



Press Release

EURORDIS welcomes new members to its Board of Directors

24 May 2024, Paris – EURORDIS-Rare Diseases Europe is pleased to announce the elections to six seats on our Board of Directors during the organisation's annual [General Assembly 2024](#).

The elections saw the appointment of six members to the Board, including four re-elected and two newly elected members.

Avril Daly, Chief Executive Officer of [Retina International](#), was re-elected to the Board. Following a meeting of the *EURORDIS Board of Officers* (taking place after elections) to the *Board of Directors*, Avril has been confirmed to continue as President of the organisation.

The two newly elected Board members are **Johan de Graaf** of the [Dutch Pituitary Foundation \(Nederlandse Hypofyse Stichting\)](#) and **Tetiana Kulesha** of *Rare Diseases of Ukraine*.

Diagnosed with a pituitary condition in 2007, Johan de Graaf progressed from seeking information to becoming a volunteer and eventually the chairman of *Nederlandse Hypofyse Stichting*. He has been a key advocate for better care for pituitary patients, focusing on medical research and international relations. His training in patient advocacy enhances his role in patient advocacy and his contributions to European Reference Networks and the European Medicines Agency.

Tetiana Kulesha, Chair of the Board of Rare Diseases of Ukraine, has played a crucial role in ensuring access to medicines and healthcare for rare disease patients amid the war in Ukraine. Her organisation's collaboration with international partners, including EURORDIS, has provided significant humanitarian aid. Tetiana's advocacy focuses on improving healthcare policies and participating in European initiatives to enhance care quality for rare disease patients.

Alexandre Mejat of [AFM-Téléthon](#), **Anna Arellanesová** of [Rare Diseases Czech Republic \(ČAVO\)](#), and **Simona Bellagambi** of [Rare Diseases Italy \(UNIAMO\)](#) were also re-elected to the Board.

Responding to the election results, **Avril Daly**, President of EURORDIS, said:

"I am thrilled to welcome our new and returning members to the EURORDIS Board of Directors. The dedication and expertise of our Board members are central to guiding EURORDIS' efforts to improve the lives of people with rare diseases.

"We are very pleased to welcome Tetiana Kulesha, ensuring the Ukrainian rare disease population, impacted by the war, is strongly represented. Additionally, Johan de Graaf's experience in patient advocacy and expertise in hands-on medical research and international relations will be invaluable.

We are grateful for our membership's support and look forward to the new perspectives our Board members will bring over the months and years to come.”

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1,000 rare disease 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 people, families, and rare disease 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 services.

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