

What is Williams Syndrome?

Williams Syndrome (WS) is a rare disorder, caused by an abnormality (a deletion) in chromosome no. 7. The lost material contains approximately 20 contiguous genes, but most notably elastin, which is the “marker gene” for WS. It 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. WS is not curable. The incidence is approximately 1 in 10,000 to 20,000. The syndrome was first described in 1961 and until now only little information exists about adults with Williams syndrome.

At present, due to its rarity, only few professionals are aware of this syndrome. Paediatricians in particular, often lack the necessary experience to make the correct diagnosis. This means that many Williams Syndrome children and their families are not given adequate opportunity to address their problems.

So far our experience with training programmes, 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.

Federation of European Williams Syndrome

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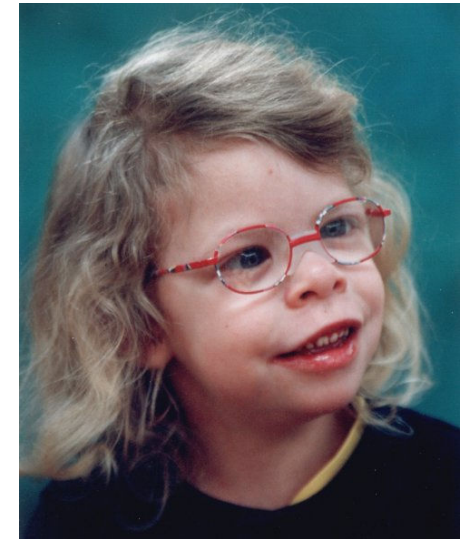
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Introduction into the



Federation of European Williams Syndrome

(FEWS)

What is FEWS?

FEWS is the *Federation of European Williams Syndrome associations*. 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 until now:

Belgium	Williams Beuren Syndroom vzw
France	Fédération Française du Syndrome de Williams et Beuren
France	Autour des Williams
Germany	Bundesverband Williams-Beuren Syndrom e.V.
Hungary	Magyar Williams Szindróma Társaság
Ireland	Williams Syndrome Association of Ireland
Italy	Associazione Italiana Sindrome di Williams
Norway	Norsk Føring for Williams Syndrom
Romania	Asociatia Williams Syndrome
Slovakia	Spoločnosť Williamsovho syndrómu
Spain	Asociación Síndrome Williams de España
Sweden	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 associations;
- 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 associations and with research institutes active in countries outside the Federation.



Our achievements so far

We have already established a hugely successful and popular programme of annual summer camps where Williams people are given unique opportunities for discovery and social interaction.

We have also taken membership with the international charity working on behalf of rare disorders - EURORDIS, and we hope to be able to participate fully in their international network.

How could you help?

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

However, we would 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).