Press release

EURORDIS-Rare Diseases Europe elects new Board of Officers

***28 November 2022, Paris* – EURORDIS-Rare Diseases Europe, a patient-led alliance of 1000 rare disease member organisations, announces a new leadership team, in line with its next-decade strategy.**

The EURORDIS Board of Directors elected a new Board of Officers at its meeting on 25–26 November. Avril Daly, EURORDIS Vice-President and Acting President since June 2022, has been appointed President of EURORDIS, to continue the legacy of Terkel Andersen, who has stepped down, for health reasons.

Mr Andersen will take the position of Immediate Past President within the Board of Directors, ensuring the continuity of the entire organisation's leadership.

Moving forward, the Board of Officers will have two Vice-Presidents instead of one, Maria Montefusco and Dorica Dan, who will work together with the President and the Board to make sure the organisation maintains its values and meets established goals.

Geske Wehr, EURORDIS General Secretary, will be joined by Simona Bellagambi, who is taking on the newly created role of Deputy General Secretary, to enhance engagement in the different membership networks.

Alain Cornet will continue to perform his duties as Treasurer, overseeing the budget, finance and procedures. The Board of Officers, therefore, comprise 6 members.

With the resignation of Terkel Andersen, who has served as President for nearly 20 years, EURORDIS will enter a new era of leadership and organisational development, to implement its revised strategy and recently adopted strategic goals for 2022–2030. Speaking of his achievements and long history of patient advocacy, **Avril Daly said:**

> *"For each one of us Terkel has been more than our president: he is a rare disease pioneer, a mentor, and a good friend. He has laid the foundation for us all. He truly excelled in his role to ensure a strong membership-based legacy, speaking on behalf of the 30 million people living with a rare disease in Europe, and provided a strategic vision to promote the rare disease cause and to shape the main policies relevant to rare diseases and its ecosystem.*
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> *"He has built consensus with EURORDIS members and other stakeholders on common action in the key areas of empowering, engaging and advocating for people with rare diseases, which reflects the purpose-based and value-driven nature of our community. This is evident in the fact that EURORDIS has now over 1000 members. For me personally the key quality Terkel possesses is his ability to really listen to his colleagues on the board the team at EURORDIS and the membership.*
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> *"True leaders recognise that one can only really lead by listening and learning. His wisdom, leadership, and dedication are now part of the organisational fabric, and I am grateful to be the one carrying his legacy of listening and learning in order to lead."*

Immediate Past President, **Terkel Andresen,** congratulated Avril Daly on her appointment and added:

> *"I am extremely honoured to see Avril take on the leading role in this hard-working and results-driven organisation.*
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> *"She has served as Vice-President with the utmost integrity and I have no doubt she will build on the organisation's transformative momentum to reach new heights.*
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> *"Her extensive experience in the area of rare diseases and her passionate advocacy for social justice and equality align perfectly with the strategic objectives for 2021–2030."*

This important change in the Board structure, which goes beyond the appointment of a new President, echoes the long-term revised strategy of a growing organisation that is EURORDIS.

In line with EURORDIS policy, the composition of the Board of Directors reflects the diversity of expertise, skills, disease areas, gender, social backgrounds, and nationalities that are critical to addressing the interests of all of the EURORDIS stakeholders.

Each director is either a person living with a rare disease or a family member or an engaged volunteer, with a proven track record of national or European advocacy and unique competencies to execute their mission as a Board member.

Members of the Board work collaboratively in the best collective interest of EURORDIS and its members, not in their respective interest of disease or country or patient organisation of origin.

The Board of Directors, composed of 75% women, represents a wide range of backgrounds, nationalities, and disease groups, from more 'common' to ultra-rare diseases.

Members of the Board of Officers

Avril Daly, living with Retinitis Pigmentosa, who has been Vice-President of EURORDIS since 2012, is an expert in rare disease research and has had a leading role in putting in place the Irish national plan for rare diseases. She has created Rare Diseases Ireland – the National Alliance on Rare Diseases – and founded Retina International, of which she is the CEO.

Dorica Dan, who is President of the Romanian Prader Willi Association and the Romanian National Alliance for rare diseases, is an expert in rare cancers, with nearly two decades of experience. She is also President of Rare Cancers Romania and a Board member of the Prader Willi International.

Maria Montefusco, who was born without fingers on her right hand, a rare disability which is called dysmelia, is an expert in international and European disability policies. She provides EURORDIS with her extensive leadership experience, particularly as the former chairperson of Rare Diseases Sweden and the secretary at the Nordic Council of Ministers.

Geske Wehr, President of Selbshilfe Ichtyose e.V., Chair of the Board of ACHSE e.V., Rare Disease Germany, and Co-lead of the European Network of Ichthyosis, has been involved in rare disease advocacy since 1997. She brings her invaluable experience in working with public authorities and health insurance providers.

Simona Bellagambi, from the Italian TSC Association, who is also a UNIAMO Board member, will bring a new contribution to the EURORDIS Board of Officers with her expertise in helpline service operations and awareness-raising activities in Italy.

Alain Cornet, General Secretary of Lupus Europe, began his involvement in rare disease advocacy when his wife was diagnosed with Systemic Lupus Erythematosus in 2004, getting involved with the lupus community as a

volunteer, treasurer, and patient advocate. Alain will continue to deploy his skillset on our Board in performing his duties as Treasurer, overseeing the budget, finance and procedures.

Members of the Board of Directors

Terkel Andersen, Immediate Past President, EURORDIS-Rare Diseases Europe.

Kirsten Johnson, The Fragile X Society (UK); Fragile X International.

Rebecca Tvedt Skarberg, Osteogenesis Imperfecta Federation Europe (OIFE), Norway.

Alexandre Méjat, AFM-Telethon, France.

Birthe Byskov Holm, Rare Diseases Denmark; Danish Osteogenesis Imperfecta Association.

Elizabeth Vroom, Duchenne Parent Project Netherlands.

Anna Arellanesová, Rare Diseases Czech Republic; Czech Cystic Fibrosis Association.

About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 1,000 rare disease patient organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

About rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date affecting an estimated 30 million people in Europe and 300 million worldwide. 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

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