



2019 ANNUAL REPORT



Dup15q Alliance provides family support and promotes awareness, research and targeted treatments for dup15q syndrome.

www.dup15.org

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BOARD OF DIRECTORS

Our Board of Directors is responsible for determining the organization's mission and purpose, ensuring adequate resources and financial oversight, and overseeing the programs and services provided by Dup15q Alliance. The Board delegates responsibility for day-to-day operations to the corporate officers and committees.

Donna Bennett (Founder, Board Member Emeritus)

David Gifford, Board Chair,
Governmental Advocacy Committee Co-Chair

Guy Calvert, D.Phil., Board Member, SAB/MAB Representative

Joe Elassal, MD, Board Member, SAB/MAB Representative

Fernando Gomez: Transitional Living Committee Chair,
International Outreach

Julia Jordanich: Governmental Advocacy Committee Co-Chair

Steve Kadner: Finance Committee Member

Tony Marmo: Treasurer, Finance Committee Chair

Mike Porath: Development/Fundraising Committee Chair

Tessa Quinlan: Conference Planning Committee Chair

Lauren Weissberg: Education and Outreach Chair

STAFF

Executive Director: Vanessa Vogel-Farley

Office Administrator: Marlene Schwan

Outreach and Education: Krissa Harris

Administrator: Naka King



LETTER FROM BOARD CHAIR DAVID GIFFORD



Dear Dup15q Community,

In my research to prepare my first letter for the annual report, I went back and re-read some of the letters from Tom Doyle. I hope that our community recognizes the contributions that Tom made over his ten year tenure on the Board of the Dup15q Alliance.

Like Tom, my wife and I are grandparents. Our first grandchild, Annabel, is our Duper. Like all parents, grandparents, siblings and other relatives, we love her dearly. We live vicariously via our daughter and her husband on their journey.

I joined the Board in 2015, wanting to support our wonderful Alliance. Previous to joining the Board, we had participated in the great family conferences, which gave me a good view into what the Alliance does for our community. Now that I am on the Board, and have accepted the challenge of being the Board Chair, I have a much better view of how our Alliance has added value to the lives of both our Super Dupers and their families.

Our Annual Report provides the statistics on how we have grown financially. We have also grown as a support organization. We have a much closer relationship with like thinking International organizations. This will benefit our Alliance, as we will share progress in regards to research in other countries both in the more global Rare Disease area as well as the more specific Dup15q disorder.

I look forward to providing more information on how we are addressing our Mission Statement throughout 2019 and into 2020. Our focus continues to be on support for our community as well as finding targeted treatments through research for our Dupers.

We, as a Board, look forward to continued growth both financial, as well as expanding research that will ultimately benefit our members.

With gratitude,
David Gifford

Thank you for your continued support.



LETTER FROM EXECUTIVE DIRECTOR VANESSA VOGEL-FARLEY



Happy 15th Anniversary to the Dup15q Alliance and Happy 25th Anniversary to our family community!!! It's been 25 years since Donna Bennett started that first list of 13 families raising children with chromosome 15q duplications and it has been 15 years since the official support organization was incorporated. Today, there are over 2,000 families from around the world affiliated with Dup15q Alliance. When I reflect on all that this community and organization has accomplished over the years, I am standing in awe of all you have done!!! Support, Clinics, Education, Research, OH MY!!!! Looking back on our anniversary year, I am proud of all of the Dup15q Alliance's achievements this year for the dup15q syndrome community!

Our focus on delivering what the community needs to improve their lives reached new heights. We improved our clinic structure to increase our clinical sites to enable access to more patient families and through our exciting partnership with the Angelman Syndrome Foundation were able to extend our clinical expertise. We started to convene monthly meetings of the clinicians to share learnings to address the ever-changing needs of those affected with dup15q syndrome.

We reached another of our amazing goals, by engaging in our first drug trial!! We were extremely proud to partner with Ovid for the trial of a new antiepileptic compound. We turned focus to the futures of those with dup15q syndrome as they enter into adulthood, we created an Adult Living Committee to help support different care and living needs as those with dup15q syndrome grow older.

Dup15q syndrome affects all aspects of a family's life and we know that parents and other family members experience an array of concerns and emotions. The Dup15q Alliance is proud to support a family counselor who is available at no charge to aid in healthy support and self-care for caregivers and family members.

And in July 2019, we were able to see each other face-to-face where more than 300 people attended our 10th International Family Conference, "Beyond All Limits", in Houston, Texas. Planning for our 2021 conference started immediately after! Colorado, here we come!!! The Dup15q Alliance is extremely grateful to our outstanding families and generous donors for your steadfast support this past year and we look forward to our vision of 2020 (pun intended :))!

In gratitude!

-Vanessa Vogel-Farley



OUR MISSION

Our Mission: through our work to raise awareness and promote research into chromosome 15q duplications, we seek to find targeted treatments so that affected individuals can live full and productive lives. Together with our families, Dup15q Alliance is working towards a better tomorrow for children with chromosome 15q11.2-13.1 duplication (dup15q) syndrome. Our mission would not be possible without our esteemed board members, valuable volunteers, dedicated donors and the numerous professionals supporting our purpose.

Programming

We are continuously creating materials and online campaigns that are accessible to the general population and can be increased in complexity to target each of the circles, allowing for a more systematic implementation of plans and goals in educating on what Dup15q Syndrome is and the important challenges that are faced when a child or adult is diagnosed and/or is living with Dup15q Syndrome. Awareness events/walks, publications in local media and providing parents with social media content to disseminate and help educate those around them to support them is key.

Education and Outreach

We are passionate about educating our families on what is known about Dup15q Syndrome. We are here to help families educate their local communities, friends, caregivers, medical professionals and each other. Dup15q Syndrome is a rare disorder such that the majority of people do not even know exists. Unfortunately, this unfamiliarity extends into the medical field as well. Advocacy has many levels and takes many forms in rare disorders, we believe in supporting our community by bringing together our families and educating them so that they can advocate for themselves.



Thank you to our Volunteers

Dup15q Alliance has many committees that appeal to a wide variety of interests and time commitments. Choosing to serve on a committee enables you to become an integral part of supporting the Dup15q Alliance community. We are so grateful for the time and thought our volunteers give each day.

Adult Life Committee

Believe Committee

Conference Committee

Education/IEP

Extended Support Network

Government Advocacy

International Committee

Junior Believe Ambassadors

State Representatives

Sunshine Committee

Thank You Committee

Teen Life Committee

For detailed descriptions or to apply to become a volunteer, please visit our website:

www.dup15q.org/committees

PROFESSIONAL ADVISORY BOARD

The Dup15q Alliance Advisory Board offers expertise on scientific developments, to provide insights on the needs of the dup15q syndrome population, and to assure that Dup15q Alliance's policies, research, grants, marketing, communications, and publications meet the highest standards of scientific rigor and accuracy. We are so thankful to the amazing individuals who serve the Dup15q community!

Stormy Chamberlain, PhD:
University of Connecticut Health Center, Farmington, CT

Edwin H. Cook, Jr., MD: Department of Psychiatry
University of Illinois at Chicago, Chicago, IL

Orrin Devinsky, MD: NYU School of Medicine

Scott Dindot, PhD: College of Medicine, Texas A&M University,
College Station, TX

Brenda Finucane, MS, LGC: Autism and Developmental Medicine
Institute of Geisinger Health System, Lewisburg, PA

Shafali Spurling Jeste, MD: UCLA David Geffen School of Medicine
Los Angeles, CA

Janine M. LaSalle, PhD: Medical Microbiology and Immunology
UC Davis School of Medicine, Davis, CA

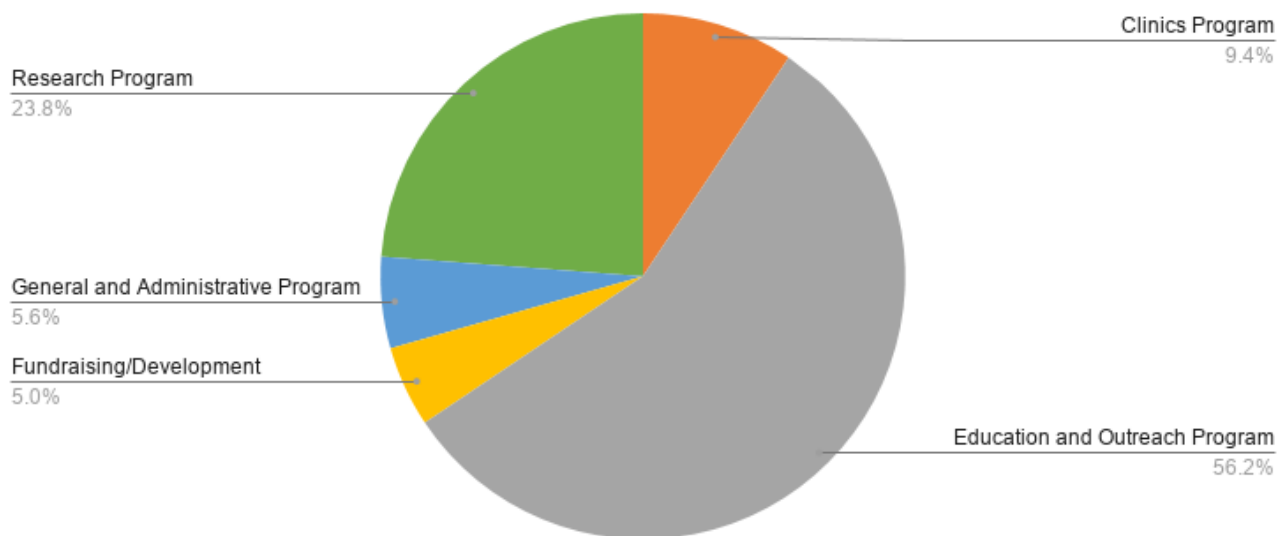
N. Carolyn Schanen, MD, PhD

Sarah Spence, MD, PhD: Department of Neurology
Children's Hospital Boston

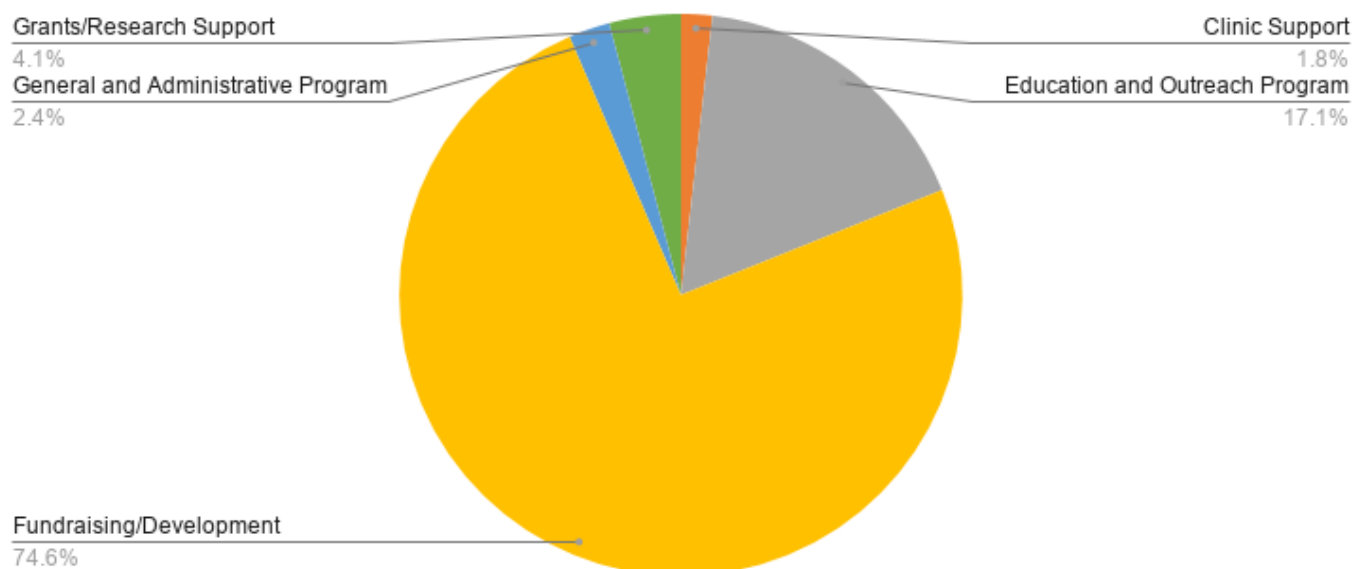
Ron Thibert, DO, MSPH: Pediatric Epilepsy Program
Massachusetts General Hospital, Boston, MA

FINANCIALS

2019 Actual Expenses (\$599,380)

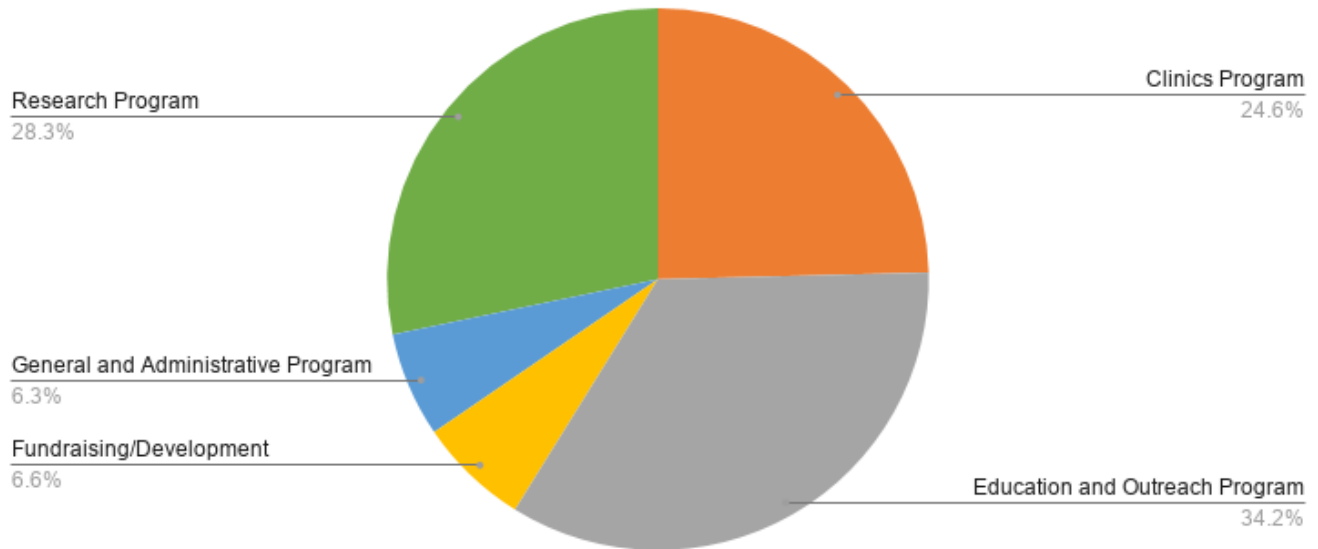


2019 Actual Income (\$558,899)

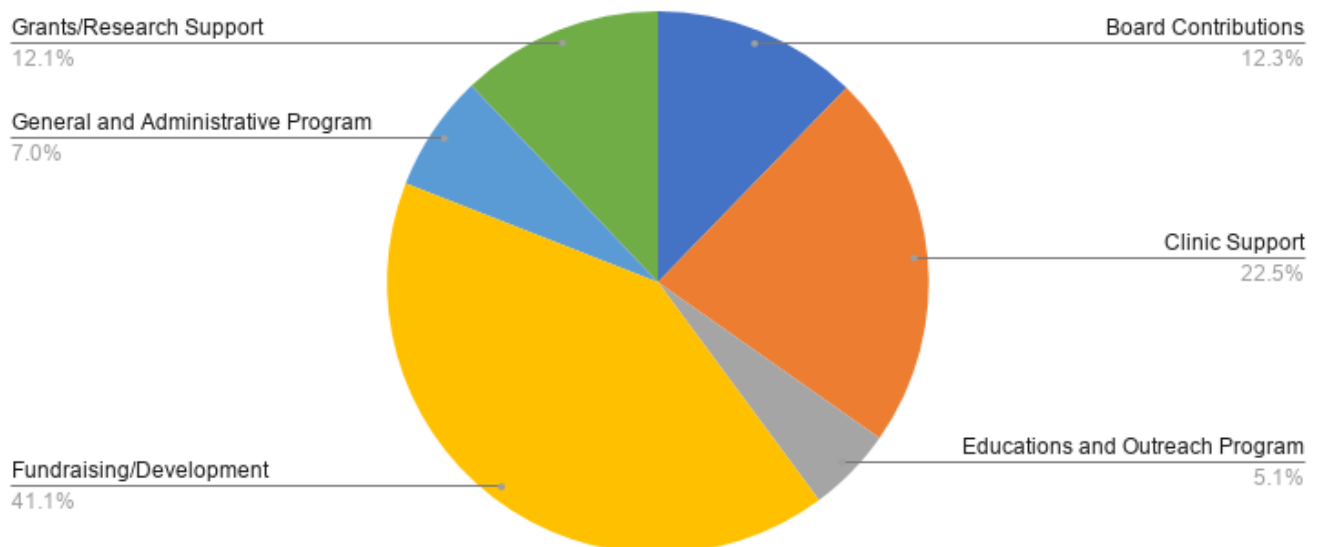


2020 BUDGET

Estimated 2020 Expenses (\$586,421)



2020 Estimated Income (\$489,239) *adjusted for COVID





Denise Anzecchino-Marck

Laura Barlow

Jim Borden

Ember Burke

Rae Casha

Tiffany Ciero

Stephanie Claxton

Heidi Curtis

Tina DeLorenzo

Carson Diddon

Amy Douglas

Jen Estvold

Emily Field

Kriss Harris

Becky Hays

Sharon Hurd Maser

Jennifer and Steve Kelly

Naka King

Ruth Kross

Karen Langford

Christina and Phil LeDonne

Cortney Manning

Cecy Martinez

Angie Mittelbuscher

Libby Powers

Heather Proctor

Tessa Quinlan

Molly and Scott Roberts

Shannon Rozovics

Kristin Siddal

Barbara Siegal

Sam Sivak

Tiffany Smith

Laura Stark

Karen Thies

Sarah Torrance

Vanessa Vogel-Farley

Lauren and Marc Weissberg

Reid Weissberg

Connie Will

ALWAYS BELIEVE!



2019 HIGHLIGHTS



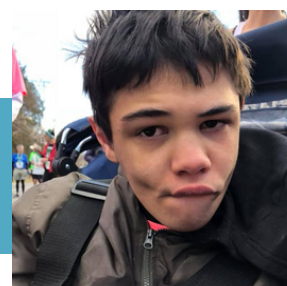
The 15q Clinical Research Network is a collaboration that strives to provide the best possible care to those affected with Dup15q Syndrome and Angelman Syndrome (two rare conditions that occur due to a problem with the same region of the 15th chromosome), while collecting clinical research data into the LADDER database (Linking Angelman and Dup15q Data for Extended Research). Each clinic is completely comprehensive yet has its own unique capabilities that leverage the expertise and specialized care available from each partnering organization. At the clinics, individuals have access to a variety of professionals all specializing in syndromes affecting the 15th chromosome.

The 15q CRN is a collaborative group that offers educational conversations between researchers and medical professionals that are involved in treating those with Angelman Syndrome and/or Dup15q Syndrome, advocacy groups and biopharma companies. We also provide a foundation to support future clinical trials by having established sites with experts and patients in place to conduct those trials when they become available.



The Compassion Experience Raised \$21,275 in 2019

February 28th is the designated "Rare Disease Awareness Day" across the world. The main objective of Rare Disease Day is to raise awareness among the general public and decision-makers alike about rare diseases and their impact on patients lives. We celebrate through dress down fundraisers at offices and through the 'Compassion Experience' - a program created to develop a sense of understanding and compassion among grade school age peers.



2019 HIGHLIGHTS CONTINUED



The Big Give Live 2019 **Raised \$47,731 in 24 hours**

On May 18th, 2019 the Dup15q Alliance hosted it's second Big Give 24 hour live event to support the FIGHT. Live streams included Dup15q doctors, researchers, parents and those who have helped build the Alliance. It was a day of sharing stories, spreading awareness about dup15q syndrome and answering questions.



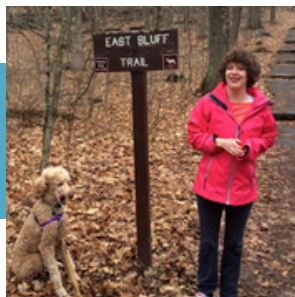
Run for a Reason **Raised \$19,662 in 2019**

Whether you wanted to run to raise awareness or to raise funds, our families excelled participating in Run for a Reason. There were a variety of races in 2019: 5k, Walk, Run, Mud Races and Athletic Events to honor our Super Dupers. Participants who raised double the entry fee had their entry fees covered by the Alliance and received a special Run for a Reason t-shirt.



Believe Walks **Raised \$17,283 in 2019**

Building off the success of previous years, our Believe Walks in Medford, NJ and Warendville, IL in 2019 were fun, educational and profitable. Friends and family gathered in their communities to help spread awareness of dup15q syndrome while having a great time walking to raise funds for those affected by Dup15q Syndrome.



RESEARCH GRANTS

With your support, Dup15q Alliance provides funding for research fellowship grants. Closely reviewed and monitored, our goal is to improve clinical care and to discover treatments, such as behavioral and drug therapies, targeted specifically for Dup15q Syndrome.

Dr. Ben Philpot -This project will generate new mouse models for the study of how extra UBE3A copies confer risk for seizures. (\$50,000 annually)

Dr. Gilles Trave - This project studies the interaction between UBE3A and HERC2 and its impact on brain development and will build the first ever 3D structure of UBE3A with and without HERC2. (\$100,000 annually -This project is jointly funded by Dup15q Alliance and Angelman Syndrome Foundation.)

Vidya Saravanapandian- This project focuses on understanding the mechanisms underlying EEG biomarkers in the (Dup15q) Syndrome. This will enable early diagnosis, prognosis, and aids in developing treatment-targets . (\$25,000 annually)

Dr. Charlotte DiStefano - This project will evaluate the use of a telehealth model of conducting remote assessments of development and clinical characteristics of children diagnosed with Dup15q Syndrome. (\$25,000)

PARTNERSHIPS

We recognize the importance of working together to achieve common goals through partnerships with other groups. Here are some of our partnerships and initiatives that are focused on improving the lives of those with rare disorders.



FAMILY CONFERENCE 2019

To my dearest Dup 15q Families,

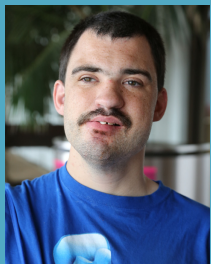
2019 Conference there and gone! What can I say other than Amazing!

Thank you for that amazing Family Conference that once again brought so much renewed energy and positive future outlooks with continuing on this journey with all of you. Our families always amaze me with their want to always make the Conference Committee feel supported and beyond grateful for all their time and effort in planning for the event. It's an event that takes much time, effort, planning, and organization that doesn't go unnoticed by all of you.

Thank you for always being our support when we need you all the most. We continue to plan for 2021 Conference amidst this unprecedented time that we have encountered. At this time, our focus remains the same while we navigate to make sure the outcome is bigger and better.

May we continue "Moving Mountains" for our children and families that need us the most.

Forever Grateful,
Tessa Quinlan



FAMILY CONFERENCE 2021



2021 International Family Conference will be held in Colorado! Westin Hotel - Westminster

*** Lots of outdoor space, walking paths and handicapped accessibility ***

Science Conference 7/6/21 - 7/7/21

Family Conference 7/7/21 - 7/9/21

Dup15q Alliance International Family Conferences are held every other year to provide families with an opportunity to meet and learn. We connect families and professionals, from the US and internationally, to provide pertinent information regarding Dup15q Syndrome advances and treatments. Tailored to benefit the entire family, our conferences include scientific, genetic and clinical discussions, respite care, sibling sessions and group activities.

HIGHLIGHTS OF 2020

Social Media

Our Facebook pages have been created as tools of support, administering up to date information regarding the Alliance and Dup15q Syndrome, with the ultimate goal of providing a safe space for our families to congregate and share.

Family Happy Hours and Round Tables – Created to allow for 'live' interaction for our families along with Q&A style sessions to inform and educate.

Volunteer Recognition – Our 'Cheers to Volunteers' thank you posts allow us to honor our volunteers while getting to know a little more about each individual.

Facebook Fundraisers – One person CAN make a difference. Throughout the unprecedented pandemic year of 2020, Birthday Fundraisers, individual 'Walks' and affiliate fundraisers were at an all time high.

New Committees

Adult Living – Created to identify the aspects of transition that are most critical and to develop the resources and strategies that will help families achieve successful outcomes for adults with Dup15q Syndrome.

Education/IEP – Developed to support parents in navigating the complexities of Special Education and the IEP Process. Since all children with Dup15q Syndrome require some form of Special Education, navigating the IEP process is an important role for parents.

Junior Believe Ambassadors JBA – Developed to provide support and help engage our youth in creating a positive impact in our community. Kids who grow up with family members or friends with special health or developmental needs are more patient, kind and supportive.

LADDER Database

By linking multiple sources of information, LADDER can expand research and accelerate the development of interventions and treatments for individuals with Dup15q and their families. We have partnered with Angelman Syndrome in this endeavor to compile an integrated database for all 15q patients.

Ovid Antiepileptic Drug Trial

The Alliance is excited to announce that its partnership with the ARCADE Ovid trial, is underway for its first drug trial of a new antiepileptic compound. The medication is in pill form and given twice a day during the trial.

PPP - Paycheck Protection Program

Due to the pandemic, we applied for and were granted a loan through the PPP allowing us to continue working to provide support and research for our families.

SUPPORT

WAYS TO DONATE:

Check or Money Order

Make payable to "Dup15q Alliance", mail to:

Dup15q Alliance

P.O. Box 1669

Highland Park, IL 60035 USA

Online

To make one-time or monthly credit card donation visit:

www.dup15q.org/donate

PayPal Giving

PayPal Giving Fund helps people support their favorite charities online. To donate via Paypal Giving Fund visit <https://www.paypal.com/fundraiser/charity/1398792>

Dup15q Alliance is a registered 501(c)(3) non-profit organization. Donations are tax-deductible in the United States, as allowed by law.

