



# 2018 ANNUAL REPORT



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

[www.dup15.org](http://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.*

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Donna Bennett (Founder, Board Member Emeritus)

Tom Doyle, Board Chair

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

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

David Gifford, Governmental Advocacy Committee Co-Chair

Fernando Gomez: Transitional Living Committee Chair,  
International Outreach

Julia Jordanich: Governmental Advocacy Committee Co-Chair

Jane Kim: Professional Advisory Board Member

Tony Marmo: Treasurer, Finance Committee Chair

Mike Porath: Development/Fundraising Committee Chair

Tessa Quinlan: Conference Planning Committee Chair

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## STAFF

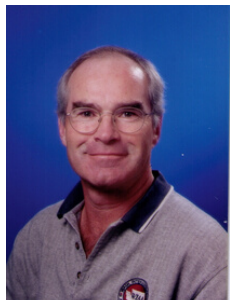
**Executive Director:** Vanessa Vogel-Farley

**Office Administrators:** Ava Markoutas, Marlene Schwan

**Outreach and Education:** Krissa Harris, Lauren Weissberg

**Administrator:** Naka King





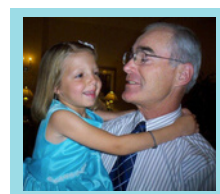
# LETTER FROM BOARD CHAIR TOM DOYLE

As 2018 comes to an end, so does my term on the Dup 15q Board. I have been privileged to serve on the board for the past ten years. I have been amazed every day with the dedication, wisdom, organization, love and adventurousness of our Dup 15q families. I had the unique opportunity to be the first grandparent on the board which allowed me to have more of that 30,000 foot view of the organization and its purposes rather than the “in the trenches” view that many of our parents experience. That “distance” allowed me to provide the wisdom that comes with life’s experiences and the rational reaction to issues that comes with being slightly removed from the daily challenges and emotions our parents and siblings face.

I’ve written before about how far we have come in my 10 years and in the rapidly approaching quarter of a century the organization has been in existence, first as IDEAS, now as the Dup 15q Alliance. I’ve written about the amazing women that started and nurtured the organization and continue to lead it today. So today, I’m going to go in a slightly different direction and provide some of my reflections of my time on the Board. Here goes with some random thoughts: In 2010, our annual income was \$64,313; in 2018 it was over \$500,000. How does that happen? Yes, our numbers of “Dupers” has grown significantly, but I attribute it mostly to the hard work and dedication of our leadership and the support of generous donors. When I started, Kadi Luchsinger had just taken over from Nicole Cleary as the Executive Director. It was a one-woman show at the time; in fact, it was a one-woman volunteer show. From there we went to a part-time paid Executive Director with two part-time staff to a full-time Executive Director (Vanessa Vogel-Farley) and now three part-time assistants doing various jobs. We have grown our donor base tremendously over those years as well. I often use the human development metaphor to describe how we moved from a teenager to a young, professional adult during those years.

We’ve followed our Mission Statement and provided Family Support. We’ve “always” had conferences, but the size and depth of presentations has grown along with the organization. We have a website that constantly gets kudos for the depth and breadth of the information that we provide for newly diagnosed families, information for families watching the development of their children and their movement into the school system, and now we are developing helpful and creative information for those who are transitioning into adulthood.

We provide contact with other parents through our social media and developed clinics for families seeking doctors who understand our kids and their needs and have resources to help families afford to travel to those sites. Recently, we recognized that we also need to take care of the caregivers and have developed a program to provide counseling for those who need it and might not be able to afford it.



## letter from Tom Doyle continued...

We've developed the "awareness" goal of the Mission Statement as well as we have worked to educate our families and, as importantly, their physicians about Dup 15q. We have aided partner organizations in other parts of the world to develop the support and knowledge they need to bring their families together and provide information on the syndrome. We have formed a group of scientists and physicians who have advocated and spread the word about Dup 15q to doctors and neurologists everywhere. Ten years ago, we had a very dedicated group of scientists and doctors who worked with us as a Professional Advisory Board (PAB). They were involved in research and education and treatment in ways that really helped our families. I remember my daughter calling long distance to talk to Ron Thibert when she couldn't get seizure activity under control in our local area. What a resource that PAB was and is! Today, because we now have some funds available, we can actually support some research grants. We have found that our money has been well spent as it has generated even more grant money for our researchers. We have made great progress.

And targeted treatment? Today, we have begun some actual drug studies to try to treat various symptoms of the syndrome, especially seizure activity. Where will we be in another ten years as these studies provide researchers with even more information and families with relief from some of the symptoms?

I have had the privilege of working with some of the most amazing, dedicated people on the board. I don't have space here to name them all, but I hope you realize how committed your board is to our Mission. They do it all for the right reasons. Obviously, they are all volunteers who just want to help make a difference. I hope you take time to thank them for their work.

Kadi was a joy to work with. She was able to dream and to put those dreams into action. She had boundless energy and brought about the needed organization and built the necessary relationships to get us on the "map" of small, rare-disease, non-profits. One of the wisest (or maybe luckiest) moves the Board made was to hire Vanessa when Kadi needed to move on to a "real job". We actually started with the idea that we would hire Vanessa part-time. By the time we were done interviewing her and seeing her skills and work ethic, we decided that we would be wasting time waiting for the job to grow into a full-time job. We tasked Vanessa with making it a full-time plus job by growing the Alliance and transforming our organization into a "well-oiled" machine. She has done that gloriously. We now have systems in place, a "brand" for everything we do, stronger relationships with the research and physician world, a great fundraising program, conferences with outside resources to help develop them, research possibilities that are amazing, and symbiotic relationships with other non-profits representing other rare-diseases...and so much more.

I believe the real heroes are you, the parents! I've often heard it said that we all have challenges in our lives; but it is how you respond to those challenges that really defines us. You are models for all of us who watch what you go through every day. I recently heard someone say, "The only disability is a bad attitude." I know there are days where you just want to throw up your hands and say, "Why me"? There are days where the challenges can be overwhelming. But know that those of us who witness your love and dedication to your children are tremendously moved and in awe of you.

And the reason we have all been brought together, those people with dup15q syndrome, I remember jogging one morning after we had heard about the diagnosis of dup15q. I agonized over the diagnosis and how it would affect the family, Grace (my granddaughter), and me. How would I explain this to my friends? How do I explain to that stranger who acts disapproving of Grace's behavior? How would I explain that Grace wasn't "normal"? I had no idea what to do with those thoughts till I had the funny sensation that I was being given an answer – "Grace will be OK; she'll do just fine." To this day, I don't know if a voice spoke that to me while I was running or my brain just figured out that it didn't really matter. Grace was all that mattered, not how I felt about it or how some outside observer felt. Grace would be OK; she would be the best she could be; we would compare her with her "best self", not with other children or other's ideas. Suddenly, things were so much clearer. My role was to help Grace grow into the beautiful person she is meant to be – whatever that looks like. Grace has the ability to change the world. By changing me and her other grandparents, her siblings, her parents, her uncles and aunts, and all those who come in contact with her, she does make the world a better place. Before Grace, I had no idea what it was like to interact with a "special needs" child. Now, where I used to not be aware of their presence, I see them everywhere I go. There is a special place in my heart for these "differently abled" children. My world is different because of Grace.

I taught for 30 years before "retiring". When I started teaching, I hoped to change the world. It wasn't long before I realized that wasn't going to happen. I realized the only person I could change was myself. And if I did that, it might make a difference in the world. So, I continue to grow, to learn, and to marvel especially where Grace is involved. She fascinates me every time I am with her. She enjoys such little, simple pleasures. She gets joy out of things that others would label as "goofy". She learns in her own way and amazes me with what she says or does on a daily basis. After her initial diagnosis, I spent a lot of time trying to figure out how I might "fix" things for her and change her life. What I found out was that she changed me!

My hope for grandparents, uncles, aunts, and others...I hope that you have the opportunity that I have had, to be involved in the life of the "Grace" of your family.

I hope that you can provide support for your children as they parent a child with dup15q. I hope that you can find time to spend with the "Grace" in your life so that you can expand her horizon and make her laugh and, maybe even, look you in the eye.

I hope that you can experience the change that your "Grace's" love will bring to your life. Maybe you or someone in your family would like to serve on one of our committees or on the board in the future. We always need new ideas and new energy.

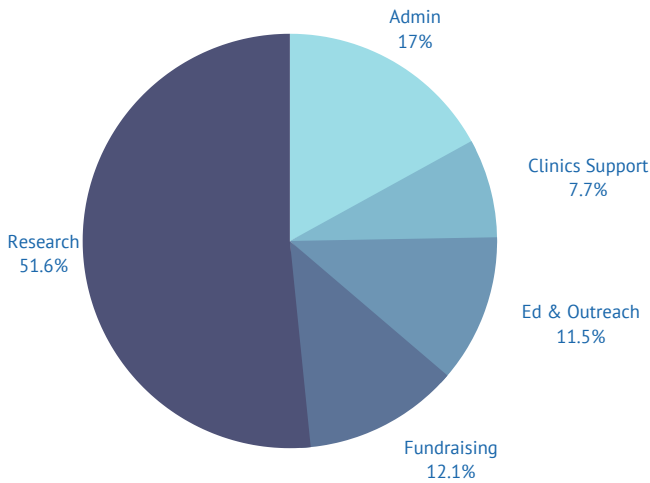
Thank you for the opportunity to serve on your board. Thank you for all your support for me and the board over those years. Thank you for supporting the Dup 15q Alliance in so many ways – your time, your talent, and your treasure. Only because of you could we have grown so much in the last ten years. I hope the Alliance can make a difference in your life in return, connecting you with other families and clinics, helping the transition from infancy to school and to adulthood, providing communication between doctors and clinics to better serve your Duper, and potentially working in conjunction with scientists and drug companies to provide dramatic and real help with your Dupers. We are all stronger when we work together.



# FINANCIAL STATEMENT

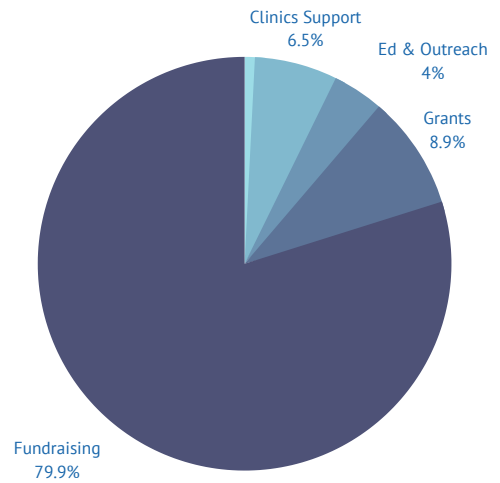
## 2018 Expenses

Total \$482,545



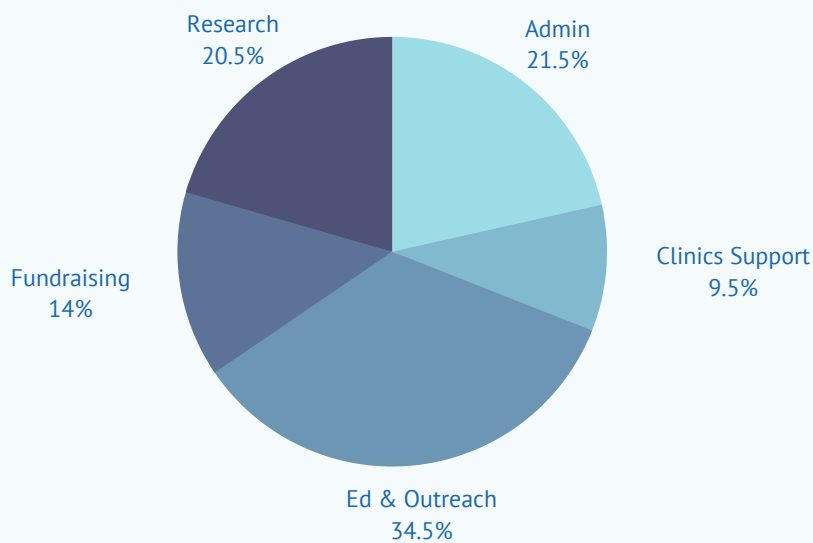
## 2018 Income by Percentage

Total \$502,160



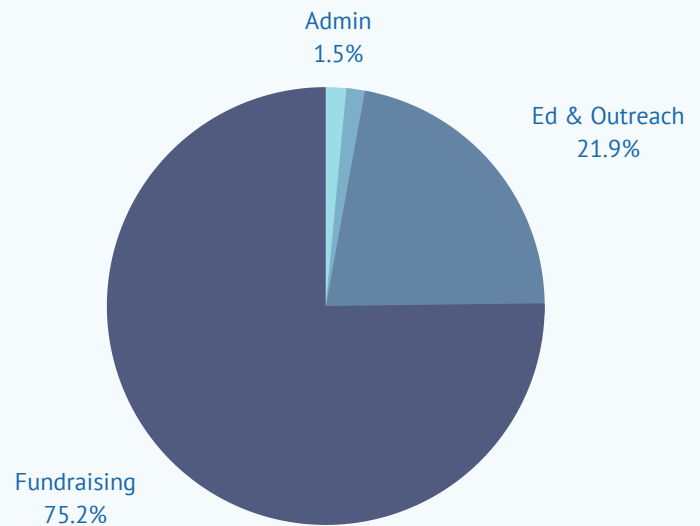
## 2019 Budgeted Expenses

Total \$632,371



## 2019 Budgeted Income

Total \$732,750



# OUR COMMUNITY

PROFESSIONALISM INTEGRITY  
COLLABORATION STEWARDSHIP

## PROFESSIONALISM

We are collegial and respectful in our professional relationships. We are dedicated to expanding our knowledge being innovative and understanding the perspectives of others. We honor and respect differences and diversity in all its forms. We strive to exhibit excellence in our work.

## INTEGRITY

We are accountable for our commitments and our actions. We are committed to ensuring the interests of the children and families we serve come first. We promote honesty and transparency in our relationships with each other and our collaborators.

## COLLABORATION

We work humbly, to identify and understand the urgencies and challenges facing our shared community; we know that they cannot be overcome alone. Whenever possible, we earnestly collaborate on the actions, programs, and initiatives we engage in. We want to go farther, so we go together.

## STEWARDSHIP

We are committed to being good listeners and to act in responsive service to the needs of the child neurology community. We are respectful stewards of the relationships and stories shared with us. We are empathetic, compassionate and positive.





# 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 constantly 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 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. We believe in supporting our community by bringing together families and patients affected by Dup15q Syndrome.



## 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!*

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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

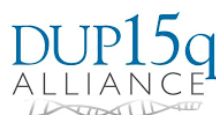
Shafali Spurling Jeste, MD: UCLA David Geffen School of Medicine  
Los Angeles, CA

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



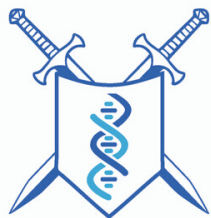
## REPRESENTATIVES

### International Reps

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  
Fedelma O'Farrell – Europe – Ireland  
Laura Piredda – Europe – Italy  
Antal de Waij – Europe – Netherlands  
Ragnhild Eikeland – Europe – Norway  
Jedrzej Sliwka – Europe-Poland  
Cecilia & Manuel Branco – Europe – Portugal  
Quino Renovell – Europe- Spain  
Nine Pecoraro – Europe -Switzerland  
Sarah Bergqvist – Europe-Sweden  
Derek & Tracy Boshard – South Africa  
Silvina & Luis Olivia – South America- Argentina  
Direcelei Pizzi Franca – South America-Brazil  
Kat Dunin – South America-Peru

### Regional Reps

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



# Thank you to our 2018 Supporters for Believing!

## **ACHIEVE Q-usader** **\$10,000+**

Ember Burke  
Adrienne Paradis  
Laura Polak  
Tessa Quinlan  
Shannon Rosovics  
Rachel Segars  
Marc and Lauren Weissberg

## **HOPE Q-usader** **\$5,000 - \$7,500**

Lindsey Caley  
Tina DeLorenzo  
Diane Gomez  
Kristina Hall-Whitesell  
Christine Hemingway  
Aiisha Sablan Ramiro

## **SUPER DUPER Q-usader** **\$2,500 - \$4,999**

Krissa Harris  
Naka King  
Scott and Molly Roberts  
Rob and Fabiana Roman

## **DUPER Q-usader** **\$1,000 - \$2,500**

Rae Casha  
Sarah Champman  
Shannon Davison  
Ivonne Ruiz Feterman  
Ryan Holmes  
Rob and Marian Kapp  
Jenn Kelly  
Stefanie Lebeilly  
Alan Lundgren  
Hallie Matzua  
Corrine Murphy  
Kristina Nelleson  
Hallie Matzua  
Samantha Polombaro  
Len Poore  
Heather Sheldon  
Laura Barteu Starkt  
Brandi Viter-Pitlik

## **BELIEVE Q-usader** **\$250 - \$500**

EmmyLou Allen  
Lacey Berger  
Tiffany Ciero  
Stephanie Claxton  
Laura Lee Cochrane Barlow  
Heather Smith Larsen

**ALWAYS BELIEVE!**

# YEAR IN REVIEW

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**45** Families organized in-person fundraisers

**60+** Social media fundraisers

**750+ US and 420+ International**

Alliance Members living with Dup15q

## CARE

We are excited to announce the addition of a family counselor who will be available at no charge to aide in healthy support and self care for duper caregivers.

## SUPPORT, EDUCATION, OUTREACH

We have begun to update the medical care guidelines by mobilizing the reciprocal communication from the existing clinics to address the ever-changing needs of those affected with dup15q syndrome.

## RESEARCH

We are extremely proud to partner with Ovid for our first drug trial of a new antiepileptic compound. We hope to provide more opportunities in the future.

## GROWTH

1,300+ members are living with Dup15q in the United States and 40 other countries. This figure includes both adults and children and reflects a 15% yearly increase over the last 3 years.

## ASF/DUP15q SCIENCE SYMPOSIUM

We co-hosted the largest science symposium to date with over 150 attendees. The most brilliant minds in Dup15q and Angelman syndromes collaborated for two days sharing unpublished data and knowledge.

## FELLOWSHIP GRANTS

We continue to support two fellowship research grants with \$25,000 each annually to further understand neurodevelopmental disorders.

<https://dup15q.org/research/grants-and-funding>



# FUTURE

## Program priorities from 2019

*At the point of diagnosis: Shortening diagnostic journey*

*At the point of navigating the community: Peer support*

*At the point of living with the diagnosis: Improvement of clinical care*

*At the point of adulthood: Transition of clinical care and living support*

*At the point of building awareness and understanding: Outreach and education*

*At the point of hoping for a better tomorrow: Clinical trials and research*

- ✔ We are on the forefront of driving research and awareness to make real progress in rare disease. Our own Mike Porath, Dup15q Alliance Board Member and Founder/CEO of The Mighty, is joining 14 others from Shire, Microsoft, and EURORDIS to form the Global Commission to accelerate time to diagnosis for children with rare diseases.
- ✔ We are piloting a program where families can upload their clinical EEGs and/or MRIs to keep on file. This service will serve as a central location where families can store information for future use, such as sending them to specialists, second opinions etc. The ultimate goal will be to look at EEGs over time and see if we can pinpoint early markers for seizure risk or brain function changes that are related to behavior.
- ✔ We are improving our clinic structure to increase positive family/patient experiences by empowering effective communication strategies and promoting positive relationships within the healthcare system.
- ✔ We are rolling out our “Bee Kind” program for families to use in their communities to educate and promote compassion in schools and among peers.
- ✔ We are working continuously with our partners and researchers to explore newborn screening possibilities for earlier detection and diagnosis.
- ✔ We are publishing updated information about what is currently understood of the characteristics of Dup15q syndrome.



# SUPPORT

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

## WAYS TO DONATE:

Donations can also be made by **check or money order**. Make check payable to “Dup15q Alliance” and send to:

Dup15q Alliance  
P.O. Box 1669  
Highland Park, IL 60035 USA

To make an **online** one-time or monthly credit card donation visit: [www.dup15q.org/donate](http://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  
P.O. Box 1669  
Highland Park, IL 60035  
Phone: 855-Dup-15qa (855-387-1572)  
<http://www.dup15q.org>