



**Dr Vanessa Ferreira**

The Portuguese Association for Congenital Disorders of Glycosylation (APCDG), CDG & Allies – PPAIN, Lisbon, Portugal

Vanessa received a bachelor's degree in Biological Sciences from Badajoz University (Spain). She holds a PhD (Sc.D.) in Cell and Developmental Biology from the Center for Genomic Regulation, University of Pompeu Fabra, Biomedical Research Park in Barcelona (PRBB). In 2014, she completed her background with an International MBA from IAE de Paris, Sorbonne Graduate Business School.

From her unique perspective of being a sister of a patient with a rare disease named Congenital Disorders of Glycosylation (CDG) and Cell Biologist, Vanessa founded the Portuguese CDG Association and other Rare Metabolic Disorders ([APCDG-DMR](#)).

Vanessa's personal journey with her sister, combined with the community needs, have been the impetus to focus the APCDG activities in 5 major areas: (1) boosting awareness, (2) uniting and liaising the community, (3) increasing research breakthroughs, (4) building resources (5) and fostering education and empowerment.

She created beneficial actions for CDG community, such as:

(1) International platform for research, awareness and education named **CDG & Allies - Professionals and Patient Associations International Network** ([CDG & Allies - PPAIN](#)), (2) CDG Global Task Force on Science and Medical Communication and Outreach ([HERE](#)), (3) with worldwide CDG patient groups, she is coordinating the request among the World Organization of Health (WHO) to declare **16th May as the annual World Congenital Disorders of Glycosylation (CDG) Awareness Day** (all information [HERE](#)). Vanessa's believes in the power of partnership as a mean for a better future for CDG children's and adults.