FOR IMMEDIATE PRESS RELEASE

*** **The Portuguese Association for CDG (APCDG) announces a new service that helps the access to scientific information on Congenital Disorders of Glycosylation (CDG)** ***

Lisbon, 13th February 2017 – The **Portuguese Association for CDG (APCDG)** launches a central source of information on CDG to facilitate access to information about CDG for patients and their families, medical doctors, researchers and other relevant rare disease stakeholders. Visit HERE and at the APCDG's blog HERE.

The information is identified, selected and collected in collaboration with the **CDG & Allies Community International Advisory Committee members (more information HERE).**

Each article deals with medical aspects, such as symptoms and treatment, but also with psychological and social aspects. The main target groups are individuals with CDG, rare diseases and people close to them, health-care professionals, parents, patient organizations and public sector staff.

"The lack of resources for and information about CDG and related rare diseases takes a significant emotional toll on patients, relatives and caregivers. Our association wants to help the community overcome this situation by facilitating access to robust information that can be easily shared for example, with medical doctors" **said by Vanessa Ferreira PhD MBA (APCDG founder).**

"The work we have been developing allowed us to identify the main interests of the CDG community. Scientific papers can be difficult to understand, select and access, therefore we decided to make them more accessible, to give a short description on what is the article about and when possible to make the articles available" stated **Rita Francisco MSc in Molecular Genetics (APCDG Volunteer, researcher and social community manager).**

This service is done in collaboration with the **CDG & Allies Community International Advisory Committee members (more information HERE)**. "There is great strength in having researchers and healthcare professionals working alongside families and patient representatives. This work is patient-centred and truly collaborative. The service provided pushes the cutting edge research forward, builds the state-of-the-art clinical knowledge, and provides needed information for families and care givers impacted by glycosylation disorders" shared **Prof Duncan Webster, MD (CDG & Allies-PPAIN medical and clinical councellor, FoG, Canada)**.

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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