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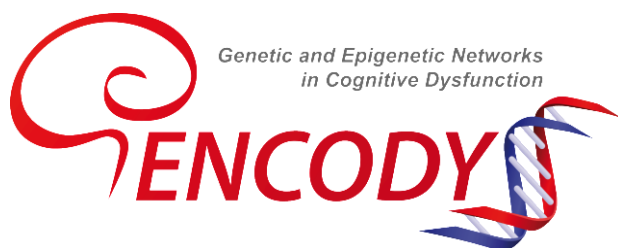
## Gencodys Patient Meeting

-Cognitive Disorders in European Research Networks-

Thursday the 28<sup>th</sup> of May 2015, Madrid

Satellite meeting of [Eurordis Membership Meeting](#)

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## **Cognitive disorders - Results from the Gencodys project and future outlook to ERNs**

(if you like to attend, please send an email to: [m.driessens@vsop.nl](mailto:m.driessens@vsop.nl) before 18 May)

Cognitive disorders can be caused by environmental factors as well as genetic factors. A definite diagnosis can only be made in about half of the patients with moderate to severe intellectual disability. The GENCODYs consortium has tried to identify the genetic causes of cognitive disorders, and the pathways involved, using next generation sequencing techniques. This meeting aims to inform patient representatives on the results of the gencodys project and to explore the future developments in setting up European Reference Networks and research projects for children with cognitive disorders.

For more information and summaries of previous patient meetings, scroll completely down:

<http://www.gencodys.eu/Patient%20entry%20.php>

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### **Accommodation**

#### **Hotel Rafael Atocha**

Calle Méndez Álvaro, 30 28045 Madrid

<http://www.rafaelhoteles.com/hoteles/rafaelhoteles-atocha/>

Tel. +34 91 468 81 00

E-mail: [atocha@rafaelhoteles.com](mailto:atocha@rafaelhoteles.com)

How to get from the airport to the Hotel Rafael Atocha

Depending on which terminal of the **Madrid Barajas** you arrive:

1. **For arrivals at Terminal 4:** 40 minutes. Direct ride on the Madrid Light Train, “Cercanías” in Spanish, line C1. Delegates should get off at “Atocha” station.

2. **For arrivals at other Terminals:** 50 minutes. Take the Madrid Metro (line 8) until “Nuevos Ministerios” station (the final station for the line) and then change to Madrid Light Train, “Cercanías”, any line. Delegates should get off at “Atocha” station.

**Rail:** Tickets for both Metro and Light Rail can be purchased at machines located at the airport; both cost about 5 EUR (including the airport supplement).

**Taxi:** For taxi rides originating or finishing at the Madrid Barajas airport there is a fixed fare of 30 EUR (no supplements apply).

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**Thursday 28th of May**

**Venue: Hotel Rafael, Atocha, Madrid, Room Prado**

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|---------------|--|
| 13.30 – 14.00 | Registration & Coffee  |
| 14.00 – 14.15 | <i>Welcome and aims of the meeting</i> by Cor Oosterwijk, director VSOP, secretary general EGAN  |
| 14.15 – 14.30 | <i>Personal introduction round</i>   |
| 14.30 – 15.00 | <i>Progress of five years of collaborative research on rare genetic disorders within the European Gencodys project</i> by Prof. dr. Hans van Bokhoven, Radboud University Medical center, Nijmegen, the Netherlands  |
| 15.00 – 15.45 | <i>GenIDA: a patient empowerment website to collect and inform on natural history of monogenic forms of intellectual disability and autism</i> by Florent Colin, Institut de génétique et de biologie moléculaire et cellulaire (IGBMC), University of Strasbourg, France & Olivier de Compiègne (Association Xtraordinaire, France)   |
| 15.45 – 16.05 | Refreshments Break   |
| 16.05 – 16.35 | <i>'SWAN UK - an undiagnosed community working with research'</i> Lauren Roberts, Coordinator SWAN UK (Syndromes without a name), Genetic Alliance UK  |
| 16.35 – 17.30 | Discussion on: <ul style="list-style-type: none"><li>• How to ensure patient access to early diagnosis using next generation sequencing</li><li>• What are future directions for research?</li><li>• How can patients and patient organisations help to facilitate research?</li><li>• How can their involvement in European research networks be stimulated and facilitated?</li><li>• Are there barriers researchers and patient representatives see that require attention?</li><li>• What are the experiences regarding accidental findings?</li></ul> |
| 17.30         | Conclusions & Closure  |