

Steps to register your expert centre on

1. Remember Orphanet registration is based on Multidisciplinary activity in centres, not clinical activity of individual practitioners
 - Any team member can register themselves, and can then input information about all team members
2. Go to www.orpha.net and from there 'register my activity'
 - Register yourself as a professional. A password will be sent to your email.
 - Does Orphanet already recognize your name? Great, check your details and ask it to send a new password
3. Ask the NRDO team (809-7475 or orphanet.ireland@mater.ie) to send you helpful files
 - A. An Excel spreadsheet of rare diseases in your speciality area
 - B. 'Orphanet Quality Questionnaire' Word file for you to document your multidisciplinary activity
4. Complete the Orphanet Quality Questionnaire in Word (30-60 min).
 - Give overall annual figures but also give a breakdown by your most frequent 3, or 5 diagnoses.
 - If you answer 'Yes' to a question, provide specific details such as MDT team member specialities, lists of grants, publications, etc. You are welcome to cut and paste from annual reports, CV's or other documents.
5. Review which rare diseases are covered by your clinic on the Excel spreadsheet
 - Your clinic will be searchable on the database in association with the diseases that you specify
6. Log in to Orphanet 'register my activity' with your password
 - Add your own contact information, and information about all team members
 - Register the clinic name and address
 - When asked if you are nationally designated, check 'no'
 - When the 'Orphanet Quality Questionnaire' opens, type 'see attached' and hit submit. Email your Quality Questionnaire Word document to orphanet.ireland@mater.ie, and we will upload it manually.
 - Add the disease associated with the centre. If it's a long list, just enter one or two, and email a marked-up copy of the Excel spreadsheet to orphanet.ireland@mater.ie and we will enter them manually for you
 - When you've completed the form, hit 'submit'
7. You are done. The form goes as far as our Office, where it will be checked for completeness - all incomplete documents will be returned. The national validator will review the submission to ensure the multidisciplinary criteria are met. Once it has passed all checks we will upload the information to Orphanet and ask you to look online to check its accuracy.

Any questions? Give us a ring at any point in the process – 01 809 7475

