European LeukemiaNet Consortium
WP 9 - CMPD

Minute of the Paris meeting, 18 November 2005

A meeting of the WP9 investigators was organized in Paris during the JAK-2 Symposium organized by dr. Jean-Jacques Kiladjian.
The following investigators attended the Meeting: Guido Finazzi (Bergamo), Tiziano Barbui (Bergamo), Giovanni Barosi (Pavia), Jean-Jacques Kiladjian (Paris), Tony Green (Cambridge), Hans Hasselbalch (Denmark), J.J. Michiels (Rotterdam), Heike Pahl (Freiburg), Annette Schmitt-Graff (Freiburg).

The meeting started at 8.00 a.m. and the investigators discussed the state-of-the-art of their respective deliverables (see attached list). Major points of discussion were:

Study protocols

1. **Imatinib in PV** (deliverable 9.15)**.** The protocol has been prepared by **drs. Hasselbalch and Lengfelder**. The study is running in Germany (about 15 patients enrolled), but not in Denmark, due to safety issues regarding potential carcinogenicity of Glivec in rat studies raised by the Danish Medicine's Agency. In addition, a proposal of the protocol and of the organizing structure was send to Novartis. Prof. Hehlmann generally agreed to a contract (proposed by dr. Fincato, Novartis) between Novartis and the EU-Leukemia-Net. However, there are some problems, such as the combination of some support of Brussels (for the net) and of the pharma industry (for the study) and the participation of centers which are not represented by persons listed in the net. The issue is particularly important, as there are other trials in preparation with the same problem, and it is now up to dr. Lengfelder and his collegue in the net dr. Michael Schatz.
2. **Velcade in MPDs** (deliverable 9.22). The protocol has been prepared by **dr Barosi**. The drug will be supplied free from the company but the financial support for the study is still pending.
3. **Randomized clinical trial of 2 phlebotomy regimens in PV** (deliverable 9.23). The protocol has been prepared by **drs. Finazzi and Marchioli.** An application for funding has been submitted to the Italian Agency for Drugs (AIFA) and an answer is foreseen in the next weeks.
4. **Anagrelide in ET** (deliverable 9.24). The protocol has been prepared by **dr. Birgegard.** This is an European multicentre observational ET at risk study in 1000 patients on anagrelide and 2000 patients on other cytoreductive therapy, followed for 5+5 years (Excels study, supported by Shire). The study is now running and recruiting patients in several countries.

Registries

1. **Rare MPD variants** (deliverable 9.17). A registry of patients with Essential Thrombocythaemia with Ringed Sideroblasts (ET/SR) has been prepared by **dr. Schmitt-Graff**. The Registry includes already a significant number of patients from Germany but there are difficulties to obtain other cases from other countries. After discussion, it has been decided to implement the Registry with biological studies to be performed in a limited number of well-characterized cases.
2. **Pregnancies in ET** (deliverable 9.18). A registry has been established by **dr. Griesshammer** on the server of the EXELS trial (see point 4 above). However, there is a project to implement the registry on an independent server in Ulm. At the moment, the registry include 25 pregnancies documented in Germany and the international page for European investigators will be ready soon.

Finally, it was discussed a proposal of **dr. Hasselbalch** regarding a protocol dealing with **Statins in MPDs.** The possibility of a study in this setting will be considered.
The meeting ended at 9.00 a.m.
The next WP9 meetings are scheduled as follows: first, a breakfast meeting during the forthcoming ASH Congress in Atlanta, Hotel Ritz Carlton, 181 Peachtree Street (downtown) on Sunday, 11 December 2005, 6.00 to 8.30/10.00 a.m. (chaired by dr. Barosi) and then during the 3rd Symposium of the LeukemiaNet in Heidelberg, Communication Center of the German Cancer Reasearch Center (DKFZ) on 31 January – 1 February 2006.
Best wishes to all

Dr. Guido Finazzi Bergamo 29/11/05