

# Special International Empowerment Camps For Williams Syndrome Patients

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[www.rirosz.hu](http://www.rirosz.hu)

[www.eurowilliams.org](http://www.eurowilliams.org)

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# What is FEWS?



**FEWS is the European Federation of Williams Syndrome associations. The federation was officially established in 2001 by all members accepting the constitution. The constitution was proofed by the Belgian Ministry of Justice as an European charity organisation.**



# What is Williams Syndrome?

- Williams Syndrome (WS) is a rare disorder, caused by a deletion in chromosome no. 7. The lost material contains approximately 20 genes, eg: elastin. It is a non-hereditary syndrome that occurs at random.
- It can affect brain development in varying degrees. It has all the characteristic problems of rare diseases. (For example: -physical problems, -lack of coordination, - muscle weakness, - possible heart defects, - occasional kidney damage, - normal development is generally delayed.)
- WS is a „lifetime programme”. The incidence is approximately 1 in 7500-20,000. The syndrome was first described in 1961.



# Goals

- to extend the real or "imaginative" limits of abilities of our youth, with the surprise of "I can do it" feeling
- to have a lot of fun and joy
- to form an integrated development program to increase the chance of handicapped youth for equal opportunities
- five-ten days of concentrated therapy improving the habilitation - rehabilitation of these people with accumulated disabilities, to promote their social reintegration



# Goals

- to produce international, non-formal educational activities, promoting a better understanding of the diversity of our common European culture and shared heritage, as well as of our common basic values
- to present opportunities for free expression of participants' sense of solidarity, to eliminate all forms of discrimination and to compensate their social disadvantages
- to utilize this unique opportunity to perform psychological research with volunteers, aiming better sleeping and therefore learning of WS people

# Camps

- Norway (2005) „Conquer the nature under the midnight sun.”
- Hungary (2006) „Actions for Equal Opportunities – an International Development Adventure Camp for Youth with Williams Syndrome.”
- Sweden (2007) „Sound and Action FEWS Camp - An Experiential Music Camp for Youth with Williams Syndrome”
- Germany (2008) „Nature and Adventure FEWS Camp”
- France (2009) „Action in Provence”
- Italy (2010) „Cerwood Camp”
- Spain (2012) „VII European Exchange for Teens with Williams Syndrome - I Feel.”

**Major support:** The YOUTH Community Action Programme of the Eur. Commission, Action 1 - Youth for Europe; then Youth in Action Programme, 1.1 Youth Exchanges

# Norway (2005)

NORTH  
CAPE



Sommarøy



POLAR CIRCLE



Russia

Finland

Norway

Sweden



Tromsø

Bodo

Trondheim

Bergen

Haugesund

Drammen

Sandnes

Stavanger

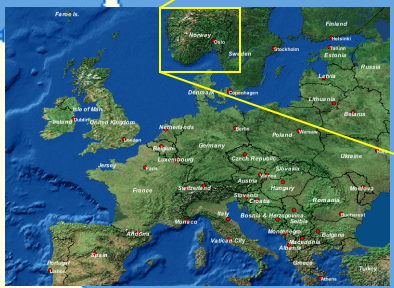
Kristiansand

Oslo

Skien

Sarpsborg

Tønsberg



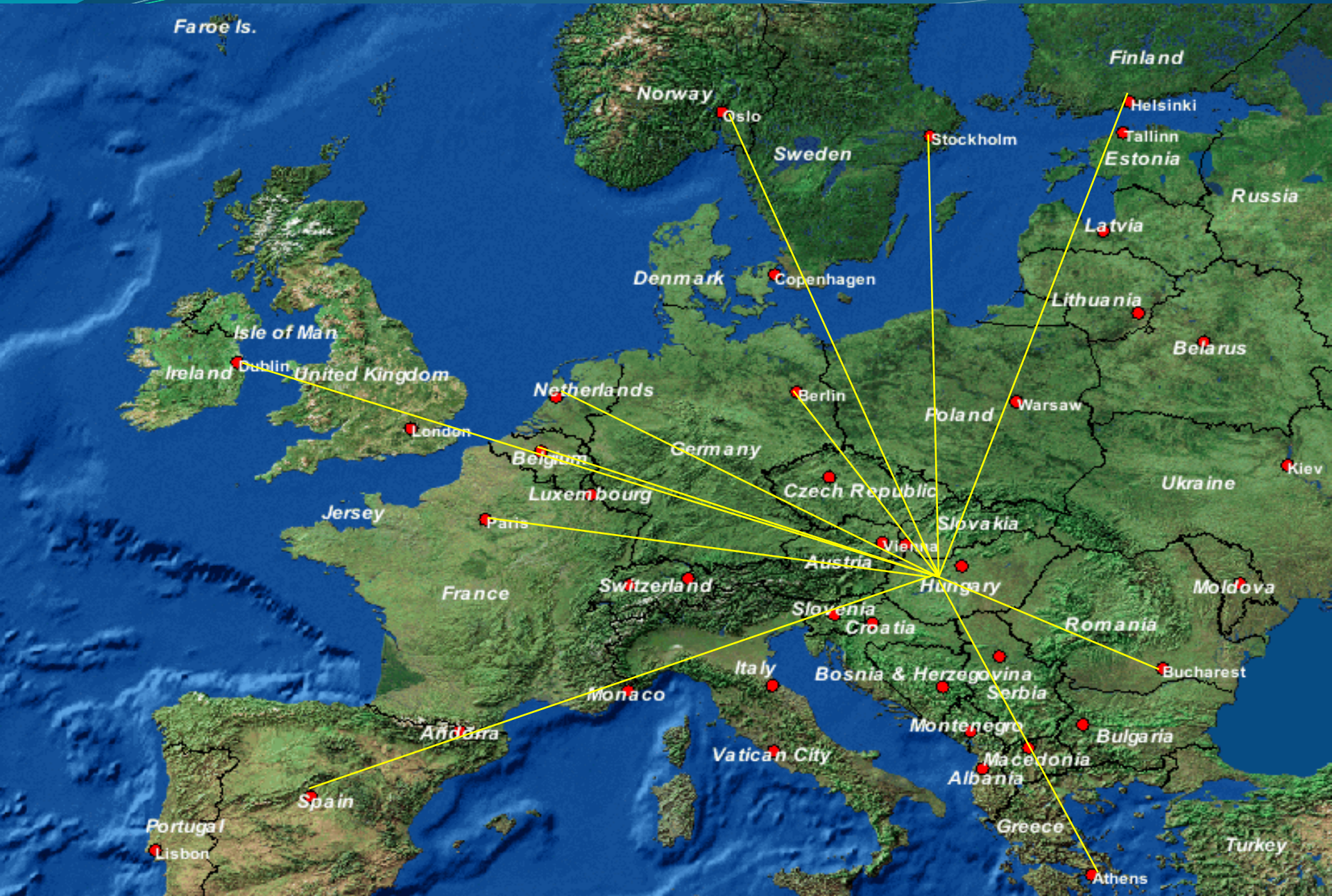


# Adventures behind the Polar Circle





# Hungary (2006)





# Get together games



# Sensomotor training





# Special swimming



# Musical development





# Musical gymnastic



# Dance therapy





# Hydrotherapy



# Dog therapy





# Art therapy



# Drama therapy





# Visiting surroundings



# Concert



# Presentation of countries



# Farewell Party



# Efficiency

- The agenda and realization of this programme in which young people from 13 countries took part was granted as **'one of the most outstanding projects of the past 7 years'** by the Hungarian Office of the European Union.
- It also won the **2007 European Youth Prize** in Brussels, in the competition of 'Best Practices of Social Inclusion and Diversity' in the category of 'Including every young people'.



# Sweden (2007)

## Sound and Action FEWS Camp in Furuboda





# „An Experiential Music Camp for Youth with Williams Syndrome”





# Germany (2008)





# „Nature and Adventure FEWS Camp”

## Langau





# France (2009)





# „ Action in Provence ”





# Italy (2010)





# „Cerwood Camp”





# Spain (2012)

Some of the activities will be related to the main theme, the 5 senses, and will alternate between activities within the facilities and in the environment and cultural visits to the city of Madrid.

## GOALS

- Promote solidarity, tolerance and respect between young people with Williams syndrome from various European countries.
- Offer the same opportunities to travel, meet youth from other European countries,
- Offer a multicultural vision for people with intellectual disabilities.
- Enjoy standard experiences.

# "I FEEL" in Los Batanes





# Summary

**Therapeutic recreation is important part of patient empowerment!**

- *When the children / Youth are alone.*
  - learning independence and well-being
  - having fun and joy
  - overcome their barriers, reinforce self-esteem
  - participating essential development programs
  - having leisure, relaxation, together with rehabilitation
- *When the families are together*
  - helping and learning from each other
  - changing experiences, good practices
  - learning „survival techniques”, skills
  - having some entertainment, recreation
  - reducing anxiety, providing emotional support
  - improving living competence

# Thank you for your attention!

## Rare Diseases Hungary European Federation of Williams Syndrome Associations



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# „Relaxing together” project

Discovering Kiskunság – area in central part of Hungary, where the Cuman (Kun) tribes were settled in 1243 by the Hungarian King Béla IVth, after the Mongolian invasion against Europe. The Mongols swept through the country, burning it virtually to the ground and killing an estimated one-third to one-half of its two million people in the Carpathian basin.



Coat of arms of Cumania

## Goals:

- *Family recreation*
- *Investigate living circumstances in a farm*
- *Learning history – nomadic life*
- *New „trainings and therapies” to develop new skills – horse riding, archery, bullwhip (try to smack), games, dance, baker’s trade in traditional oven*
- *Visiting surroundings on foot and by wagon*
- *Having fun and joy*