

GFB

BETA-SARCOGLYCANOPATHY FAMILY GROUP



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GFB ONLUS HAS FINANCED THE FIRST CLINICAL TRIAL FOR THE LGMD2E

On 20th November it was held the **fifth conference call** with Dr. Jerry Mendell and Dr. Rodino Klapac Louise and Dr. Erik Pozsgai. Some families of the GFB ONLUS and Dr. Massimiliano Cerletti, a member of the Medical-Scientific Committee of the Association were also present during the call. Discussion topics were the reports with all the results of the preclinical phase sent by Dr. Mendell in November and the various authorizations necessary for the first clinical trial for the LGMD2E. Dr. Mendell also communicated us the vector was modified by inserting a promoter specific for heart and diaphragm so to realise a therapy also helpful for treating the heart and breathing.

In the American laboratories they are already working to get ready for the systemic injection in the whole body of the patients.

After considering the positive results of the reports, GFB ONLUS has decided to go on financing the project and we have sent a **bank transfer of 200.000\$** to Columbus for starting already for January with the clinical trial, that will be on 3 patients over 18 years old. Foreseen for January a **second amount of 150.000\$** for the conclusion of the first trial that will last one year. GFB ONLUS is willing to support the project in Columbus also in the future.

For financing these researches GFB ONLUS has created a **special FUND FOR THE RESEARCH** with its bank account of Banca Prossima.

All the donations received on this bank account will be used for financing the American projects and the scientific research on the LGMD2E.

FUND FOR THE RESEARCH: Gruppo Familiari Beta-sarcoglicanopatie Onlus

Code IBAN: IT33X0335901600100000076500 BIC /SWIFT code BCITITMX

All the information on the project and updated information will be present on the site of the Association:
http://www.beta-sarcoglicanopatie.it/index.php?option=com_content&view=article&id=166&Itemid=111

VOTE THE VIDEO OF GFB ONLUS IN THE CONTEST 1° NATIONAL PRIZE BARRIER-FREE TOURISM

Until the 22nd February 2016 you can vote the video of GFB ONLUS on the event: "GFB ONLUS celebrates the arrival of its bus", on the site Premio turismi accessibili (Prize Barrier-free tourism).

Before accessing the link it is necessary a registration in the field "registrati" (Registration) and then you can vote in the field "Vota" (Vote)

<http://www.turismipertutti.it/articoli/item/38-il-gfb-onlus-festeggia-l-arrivo-del-suo-pulmino#add-review>

THIRD ANNUAL MEETING OF GFB ONLUS

Also in 2016 GFB ONLUS proposes the third annual meeting of the families of the Association and supporters, that will be held from 13th to 16th August in Valmalenco (SO - Italy). This meeting is part of the project "Sport, environment and disability" of the Association, financed by the foundation Provaltellina, with the call "Services to the Person".

It includes a helicopter flight and a boat cruise on Como lake. Anyone interested in taking part, can enroll by sending an e-mail to info@beta-sarcoglicanopatie.it

happy new year from GFB ONLUS