



GFB BETA-SARCOGLYCANOPATHY FAMILY GROUP

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Newsletter no. 3 - dicember 2014

DURING THE “LGMD DAYS” MEETING LGMD EuroNET HAS BEEN FOUNDED, THE UILDM-GFB CONVENTION HAS BEEN SIGNED.

The second GFB ONLUS meeting took place on the Venice Lido on October 15th, 16th and 17th. During the meeting LGMD EuroNET, a network of researchers, physicians and patients associations was established. The network will be dealing continuously and systematically with limb-girdle muscular dystrophy (LGMD). The second LGMD EuroNET meeting is scheduled to take place in Naples, in May 2015. During the second day of the meeting an important convention between Uildm (*Unione Italiana Lotta Alla Distrofia Muscolare*- Italian union to fight muscular dystrophy) and GFB ONLUS was signed. The National Uildm president, Luigi Querini, has stressed the importance of cooperation between the associations.

The videos of the meeting are available on the GFB ONLUS website www.lgmd2e.org



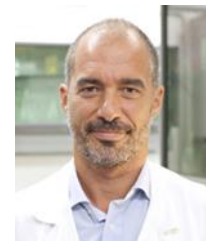
THE 2014 CALL FOR VOLUNTEERS FINANCES THE GFB ONLUS PROJECT “SPORT, AMBIENTE E DISABILITÀ” (“SPORT, ENVIRONMENT AND DISABILITY”)

The GFB ONLUS “*Sport, ambiente e disabilità*” (Sport, environment and disability) project has been financed by the 2014 call for volunteers, which has earmarked a contribution of 11.479 euro. The project includes a few excursions for disabled people in the Sondrio province, which are due to take place from May to October 2015.

<https://www.dropbox.com/s/ruahqwe7vgueb7t/approvati-BV14.xlsx?dl=0>

PROFESSOR TORRENTE HAS JOINED THE GFB ONLUS SCIENTIFIC AND MEDICAL COMMISSION

Professor Yvan Torrente has been a member of the GFB ONLUS scientific and medical commission for a couple of months, together with Cerletti Massimiliano, Roberto Maggi and Paola Bonetti. Professor Torrente has been dealing with muscular dystrophy for years; he currently works at the Stem Cells laboratory of the department of medical – surgical physiopathology and transplant of the Milan university *Università degli Studi di Milano, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico di Milano*.



IN THE UNITED STATES A CONSORTIUM FOR LGMD DYSTROPHY HAS BEEN FORMED

In January 2014 the “Consortium of LGMD Family Foundations” was formed in the US. It comprises the following organizations, which deal with LGMD.

LGMD2A: COALITION TO CURE CALPAIN 3

LGMD2B: JAIN FOUNDATION

LGMD2C: KURT+PETER FOUNDATION

LGMD2D: LGMD2D FOUNDATION

LGMD2I: LGMD2IFUND

<http://www.lgmd-diagnosis.org/>

THE FONDAZIONE PROVALTELLINA FINANCES THE GFB PROJECT

GFB has been promoted by the *Fondazione Provaltellina*, which has earmarked 19.500 euro for the GFB project “Acquisto di un pulmino disabili e servizi connessi” (Purchase of a bus for the disabled and related facilities). The purchase of the bus is due shortly.

http://www.provaltellina.org/wp-content/uploads/2014/05/elenco_contributi-bandosociale_2014.pdf

SECOND ANNUAL MEETING FOR THE GFB ONLUS FAMILIES



As a part of the GFB ONLUS project “Sport, ambiente e disabilità” (Sport, Environment and disability) the second GFB family meeting will take place in Italy, from August 8th to August 11th. 8 apartments with facilities for the disabled will be available for the overnight stay in Torre Santa Maria, Valmalenco Italy. Activities include an excursion to Switzerland on the Bernina red train as well as a funicular ride from Chiesa Valmalenco to lake Palù. For further information or to book: info@beta-sarcoglicanopatie.it

Merry Christmas and a happy new year from GFB ONLUS