



**The Mitochondrial European Educational Training Project  
(MEET)  
Funded within the frame of PEOPLE Marie Curie Actions  
Presents**

**MEET Symposium 2016  
From bench to bedside, and back:  
Patients MEET Researchers  
29 – 30 January 2016**

Radboud University Medical Centre, Radboud Auditorium  
Geert Groteplein 15 (route 296)  
6525 EZ Nijmegen (The Netherlands)

For additional info: <http://www.itn-meet.org/MEET-Symposium-2016>  
For registration: <http://www.paoheyendael.nl/meetsymposium>

**NO PARTICIPATION FEE IS REQUESTED! ONLY ON-LINE REGISTRATION IS AVAILABLE!**

**Register now!**

Deadlines for registration: **January 16, 2016.**

<http://www.paoheyendael.nl/meetsymposium>

**THE MEET CONSORTIUM OFFERS 15 FULL FELLOWSHIPS!**

Please read all information carefully before you apply!

**Fellowships cover: travel, accommodation and subsistence costs to attend the Symposium.**

Fellowships are addressed **ONLY** to patients or Representative of Patients' organizations.

Applicants for fellowships must submit their request together with a reference letter from Patients' organization with whom applicants are collaborating or with a motivation letter with a cover letter.

**Applications must be sent to [serena.paterlini2@unibo.it](mailto:serena.paterlini2@unibo.it)**

**Deadline for sending applications: January 4, 2016 at 18.00 (Brussels time)**

Within the context of a deep collaboration between various European fundamental and translational laboratories, the MEET project represents a platform for the training of 14 young scientific investigators in the field of mitochondrial medicine.

A 2-days scientific symposium specifically addressed to patients, their families and associations/foundations will be held in Nijmegen (The Netherlands) in late January 2016. An important peculiarity of this symposium is the direct and proactive role of the young MEET researchers in the organization process.

The main goal of this conference is to exchange the most up-to-date knowledge advances regarding mitochondrial medicine crossing the *gap/bridge* between patients and researchers.

Delivering the outcomes of the MEET projects to patients and their associations and balance optimistic expectations and realistic progresses is another important task to be fulfilled.

The target audience of this symposium is patients, clinicians and researchers. It is intended as a bidirectional and challenging communication from patients to researchers and *vice versa* with the crucial intermediate role of clinicians.

After the welcome and introduction speech, we propose to leave the floor to the people representing the only ultimate reason for mitochondrial disease research, i.e. patients. Right after, patients' families and their associations will give insight of the domestic every day patients' care. Different biomedical expertise are working in such a multifaceted area of research, a well-known experienced medical doctor with also a deep understanding of the basic research will close the first "from the different angles" session. Therefore, instead of the usual "*from bench to bedside*" approach we propose a "*from bedside to bench*" perspective.

After the first session depicting the different major actors, their feelings and their experiences with mitochondrial diseases, a more clinically-orientated session will analyze the difficulties of the diagnostic process. This will lead us to the third session, the most research orientated part of the symposium, where the importance of basic research (the study of the physiology to understand the pathology) and of its tools (cellular and animal models) will be highlighted.

The last session will give an overview of how the knowledge has been used to develop potential treatment strategies.

# Symposium Program:

Friday, January 29<sup>th</sup>

## The opening

09.00 – 09.15	<i>Welcome to the symposium</i>	<b>J. Smeitink</b>
09.15 – 09.30	<i>What is the MEET project and its objectives</i>	<b>G. Gasparre</b>
09.30 – 09.45	<i>Meet the MEETers (1<sup>st</sup> video from the fellows)</i>	<b>E.F. Iannetti</b> (Fellows Representative)

## Session 1: Mitochondrial diseases: from the different angles

Chairman: **P.Willems**

09.45 – 10.00	<i>In the head of the patients: personal experience, how to deal with the disease</i>	<b>R. Scott</b>
10.00 – 10.30	<i>In the heart of patient's family, how they deal with the disease:</i>	Patient's parents: <b>family Polderman</b> interviewed by Maaïke de Vries
10.30 – 11.00	<b>Coffee Break (with activities)</b>	
11.00 – 11.15	<i>The value of a national patient organisation</i>	<b>P. Santantonio</b> (MITOCON)
11.15 – 11.45	<i>Through the landscape of mitochondrial diseases: from mitochondrial to nuclear DNA and beyond</i>	<b>V. Carelli</b>
11.45 – 12.00	<i>2<sup>nd</sup> part of the MEETers Video</i>	<b>MEET Fellow</b>
12.00 – 14.00	<b>Lunch break (with activities)</b>	

## Session 2: The long road to a diagnostic and the follow up of the disease

Chairman: **J.A.Mayr**

14.00 – 14.15	<i>3<sup>rd</sup> part of the MEETers Video</i>	<b>MEET Fellow</b>
14.15 – 14.45	<i>Phenotypic heterogeneity: the impact on the clinical, biochemical and genetic diagnosis</i>	<b>R. Rodenburg</b>
14.45 – 15.15	<i>The diagnosis seen from the other side</i>	Patient's parents: <b>family Masselink</b> interviewed by Maaïke de Vries
15.15 – 15.45	<b>Coffee Break (with activities)</b>	
15.45 – 16.15	<i>The 100,000 Genomes Project in England</i>	<b>P. Chinnery</b>
16.15 – 16.45	<i>Towards the harmonisation of outcome measures for children with mitochondrial disease</i>	<b>S. Koene</b>

**Saturday, January 30th**

## Session 3: The basic research

Chairman: **V. Tiranti**

09.00 – 09.30	<i>From gene defects to mitochondrial metabolism</i>	<b>C. Garone</b>
09.30 – 10.00	<i>In vivo and In vitro Models, why do we need them?</i>	<b>M. Zeviani</b>
10.00 – 10.45	<b>Coffee Break (with activities)</b>	

## Session 4: On the way to possible treatment

10.45 – 11.15	<i>Power to the People! Democracy and Mitochondrial Donation</i>	<b>R. McFarland</b>
11.15 – 11.45	<i>Mitochondrial disease drug development</i>	<b>J. Smeitink</b>

## The closure

11.45 – 12.00	<i>Pre-closure</i>	<b>J. Smeitink</b>
12.00 – 12.15	<i>The circle closes: The voice of patients at an international level</i>	<b>E. Van der Veer</b> (International Mito-Patients Chairman)
12.15 – 14.00	<b>Lunch break (with activities)</b>	

**NCMD 20<sup>th</sup> celebration**

**Side activities during the afternoon**

**List of Speakers with their Affiliations:**

<b>Carelli, Valerio</b>	Department of Biomedical and Neuromotor Sciences (University of Bologna, Italy)
<b>Chinnery, Patrick</b>	International Centre for Life; Institute of Genetic Medicine (University of Newcastle, UK)
<b>Garone, Caterina</b>	MRC Mitochondrial Biology Unit (University of Cambridge, UK)
<b>Gasparre, Giuseppe</b>	Department of Medical and Surgical Sciences (University of Bologna, Italy)
<b>Koene, Saskia</b>	Nijmegen Centre for Mitochondrial Disorders (NCMD, Nijmegen, The Netherlands)
<b>McFarland, Robert</b>	Welcome trust center for mitochondrial research (University of Newcastle, UK)
<b>Rodenburg, Richard</b>	Nijmegen Centre for Mitochondrial Disorders (NCMD, Nijmegen, The Netherlands)
<b>Santantonio, Piero</b>	Mitocon (Rome, Italy)
<b>Smeitink, Jan</b>	Nijmegen Centre for Mitochondrial Disorders (NCMD, Nijmegen, The Netherlands)
<b>Van der Veer, Elija</b>	International Mito Patient Chairman (IMP, Amsterdam, The Netherlands)
<b>Zeviani, Massimo</b>	MRC Mitochondrial Biology Unit (University of Cambridge, UK)