EURORDIS GENERAL ASSEMBLY
18 MAY 2022

CANDIDATES TO THE BOARD OF DIRECTORS' ELECTION

TERKEL ANDERSEN, DANISH HAEMOPHILIA SOCIETY, DENMARK

Terkel Andersen was elected President of EURORDIS-Rare Diseases Europe in May 2003 and has been a member of the EURORDIS Board of Directors since 1997, when the organisation was founded.
A person with hemophilia himself, Terkel has broad experience in disability and health issues becoming involved in the rare disease field in 1983 when he joined a Nordic project on the mapping of problems related to rare diseases. Terkel served as president of the Danish Haemophilia Society 1985-2017. He was one of the founders of the Danish Alliance of Rare Disorders in 1986 and worked as the first Executive Director of the Centre for Rare Diseases and Disabilities of the Ministry of Social Affairs in Denmark from 1990 to 2001. From 1992 to 2002, he served on the executive board of the World Federation of Hemophilia; and from 1993 to 1999, he was chairman of the European Haemophilia Consortium. In his professional capacity Terkel worked with the Danish National Council for Volunteering until October 2018. Terkel represents EURORDIS at International Conferences throughout Europe and beyond. Since 2018 Terkel Andersen is member of the Agrenska Board of Directors

KIRSTEN JOHNSON, FRAGILE X SOCIETY, UK

I am Chair of the Board of The Fragile X Society (UK) and Chair of the Board of Fragile X International, an AISBL registered in Brussels. Fragile X Syndrome is a rare disease, affecting 1 in 4000 males and 1 in 4000 females. I am a carrier of the Fragile X gene and have two daughters with Fragile X Syndrome.

I have a wealth of boardroom experience and will bring to EURODIS expertise in setting strategy, writing statutes, hiring staff, governance, budgets and overseeing organisations. In regard to the person specifications, I am self-employed and able to give the time required to this position; I am willing to encourage membership of EURODIS from other organisations; I enjoy working as part of a multi-cultural team; I have extensive public speaking experience; I led our Society in joining the Disabled Children's Partnership and worked with this multi-stakeholder group in calling for improvements to disabled children's lives in the UK. In regard

to virtual meetings, I have chaired and participated in numerous online meetings, and I am confident in this medium.

Recently, I was one of the authors of an article in Cells which called for the eradication of 'mental retardation' in the Fragile X gene nomenclature. I'm pleased to say that the gene name has been changed because of our advocacy. I hope to continue my work in building a more inclusive society for all our families affected by rare disease, so that they do not face stigma and discrimination.

I would like to join EURODIS because I believe in its mission and values, and believe I have skills to offer the Board. I already work across Europe with my colleagues in the Fragile X community and welcome the opportunity to represent the interest of rare disease patients from all European countries.

REBECCA TVEDT SKARBERG, OSTEOGENESIS IMPERFECTA FEDERATION EUROPE (OIFE), NORWAY

Rebecca Tvedt Skarberg, (1975) lives in Oslo, Norway. Her personal experience living with a rare condition comes from being born with osteogenesis imperfecta (OI), Rebecca uses a powered wheelchair to get around. She lives independently with her husband Knut Erik and their two cats.

Rebecca is a trained social worker with additional degrees in psychology and counselling. She worked for the Norwegian National Welfare office (NAV) 2001 - 2014. From 2014 Rebecca has worked for the Norwegian National Advisory Unit on Rare Disorders (NKSD). Rebecca works on strengthening patient involvement, strategy and planning of services for rare disease, as well as international issues. In 2022 she was head of the program committee for the Rare Disease Day Norway.

Rebecca started volunteering from an early age. In the 90´s she served on the board of the Norwegian OI Organization (NFOI) and on the board of the first resource center for OI and other similar rare conditions in Norway (TRS). 2007 - 2015 she served on the board of The Norwegian Federation of Organizations of Disabled People (FFO) and had many other commitments tied to that role. One of the most meaningful tasks was serving on the project board that lead to the establishment of the Norwegian National Advisory Unit on Rare Disorders (NKSD).

Rebecca has also been engaged in international volunteer work through OIFE and EURORDIS. She was involved in the establishment of BOND ERN and was elected ePAG when ERNs were launched in 2016. Rebecca has been part of the SC in BOND and has contributed to many working groups in the ERN. She attended EURORDIS Leadership school of 2019. She has been a part of the establishment of the EuRR-Bone registry from 2020, especially working on patient involvement. In 2019-2021 she served on the Rare2030 panel of experts.

Rebecca has been personally invested in disability rights, equity, and patient advocacy from an early age. She hopes to contribute to the board of EURORDIS with her experience and her drive help empower people and engage professionals to spread awareness and knowledge about rare disease.

GESKE WEHR, SELBSTHILFE ICHTHYOSE E. V., GERMANY

My eldest son who was born in 1996 suffers from an autosomal recessive congenital Ichthyosis. This is a genetic keratinisation disorder with a prevalence of 1 in 150.000. Luckily this condition is not life-threatening, but good therapy and ongoing care is necessary and very time consuming. It's a visible disease with associated social problems. Since 2019 I am president of ACHSE - Rare Diseases Germany and since 2010 I am engaged in the European Network for Ichthyosis as voluntary CEO.

In 2012 I was first elected to the EURORDIS board of directors, and it is great to give my skills and my knowledge, my ideas, and questions to this strong and steadily growing, wonderful organisation for people living with a rare disease. In 2017 I started being General Secretary; Being contact partner for all members of EURORDIS, supporting the Board of Officers and spending more time on EURORDIS tasks makes me happy. The projects I attend are highly professional led and I appreciate being part of those.
I would very much like to have the opportunity of further supporting the aims and targets of EURORDIS, to move policy and improve the quality of life for all people in the Rare Disease community.
