



GFB

Gruppo Familiari Beta-sarcoglicanopatie

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NEWSLETTER N.3

BRAZIL JOINS THE JOURNEY PROJECT

JOURNEY PROJECT update from Sarepta Therapeutics (Massachusetts, USA): a natural history study of patients with LGMDR3/2D, LGMDR4/2E and LGMDR5/2C.

The Journey study was also extended to Brazil reaching 26 centres worldwide.

BRAZIL

Hospital de Clinicas de Porto Alegre (HCPA) - PPDS

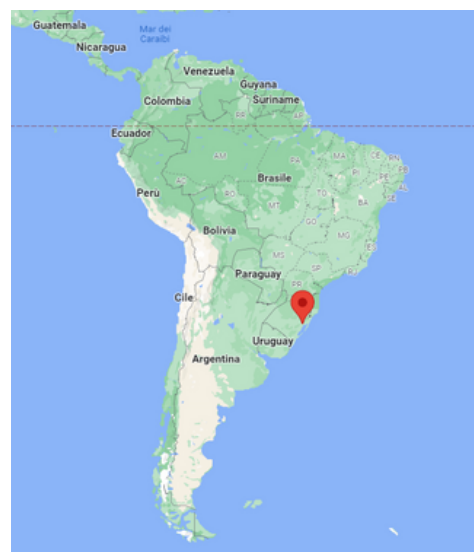
Porto Alegre, Rio Grande Do Sul, Brazil, 90035-903

Contact: SareptAlly@sarepta.com

Principal Investigator: Jonas Morales Saute, MD

For information contact: SareptAlly@sarepta.com

Website: <https://clinicaltrials.sarepta.com/journeyLGMD>



**QUALITY
PROJECT**

QUALITY PROJECT UPDATES

The QUALITY project is promoted by the GFB organisation, to structure international patient data collected over the past years, study patients' quality of life, and encourage patient participation in natural history studies and clinical trials.

The **5th phase** of the Quality project has begun. In the first 4 phases, 398 questionnaires were completed. There are 175 patients participating in the project, suffering from Lgmd2c/R5, LGMD2e/R4 and Lgmd2d/R3.

Recruitment is still open by writing to segreteria@beta-sarcoglicanopatie.it.

For more information please visit <https://www.beta-sarcoglicanopathy.org/>

2013-2023 | 10 YEARS OF GFB

GFB CELEBRATED ITS FIRST 10 YEARS OF RESEARCH: 2013-2023 WITH A CRUISE ON LAKE COMO

Relive the event with us by looking at all the photos, videos collected and articles published in newspapers and websites.

PRESS REVIEW: <https://www.beta-sarcoglicanopatie.it/?view=article&id=290:2023-rassegna-stampa&catid=16:rassegna-stampa-di-gfb-onlus>

PHOTOS: <https://www.beta-sarcoglicanopatie.it/?view=article&id=292:foto-evento-10-anni-di-gfb&catid=2:uncategorised>

VIDEO: https://www.youtube.com/playlist?list=PLKM8eCjMkcIT3kj8zBJ-yYqaqg_TVEc_

This and much more we will continue to do! Together for research!

MAKE THE HISTORY OF LIMB-GIRDLE DYSTROPHIES WITH US

APRIL 10TH 2023

Celebrate 10 years of GFB research with us.
Lake Como cruise:
Colico, Villa Carlotta, Isola Comacina, Bellagio

TOGETHER WE CAN

Sign up here www.lgmd2e.org

10 ANNI DI RICERCA
GRUPPO FAMILIARI
GFB ONLUS
2013-2023

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XXIII AIM NATIONAL CONGRESS | 8-10 JUNE 2023



GFB will participate in the XXIII National Congress of the Italian Association of Myology to be held in Padua (Italy) from 8 to 10 June 2023 where the updated poster on the Quality Project study will be presented.

INTERNATIONAL LGMD CONFERENCE | 27-29 OCTOBER

GFB will participate in the Limb-girdle muscular Dystrophy International Conference to be held in Washington (USA) from 27-29 October 2023. More information at the link: <https://thespeakfoundation.com/>



UPCOMING GFB EVENTS

8-10 JUNE | GFB's participation in the AIM Congress - Padua, Italy

27-29 OCTOBER | GFB will participate in the Limb-girdle muscular Dystrophy International Conference to be held in Washington (USA) from 27-29 October 2023.