

A Personal Message From a Parent of a Child With CDG

These profound words are shared by a parent who has a child with CDG. Her wish is that these messages can bring you comfort, hope and understanding as you move forward.

“I know it’s scary right now. You’ve got millions of questions circling in your mind. You may be asking yourself, ‘What now? Where do I begin?’

I wish I had easy answers for you. The truth is that every parent’s and every child’s CDG journey is different.

You have been given a chance to gain a different perspective on what is important. You have been given the chance to celebrate every small victory that most parents take for granted. You have been given the chance to learn more about your child than most parents will ever know. You have been given the chance to care differently for your child from what most parents will ever be able to do.

As time passes, your ‘new normal’ will no longer feel new. You will gain answers to the unknowns every day. You are sprinting through a marathon right now. Regardless of what CDG sub-type your child has, you may be surprised at the obstacles you both can overcome. The time will come that you will be able to slow down and catch your breath.

Love for your child will carry you through even on the hardest days. Your life may no longer be the same, but the feelings of gratitude for this special child will far outweigh the feelings of stress on tough days ahead. The tears of confusion and sadness will eventually change to tears of joy.

Know that you are not alone, no matter how isolated you feel at this moment. Your child’s health care team can answer your questions and help you face the challenges. Over time, they have become our CDG heroes.”



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