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"Coming here, you will discover yourself, discovering others"
Romanian Prader-Willi Association

ASOCIACIÓN MADRILEÑA
PARA EL SÍNDROME DE
PRADER-WILLI



ADULT PRADER-WILLI SYNDROME PATIENTS THERAPEUTIC CYCLES

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Prader-Willi syndrome (PWS) is a complex genetic disease that arises from lack of expression of paternally inherited imprinting controlled genes on chromosome 15q11-q13. The frequency is between 1/10000 and 1/30000. Life expectancy of the patients is getting longer and nowadays it is common to see patients with PWS above the 5th decade.

The B.I.R.D. Foundation is committed to offer clinical and molecular diagnosis, genetic counselling and guidelines to parents with affected children but also several therapeutic cycles for adults with PWS.

The major concerns with the PWS adults are obesity and behavior. Growth hormone therapy is helping PWS patients develop a better muscular tonicity and achieve a taller stature but hyperphagia is constantly present.

4 - 6 therapeutic cycles for 2 - 4 weeks are organized for adults with PWS every year. During these cycles a team of specialists helps the PWS patients reduce their body weight. Knowing the complexity of the psychological effect of their condition on most of the PWS patients the cycle is structured in a way to resemble a gathering of friends that share the same problem. The basis of these cycles is the occupational therapy and the daily activities of the participants are structured in order to be as entertaining as possible to help them distract from food. There are 5 hypocaloric meals a day on a strictly fixed timetable as we know that being able to plan their daily meals helps PWS patients control their hunger. Among the activities are various sports, music, drawing, trips to nearby locations, social games. During the stay the participants live inside the structures of the foundation and are always watched over by the staff. A strict control is needed to help them follow the dietary rules. The patients' health is constantly controlled by medical specialists and a complete clinical evaluation is made before and after the therapeutic cycle.

The B.I.R.D. Foundation has done 21 cycles since 2002 with this multispecialist approach of medical doctors, nurses, psychologists, educators as well as students and volunteers. On average the participants lose between 6 to 9 kg of body weight and consider their stay as a pleasant one.

The importance of these cycles is to help the PWS patients reduce their body weight, socialise with other PWS patients and, not last, to offer some relief to the families.