# ePAG EpiCARE APPLICATION FORM

*Required fields

## Details of the Patient Organisation

1. Name of the Patient Organisation: * (in local language and in English if applicable)

   _____

2. Acronym: _____
3. Type of an organisation: *
   a) Patient Organisation
   b) European Federation
   c) International Federation
   d) Other, please specify: _____
4. Disease, condition, syndrome or malformation represented: *

   _____

5. Is your Patient Organisation legally registered and operating in European countries? *
   a) Yes
   b) No
6. Registered address of your Patient Organisation: *

   Street address: _____

   City: _____

   State/province: _____

   Postal code: _____
7. Country where your Patient Organisation is registered: *

   _____

8. Email address: *

   _____

9. Phone number: *

   _____

10. Website: *

_____

11. Legal status of your Patient Organisation: *

_____

12. Date on which your Patient Organisation was registered (DD/MM/YYY): *

_____

13. Contact person at your Patient Organisation: *

_____

14. Email address of the contact person at your Patient Organisation: *

_____

15. Phone number of the contact person at your Patient Organisation: *

_____

16. Number of members of your Patient Organisation: *

_____

17. Number of staff working for your Patient Organisation: *

_____

18. Number of volunteers in your Patient Organisation: *

_____

19. Is your Patient Organisation a member of a National Alliance for Rare Diseases and/ or any international organisations? *

    a) Yes
    b) No

If yes, please provide details:

_____

_____

_____

## Details of a Candidate for ePAG EpiCARE Advocate

1. First and last name: *

   _____

2. Email address: *

   _____

3. Country: *

   _____

4. Role in the Patient Organisation: *
   a) Staff
   b) Volunteer
   c) Other, please specify: _____

5. Native language: *

   _____

6. Level of English: *
   a) Native
   b) Advanced
   c) Good
   d) Intermediate
   e) Basic

7. Other languages spoken and level of competency:

   _____

   _____

## Experience of a Candidate for ePAG EpiCARE Advocate

1. Do you have knowledge of, or experience of living with, one of the rare and complex epilepsy included in the scope of the ERN EpiCARE? *
    a) Yes
    b) No

If yes, please indicate in what capacity:

a) Patient
b) Parent/caregiver
c) Family of patient
d) Other, please specify: _____

2. Do you have experience in representing the interests and the needs of your community? *
    a) Yes
    b) No
3. Do you have experience in collaborating with clinicians? *
    a) Yes
    b) No

4. If you have any experience in these fields, please select the items from this list:
    a) Clinical decision support tools (for example patient pathways, consensus statements, etc.) & Clinical Practice Guidelines
    b) Data & Registries
    c) Education & Training
    d) Evaluation & monitoring
    e) Outcome measures
    f) Research
    g) Social care
    h) Advocacy
    i) Communication & outreach
    j) Conflict management
    k) Events organisation
    l) Legal and ethics
    m) Project management
    n) Team management
    o) Translation
    p) Workshop facilitation
    q) Other, please specify:

    _____

    _____

5. Short biography (max 250 words): *

6. Short motivation letter (max 250 words): *

Please explain why you wish to become an ePAG EpiCARE advocate, what are your areas of interest and how you meet the skills and experience required.

## PLEASE SEND THE FOLLOWING DOCUMENTS WITH YOUR APPLICATION

Letter of endorsement signed by the legal representative of your Patient Organisation following the template available at ERN EpiCARE website. *

In case of joining as an ePAG EpiCARE Advocate, I agree to my contact details being stored on the ePAG EpiCARE contact database for the purposes of managing my involvement as ePAG Advocate. *

a) Yes
b) No

In case of joining as an ePAG EpiCARE advocate, I agree to my contact details being stored on the EURORDIS contact database for the purposes of managing my involvement as ePAG Advocate. *

a) Yes
b) No

By signing this form,

i. I confirm I have read and I agree with the ePAG EpiCARE Terms of Reference.
ii. I understand and agree to the minimum level of commitment required for the role.
iii. I agree that ePAG EpiCARE shares the data included in this application form with the ePAG, the ERN EpiCARE Coordinator and project manager to discuss my application.

Name and surname: _____

Date (DD/MM/YYYY): _____

Please sign here: