

Aim

In MDS well-characterized archived material is scarce (compared to AML). In several places local archives exist, but these differ in content. Therefore, it is hard to combine samples from different centres for collaborative studies. The main goal will be to establish a European sample bank, containing bone marrow and blood samples from MDS patients which can be used for translational studies. This does not necessarily mean that a central storing facility arises, however a central database should deliver information on which centre has stored what kind of samples.

How to reach the goal

Make an inventory of translational studies in preparation by European MDS groups. Using this list, define a selection of common study questions to address.

Cooperate with 'translational' groups in LeukemiaNet: Diagnostic, Cytogenetic, MRD and Gene Profiling Work Packages: what plans do they have? Similar question for other leukemia WP within LeukemiaNet.

Make an inventory of which centre is most experienced in which technique. For standardization, it would be best if samples gathered from several centres will be investigated by one centre which has most outstanding experience with that particular technology.

Especially for MDS studies, it is extremely important that all labs that are involved use the same protocol for preparation of the sample. Therefore, a standard protocol needs to be defined. UMCN has protocols tested and described extensively and will exchange these with other centres.

Develop a database for information on which centre has stored what kind of samples. Forms should be designed which can be completed via internet. These forms should include all relevant information concerning the stored sample (what kind of sample, protocol used for preparation, which diagnosis, cytogenetic information). Therefore, a technician is required, who is experienced in developing databases as well, and in particular knowledge of Access is required. A position for 0.4 fte over ..years would be preferable. In addition, possibilities for cooperation with the Central Information & Communication Structures (CICS) WP of LeukemiaNet will be explored.

Initially, MDS centres of excellence (UMC St Radboud (Netherlands), University of Dundee (Scotland), Hopital Avicenne (France), Karolinska Institutet (Sweden), Medizinische Hochschule Hannover (Germany), Fondazione Collegio Ghislieri (Italy)) may start setting up the above described structure for sample banking. Later on other centres will benefit from this structure.

Summarized

- 1) Centralized database: property of samples remains with the participating centres.
- 2) Consensus protocols: allowing combining samples with uniform quality.
- 3) Standardize time of collection: diagnosis-CR-AML.
- 4) Cell type: bone marrow/ blood, granulocytes.
- 5) Standardize what to store: viable cells, RNA, DNA, protein (serum).
- 6) Overview of research interests (including Haferlach initiative).

Questionnaire

A questionnaire will be sent around to make an inventory of which centre has stored what kind of samples.