

GFB

Gruppo Familiari Beta-sarcoglicanopatie



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**April 19th: FIRST NATIONAL CONFERENCE GROUP FAMILY BETA -
SARCOGLYCANOPATHIES**

SARCOGLYCANOPATHIES: WHAT NEXT?

Sarcoglycanopathies and limb-girdle muscular dystrophies, scientific research and clinical aspects

GFB is inviting you to the first national convention of Beta-sarcoglycanopathies Family Group where various issues related to the scientific research and clinical aspects of limb-girdle muscular dystrophies will be treated. It will be in Milan, on Friday, April 19th, 2013. Oral presentations will be mostly in Italian language but probably with also a simultaneous translation into English and the direct stream. The final program and the registration form will be in the next newsletter.

For more info:

http://www.beta-sarcoglicanopatie.it/index.php?option=com_content&view=article&id=121&Itemid=108

Among the many speakers at the conference:

- ✓ **Jerry R. Mendell, MD** Professor of Pediatrics and Neurology
Director, Center for Gene Therapy
Director, Paul D. Wellstone Cooperative Muscular Dystrophy Research Center
The Research Institute at Nationwide Children's Hospital, Columbus Ohio USA
- ✓ **Lousie Rodino-Klapac**, Center for Gene Therapy Principal Investigator
Neuromuscular Disorders Principal Investigator
The Research Institute at Nationwide Children's Hospital, Columbus Ohio USA
- ✓ **Massimiliano Cerletti**, Group Leader
Principal Investigator/Muscle Stem Cell Unit

Progenitor Labs Ltd (GlaxoSmithKline)

London BioScience Innovation Centre London, United Kingdom

PhD Principal Investigator Harvard-GlaxoSmithKline Skeletal Muscle Program

Department of Stem Cell and Regenerative Biology

Harvard University and Harvard Stem Cell Institute Cambridge, MA USA

- ✓ **Robert Pleticha**, Online Patient Communities Manager, EURORDIS (rareconnect)
- ✓ **Saverio Tedesco**, Senior Research Associate
Cell & Developmental Biology, Div of Biosciences, Faculty of Life Sciences
University College London, London, United Kingdom
- ✓ **Anna Ambrosini**, Research Program Manager
Telethon Foundation, Milan
- ✓ **Giacomo Comi**, Department of pathophysiology and medical-surgical transplant, University of Milan
- ✓ **Doriana Sandonà**, Faculty: Medicine and Surgery
Research group: ER processing of skeletal muscle membrane proteins, Department of Biomedical Sciences, University of Padua
Claudio Semplicini, Department of Neuroscience, University of Padua
- ✓ **Gian Maria Fimia** Ph.D. Cell Biology Laboratory, National Institute for Infectious Diseases, Lazzaro Spallanzani IRCCS Rome

FROM NOVEMBER GFB IS A MEMBER OF “ALLIANCE TREAT-NMD”

<http://www.treat-nmd.eu/about/membership/organizations/>

THE O.Ma.R HAS PUBLISHED A PRESS OF GFB

The O.Ma.R (Italian Observatory rare diseases) on 29th november 2012 published a statement “Beta-sarcoglycanopathies, the Group of GFB families seeks other Italian patients with this disease.”

<http://www.osservatoriomalattie.it/storie/3257-beta-sarcogliacanopatie-il-gruppo-dei-familiari-gfb-cerca-altri-pazienti-italiani-affetti-da-questa-patologia>

We wish you a Merry Christmas and a 2013 full of pleasant surprises!