

Friday May 17th

Opening Avril Daly, president Eurordis

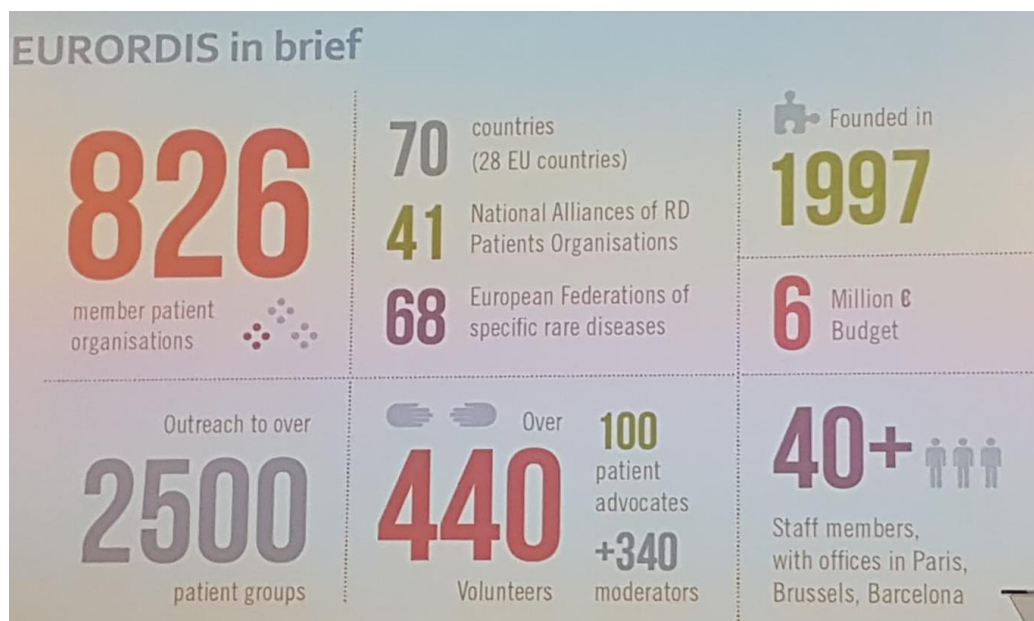
Progress in ERN's, patient involvement through ePAGs. There are strong developments in international cooperation: research recognition of rare diseases and ambitious goals – like work with Global Commissions, the NGO committee, the WHO and IRDIRC (international rare diseases consortium). Eurordis launched the European Joint Program. They aim a wider adoption and adherence to the principles of holistic (comprehensive) care.

Eurordis finds challenges in a few countries where national plans are running out of date. There is no European forum with patient representatives to replace the CEGRD (Commission Expert Group on rare diseases). There is a slow implementation of patient rights directive of cross boarder health care, inequalities across Europe, e.g. in access to approved medicines, no progress in assuring patient involvement in HTA (Health technology assessment). Eurordis is also working on making ePAGs fully functional. It's complex to managing, supporting and delivering in an increasingly complex environment, like a new EU parliament.

Rare 2030

A program making sure we can propose policies to address at European and national level such as: health economic aspects of rare diseases and ethical aspects of new health technologies.

Eurordis in brief:



ECRD Vienna 2018:

European conference in rare diseases and orphan products was held in Vienna with 857 participants from 58 countries.

Rare disease day 2018:

Successful campaign with 90 participating countries worldwide (28 EU countries). A rare disease video was translated in 35 languages. There was a new interactive face-paint social media campaign. And a strategic review in preparation of the future of Rare Disease Day was initiated.