

DUP15Q ALLIANCE

2017 IN REVIEW



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

WWW.DUP15Q.ORG



FROM THE BOARD CHAIR

Tom Doyle

Dup15q Alliance – 2017

Did you ever wonder what the “WHY” is for the Dup15q Alliance? Why does our organization exist? Our Mission Statement is very clear about our “WHY”: “Dup15q Alliance provides family support and promotes awareness, research and targeted treatments for chromosome 15q11.2-13.1 duplication syndrome.” I hope that you see our “Why” in everything we do from family conferences, to social networking, to our registry and our Professional Advisory Board, our research grants, our outreach to families and physicians, our work with potential targeted treatments, and, yes, our fundraising. The “Why” allows us to dream; to dream of a future where we can find answers and treatments, help with IEPs and living arrangements, and friends who understand what we are living through. As the board chair, I am so excited to experience the love and insight and commitment of so many of our families. We truly are blessed. 2017 was a year of growth and development for the Alliance. Vanessa Vogel-Farley led us through a needed restructuring to transition us from a smaller organization to one that is actively involved in leadership with other organizations such as NORD, AES, and Angelman’s and which is prepared to dive into the research world and work on targeted treatments with Pharmaceutical companies as well as apply for grants to assist us in our important work. The family conference was once again a great success and a wonderful opportunity to gather with our Dup15q “family”. Thanks to Tessa Quinlan and her tremendous, hard working committee of volunteers for their dedication and professionalism. Thanks, also, to Tessa for her willingness to head up the next family conference in Houston, scheduled for July of 2019. My advice would be to start planning ahead now as this will be another great opportunity to share our dreams and visions for the Alliance and for our “Dupers”. Thanks to our Board for their willingness to serve and to make difficult decisions with grace and professionalism. We know that we could not possible find success without all of our Dup15q families and supporters, however. Thank you to those of you who volunteered time, who provided us with input and ideas, who held Dup15q fundraisers, who supported others through social media and regional gatherings, who provided financial support to help accomplish our “WHY”. None of this could be done without you. While we wish that no one would ever have to face a Dup15q diagnosis, we know that our numbers will grow as awareness grows in the medical community. Our numbers internationally are growing as well. We have “Dupers” on every continent (except Antarctica as far as I know) and “sister” organizations are growing in many parts of the world. We still have much work to do! If we want to successfully reach our “WHY”, we need you even more. We are looking for committee members, board members, fundraisers, science “nerds”; we need YOU. We’d love to find a place for all who want to be an active part of our “WHY”, whether you are a parent, an aunt, uncle, grandparent, brother, sister, or just an interested party. Help us to do some of the “WHAT” that is needed to help us reach our Mission of accomplishing the “WHY”!

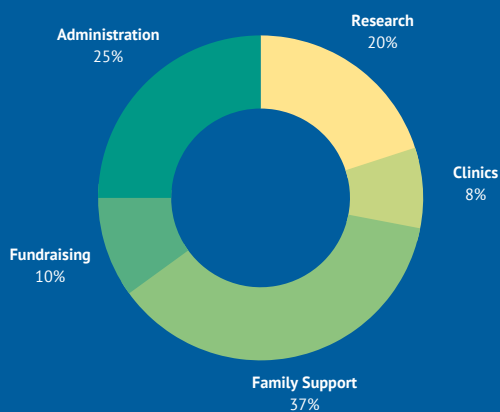
Thanks for all you do!

Tom Doyle

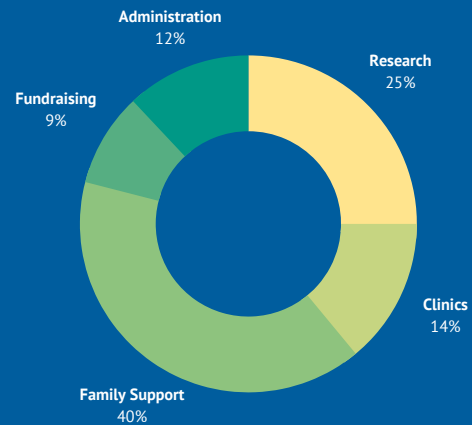
Board Chair

FINANCIAL STATEMENT

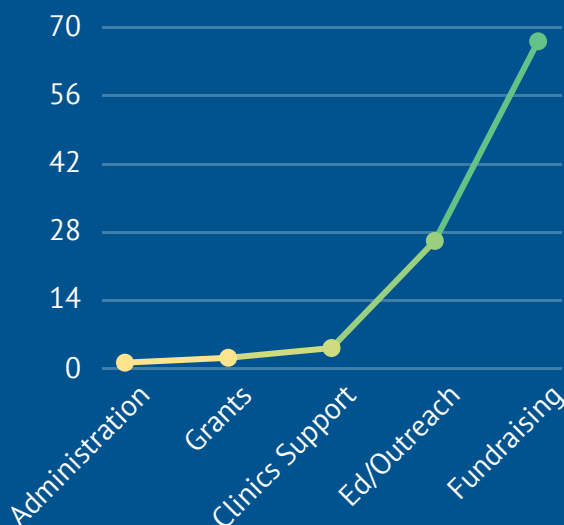
2017 Expenses (Total \$404,700)



2018 Budgeted Expenses (Total \$426,465)



2017 INCOME BY PERCENTAGE (TOTAL \$337,730)



2018 BUDGET

Approved 2018 Budget	Amount
Income Goals	
Clinics Program	\$30,000
Educations and Outreach Program	\$20,000
Fundraising Program	\$401,000
General and Administrative Program	\$4,000
Research Program	\$47,160
Total Income	\$502,160
Budgeted Expenses	
Clinics Program	\$60,000
Education and Outreach Program	\$96,800
Fundraising Program	\$37,200
General and Administrative Program	\$132,045
Research Program	\$106,500
Total Budgeted Expenses	\$432,545

2017 IN REVIEW

DUP15Q ALLIANCE



Dup15q Alliance
P.O. Box 1669
Highland Park, IL 60035
Phone: 855-Dup-15qa (855-387-1572)
<http://www.dup15q.org>

OUR MISSION

Dup15q Alliance provides family support and promotes awareness, research and targeted treatments for chromosome 15q11.2-13.1 duplication syndrome.

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.

PROGRAMS

The creation of materials and online campaigns that are accessible to the general population and can be increased in complexity to target each of the circles allows for a more systematic implementation of plans and goals in educating on what dup15q syndrome is and what the important challenges are faced when a child or adult is diagnosed and/or is living with dup15q syndrome. Awareness events/walks/publications in local media/ providing parents with social media content to disseminate to help educate those around them to support them is key.

EDUCATION AND OUTREACH

- Educating our families about what is known about dup15q syndrome. Helping them to educate their local communities, families, caregivers, medical professionals and each other. Dup15q syndrome is a rare disorder such that the majority of people (including medical personnel) do not even know exists and unfortunately this unfamiliarity extends into the medical field as well. Advocacy has many levels and takes many forms in rare disorders and dup15q syndrome is no different. Supporting our community by bringing families and patients affected by dup15q syndrome together.

RESEARCH

- Supporting existing research and pushing forward new research into dup15q syndrome to answer the questions of those affected by dup15q syndrome, better characterize the disorder and to find new treatments and medical care recommendations.

CLINIC/TREATMENTS

- Improving medical care and treatment for those with dup15q syndrome in a multidisciplinary whole patient approach. In addition we encourage, engage and support partnerships with industry and research to assist in any way we can to assist in the development of novel effective treatments for dup15q syndrome.

2017 IN REVIEW

DUP15Q ALLIANCE

STRUCTURE

A LITTLE HISTORY AND CURRENT ROLES

The Dup15q Alliance is a 501(c)3 non-profit corporation, that was registered in the State of Oregon on February 6th, 2004, under the name ISODICENTRIC 15 EXCHANGE ADVOCACY & SUPPORT (IDEAS), on June 3rd, 2011 the name of the organization was changed to Dup15q Alliance.

The Dup15q Alliance is supported by a Board of Directors that oversees the overall policy and direction of the Dup15q Alliance. Our Board of Directors is responsible for determining the organization's mission and purpose, ensuring adequate resources and financial oversight, and supervision of the programs and services provided by Dup15q Alliance. The board delegates responsibility for day-to-day operations to the executive director, active board members and committees. Additionally, the Dup15q Alliance is supported by a Professional Advisory Board made up of scientists and clinicians that perform dedicated research related to dup15q syndrome and a Clinics Working Group made up of medical clinicians that provide medical support to dup15q syndrome patients in various capacities. Our Professional Advisory Board provides medical and research expertise relevant to the organization. These groups strive to be at the forefront of dup15q syndrome related research and care, pushing the field forward with input from the Dup15q Alliance Community members.

The Executive Director, the administrative support staff and organizational committees are responsible for the day-to-day operations of the organizations. The Board positions are unpaid, the Executive Director and administrative support staff are paid positions, the committee members are unpaid positions. Each committee is overseen by a member of the Board of directors and/or the executive director or administrative support staff, with a clear and directed purpose/project/timeline.

The Dup15q Alliance is a rapidly growing rare disorder organization, with our membership increasing by, on average, of one new family per week with verifiable dup15q syndrome. The Dup15q Alliance, while based in the United States, represents patient/patient families from around the world, and we strive to operate on an inclusive structure. The Dup15q Alliance's mission exceeds geographic boundaries with regard to research, medical findings and family support. However, the importance of being able to connect with other families that share a culture/language/region is apparent and Dup15q Alliance has the ability to provide international connections and support to families diagnosed with dup15q syndrome and provides encouragement and assistance in the creation of local (country) specific support organizations.

2017 IN REVIEW

DUP15Q ALLIANCE

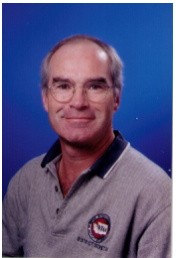
LEADERSHIP

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, Co-Founder, Emeritus Board Member In 1987, Donna Bennett enrolled her son, Josh, at Elwyn Institute in Elwyn, PA. There, they met Brenda Finucane, a genetic counselor. Together, Brenda and Donna made a powerful advocacy team for people affected by chromosome 15q duplication. Although they knew Josh's symptoms well, they could not find any information in the literature about the disorder, and they couldn't find any other people who had a similar diagnosis. One day, Brenda noticed a letter from a parent in the "Letters and Search" column of a 1990 issue of Exceptional Parent magazine. From the description, she recognized a child who was very similar to Josh. She encouraged Donna to write to the magazine, and Donna's letter was published in the April/May 1992 issue. Soon, three families responded to Donna's inquiry. When Brenda learned that there were four families who had found each other, she encouraged Donna to start a support group. This was the birth of IDEAS, which we now know as Dup15q Alliance. Brenda and Donna nursed the fledgling group out of Brenda's office at the Elwyn Institute for years. During this time, the institute underwrote the cost of the group's newsletters and the first two IDEAS conferences. Acting on a lead given by one of the families who wrote to Exceptional Parent, Donna contacted MUMS (Mothers United for Moral Support) National Parent-to-Parent Network. This organization connected her with 14 more families. Then, at Brenda's suggestion, Donna connected with the Alliance of Genetic Support Group (now the Genetic Alliance) in Washington, D.C. IDEAS gained 11 more families. The Exceptional Parent exposure also continued to grow the group. When asked in the early years how they found IDEAS, 26 families said they found the group through the magazine or its Resource Guide. By 1995, IDEAS was serving 45 families. From there due to the efforts of these 2 astounding efforts the Dup15q Alliance has just continued to grow to now 1300+ families!



Tom Doyle, Board Chair I am the grandfather to Grace Lowell and joined the board to try to support the families who are living with dup 15q. My "real job" was as a high school teacher and athletic director for 30 years. Now I am doing some work with high school athletics, mentoring new athletic directors, and teaching workshops on True Colors. Volunteering has been part of my DNA since introduced to it in high school and I understand more and more as I get older how important it is to "give back" to those who need some type of support. The moms and dads who so courageously, graciously, and patiently raise their dup 5q sons and daughters are the real heroes. I am honored to be a part of their journey.



Guy Calvert, D.Phil., Board Member, Science/Research Guy joined the board in 2011 and headed up the Alliance's research agenda. By background he is a math PhD, and works at Twitter on the marketplace engineering team as a data scientist with a focused on auction design. He came to Twitter after 7 years at Google as a research analyst where he also focused on ad auctions, and 10 years on Wall Street as a quantitative analyst. He also spent a year as a road gambler, playing poker tournaments and cash games. Outside of work he enjoys spending time with his wife and two children, reading, playing board games, fighting for freedom, driving medical research, and contesting the World Series of Poker.

David Gifford, Board Member, Governance Rosemary and I have been married for 47 years. We have 2 wonderful children, David and Sarah, and five beautiful grandchildren. Our first grandchild, Sarah and Mike Porath's daughter Annabel is a Dup15q child. She is a wonderful, magical child, now 10 years old. She is the reason that I learned about this organization, and why I wanted to be on the Board. I am an engineer by education however I have been involved in project management for over 30 years. I believe that this experience will benefit our organization and I am currently concentrating on our organization's governance. I believe we are on the cusp of moving in a very exciting growth of our alliance regarding growth in the science and research fields as well as improving the key clinics that our families will be interfacing with, and all the while improving the key support for our families. I am very proud to be involved with this organization.



Fernando Gomez, International Chair, Transitional Living Fernando Gomez joined the Dup15q Alliance Board in 2013 to support the International Relations projects. He and his wife Diane live in New Jersey and are the parents of two beautiful teenagers: Allison (19, Dup15q) and Michael (16). After an extensive career in Technical Sales and Marketing roles, Fernando is now the General Manager of a Consulting firm. He earned a BS Degree in Electrical Engineering from Rutgers University and an MBA from Lehigh University. When not at work, Fernando and Diane work on the flower and vegetable farm in the growing season, ride the tractor and bike/trike with the children, or splash in a swimming pool somewhere, as school and work schedules allow.

2017 IN REVIEW

DUP15Q ALLIANCE

LEADERSHIP, CON'T

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.



Jane Kim, MD I am the parent of a 4 year old boy with Dup15q syndrome. I am also a practicing adult neurologist with Kaiser Permanente in Northern California. I help with the management and operations of the Dup15q clinical network. When my son was first diagnosed, the Dup15q Alliance was the main place where I was able to find information about Dup15q syndrome and connect with other families. I wanted to be part of the Dup15q Alliance board because I believe in its mission and want to help the Alliance grow and thrive. I wanted to use my medical knowledge and background as a neurologist to help. I have the unique perspective of being both a clinician and a parent. There is still a lot we don't know about Dup15q syndrome, including the natural history and best treatments. The more we learn, the more it will help my son and others with his same condition. My son inspires me. He has significant delays but he still has a smile on his face most days and tries his best. He has intractable epilepsy and his life is not always easy. He teaches me that no matter how hard life can be, you have to keep going and make the best of things. The Dup15q clinicians also inspire me. They are dedicated and committed to helping our kids. They are always looking for new research ideas and ways to improve care. Most importantly, they show so much compassion and touch the lives of our kids and their families in more ways than they know. I enjoy traveling when I can, trying new restaurants and being outdoors.

Tony Marmo joined the Dup 15q Alliance board in July of 2016. Tony lives in Upper Saddle River, NJ with his wife, Nicole, and three children, son Tyler, and daughter's, Samantha and Madison. He has extensive experience in the healthcare market and in non-profits and brings a wealth of knowledge to the board. Tony owns and operates Martab Medical, a business focused on providing innovative products and services to the healthcare market and is the founding member and managing partner of the Marmo Group, LLC, a company that invests in start-up medical device companies that create new and innovative products and services. He has served as the President of the Board of Directors for the Independent Medical Distributors Association (IMDA) and worked on the Epilepsy Therapy Project as a reviewer of medical devices focused on Epilepsy. Tony and his wife, Nicole, helped establish and served on the Board for the Garden Academy, a school that serves children with Autism. When Tony joined the board, he indicated that he'd "like to serve on the Board to help promote awareness as well as advance clinical research for people living with DUP 15 Syndrome. Specifically, I'd like to leverage my 20 plus years of experience in the medical device and healthcare industry to help the DUP15 Alliance and its research partners discover targeted treatments that will help improve the lives of our children." We are grateful to Tony for his willingness to share his expertise and his passion with our families and the Dup 15q Alliance.



Mike Porath I'm the dad of a 10-year-old girl with Dup15q syndrome. My wife Sarah and I also have two younger boys and we live in the suburbs of Los Angeles. The Dup15q Alliance and the people in our community (all of you!) have been so helpful to our family in so many ways. I joined Dup15q Alliance's board several years ago with the hope that I could help it support more families and drive more research that I believe will ultimately lead to improving the quality of life for people with Dup15q syndrome. Currently I serve as fundraising chair. I have spent most of my career working as a journalist and digital media executive at ABC News, NBC News, The New York Times and AOL. A couple of years ago, Sarah and I decided to build The Mighty (TheMighty.com), a media and digital health company designed to help people facing any kind of health condition. The inspiration for The Mighty was of course our daughter Annabel, but it was also Dup15q Alliance. I love being part of this community.

Tessa Quinlan I have been married for 15 years to my husband and we welcomed three children into our lives. Gavin age 12 (dup15q), and our two daughters, Ava age 10, and Addisyn age 6. They are all blessings in our lives. I currently work part time for my son's private therapy clinic as a parent liaison working with families entering the special needs system or already in the system. I provide them assistance when it comes to academic resources, referrals, resources state funding within our state, recreational outlets for their child, and just an ear to listen. I love what I do. We became a large part of the Dup 15q Alliance because we really want to know more about a syndrome that has entered our lives unannounced. We also want to make sure that we give back to a community that has done so much for us and for our child. We never stop believing the world of possibilities for Gavin. We never take anything for granted and wish upon the milestones we have not accomplished yet. And if they never do, we can't say we didn't try. I chose to become a member of the Board because I want to be involved in something that I truly believe in. I want more for our children. And the only way to do it is to become involved in any aspect of the charity that you feel comfortable with. I am glad for my decision. So thank you for letting me serve.



2017 IN REVIEW

DUP15Q ALLIANCE

LEADERSHIP-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!

- Agotino Battaglia, MD:** The Stella Maris Clinical Research Institute for Child and Adolescent Neurology and Psychiatry Calambrone (Pisa), Italy
- 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 in Lewisburg, PA.
- Shafali Spurling Jeste, MD:** UCLA David Geffen School of Medicine
- Janine M. LaSalle, PhD:** Medical Microbiology and Immunology, UC Davis School of Medicine, Davis, CA
- Lawrence T. Reiter, PhD:** Department of Neurology, University of Tennessee Health Science Center, Memphis, TN
- 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

LEADERSHIP-STAFF

Executive Director -Vanessa Vogel-Farley
Office Administrator: Andrea Worthen/Elyse Linderman
Outreach and Education : Lauren Weissberg
Administrator: Naka King

2017 IN REVIEW

DUP15Q ALLIANCE

STRUCTURE

WE ARE READY FOR THE FUTURE

As our mission is dup15q syndrome specific, we represent all patients and families affected by dup15q syndrome whether part of our membership or not. Our support is given regardless of race, ethnicity, age, gender, or sexual orientation.

Dup15q Alliance is the largest patient advocacy group for dup15q syndrome that is in existence worldwide and is the leader in collection of the latest dup15q syndrome related research and clinical recommendations. The Dup15q Alliance has over two decades of amazing successes that have changed the landscape of what is known and possible with regard to dup15q syndrome, as well as providing more than 1,000 of patients, their families, support networks, researchers, and clinicians information, support, connections, clinical support and generally helping those affected by dup15q syndrome to the best lives they are able.

All of the work and dedication by all involved over the past 20+ years has truly put Dup15q Alliance in a position to take the organization to the next level. To that end, in the last year Dup15q Alliance has gone through many large changes including transitioning from a having a dup15q parent serve as the Executive Director since founding, to a non-dup15q parent being hired in a full-time position. As part of this change in staffing structure, the business side of the organization was evaluated and systems were instituted to ensure financial compliance in all aspects of operations. Additionally, in the past year, discussions with private sector/industry have moved into support phases of the organization and our Mission, both directly and indirectly.

Dup15q Alliance is a part of many organizations that complement the Alliance's membership (rare disorder patients/families), the Mission (advocacy, support, research, medical recommendations) and the co-morbid diagnoses that are part of the dup15q syndrome (epilepsy, autism, etc) and having full-time organizational staffing has enabled Dup15q Alliance to take more active roles to learn from and contribute more to the rare disorder field.

Thank you many THANK YOU!

Thank you to our 2017 Supporters for Believing!

ACHIEVE SPONSOR: \$10,000+

Simon and Rachel Segars

HOPE SPONSOR: \$5,000-\$7,499

Monica Reina-Kadner & Noah Kadner Shannon and Jeff Rozovics
Angela and Mike Rozovics
Julia and Ed Jordanich
Child Neurology Foundation
Sister Chicks
The Simons Foundation

DUPER SPONSOR - \$1000-\$2,499

Lauren Frear	Gary Freidman
Jane & Lawrence Kim	John Paloucek
Paul and Anne Karch	Bruce and Deb Lindgren
Lauren & Marc Weissberg	Amanda Byrne
Colin Trueman	Laura Stark
Patty Huppenbauer	Katrine G Pedersen
David and Rosemary Gifford	Peter Pinto
Christine & George Hadaya	All County Waterproofing LLC
Bob and Barbara Petersen	Buffie Anderson
Elaine & Yogi Lowell	Hawaiian Dredging Construction Co. Inc. Randy Johnson J
Steven and Caryn Sprovieri	Joseph Podwika
Sarah Spence	Quiet Professional, LLC
Autism Science Foundation	Oliver Quigley
Building Stephen's Place, LLC	

BELIEVE SPONSOR: >\$500

3 Stix LLC
Eight Point Distributors
John & Delight Eilering
Dave and Sheila Farry
Beth Jackson
Kawika's Painting
Londonberry High School
Painting Dynamics, Inc
Sprovieri's Custom Counters



Dup15q Alliance Regional Reps

Joanne Poore
Lindsey Borden
Lisa Feehery
Rylie McHam
Tiffany Ciero
Kirstin Siddall
Shannon Rozovics
Tessa Quinlan
Todd & Katie Supina
Lanae Follett
Robert & Adrienne Paradis,
Emmylou Allen
Ivonne Ruiz
Rachel Segars



Dup15q Alliance International Reps

Derek & Tracy Boshard - South Africa
Anne Tiplady, Belinda McDonald, Chris Chair - Australia
Alison Kalnicki, Denis Myers - Canada
Ursula Pail - Europe - Austria
Mieke Vanhove - Europe - Belgium
Kamilla Jakobsen - Europe - Denmark
Pamela Taylor - Europe - England
Helene Frisch, Stefanie Lebailly- Europe France
Ute Wolf - Europe - Germany
Antal de Waij - Europe - Netherlands
Ragnhild Eikeland - Europe - Norway

SUPER DUPER SPONSOR: \$2,500-\$4,999

Susan & Brian Gazewood
Ruth Kross
Hayley Doyle
Lisa and William Feehery
Randy Johnson

ADVOCATE SPONSOR: \$500-\$999

Midwest Welding Equipment Repair
Simeon Kriesberg & Martha Kahn
Kenneth & Sandra Weissberg
Maria Carney
Yelani Naranjo
Brandon Cruz & Kristina Hernandez
Aiisha & David Ramiro
Terry and Karen Langford
Dagoberto Cabral
Mary Lou Rebmann
Mary McCloskey
Laura Gamarekian
Eileen O'Connor

Chromosome Q-usaders

Lacey Berger - Communities for the Cause
Heather Sheldon - Miles for Myles
Krissa Harris - Hattie's Warriors
Adrienne Felterman - Kendra Scott Gives back
Lauren Weissberg-Hope for Holden
Cortney Manning - Believe in Brielle
Colleen Lowell - Seattle Believe Walk
Aiisha Sablan Ramiro - Hawaii Believe Walk
Ruth Kross- Warrenville Believe Walk
Tina Delerenzio and Christine Hemingway - NJ Believe Walk
Stephanie Lebeilly - France Believe Walk
Ivonne Ruiz and Christine Hemingway - Miami Believe Walk
Roxanne and Aivry Zamora - Victory Lakes Fundraiser
Jim Borden - NYC Marathon Running for Andrew
Laura Stark - Crawling for a Cure
Mike Porath - Death Valley Marathon
Doreen Gladis and Son Pavel-Ornament Fundraiser

PROGRAM HIGHLIGHTS AND INITIATIVES

The past year also marks the planning and hosting of our 9th bi-annual Dup15q Alliance Family Conference as well as our annual Dup15q Alliance Science Symposium. Both of these large events brought together the dup15q syndrome community, and each of these conferences has grown in interest and size. We had our largest Dup15 Alliance Family Conference ever with 381 attendees!!

In the past year we proudly supported 9 new research publications.

<https://www.dup15q.org/research/published-articles/>

In the coming years, focusing on the upcoming year, the balancing of the organizational membership growth and support while actively participating in existing and new partnerships will be an exciting challenge. In the past year, evaluation of the overall organization and the goals for growth and development have laid the framework for strengthening the Board of Directors and Committee involvement in the day-to-day operations of Dup15q Alliance. Finding individuals with the necessary skills and time needed to dedicate to the Alliance to provide the guidance and oversight essential to take Dup15q Alliance to the next level will need to be done in a clear and concise manner.

INITIATIVES

COMMUNITY

The Dup15q Alliance maintains a comprehensive database of all member families and the goal to maintain the most up-to-date contact information for our families enabling the Alliance to connect newly diagnosed families with others to share support.

- Help to organize an annual regional gathering for each of our regions.

CONNECT

- Keep Dup15q Alliance families, friends and supporters up-to-date on the latest information regarding chromosome 15q duplications, medical care recommendations and opportunities for research.

ENGAGE

- Support at least 10 new Chromosome Q-usaders to raise awareness for dup15q syndrome in their communities.
- Develop a peer education program for use in communities and schools to increase support and education around dup15q syndrome to improve the everyday lives of dupers.

RESEARCH

- Collect information from our families about dup15q syndrome, treatments, outcomes and questions to enable families, researchers and physicians to better understand the characteristics of the syndrome help determine areas that need further research and develop targeted treatments to improve the lives of those affected by Dup15q Syndrome.
- Compile the needed data and analysis for research grants and partnerships with industry to develop new treatments.

CARE

- Update medical care guidelines that take into account current experiences and needs of those affected by dup15q syndrome.
- Substantially increase Tyler's Travel and Clinic Support Fund to enable as many affected by dup15q syndrome to be cared for by one of the Dup15q Alliance Multidisciplinary Clinics.
- Add up to 5 new Dup15q Alliance Clinic locations.
- Support of dupers and families that are transitioning to different care needs as they grow older and looking into the future.