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We would like to welcome you to the wonderful world of HCU Network America! If you are receiving this letter, your child or someone within your family has been diagnosed with a Cobalamin defect. If the diagnosis is recent, it can be a confusing, overwhelming, and scary time for you and your whole family; but rest assured you are not alone on this new journey of life. I am a father of a child diagnosed with Cobalamin C defect and I'm here to help you along with all my friends from the HCU Network of America. The HCU Network of America is full of valuable resources and information to help you navigate this new journey in your life.

Brandon and his family enjoying time together on vacation. Their son, Mason, is diagnosed with Cobalamin C.

Our mission at The Homocystinuria Network of America is to help patients with Homocystinuria and related disorders manage their symptoms and help improve their quality of life. If you take a look at "The Toolkit for Cobalamin" under "Resources" on the website, you will get an overview of the information we provide about stages of development and expectations from infancy to adulthood. The site also includes information on management, research, patient stories, special education and much more.

Brittany and Dana enjoying time together during the HCU Network family conference in Maryland. Mothers to Grayson and Carson diagnosed with Cobalamin G.

While many people need some time to process all of this new information, others are eager to immediately learn about their child's Cobalamin defect. Whichever phase you are in, know that you are not alone and that we are here to help you. Cobalamin defects are considered a "rare disease" and it is possible that your child is the only one in your community affected by this. With the power of technology you have access to the families of HCU Network America that have been in the same position as you and are eager to help!

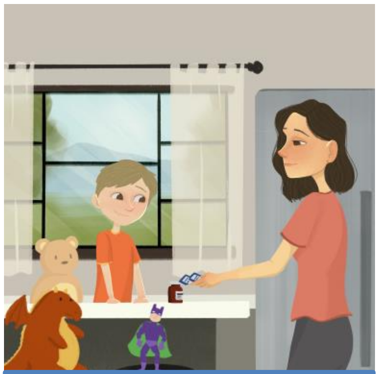
There will be some difficult days ahead of you where you will feel like no one else understands what you are going through. Know that you are not alone. Don't give up hope. Many of the families in the HCU Network have gone through exactly what you're going through and want to help. In these toughest times you have to stay positive for your child and for the rest of your family. There will also be days where your child does something truly amazing that you never thought they'd be able to do.

Don't ever underestimate the power of positivity and leverage your new friends in the HCU Network!

Sincerely yours,

Cobalamin Steering Committee

CblSC@hcunetworkamerica.org



An illustration from "Time for a Shot." A social story published by the committee to support families giving their children injections.