September 9 - 11 2007 - Lowe Syndrome Meeting in Formignana, Italy

Lowe Syndrome Meeting in Formignana, Italy - September 9th-11th 2007
Convegno Internazionale sulla Sindrome di Lowe

09-09-2007 *Teatro Comunale di Formignana (FE), dal 6 al 9 settembre 2007*

La Sindrome di Lowe è una rara malattia genetica che colpisce i maschi e causa disabilità fisica e psichica. Si chiama anche Sindorme Oculo-Cerebro-Renale. L'Associazione Italiana Sindorme di Lowe organizza presso il Teatro Comunale di Formignana (FE) un convegno internazionale dal 6 al 9 settembre 2007. Per informazioni contattare tel/fax 0533-59587 cell. 346-8633242 e-mail formignana.aislo@libero.it

Lorrane Thomas, chair of the UK Lowe Symdrome Trust and family were invited to the Italian **AISLO** (Associazione Italiana Sindrome di Lowe) that was initiated by Anna Maria Dinelli president of AISLO and organised and funded by the community of Formignana.

The meeting was held in the local theatre (*Teatro Comunale di Formignana)* and the families were also invited to a special mass at the church by cardinal Tonini with local dignitaries. Also invited to the meeting were Fabrice Riou, President of the **ASL (L'Association du Syndrome de Lowe**) France and Debbie Jacobs who is President of the **LSA** (Lowe Syndrome Association USA). The community had also organised translators, a creche for the children and a very social agenda. The familes stayed at a hotel in nearby Copparo.

The LST, Lorraine, Andrew and Oscar Thomas would like to thank everyone involved and to say how overwhelmed we were by the welcome and hospitality, not mention the incredible generosity and organisation.

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The cardinal opens a medical meeting

Formignana. The heroism of a mother and father in helping their son afflicted with a rare disease. The help of volunteers, of Italian and foreign researchers, of schools and institutions for a subject for which it is difficult to give more effective answers.

This is the theme of an international convention on Lowe's syndrome which will take place at the communal theatre of Formignana from today until Sunday, organised by the Santo Stefano Association of the parish of Formignana, along with the Italian Lowe's Syndrome Association ("Aislo", of which the national president is Anna Maria Dinelli, the mother of Stefano, who has the disease) and along with the

Mario Negro Sud di Chieti Consortium, under the sponsorship of the commune of Formignana.

[The convention on] the pressing topic has been preceded by an extraordinary local council meeting which took place a few evenings ago where the debate focused on the problem of recognising the disease and the necessity of diagnostics and funds for scientific research. Underlining the importance of the convention, priest Don Rosario Bonaccio announced that “on Thursday, the Cardinal Emeritus of Ravenna, Ersilio Tonino, will be present in church, while the last mass on Sunday will be celebrated by Monsignor Paolo Rabitti, archbishop of Ferrara-Comacchio.

The researcher from Abruzzo, Antonella De Matteis, summarising the research, said that, among the speakers, “The speech of Professor Robert Nussbaum, who discovered the syndrome in the USA, will be very important. [He is] a world-renowned researcher and geneticist from the University of California at San Francisco.” Associations are present in the USA , Italy , France and the United Kingdom. Representatives of local institutions who made *[will make?]* speeches include: the mayor of Formignana, Daniela Montoni; the president of the Association of the Communes of Copparese and the mayor of Copparo, Maria Teresa Bertuzzi; and the social services councillor of the Province of Ferrara, Diego Carrara.

Up to now, central governments have given very little for research on this syndrome, but the people present [at the local council meeting] said that, in contrast, “in Emilio Romagna, the regional government, the provincial government and the communes are allocating significant funds to aid [the research]. Stefano and his mother are examples for the area.”

The scholastic director Giovanni Roncarati and the teacher Rita Cabrini highlighted aspects of scholastic integration and the educational project of the comprehensive school of Tresigallo ; the infant neuropsychiatrist Patrizia Folegani (of the medical service of Ferraraand Cento) discussed the problems of insertion *[into society? into school?]*; Antonella Dalla Muta discussed the experience of the Casa Viva di Copparo Foundation.

Franco Corli