# Patient Journey Prader Willi Syndrome



Note: My little girl seemed unusually tired, respond poorly to stimulation, have a hard time waking up or have a weak cry!

... delayed motor development ...



... poor responsiveness ...

... genetic diagnosis

Note: Care for life ... happiness as part of the treatment!

... rehabilitation program everyday & low caloric diet ...

- 1. Pre-Diagnosis: Poor muscle tone; Distinct facial features Poor sucking reflex and difficult feeding; Almost no cry.
- 1st Symptom: Hypotonia and difficulties in feeding; Poor responsiveness; Sitting up and walking — later Hypotonia and difficulties in feeding; unusually tired, respond poorly to stimulation, have a hard time waking up or have a weak cry. Sitting up and walking later.

#### 2. Diagnosis

Unusual food-seeking behaviors, hypogonadism

Intelectual disability;

Delayed motor development Speech problems

Small hands and feet

Thick saliva, dental problems caused by gastric acid reflux. Overweight if not eating low calorie diet

#### 3. First Treatment

Delayed in motor development weeks every 3 months

Surgery – some cases of

### 4. Follow-Up Care...

Delayed in motor and intellectual development, behavior problems, Speech problems

> A special behavior. Easily stressed. Often anxiety with changes. Autistic symptoms, social interaction difficult some develop psychiatric diseases

Overweight and sleep apnea; Medication & rehabilitation Support for education & school integration & inclusion into community; a proper job and qualification

### Ideally:

Improvement of muscle tone Special technics for feeding and stimulating exercises Special technics for feeding

Medical treatment and early rehabilitation intervention

Note: Medication & rehabilitation Support for education & school integration & inclusion into community

**Ideally:** GH Treatment Sex hormone treatment Permanent rehabilitation program; Education and work Independent life skills

### **Ideally:**

Improvement in general health and reduced weight



Information and European support groups:

www.apwromania.ro

## Ideally:

Maintaining the weight, even reducing it Relevant school education, individual approach. NO one can ever live alone, need supervision of food and eating. Need much personal support to avoid behavioral problems.

Education and work. Cannot live independent, but many learn many skills

Work: must be sheltered and reduced hours: no. one can work normally 8 hours per day. They do not have the strength.