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

<table>
<thead>
<tr>
<th>Stage of Journey</th>
<th>Timeline</th>
<th>Clinical Presentation / Symptoms</th>
<th>Identify Patient Needs</th>
<th>Ideal Outcome / Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-diagnosis</td>
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<tr>
<td>First symptom</td>
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<tr>
<td>Diagnosis</td>
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<td>First treatment</td>
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<td>Surgery</td>
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<tr>
<td>Follow up care</td>
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<td>etc.</td>
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</tbody>
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- 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