

PRESS RELEASE

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On WORLD RETINA DAY, September 25th, 2021, Retina International highlights the impact of the COVID-19 Pandemic on the inclusion and wellbeing of its global patient community.

DUBLIN, September 25th, 2021 – The members of Retina International are highlighting the **effects of the COVID-19 pandemic on the wellbeing and inclusion of the patients** they represent on World Retina Day 2021. 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:

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

People living with retinal degenerations were amongst the first groups to self-isolate during the first wave of the pandemic. In a 2020 study undertaken by RI, **62.96%** of participants indicated that **COVID-19 had had a negative impact on their lives**, citing the impacts on **mental health, independence, and mobility**; the inability to judge distance and to navigate in a safe way turned an already isolated group inward, and indoors. The 14.81% of participants that reported COVID-19 as having a positive effect on their lives cited factors such as working from home, and not having to commute in dark or unsafe conditions. As we begin to emerge from COVID-19 restrictions, there is a clear need to **implement and protect enabling practices that ensure the safe, accessible mobility and inclusion** of those living with a visual impairment in the workforce and society.

The isolation experienced as a result of COVID-19 restrictions, and their impact on the inclusion and wellbeing of those living with retinal dystrophies, was further compounded by the **implementation of virtual and digital technology**

“solutions” that did not address key accessibility requirements for the visually impaired. As we move towards a world of digitized healthcare – which has been fast tracked as a result of the COVID-19 pandemic, **urgent consideration must be given to the challenges of digital poverty**, which impact the process of validating and standardizing home health monitoring and care, in particular for the ageing and vision impaired community.

The unprecedented pressure that COVID-19 put on our health systems worldwide has resulted **in delays in access to medical care and support for those living with retinal degenerations**. In the same RI study, **40%** of participants experienced a **delay in follow-up appointments** with their eye doctors, and **16.67%** reported a **delay in treatment plan**. This demonstrates an unacceptable lapse in care for retina patients; due to which the subsequent effects on waiting lists, and delays in access to treatments has and will continue to result in **needless vision loss**.

Dr. Julianna Sallum MD, PhD., expresses that, “Now, after more than a year and a half in the pandemic, the impact on the vision care of the population is finally being seen. Waiting lists have grown and delivery of care has still not recovered to the pre-pandemic pace. Those living with age related macular degeneration stopped treatment, and those that were not diagnosed due to clinic closures have lost the ideal time to start treatment. Patients with diabetes, who are considered high risk individuals for COVID-19, have also experienced interruptions to their treatment. We are now asking ourselves how much vision has been lost? When will we be able to return safely to the clinics?”

The negative impacts of COVID-19 measures on **research and innovation** have also been well documented during this period. The **halting of research** during the initial lockdown in 2020 has impacted the progression of lab-based research significantly, and patients are concerned about **subsequent future challenges to the development pipeline of treatments**. However, of particular concern to those affected by Retinal Dystrophies, clinicians, and researchers alike are the challenges posed by the pandemic to the development of clinical trials.

Mr. Franz Badura, Chair of Retina International states that: “The huge negative impact of COVID-19 on the research and scientific community has compromised the development of clinical trials and treatments for those living with retinal disease. I believe that with the prioritisation and protection of research by policy-makers, the scientific community can overcome this and be able to make up for the time unavoidably lost with new clinical and scientific findings.”

In light of the consequences of COVID-19 on our community, Retina International is calling on governments worldwide to prioritise and protect the wellbeing and inclusion of those affected by retinal disease. We ask that urgent consideration be given to the following call to action:

1. Implement measures **that enable the safe mobility and accessible inclusion** of the vision impaired community in society and the workplace;
2. Improve awareness on the issues of **digital poverty**, and ensure that digital services are inclusive and accessible, with particular consideration for the ageing and vision impaired community;
3. **Prioritise care and treatment** for retinal dystrophies in times of crisis;
4. Preserve essential **retinal research and development** from disruption in times of crisis, and;
5. Promote the **inclusion and wellbeing** of the vision loss community.

Retina International

Retina International is a global umbrella organisation for patient-led charities and foundations who support research into rare, genetically inherited and age-related retinal conditions.

RI believes that education leading to participation is a key driver in successful innovation.

Retina International strives to educate its community who in turn will be the educators of their peers, of all relevant stakeholders and decision makers and will utilise the understanding to Participate as informed actors in development of research, through the provision of advice, and perspective to all stakeholders and decision makers allowing the community to better Innovate to support and promote research for unmet need.

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