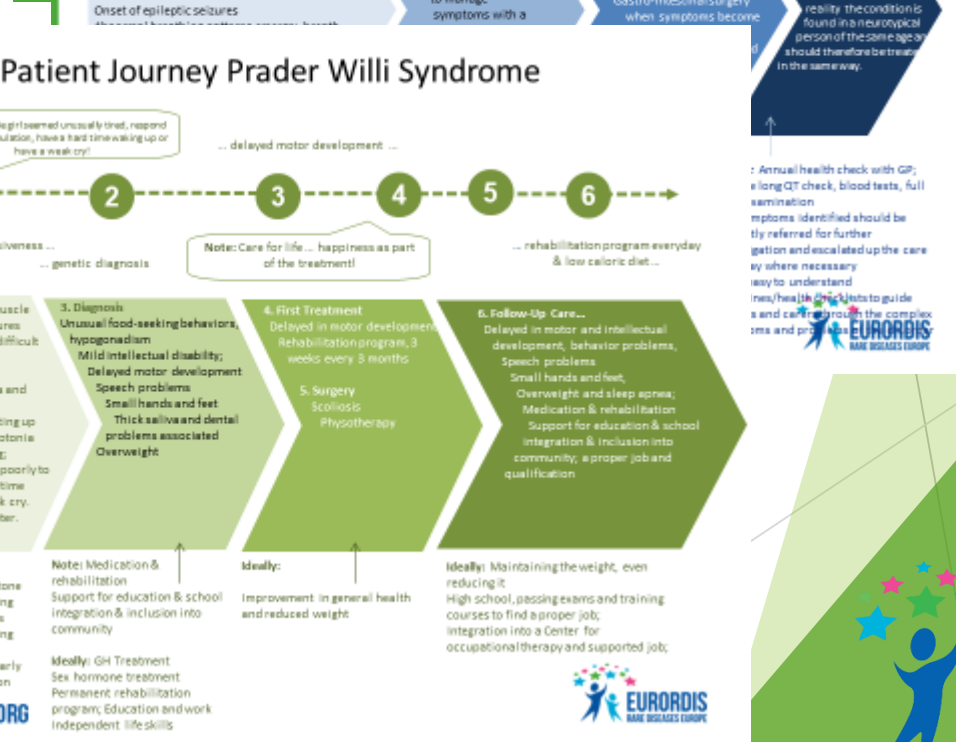
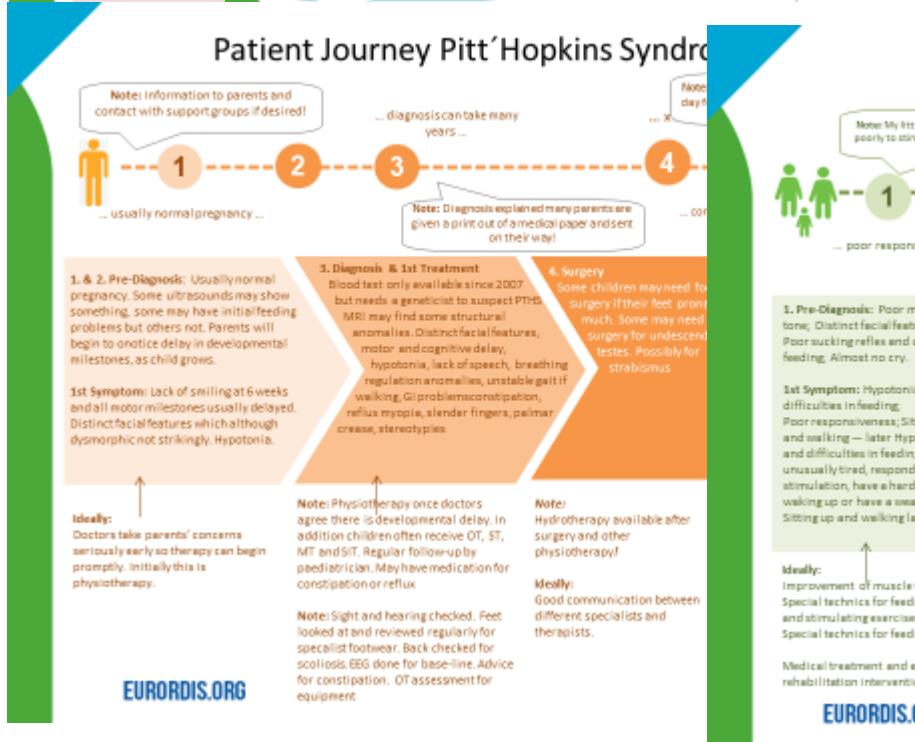
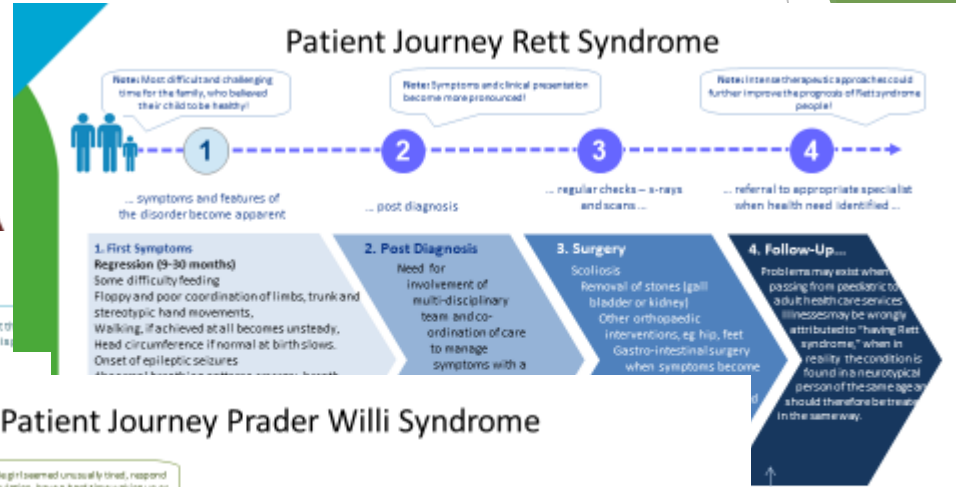
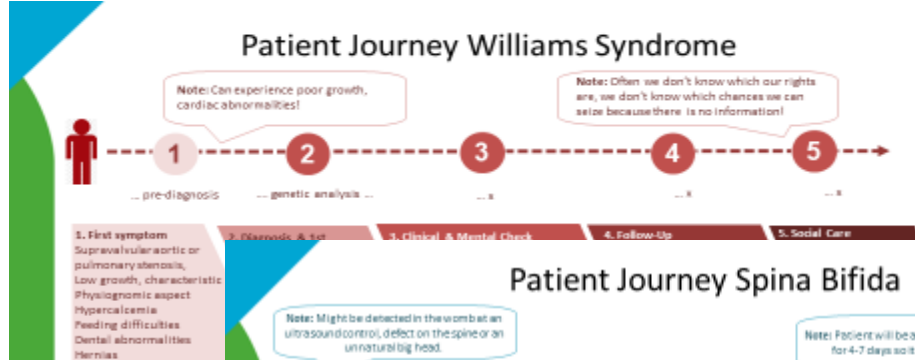




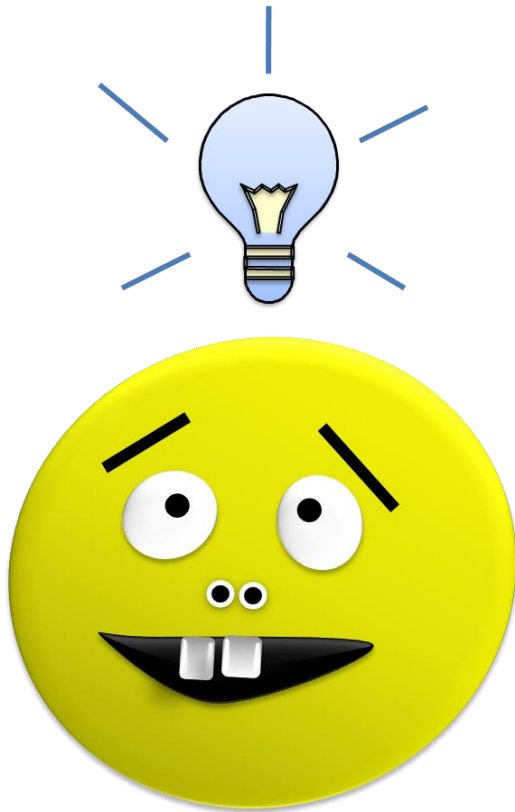
# DEVELOPING PATIENT JOURNEYS



# THE ePAG COORDINATING GROUP of the ERN-ITHACA



# INITIAL SITUATION



- ▶ Unofficial gatherings back to back to other meetings
- ▶ How can we represent the other diagnostic groups
- ▶ How can we create a template that suits every disorder
- ▶ Summarise our experience and wishes in a template

# CONTRIBUTION TO PATIENT ENGAGEMENT

Stage of Journey	Timeline	Clinical Presentation / Symptoms	Identify Patient Needs	Ideal Outcome / Support
Pre-diagnosis		•	•	•
First symptom		•	•	•
Diagnosis		•	•	•
First treatment ...		•	•	•
Surgery		•	•	•
Follow up care		•	•	•
etc.		•	•	•

- ▶ Better understanding
- ▶ Better knowledge
- ▶ More confidence
- ▶ Stronger voice

# SUCCESS FACTORS



- ▶ Using a common template with specific questions
- ▶ Describe our experience and desires in a structured way
- ▶ Doing the mapping exercise in your own home environment
- ▶ Having a face2face meeting to present your patient journey
- ▶ Having a facilitator collecting the information to one document is crucial

# LESSONS LEARNED



- ▶ Need of a facilitator
- ▶ Commitment to the exercise
- ▶ Different diagnosis/similar needs
- ▶ Healthcare varies between countries for some syndromes
- ▶ Important to get other parents inputs
- ▶ Similar needs/psychological support for parents
- ▶ More united group