

FOR IMMEDIATE RELEASE



May 16th is the Third World Congenital Disorders of Glycosylation (CDG) Awareness Day. The worldwide CDG patient community joins efforts around this day to put together awareness, fundraising and education campaigns with a global dimension.

2nd May 2018 - Congenital Disorders of Glycosylation (CDG) are a family of rare metabolic disorders. There are approximately 100 different forms and the great majority still do not have a CURE. From 2 to 16 May, the CDG patient community will encourage families, friends, researchers, clinicians and companies of this community to participate in a variety of activities that will ultimately accelerate treatments and improve care for CDG children and adults.

Theme for this Year

The theme is “CDG is rare, but research should not be”.

“The CDG community is more prepared and committed than ever to join efforts that will put a spotlight on the hurdles that people with CDG and their family members face every day. This year, May 16th will be a historic day as the CDG global voice will set up lots of activities around the world aimed to raise awareness, to educate and to fundraise for a group of diseases who urgently needs treatments and good medical care”, said **Vanessa Ferreira** who created this day back to 2016 (**APCDG founder and sister to a CDG patient**). Indeed, **Duncan Webster** (**Foundation Glycosylation – FoG president and father to a CDG patient**) believes that “This day is important to raise awareness in order to continue to build on the great progress to date. More children are being diagnosed and the CDG families are joining together and collaborating with healthcare teams and researchers. Treatments and therapies are urgently needed! Support the fight for the beautiful children in need!”

Aiming to reach these goals and to respond to the needs of the CDG Community, CDG worldwide patient groups have partnered up for the 2018 World Congenital Disorders of Glycosylation (CDG) Awareness Day campaign, which kicks off TODAY. “**CDG CARE** is delighted to support this year's World CDG Awareness Day Campaign! Through our efforts to raise awareness, promote education, facilitate collaboration and increase fund development reserves, we will be able to effectively advance CDG diagnosis and treatments options for the CDG Community.”, said **Andrea Berarducci** (**CDG CARE president and mother to a CDG patient**).

“With global joint efforts we will make this day our CDG day. Together we support research but also spread information about this syndrome” added **Anne-Kristin Ottosson** (**Swedish CDG organization**).

Until the big day (May 16th) there are many ways you can join this campaign, support the CDG Community and raise awareness for these patients and families. “As a CDG community we have reached a new level of collaboration in order to achieve new treatments and an ultimate cure for CDG. There is so much determination and willingness to help among the various patient-driven groups; It’s inspiring! This year, on

May 16, we are going to do everything in our power to educate our community about CDG. Kids and adults with CDG deserve the attention of the researchers and we are their voice. ", said **Misak Zetilyan** ([Amour Fund founder and father to a CDG patient](#)).

"Communicating and recognizing CDG is essential. It helps to improve diagnosis and research. Then, for CDG families and relatives, knowing more about the disease is of great help for its management and therefore to improve quality of care and consequently, better quality of life.", added **Nathalie Harvey** (**CDG patient representative from France and member to [Les P'tits CDG](#)**).

"Research is definitely the key to open new avenues for earlier diagnosis, better management and new therapeutic solutions for CDG. May 16 is the day to raise our united voices and let the world hear about our strength and determination. Only an informed and educated community can understand the importance of participating and contributing for projects that will lead to research advances and ultimately better life quality for patients and their families." added **Carlota Pascoal** (**MSc, CDG researcher and volunteer for [APCDG](#) and [CDG & Allies - PPAIN](#)**).

How to participate:

1. Use our social tips & Follow us on Facebook (Go [HERE](#))
 - a. Share our digital poster (Go [HERE](#))
 - b. Change your Facebook and Twitter cover and profile picture to the World Congenital Disorders of Glycosylation (CDG) Awareness Day Facebook and Twitter cover (Go [HERE](#))
 - c. the Email signature that support the World Congenital Disorders of Glycosylation (CDG) Awareness Day.
 - d. Use our suggested Social media posts and use our official hashtags: *#WorldCDGDay* *#CDGAwareness* *#CDG* (Go [HERE](#))
2. Spread World CDG Awareness Day go [HERE](#)
3. Join our campaign "Put your Heart into raising CDG Awareness". It is so SIMPLE! To join our smiles gallery go [HERE](#)
4. Plan an event to celebrate the World CDG Awareness Day and share it with us [HERE](#). We will help you disseminating it!
5. Become a Volunteer [HERE](#)
6. There are many materials, like posters, banners, and email signatures FREELY available and prepared for you [HERE](#)!
7. A press kit is available [HERE](#)

Conclusion

As World Congenital Disorders of Glycosylation (CDG) Awareness Day is approaching, the CDG community needs everyone's support in raising awareness, educating and raising funds to help children and adults living with CDG. "We need the world to know about CDG, because only through the incredible support of people we can find answers and a cure. Talking about this rare disease can change many lives and on May 16th we need you to help us spread the word and educate our communities about it.", said **Barbara Vulso** (**[CDG Italian](#) and Ireland patient advocate and mom to Leo**).

Creating awareness will help the CDG community their goals and more research for CDG becomes a reality. Raising awareness and increasing knowledge about CDG among the whole community is the only way we can move forward, as "By uniting our efforts, we will build a less bumpy road. Dissemination is the way to spread knowledge. We dream to build a basis to improve the quality of life of CDG families. The World CDG

Awareness Day is a beacon of hope that drives more resources and scientific knowledge that will help CDG families to know how to face the difficulties associated with this disease”, stated **Sandra Pinto and Jorge Palomero (CDG parent advocates, architects specialized in universal architecture and parents to Martin, members to [APCDG](#) and [AESCDG](#)).**

Let your voice be heard! The CDG Community needs you and thanks you for your support and efforts.



Learn more about the Global CDG patient community [HERE](#).

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