

## ERN-Skin PEP & Scientific Days / 20-21 April 2023 Draft Agenda

### Day 1 : 20th April 2023 : Patient Education Program Day

#### 10h00-15h00 Patient Education program - Patient formation

10h00-10h15	Introduction Patient Education Program : what does that mean?
10h15-11h15	How to build a PEP (2 speakers)
11h15-11h45	Experience in chronic diseases (1 speaker)
11h45-12h15	Patients/ Families' expectations (e-Pag)
<b>12h15-13h15</b>	<b>Lunch</b>
13h15-14h15	Experiences/Exemples HCP1, HCP2, HCP3 (depending on ongoing survey result)
13h15-14h30	Parallel round tables (for each thematic groups): projects
<b>14h30-15h00</b>	<b>Break/ discussion/ ....</b>

#### 15h00- 17h0 Formation on Clinical trials

15h00-16h00	European rules for clinical trials in rare diseases (speaker from EMA)
16h00-17h00	Politics and experiences of Companies/start up (2-3 in different fields concerning repositioning treatments and new molecules)

17:00

**End of day-1**

*TSVP*

## Day 2 : 21st April 2023 : Scientific Day

<b>Thematic group 1 short summary a` 10 min</b>	08h30-9h30
Thematic group 2	
Thematic group 3	
Thematic group 4	
<b>Keynote lecture:</b> ERN Eye: Advances and challenges in the last 5 years	09h30-10h15
<b>Break</b>	10h15-10h45
<b>Interesting clinical cases I</b>	10h45-11h45
<b>Lunch</b>	11h45-12h30
<b>Thematic group 6: short summary a` 10 min</b>	12h30-13h30
Thematic group 7	
Thematic group 8	
Thematic group 9	
<b>Keynote lecture:</b> Odile Cohen-Haguenauer, Paris Diderot University: 30 years of gene therapy	13h30-14h15
<b>Break</b>	14h15-14h45
<b>Interesting clinical cases II</b>	14h45-15h15
<b>Summary and further progress</b>	15h15-16h00