International Meeting of People with Rare Diseases

“Exchange Experience”

13-14 December 2014

Hotel Jasmin

 Sofia

Draft Agenda

Saturday 13 December

10.00-11.00 Registration

11.00-11-10 Welcome & Introductions

11.00-11.30 **National Plans** – Goals and Sustainability - Bulgarian experience

11.30-12.00 Institute for Rare Diseases and Orphan Drugs

Prof. Rumen Stefanov

12.00-12.30 International collaborations. Retrospective overview

Mr. Vladimir Tomov

12.30-13.00 Introduction of Patients representatives of Huntington's disease from Poland – Mrs. Maria Danuta

13.00-14.00 Lunch (Restaurant Jasmin}

14.00-16.00

- Bulgarian Volunteer Organisation “Why Volunteer”

- Introduction of Patient representatives from BiH - Mr. Boris Djurovich

- Introduction of Patient representatives from Belgium – Mrs. Lut De Baere

- Introduction of Patient representatives from China – Mr. Zhangchan Liu

- Introduction of Patient representatives from Georgia – Mr. Boris Machavariani

- Introduction of Patient representatives from Greece – Mrs. Marianna Lambrou

- Introduction of European Huntington Association – Mrs. Beatrice Maria Bernadette De Schepper

16.00-16.30 Coffee break

16.30-17.00

- Introduction of Fabry International Federation – Mrs. Lut De Baere

- Introduction of Patient representatives from Macedonia – Mrs. Vesna Aleksovska,

- Introduction of Macedonian Pulmonary Hypertension Organization – Mrs. Gurgica Kjaeva

 - Introduction of Patient representatives from Russia – Mrs. Svetlana Karimova

 - Introduction of Russian Fabry and Rare Diseases Organization – Mr. Michail Kuznetsov

 - Introduction of Patient representatives from Serbia – Mr. Dragan Djurovich

19.30 Gala Dinner

Sunday 14 December Workshop

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10.00-10.45 *Exchange experience related to Treatment access*

10.45-11.30 Problems related to rehabilitation and social services

11.30-12.00 Coffee break

12.00-13.00 Prevention and social adaptation

13.00-14.00 *Closing remarks and Lunch*