orphanet

*Please note - If you cannot complete all sections below those indicated ** are necessary to achieve Orphanet validation of your service.*

Orphanet Quality Criteria Form

Name of Clinic: Purple hair & lumpy disease (PHLD)

1. **** How many patients did you see with this disease or group of diseases last year?**

12 with both purple hair & lumps, 3 other cases with purple hair alone & 4 with lumps alone

**Number of new cases last year: 2/3

**Percentage of patients from other regions from the country: 25%

Percentage of patients from abroad: 0%

2. **** Do you provide expert advice/second opinion to Other clinicians (mail, telephone)?** Yes

Number of expert opinions given last year: 8

3. ****Is your centre multi-disciplinary, integrating medical, biological, paramedical, psychological and social needs (such as a rare disease board)?**

Yes

**Please expand your answer:

We have a dermatologist, an orthopedic surgeon, a dermatology nurse, a wound care nurse, a specialist radiologist, a pathologist, a paediatrician, a psychologist, an occupational therapist, physiotherapist, chiropodist, clinical geneticist or genetic counsellor.

4. ****Does your centre organise collaborations to ensure the continuity of care between childhood, Adolescence and adulthood, if this is relevant?**

Yes we collaborate with two adult hospitals, and have adolescent clinics where both paediatric team and the adult team attend for at least two OPD appointments prior to completing transfer. We ensure full transfer of medical information (pathology, radiology as well as clinical notes).

5. Does your centre have appropriate arrangements in place for referrals within your country and from/to other EU countries (if applicable)?

Our special interest is well recognised by the Clinical leads & colleagues working in dermatology & orthopaedics nationally and within Europe.

6. *Does your centre have quality management procedure(s) in place to ensure quality of care (including National and/or European legal provisions), and does your centre participate in internal and external quality schemes, if applicable*? If yes, please describe:

(Please describe any European or other Quality schemes that you might adhere to)

7. **Does the centre publish peer reviewed publications? Yes

Number of publications on the disease(s) over the past five years: 4

Number of abstracts and posters published on the disease(s) over the past five years: 10

8. Have you obtained grants for studies on this disease or group of diseases?

Yes we obtained a grant totalling €10,000 in Nov 2014 through St Elsewhere Hospital Foundation to carry out a natural history study on the condition in an Irish context

9. Do you participate in systematic clinical data collection?
If yes, please describe:

We have a database where all patients care is logged. Data is entered by the specialist nurses following OPD visits. Where patients consent we participate in a European study collating data on this disorder.

10. Do you participate in clinical trials? If yes, please describe:

Yes through the European group, our patients are offered the opportunity to participate in trials.

11. **Do you teach and train for this disease or group of diseases? If yes, please describe:

Yes we run a module annually on this disorder to trainee doctors, nurses & other HCPs. We also present regularly at medical grand rounds

12. Do you have links and collaborations with patient organisations?
If yes, please describe:

Patients with PHLD disorder have formed a sub-group within the Irish Skin Foundation. We attend & give talks at their annual meeting, have helped write information sheets for their website. They publicise any new trials. They helped fund raise to buy necessary equipment for our clinic.

13. Does the centre have links and collaborations with other centres at national, European or international

Yes we attend the annual European and other conferences. Dr Freckle is on the European board as an expert advisor on this disorder.