What is Williams syndrome?

Williams Syndrome (WS) is a rare disorder, caused by a microdeletion in chromosome number 7. The lost material contains approximately 20 contiguous genes, with most notably elastin, which is the “marker gene”. WS is a non-hereditary syndrome that occurs at random and shows a wide variation in ability from person to person. It can affect brain development in varying degrees, combined with some physical effects or physical problems. These range from lack of co-ordination, slight muscle weakness, possible heart defects and occasional kidney damage. Development is delayed and atypical. The incidence of WS is thought to be somewhere between 1:7,500 to 1:20,000.

At present, due to its rarity, too few front-line medical and social care professionals are aware of this syndrome. Paediatricians in particular often lack the necessary experience to make the correct diagnosis, and this means that many Williams Syndrome children and their families are not given adequate opportunity to address their problems. However, we in the FEWS, are dedicated to redressing this imbalance, by helping to raise awareness and by facilitating a cross-border exchange of knowledge.

So far our experience with interventions, such as physio-, occupational- and language-therapies have shown very good results. It is important to start with therapies as early as possible, in order to achieve the best possible results.

European Federation of Williams Syndrome

Website: http://www.eurowilliams.org

Patron: Duke Leopoldo Torlonia

Chairman: Susan E.Cooper

E-mail: president@eurowilliams.org

Secretary: Paul Pyck

E-mail: paul.pyck@eurowilliams.org

Bank account:

Federation of European Williams Syndrome

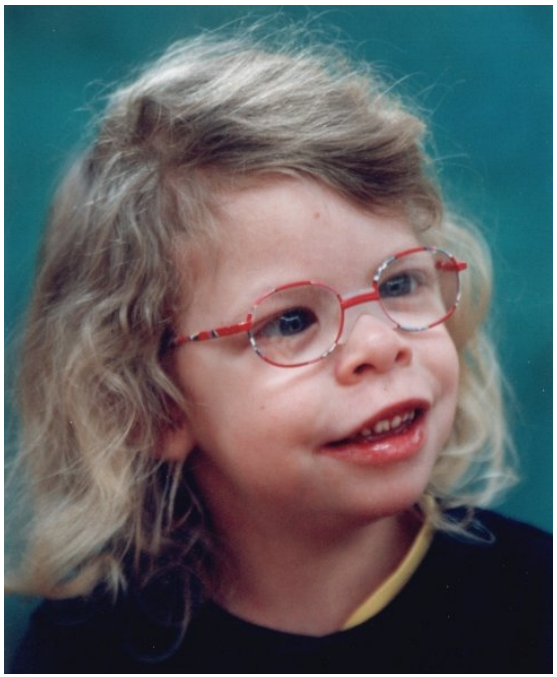
Bank of Ireland, Ballinasloe, Co Galway, Ireland

IBAN: IE31 BOFI 903680 40876816

BIC Code: BOFI IE 2D

FEWS

European Federation Williams Syndrome



Introduction into the European Federation of Williams Syndrome (FEWS)

What is FEWS?

FEWS is the Federation of European Williams Syndrome organisations. The initiative to form a pan-European federation was first taken in 1999, and our constitution was granted formal acceptance by the EU in 2004.

Members of the FEWS are:

Belgium	Williams Beuren Syndroom vzw
Czech Republic	Willík
France	Williams - France
France	Autour des Williams
Germany	Bundesverband William-Beuren Syndrom e.V.
Hungary	Magyar Williams Szindróma Társaság
Ireland	Williams Syndrome Association of Ireland
Italy	Associazione Italiana Sindrome di Williams
Netherlands	Vereniging VG Netwerken - Oudernetwerk Williams Syndroom
Norway	Norsk Førening for Williams' Syndrom
Poland	Stowarzyszenia Zespołu Williamsa
Romania	Asociata Williams Syndrome
Slovakia	Spoločnosť Williamsovho syndrómu
Spain	Asociación síndrome Williams de España
Sverige	Williams Syndromföreningen I Sverige
UK	The Williams Syndrome Foundation

Our goals

The Purpose of FEWS is the pursuit and achievement of the following objectives:

- The spreading of awareness of Williams Syndrome
- Co-ordination and federation of national and regional Williams Syndrome organisations
- The support of individuals with Williams Syndrome and their families
- The co-ordination of research into Williams Syndrome in research institutes in the member states, avoiding the unnecessary overlapping of economic resources
- The promotion of targeted scientific research projects
- The translation of publications into the languages of the member states
- The organisation of international congresses
- The promotion of educational programmes
- The promotion and management of contact between different WS organisations and with research institutes active in countries outside the Federation.

Our achievements so far

Since several years we have established a hugely successful and popular program of annual summer camps where Williams people are given unique opportunities for discovery and social interaction.

In 2014 an International Conference is held in Budapest, the main aim of which is to help professionals in countries which have limited expertise in WS, to improve their knowledge and awareness of the syndrome.

FEWS is also affiliated with the European Organisation for Rare Diseases (EURORDIS), and we hope to make full use of their powerful resources.

How can you help?

Our greatest need as a young charity, is financial support.

However, we would also be most grateful for help in any of the following areas:

- To initiate social, educational and cultural programmes that will benefit the individuals with Williams Syndrome
- To inform and support their families
- To organize family respite and international holiday camps
- To coordinate international conventions for the mutual exchange of recent research and professional advice
- To help us raise the general awareness of the syndrome

Contacts

For further information please review our website, or contact the Chairman or the Secretary (addresses overleaf).