



Seeking A Cure For
Retinitis Pigmentosa, Macular Degeneration,
Usher Syndrome and Allied Retinal Dystrophies

PRESS RELEASE

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Retina International announces the launch of *Know Your Code* – a genetic testing advocacy portal to mark WORLD RETINA DAY, September 26th, 2020.

DUBLIN, September 25, 2020 – Retina International has announced the launch of a new genetic testing advocacy portal, ***Know Your Code*** www.retina-kyc.org, to mark World Retina Day 2020.

The portal, supported by an unrestricted educational grant from the Allergan Foundation, is being 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.

This online platform will equip 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.

Leighton Boyd, Chair of Retina Australia and a person living with an IRD expressed the urgent need for accessible and affordable genetic testing services. Speaking

from Melbourne he said “IRDs are actionable conditions, even if there is no treatment for a person’s specific gene at the moment, knowing your code can help you better understand inheritance patterns and the likely progression of your condition. These are essential services and should be universally available for the empowerment of patients, the progress of research and access to potential therapies”.

CEO of Retina International Avril Daly added; ‘there are unfortunately significant variabilities in access to genetic testing services globally. We understand that Genetic Testing may be considered a niche or unnecessary in already overstretched health care systems, but for the IRD population it is the only way of obtaining an accurate diagnosis. Knowing your code allows patients to not only better understand their condition, but to take action to live with their condition to the best of their ability in the absence of a treatment. Patients don’t just want genetic testing, they *need* genetic testing, and we hope that this new web portal will provide our patient community, and those who support them, with the tools to advocate for this access’.

Michel Michaelides, Professor of Ophthalmology at the Institute of Ophthalmology, Moorfields’ Hospital London said at the launch of the portal; ‘This is a landmark piece of work that is of utmost importance to patients affected by IRDs and their families. Genetic Testing is essential in order to have a clear diagnosis of an IRD and provides the opportunity for patients to make informed choices about how they live with their condition. Unfortunately, this choice remains unavailable to many due to inequitable access to genetic testing services. The Know Your Code portal has been designed to provide patients and those who support them with information that can help them to better understand the process through the provision of validated information’.

IRDs are actionable conditions, and without access to genetic testing services, patients live with inaction. Retina International and its 46 members on all continents believe there is an urgent need for the disparity in genetic testing & counselling services to be addressed. For this reason, our call to action for World Retina Day 2020 is to open the door for everyone to access affordable genetic testing services and know their code.

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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.

For more information, please contact:

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Visit our website: retina-international.org

Or the Know Your Code portal site: retina-kyc.org