16th May as annual World Congenital Disorders of Glycosylation (CDG) Awareness Day Manifesto

The World Congenital Disorders of Glycosylation (CDG) patients voice is an united community dedicated to fight against the impact a rare disorder called Congenital Disorders of Glycosylation (CDG). If you have not heard of it, that is because it only affects about one in 20,000 people, which means that it is a Rare disease.

CDG are chronic serious genetic, life-altering and often life-threatening or fatal diseases due to multiple organ failure. 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 includes economic burden, decreased productivity (both patient and caregivers), reduced social functioning, and lowered quality of life. In fact, despite the rapid advances in the field of Rare Diseases, fewer than 5% of rare diseases have drug therapies available[1]. Most of rare diseases, like CDG, still have no treatment options at all. Taking the risk on a drug for CDG children's and adults may not promise returns as high as common drugs. Additionally, scientists are making great progress each day, but more funding for CDG research needs to be given.

CDG patients, are amongst the 36 million Europeans living with rare diseases. A disease in Europe is defined as rare, also known as an orphan disease, if it has a prevalence of less than 5 per 10 000. In the USA, a disorder is defined as rare when it is one that affects fewer than 200,000 individuals, or one in 10 Americans[2]. Rare diseases are believed to affect more than twice the number of all U.S. cancer patients! At least 30 million Americans and 36 million Europeans are affected by one of almost 7,000-8,000 orphan diseases[3]. The list of rare diseases increases by about 250 each year[4] (an average of five new conditions discovered every week[5]). It is estimated that approximately one out of five people personally know an individual suffering from a rare disease[6]. Indeed, it has been projected that for the top 350 rare diseases, approximately 27% of patients

[1] http://criteriuminc.com/wordpress/index.php/orphan-drug-development-why-they-are-so-important/
[2] http://www.phrma.org/sites/default/files/pdf/Rare_Diseases_2013.pdf
[3] http://features.blogs.fortune.cnn.com/2014/01/21/wall-streets-next-bet-cures-for-rare-diseases/
[4] http://www.bioresearchonline.com/doc/quantifying-the-potential-value-of-orphan-drugs-0001
[5] http://criteriuminc.com/wordpress/index.php/orphan-drug-development-why-they-are-so-important/
[6] http://www.checkorphan.org/grid/news/treatment/fighting-rare-diseases-pathway-from-orphan-drug-development-to-market-access

will not reach their first birthday[7]. This highlights the huge societal impact of these diseases.

You can imagine the loneliness of having CDG, a disease that most people have never heard of, that has no treatment, and that suffers the impact of lack of funding to support medical researcher. By recognizing the 16th May as annual World Awareness Day on Congenital Disorders of Glycosylation (CDG), you will also open doors for other common disorders where glycosylation is also affected such as cancer, inflammation, Alzheimer's disease and diabetes! It will create awareness, access to resources and create opportunities for funding & research.

AWARENESS for CDG is key! Please join us, Help us raise Congenital Disorders of Glycosylation (CDG) awareness globally, in all countries of the world, add your name to our petition to make available at

https://www.change.org/p/congenital-disorders-of-glycosylation-cdg-world-awareness-day-on-may-16th

16th May as annual World Awareness Day on Congenital Disorders of Glycosylation (CDG)!

WE CAN MAKE A DIFFERENCE! YOU CAN MAKE A DIFFERENCE!

We are asking for your support to increase awareness and visibility of CDG disease.

JOIN THE FIGHT

Sign our online petition available at https://www.change.org/p/congenital-disorders-of-glycosylation-cdg-world-awareness-day-on-may-16th

Help us make 16th May as the official annual **Congenital Disorders of Glycosylation (CDG) World Awareness Day** —a day that can help save lives.

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

Author and Bibliography used to perform this manifesto: Vanessa Ferreira. MBA thesis project: Embracing orphan diseases. IAE Paris. Sorbonne Graduate Business School. 2014.

[7] http://www.ddw-online.com/therapeutics/p211490-challenges-and-opportunities-in-the-treatment-of-rare-diseases-spring-13.html

(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.

About Portuguese Association for CDG and related Rare Metabolic Diseases (APCDG):

Founded in 2010, the APCDG (www.apcdg.com) is a family leaded nonprofit-organization aimed at fostering breakthrough research that make an important difference in the lives of patients and their family members. APCDG actions are performed at the national and international level. APCDG is committed to finding a cure for Congenital Disorders of Glycosylation (CDG) and closely related diseases, improving treatment options and providing information and support to people with Congenital Disorders of Glycosylation (CDG) through research, education, awareness programs, and advocacy. APCDG major priority is to provide a complete and holistic view of the patient as a person. Please visit www.apcdg.com

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IMPORTANT, please read when using our resources:

Importantly, our resources cannot be used for commercial or fundraising purposes.

Our work is publicly available to help the CDG community and related rare disease communities. Importantly, our resources are done by volunteers. We do not receive government funding. We rely solely on donations in order to continue our projects. Consider to make a donation using Paypal, debit or credit card or bank transfer. Your donation will help fund advocacy efforts, awareness, education and research.

All details are found at http://www.apcdg.com/get-involved1.html