PROGETTO DDD ETS

Associazione iscritta al RUNTS in data 07/02/24 al n° 1958 se z. g

20th C3G Family Conference

Iowa City, October 4th 2025

Progetto DDD ETS

- Our association **Progetto DDD ETS** was established in **2010** as a non-profit organization by the parents of a boy affected by DDD since 2004 and a group of their friends, and registered as ETS (Ente del Terzo Settore) on 7 February 2024
- Our goals are:
  - **finance scientific, clinical and experimental research projects** of public and/or private non-profit institutions to study **C3G** pathology, pursuing exclusively solidarity and social utility purposes;
  - **support patients and their families**;
  - to be a point of reference for the **dissemination of knowledge** on C3G (causes, symptoms and possible therapies).
- We **raise funds** through **donations, fundraising events** and the destination of the **5 x 1000**

Our philosophy

Zero cost association

- The association has **no paid staff**
- **All** secretarial **costs**, postal (letters, stamps, etc.), travel, promotion of activities are **paid privately**
- All the **administrative, accounting and tax compliance** part is carried out **free of charge by** our **friend** and partner Marco Nava (BC& Studio di Consulenza Societaria Tributaria Legale)
- All the **maintenance and evolution** of the **website** is carried out **free of charge** by our **friend** Antonio Cova
- **All revenue is used exclusively to fund research**

Based on the contributions and initiatives of members and friends

- **100%** of our **funds** come from **friends, family and patients** with **C3G**

C3G patients of our association

Trentino Alto Adige
2 casi

Svizzera
Canton Ticino
1 caso

Friuli
1 caso

Veneto
2 casi

Lombardia
21 casi

Emilia Romagna
2 casi

Piemonte
2 casi

Marche
2 casi

Liguria
2 casi

Toscana
1 caso

Abruzzo
2 casi

Lazio
4 casi

Puglia
3 casi

Sicilia
3 casi

Total 2025:
48 patients

What we are funding

With 95% of our funds

- We contribute to **financing** the activities on C3G of the Clinical Research Center for Rare Diseases of Istituto Mario Negri in Ranica (Bergamo): since 2019 (this year is the seventh year) we have been funding the **costs of four researchers**, dedicated to C3G research projects.
- we took the **commitment** for **nine years**
(three **2019-2021** plus three **2022-2024** plus three **2025-2027**)

With 5% of our funds

- We contribute to **financing** some **clinical activities** concerning the C3G of the Nephrology and Pediatric Dialysis Unit of the Ospedale Maggiore Policlinico Foundation in Milan (e.g. the purchase of kits for the Laboratory for functional characterization (C4d and C5b9) or other)

Other activities

Periodic updates to Italian C3G families through

- a **quarterly email** with all the updates/news we have
- a **biannual Italian family meeting**

Fundraising events 2025

- September 28 **wine auction**
- October 21 **piano concert**

MUSEO della Collegiata CASTIGLIONE OLONA

Evento Benefico
Vino "Il Collegiata"

Domenica 28 settembre
ore 15.00

Chi darà un'offerta ritirerà la bottiglia "Il Collegiata" e potrà partecipare alla degustazione e alla visita della vigna.

SPECIALE
Asta Bottiglia
MAGNUM

100 bottiglie di Merlot, prodotto da Francesco Nutricati sui ronchi della Collegiata, a sostegno di
PROGETTO DDD ETS ONLUS

Museo della Collegiata,
via Cardinal Branda 1 - Castiglione Olona
www.museocollegiata.it

Pianista
LUCA BURATTO

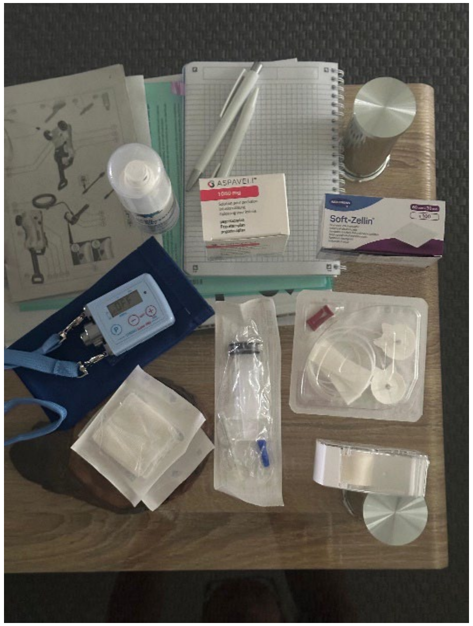
MUSICA per la Ricerca

Martedì 21 Ottobre 2025 | Ore 20:00
Villa Necchi Campiglio, Milano

2025 important news 1 of 3

USA: two treatments available

- On **March 20, 2025** in the USA, the FDA approved **Iptacopan**, trade name Fabhalta, of the Swiss pharmaceutical company Novartis, as the first medicinal treatment for C3G
- On **July 28, 2025** in the USA, the FDA approved the second drug for the treatment of C3G and IC-MPGN (**Pegcetacoplan**, trade name in the USA Empaveli, of the pharmaceutical company Apellis), for all patients aged 12 and over



Europe and Italy: same two treatments in the approval phase

- The European Medicines Agency (**EMA**) protects and promotes human and animal health by **evaluating and monitoring medicines** within the **European Union** (EU) and the European Economic Area (EEA)
- The Agency's main responsibilities are **authorising** and monitoring medicines in the EU. **Companies** apply to it for a single marketing authorisation, which is issued by the European Commission. If granted, this enables them **to market the medicine** concerned throughout the EU and the EEA
- **AIFA** (Agenzia Italiana del Farmaco) is the national public body that **regulates medicines for human use in Italy.** AIFA governs pharmaceutical expenditure and follows the life cycle of the medicine to ensure its effectiveness, safety and appropriateness as well as access to the national territory. Specifically, AIFA manages the **authorisation** processes for clinical trials, the manufacturing of medicines and active substances as well as inspection and pharmacovigilance activities

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Europe and Italy: same two treatments in the approval phase

- Both drugs (**Iptacopan and Pegcetacoplan**) are in the EMA's and AIFA's **approval cicle**
- For clarity, Apellis operates only in the USA, while for **Europe** the pharmaceutical company that has an agreement with Apellis to deal with **Pegcetacoplan** is the **Swedish SOBI** (Swedish Orphan Biovitrum), with the commercial name of the drug in Europe Aspaveli
- We hope that in a short time (we **hope in 2026**) **Europe** and **Italy** will also officially **approve** the use of these drugs to treat our disease

Our role as facilitator

- We **facilitate** and strengthen the **collaboration** between **Italian C3G stakeholders** and the **International Network on C3G** (patient's associations, nephrologists, researchers)
- In particular, since we recognize and appreciate the exceptional work done by the University of Iowa and the Molecular Otolaryngology and Renal Research Laboratories (MORL), we **promote** the **collaboration** between **Italian** nephrologists and researchers and **MORL**
- We believe that the **possible solution** will come from a **global collaboration**

Contacts

Read more: www.dddets.org

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