

Ipnet-endorsement of Porphyria Expert Clinical Centers (PECC)

Centers can apply to be a *cutaneous*, an *acute* or a *full* PECC. The procedure and criteria are based on similar procedures in other countries and in the ERN initiative where clinical expertise was vetted and endorsed and inspired by the relevant scientific literature.

If your center was endorsed via a national or international procedure for clinical expertise in the field of porphyria, simply upload the file you submitted for that endorsement procedure. The *Ipnet PECC Working Group* (see below) will check if the criteria used align sufficiently with the Ipnet criteria and if so, your Ipnet endorsement will immediately be finalized. If the criteria do not align sufficiently with the Ipnet criteria, the Ipnet criteria (below) will apply.

Procedure:

- The candidate PECC is a full or associate Ipnet member
- The candidate PECC receives endorsement by the hospital management (only one center per hospital/hospital group), which countersigns the application
- The candidate PECC collects porphyria patient organisation endorsement (national/international)
- The candidate PECC applies for Ipnet endorsement (criteria and application form below).
- The PECC application is evaluated by the Ipnet PECC Working Group, consisting of at least 3 clinicians, one lab specialist and a patient organization representative, at least one of whom is a Board Member. The endorsement is based on compliance with the following criteria:

A Porphyria Expert Clinical Center (PECC) is a single health care provider or a formalized collaborative network of health care providers, that adheres to the following minimum criteria:

- The PECC can provide directly or in collaboration, highly specialized, multidisciplinary patient care: diagnostics (Ipnet EQAS endorsed diagnostic facility on site or formalized collaboration with an Ipnet lab off site), counselling, treatment, holistic care, follow-up and transition from childhood to adulthood, for porphyria patients
- The PECC multi-disciplinarity is illustrated by the availability of a list of specialists involved in the care for porphyria patients, on request. These specialists at least include: internal medicine (e.g. at least one of the following: general internal medicine/emergency medicine/hematology/hepato-gastroenterology/endocrinology/ metabolic diseases), AND dermatology AND genetics. The PECC has access to the following specialities: pediatrics, psychology, psychiatry, emergency medicine and intensive care.
- The PECC can guarantee continuity of care, therefore the PECC includes more than one designated clinical porphyria specialist and takes responsibility to coach, train and appoint new clinical porphyria specialists to ensure continuity.
- The PECC coordinates the active (i.e. patient contact over the last 5 years) care for a minimum of:
 - 20 patients, in either cutaneous OR acute porphyria, to be endorsed as a cutaneous OR acute PECC
 - OR 40 patients with cutaneous (20 or more) AND acute (20 or more) porphyria, to be endorsed as a full PECC

- The PECC has experience with the treatment modalities for these patients (e.g. drug treatments for porphyria, hemin infusions, EPP prevention and treatment, liver transplantation, bone marrow transplantation, phlebotomies).
- The PECC contributes to implementation of guidelines and care standards, their diffusion and the creation of awareness, the education of patients, caregivers and health care providers, in collaboration with the national and/or international learned societies (e.g. Ipnet) in the field and patient organizations.
- The PECC participates in research (i.e. national/international registries, basic science, clinical trials and peer-reviewed publications, contributions/presentations at international conferences).
- The PECC has been involved in all of the above for a minimum of 3 years at the time of endorsement.
- The endorsement is re-evaluated every 5 years.
- The PECC nominates a coordinator or clinical lead for the centre.
- The PECC is open for visitation by the Ipnet PECC Working Group.

APPLICATION FORM: <https://no.surveymonkey.com/r/IpnetPECC>