



Project Logo



Rare Disease Day 2015: Information Stand on Phenylketonuria



Rare Disease Day®

Rare Disease Day takes place on the last day of February each year. The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

Where?

You'll find us at Aston University Main Building, Lower Foyer, Aston Triangle, Birmingham (UK), B4 7ET.



When? We look forward to seeing you on Friday 27th February 2015 from 10.00 to 12.00!

What?

The Aston University Neuropsychology Laboratory - directed by Dr Cristina Romani - will organize an event to raise awareness on rare diseases. The focus will be on the metabolic disease of Phenylketonuria (PKU). The event will include:

- recipes to prepare delicious low-protein meals.
- games highlighting particular aspects of living with PKU and on PKU diet - **If I gave you a cookie, would you be able to tell whether it is a normal cookie or a low-protein one?**
- exhibition of posters and flyers about *Rare Disease Day 2015*.
- information about our neuropsychological studies on adults with PKU (Trepaphen FP7-PEOPLE-2012-IEF- Marie Curie Actions).
- videos showing the difference between staying on and off diet.

To find out more about our event contact us at l.palermo@aston.ac.uk (Dr. Liana Palermo); defelics@aston.ac.uk (Sara de Felice); c.romani@aston.ac.uk (Dr. Cristina Romani) or on +44 (0)121 204 5470

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PKU is an inherited metabolic disease which, if left untreated, results in severe mental retardation and motor deficits. The main symptoms can be eliminated by following a restrictive low-protein diet, although it is unclear whether this diet should be maintained after adolescence.

The event will be open to students, staff and everyone who will be happy to know more!

TREPAPHEN **TREPAPHEN** is a research project supported by the EU Marie Curie fund (FP7-PEOPLE-2012-IEF -Marie-Curie Action: "Intra-European fellowships for career development").

MARIE CURIE ACTIONS The project aims to explore the association between measures of metabolic control, cognitive performance and neurological health in adult patients with Phenylketonuria (PKU). The assessment of associations among cognitive, neurological and metabolic measures will enable an unprecedented level of understanding of this disorder, tracking the difficulties experienced by patients from the biological to the behavioural level. This will answer the question of whether or not adult patients should maintain a strict diet, a controversial policy issue across European Health Services.



To find out more about our research contact us at c.romani@aston.ac.uk (Dr. Cristina Romani) l.palermo@aston.ac.uk (Dr. Liana Palermo)

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Dissemination of TREPAPHEN results among students and general public

Symposium

Cognitive impairments in inherited metabolic disorders: State of the art and future directions



5th Conference of the European
Societies of Neuropsychology
Tampere 9-11 September 2015



**Organization of a Symposium at the 5th Conference of the European Societies of Neuropsychology
(ESN), Tampere (Finland), 9-11 September 2015**