*This document is a template which needs to be adjusted. The comments and sections tracked in yellow highlight where the document needs changing*.

**PATIENT ORGANIZATION NAME AND ADDRESS**

Place, date

**Re: Letter of endorsement – Designation of ePAG Advocate for XXXX (name of ePAG/ERN)**

To EURORDIS,

I am writing to you on behalf of ORGANIZATION NAME to inform you that we completely endorse NAME THE PERSON REPRESENTING THE ORGANIZACION as our ePAG Advocate for the (name of ERN) European Patient Advocacy Group.

***ADD A DESCRIPTION OF THE PO 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.*

*A panel from the SAC compiled all of the published research papers on CONDITION/DISEASE NAME, reviewed them all and have assembled the most definitive guide to diagnosis and treatment of CONDITION/DISEASE NAME ever written.*

*This paper has had the honour of being published in Nature Reviews Genetics - the first paper of its kind to be published in such a prestigious journal. NAME OF THE PERSON WHO IS GOING TO REPRESENT THE ORGANIZACION was instrumental in initiating this project and is named as a co-*author.

***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 ORGANIZACION has been a staunch believer in the global cause of supporting CONDITION/DISEASE NAME and has served us so well as Chairman. 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.*

*Please see her CV attached.*

On behalf of the ORGANIZATION NAME,

Yours faithfully,

NAME AND SURNAME OF THE PATIENT ORGANIZATION’s REPRESENTATIVE

POSITION

SIGNATURE

DATE

**Annex I**

**Please indicate whether the designated ePAG advocate has experience in the following fields by completing the list below.** EURORDIS is collecting this information with the aim to map the ePAG advocates’ skills and competences. Please note that this information will be stored in the EURORDIS contact database.

Clinical decision support tools (for example patient pathways, consensus statements, etc.) & Clinical Practice Guidelines

Data & Registries

Education & Training

Evaluation & monitoring

Outcome measures

Research

Social care

Advocacy

Communication & outreach

Conflict management

Events organisation

Legal and ethics

Project management

Team management

Translation

Workshop facilitation

Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Languages spoken**

Native language: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Other languages: please complete the table below:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Language | Native | Advanced | Good | Intermediate | Basic |
|  |  |  |  |  |  |
|  |  |  |  |  |  |
|  |  |  |  |  |  |