In 2020 Retina International has initiated a 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 order **To advocate effectively for equitable, affordable,**

**accessible and timely genetic testing for IRDs**

**The existing processes and systems in 18 countries in Europe, and most recently, those in Australia, have been investigated. The results are going to be published in 2021**

**The conclusions are providing the ground for bringing the project to a next level by broadening the scope from geographical (international) and from patients needs’experience perspective.**

In 2021 we, Retina International, are seaking to encourage patients with IRDs to share their thoughts on the genetic testing services (genetic testing and genetic counselling), their experience and recommendations about these services.

The objective of the study of the patients perspective is to help clinicians, genetic specialists, researchers and eye care professionals to understand the information and support patients will need to navigate to the diagnosis, prognosis and care for their conditions and to facilitate further policy actions and research development in the IRDs domain.

Patients living with IRDs and their caregivers/family members from different countries and regions will be invited to share their experience.

With the aim to prepare an accurate questionnaire, at the initial stage, we would like to collaborate with a focus group of 8 patient representatives from the following countries:

1. Australia
2. Brazil
3. Germany
4. France
5. Poland
6. Russia
7. USA

Focus Group Meeting Schedule:

To allow the participation of representatives from different time zones, 2 time options for each meeting will be provided. participants can decide which time suits them best.

Meeting 1 taking place **Wednesday April 21st Morning 9am CET (option 1.), and, 5pm CET (option 2.)**

Meeting 2 taking place **Wednesday May 5th Morning 9am CET (option 1.), and, 5pm CET (option 2.)**

Meeting 3 taking place **Wednesday May 26th Morning 9am CET (option 1.), and, 5pm CET (option 2.)**

Objective: The objectives of hosting the focus group is to help frame the survey questions with respect to accessing genetic testing and counselling.

Meeting 1 is a 1 hour kick off meeting- no pre-reading material.

Agenda:

Introductions

Explaining the focus group to participants in more detail and answering any questions

Outlining the survey modules

Meeting 2 is a 1 hour meeting with pre-reading material of 1 hour

Pre-reading material is draft 1 of survey questions for review issued at least one week in advance.

Agenda:

Review and clarity on feedback of survey questions

Meeting 3 is a 1 hour meeting with pre-reading material of 1 hour

Pre-reading material is final review of survey questions.

Agenda:

Review and discuss final survey questions.

Language: The meetings will be held in English.

We are asking for a patient or parent who has gone through genetic testing for their IRD within the past 5 years to participate in the Focus Groupe.

If a patient or parent is not possible, then a patient advocate is an option but a patient or parent is preferred.