



The reference resource for rare diseases and orphan drugs



Improve the **visibility** of
your activities related to
rare diseases by
registering them with
Orphanet

researchers
medical professionals
laboratories
patient organisations
clinical trials



Register or update your rare disease activity with Orphanet



Step 1 : Create your account on www.orpha.net

The screenshot shows the Orphanet homepage with a search bar and navigation links. The 'Registration' button is highlighted with an orange circle. To the right, a separate screenshot shows the 'Registration Form' page with fields for 'Login' and 'Password'.

Step 2 : Enter your details

The screenshot shows the 'My workspaces' section with four buttons: 'Update my activities', 'Update my personal profile', 'Register a new activity', and 'Access my forms (in progress or already submitted)'. The 'Update my personal profile' button is highlighted with an orange circle.

The screenshot shows the 'Registration Form' page with a sub-section for 'Personal data'. It includes fields for 'The country you are working in is:' (set to FINLAND) and 'Your last name is:'. A link 'Update my personal profile' is visible on the left.

Step 3 : Register or update your activity

The screenshot shows the 'Registration Form' page with a sub-section for 'New activity'. It includes a list of activity types: 'Expert centre(s)', 'Medical laboratory(ies) (Diagnostic tests and Quality assurance)', 'Patient organisation(s), umbrella organisation(s) and alliance(s)', 'Research project(s)', 'Patient registry(ies)', and 'Clinical trial(s)'. A link 'Register a new activity' is visible on the left.