Present
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Future meetings
-ESH / EHA, annual diagnostic work-up, Focus on Anemia and Myelodysplasia. Feb. 29th- March 2nd, 2008, Paris.
-First International ELN Workshop on standardization of flow cytometry in MDS.27 and 28 March 2008, Amsterdam.
-ESH, conference on myelodysplastic syndromes and bone marrow failure. Albufeira, Portugal, May 15-18, 2008.
-EHA meeting in Copenhagen. Thursday, June 12, 2008.

Study proposal: 'Prognostic significance and longitudinal assessment of patient-reported quality of life and symptoms in intermediate II and high risk myelodysplastic syndromes.
F. Efficace, GIMEMA Data Center, University of Rome

Deliverables:
-Evidence based data on the value of collecting patients reported QoL and symptom parameters in routine practice;
-A more refined prognostic tool to help clinicians better manage patients with higher risk MDS.
Study design was presented.
Estimated recruitment period: 2/3 Years (based on actual number of participating centers).
Patient reimbursement: 100 Euro for each patient enrolled onto this study.
The protocol is nearly finished. Writing committee: GIMEMA, Amadori, Lübbert, Deschler, ……. Advisory board: MDS experts. The protocol will be discussed during next EORTC LG meeting. Efficace will prepare a grant proposal.
Suggestions:
Is treatment heterogeneity included in analysis?
Exclude young patients that are candidates for SCT and intensive chemotherapy.
Extension to low risk MDS?
For further information, please contact: f.efficace@gimema.it

Frailty index / Comorbidity score
M. Lübbert / B. Deschler

General Aims:
To provide a common language to evaluate elderly MDS/AML patients using simple geriatric tools. Establish age related prognostic and predictive markers.

Summary:

- Decreased Performance Status and Fatigue are the most prominent patient-specific predictive parameters for survival.
- Age is not a specific marker.
- Disease-specific parameters strongly predictive in this patient cohort: Blasts > 20% (=WHO AML).
- Single parameters of function correlate with one another and ADL, IADL (Spearman $p<0.05$).
- Lab-values: Urea correlates with function and symptom scales.
- Hemoglobin shows weak correlation to assessment instruments and QOL (sufficient transfusion?).

Related Works: Allogeneic SCT in MDS. Patient selection is the key.
What defines 'adults who are not candidates for traditional cytotoxic chemotherapy'?
We continue to better define relevant comorbidities and patient-specific factors.
Up to now 172 patients have been included. Aim is to include 180 patients.
RNA and DNA samples from patients have been stored.
For further information, please contact: Barbara.Deschler@uniklinik-freiburg.de

Update on therapeutic guidelines in MDS
L. Malcovati

Interpretation of recommendations and flow diagrams for treatment of MDS (Low IPSS risk, Intermediate-1 IPSS risk, Intermediate-2 or High IPSS risk) were presented.
A draft of the therapeutic guidelines approved by the expert panel during the ELN MDS WP meeting in Paris, September, 2007, will be presented on the ELN website.
A publication of the therapeutic guidelines in Hematologica Journal: in preparation.
Development of a web-based training program using virtual patients to exercise the therapeutic guidelines and supervised by experts and European clinicians.
An interactive website is being set up to propose the clinical scenarios to physicians.
Suggestion: after a year evaluation of response obtained by web based tool.
No data available on lenalidomide vs. growthfactor?

Yearly update of the guidelines for diagnostic standards in MDS and AML
E. Hellström-Lindberg

Aspects of the WHO classification edition 2008 were summarized.
ELN guidelines for diagnosis and prognosis:

- WHO according to the new edition, MDS and AML (only tables)
- Guidelines for assessment
- Choice of prognostic scores
- Section on IF (informative)
- Recommendation for follow-up

Suggested work process before fall 2008:

- Eva Hellstrom-Lindberg - update of MDS and MDS/MPD parts
  - Send on to
- Anna Porwit / Arjan Van de Loosdrecht - check / addition of IF standards
  - Send on to

- Representative for the cytogenetic group WP11: H. Rieder, D. Haasse
  - Send on to
- Michael Lübbert - addition of AML parts
  - Back to EHL, then out to
- WP 5 and 8
  - Comments to EHL and ML, final touch and then publication on ELN Net.

No double classification recommended, therefore EH suggests to exclude the FAB from the guidelines. However, most diagnosis are performed by hematologists in peripheral hospitals. Can we expect them to classify according to WHO only? Include recommendations for Jack 2 analysis in the guidelines.

Incorporation of Immunophenotyping in diagnostic guidelines in MDS/AML
A van de Loosdrecht

Conclusions MDS and FCM:

- FCM classifies patients with *multi*-lineage aberrancies in MDS not otherwise determined by cytology (WHO) → *upgrading* of MDS from RA → [flow] RCMD (!)
- MDS-dysplasia score correlates with IPSS and WPSS.
- MDS-dysplasia score identify patients at risk for high transfusion dependency and/or rapidly progressive disease.
- Expression of infidelity markers by FCM might be the most strong predictor of disease progression in low-int-1 risk MDS.

Selected identified problems on FCM in MDS:

- Sample processing.
- Instrument settings.
- Choice of Ab panel/reagents.
- Interpretation of flow aberrancies and patterns.
- Flow cytometric scoring system.
- No multicenter studies.
- No prospective studies.

Current strategies on FCM in MDS, future directions within ELN*:*

- Within the dutch flow WP on MDS: intensive multicenter training program 2007→ ongoing.
- A validation program within the HOVON collaborative groups [hovon89]; a phase-II randomized prospective multicenter study for low-int-1 risk MDS using lenalidomide +/- Epo/G-CSF: in q3/2008.
- First ELN workshop on flowcytometry in MDS (27-28 March, Amsterdam, NL).
- Goal: q3-4/2008: consensus document.

Identification of AT (=acquired alpha thalassemia) MDS: brief update on a Network project
M. Lübbert

- rare alpha thalassemia acquired during MDS.
- elderly North European (m>f=9:1).
- somatic ATRX mutations (more severe thalassemia than with inherited trait).

- effects on DNA methylation and chromatin under active investigation.

The aim is to extent this study to other centers and to determine feasibility and build up a central database for correlation with clinical parameters.

For further information, please contact prof. Lübbert by email luebbert@mm11.ukl.uni-freiburg.de

Feedback on ongoing studies with lenalidomide in high risk MDS
D. Bowen

Proposal: to merge data from phase II studies on lenalidomide in high risk MDS. Further development of new studies delayed by Celgene due to registration issues.

Update on European MDS registry study
D. Bowen

Organization, objectives, study population and study visits were presented.

Progress with set-up:
-Most countries have submitted or obtained ethical approval.
-Contract with Novartis signed. Country contracts signed or under negotiation.
-First patient recruitment April 1st 2008.

Data entry:

- Launch training for country co-ordinators.
- Training manual and video.
- Email help desk.
- Web-based entry from each *study* site.
- Data manager for each *country* site validates all data before formal incorporation into database.

Short discussion on serum versus plasma samples for proteomics. At the University of Leeds they have compared these two kind of samples, and a quality assurance has been performed. The study will use serum samples for proteomics.

Future of ELN MDS WP8
T. de Witte

-Joined Working Group EHA/ELN?
-Maintain our independence as ELN working group?
-Funding needed for any solution.