



**Statement of Support from Associations to support
“16th May, the World Congenital Disorders of Glycosylation (CDG) Awareness Day”.**

The undersigned Mr/Ms, _____
on behalf of _____
Website _____ VAT registration number _____
DECLARE:

Our support for the initiative of the Portuguese Association for CDG (APCDG) in full partnership with worldwide CDG Patient Advocacy Groups and devoted to Helping Congenital Disorders of Glycosylation (CDG) community in its application to the World Health Organization for the declaration of 16th May as the annual World Congenital Disorders of Glycosylation (CDG) Awareness Day (1).

The entity I represent shares the view that the establishment of such a day would be an effective means of raising awareness and visibility throughout our society of the need to provide appropriate health, educational, social support to individuals suffering from Congenital Disorders of Glycosylation (CDG). Likewise, the declaration of such a day is an expression of society’s recognition of the difficulties and obstacles confronting individuals suffering from Congenital Disorders of Glycosylation (CDG) and their families throughout their lives.

It is also offers a channel to proclaim highly deserved understanding and solidarity for the daily efforts life imposed on individuals, and their families, affected by this chronic serious genetic, and often life-threatening condition. Nowadays, the number of disorders harboured under the umbrella term CDG has grown to some 85. No effective treatment is known for CDG, and only three CDG types have a therapy. The type and severity of problems associated with CDG vary widely among affected individuals, sometimes even among members of the same family. Walking, jumping, climbing ladders, running, reading, talking amongst other activities, prove to be difficult, often impossible in the majority of patients. The impact of this disorder goes beyond the physical manifestations of the disease. It may include economic burden, decreased productivity (both patient and caregivers), reduced social functioning, and lowered quality of life.

I therefore urge all those working in educational, health, and social spheres to declare their support for **16th May as, the World Congenital Disorders of Glycosylation (CDG) Awareness Day.**

Date:
Signature:

Note:

- (1) 16th May is the day of birth of Pf Jaeken's, the medical doctor that reported the first CDG patients more than 30 years ago. This was decided using doodle selection amongst the CDG community.

The World Congenital Disorders of Glycosylation (CDG) Awareness Day is an initiative of the Portuguese Association for CDG (APCDG) in full partnership with world CDG patient groups, representatives and professionals. For more information visit <http://www.apcdg.com/world-cdg-awareness-day.html> or contact: sindromecdg@gmail.com

This resource was elaborated by the Portuguese Association for CDG.

Detailed information is available at: <http://www.apcdg.com/world-cdg-awareness-day.html>