

PRADER – WILLI, Czech Republic



From the beginning to the present

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ABOUT THE ASSOCIATION

- brings together patients with PWS, their parents and sympathizers
- at the current time it has around 40-50 registered members
- the precise number of persons with PWS in the Czech Republic is not known
(about 120 which were or are treated with GH patients are currently registered in the national database of patients)
- the estimated number of patients is therefore around 200–250





Association's Aims

- to increase knowledge of PWS among the expert and lay public (media, information materials, workshops)
- to provide the latest information about treatment to families
- regular meetings of families and passing on of personal experience
- advice on social support, social services, integration and assistance
- creation of housing for the group of adults with PWS
- support for the establishment of a specialized workplace for paediatric and adult patients with PWS



How we started

- established in 2003 at the time some of the symptoms of the syndrome could be treated with growth hormone
- established by parents
- the parents work for the association in their free time
- in the beginning no experience
- milestones

2007 6. International conference in Cluj Napoca (Romania)

2008 Germany Silberbach German / Czech workshop

➔ Berlin – home for adults - EJJ Lazarus



- 2013 8. International conference in Cambridge - more information

EJJ-Lazarus
miteinander – füreinander

**Lebensraum
in Biesdorf**

Wohngruppe
für Menschen mit Prader-Willi-
Syndrom (PWS)

Debenzer Straße 36-44
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Housing for adults with PWS



- **first in the Czech Republic**
 - has started in January 2021
 - 5 adults – 3 women, 2 men
 - respects the specifics of PWS
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- housing was created as a separate household within the existing social facility Domov Maxov, it is a similar model as in Berlin - a large apartment, each user has his own room with bathroom, shared space with kitchen, without free access to food
 - has trained staff, 24-hour supervision
 - clearly structured day – various therapeutic workshops, plenty of exercise – especially walking outdoors, weight control

What preceded it

11 years of convincing authorities and providers

and last 2 years cooperation with the management of Domov Maxov

- mediation of information about PWS and specific experiences with housing in neighboring countries, organizing visits to several facilities in Germany, active cooperation with the management - informing families, survey of interest etc.

And at the end

We did it



Association's Activities

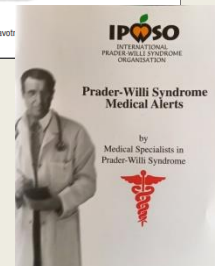
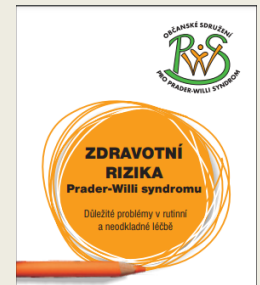
Regular family gatherings - a place where families can best pass on the experience

- weekend meetings are held twice a year
- one is always with a professional program, the lecturers are from the ranks of doctors, psychologists, social workers, rehabilitation workers, etc., the children are cared for by volunteer assistants
- the second one more focused on walks, trips
- part of the program is for children with PWS and their siblings – competitions, disco



Information materials

- association initiated the creation of information leaflets, in cooperation with doctors the first brochure concerning PWS and treatment in CR, Czech version of Medical alerts (translation of the original IPWSO)
- a chapter on PWS in Methodology for Teachers
- translations of professional articles from IPWSO





Association's Activities

Media

- several articles about PWS and the association, interviews, were published in newspapers, magazines
- PWS was the subject of several documentary films and part of the series on of Rare Diseases' Day on the Radio.

In some cases, these programs have helped diagnose older children.

Seminars and education

- The members of the association participate in professional seminars on PWS, social issues, the association is active in initiatives of CAVO (Rare Diseases, Czech Republic) to increase awareness of rare diseases (eg seminars at medical faculties, events on VO Day, etc.).
- Provides materials and mediates contact between families and students of medical and social schools
- Cooperation with doctors and other experts
- Participation in studies, surveys

Website and FB

Participation in organizing concerts in support of the association





Membership in other associations

- ČAVO (Rare Diseases, Czech Republic)
- Aliance (Alliance for Individualised Support, Czech Republic)
- IPWSO (International Prader - Willi Syndrome Organization)

Contacts

Website: prader-willi.cz

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THANK YOU

