



## Who are we?

The European Federation of Williams Syndrome (FEWS) is the official association of national organisations across Europe which are actively involved in supporting people with the rare genetic condition, Williams Syndrome (WS).

## Our goals

- To spread awareness of Williams Syndrome at the European level, by amplifying the awareness-raising activities of individual national associations.
- To ensure effective co-ordination of, and collaboration between, national and regional WS organisations in Europe, avoiding the unnecessary duplication of resources.
- To help direct individuals with WS, as well as their families and carers, to their relevant national or regional associations and to appropriate potential providers of support.
- To co-ordinate international research efforts by connecting relevant research institutions and professionals with WS organisations.
- The sharing and translation of relevant publications and guidance materials into the languages of member associations.
- To organise and participate in international congresses.
- To promote and manage contact between WS organisations and research institutes outside of Europe.
- To identify and secure funding to support the organisation of leisure and educational camps for individuals with WS from member associations, hosted by volunteer member associations on rotation.

## Our ways of working

Each of our member associations support FEWS by:

- participating in FEWS meetings, including by bringing ideas, experiences and ensuring timely follow-up on actions.
- arranging for timely decisions to be taken by individual member associations where these are required to ratify a decision or recommendation taken by the Board of FEWS.
- sharing resources across the network to avoid duplication of effort or cost, with a particular emphasis on making resources of the larger, more established associations available to the smaller associations.
- paying annual membership fees promptly, which are tiered depending on the financial standing of each member organisation.



## Our achievements in 2020-21 have included:

- Continuing to secure a specialist venue, “Frambu”, in Norway, for a FEWS Youth & Cultural Exchange of 60 participants to now be held in 2022 following the disruption of the Covid pandemic.
- Running our fourth and fifth annual FEWS Photo Contests to coincide with the Europe-wide WS Awareness Day, resulting in great engagement on social media.
- Supporting the development of coordinated International Guidelines for WS, to be published in 2022.
- Providing funding and/or support for two European research projects: the impacts of Covid in the WS community, and Anxiety and family well-being.

## Our key objectives for 2022 are:

- Finally, to bring together individuals with WS and families from across Europe by holding a FEWS Youth & Cultural Exchange in Norway.
- Organising an International Conference on WS in The Netherlands in the autumn.
- Implementing a refresh of our brand identity, to give it a more modern character.
- Investigating the development of an online knowledge platform for FEWS associations and their members.
- Welcoming additional member associations to the FEWS family.

## Our longer-term aspirations include:

- Continuing to develop active working relationships with other rare disease organisations in order to share experiences, operating lessons and resources.
- Securing reliable core funding to support the employment of a staff member that can be a permanent point of liaison for the FEWS member associations and with external bodies such as Eurordis.
- Living with equality for all persons with WS, everywhere!

**President** Jon Lovell, UK | **Secretary** Paul Pyck, Belgium | **Treasurer** Twan de Kruijf, The Netherlands  
**Directors** Sabina Halupka-Rešetar, Serbia & Zazo Pier Francesco, Italy

