FEWS

European Federation
Williams Syndrome

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 2019 have included:

- Identifying and reserving a specialist venue, “Frambu”, in Norway, and securing Eurasmus+ funding for a FEWS Youth & Cultural Exchange of 60 participants to be held in 2020.
- Running the third annual FEWS Photo Contest to coincide with the Europe-wide WS Awareness Day, resulting in a significant increase in positive engagement on social media.
- Organising a national seminar, accredited by the Health Council of Serbia, for 100 families and professionals to learn from specialist researchers from across Europe on key aspects of living with WS.

Our key objectives for 2020 are:

- To continue to support the development and growth of newly-established WS associations, such as those in Serbia and Bulgaria, by sharing best practice and resources across the FEWS network.
- To inform the development of a European Rare Diseases registry by engaging with the European Reference Network on Rare Congenital Malformations and Rare Intellectual Disability network (ITHACA) and its appointed solution provider, OpenApp.
- To bring together individuals with WS and families from across Europe by organising a FEWS Youth & Cultural Exchange in Norway.
- Campaign for better recognition of the support and inclusion needs of individuals with WS that are over 30 years old.

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;
- Refreshing the FEWS brand to make it more compelling on an emotional level.

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

vzw Williams-Beuren syndroom, Belgium | Williams Syndrome Association Bulgaria | Willík - spolek pro Williamsův syndrom, z.s, Czech Republic | Dansk Forening for Williams Syndrom, Denmark | Williams France | Williams-Beuren-Syndrom Bundesverband e.V, Germany | Magyar Williams Szindróma Társaság, Hungary | Williams Syndrome Association of Ireland | Associazione Italiana Sindrome di Williams, Italy | De Nederlandse Vereniging Williams Williams Beuren Syndroom, Netherlands | Norsk Forening for Williams Syndrom, Norway | Udruzenje za Vilijamsov sindrom, Serbia | Spoloc nost Williamsovho syndrómu, Slovakia | Associacion Sindrome Williams de España, Spain | Williams Syndromforeningen, Sweden | The Williams Syndrome Foundation, United Kingdom