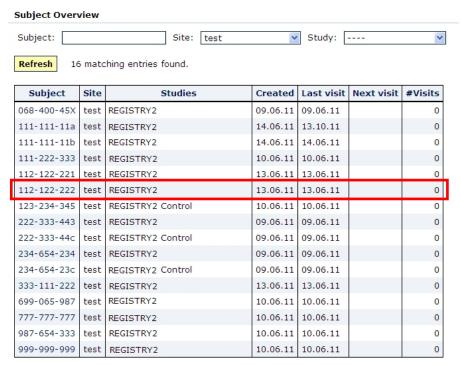


## **Transfer of existing REGISTRY participants** into REGISTRY 3

The transfer of existing REGISTRY participants (R2) [and their] data into the new REGISTRY study design (R3) is done automatically, prior to the launch of the system. However, you do need to manually enroll <u>every</u> participant (i.e. existing R2 participants and new participants) into the REGISTRY (R3) study.

This means that when accessing REGISTRY after the system change over all previously entered R2 data will be available in the new R3 system for the study site staff.



pic: 1

It is essential that all visits that have ever taken place within REGISTRY before the change over of the system are at the very least <u>created</u> (shown below) before the participant is enrolled into the REGISTRY 3 study. It is not essential that all of the data for those visits is entered at that time but the visits previously done must at least be created.

This is very important because the REGISTRY 3 study CRF differs from the REGISTRY 2 study CRF (some assessments from REGISTRY 2 are no longer administered or have been changed, such as the Hamilton, Becks, etc.). Once a participant is enrolled in REGISTRY 3 (R3) it will not be possible to <u>create</u> REGISTRY 2 visits. Then you will not be able to enter the data set for those visits that you have collected in the past.



## EUROPEAN HUNTINGTON'S DISEASE NETWORK

## How to create a REGISTRY 2 visit in the new REGISTRY system?

Choose the respective participant from the participant list, by clicking on the pseudonym/HDID in the first column in the overview table (pic: 1).

An overview for the participant is presented, showing all **REGISTRY 2 visits** that have been entered for the participant (Ongoing Visits and Completed Visits).



pic: 2

If a REGISTRY visit that took place in the past is not listed and you do have data for the visit available at the clinic; that REGISTRY visit **MUST** be created before any further step is taken.



pic: 3



## EUROPEAN HUNTINGTON'S DISEASE NETWORK

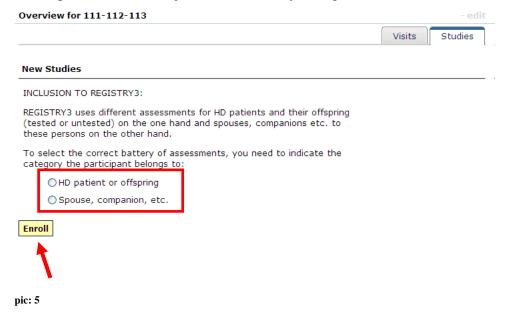
When confident that all visits have been created (the data can be entered at a later point) for REGISTRY 2, the participant can then be transferred from REGISTRY 2 to REGISTRY 3 as demonstrated below:

Click on the 'Studies' tab.



pic: 4

Then the participant needs to be **enrolled** into the correct subject category, within the inclusion dialog. Choose whether the person is an HD patient or offspring of an HD patient OR a spousal control subject without family background of HD.



After clicking on 'Enroll' the participant will be transferred from REGISTRY 2 to REGISTRY 3 (R3).

Afterwards data entry and visit creation for visits taking place after the R3 launch date (mid June 2011) can be entered.