

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: **Sandro Bellinzis – In the quest for CDG awareness**

The father who became a fierce advocate

14th July 2018, By Sandra Brasil (CDG community social manager and postdoc researcher.
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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 Sandro Bellinzis, a patient advocate at [CDG Italia](http://www.cdgitalia.com). We are thankful for his efforts to spread CDG awareness. Welcome Sandro — it is a delightful experience to have you at CDG One-to-One!

Part 1 – Fatherhood and Patient Advocacy

Q1: Sandra Brasil: Sandro, you are the father of Benedetta who was diagnosed with CDG. What have been the main difficulties you have faced after the announcement of the diagnosis? How do you manage to overcome them?

Sandro Bellinzis: Benedetta, who is now 6 years old, has SLC35A2-CDG also known as CDG Type 2M, which was diagnosed in June 2015, just before the World Conference in Lyon. The main issues were not the ones we had to face after receiving the diagnosis but were the issues of what to do or where to go with her, before we got the diagnosis. We were lucky that the doctor in the Gaslini Children's Hospital in Genoa was and still is an outstanding person who gave us hope and strength after coming from our island (Sardinia) where they told us that Benedetta was likely to not survive her first year.

Q2: Sandra Brasil: How did CDG impact your family and professional life?

Sandro Bellinzis: When Benedetta was born, we lived and worked on the mainland of Italy in the northwestern region of Piedmont, in a very nice little town called Saluzzo near the Alps, but we were

alone without any family, only friends who helped us as much as they could but most of them lived more than 30 minutes by car away from us. At that point we decided that it would be best if Viviana went back with Benedetta to Sardinia, where her mother, brother and my parents live for the necessary support. I was lucky to have an employer who understood the situation and finally gave me the green light to work from Sardinia where I made my home-office and travel from there to the office on the mainland once a month and visit trade shows and customers all over Europe. Furthermore, it has been of great impact also on our personal lives, especially after receiving the diagnosis, we documented ourselves about CDG as good as we could and finally finding that things are not that bad as they may seem. It's tough, for sure, but we have seen and made friends with so many other children and families over these years in various hospitals which have had even more difficult situations, that we find ourselves to be lucky to have our Benedetta the way she is. This does not mean that we don't do anything for her, on the contrary, internet and traveling for my work is helping me to get many answers. I have been to Münster to see Dr. Marquardt when I was at a trade show in Münster, I have been to a meeting in Leuven specially for CDG families from Belgium and The Netherlands a few years ago where I came to know some interesting things from Dr. Eva Morava about Galactose and how it may also be of help to other types of CDG besides SLC35A2.

Q3: Sandra Brasil: You are also a patient advocate at [CDG Italia](#). Can you tell us about the mission, goals and briefly the most relevant projects that [CDG Italia](#) is developing at the moment?

Sandro Bellinzis: The CDG Italy Association was officially founded on November 14th 2017 (my birthday) this year is for us the starting year and we want to do as much as possible activities to spread the word about CDG through our members to let families with a possible case of CDG know they have a place where to go for information and support. If necessary we can also give some minor financial support to families who are in need because also in Italy not everything is paid for by the National Healthcare System. One of the most important things we as an association are doing right now is organizing a CDG family meeting in occasion of a conference on rare diseases which takes place at the end of November this year. At the moment we mostly know each other from our Whatsapp CDG Italy group chat. We also made a 2018 calendar at the very last moment last year between November and December for fundraising.

Q4: Sandra Brasil: What part of your work so far, as a CDG patient advocate, do you think is most impactful?

Sandro Bellinzis: We have started spreading the word about CDG in our family surroundings, the place where we live, the people we know, their friends and by doing so we have had a great return in fundraising. We don't want to overload people in our community with CDG, so we organize 2 maximum 3 events a year. Two years ago, we organized an information meeting about CDG on May 16th we expected 50/60 persons to participate we had t-shirts printed with the CDG slogan and at the end we found ourselves amidst of almost 300 persons, all interested to know what CDG is about and where to donate for this cause. At the time we didn't have a CDG Association, so we donated the funds we raised to [APCDG](#) for research. All events so far organized by us or by someone else on

behalf of Benedetta or CDG research have had a great attendance and participation not only from people from our community but also from family or friends from all over Italy.

Q5: Sandra Brasil: In general, clinicians are still widely unaware of CDG. Do you agree with this statement? What do you think can be done to improve this situation?

Sandro Bellinzis: Yes, this is unfortunately true also because CDG, like always has been said, is widely unknown, it is like an iceberg of which you only see the top but the big chunk is underwater. Just the fact that there are less than 1.200 cases of all CDG types put together in the world, it is not a surprise that clinicians are widely unaware of the universe called CDG. In most cases we are the ones informing the clinicians about CDG and its implications, except for when we go to the Gaslini hospital or to Catania to Dr Rita Barone. What we can do is simple from our point of view inform as many people as we can through organization of events, talking about CDG and having articles on the local papers or television.

Q6: Sandra Brasil: In your opinion, why are collaborative initiatives between patient groups and the scientific – medical community so important for CDG?

Sandro Bellinzis: Because only through these initiatives we as families have a quicker and more detailed and advanced access to the information that we could need and being able to inform the clinicians we get in touch with about CDG.

Q7: Sandra Brasil: What can people do to get involved and help the CDG cause?

Sandro Bellinzis: Organize events of whatever kind or help us spread the word. As an example, at the end of May the local thermal pool complex organized a swim-marathon and all the money from the participants as well various donations were dedicated to Benedetta. We seized the occasion to print new t-shirts, new information leaflets and were present most of the day to inform people about CDG. People want to be informed but need to be in a simple way, no doctors talk or language, simple ABC so that they can understand what it is and this info is still lacking a bit.

Part 2: Personal life and hobbies

Q8: Sandra Brasil: How do you balance your family life with your role as CDG patient advocate?

Sandro Bellinzis: With greatest difficulty because family life, work and CDG related activities are extremely difficult to combine and only with a lot of patience, sacrifice and effort we only manage to balance for not even 40%. But it is this 40% that gives me/us hope that we can cope one step after another. We are not perfect, and we do what we can. I think that we are like smartphones, many people have a 1.000 € smartphone and use it only for chats on social networks like Facebook,

Twitter, Whatsapp, Instagram etc. To do this you would not need a smartphone like that because they used it for less than 5% of its real capacity. I feel that we CDG families are a bit the same, we are not superhumans but just humans like everyone else, just that we have learned to use more of the capacities we all have inside us. I have always been curious to know where I sometimes get the strength to do the things that I need to do with or for Benedetta and which, if Benedetta would not have been born as a special child, I probably would have never done or discovered.

Q9: Sandra Brasil: Can you tell us a little bit about yours and your family hobbies?

Sandro Bellinzis: I have a lot of hobbies, only that most of them I can't do because of a lack of time. I like travelling and I do so for my work, I like going to the beach and although I live at less than 1 km from the beach, this year I have not been there once. I like shooting pictures, various sports among others football, I like walking in the nature from the beach to the mountains and here on Sardinia we have a lot of it. I like to stay with my family and many things which however I can't do as much or as often as I would.

Who is Sandro Bellinzis?



Sandro Bellinzis is a committed CDG Patient Advocate and Father of Benedetta who was diagnosed in 2015 with SLC35A2-CDG. In 2017, he created a non-profit association – CDG Italia – dedicated to promoting CDG awareness and education. Alongside to Viviana (his wife and Vice-President of CDG Italia) he has been presiding over the organization and dedicating his time to develop several initiatives to increase CDG awareness, pushing to improve CDG patient's lives.