A Family’s Story: Supported by CDO

I have just had the results of my daughter’s genetic testing come back. It was frustrating since she had genetic testing done as a toddler and they didn’t find anything concrete until after the second test early this year.

Pending our appointment with the pediatrician, he rang to give us some details about the results so I can study it before the appointment. I was expecting the research to take months, but once I stumbled into CDO, it was surprisingly quick. Within a day, I got a reply, some information and offer of help from a doctor to answer any question. All from a very caring lady.

Thank you so much for the help. I feel like my daughter and our family finally belong somewhere. - Mother to Makyla

Chromosome Disorder Outreach
Impact Report 2017

Mission Statement
Chromosome Disorder Outreach Inc. is dedicated to providing support and information to anyone diagnosed with a rare chromosome or gene disorder. We actively promote research and a positive community understanding of all chromosome disorders so that all affected will have a greater chance at a much fuller life.

Chromosome Disorder Outreach, Inc.
P.O. Box 724
Boca Raton, FL 33429
Connections

We have been maintaining a highly detailed patient registry for 26 years recording symptoms associated with specific chromosome and gene disorders. Through this registry and our unique networking programs we bring individuals and families together who share the same or similar chromosome disorders. In combination they are able to provide inspiration and encouragement to each other with the ultimate goal being to improve the quality of life of all those affected.

Membership

Chromosome Disorder Outreach has over 6,500 members, representing all 50 states (plus Puerto Rico) and 75 countries around the world.

CDO members may be individuals living with rare chromosome disorders, parents, grandparents, or medical professionals.

Hope

Through our social media and networking programs, our members share stories of optimism and inspiration daily. If someone is going through a difficult time, experiencing a challenging situation or simply needs to hear a friendly voice, there is always support available.

Support

Our new website (www.chromodisorder.org) launched in 2017 with frequently updated Ask the Doctor, Library and Latest Research sections. These offer immediate assistance to the many concerns rare chromosome disorder patients face. We add approximately 50 new publications to our library monthly. And our Latest Research page (containing synopses of the most important new chromosome disorder publications) is updated every few weeks. Education is crucial to better understanding and effective treatments of rare chromosome disorders.

Answers

It is typical for many patients to wait months for a genetic counseling appointment to explain test results. Our staff geneticist can locate data on even the most rare chromosome disorders – sometimes within just 1 day. Individuals and family members can read through this material, attain a general understanding of the disorder and formulate even better questions for their upcoming appointment. And if a patient or family member has a more technical question after reviewing the information provided, our geneticist can help.

Financials

2017 Allocation of Expense Dollars

CDO is a 501C3 non-profit organization. Complete registration and financial information is available by contacting the State of Florida Division of Consumer Services, 800-435-7352.