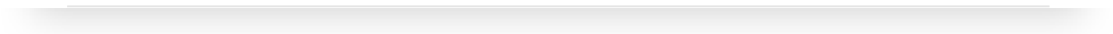




Newsletter n.2 - 2024



Save Ahmed and his family from Gaza



[Watch the video](#)

\$25,000 TO GET OUT OF GAZA TO EGYPT

Ahmed is a young man who is a member of GFB and suffers from LGMD2E Muscular Dystrophy. On 12 May, his home in the Gaza Strip was destroyed by Israeli shelling, his grandfather was hit and died. Ahmed and his family want to get out of Gaza and escape to Egypt, where his grandmother has already moved. GFB is organizing the fundraiser to help Ahmed escape.

DONATIONS

BY BANK TRANSFER TO ACCOUNT:

GRUPPO FAMILIARI BETA-SARCOGLICANOPATIE

Iban IT86T0306909606100000076500

bic swift BCITITMM

WITH PAYPAL:

Header: Gruppo Familiari Beta-sarcoglicanopatie Onlus

EMAIL: info@beta-sarcoglicanopatie.it

As of today, donations received are 490 € / \$25,000

MANY SMALL DROPS FILL A VASE, 1€ IS ENOUGH, TOGETHER WE CAN

Visit of Italian's Minister of Disability Alessandra Locatelli for the inauguration of the new GFB headquarters



[Photo gallery](#)

GFB, THE DYSTROPHY, NEW SPACES “A PROJECT THAT MUST BE SUPPORTED”

Davide Menegola's welcome

Beatrice Vola's satisfaction

<Today we are fulfilling a commitment that you had to fulfill as an assessor, in the meantime, you have become a minister and we are happy about that because you are a wonderful person who has made your political activity a mission and your closeness with the people testifies to that. Welcome to Talamona and to Valtellina.> “Here you find a cross-section of our community, which is full of people who have their hearts in their hands and manage to transform their difficulties by bringing out the best, creating these important situations> This was said by Davide Menegola yesterday afternoon, president of the Province, as well as the mayor of Talamona, as he welcomed Minister Alessandra Locatelli, who was in the village for the ribbon-cutting ceremony of the new Gfb headquarters, a foundation that has been helping those suffering from a rare form

of limb-girdle muscular dystrophy for more than a decade. A foundation that also supports scientific research to find targeted cures for this disease.

ACCESSIBLE

Yesterday, as Gfb President Beatrice Vola explained, the space, which is the foundation's headquarters, was inaugurated and made accessible on all four floors "so that it can accommodate frail people, people who cannot move, who have cardiac and respiratory problems." "Therefore, devices have been installed everywhere, from toilets to air conditioners to indoor elevator. And up to 15 people can be received here."

COMFORTABLE

A comfortable space, a real well-furnished and equipped home that the Foundation plans to make available not only to those who are affected by the specific disease but in the future also to those who need it. Gfb deals with research and applications of scientific pathways, a specific issue related to experimentation, so purely health-related." - the minister says. "I will ask my offices to interface with those at the Ministry of Health to see if we can send forward the pathway of experimentation they are following so that it will also arrive in Italy." Locatelli (Italian Republic's Minister of Disability) appreciated the work done on the facility "carrying out a project that is not just for the association itself but serving those in need, and this is a part that truly identifies and characterizes our volunteer world that is special."

RETHOUGHT

"This facility has been reorganized, rethought, and restructured in a functional way based on the characteristics of those who may be in need and it is a place that is not medicalized, but has reasonable accommodations to be a home and therefore a place of family welcome and joy, certainly not depression." "Because one has to have a course of treatment, but it also has to be a path of sharing, maybe in a big and beautiful place like this."

S. Ghe.

[More information](#)

Upcoming GFB activities

5-8 June 2024 | AIM 2024 congress in Rome - Poster and information table with Dr. Carles Sanchez Riera

9 June 2024 | DunDunRun in Talamona (SO) - provincial race and mountain walk, part of the proceeds will be donated to GFB

August 2024 | Fourth charity raffle "You donate.... they get cured"

25-29 October 2024 | ICNMD congress 2024 in Perth - Australia - Poster on GFB activities.



GFB - Gruppo Familiari Beta-sarcoglicanopatie Ets

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