EURORDIS Vision, Mission, Strategy
(DRAFT)

27 May 2021

Final Draft Yann Le Cam, for the AGA 10 June, based on Stakeholders 360° Assessment, Survey to Members on Strategy, Rare 2030 Survey, post-Board of Directors Meetings and Leadership Team Meetings, both with Philanthropy Advisors,

0 Who We Are

(We need to tell "who we are". This is what appears first in the website, leaflets, letters, any communication when introducing Eurordis.

EURORDIS-Rare Diseases Europe is The Voice of People Living with Rare Diseases in Europe.

EURORDIS-Rare Diseases Europe is a unique non-governmental alliance of 962 member organisations representing people living with rare diseases, working together across borders and diseases to improve the lives of 30 million persons living with a rare disease in Europe.

By empowering organisations and advocates, as much as by partnering with strategic partners and key stakeholders, EURORDIS mobilises the rare disease community and strengthens the people's voice to shape policies and innovative solutions driven by the needs in research, diagnostic, therapies and social inclusion of all affected persons.

1 Our Mission

(this is our raison d'être, our enduring purpose, what we are and why we do it)
(unchanged, only adjusted: "all persons" instead of "people")

EURORDIS works across borders and diseases to improve the lives of all persons living with a rare disease.

2 Our Vision

(this is our dream, the world is a place where…)
(changed, as our vision has evolved; it tells the change we want to see in the world)

EURORDIS' vision is a world where all persons living with a rare disease can live longer and better lives, reaching full potential and well-being, included in a society that leaves no one behind.

Our vision of the full potential and well-being for persons living with a rare disease and their families is:

- To be recognised as equal citizens and have their rights fully respected,
- To be diagnosed timely and accurately,
- To be supported with state of the art medical and social care, and possibly be cured,
- To be included in society in all aspects of life and live independently.

3 Our Strategy

(this is our long term strategy to fulfil our mission to progress toward our vision)
(we defined it in 2010, adjusted it in 2015 and are revisited now for 2020-2030)

EURORDIS' strategy to improve the lives of all persons living with a rare disease is to:

- **“Empower”**: To empower organisations and advocates representing persons living with rare diseases across all rare diseases and all European countries with the knowledge and skills they need to fight for better lives,
- **“Partner”:** To catalyse networks to exchange experience, co-produce knowledge, deploy actions as well as to cooperate with strategic partners and key stakeholders (including policy makers), supporting active and meaningful patient engagement improving the lives of persons living with a rare disease
- **“Advocate”:** To advocate for policies and innovative solutions driven by the needs of people living with a rare disease.

Placing People First, based on evidence and personal experience of unmet needs, in the areas of “research and knowledge”, “healthcare services and standard of care”, “development and access to diagnostic and therapies”, “persons’ data and digital health”, integrated social care and social inclusion”.

Full text version:

EURORDIS’ strategy to improve the lives of all persons living with a rare disease is to:

- **“Empower”: To empower organisations and advocates representing persons living with a rare diseases across all rare diseases and all European countries with the knowledge and skills they need to fight for better lives**: to unite into a legitimate and credible citizen movement in the EU and Europe at large; to exchange experiences and promote collaboration among organisations and advocates; to build the capacities of advocates and organisations, with the knowledge and skills needed to fight for better lives at the national, European or international level for their disease or across rare diseases.

- **“Partner”: To catalyse networks to exchange experiences, co-produce knowledge, deploy actions as well as cooperate with strategic partners and key stakeholders (including policy makers), supporting active and meaningful patient engagement improving the lives of persons living with a rare disease:** to establish a strong public-private partnership for collective responsibility and co-creation of solutions; to connect and align with all relevant stakeholders who have the biggest impact to improve the lives of persons living with a rare disease; to structure the organisations into networks sharing common goals; to initiate or to engage with existing networks of clinicians, researchers, companies; to promote and support the engagement of persons living with rare diseases in knowledge generation, innovation, expertise and decision-making processes so that the people’s voice is active, amplified and meaningful in research, diagnostics, therapy development, as well as in both healthcare and social policies and services.

- **“Advocate”: To advocate for policies and innovative solutions driven by people’s needs** to be the voice of persons living with rare diseases in Europe; to advocate for the respect of rights of all persons living with a rare disease and the promotion of social justice to equitably address their needs; to advocate to ensure that healthcare and social policies and services, research, data and digital health, and the development and access to diagnostic and therapies take into account the real needs of the persons living with a rare disease. Our advocacy is evidence-based and fuelled by the eal-life experiences of the rare disease community.

4

Our Values

(unchanged, except for “people” instead of “patient”)

People **first**
Authentic
Courageous
Collaborative
Innovative
Professional
Solidarity
Social justice & equity

5

Our Strategic Objectives 2020-2030

(The Strategic Objectives are written as “ What success looks like by 2030” / “What do we want to win at in the next 10 years” when executing our strategy to fulfil our unique and specific mission in order to achieve measurable goals advancing our vision.)
(After the AGA, these Strategic Objectives will be transformed into more explicit directions by the Board and the staff on the areas where we want to operate and how we will operate)

To adapt to a rapidly changing environment (as indicated in the Rare 2030 trends),
to best contribute to the achievement of the preferred scenario in the Foresight Rare 2030 and policy recommendations by 2030,
and to respond to the changing needs of a growing patient organisation,

By 2030, EURORDIS:

- **Has promoted and facilitated the implementation of a new European policy framework to achieve measurable goals** prolonging and improving the life of persons living with rare diseases and their inclusion in society, while designing a European model of care
- **Has redefined and focused its unique role in the rare disease ecosystem;** is leading impactful and motivated networks of member organisations and advocates across diseases and borders, enabling to relay people’s needs and integrate European and national actions in key policy areas; and as a driver of change, is creating synergies across partners and key stakeholders to achieve better and faster results.
- **Has regularly assessed and consolidated its priority areas of operations to both respond to the demands of organisations and advocates while aligning with internal capacity,** progressively focusing on the new challenges of data and health digital technologies as well as on a holistic, life-long approach towards inclusion in society; as much as to strengthen its priority on changing the game in research and knowledge, early diagnostic, development of and access to transformative or curative therapies, integrated care, national and European healthcare pathways and cross-border healthcare.
- **Has achieved a “leave no one behind” strategy** inclusive of genetic and non-genetic rare diseases -rare cancers, rare infections and rare poisonings- putting more focus on Eastern and Southern Europe, changing the game on very rare diseases and promoting the next generation of young advocates

6

Our Organisational Strategic Alignment

(Over the Summer & Autumn 2021, and thereafter on a regular basis, the BoD & Staff will review the organisational capacities and organisational architecture of EURORDIS to best support its Strategic Objectives 2021-2030 such as capabilities for strategy deployment, projects development, diversification of resources, segmented communication and digital communication, rules of engagement for networks, data & digital health, early diagnostic work, social inclusion work, advocacy based on evidence and first hand experiences, rare

cancers, rare infections, very rare diseases, Europe at large, Eastern & Southern Europe, new patient groups, next generation advocates (not a limited list).

Over the Summer & Fall 2021, and thereafter on a regular basis, the staff leadership team will revise and adapt the management systems (people, workplace, information systems, finance and budget, project development & management, advocacy method & prioritisation, overall monitoring of all actions or programmes or projects and performance measurement)

7

Our measurable Goals

(Measurable goals will be defined along the final more detailed Strategic Objectives and the Theory of Change, in parallel to the work of Philanthropy Advisors on the Performance system)