

# NODCC HELPS FAMILIES COPE

Imagine being told your child is missing something that you didn't even know existed. This is what many families experience when they first learn that their child has a disorder of the corpus callosum. A diagnosis requires a great deal of education for families on top of the emotional rollercoaster they will go through. The NODCC plays a key role in helping families navigate this journey.

*"What a phenomenal organization! Just when I thought that our family was on an island by ourselves dealing with my son's diagnosis, we are among thousands of others dealing with the same issues."*

Wendy Wesley-Tabor

*"We just attended our first conference through the NODCC and are blown away by how incredible this community is...everyone treats you like they've always known you. The lectures and discussions were beyond helpful, and I am so thankful to have this incredible organization to help support our daughter."*

Felicia Charbonneau

*"As both a physician and a father of a son with a DCC, the NODCC has always been and continues to be the premier source of education and communication for me for all things related to disorders of the corpus callosum."*

Paul Guilbault, MD

*"Our team has not only been able to conduct research on disorders of the corpus callosum, but we've been able to develop a greater understanding of the conditions from the interactions with individuals at NODCC gatherings."*

Dr. Elliott Sherr, University of California,  
San Francisco, Brain Development Research Program



## WE NEED YOUR HELP.

THE NODCC DEPENDS ON GENEROUS DONATIONS TO PROVIDE RESOURCES AND SERVICES TO THOSE AFFECTED BY DISORDERS OF THE CORPUS CALLOSUM. THE ORGANIZATION'S YEARLY OPERATING BUDGET IS FUNDED PRIMARILY THROUGH INDIVIDUAL GIVING AND LOCAL FAMILY FUNDRAISERS.

TO DEVELOP NEW PROGRAMS AND SERVICES, WE NEED ADDITIONAL SUPPORT FROM FOUNDATIONS, COMPANIES, AND OTHER ORGANIZATIONS WHO SHARE OUR VISION TO HELP SPECIAL NEEDS INDIVIDUALS AND FAMILIES COPE WITH A LIFELONG CONDITION.

### NATIONAL ORGANIZATION OF DISORDERS OF THE CORPUS CALLOSUM

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## HOW WE HELP FAMILIES & HOW YOU CAN SUPPORT US



The NODCC is a 501(c)(3) nonprofit established in 2003 for individuals with disorders of the corpus callosum, their families and professionals. Our mission is to enhance the quality of life and promote opportunities for individuals with disorders of the corpus callosum. The NODCC is the leading organization for disorders of the corpus callosum seeking to raise the profile, understanding and acceptance of these disorders through education, networking, advocacy, and being a catalyst for research.

[WWW.NODCC.ORG](http://WWW.NODCC.ORG)







## WHAT IS THE CORPUS CALLOSUM?

The corpus callosum is the largest and most important pathway of nerve fibers that allow for direct communication between the left and right hemispheres of the brain. As we coordinate movements or think about complex information, the hemispheres of our brain are communicating with each other. How do the halves communicate and work together? They use the corpus callosum! The corpus callosum is like a superhighway for moving information between the two sides of the brain.

## WHAT ARE DISORDERS OF THE CORPUS CALLOSUM (DCC)?

With a disorder of the corpus callosum, the superhighway isn't working (or information gets stuck) so the brain has to use 'side streets' (or other pathways) to get information from side to side. Disorders of the corpus callosum are not illnesses or diseases. They are abnormalities of brain structure and can only be diagnosed by a brain scan (such as a MRI, CT, or ultrasound). When the corpus callosum does not develop or develops abnormally, it cannot be repaired or replaced.

*Recent data analysis shows a frequency of diagnosis (in individuals under the age of one year) to be one in every 2,053 individuals.*

## WHAT CHALLENGES COME WITH DISORDERS OF THE CORPUS CALLOSUM?

Some people with these conditions require medical intervention due to seizures or other medical conditions, but many others do not require medical treatment. However, many children with a corpus callosum disorder will need treatment to help overcome or cope with developmental delays, and others will need assistance into adulthood to help with difficulties in social and/or behavioral functioning.

Individuals with disorders of the corpus callosum may face a variety of challenges that cover a broad range of disability. Since it is a brain disorder, the disabilities are not always visible to the eye. A child with a DCC can look typical but may be far behind socially or developmentally.

# NODCC ACCOMPLISHMENTS

SINCE 2003

- Recognized as the leading organization for gathering and disseminating information on DCC
- Hosted 12 national conferences and numerous regional gatherings for DCC individuals and their families and caregivers to learn about the diagnosis, effective therapies, coping strategies and other resources
- Registered members from every state in the United States plus 87 other countries
- Distributes 250-400 information packets a year to newly diagnosed individuals and families, and fielded questions via phone and email
- Created website (nodcc.org) which receives 25,000 unique monthly visitors
- Established database of DCC-affected individuals to facilitate research



## OUR GOALS

FOR THE NEXT 5 YEARS

As the leading organization for callosal disorders, the NODCC must continue to evolve and provide up-to-date resources electronically in today's digital world.

Our goals for the next 5 years are to:

- Create educational resources to address the various types of problems that arise for individuals at different places on the DCC spectrum
- Develop improved understanding and documentation of the behavioral syndromes resulting from DCC and identify appropriate and timely intervention strategies
- Coordinate regional teaching conferences for DCC-affected families, caregivers, therapists and medical personnel
- Digitize resources and toolkits for delivery of timely information while maintaining a dynamic and resourceful website to support our community
- Increase presence across social media platforms to improve the dissemination of information and engage with DCC community