

CDG One-to-One Interviews, a series of interviews with some of the brightest minds, who make a difference in the lives of CDG Children and Adults. This is an initiative led by the **Portuguese Association for CDG (APCDG, www.apcdg.com)**, coordinated by Dr Vanessa Ferreira, under the scope of the **CDG & Allies-PPAIN (<http://www.researchcdg.com>)**.



Title: **Bobby Ng – A man on mission: Understanding why sugars matter!**

My name is Sandra Brasil and I'm a CDG Patient Community Liaison at the Portuguese Association for CDG ([APCDG](http://www.apcdg.com)). Today, I have the pleasure to talk with Bobby G Ng, a researcher in Prof. Hudson Freeze laboratory at Sanford Children's Health Research Center. His remarkable and relentless work in the CDG field is impressive. Welcome Bobby—it is such a rewarding experience for us to have you at CDG One-to-One!

Part 1: Researching CDG and being part of a Community

Q1: Sandra Brasil: Bobby, according to Pubmed you have 41 papers published, all in the field of Congenital Disorders of Glycosylation (CDG). What drew you to this field?

Bobby G Ng: I've always had a fascination with science and how things worked, especially when it came to human biology. When I had the chance to work on a disorder that not only allowed me to explore my scientific curiosity, but also work with families.... I couldn't pass up that opportunity.

Q2: Sandra Brasil: Some of your work has focused on some of the less common types of CDG. Why did you focus on those particular CDG?

Bobby G Ng: I wouldn't say we specifically focused on the "rarer" types of CDG. It's just where the science took us. I'm a firm believer in once you find one case..... you'll find many more. This was especially true with our ALG1-CDG publication. Once we started looking we found so many more cases.

Q3: Sandra Brasil: Part of your work is liaising with physicians that identify CDG cases. What is your opinion about the current CDG awareness among the medical community?

Bobby G Ng: I believe that awareness within the USA among clinicians has gotten much better over the last ten years. Especially since whole exome sequence has increased diagnostic success. Today, the chances of a doctor encountering a CDG patient is very likely. Yet, there is still a lot of work to be done.

Q4: Sandra Brasil: You still have a lot of work ahead of you, but what have been the 3 biggest findings during you have done during your lab research work?

Bobby G Ng: I would say that 1. CDG is not nearly as rare as some people think. 2.) the emergence of de novo mutations as a cause of CDG is changing the way we think about this group of disorders. 3.) There is still so much we do not know about glycosylation and as more cases of CDG are identified, it not only increases our knowledge but will challenge us to think outside the box about the basic science behind many of these CDG genes.

Q5: Sandra Brasil: As a researcher, what challenges have you faced working in the CDG field?

Bobby G Ng: As with many rare diseases, funding is usually the biggest hurdle. From the research side, finding additional cases can be a big hurdle.

Q6: Sandra Brasil: You have recently published a review on Trends Genetics about the perspectives on CDG. Can you make a brief summary of this work for our readers?

Bobby G Ng: Trends in Genetics asked us to address topics that either have not received much attention or have presented unique problems to the scientific community. This is why we devoted a good portion of the article to the rise of de novo mutations in CDG and to newer technological tools to help us understand glycosylation.

Q7: Sandra Brasil: Besides being a researcher and lab manager, you are also part of the medical advisory board of [CDG Care](#). What are the 3 major lessons you have learnt from working in tight collaboration with CDG patient families and groups?

Bobby G Ng: Over the last twelve years I have learned many important lessons from working with CDG families including 1.) sometimes the most important thing you can do is just listen to the family. 2.) knowledge is power, often times a family is simply looking for a definitive diagnosis, which can provide an immense relief and occasionally we get lucky and a therapy is possible. 3.) More is accomplished when we all work together, whether from the scientific and advocacy sides.

Part 2: Personal life and hobbies

Q8: Sandra Brasil: Tell me a little bit of what you like to do when you aren't working on research.

Bobby G Ng: My wife and I have two kids of our own, which pretty much takes up all my time outside work. But even then, my mind is still thinking about work.

Q9: Sandra Brasil: What's your secret to find a good balance between your busy work and personal life?

Bobby G Ng: It can be hard finding that balance, especially when you know that families are looking for answers. Sometimes you just have to put the computer or iPhone away and not check email during the weekend.