



**GFB**

## **Gruppo Familiari Beta-sarcoglicanopatie**

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### **NEWSLETTER N.5**

#### **GREAT NEWS FOR LGMD2C-R5 PATIENTS**

On Aug. 3, a clinical trial for Lgmd2c-R5, led by Atamyo Therapeutics, was published on ClinicalTrials.gov.

The study involves administration of the ATA-200 gene therapy on 6 ambulant patients at different doses. It will start on January 1, 2024.

The clinical centers that will do the clinical trial have not yet been published.

<https://classic.clinicaltrials.gov/ct2/show/NCT05973630>

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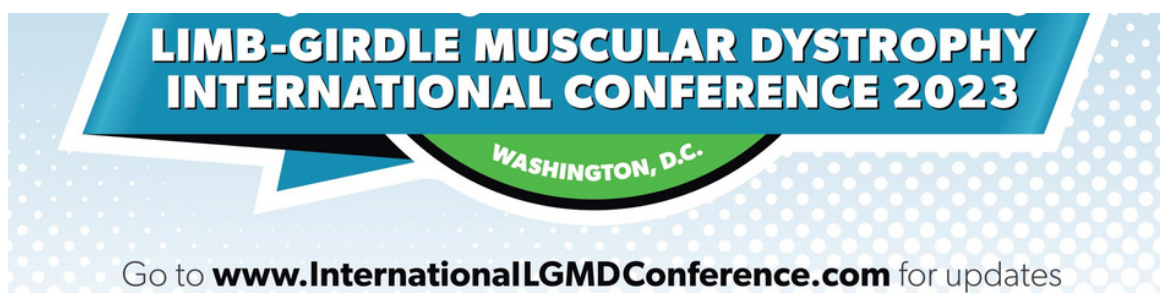
#### **LIMB-GIRDLE MUSCULAR DYSTROPHY INTERNATIONAL CONFERENCE 2023**

The INTERNATIONAL CONFERENCE ON LGMDs this year will be held in Washington, DC (United States) from October 27-29, 2023. It will be organized by the Speak Foundation, you can already register for the event at the link: <http://www.internationallgmdconference.com>

During the conference, it will be possible to make connections with patients and caregivers living with the same LGMD subtype.

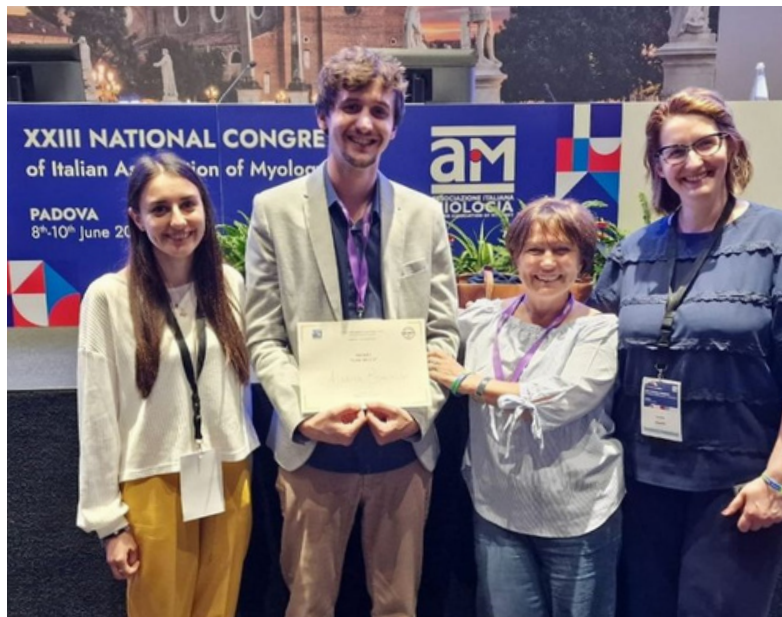
There will also be numerous opportunities to connect in person through networking events, sessions and breaks.

More information at the link: <https://thespeakfoundation.com/>



## **GFB AWARD IN BEST POSTER SECTION AT AIM 2023 CONGRESS**

At the end of the panel discussion of associations participating in the XXIIIrd AIM Congress, GFB awarded a prize in the Best Poster section to young researcher Alberto Benetollo (University of Padua, research team of Dr. Dorianna Sandonà) for his research entitled: "A potential treatment for sarcoglycanopathy: pharmacological profile of X17 CFTR corrector and its efficacy with a new regiment of administration." More pictures of the congress at the link: <https://www.beta-sarcoglicanopatie.it/?view=article&id=298&catid=2>



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## **ECM COURSE "LET'S...MOTOR REHABILITATION IN MUSCULAR DYSTROPHIES!"**

The UILDM Medical and Scientific Commission has organized the CME course "Let's...Motor Rehabilitation in Muscular Dystrophies!" to be held on October 21, 2023 in Pordenone (Italy).

The course is intended for Physiotherapists, Occupational Therapists, TNPEE, Physiatriests, Neurologists, Child Neuropsychiatrists. The program includes a theoretical and a practical section.

For more information contact the GFB secretariat at [segreteria@beta-sarcoglicanopatie.it](mailto:segreteria@beta-sarcoglicanopatie.it) or 3347589762

# SUPPORTERS 2023

In 2023 GFB received these contributions:

|             |                                                    |
|-------------|----------------------------------------------------|
| 500 €       | Donazione NN per la ricerca scientifica da Roma    |
| 40 €        | Donazione NN per la ricerca scientifica            |
| 25.000 €    | Contributo NN per la ricerca scientifica           |
| 50 €        | Donazione NN per la ricerca scientifica            |
| 50 €        | Donazione NN per la ricerca scientifica            |
| 12.939,31 € | Contributo 5x1000 anno 2022                        |
| 20 €        | Donazione NN per la ricerca scientifica            |
| 1.200 €     | Donazione NN per la ricerca scientifica da Treviso |
| 350 €       | Donazione NN per la ricerca scientifica            |
| 100 €       | Donazione NN per la ricerca scientifica            |
| 100 €       | Donazione NN per la ricerca scientifica            |
| 100 €       | Donazione NN per la ricerca scientifica            |
| 100 €       | Donazione NN per la ricerca scientifica            |
| 40 €        | Donazione NN per la ricerca scientifica da Sondrio |
| 200 €       | Donazione NN per la ricerca scientifica            |
| 100 €       | Donazione NN per la ricerca scientifica da Lecco   |
| 200 €       | Donazione NN per la ricerca scientifica            |
| 40 €        | Donazione NN per la ricerca scientifica            |
| 60 €        | Donazione NN per la ricerca scientifica            |
| 50 €        | Donazione NN per la ricerca scientifica            |
| 100 €       | Donazione NN per la ricerca scientifica            |
| 50 €        | Donazione NN per la ricerca scientifica da Sondrio |
| 41.389,31   | TOTALE                                             |

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## UPCOMING GFB EVENTS

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

**September 10, 2023 - January 28, 2024** | GFB's third charity raffle "You donate ....they get cured"