

# Impression

the discussion always goes into the direction of finding the diagnosis instead of focussing on the registry

# REGISTRY FOR UNDIAGNOSED PATIENTS

- The data of which pt. go into the registry
  - All patients presented at the centre of Expertise
  - „All who want to“ versus „all who really show up“
  - Patient flow integrated
- To what extent do we need these data in the registry
  - Should this be a generic data base for all data for all purposes and for all RD
- Who owns the data
  - The patient, of course
  - The custodians may be many, the systems and data schemes as well
- Minimal data set

# Next steps

- Define goals/purpose of the registry
- European and national (and other) cross talk needed
- Minimal data set has to be consented
- Pragmatic approach