

GFB

BETA-SARCOGLYCANOPATHY FAMILY GROUP



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CONSORTIUM OF LGMD FOUNDATIONS ANNOUNCE FIRST ANNUAL LGMD AWARENESS DAY - 30 SEPTEMBER 2015

The first annual Limb Girdle Muscular Dystrophy (LGMD) Awareness Day is going to be launched later this year thanks to the unified effort of a number of non-profit foundations from around the world that are collaborating to promote global awareness.

For learning more about what is going to happen in September please visit lgmd-info.org. The site also features spotlight interviews and LGMD resources along with information about patient organizations.

If you are interested in participating in the first ever LGMD Awareness Day, there is a number of things you can do. These include becoming an "Ambassador" for LGMD Awareness Day or organizing an event to raise awareness and (if interested) solicit donations for your favourite LGMD charity.

To find out more about what others are doing please visit the Limb Girdle Awareness Day Facebook page



KINECT, A VIDEOGAME FOR CLINICAL TRIALS

A team at the National Children Hospital of Columbus Ohio believes that the videogame KINECT could be used in the future clinical trials for all those patients with serious muscular deficits.

More information: <http://www.livescience.com/50214-clinical-trials-may-open-for-kids-evaluated-with-kinect-tech.html>

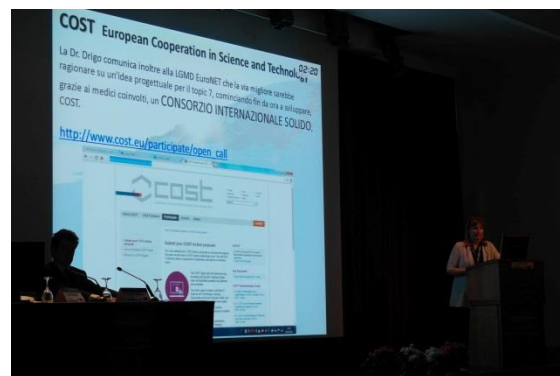
A CLINICAL STUDY ON ABOUT THIRTY PATIENTS WITH LGMD2E WAS PUBLISHED

On 28th April 2015 the magazine “American Academy of Neurology” published a clinical study on the LGMD2E carried out by E. Pegoraro and C. Semplicini with some other European centres. The clinical study was carried out on thirty-two patients followed in various European clinical centres. In the article are many information about motor, respiratory and cardiac problems of patients. Some families of GFB ONLUS have been included in this study.

More information : <http://www.ncbi.nlm.nih.gov/pubmed/25862795>

SECOND MEETING IN NAPLES OF THE LGMD EuroNET

On Friday 22nd May 2015 LGMD EuroNET had its second meeting in Naples during the 15° National Congress AIM. In the section “Future Projects and Programs”, Vola Beatrice (president of GFB ONLUS) and Prof. Corrado Angelini presented the LGMD EuroNET, followed by a meeting of the LGMD EuroNET, for planning the request for an European project for girdle muscular dystrophies. GFB ONLUS also showed the poster titled “Beta-sarcoglycanopathy: what’s new?”



More information: www.beta-sarcoglycanopathie.it

THE REPORTS OF THE MEETING “LGMD DAYS”, ORGANISED BY GFB ONLUS, IN THE MAGAZINE ACTA MYOLOGICA

In the month of December 2014 the magazine ACTA MYOLOGICA published the reports of the meeting “LGMD DAYS”, organised by GFB ONLUS in Lido di Venezia, in the days 15-17 October 2014.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4369845/>

GFB ONLUS HAS BEEN INCLUDED IN THE WEBSITE OF THE TREAT-NMD

The presentation of GFB ONLUS has been included in the website of the TREAT-NMD, in the section dedicated to the patient organizations for the girdle muscular dystrophies, to the link

<http://www.treat-nmd.eu/lgmd/patient-organizations/>

MARCO GAVAZZI, AMBASSADOR OF GFB ONLUS



Marco Gavazzi, left in May 18th from Talamona (Italy) on foot for a pilgrimage to Rome (Italy) as ambassador of GFB ONLUS. He returned to Talamona by train in June 18th.

He walked for about 40 kms a day, for 25 days, starting from SENTIERO DEL VIANDANTE, up to Lecco. He took then some bypaths to Pavia. From Pavia to Firenze he took FRANCHIGENA path and then walked up to La Verna along LA VIA DI SAN FRANCESCO, passing from Assisi, Rieti up to Rome, where he arrived in June 11th.

All images of the pilgrimage to the link:

http://www.beta-sarcoglicanopatie.it/index.php?option=com_content&view=article&id=170&Itemid=112

SECOND ANNUAL MEETING OF GFB ONLUS



GFB ONLUS has organized its Second Annual Meeting, that was held in Valmalenco (Italy) in August from Saturday 8th to Thursday 11th.

On Sunday 9th it was planned a trip by the Red Train of Bernina, from Tirano (Italy) to St. Moritz (Switzerland).

In August, on Monday 10th, the families of GFB ONLUS have planned to go to Lake Palù in Chiesa Valmalenco.

More information to the link : info@beta-sarcoglicanopatie.it

A NEW BUS FOR GFB ONLUS

In July, on Saturday 11th, GFB ONLUS inaugurated its new bus equipped for the transport for disabled people, bought thanks to the contribution of numerous sponsors (Fondazione Provaltellina, Società Iperal Spa, BIM, Comunità Montana di Morbegno, Coro Onevoice di Roma, ditta Comtech, Fondazione Creval, Uildm Sondrio, Banca Intesa S. Paolo).

<http://www.valtellinanews.it/articoli/Talamona-il-GFB-Onlus-festeggia-l-arrivo-del-nuovo-pulmino-FOTO-20150712/>

<https://www.youtube.com/watch?v=pqPgardZgh8>



THEATRE IN TREVISO IN SUPPORT OF GFB ONLUS

In June, on Saturday 27th a theatre was held in Treviso (Italy) in support of GFB ONLUS, organised by some families of patients living in the area. Anyone who wants to support our Association can organise a fundraising event in his/her town/city by contacting the secretariat of GFB ONLUS number +393497244391 or mailing to info@beta-sarcoglicanopatie.it

A NEW PATIENT SUFFERING FROM LGMD2E IS NOW PART OF GFB ONLUS FROM NORTH CAROLINA USA

From the month of June a new American family, living in North Carolina, is part of GFB ONLUS. The association has at the moment 27 patients suffering from LGMD2E and other 59 patients suffering from another sarcoglycanopathy.

IRCCS E. MEDEA: MEETING " LIMB GIRDLE MUSCULAR DYSTROPHY FROM DEFICIT OF CALPAIN 3"

Save the date: the Meeting, organised in cooperation with Associazione Italiana Calpaina 3 onlus (AICa3) and Policlinico di Milano, thanks to interventions of national and international experts, is going to be held in November 14th 2015 at the Scientific Institute E. Medea a Bosisio Parini (LC Italy). It is intended to provide patients with an updated picture of the state of the art in the diagnosis and prospects of therapy and rehabilitation of girdle dystrophy. Read the program at:

http://www.emedeaitalia.it/formazione/corsi_convegni/doc_convegni/Depliant_calpaina_email.pdf

FUNDED THE PROJECT OF DORIANNA SANDONA' ON THE LIMB GIRDLE MUSCULAR DYSTROPHY

The Italian foundation Telethon has funded the project of Dorianna Sandonà, that will test the efficacy of a new potential drug therapy in the animal model of sarcoglycanopathy.

<https://www.telethon.it/news-video/speciale-progetti-finanziati-2015/progetti-finanziati>
