



First International PWS Caretaker's Conference

Development of Guidelines & Standards

03. June 2008 – 05. June 2008
Herne, Germany

Since 1996 the institutions Regens Wagner Absberg and two years later the Diakonische Stiftung Wittekindshof has offered special Prader-Willi Syndrome (PWS) programs in living, working and recreation.

Based on cooperation with another institution - Rehabilitationszentrum Thüringer Wald, Schleusingen - in 2003 the working group of "AG Innovation PWS" was founded. One of the primary goals of this group is to help develop the competencies of direct care of individuals with PWS. This group has developed standards and guidelines for day living and working in Germany. Another project developed by "AG Innovation PWS" is a curriculum which is used to educate caretakers in the specialized field of PWS. Although the group has achieved these initial goals, they realize they have many other things to accomplish.

In 2002 the IPWSO began an exploration of services for individuals with PWS including group homes, supportive living situations, rehabilitation programs and respite care. The impetus for this fact gathering was the growing membership request on how to develop care services for their expanding older PWS population. Through this study of successful global programs it was evident that there are basic universal perceptions in care giving for this challenging syndrome.

From discussion during the PWS Expert's Meeting in Toulouse 2006, the idea of a conference to extend this knowledge base over borders was born and an IPWSO task force, in a joint effort with Diakonische Stiftung Wittekindshof and Regens Wagner Absberg was established.

The main goal of this conference is to utilize universal basic information to develop guidelines and standards for the caretaking of individuals with

Prader- Willi Syndrome. These results (basic components) could then be modulated by any country to fit their individual culture and reality.

The first step began at the International PWS Conference in Cluj, 2007, where topics were developed for discussion at the First PWS International Conference in Herne, Germany. This conference, a think-tank, will serve as the foundation of a dynamic process.

This conference is organized by:

- Diakonischen Stiftung Wittekindshof,
- Regens Wagner Stiftung Absberg und
- International Prader-Willi-Syndrom Organisation (IPWSO)

The venue, for accommodations and conference is Akademie Mont-Cenis www.akademie-mont-cenis.de , an architecturally unique Conference Center. Situated in the northwest of Germany, the city Herne (in the region Ruhrgebiet) is conveniently located close to airports and transportation will be provided to the venue.

To obtain more information about the conference at www.pws-caretakers-conference.de.

Ansprechpartner

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