



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:

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

**\*\***Total number of patients seen last year:

**\*\***Number of new cases last year:

**\*\***Percentage of patients from other regions from the country:

Percentage of patients from abroad:

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

Number of expert opinions given last year:

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

**\*\***Please expand your answer:

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

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

**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:**

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

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

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

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

**9. Do you participate in systematic clinical data collection?**

If yes, please describe:

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

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

**12. Do you have links and collaborations with patient organisations?**

If yes, please describe:

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