

# 2015 ANNUAL REPORT



Providing family support and promoting research and targeted treatments for chromosome 15q11.2-13.1 duplication syndrome.

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# From the Board Chair

Dup15q Alliance's mission is to provide family support and promote awareness, research and targeted treatments for chromosome 15q11.2-13.1 duplication syndrome.

Change is inevitable; growth is optional (John Maxwell). Change is in the air and seems to be the only thing we can count on for sure. The real question is how we adjust and grow when that occurs. People often compare the age of organizations to the age and development of a person. If that is true, Dup15q Alliance is quickly approaching our mid-twenties with the life and energy of those years, but also with the changes and challenges that come with that stage of life.

We are growing and represent around 1,000 families now. We are expanding our involvement in the science and genetics of dup15q syndrome as we grow our clinic relationships, fund study projects, and bring scientists, doctors, and families together at our biennial conferences or our annual science meetings. The organization, like a twenty-something is trying to manage new income levels, resources and growing donations with the new expenditures required to support all the needs associated with our mission.

We see change in our board make-up as we brought on three new members this fall in Tessa Quinlan, Elaine Lowell, and David Gifford who will all bring great passion and expertise to the organization. We said goodbye to Board Members, Karen Sales, Paul Karch, and Linda Meagher who gave so much of themselves, their time, talent, wisdom, and selves to all of us. We recognize that we had more applications and more qualified candidates for those openings than ever before and are so grateful to those who applied and whom we hope to engage in committee work and eventually board work as more positions open up.



We know there will be changes in the near future in our administrative team (How do you replace someone like Kadi Luchsinger?), we are going to the west coast for a conference for the first time, we are working with our Italian counterparts to help facilitate a science meeting this fall in Milan and with our Australian families to work through the process of setting up their country's version of a non-profit.

There is life and vitality and the excitement of a growing family, new opportunities, visions of what we can be that comes with that age. We have hopes and dreams of what we will yet become and a commitment to pursue that.

We aren't perfect. We make mistakes as we go, but we keep plugging on, trying to learn lessons from our errors and choosing to embrace the change and to grow. We thank all of you, our families, for supporting us in our Mission, for reminding us when we are getting off track, and for volunteering and participating in so many ways. We are all walking this together, maturing and growing together. Thank you for your hours and hours of time, for your wisdom and suggestions, and for your financial commitment to help us move steadily toward our thirties!

Sincerely,  
Tom Doyle



# Leadership

We welcomed three new Board members and one PAB member.



In 2015, three board members stepped down from the Board. We are grateful to Paul Karch, Linda Meagher, and Karen Sales, who gave many years of service to Dup15q Alliance.

We also welcomed three new board members – David Gifford, Elaine Lowell and Tessa Quinlan. David and Elaine have granddaughters with dup15q syndrome, and Tessa has a son who is affected. We thank them for volunteering their time and look forward to the new energy and insight that they will provide.

Dup15q Alliance’s Professional Advisory Board (PAB) provides the Alliance with medical and research expertise. This year we added one member to the PAB – Dimitrios Arkilo, MD of the Minnesota Epilepsy Group. Dr. Arkilo specializes in pediatric neurology and epilepsy and is also the director of the dup15q clinic in St. Paul, MN. He has seen over 30 children affected by dup15q syndrome.

## Board of Directors

### Officers:

- Tom Doyle (WA), Board Chair
- Elaine Lowell (WA), Secretary
- Kadi Luchsinger (NY), Executive Director

### Board Members:

- Donna Bennett (PA) – Co-Founder
- Guy Calvert (CA)
- Adrienne Campolmi (NC)
- David Gifford (PA)
- Fernando Gomez (NJ)
- Jane Kim (CA)
- Rylie McHam (OH)
- Mike Porath (CA)
- Tessa Quinlan (IL)



## Professional Advisory Board

- Dimitrios Arkilo, MD  
*Minnesota Epilepsy Group*
- Agatino Battaglia, MD, DPed, DNeurol  
*Calambrone, Pisa, Italy*
- Stormy Chamberlain, PhD  
*University of Connecticut*
- Edwin H. Cook, Jr., MD  
*University of Illinois at Chicago*
- Orrin Devinsky  
*NYU Langone Medical Center*
- Scott Dindot, PhD  
*Texas A&M University*
- Brenda Finucane, MS, LGC  
*Geisinger Health System*
- Shafali Spurling Jeste, MD  
*UCLA Center for Autism Research & Treatment*
- Janine LaSalle, PhD  
*UC Davis School of Medicine*
- Lawrence T. Reiter, PhD  
*University of Tennessee Health Science Center*
- N Carolyn Schanen, MD, PhD
- Sarah Spence, MD, PhD  
*Children’s Hospital Boston*
- Ron Thibert, DO, MsPH  
*Massachusetts General Hospital*

# +Membership

Dup15q Alliance serves members around the world. The Alliance is incorporated in the United States, but international families affected by dup15q syndrome also rely on the support and advocacy provided by the organization. The Alliance is able to provide a private online forum for members to communicate, regardless of their location. The organization also facilitates family matches, allowing families to connect with other members in their general geographic area.

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The chart below illustrates Dup15q Alliance’s affected family membership by international distribution. Ninety-eight percent of the membership served by Dup15q Alliance is in North America, Europe and Australia.

More than 70 percent of the Alliance’s membership is located within the United States. This image illustrates the membership distribution:

**East North Central:** Wisconsin, Michigan, Illinois, Indiana, and Ohio

**Atlantic:** Delaware, Maryland, Virginia, W. Virginia, N. Carolina, S. Carolina, Georgia, & Florida

**Northern Atlantic:** New York, Pennsylvania, and New Jersey

**New England:** Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, & Connecticut

**Pacific:** Alaska, Washington, Oregon, California, and Hawaii

**West North Central:** Missouri, North Dakota, Nebraska, Kansas, Minnesota & Iowa

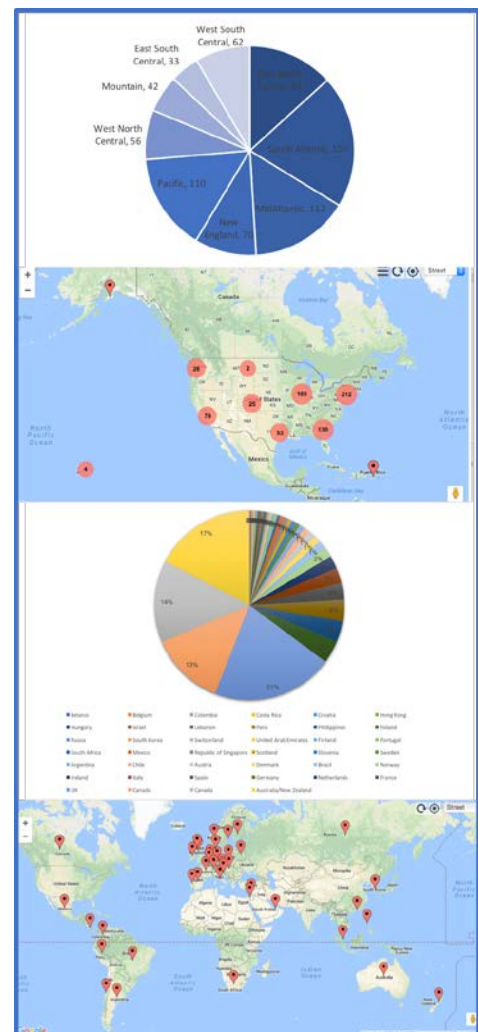
**Mountain:** Idaho, Montana, Wyoming, Nevada, Utah, Colorado, Arizona, & New Mexico

**East South Central:** Kentucky, Tennessee, Mississippi, and Alabama

**West South Central:** Texas, Oklahoma, Louisiana, and Arkansas

Outside of the United States, more than fifty-five percent of the remaining Alliance membership is located in Europe, primarily in Western Europe.

European organizations supporting dup15q syndrome are also a significant source of support for affected families. Dup15q Alliance collaborates with these international organizations to better serve all members of this community.





# Fundraisers



Our summer fundraiser coordinated with the Stronger Together Conference, by assembling a chain with words of hope from all of our generous supporters. Donations made to Dup15q Alliance before the conference began added a *Link of Love* to the chain. Donors could return their paper link or fill out a virtual link with their names, the names of their favorite person with dup15q syndrome, and/or well wishes. The *Links of Love* chain was displayed in Orlando during the conference. The chain, which raised more than \$17,000, had more than 200 links, and was admired by many at our family conference.



On September 13, 2015, we launched a new event, the Dup15q Alliance Believe Walk. Walks were held in Syracuse, NY; Seattle, WA; Appleton, WI; Cherry Hill, NJ; and Chicago, IL. In conjunction with the event, three states, Wisconsin, Illinois and Tennessee, declared September 13, 2015 to be Dup15q Awareness Day.

In total, more than 1,000 walkers raised over \$62,000, in weather that ranged from rainy in Seattle, to windy in Syracuse, to a beautiful fall day in Appleton. Thank you to everyone who worked to organize these new events, and to the walkers who raised money and awareness for Dup15q Alliance!



**\$15,000 in 15 days for  
DUP15q  
ALLIANCE**  
Together we can make a difference!

Each year, between Valentine's Day, February 14, and Rare Disease Day February 28, Dup15q Alliance sponsors a campaign to raise \$15,000 for support and research into dup15q syndrome. In February 2015 we held the XXth \$15,000 in 15 Days, and 2015 was our best year to date! Families raised money by conducting email campaigns, bake sales, organizing wear jeans to work days, selling BELIEVE bracelets and t-shirts, etc. This year, a generous dup15q family also generously agreed to match funds up to \$15,000. These fundraising efforts brought us to an amazing total of \$69,000!



Many friends and family members hosted events to benefit Dup15q Alliance this year. Without our tireless volunteers and member families, we would not be where we are today. From the Little Miss Sunshine Walk to the Sangria & Sandals party and many in between, supporters of Dup15q Alliance came together to celebrate their kids, raise awareness of dup15q syndrome and collect money for research and support. A heartfelt thanks to all who volunteered their time to organize and participate in these events!



Dup15q Alliance awards two new grants.

# New Fellowship Awards

For the first time, Dup15q Alliance invited applications for two new fellowship grants from graduate students, medical students, and postdoctoral fellows interested in pursuing careers in basic and clinical research relevant to dup15q syndrome. Priority went to projects addressing current Dup15q Alliance research priorities, including both clinical and bench science aspects of dup15q syndrome specific phenotypes, including autism and epilepsy, SUDEP and hypotonia.

We received ten high-quality proposals, but in the end, Kevin Hope and James Fink were named winners. Detailed information about their projects can be found in the *The Mirror* ([www.dup15q.org/newsletter/2015-vol-3-we-are-stronger-together](http://www.dup15q.org/newsletter/2015-vol-3-we-are-stronger-together)).

This award is particularly exciting because directly funding research empowers the Alliance to drive work into areas that are important to dup15q syndrome. The grant winners are at an influential stage in their careers, and these grants could spark long-

term commitments to dup15q syndrome research. Additionally, these grants allow mentors to invest in new dup15q syndrome projects, and may help generate results that can then be used to apply for large-scale funding from agencies such as the National Institutes of Health.

Kevin Hope is a neuroscience graduate student working with Lawrence T. Reiter, PhD at the University of Tennessee Health Science Center. His four years of funding will support his PhD thesis work, aiming to find out which genes in the duplication act together to result in the major clinical features of dup15q syndrome.

James Fink is a graduate student working with Eric Levine, PhD at the University of Connecticut Health Science Center in Farmington, CT. His three-year grant will focus on understanding what causes the increased risk of seizures in dup15q syndrome.



**Eighth  
International  
Dup15q  
Alliance  
Family  
Conference**



**News**



**Dup15q Alliance’s website wins a 2015 American Web Design Award!**

In 2015, GD USA selected our website, *www.dup15q.org*, for a national graphic design award. We owe a huge thank you to GlobalCloud for the beautiful design and to GD USA for the honor. This would not have been possible without donations to make the new website a reality, the families who have allowed us to share their beautiful photos and stories, and our scientific advisors who keep our information on the cutting edge.

**Dup15q syndrome featured in PBS documentary**

On April 23, a new documentary premiered on PBS. The documentary focused on innovation at Geisinger Health System in Lewisburg, PA, home to one of the dup15q clinics, and features a segment on treating those with dup15q syndrome at around the six-minute mark. The documentary can be seen here - *www.dup15q.org/news/dup15q-syndrome-featured-in-pbs-documentary*.

**Stronger Together**

Every two years, Dup15q Alliance hosts an international family conference. In addition to sessions on research, treatment and therapies for dup15q syndrome, we foster a sense of camaraderie and understanding that our member families often have trouble finding in their home communities.

In July 2015, Dup15q Alliance held the Stronger Together Conference in Orlando, Florida. Over 350 participants gathered for science-based sessions (genetics, the International Registry, clinic updates, GI issues and epilepsy), family-centered sessions (parenting, sibling issues, extended family session), school and employment sessions, and developmental issues (potty training, communication, and many more. A full list of sessions and the binder material is available here <https://www.dup15q.org/events/family-conferences/stronger-together-2015/>



# Finances

## 2015 Income Statement

### Income

Conference	\$ 52,690.45
Fundraising	245,520.51
Grants	3,500.00
Interest	310.17
Memorials	2,685.00
Store	7247.21
<b>Total</b>	<b>\$ 312,133.34</b>

### Expenses

Independent Contractors	\$ 24,608.98
Administration	24,698.25
Bank Charge	120.06
Conference	102,682.59
Education and Outreach	2,257.23
Fundraising	6081.25
General Administration	9,262.88
International	2,552.86
Legal/Professional Fees	2,724.04
<i>The Mirror</i>	2,446.84
PR and Marketing	3,403.12
Priority Projects	40,074.00
Registry	15,502.85
Research Grants	50,000.00
Research Roundtable	8,126.12
Store	9,276.72
Website	2837.46
<b>Total</b>	<b>\$ 306,653.25</b>

Net Income \$ 5,480.09

## Balance Sheet

As of December 31, 2015

### Assets

Checking/Savings Accounts	\$ 138,112.67
Money Market Account	307,809.46
True Family Restricted	1,551.08
<b>Total Assets</b>	<b>\$ 447,473.21</b>

### Liabilities and Equity

Credit Card—IDEAS	48.82
Opening Balance Equity	\$ 441,993.12
Net Income/Loss	5,489.09
<b>Total Liabilities and Equity</b>	<b>\$ 447,473.21</b>

## 2016 Budget

### Estimated Income

Conference	\$ 0
Fundraising	300,000
Grants	15,000.00
Interest	300
Memorials	500
Store	8,000
<b>Total</b>	<b>\$ 323,800</b>

### Expenses

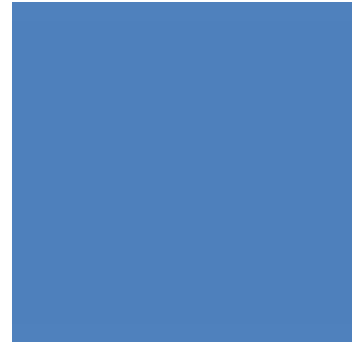
Independent Contractors	\$ 80,000
Administration	30,000
Bank Charge	100.00
Clinics database	10,000
Clinic Support	25,000
Education and Outreach	10,000
Fundraising	25,000
General Administration	12,000
International	15,000
Legal/Professional Fees	2,500
<i>The Mirror</i>	3,000
PR and Marketing	10,000
Priority Projects	25,000
Registry	13,000
Research Grants	50,000.00
Research Roundtable	15,000
Store	6,000
Website	10,000
<b>Total</b>	<b>\$ 342,600</b>

Net Income \$ -18,800





## From the Finance Officer



Thanks to all who have supported Dup15q Alliance in so many ways. We are able to operate because of the love, dedication, and commitment of so many of you. We rely heavily on you sharing your time, talent, and treasure with us and, through us, with more than 1,000 individuals and families who live each day with dup15q syndrome. It can only be done through your support.

We operate on a two-year budget cycle because one year has a family conference and the next doesn't. In 2014, with no family conference we raised nearly \$335K and spent just over \$251K for a net profit of \$83K. In 2015, the conference expenses affect us both with a slight reduction of donations as families are using their resources to attend and with higher costs related to the conference. So this past year, we raised \$312K and spent \$306K. We were able to keep the budget in the black, however, with a \$5,500 profit margin. In addition, we were able to fund two research grants at \$25K each and hope to add more to that in the future. We also spent \$40K on what we call, Priority Projects. Last year that included funding a research database (or registry) for our dup15q clinics. We are committed to good stewardship of the gifts and resources of our organization.

Last year, we received many donations from our families and from outside sources. We know that the economics of the times are difficult for many. Having said that, we can tell you that 13% of our immediate dup15q families donated last year to help fund our

website, research, support, conference, and other initiatives. We also know that many of your siblings, grandparents, uncles, aunts, and friends contribute in addition to that number. We hope to increase our fundraising so that we can support our families even more than we are able to today. If you are one of those 13%, thank you so much for making us part of your annual gifting. If you aren't one of the 13%, would you consider even a small donation? We would like to see that number of donors double or triple this year. It helps us with grant writing and major gifts if we can point to the support of our own families. So consider a gift, even a small one, to help us raise that number. Again, we thank you!

In this document, you will find some financial information about Dup15q Alliance. Should you ever have questions about our financial situation or budgeting process, please feel free to contact me and I will be happy to try to answer your questions. I am moving from the Finance position to the Board Chair. We are grateful to Adrienne Felterman who has graciously volunteered to assist us with the treasurer responsibilities.

Thank you one more time for all you do to help us to accomplish our Mission: Dup15q Alliance provides family support and promotes awareness, research and targeted treatments for chromosome 15q11.2-13.1 duplication syndrome.

Tom Doyle

# Contact Information

Dup15q Alliance

P.O. Box 674, Fayetteville, NY 13066 USA

855-dup-15qa (855-387-1572)

info@dup15q.org

# Social Media

Website: [www.dup15q.org](http://www.dup15q.org)

Facebook: [www.facebook.com/pages/Dup15qAlliance/245152512165738](https://www.facebook.com/pages/Dup15qAlliance/245152512165738)

Twitter: [www.twitter.com/dup15q](https://www.twitter.com/dup15q)

BigTent: [www.bigtent.com/groups/dup15q](https://www.bigtent.com/groups/dup15q)



# Communication

Dup15q Alliance uses various methods of communication to reach both internal and external interests and members.

Member-focused information is delivered via the quarterly newsletter, *The Mirror*, as well as through periodic emails and mailings. The newsletter is available on Dup15q Alliance's website, is emailed to members and is available by mail, if requested.

Dup15q Alliance also provides an online community to members on a social network platform, BigTent. This is a community allowing Alliance members to discuss issues, plan events, share stories, and provide support to others.

Dup15q Alliance provides a website for both internal and external partners. The website can be found at [www.dup15q.org](http://www.dup15q.org). Other online social networks include Twitter and both a parent support group and public page on Facebook. Dup15q Alliance is able to share organizational information and interests with individuals and other organizations using these social networks. The use of these social media platforms has increased awareness of the Alliance's mission as well as significantly assisting in fundraising efforts.

