



# ERN-EYE

## THE JOURNEY SO FAR

**Avril Daly**

**CEO Retina International**

**VP EURORDIS**

**3<sup>rd</sup> ERN Conference – Vilnius. March 9<sup>th</sup>**

# A Sensible Route to Diagnosis and Care!

## Improve care of EU citizens with Rare Eye Diseases –

- Urgent need to coordinate care for patients with Rare Eye Diseases through EUROPEAN REFERENCE NETWORK (ERN)
- 30 HCPs applied in
- 13 member states

# Our Big Audacious Goals for ERN- EYE -

## A New Focus on THE EYE

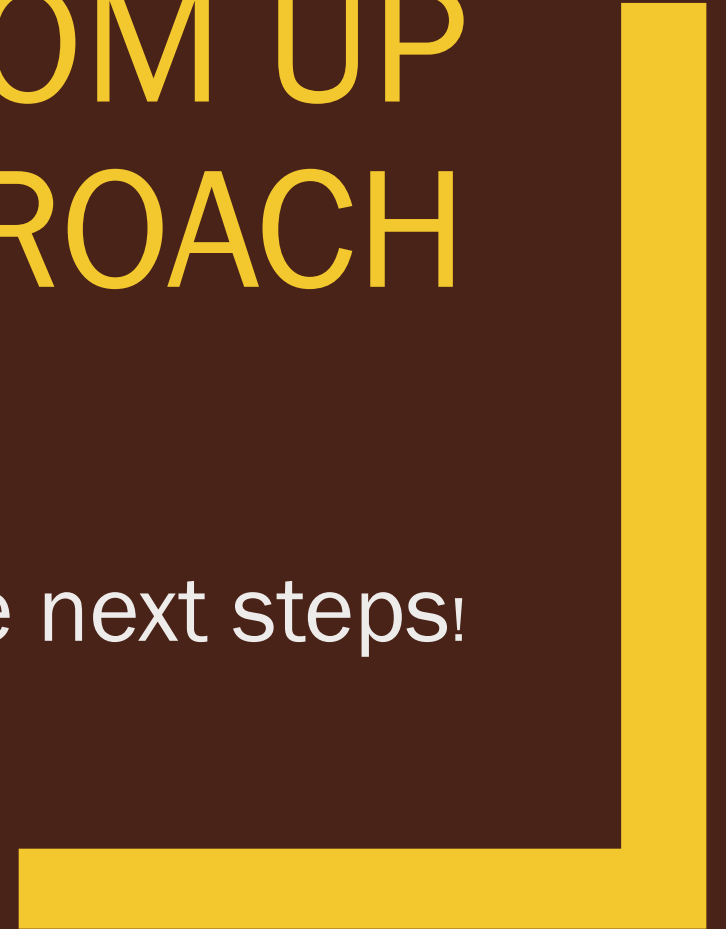
- Improve trajectory for patients with Rare Eye Disease in the EU
- Reduce the time to diagnosis and care
- Secure accurate diagnosis for the undiagnosed patient population
- Ensure molecular diagnosis to the largest number of patients
- Reduce inequality and improve access to high quality care in the EU
- Facilitate involvement of patients in clinical trials
- Enable access to innovation and faster generation of knowledge, evidence base and research

# But Which Rare Eye Diseases?

- Rare Retinal Disease
- Neuro Ophthalmology
- Paediatric Ophthalmology  
and Rare Eye Immune  
Diseases
- Anterior Segment

# PUTTING THE PUZZLE TOGETHER – BOTTOM UP APPROACH

Together – The patients agree next steps!



# First Things First!

Need to  
Publicise the  
ERN Process  
to Patients  
and Learned  
Societies

- Opportunity of first announcement and presentation at EURORDIS AGM – Madrid 2015
- Meeting with patients representing all rare eye disease areas on process
- Agreed RI would organise meeting with learned societies and patients

EURetina, Nice,  
September 2015

Over 5,000 Eye  
Care Specialists  
in EU and Beyond

## 2 Round Tables and one patient symposium organised

- 1<sup>st</sup> Round table - European ophthalmology specialists and clinical researchers potential of ERN process for the community
- 2<sup>nd</sup> Round table - patient representatives to discuss patient role and advocacy activities
- A Patient Symposium on ERN process – a first for the conference

Initial Meeting  
Ophthalmologists and  
Patient  
Representatives -

Zurich, February 26<sup>th</sup>  
2016





# Attention Turns to ePAG Elections –

## March 2016

The nominated ePAG members represent 4 patient groups:

- Christina Fasser (Retina International, Switzerland)
- Michael Längsfeld (PRO RETINA Deutschland, Germany)
- Paula Morandi (Mitocon Onlus, Italy)
- Gaëlle Jouanjan (France & Anirida Europe, France)
- Daniela Brohlburg (ProRetina Deutschland, Germany)

Kick Off  
Meeting ERN-  
EYE Applicants  
at Hub -

Strasbourg  
April 18, 2016



LEAVE THE SCIENTIFIC AND CLINICAL DECISIONS  
TO PROFESSIONALS –  
BUT ALWAYS WITH PATIENT REPRESENTED FOR  
ADVICE AND SUPPORT!

True meaning of collaboration.....

Accreditation –  
December  
2016



Now -

## Need to Focus on Further Development of ERN-EYE ePAG

Patients must be represented across committees of ERN-EYE

- Significant undertaking to raise awareness
- A mapping exercise reaching out to 30 groups acting for the Vision Impaired in Europe -January 2017 to ensure a broad representation of patients
- Two patient representatives willing to go forward for election spring 2017
- Many interested but concerned about lack of resource and support, will watch with interest

# Looking to the Future of Patient Representation and Leadership!

## ERNs are a - Hub and Spoke Model

- Patients will need to be involved centrally, on various committees but it is critical there is good representation on national HCPs
- This will require a step wise process of awareness, engagement and education
- ePAGs are charged with the development of ePAGs centrally and locally

**MUST PROVIDE LEADERSHIP,  
TRAINING AND EDUCATION ON  
COMPLEX SUBJECTS**

But How?

# Building on Patient Knowledge and Expertise - Effective Collaborative ERNs

- EURORDIS will develop **training and leadership modules** to support ePAG members to in the operational development and delivery of ERNs
- To ensure effective participation in complex areas EURORIDS will develop **transversal Focus Groups** on specific areas across all ERNs e.g. Research & Registers, Clinical Outcomes & Guidelines.
- The Focus Groups will provide the opportunity to **brain storm, share learning and experience** across ERNs will be critical
- EURORDIS experts will chair appropriate groups to ensure transfer of most up to date information on specific areas .
- Focus Groups will work across ERNs where appropriate



# MAKING PATIENT EXPERTISE VISIBLE ACROSS EUROPE

EURORDIS Commitment to Patients!



# European Patient Advocacy Groups –

## A Model of True Patient Engagement

- To ensure ERNs are **anchored into national health systems**
- To **connect knowledge and experience** of leading clinicians, researchers and patients to generate knowledge
- To **eliminate the diagnostic odyssey**
- To have **open access** to leading treatment locally, prescribed against evidence based guidelines
- To ensure **transparency of outcomes of care** to drive quality improvement
- To **create a critical mass of patients and data**, pushing the pace of research and evidence based practice

**THANK YOU!**

And good luck to all!

