ISTITUTO DI RICERCHE FARMACOLOGICHE MARIO NEGRI
CENTRO DI RICERCHE CLINICHE PER LE MALATTIE RARE
ALDO E CELE DACCO'
Villa Camozzi, Ranica- BERGAMO
Italy

November 8, 2002
14.00-18.00

European Symposium

FINAL PROGRAM

The role of patient support groups for rare disease

activities uch as Seminars, Workshops, and Courses on rare diseases and orphan drugs.
The scope of the proposal is to offer the opportunity to investigators, physicians, health authorities patient and their supporter, to improve their knowledge on rare diseases from a general point of view.
The European Commission is supporting the activities of the School with a cycle of coferences and symposia which will cover several topics such as:
"The role of patient support groups for rare disease". "Methodology for clinical research on rare disease", "Priorities in research and development of orphan drugs", "Organization and implementation of Database Registries for Rare Diseases" "State of the art of gene therapy for rare diseases", “Socioeconomic burden of a rare disease on the families”.
This program will be carried on with the collaboration of UNIAMO, the Italian Association for rare diseases; Accademia Nazionale di Medicina; AGRENSKA, Swedish Center for the families of children with rare disabilities, Centro de Investigacion sobre el Sindrome del Aceite Toxico , Centros Nacionales de Salud Pública, Madrid and the Spanish Federation of Rare Diseases.

The first symposium of the series is
The role of patient support groups for rare disease
which is aimed to bring together different experiences in Europe in the organization of patient support.

The Symposym will take place at the Clinical Research Center for Rare Diseases, ALDO E CELE DACCO', which is located in Ranica, near Bergamo Italy.

European Symposium

Program

13.00	Registration
14.00	Welcome address and Presentation of the Clinical Research Center for Rare Diseases Aldo e Cele Daccò **Giuseppe Remuzzi, Mario Negri Institute**
14.30	Introduction to the Symposium **Arrigo Schieppati, Mario Negri Institute, Italy**
15.00	Rare disease support groups in Scandinavia **Anders Olauson, Agrenska Center, Sweden**
15.30	Rare disease support groups in Spain **Rosa Sanchez de Vega, Associacion de Aniridia, Spain**
16.00	Rare disease support groups in Italy **A. Sessa, Uniamo, Italy**
16.30	**Round the Table discussion: How patients support group can collaborate to implement research on rare diseases**
16.31	**Chairperson: Moises Abascal Alonso, FEDER Maravillas Izquierdo Martínez Instituto de Salud Carlos III, Spain**

For Information

Scientific Secretary:	Arrigo Schieppati, Erica Daina
Organizing Secretary	Daniela Riceputi
Address	Clinical Research Center for Rare Disease Aldo e Cele Dacco Via G.B. Camozzi,3 – Ranica Italy Tel 0039 035 511 111 – 0039 035 516516 Fax 0039 035 514503 Email raredis@marionegri.it

The Clinical Research Center for Rare Diseases Aldo e Cele Daccò is located in Ranica, approximately 5 km from Bergamo. You can reach it by:
Car: leave the motorway A4 Milano -Venezia at the Bergamo exit. Follow the signs for "Valle Seriana" until you reach the turn off to Ranica, when you reach the center of Ranica, you will see the road si- gns for Villa Camozzi.
Train/bus: if you arrive by train, take bus n. 1 directly outside the station, and get off at the second stop. Cross Viale Papa Giovanni XXIII and take bus n.II / A in Via Tiraboschi. Get off at the terminus in Ranica and follow the road signs for Villa Camozzi