RETINA INTERNATIONAL

SENDING A RED ALERT

Financial Disclosure: This project was made possible by an unrestricted grant from Spark Therapeutics, support from Creative and Image Now Films.
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AKNOWLEDGEMENTS: Retina International wishes to thank contributors and advisors: Frans Cremers (NL) Dr. Juliana Salum, Dr. Ségoléne Aymé, Dr. David Barton, Dr. Kirk Stephenson, Prof. Jane Farrar, Prof. Andrew Green, Dr. Sallyanne Lynch, Dr. Matthew Carrigan.

RETINA INTERNATIONAL WITH THE COLLABORATION OF PATIENTS, CLINICIANS, SCIENTISTS AND ALLIED HEALTH PROFESSIONALS HAS DEVELOPED AN ONLINE TOOLKIT TO EDUCATE THE RETINA COMMUNITY AT LARGE ON THE IMPORTANCE OF **ACCESS TO** AND **REIMBURSEMENT OF** GENETIC TESTING SERVICES FOR RARE EYE DISEASE (RED) AND INHERITED RETINAL DISEASE (IRD)

WHY THIS COMMUNITY NEEDS BETTER ACCESS TO GENETIC TESTING SERVICES

Rare Eye Disease (RED) and Inherited Retinal Diseases (IRDs) cause severe vision loss and the impact on quality of life is immense. While potential treatments are emerging the genetic characteristics of REDs & IRDs mean a genetic diagnosis is a pre-requisite for inclusion in clinical trials.

However, low awareness among patients and medical professionals as well as issues of cost have resulted in a barrier to access.

But – these challenges can be mitigated by educating advocates across disciplines to work in synergy to change this reality.

THE METHOD: HOW WE DEVELOPED OUR TOOLKIT

Retina International worked with its patient members, clinicians and researchers using focus groups, webinars and surveys to establish the level of knowledge in the first instances in each country and then among individual patients and their representatives.

The surveys provided clarity on the level of knowledge of the medical professionals in the field of general practice and ophthalmology.

Retina Internationals Scientific and Medical Advisory Board worked with a team of patient leaders drawn from seven countries to collate the information generated and write content.

A design team with expertise in accessible media facilitated the production of simple user friendly downloadable materials including text, audio, and visual content for global application.

WHAT WE LEARNED:

A Retina International patient survey on genetic testing for IRDs highlighted that research facilities are being relied upon by the majority of patients for test results.

62% of respondents to the survey had had a genetic test. **53%** of those who have received a result have done so through participation in a research project – the over reliance on research grade testing is unsustainable and raises many concerns.

39% of those who have had a genetic test have shared the result with an IRD register.

73% of organisations who responded to the survey stated that genetic counciling services were available in their country, but optional.

Worryingly only **14%** of ophthalmologists have referred patients for a genetic test, dropping to **3.33%** referred for testing by a family doctor and **1%** by an optometrist.

These figures highlight the lack of awareness among medical professionals of the importance of genetic testing for REDs & IRDs.

90% of those surveyed stated that their local patient organisation assisted them in providing information on genetic testing services.

Retina International is concerned that **66%** of respondents are waiting over one year for test results.

CONCLUSION

The provision of online capacity building and advocacy tools is far reaching. Such tools educate stakeholders across all disciplines and encourages collaboration and coordination of effort informing impactful advocacy campaigns, ***nationally, regionally and globally.***

Understanding the rapidly evolving field of genetic testing for Rare Eye Disease and Inherited Retinal Disease is critical to building a confident well informed voice for the retina community. Enabling it to **collaborate effectively** in achieving its collective goals. Equitable access to and reimbursement of Genetic Testing Services will empower patients through **knowledge**, aid **discovery**, improve **access** to clinical trials for small populations, **expedite innovation**, improve access to therapy and the delivery of **care.**

THE RETINA PATIENT COMMUNITY IS **SEEING RED!**

THE TIME HAS COME TO SEND A **RED ALERT** TO GLOBAL GOVERNMENTS THAT GENETIC TESTING IS NOT A LUXURY IN THE HEALTHCARE SYSTEM - IT IS AN INSTRUMENT TO PROVIDE BETTER HEALTHCARE AND IMPROVE THE LIVES OF MILLIONS OF CITIZENS WHO STRIVE FOR A BRIGHT FUTURE WE CAN ALL SHARE!