*Epags Call open from March 17th - April 21 2025*

*There is no obligation to be a member of EURORDIS - ERN ITHACA welcomes officially registered patient organisations in the first place.*

Place, date

**PATIENT ORGANISATION NAME AND ADDRESS**

**Re: Letter of endorsement – Designation of ePAG advocate for XXXX ERN ITHACA 2026-26**

**To ERN ITHACA**

**Are you Member of EURORDIS ?**

**YES**

**NON (*please send us the official Articles of your Patient Organisation)***

I am writing to you on behalf of ORGANISATION NAME to inform you that we completely endorse NAME THE PERSON REPRESENTING THE ORGANISACION as our ePAG advocate for ERN ITHACA’s Patient Advisory Board (PAB)

***ADD A DESCRIPTION OF THE ORGANISATION MISSION AND MAIN ACHIEVEMENTS – SEE EXAMPLE BELOW***

*ORGANIZATION NAME was founded in xxxx and currently its constituent members support families in xx countries and maintain contact with single families globally.*

*Our mission is to act as a forum of best practice for support groups of people with CONDITION/DISEASE NAME, including organising an International Conference every two years; to act as a resource base for the families of people affected by CONDITION/DISEASE NAME throughout the world and to promote and advise on research into the wider manifestations of the Syndrome Worldwide, the experts who know most about CONDITION/DISEASE NAME - within their specific disciplines, have formed an international Scientific Advisory Committee (SAC). We ensure the SAC is aware of the needs of families and carers, so they can publish relevant information, present at conferences and answer questions on our Ask the Expert facility.*

*…*

***ADD A BRIEF REFERENCE DESCRIBING THE MAIN ACHIEVEMENTS OF THE PATIENT ADVOCATE WHO IS BEING DESIGNATED (tasks in the organisation) – SEE EXAMPLE BELOW***

*NAME OF THE PERSON WHO IS GOING TO REPRESENT THE Organisation has been a staunch believer in the global cause of supporting CONDITION/DISEASE NAME and has served us so well as Chairman.*

*He/She was instrumental in initiating the research paper project and was named as a co-author.*

*I have no hesitation in recommending him/her to represent us in this function as an ePAG Advocate.*

*I am convinced that he/she will make a valuable contribution to the ePAG and the patients living with a rare disease.*

On behalf of the ORGANISATION NAME,

NAME AND SURNAME OF THE PATIENT ORGANIZATION’s REPRESENTATIVE

POSITION, SIGNATURE, DATE