

FOR IMMEDIATE PRESS RELEASE

*****The Portuguese Association for CDG (APCDG, www.apcdg.com) launches two pioneer projects focused on better understanding the symptoms experiences and their emotional impact from the expert perspective of families living with CDG*****

Lisbon, 10th October 2016- Two research projects will document, for the first time, CDG symptoms and their emotional experiences among affected patients and families. These projects result from a fruitful collaboration between Pf Liz Forbat (Australia) and Pf Luísa Barros (Portugal), who embraced CDG as Working Groups Leaders at the CDG & Allies – Professionals and Patient Associations International Network (CDG & Allies PPAIN, more information [HERE](#)). Both works are an unique key contribution for CDG children's and adults standards of care and the emerging evidence base.



The Portuguese Association for CDG single goal is to find © **A. C. U. R. E.** by boosting Awareness with a Community United leading Research, creating community friendly Resources, increasing Empowerment and Education among CDG community. “CDG & Allies PPAIN are drivers of exciting newly emerging patient-driven research models. We want to create a research culture that prioritises patient concerns and this international collaboration will put patient and family issues front and centre”, **said Merell Liddle (Mother, Patient Advocate, Health Psychologist, Australia).**

CDG are a rapidly expanding, serious and chronic rare metabolic disease for which there is no cure. The uncertainty, conflicting information, misdiagnosis, frequent trips to different doctors and specialists cause stress and anxiety among patients and their family members. “Both projects address a significant gap in knowledge related to the symptom profile of these serious rare diseases”, **stated Vanessa Ferreira, PhD MBA (sister to a CDG adult patient, APCDG Founder and volunteer).** “Clinicians do not know enough about the impact of living with these rare conditions. This work is an important step toward building a picture which will be helpful to families and clinicians world-wide”, **added Pf Dr Liz Forbat (Professor of Palliative Care in Canberra, Australia).** “When it comes to the direct experience of living with a rare disease, families are the experts. The insight provided by the description of their daily experience and the solutions they have been discovering to cope with the many challenges of living with CDG is a major contribution to all professionals and to other families that will face this diagnostic in the future!”, **said Pf Dr Luisa Barros PhD (Professor at Faculdade de Psicologia, Universidade de Lisboa, Portugal).**

In parallel to these projects, the campaign **#CDGBelieve/#CDGAcredita** will be launched. It aims at sharing inspirational quotes that may help families to overcome the feeling of isolation. Follow the campaign on Facebook ([SindromeCDG page](#)) and related social networks ([@CDG Portugal](#), [LinkedIN](#)). “Understanding the psychological impact of this condition among CDG families will help to identify the major key points in this area with the perspective of giving better support for CDG families”, **stated Dorinda da Silva PhD (APCDG and CDG & Allies-PPAIN post-doc researcher).** “We count with a wonderful international team. I truly believe these projects will bring very defined and important benefits to the CDG community”, **said Rita Francisco, MSc Molecular Genetics (APCDG CDG & Allies-PPAIN researcher and social community manager).**

Notes for editors: For more information about Pf Forbat and Pf Barros' projects visit [HERE](#) and [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.

Contact: Rita Francisco, MSc Molecular Genetics. Researcher at Working Group CDG & Heart. Learn more [HERE](#). CDG community social manager. Email: publicationscdg@gmail.com