

FOR IMMEDIATE PRESS RELEASE

Pf Dr David Coman (Australia) and Pf Dr Belén Perez (Spain) join the CDG& Allies – Professionals and Patient Associations International Network (CDG & Allies-PPAIN).

- CDG & Allies-PPAIN is formed by more than 25 collaborators
- Patients and families are involved in all decisions, coordination and creation of pioneer research projects
- All collaborators work in an altruistic manner to increase knowledge related to CDG

12th December 2016 – [CDG & Allies- PPAIN](http://www.apcdg.com/) was created in February 2016 by the Portuguese Association for CDG (APCDG, <http://www.apcdg.com/>) in full collaboration with **Pf Paula Videira PhD** (Nova University in Lisbon). “CDG & Allies PPAIN aims at maximization existing resources and avoiding duplication of efforts.



CDG & Allies – PPAIN
CDG & Allies - Professionals and Patient
Associations International Network

Currently, our network is orphan of funding but rich in collaborators like Prof Coman and Dr Belén P González, among others. Together they have a single goal: to ameliorate the quality of life of CDG patients and their family members”, **said Vanessa Ferreira PhD, MBA (sister to a CDG patient, APCDG and CDG & Allies PPAIN founder and volunteer coordinator).**

“I have a strong clinical and research interest in the CDG, these are truly amazing families. I look forward to working with CDG & Allies PPAIN and being a focal clinical point for CDG in Australia.” **stated Prof David Coman, MD (CDG & Allies PPAIN collaborator, Australia).** “I work on genetic diagnosis as well as in novel therapeutic approaches for CDG in Spain. I am really glad to join

this family association because the research on rare disease is tough, as you all know, so the patients’ families and their children are the booster of our investigations” **added Dr Belén Perez (CDG & Allies PPAIN collaborator, Spain).** “The efforts of the “Portuguese Association for CDG, APCDG” are passionately committed to supporting and driving the most promising research to find therapies and a cure for CDG. With this in mind, the APCDG led CDG International Networking led by patient and families in collaboration with professionals”, **completed Rosália Félix (vice-president to APCDG and mother to a CDG adult patient).**

Prof David Coman will be involved in the WG CDG & Ophthalmology and CDG Patient reported Outcomes (*PROMs*) (learn more [HERE](#) and [HERE](#)). Dr Belén Perez will join the WP Clinical and therapeutic CDG research (learn more [HERE](#)).

CDG & Allies PPAIN achievements obtained from February 2016 until December 2016 include:

- 4 articles (1 published and 3 submitted),
- 3 researchers awarded with the “Liliana Scientific Scholarships for CDG”,
- 2 patient friendly documents,
- 2 steering committees involving families, researchers and physicians,
- 12 new research lines have been created and
- Attendance to 5 conferences by direct invitation or selection of abstracts to be presented at high level conferences.

This growing team of experts aims at contributing to make a difference in the lives of CDG children and adults. If you are a patient, family member, researcher or physician who would like to collaborate with CDG & Allies- PPAIN contact sindromeCDG@gmail.com or visit [HERE](#).

About the Portuguese CDG and Other Metabolic Rare Disorders Association (APCDG):

Founded in 2010, APCDG (www.apcdg.com) is a patient led and centric non-profit association, whose particular goal is to stimulate new research lines that makes a difference in the lives of patients and families. APCDG initiatives are developed both nationally and internationally. APCDG is committed to finding a cure for Congenital Disorders of Glycosylation (CDG) and related disorders, improving the treatment options and giving information

and support to people with CDG, through research, education, awareness programs and advocacy. APCDG top priority is to give a complete and holistic perspective of the patient as a person. Go to our website: www.apcdg.com

About [CDG & Allies-PPAIN](#): With the help of a broad network of scientists, physicians, families and patient advocacy groups, we have established a patient-led national and internationally unrivaled infrastructure for research, awareness and education for CDG. The research on Glycosylation disorders is primarily dedicated to Congenital Disorders of Glycosylation (CDG). The advances and innovations achieved for CDG through CDG & Allies - PPAIN will impact on a large number of patients, namely, all human diseases characterized by abnormal protein glycosylation such as cancer, inflammation, Alzheimer's disease and diabetes.

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