12:30 h | Round table
Judith Armstrong Morón
Manel Esteller Badosa
Juan Ausió
Marian Mellen
Ángeles García Cazorla
Moderation
Yolanda Corón Blázquez

13:00 h | Talking with the Gazes, a New Future in Sight
Eneko Sese
Business Development Manager, Irisbond

15:30 h | Communication with the Gaze for Children with Rett Syndrome and its Use
Borja Romero
Support Technologies Advisor, BJ - Adaptations

16:00 h | Screening of the Documentary, Candidate for the Goya 2016 "Linea de Meta" (Finishing Line)
Yolanda Corón Blázquez
Josele Ferré
Protagonist or the Documentary film
Delegate in Valencia of the AESR and father of a girl with Rett Syndrome

17:00 h | Closing

The aim of this Seminar on Rett Syndrome is to exchange knowledge about this pathology, bringing together the latest advances by relevant international researchers, as well as showing how to carry out a correct approach and follow-up of a research project by professionals in the field. It is also intended to share experiences and establish synergies in order to optimize the destination of funds, raised mainly by affected parents.

To this end, the Spanish Association of Rett Syndrome (AESR) and the Catalan Association of Rett Syndrome (ACSR) have created a common fund (FINRETT) aimed at financing research projects in Rett Syndrome. The management of these funds will be carried out through a Monitoring Committee made up of people designated by both associations. In addition, a Scientific Committee will be created unanimously chosen by this Monitoring Committee, which will be in charge of studying the existing and newly created research projects, and will decide which one of them will be used for the funds raised, according to criteria feasibility and quality.

This is why the conference is aimed at this Scientific Committee, the Monitoring Committee, researchers, scientists, health professionals, students, parents affected, relatives, donors and all those that may be interested on these matters.

Rett Syndrome is a serious neurodevelopmental disorder and causes multidisability. It almost exclusively affects the female sex because the cause of this syndrome is found in the mutations of genes linked to the X chromosome. All affected by this syndrome are totally dependent and is the second most frequent cause of intellectual disability in women following Down Syndrome. There is no cure or effective treatment for this syndrome. There is no medical record, but it is estimated that in Spain there will be about 2,500 patients, many of them still undiagnosed. The AESR ensures the quality of life of those affected and promotes research and treatment according to the severity of the syndrome.

www.uimp.es

GOBIERNO DE ESPAÑA
MINISTERIO DE EDUCACIÓN, CULTURA Y DEPORTE

UIMP
Universidad Internacional Menéndez Pelayo

Santander 2017

GENERAL INFORMATION

→ Until June 16th, 2017

Santander
Campus de Las Llamas
Avda. de los Castros, 42
39005 Santander
Tel. 942 29 87 00 / 942 29 87 10
Fax 942 29 87 27
informacion@sa.uimp.es

Madrid
C/ Isaac Peral, 23
28040 Madrid
Tel. 91 592 06 31 / 91 592 06 33
Fax 91 592 06 40 / 91 543 08 97
alumnos@uimp.es

From 9:00 to 14:00 h
From 16:00 to 18:00 h (except Fridays)

→ From June 19th, 2017

Santander
Palacio de la Magdalena
39005 Santander
Tel. 942 29 88 00 / 942 29 88 10
Fax 942 29 88 20

From 9:00 to 14:00 h
From 15:30 to 18:00 h (except Fridays)

→ Scholarship applications

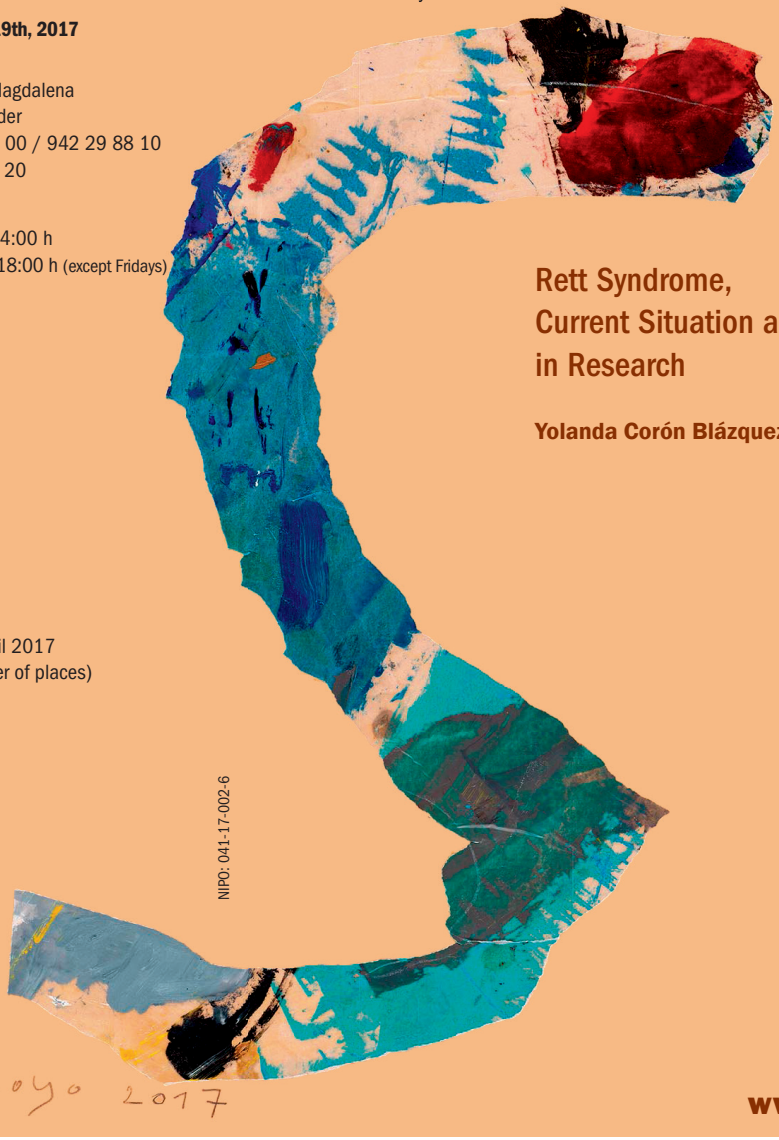
Until 17th May, for courses starting before 7th July 2017

Until 12th Juny for courses starting from 10th July

→ Enrollment

From 24th April 2017
(limited number of places)

@UIMP
fb.com/uimp20



Rett Syndrome, Current Situation and Trends in Research

Yolanda Corón Blázquez

NIPO: 041-17-002-6

Santander
10-12 July, 2017

www.uimp.es

→ Code: 63FI | Fee: B | ECTS: 0,5

Other collaborations

FUNDACIÓN RENTA · Valdecilla FUNDACION · BJ ADAPTACIONES · IRISBOND · COLEGIO OFICIAL DE FARMACÉUTICOS DE CANTABRIA · mediterráneo

Organized in collaboration with

Síndrome de RETT ASOCIACION ESPAÑOLA

Collaborations

ASSOCIACIÓ CATALANA DE LA SÍNDROME DE RETT · FUNDACIÓN RAMÓN ARECES

Rett Syndrome, Current Situation and Trends in Research

Director
Yolanda Corón Blázquez
Delegate in Cantabria of the Spanish Association of Rett Syndrome

Academic Secretary
Concepción Solanas Guerrero
Physician, Specialist in Preventive Medicine and Public Health.
Scientific Secretary of the Ethical Committee of Clinical Research of Cantabria

10-12 July, 2017

Monday 10

10:00 h | Opening

10:30 h | Our Rett Future: Share, Care, Cure
Thomas Bertrand
President of Rett Syndrome Europe (RSE)
Paris, France

11:00 h | Accelerating Research Through a Full Spectrum Research Strategy and Empowering Families
Paige Nues
Director of Family Empowerment, Rett Syndrome Foundation (RSF)
California, USA

12:00 h | On the Road to a Cure for Rett Syndrome
Mónica Coenraads
Executive Director, Rett Syndrome Research Trust (RSRT)
Conneticut, USA

12:30 h | Parents at the Heart of the Roadmap Effort
Rachael Stevenson
Co-Founder & Executive Director, Reverse Rett
Manchester, UK

13:00 h | Round table
Thomas Bertrand
Paige Nues
Monica Coenraads
Rachael Stevenson
Moderation
Yolanda Corón Blázquez

15:30 h | Life of a Biomedical Research Project
Concepción Solanas Guerrero

16:00 h | Scientific, Ethical and Legal Evaluation in Research Projects
Susana Álvarez Gómez
Degree in Medicine and Surgery, Specialist in Family and Community Medicine
Medical Inspector of the Social Security Administration
Madrid, Spain

16:30 h | Challenges of Future in the Evaluation of Projects by CEIC / CEIm
Andrés García Montero
Doctor in Biology, Researcher, National Bank of DNA Carlos III
Madrid, Spain

17:00 h | Round table
Susana Álvarez Gómez
Andrés García Montero
Moderation
Concepción Solanas Guerrero

Tuesday 11

09:30 h | Therapies for Rett Syndrome Targeting MECP2 at the Level of the Gene and Protein
Stuart Cobb
Institute of Neuroscience & Psychology. University of Glasgow
Glasgow, UK

10:00 h | Understanding Rett Syndrome and the Molecular Consequences of MeCP2 Deficiency through Novel Transgenic Mice
Nicoletta Landsberger
San Raffaele Rett Research Unit. San Raffaele Scientific Institute
Milan, Italy

11:00 h | Rare Disease Natural History Study: Providing Guidance for Clinical Trials
Alan Percy
Professor/Director, Rett Syndrome Clinic, University of Alabama at Birmingham, Division of Neurology
Birmingham, USA

11:30 h | Modeling an Epigenetic Disease Rett Syndrome
Yi Eve Sun
Lab Director. Professor, Tongji University of Shanghai, China & David Geffen School of Medicine at UCLA
Shanghai, China

12:00 h | Round table
Stuart Cobb
Nicoletta Landsberger
Alan Percy
Yi Eve Sun
Moderation
Yolanda Corón Blázquez

15:30 h | N-terminal Post-Translational Modifications of MeCP2, their Role in Rett Syndrome
John Vincent
Molecular Neuropsychiatry and Development Laboratory, Centre for Addiction and Mental Health
Toronto, Canada

16:00 h | Early Motor Phenotype Detection in a Female Mouse Model of Rett Syndrome is Improved by Cross-Fostering
Janine LaSalle
UC Davis Genome Center. Microbiology – Medicine. College of Biological Sciences
California, USA

16:30 h | Round table
John Vincent
Janine LaSalle
Moderation
Concepción Solanas Guerrero

17:00 h | Presentation of the Solidarity Book "Relatos con Causa" (Tales with a Cause)
Yolanda Corón Blázquez
Isabel Carril
Director of Publications at Editorial Bruño
Juan Fernández Armenteros
Director Obra San Martín Foundation

Wednesday 12

09:30 h | Molecular Studies: beyond Genetic Diagnosis
Judith Armstrong Morón
Dr. Genetic. Faculty Assistant of the Section of Genetic and Molecular Medicine
Sant Joan de Déu Hospital
Barcelona, Spain

10:00 h | Neurotransmission and Brain Connectivity in Rett Syndrome
Ángels García Cazorla
MD, PhD Neuropediatrics. IP Laboratory of Synaptic Metabolism, Sant Joan de Déu Hospital
Barcelona, Spain

10:30 h | Epigenetics and Genetics of Rett Syndrome
Manel Esteller
Degree in medicine and surgery. Director at Cancer Epigenetics and Biology Program (PEBC) - IDIBELL
Barcelona, Spain

11:30 h | MeCP2 and the Structural and Functional Organization of Neuronal Chromatin during Brain Development
Juan Ausio
Professor, Biochemistry/Microbiology Department. Chromatin Assembly and Transcription
University of Victoria, Canada

12:00 h | 5 (Hydroxy) Methylcytosine, the Language of MeCP2
Marian Mellen
Research Associate at the Heintz lab at The Rockefeller University. Molecular Biology
New York, USA