

Annex 2024-1 ERN ITHACA PAB ToR Annex 05/2024

Calendar - 2024

*(PB) Patient Board		
*(PAB) Patient Advisory Board		
SC	22/04 -16h	Task forces agenda /Updates/Administration task
PAB	27/05-16h	Task forces - ngoing projects
SC	10/06-16h	Patient Workshop Brainstorm
PAB	17/06-16h	Info ITHACA Call for new ePags 15/06 - 15/09 (New and Renewal)
SC	08/07-16h	1st draft of Patient Workshop
SC	23/09 -16h	Applicants selection
PAB	30/09-16h	ePAGS/welcome meeting
SC	14/10-16h	2 nd draft of Patient Workshop/other
PAB	28/10-16h	3rd draft of Patient Workshop
SC	25/11-16h	Finalisation Patient Workshop
PAB	12/12/2024 Day	Bucharest - Patient Workshop (followed by ITHACA Board 13-14 Dec)

Other dates will be added or modified as required.

Other related activities

- June15 - Sept 15: Call for ePags (new and renewals) (2024-25)
- June 2 – 18h45: Excom Berlin (1h) at ESHG (also online)
- Sept - Excom online
- December 12 - Bucharest – PAB Workshop
- December 13, 14 - Bucharest ERN ITHACA Board meeting (13) + Research (14)

2024 Update on ITHACA working groups and patient participation

WG - ePags involvement

- Work package 1; 2; 3 Management/Dissemination /Evaluation - Coordination Team
Excom and Board: chair and cochair
- Work Group 14 Patient advisory Board: PAB members & PB
- Work Group 5 NDD Neurodevelopmental disorders
- Work Group 8 Teaching and Education
- Work Group 11 Guidelines
- Work Group 13 Spina Bifida and other dysraphisms

WG - Low participation due to workload at this stage

- Work Group 4 CPMS 2.0 Healthcare
- Work Group 6 Foetal medicine Healthcare
- Work Group 7 ILIAD registry Healthcare mostly
- Work Group 9 APOGeE Coordination Team
- Work Group 10 European Certificate Coordination Team
- Work Group 12 Research Healthcare mostly
- Work Group 15 ELSI advisory Board not yet started

2024 ePags Task Forces

- TF Administrative: ToR update; Elections process; Partnership
- TF Annual Patient workshop
- TF Evaluations, Monitoring Patient involvement
- TF Mentorship project
- TF EPI ID Leaflet
- TF Webinar
- TF Production of various publications (Lay versions, Patient Journeys, Posters)