

## Agenda for Auto-Immune Blistering Disease workshops

Padlet: <https://padlet.com/billaltdbirt/auto-immune-blistering-disease-workshops-dwvh92il20ze9bns>

### Knowledge of the disease: Initial package Doctor, Nurse Duration: 1h15 to 1h30

**Objective:** To acquire general theoretical knowledge of AIBD: mechanism of bubble formation, importance of biological monitoring of antibodies, Tools useful for diagnosis, clinical presentations of AIBD

Steps	Tools and instructions	e-ETP adaptation
<b>Introductions</b>		
<b>Brainstorming</b>	<p><i>“What do you know about the disease?” (tool: Post-its: 1 word per Post-it)</i></p> <p><i>If concepts have not emerged, a facilitator adds Post-its</i></p> <p><i>Reworking of the Post-its, then reformulation and prioritisation of the ideas on a table using the following categories: mechanism, cause, symptoms, treatment; discussion of the different ideas with the group.</i></p>	<a href="https://padlet.com/billaltdbirt/brainstorming-5dmamg0ron7bpm4">https://padlet.com/billaltdbirt/brainstorming-5dmamg0ron7bpm4</a>
<b>Fact or Fiction smileys</b>	<ol style="list-style-type: none"> <li>1. The disease may be contagious T/F</li> <li>2. The disease is hereditary T/F</li> <li>3. Abnormal antibodies are produced in the blood and bind to the skin T/F</li> <li>4. Binding of antibodies in the skin or on mucous membranes is responsible for the formation of bullae T/F</li> <li>5. Erosions in the mouth do not correspond to mouth ulcers, but initially to bullae that have broken through T/F</li> <li>6. The disease can be cured T/F</li> <li>7. The disease is common T/F</li> <li>8. It is a serious disease T/F</li> </ol>	Padlet Auto-Immune Bullous diseases: Fact or Fiction Quiz Or Screen share Power point
<b>Review of key points</b>	<b>Power point “Knowledge of the disease”</b>	Padlet or Screen share

### Transition to the “Knowledge of the treatment” session

### Knowledge of the treatment: Initial package Doctor, nurse Duration: 1h15 to 1h30

**Objective:** To teach patients how to manage their treatments: how to take the treatment (dosage, method of administration, how to apply the ointment, etc.), monitoring, side-effects. Only the treatments of patients who are present will be discussed.

Steps	Tools and instructions	e-ETP adaptation
<b>Introduction to each person’s treatment</b>		
<b>Language object</b>	<ol style="list-style-type: none"> <li>1. Presentation of different (false) treatments on the table.</li> <li>2. Everyone chooses what appeals to them (around objects per person).</li> <li>3. Discussion and reajustement of comments</li> </ol>	Padlet: Photos of objects placed on a slideshow and numbered
<b>Role plays</b>	Each person chooses one or two situations and proposes a course of action to discussion with the group.	Padlet: Slideshow of roleplay cards on screen share
<b>Summary of key points</b>	<b>Power point « Knowledge of the treatment »</b>	
<b>Conclusion</b>		

**Experience of the disease: initial package** Psychologist,  
Nurse *Duration: 1h30 to 2h*

**Objective:** To provide a space for patients to talk and listen in a group, to bring them together, to encourage them to share and pool their subjective experiences (feelings, commonalities, differences, resources), and to create a group time-space where everyone can put down something and take something from it.

Steps	Tools and instructions	e-ETP adaptation
<b>Introductions</b>	Tour of the table	
<b>Discussion time</b> on the theme “experience of the disease”		
<b>Photo expression workshop</b>	<ul style="list-style-type: none"> <li>• Suggestions for <b>artistic photos</b> laid out on the table (Art-language tool for well-being and ill-being, selection of 25 photos)</li> <li>• ‘We suggest that you define the theme of ‘experiencing illness’ using two sub-themes: ‘well-being’ and ‘ill-being’. You can choose one photo that expresses well-being and another that expresses discomfort. You can handle the material, leaving it on the table for others to choose the same photo. Everyone will present their choices to the group.</li> <li>• Time for reflection, with each patient choosing 0, 1 or 2 photos.</li> <li>• Time for individual expression to present their photo(s) to the group.</li> </ul>	<p><b>Scanned photos shown as a slideshow with a number</b> <b>Screen sharing</b> Each photo is numbered</p>
<b>Time for discussion and collective global expression</b>		
<b>Conclusion</b>	<ul style="list-style-type: none"> <li>• Invitation to participants to give feedback on the session</li> <li>• Information on the possibility of individual time with the psychologist in the form of a dermatological consultation (if not discussed and proposed during the workshop).</li> <li>• Thank yous</li> <li>• Closing of the group</li> </ul>	

**“I’M TIRED OF BLISTERING!”** Psychologist and Nurse IDE

**Duration : around 2h30**

**Objective:** Patients will be able to better manage their fatigue to improve their quality of life in the context of AIBD.

Stages	Tools and Instructions	e-ETP adaptation
Introductions		
Brainstorming on the theme of “fatigue”	<p><u>Sub-objective:</u></p> <ul style="list-style-type: none"> <li>Express your subjective experience of fatigue linked to the AIBD.</li> <li>Make the group realise that there are different types of fatigue, not just one (multi-causal, multi-factorial, multi-significant).</li> </ul> <p>“Write one word per post-it, several post-its possible, to express your experience of fatigue. Put them on the table.”</p> <p>The group then tries to classify them with the facilitators. We observe the classification together before moving on to the theoretical phase.</p>	<p><a href="https://padlet.com/billaltdbirt/brainstorming-5dmamg0ron7bpm4">https://padlet.com/billaltdbirt/brainstorming-5dmamg0ron7bpm4</a></p>
Theoretical knowledge	<p><u>Sub-objective:</u></p> <p>To become aware of the different causes, the different factors that generate fatigue and the different clinical signs in the context of the AIBD.</p> <p>Identify concrete actions that can be taken to remedy the situation.</p> <p>The speakers provide participants with theoretical content. ‘Listen and pick up anything that may be useful and interesting for your situation’.</p>	<p>Power point on fatigue : ‘Blistering is tiring’</p> <p><a href="https://acrobat.adobe.com/id/urn:aaid:sc:EU:975bcdcf-862d-4496-83de-a859c5939924">https://acrobat.adobe.com/id/urn:aaid:sc:EU:975bcdcf-862d-4496-83de-a859c5939924</a></p>
Reinforcing skills & assessment	<p><u>Sub-objective:</u> To know how to take concrete action to remedy the situation.</p> <p>Think about and propose possible concrete actions to put in place for each of your respective situations. You can work on this as a group or individually, and we will take up your proposals as a group. Define at least 2 actions each. Note: If necessary, depending on the group dynamics, leave the slide of concrete actions presented as a support.</p> <p>Present the proposals and go over them with the group, then add to them if necessary.</p>	
Conclusion	<p>Invitation to participants to give feedback on the session</p> <p>Information on the possibility of individual time with the psychologist in the form of a dermatological consultation (if not discussed and proposed during the workshop).</p> <p>Thank you</p> <p>Closing of the group</p>	

