Template letter for Government in English to Advocate for inclusion of Congenital Disorders of Glycosylation (CDG) and related diseases in the government health topics ensuring better quality of life of patients and families affected by these diseases.

IMPORTANT, please read before 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

***

Template letter for Government in English to Advocate for inclusion of Congenital Disorders of Glycosylation (CDG) and related diseases in the government health topics ensuring better quality of life of patients and families affected by these diseases.

Source used to perform this template letter: Vanessa Ferreira. MBA thesis project: Embracing orphan diseases. IAE Paris. Sorbonne Graduate Business School. 2014.

For more information: sindromecdg@gmail.com

Date

[Name of Publication]

[Address 1]

[Address 2]

Dear **[Contact Name],**

Insert person's name and relation was diagnosed with 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 the most forms of CDG, still have no treatment options at all. Taking the risk on a drug for *insert the person's name* and his/her peers 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.

*Insert relation and person's name, * is one of 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]. In addition, it has been projected that for the top 350 rare diseases, approximately 27% of patients will not reach their first birthday[7]. This highlights the huge societal impact of these diseases.

To conclude, you can imagine the loneliness and daily impact of having CDG, a disease that most people have never heard of, that has no treatment, and that is not being studied by many medical researchers. By adding Congenital Disorders of Glycosylation to your health topic list, this will also open doors for common diseases for which growing knowledge on the basic biological mechanism named glycosylation, is as well affected. Few examples are: Alzheimer disease, cancer, infectious disease, diabetes and chronic liver disease! Thus, having CDG in the government health topics, will create awareness, increase knowledge and access to resources for rare and common diseases. Together, will create opportunities for funding and research needed for a better quality of life of patients and families affected by these pathologies.

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

I appreciate your time and consideration.

Sincerely,

About *insert the name of your national CDG Patient Advocacy Group or the name of a Patient Group that represents CDG at World level. Then do a short description about the organisation*. A list is available at http://www.apcdg.com/cdg-patient-groups.html

To learn more about World CDG actions, visit and share: http://www.apcdg.com/

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

Source used to perform this template letter: Vanessa Ferreira. MBA thesis project: Embracing orphan diseases. IAE Paris. Sorbonne Graduate Business School. 2014.

For more information: sindromecdg@gmail.com