

## EUMDS Registry Newsletter



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### Hello!

We would like to welcome you to our third EUMDS newsletter.

To subscribe/unsubscribe to the EUMDS Registry Newsletter, please send a mail to:

[j.droste@hemat.umcn.nl](mailto:j.droste@hemat.umcn.nl) with the word "Subscribe" or "Unsubscribe" in the subject line.

### Send Your Suggestions

Is there anything you'd like to see in the next newsletter? We'd like to hear from you! Please contact us if you have any suggestions, questions, or comments concerning any of the topics described in this Newsletter and on the Registry in general either by emailing Jackie Droste at [j.droste@hemat.umcn.nl](mailto:j.droste@hemat.umcn.nl) or calling at +31 24 3614794.

### Ethical Committee

The majority of the countries already have approval for the protocol from their ethical committee(s). When you have approval please inform the project management and send a copy of the letter of approval!

### Operational Team

At the moment 9 countries have employed a coordinator. We would like to welcome these coordinators to the Operational Team.

The first Operational Team meeting took place the 26<sup>th</sup> of March in Amsterdam. All countries were represented except for one (due to other obligations). During this meeting, the organisation of the registry was presented and the responsibilities of the people involved in the registry were discussed. The main objective of this meeting was the database training. Everybody was enthusiastic about the database. At the end there was some time to test the database.

### Contracts

Until this moment already 9 countries have approved and signed the contract between the referral site and the sponsor.

### Website

Great news! Our website [www.EUMDS.org](http://www.EUMDS.org) is available, with many thanks to our colleagues in York!

### Database

The database was tested during the week of the 25<sup>th</sup> of February. From the beginning of April the final database is open and you can start including the first patients.

### Meetings

The next Steering Committee meeting will be in Copenhagen, Denmark at the 11<sup>th</sup> of June and the next operational team meeting will be in Paris the 22<sup>th</sup> of September.

The third Monday of each month from 16.00 to 16.45 h a teleconference for the operational team is scheduled, starting the 21<sup>th</sup> of April.

### Start of the study

The study started the first of April 2008. We hope that you all will start including patients immediately and that we will make a success of this study together!!

### New item Introduction

Starting the fourth newsletter, a new item is introduced. Each newsletter a coordinator from the operational team is invited to introduce her/himself and to write a summary how the registry is organised in her/his country. (Organisation/network, how many people are involved in the EUMDS etc.)