loss have a role in the development and execution of benchtop and clinical research studies. Discussions were facilitated on how patients and their caregivers can bring stakeholders together to address gaps in research, and the unique roles patients play in prioritizing a research agenda – before and during clinical development.

Upon completion of the course participants will demonstrate the ability to:
- Recognize, describe and discuss what patient data is.
- Evaluate and interpret patient data.
- Illustrate the importance of Patient Reported Outcome Measures
- Incorporate and practice patient engagement in their research.

Expert patient advocates and researchers spoke at the online event, including presentations from eminent clinician-professors, I would name them and Retina International member organisations Fighting Blindness Ireland and Foundation Fighting Blindness.

Retina International and ERN-EYE

In 2020, Retina International has continued its longstanding commitment for improving the care of the EU patients with rare eye diseases by sharing its expertise and knowledge with the clinicians, researchers and patients from the European Reference Network dedicated to rare eye diseases – ERN-EYE.

To ensure that the needs and priorities of patients with rare eye diseases are adequately addressed, Retina International has increased its involvement in the work of the ERN-EYE through its direct participation to the different working groups (WGs) and transversal working groups (TWGs).

Christina Fasser and DrPetia Stratieva are continuing to represent Retina International at this level, contributing to Working Groups pertaining to “Retinal Rare Eye Diseases” - in which specific clinical guidelines are currently under discussion – and Transversal Working Groups related to: “Low Vision, Daily life and Patients Groups”, “Genetics Diagnostics”, “Registries & Epidemiology” and “Research”.

Retina International’s goal with regard to our participation in the ERN-EYE is to contribute to the joint effort in overcoming differences in quality of patient care across EU member countries, improving genetic testing and genetic counselling processes, and establishing a joined rare eye disease database, all of which will to enable the best advances in research and development for retinal degenerative conditions.
Looking Forward to 2021: The year of Inclusion and Wellbeing

Retina International are delighted to announce that our theme for 2021 will be: Inclusion and Wellbeing.

COVID-19 has laid bare the deep inequities in our healthcare systems and societies as a whole. Bolstered by the findings in our own research studies, it is clear that there is a significant unmet need to ensure the wellbeing and adequate support of those who are visually impaired.

Retina International will strive to put the patient voice and experience of those living with visual impairments at the centre of a global re-imagination of health systems and social supports, as we begin to “build back better” from this global pandemic.

With this, we present our upcoming programme for Quarter 1 of 2021:

**January 12th**  
Retina Action Universal Call to Action  
Webinar: Call to Action Launch. Click here to register

**January 21st**  
Webinar: IRDCOUNTS: The Cost to Wellbeing when living with an IRD.  
Click here to register.

**February 28th**  
International Rare Disease Day

**March 8th**  
International Women’s Day
A Year in Review:
Retina International Membership Highlights of 2020

2020 has posed numerous and unique challenges for those living with retinal degenerations. Public Health and social distancing measures have had far reaching impacts on the retina community, including but not limited to the halting of research and clinical trials, limiting of access to essential supports and services, and an increase in social isolation & loneliness for those who are living with low vision.

Despite this, our membership has worked tirelessly to reimagine their approach and adapt how we reach and support our community through undoubtedly challenging times. We would like to thank our Members for all of their work and contribution, and to take this opportunity to showcase some highlights submitted by our Membership from the past year.
Introducing our New Candidate Members:

At our 2020 General Assembly, three new Candidate Members were approved. They are: The Choroideremia Research Foundation (US), Retina Bulgaria, and the Usher Syndrome Coalition (US). We are delighted here to welcome and introduce these organisations and their work to our extended Retina International network.

Usher Syndrome Coalition

First identified in 1914, Usher syndrome is a rare disease and the leading genetic cause of combined vision and hearing loss. In 2008, a handful of researchers and families devoted to supporting those affected by Usher syndrome met to discuss ways in which they could work together. The outcome of the meeting was the creation of the Usher Syndrome Coalition, the largest organization dedicated exclusively to the Usher community worldwide.

For the past twelve years, the Coalition has worked to build the community, provide the latest information and resources, and serve as the bridge between the Usher community and the research community. The Coalition educates and connects individuals, families and service providers worldwide through its annual USH Connections Conference, online email group (USH Blue Book), international USH Trust registry, educational USH Talks, research updates, and partnerships with other USH related organizations.

A strong youth presence strengthens the foundation of any organization, and the Coalition is no exception. Over the past two years, a small core of young adult leaders has emerged who are taking the organization in new directions. We were proud to launch a new section on our website, curated by, and dedicated exclusively to, youth with Usher syndrome. A private Facebook group, now with more than 130 members between the ages of 18 and 28, provides a fun and safe place to connect, and video calls cement these online connections.

FB moderator Megan Lengel also created a detailed blog about her college experiences. Check it out! These are just some of the exciting initiatives that the Coalition offers. Stay in touch by checking our website for research updates, or to learn more about our USH Ambassadors program. If you have any questions, or need additional information, you can reach us at info@usher-syndrome.org
Retina Bulgaria

In 2020 Retina Bulgaria has stepped further with the implementation of a 2-years project “Vision for Vision” with the financial support provided by Iceland, Liechtenstein and Norway under the EEA Financial Mechanism (www.activecitizensfund.bg). The main objective of the “Vision for Vision” project is raising the awareness of the central and local authorities in Bulgaria concerning the number and problems of the people with visual impairments.

The “Vision for Vision” project is being implemented by Retina Bulgaria Association in partnership with: Foundation for Local Government Reform (FLGR) – providing capacity for work in municipalities, and Blindrafelagid - Association of People with Visual Impairments providing experience and opportunities to share good international practices. The task is to encourage, through civic engagement and research, an informed debate leading to synergy between the various stakeholders and development of public-private partnerships with a view to formulating and proposing policies to ensure eye and visual health in Bulgaria.

During the year the following activities have been performed:

- Preparation and publication of an analytical report on the state of play of the visual health in Bulgaria.
- Consultative meeting with leading eye and visual health experts for discussion and supplementation of the results and conclusions of the report and to coordinate follow-up, as well as to cooperate with them towards resolving the problems identified.
- Workshop with representatives of patient organizations, Blindrafelagid Icelandic Association of the Visually Impaired, Union of the Blind in Bulgaria, representatives of local authorities, eye / visual rehabilitators, health Roma mediators.
- Training regional trainers of visually impaired people.
- Launching a national information and education campaign for the visually impaired and blind people with seminars in the 6 regional centres of the country (in the cities: Montana, Pleven, Varna, Burgas, Plovdiv and Sofia).

In September Retina Bulgaria has started the implementation of a 10 months' project “Vision and COVID-19” with the support of the Public Board of Telus International in Bulgaria aiming to minimize the impact of COVID-19 on targeted societies. The project’s goal is to improve the access to healthcare of the visual impaired society in the country by increasing the awareness of the HCPs on the specific needs of the visual impaired in the case of their visits in hospitals.

An educational video developed by the ERN-EYE has been translated and adapted to Bulgarian and is distributed with the support of the Bulgarian Ophthalmological Society.

A monthly e-newsletter is issued and distributed among the visual impaired society and the friends of Retina Bulgaria. Retina Bulgaria has organized its first webinar for patients with IRDs for sharing experience of living with the conditions.
Choroideremia Research Foundation

“I grew up knowing that my dad was gradually going blind. It was often difficult for him and for our family knowing that he was losing his vision. However, Dad is an amazing man, and he has never let blindness stop him. For a long time, Dad was told that he had a retinal degenerative disease called **retinitis pigmentosa**. However, in the 1980’s he learned he had choroideremia (CHM). Based on our family tree, I knew from a young age that I was a “carrier” of the disorder causing my dad to go blind.

When our son was 4 years old, his ophthalmologist told us that his retinas were showing signs of CHM. At first, I was devastated and sad. I grappled with feelings of guilt in the face of the diagnosis. However, with the help of the CRF, I learned much more about CHM and the various research trials being conducted, discovered a supportive community, and found rays of hope.”  
Stephanie Sims, MD - CRF Board Member

Photo: Stephanie and her family.

The Choroideremia Research Foundation (CRF) was established by patients in 2000 to raise funds in support of scientific research leading to a treatment or cure of CHM. The foundation has funded over $4 million to research CHM across six countries. Our CRF members, spanning over 30 countries, also work to educate people affected by the disease and to inform the public. CRF hosts CHM-focused, international science symposia, dedicated to connecting international researchers, clinicians, institutions, and pharma/biotech companies. CRF also hosts in-person patient education conferences and regional meetings which will resume in 2022. Free online socials and interactive chats are available for “CHMers” and family members, as well as free educational webinars on topics such as gene therapy, stem cell therapy, genetic testing, nutrition for eye health, assistive technology, and more. To view some of these recorded programs, please visit [https://www.youtube.com/curechm](https://www.youtube.com/curechm).

For more information on CRF, or to register for our mailing list, please visit [https://www.curechm.org](https://www.curechm.org) or email [info@curechm.org](mailto:info@curechm.org).
Updates from our Full Members

Below you will see updates from some of our Full Members around the globe, the range of which include outreach & awareness activities, patient support services, and research. The scope of advocacy and activism carried out by these organisations on behalf of those living with retinal degenerations is a true reflection of our innovative and engaged community, and we hope you enjoy reading through the year’s events.

Retina Australia

The following is an excerpt from Retina Australia’s Chairman’s Report by Leighton Boyd:

“Following an eventful year in which our activities have been curtailed by COVID-19, the Board and staff of Retina Australia have grasped the opportunity to develop new skills including the use of Zoom meetings, Webinars, and Social Media. We have also launched some new fundraising projects including a Trivia Night and a partnership with Goodwill Wines. We are looking forward to expanding our fundraising projects in 2021.

I am also hopeful that we will have new vigour in pursuing our mission of “assisting those affected by vision loss from inherited retinal diseases by providing support, information and funding for research”. Above all, the Board will continue to raise awareness of inherited retinal disease in the community across Australia. I look forward to the next year with enthusiasm.”

Click here to view the Retina Australia Newsletter
Retina Brasil

Retina Brasil have had many activities over the course of 2020, participating in international and national projects regarding genetic testing, pandemic awareness materials for the visually impaired, and engaging with specialists across the Iberoamerica region to name but a few. Below is a snapshot of some of Retina Brasil’s highlights in the past year:

1) Efforts to obtain genetic testing in the national health system (three levels: municipal, states and federal). These efforts have been made through bill projects.

2) Training Course for regional leaders of Retina Brasil. Two virtual courses about advocacy and scientific themes to help the regional groups with their activities.

3) Virtual Informational Campaigns in the first month of the pandemic. Retina Brasil produced videos and lives on topics such as cleaning the house and objects, personal care and other important topics related to the prevention of COVID-19. The materials were made by visually impaired people for the visually impaired one.

4) Throughout the year we hold many webinars with doctors, lawyers, low vision specialists Participation in Retina Iberoamerica (formed by associations of patients with retinal diseases in Brazil, Argentina, Chile, Colombia, Puerto Rico, Spain, and more).

5) In training: a group of young people from Retina Brasil and Retina Iberoamerica.

6) Disclosure to RB members of the approval by the Brazilian health authorities of the gene therapy for the RPE65 gene mutation and of the measures for the implementation of this innovative therapy in Brazil.

7) RB’s relationship with the Ministry of Health with a view to introducing drugs to treat AMD and Diabetic Retinopathy in the Brazilian public health service.


Fighting Blindness Canada

FBC-Funded researcher works to solve a stem cell mystery

Fighting Blindness Canada (FBC) funded researcher Dr. Michel Cayouette (Institut de recherches cliniques de Montréal), has identified two molecules (Pou2f1 and Pou2f2) that drive stem cells to make cone photoreceptor cells. Cone photoreceptor cells are the light sensing cells responsible for detail and central vision, and are lost in eye diseases like retinitis pigmentosa and Stargardts.

Stem cells have the ability to make many new types of cells and are being considered as treatments for blinding eye diseases, replacing cells that have been lost or damaged. A large challenge is that while stem cells like retinal progenitor cells (RPCs) can make different retinal cells (i.e. photoreceptor, retinal ganglion, and Muller glial cells), it isn’t clear how RPCs decide which cell type to make or if this process can be controlled to create the specific cells that are needed for treatment.

Dr. Cayouette’s research sheds light on this process, showing that Pou2f1/2 are turned on when RPCs are making cone cells, and off when RPCs aren’t. The results of Dr. Cayouette’s research also shows that artificially turning on Pou2f1/2 drives RPCs to make more cone cells. Dr. Cayouette and his team are now studying if this information can be used in regenerative medicine. This exciting discovery is giving scientists the information and inspiration they need as they develop stem cell therapies.

Learn more about the scientists behind this research in this interview with Dr. Cayouette and his PhD student Awais Javed.

Learn more about FBC’s mission to fund sight-saving research at fightingblindness.ca

Photo: Stock photo: stem cell research in a lab
Retina France

Retina hikes in France

The lasting pandemic that we are experiencing but also the growing use of the web and new technologies must lead the associative world and in particular patient associations to review their thinking, action and awareness software.

This pandemic does not allow us to organize our big events with thousands of people like choir concerts, but nothing prevents us from seeing more modestly. We are by nature optimistic, we believe in solidarity and we have shown that the momentum of the heart is always present.

On foot, by running or by bike and always in small groups while respecting barrier gestures, Retina France has organized several hikes in the country in order to raise funds and raise awareness among the general public about low vision.
Fighting Blindness Ireland

Like many things this year, the Fighting Blindness Annual Retina Conference was a very different experience. Not to shy away from a challenge, we moved to an online platform and welcomed over 800 attendees over two days. Highlights of the Scientific Programme included keynote speaker Dr Pearse Keane, an Irish ophthalmologist at Moorefield’s Eye Hospital, who presented on his work developing artificial intelligence (AI) algorithms for the earlier detection and treatment of retinal disease.

A spotlight was also put on the significant work underway by early stage researchers and clinicians. Congratulations to Dr Ema Ozaki of Trinity College Dublin who secured the Retina 2020 Early Investigator Award based for her research on the role of SARM1 in photoreceptor cell death in mice.

Unravelling the genetics behind retinal disease, many other speakers shared their latest observations. This included an excellent talk by Dr Dhaenens of France which explored the sex ratio imbalance in Stargardt disease associated with mild ABCA4 alleles and the fantastic discovery at Radboud University in the Netherlands towards the genetic defect that causes Retinitis Pigmentosa type 17 (RP17). This year’s Poster Award went to Laura Whelan, a PhD student at Trinity College Dublin. You can listen to Laura’s winning sizzler on our YouTube channel. The day ended with thought-provoking discussions into the important role Science Communications and Public and Patient Involvement plays in R&D.

The playback of the Scientific Programme is available to watch at retina.ie.

Over 300 people registered for our Public Engagement Day to hear from international rugby player Ian McKinley, Judith Potts of Esme’s Umbrella Group in the UK, Prof David Keegan a Clinical Ophthalmologist, Ben Shaberman from Foundation Fighting Blindness, Claudette Medefindt at Retina South Africa and Christina Fasser, former President of Retina International. A strong theme that emerged from the day is the positive impact of moving our services onto a virtual platform in response to COVID-19 restrictions. For many of our members, this is a huge advantage as it allows them to stay connected and up to date without the stress that can come when travelling to a physical meeting. The full recording of the Public Engagement Day is available to watch back on our YouTube channel.

Lifetime Achievement for Christina Fasser

The Retina Conference closed on a high with the virtual presentation of the Retina Empowerment Award which celebrates people who have made an impact on the lives of people living with sight loss. This year, Fighting Blindness Ireland honoured Christina Fasser with a lifetime achievement award to mark her recent retirement and service as President of Retina International after 28 years. Her acceptance speech was a fantastic and uplifting end to Retina 2020.
RP Association in Norway grants NOK 3 million for 3-year doctorate.

Ophthalmologists and geneticists at Haukeland University Hospital in Bergen, Norway are currently conducting a study on 10 families with the goal of finding a new mutation causing inherited retinal dystrophy. The RP Association is proud to have secured funds for this project that will expand the IRD research community in Norway and provide valuable information on pathological mutations found in Norwegian families. NOK 500,000 comes from our own research fund and NOK 2,500,000 was granted to us for the project through «Jon S. Larsens stiftelse», a large research foundation for eye research generously donated by the late Dr. Jon S. Larsen.

The project is a collaboration between «Ophthalmo-genetic research group» headed by professor Eivind Rødahl at Dep. of Ophthalmology and the «Gene Hunting Group» headed by professor Per Knappskog at Dep. of Medical Genetics. These groups have worked together for many years and have found several new genes that causes retinal disease. The candidate for this doctorate is molecular biologist Roya Mehrasa under supervision of researcher Ove Bruland (PhD).

Photo: PhD-candidate Roya Mehrasa in the lab at Haukeland University Hospital, Bergen/Norway

Patients with IRDs in Norway have for several years had access to diagnostic exome sequencing. This analysis screens for all the genes currently known to cause retinal diseases. Haukeland University Hospital was the first to offer this comprehensive analysis in Norway, and it lead to far more patients receiving their genetic diagnosis. However, a genetic diagnosis is not found in 20-30% of patients. One reason for this is that these patients have mutations in genes not currently known to be causing disease. The primary goal of the project is to find one (or more) new genes associated with IRD. Knowing the genetic cause of a disease is important to give a correct diagnosis and could enable development of treatments in the future. It is also vital in order to answer questions from patients about disease progression and the risk of inheritance in their children.

The research group has already found a candidate gene that they suspect is the genetic cause of retinal disease in some of their patients. However, a lot of work in the lab is required to demonstrate this with certainty. They are, as of December 2020, waiting for an animal model to use in their studies.
FARPE Spain

FUNDALUCE, A Spanish Treasure to Support Research (English)
The Federation of Associations of Inherited Retinal Dystrophies of Spain (FARPE) was established 30 years ago, around the same time researchers identified the first ever gene associated with a disease which at that time was rarer and much less known than today: Retinitis Pigmentosa. Today, more than 270 genes are known to explain why retinal dystrophies occurs and, although it is still early days, many advances have been made. Notably, the first gene therapies against these eye diseases, which lead to visual impairment and even blindness, are already on the market in some countries.

Since its inception, FARPE has established a partnership with scientists and researchers, strengthened more and more ties with laboratory leaders, and facilitated collaborations that address unmet need. This effort to collaborate in the search for treatments took a momentous step 20 years ago, with the birth of the Foundation to Fight Blindness (FUNDALUCE), an initiative that supports our advocacy work with the necessary means to finance and promote projects related to retinal dystrophy. It is a small great treasure that involves patients fully in the battle against vision loss.

FUNDALUCE has been providing hope to patients and researchers for two decades through the annual call for financial aid that, with its ups and downs, has been increasing progressively to add up to the more than 600,000 euros, which has already distributed among twenty projects. The Foundation obtains its funds from donations from the regional associations that make up FARPE, which consists of company donations in addition to the generosity of many individuals who contribute their valuable grain of sand to form this great mountain. The amount of annual aid has grown directly proportional to that of donations to the point that the call for the Fundaluce Prize 2020 amounts to 45,000 euros, 50% more than the previous year.

In these times of pandemic, in which we have necessarily learned the tremendous value of research for our health, FARPE and its Foundation emerge as organizations that have been touting this need for 30 years, and hope that the dramatic experience of coronavirus will help Spanish and European governments and administrations to listen more to their demands and those of so many other organizations that also demand more support for science. The fight doesn’t end in one or more vaccines against a deadly virus that has made our world wobble. Much remains ahead of us to improve our health, and despite the great and hopeful advances, for those of us with Inherited retinal dystrophy, knowing the gene that causes it remains elusive. FUNDALUCE is not just a progressive initiative that provides funding to research teams to carry out their work. This Spanish Foundation is, above all, an example that patients should not be mere spectators in work and scientific advances, but we must rise as main protagonists, because we can contribute much more than we believe to the history of our future therapies. We are very proud of FUNDALUCE, our little great treasure that we want to share with all of you, because that is our wealth, moving forward together and united.
FUNDALUCE, Un Tesoro Español Para Impulsar la Investigación (Español)

La Federación de Asociaciones de Distrofias Hereditarias de Retina de España (FARPE) nació hace 30 años, a la par que se identificaba en los laboratorios el primer gen causante de una enfermedad entonces más rara y mucho menos conocida que en la actualidad: la retinosis pigmentaria. Hoy en día, se conocen más de 270 genes que explican por qué se produce una distrofia de retina y, aunque es prematuro lanzar las campañas al vuelo sobre una pronta curación, ya se comercializan en algunos países las primeras terapias génicas contra estas patologías oculares, que conducen a la discapacidad visual e incluso a la ceguera.

Desde sus inicios, FARPE ha establecido una alianza con los científicos e investigadores, ha estrechado cada vez más lazos con los responsables de los laboratorios y se ha puesto a su disposición para aquello en lo que pudieran colaborar y pudieran necesitar. Ese empeño por caminar juntos en la búsqueda de tratamientos dio un paso trascendental hace 20 años, con el nacimiento, en el seno de FARPE, de la Fundación de Lucha contra la Ceguera (FUNDALUCE), una herramienta con la que el apoyo verbal y anímico se traduce en la necesaria inyección económica para financiar e impulsar proyectos relacionados con las distrofias de retina, un pequeño gran tesoro que nos implica de lleno a los pacientes en la batalla contra la pérdida de visión. FUNDALUCE lleva dos décadas nutriendo de esperanza a afectados e investigadores mediante la convocatoria anual de una ayuda económica que, con sus altibajos, ha ido incrementándose de forma progresiva hasta sumar los más de 600.000 euros que ya ha repartido entre una veintena de proyectos. La Fundación obtiene sus fondos de las donaciones procedentes de las asociaciones regionales que integran FARPE, de las que hacen algunas empresas y de la generosidad de muchos particulares y anónimos que aportan su valioso grano de arena para formar esta gran montaña. La cuantía de la ayuda anual ha crecido de forma directamente proporcional a la de las donaciones hasta el punto de que la convocatoria para el Premio Fundaluce 2020 se eleva a 45.000 euros, un 50% más que la del año anterior.

En estos tiempos de pandemia, en los que hemos aprendido forzosamente el tremendo valor de la investigación para nuestra salud, FARPE y su Fundación emergen como organizaciones que llevan 30 años pregonando esta necesidad y confían en que la dramática experiencia que nos hace pasar el coronavirus sirva para que los Gobiernos y Administraciones españolas y europeas escuchen más sus demandas y las de tantas otras organizaciones que también reclaman más apoyo a la ciencia. La lucha no termina en una o varias vacunas contra un virus mortal que ha hecho tambalearse a nuestro mundo. Queda mucho recorrido por delante por mejorar nuestra salud y, a pesar de los grandes y esperanzadores avances, para los que padecemos una distrofia hereditaria de retina, conocer el gen que la provoca sigue siendo un cara o cruz. FUNDALUCE no es solo un buen instrumento que proporciona fondos a los equipos de investigación para desarrollar su labor. Esta Fundación española es, sobre todo, un ejemplo de que los pacientes no debemos ser meros espectadores en el trabajo y los avances científicos, sino que hemos de alzarnos como protagonistas principales, porque podemos aportar mucho más de lo que creemos a la historia de nuestra futura curación. Nos sentimos muy orgullosos de FUNDALUCE, nuestro pequeño gran tesoro que queremos compartir con todos vosotros, porque esa es nuestra riqueza, avanzar juntos y unidos.
Conversation evenings in Sweden

Last week we hosted our first conversation evening in Sweden over Microsoft Teams and telephone. It was a brave group of approximately 10 persons who met up, and all of them using Teams even it though there was possibility to connect to the meeting over phone for those who wanted. Some even had their cameras on during the meeting.

We’ve had our Spring meeting and Autumn meeting over Microsoft Teams and phone, and on the Autumn meeting several expressed their wish to talk to other IRD patients.

The good thing about having a virtual meeting was that there was participant from all parts of Sweden. We live in a long country 1500 km from north to south, which makes it difficult to get participants from all of Sweden in one physical meeting. The group was also mixed when it came to ages and some participants were new in the RP association.

This first evening was dedicated to the subject “Service from the society”, and discussed what help is available with regard to sighted guides and being able to do shopping and other activities such as unemployment benefits, sick care etc. The conclusion was that the service differed widely between different cities, which it shouldn’t do.

To start with it was a bit nervous and quiet, but then the conversation flowed and the evening went on for two hours. Other subjects also popped up like how to shop online - in this case the elders wanted to learn from the younger who are more or less professional. There was also discussion about meeting and being assessed by administrators who will decide if we will be eligible for social welfare. It was highlighted that it can be difficult for an administrator who sees us in our home serving traditional Swedish “fika” (coffee and cookies). In our home we look like we don’t have any issues, and our difficulties outdoor in the dark Swedish winters are not apparent or visible to the administrator. There was an idea that the RP association would together with the blind union create an information campaign to inform authorities of how RP works.

The planned coming meetings are regarding how our needs as IRD patients are being met by healthcare personnel, meeting technology on the net such as Zoom or Microsoft Teams (how to mute by key shortcuts etc.), and also a special evening dedicated for parents who have children with RP.
Retina Suisse - Switzerland

Retina Suisse are delighted to share a series of conferences, held this Autumn in both German and French. We allowed the wider public to look the registered videos on our website.

The first video showed the eye as most important organ. The second video is about the visual perception of people with visual impairment, like CBS and filling-in. The third video explains the measurement of visual acuity and the fourth video shows the collaboration of retina, optic nerve and visual cortex. “Genetics: Four Letters Form a Library” is the title of the fifth video and last but not least, we speak in the sixth video about our patient registry with Swiss specialities like Malattia Leventinese, Zermatt macular dystrophy and its "extensions" to the Allalin-Region and the "Sense"-region. On December 15th and 16th we hosted conferences in French and German about AMD. The series will be continued in January with a conference about the development of therapies and the process of recognition of new drugs in Switzerland. On March 21st, the first conference in Italian will be held about AMD. We plan to continue in this language as well, since we now have a new CEO in the Hospital of Lugano with experience in treatment of IRDs. He studied with Prof. MacLaren in Oxford last year.

The videos can be seen on our website at the following link:

https://retina.ch/angebote/webinare/
Retina UK

Doing things differently has been a theme for 2020 here at Retina UK. As the year comes to a close we have been reflecting back on the most unusual of years and celebrating the fantastic achievements of our amazing community.

Helpline
With so much uncertainty at the start of lockdown, we prioritised the support available via our helpline and upgraded the system and telephone number in April to make it easier for people to contact us. Calls have increased by 33% and we have supported more people expressing feelings of isolation and anxiety, as well as practical issues and questions about daily living with an inherited, progressive condition. All of our Helpline volunteers are living with an inherited sight loss condition and can therefore provide information and advice based on personal experience.

Mental health support and training
We have been very aware of the impact of the pandemic on the mental health of our volunteer helpline team. The frequency and type of calls they receive, as well as challenges in their own sight loss journey, led us to partner with Arthur Ellis, a mental health service based in Milton Keynes. Arthur Ellis have produced a toolkit for our volunteers and staff which provides self-help support to protect and look after their own mental health. We do plan to make the toolkit more widely available in 2021.

Local group meetings
Our local peer support groups haven’t been able to meet up face-to-face but that hasn’t stopped them! Many of our groups have taken to Zoom to keep in touch and support each other. They have heard from some great guest speakers and have shared ideas, told lockdown stories and had general chats and catch ups. We plan to continue offering these online meetings alongside face-to-face groups (when we can re-start them) in 2021.

Podcast
We introduced a new Podcast for Retina UK in 2020 and the last few months have seen very interesting talks about the new MyEyeSite app; developed to give people living with rare eye conditions ownership of their own digital medical data; and a conversation with three of the first patients to receive the Luxturna treatment here in the UK. All of our newsletters are also available in audio format in the same place. You can listen to them at: https://anchor.fm/retina-uk.

Audio content
Thanks to sponsorship secured by our Fundraising team, we were able to implement the use of returnable memory sticks instead of CDs for the Winter 2020 edition of our Newsletter, Look Forward. This change was taken as a result of feedback from our community about the type of devices they use.
Gene Vision
A new website, Gene Vision, was launched in early December by Professor Mariya Moosajee and her team. Retina UK provided funding for the project and supported the creation of condition specific content in an accessible, easy to understand language. It is intended for adults, children and their families who are diagnosed with rare genetic eye diseases and provides detailed information about individual conditions and clinical trials.

Fundraising campaigns
Our Fundraising team also successfully completed two successful large appeals in 2020. They were generously supported by our community who have also praised the awareness raising it resulted in.

Trustees
Our volunteer Trustees have met more regularly (online) during the pandemic to support the work we are doing and to ensure that we came through what has been at times a very tough period. Their support and positivity has been invaluable. We would particularly like to pay tribute to our chairman, Don Grocott. Don had planned to retire as Chairman in 2020 but stayed on and we are forever grateful for his hard work and good humour.
The recent news of licensing for the first COVID-19 vaccine has been greeted with positivity but we know the pandemic isn’t over yet. I know that all of the team feel incredibly proud to be part of the charity and have been continually uplifted and motivated by our wonderful community in this most unusual of years. We’re looking forward to 2021 and are forging ahead with our plans for an online Annual Conference and Professionals’ Conference in April.
Foundation Fighting Blindness (USA)

Hiring of Peter Ginsberg as Executive Vice President, Corporate Development, Chief Business Officer

On December 10th, FFB announced their appointment of Peter Ginsberg as the Executive Vice President, Corporate Development, Chief Business Officer. Please see an excerpt from their press release below:

“Foundation Fighting Blindness Appoints Peter Ginsberg as Executive Vice President, Corporate Development, Chief Business Officer Mr. Ginsberg brings twenty-five years of rare disease corporate development, finance, strategy, and investment leadership experience.

The Foundation Fighting Blindness, the world’s leading organization committed to finding treatments and cures for blinding retinal diseases, has announced the appointment of Peter Ginsberg as executive vice president, corporate development, chief business officer. Mr. Ginsberg will oversee the development of financial plans and processes while providing leadership on business transactions, strategic planning, and new activities aimed at creating novel revenue streams across the Foundation Fighting Blindness and RD Fund.

He will report to the Foundation’s chief executive officer, Ben Yerxa, PhD. “I have known Peter for many years and am privileged to bring his extensive business development and finance expertise to this new role,” commented Ben Yerxa. “Not only has he led record-setting transactions with large and small biopharmaceutical companies, he has worked extensively within ophthalmology, inspired by his long-time mentor who has retinitis pigmentosa.”

“Joining the Foundation is a great honour, and I look forward to building on our current programs and creating new avenues to accelerate achievement of our mission,” added Peter Ginsberg.”

Click here to view the full press release.

Foundation Fighting Blindness Merchandise Store

FFB have also launched an official Foundation Fighting Blindness Merchandise Store – ShopFightingBlindness.org. You can demonstrate your support of the Foundation with a variety of branded apparel and merchandise. From shirts to hats to items for your furry friends, these products will help to increase awareness for the Foundation and support our mission.
Acknowledgements

Retina International would like to thank again our members, and various collaborators over the course of 2020. 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 2021.

Retina International Network of Partners

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