


DUP15q ALLIANCE



Providing family support and promoting awareness, research and targeted treatments for chromosome 15q duplication syndrome.

Leadership

Learn about the Board of Directors and Scientific Advisory Board.

Page 2

Membership

View the distribution of members throughout this global alliance.

Page 3

International Conference

Biennial conference brought dup15q families together in Philadelphia.

Page 4

Events

2011 events that support Dup15q Alliance's mission, raising funds and awareness.

Page 5

Financial Status

Dup15q Alliance continues to prosper thanks to its many supporters.

Page 7

Communications

Find out how you can learn more about Dup15q Alliance.

Page 8

Message from the Board Chair

Len Poore

Our organization was initially formed in 1994 by Donna Bennett and Brenda Finucane by bringing together thirteen families, each raising a child with the chromosome 15q duplication. In 2004 the group incorporated and became a 501(c)(3) non-profit organization, and with that IDEAS (IsoDidentric 15 Exchange, Advocacy, and Support) was formed.

As we look back to where it started in 1994 and our incorporation in 2004, no one could have imagined how significant 2011 would be for the organization. Our 6th international conference returned to the site of the first conference, Philadelphia. During the conference we made two major announcements, our name change and the launch of the medical registry. Our new name, Dup15q

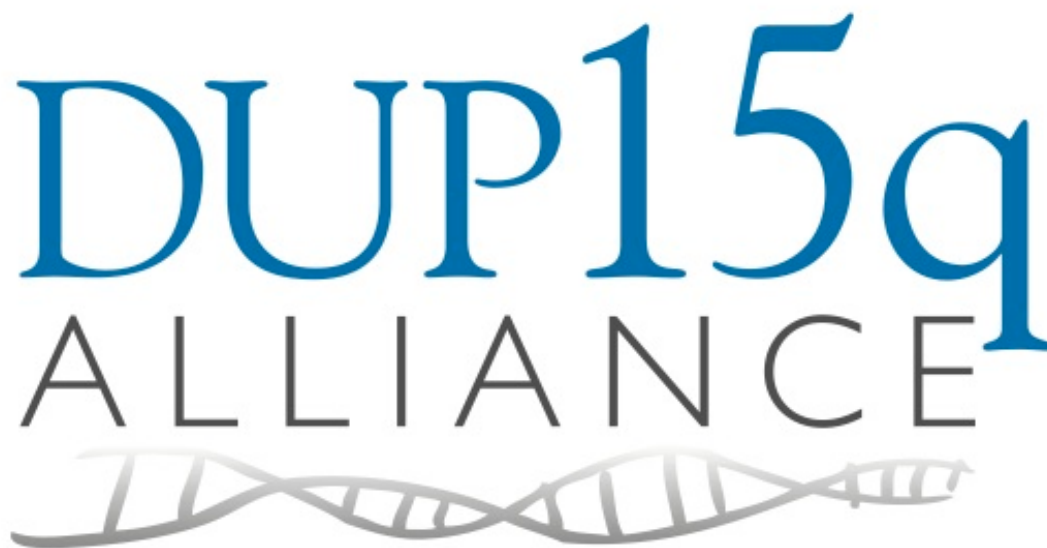
Alliance, is more recognizable by the medical and research community, as well as to our families. Our medical registry will impact the research community of dup15q syndrome for years to come. A record 332 people attended the conference where they sat in on many educational sessions and had the opportunity to meet other families, an experience they will remember for a lifetime. Those memories were in large part the result of our Conference Chair, Cindy Johnson. On behalf of the Dup15q Alliance we extend our special thanks to Cindy.

Another significant accomplishment of 2011 is the first Dup15q Clinic, which opened at Massachusetts General Hospital in Boston. The clinic is being facilitated by Dr. Ronald Thibert, and we are thankful for his support and efforts to start this clinic. Dr. Thibert also hosted a collaboration meeting with physicians and researchers from Mass General Hospital, Boston Children's Hospital and Beth Israel Deaconess Medical Center,

with the intent to collaborate relating to the multidisciplinary approach at the clinic, as well as current and future research.

Financially our organization is strong. We exceeded our fundraising goal in 2011, while continuing to closely manage our expenses. We thank the many families who held fundraising events and also to those who donate, as it is only with your support that our organization continues to grow. Details on our 2011 financial results as well as our 2012 budget are included within this report.

I want to thank the board of directors and our medical advisory board, as their efforts allowed us to accomplish more in 2011 than any previous year. I also want to thank the many volunteers who serve on our various committees, including research, fundraising and conference. Finally, I want to thank our Executive Director, Kadi Luchsinger, as her passion and drive continually challenge us to meet and exceed our goals.



Board of Directors

At the June board meeting held at the 2011 conference in Philadelphia, the following board members were re-elected for two-year terms: Kadi Luchsinger as executive director, Rachel Doucette as VP of communications, Karen Sales as corporate secretary, and Linda Meagher as a board member. Dup15q Alliance was very fortunate to have a number of people submit their names and applications as candidates for the two open board positions.

At the July board meeting, Paul Karch of Wisconsin and Guy Calvert of California each were elected to two-year terms on the board. We look forward to Paul and Guy adding their energy to the board. We very much appreciate the commitment that board members and their families make of their time and efforts in supporting Dup15q Alliance.

Officers:

Board Chair - Len Poore (MA)
 Executive Director - Kadi Luchsinger (NY)
 VP of Communication - Rachel Doucette (MA)
 VP of Finance - Tom Doyle (WA)
 Corporate Secretary - Karen Sales (IA)

Board Members:

Donna Bennett (PA) - Co-Founder
 Guy Calvert (CA)
 Paul Karch (WI)
 Rylie McHam (OH)
 Linda Meagher (TX)
 Mike Porath (CA)
 Patti Rubel (VA)

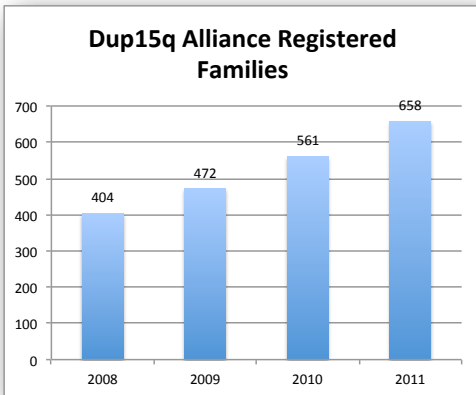
Scientific Advisors:

Agatino Battaglia, MD, DPed, DNeurol
 Calambrone, Pisa, Italy
 Edwin H. Cook, Jr., MD
 University of Illinois at Chicago
 Brenda Finucane, MS, CGC
 Elwyn Training and Research Institute
 Janine LaSalle, PhD
 UC Davis School of Medicine
 Lawrence T. Reiter, PhD
 University of Tennessee Health Science Center
 N Carolyn Schanen, MD, PhD
 Nemours Biomedical Research
 Sarah Spence, MD, PhD
 Children's Hospital Boston
 Ron Thibert, DO, MsPH
 Massachusetts General Hospital

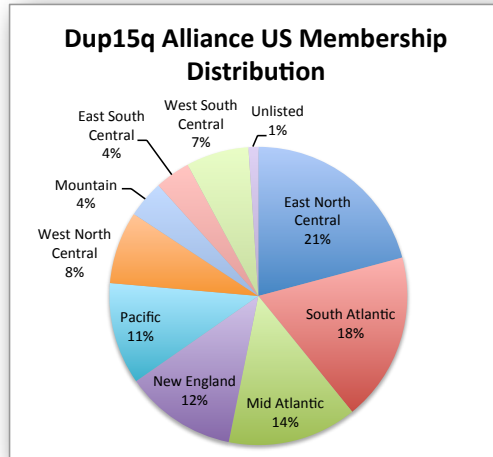
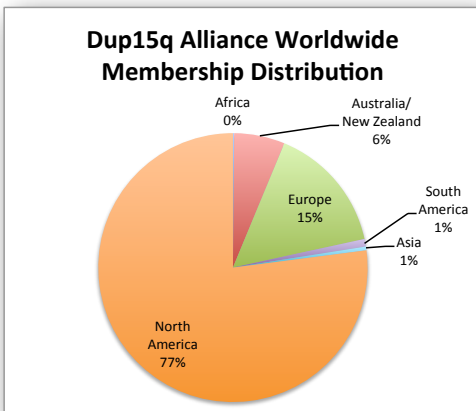
Dup15q Alliance Membership

Dup15q Alliance serves members around the world. While the organization is incorporated in the United States, international families affected by chromosome 15q duplication syndrome 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.

As of December 31, 2011, Dup15q Alliance had 658 registered families, continuing its steep growth trend with a 17% increase in members during 2011.



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



More than seventy percent of the membership served by Dup15q Alliance is located within the United States. The chart above illustrates the Alliance's membership distribution by US Geographical Division. The US divisions are defined as:

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

South Atlantic: Delaware, Maryland, District of Columbia, Virginia, West Virginia, North Carolina, South Carolina, Georgia and Florida

MidAtlantic: New York, Pennsylvania and New Jersey

New England: Maine, New Hampshire, Vermont, Massachusetts, Rhode Island and Connecticut

Pacific: Alaska, Washington, Oregon, California and Hawaii

West North Central: Missouri, North Dakota, South Dakota, Nebraska, Kansas, Minnesota and Iowa

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

East South Central: Kentucky, Tennessee, Mississippi and Alabama

West South Central: Texas, Oklahoma, Louisiana and Arkansas

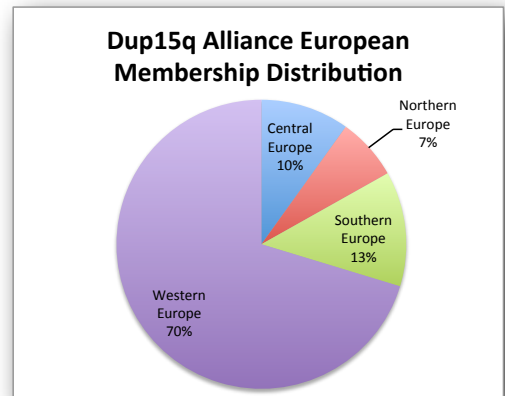
Outside of the United States, more than half of the remaining Alliance membership is located in Europe, primarily in Western Europe. The chart below illustrates the Dup15q Alliance's membership distribution by European Geographical Division. The European divisions include:

Central Europe: Germany, Poland and Austria

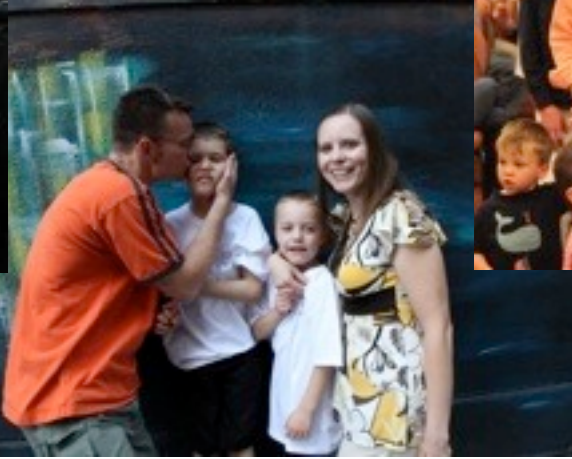
Northern Europe: Denmark, Norway and Sweden

Southern Europe: Spain, Portugal and Italy

Western Europe: Great Britain, Ireland, France, Belgium and Netherlands



European organizations supporting chromosome 15q duplication syndrome are also a significant support to affected families. Dup15q Alliance collaborates with these international organizations to better serve all members of this community.



Sixth International Conference on IsoDicentric 15 and Related Disorders

June 23-25, 2011 in Philadelphia, Pennsylvania.

Photo credit to Rick Guidotti, www.positiveexposure.com

In June 2011, the Sixth International Conference on IsoDicentric 15 and Related Disorders was held in Philadelphia. It was attended by 332 people, the highest number yet for a dup15q conference.

In addition to research updates, small and large group sessions, and workshops, attendees made new friends and caught up with old ones, networking to make the weekend great and this organization strong. This conference was a special occasion for attendees who connected in person with their dup15q family—many for the very first time. People gave generously at the silent auction and raffle, raising over \$10,000 in just one evening.

Those three days in Philadelphia were particularly momentous because of the important developments unveiled: a new name that reflects this organization's focus, a new multidisciplinary clinic dedicated especially to dup15q, and a

new registry that will help us all understand more about the syndrome.

The United We Stand Conference was a success thanks to the dedication and two years of hard work from the Conference Committee, led by Cindy Johnson. The committee's tireless efforts resulted in a conference that educated, entertained, and joined us all in the common causes of learning about dup15q syndrome, supporting our loved ones, and building community.

We are now looking ahead to the Seventh International Conference on Chromosome 15q Duplication Syndrome which will be held in Bloomington, Minnesota on July 25–27, 2013.

Not only will there be lots of valuable information, there also will be plenty to keep you busy outside the conference! Minnesota Wildlife Refuge is across the

street, the Mall of America (with Nickelodeon Universe and Minnesota Sealife Aquarium) is a shuttle ride away, and several zoos are in the area.



Dup15q Alliance Events

Dup15q Alliance events bring together families, raise funds and increase awareness of Chromosome 15q Duplication Syndrome.

Regional Gatherings

Every year Dup15q regional gatherings are held across the country. In 2011, regional gatherings occurred in the Northwest, California, Midwest and Mid-Atlantic regions. All those who participated appeared to have a wonderful time, connecting with other Dup15q families and seeing old and new friends.

The Northwest gathering was held in Bellevue, Washington and the Midwest gathering occurred in Minneapolis. Both of these gatherings were held over Labor Day weekend. The Washington gathering was held at a swim club and was hosted by the Lowell family. Families enjoyed swimming, various treats and great conversation.

The Midwest gathering is an annual event with a different host and location each year. The 2011 Minneapolis gathering included a trip to the Minnehaha Park, the Minneapolis Zoo, the Mall of America and swimming. The Mid Atlantic gathering occurred in August, and took place at a restaurant in New Jersey. The California gathering was held at the Porath's home in La Crescenta. Families enjoyed sharing experiences and meeting new friends while the kids enjoyed a variety of activities.

Regional gatherings are usually informal, family-friendly events, and are a great way for people to socialize and share their experiences with other Dup15q families who truly understand and "get it". Regional gatherings can be simple to plan, and are really fun! Should you be interested in hosting a regional gathering in 2012, please contact your regional representative.

GQ Fundraiser

For the second year in a row, Tessa and Mike Quinlan of Mokena, Illinois, along with the rest of their family, have organized the GQ Fundraiser, in honor of their 7 year-old son, Gavin, dup15q.

On May 8, 2010 they raised \$6,000 for Dup15q Alliance (then called IDEAS) and in year two (October 1, 2011) they increased their fundraising to \$12,000. There are plans in the works for the third annual event on October 6, 2012.

The event is a three-hour evening fundraiser with door prizes, raffles, and silent auctions. Food, entertainment and drinks are provided for a flat fee of \$30. Of that, \$10 goes to Dup15q Alliance. Each person who registers receives a copy of the Dup15q

Alliance brochure to educate them on the syndrome and our organization.

In year one a band played as entertainment, but in year two the Quinlan Family decided to cater the event to Gavin's likes. Gavin became a lover of Elvis thanks to his bus driver, so they hired an Elvis impersonator for the event! Thanks to Tessa's family there was also a surprise visit from the Chicago White Sox mascot, SouthPaw, a favorite of Gavin's.

As Tessa writes, "The evening goes by fast, but it is worth every minute of hard work. My husband and I enjoy putting on such an event and giving back to a community that supports us without any question."



More Dup15q Alliance Events

Pasadena Half-Marathon

In May 2011, Mike and Sarah Porath held a fundraiser for Dup15q Alliance. They ran the Pasadena Half-Marathon and raised money through social networking, direct email and a personal website. It was their first organized fundraiser, so they weren't exactly sure how it would go. They set a goal of \$5,000 and ended up raising almost \$18,000!



The Poraths believe there were two main factors to their success. First, the sheer volume of people they reached out to, and second the fact that they were very specific about where the money raised was going. They described the genetic registry, explaining it was a new tool for the Alliance, and how valuable it would be for the group, and for them personally.

They set up a website through First Giving, allowing them to upload their own pictures, video and text. By adding personal email addresses from our own contact lists, the website helped to keep track of who they had emailed, and if and how much they donated. The website also generated a personal thank you email any time anyone donated. The Poraths also took it a step further and wrote personal notes to everyone who donated. First Giving also provided a tax receipt for all donors. Facebook and direct emails were also very effective.

They posted their progress frequently and asked friends to share with others.

The Poraths emailed people directly, as well, giving them the link to First Giving.

They hope to make this an annual fundraiser and expand it to get more runners involved, though they may choose a different event. "We were blown away by the support we received and look forward to doing it again," Sarah Porath explains.

KayJay 5K

The Ebensperger family held their first annual "KayJay 5K" in Wheeler, Wisconsin on September 24, 2011. It is a 5 mile run/1 mile walk with all of the proceeds going directly to Dup15q Alliance. The run was named after the Ebensperger's 10 year old son, Kayden Jayce who has dup15q. They



not only wanted to raise awareness about Kayden's diagnosis, but also wanted to thank the Dup15q Alliance for helping to offset the cost of attending conferences in years past.

The Ebenspergers feel every penny raised can help toward research, advocacy, and support so they try to help in any way they can. Considering they live in a village of 300 people, the

first year KayJay 5K was quite successful, raising a total of \$6,444! About 90 participants, including 10 dup15q families, came out to support the cause with countless others volunteering their time.

Besides having the run and walk, there was a large raffle, bake sale, bounce houses, games, and barrel train rides for the kids, as well as refreshments and door prizes for participants. There were a few families that raised money through online donations prior to the event which was very helpful in achieving their fundraising goal.

"It was so great to bring an event like ours to this tiny community while at the same time supporting an organization so near and dear to our hearts," writes Teana Ebensperger. "We feel truly blessed to have such

wonderful friends and family showing so much love for Kayden and his friends by supporting this event and such a wonderful organization like Dup15q Alliance."

They have already started getting calls about when the next one will be - September 22, 2012. They are hoping to surpass their total from last year with an even bigger, better event.

Financial Status

Tom Doyle

2011 was a challenging financial year for the Dup15q Alliance as it was both a conference year and a year that saw the initiation of our Registry. Every other year, our budget swells with the expenses and income related to our international conference. Putting on this biennial conference takes a lot of resources - both financial and volunteer commitment. In order to make the conference affordable, the board kept the registration fees at the lowest level in some time. They were able to accomplish this because of the

generous support of our families and friends as well as some corporate support and family fundraisers. As a result, attendance was at an all-time high in Philadelphia.

The next challenge to our fiscal budget came in the form of the Registry, a critical component in helping research related to dup15q. The initial cost of the Registry was \$37,000 and was not in our original budget. The board had to move resources, cut spending in other areas, and increase fundraising to cover our budget. The overall result was that our budget demonstrates that we spent more than we brought in last year, but less than

expected when we added the cost of the Registry. We are fortunate to have funds to be able to cover these important line items in our budget.

As we budgeted for 2012, a non-conference year, we took care to make sure that our budget is once again balanced so that we can continue the process of stabilizing and improving the financial status of Dup15q Alliance. We are very grateful to all our families, friends, and supporters for making it possible for us to pursue our mission with financial stability. Thanks for your support.

2 0 1 1 I N C O M E S T A T E M E N T

Income

Conference	\$ 40,146.90
Fundraising	107,011.38
Interest	731.34
Store	1,704.52
Total	\$ 149,594.14

Expenses

Independent Contractors	\$ 27,400.00
Administration	2,185.68
Conference	67,660.32
Education and Outreach	467.70
Fundraising	4,095.92
General Administration	5,784.44
Legal/Professional Fees	692.14
<i>The Mirror</i>	4,749.71
PR and Marketing	5,339.52
Registry	36,725.00
Research Grants	-
Research Roundtable	6,916.59
Store	624.61
Supplies/Computers	2,624.84
Website	449.30
Total	\$ 165,715.77

B A L A N C E S H E E T A S O F D E C E M B E R 3 1 , 2 0 1 1

Assets

Checking/Savings Accounts	\$ 25,494.90
Money Market Account	251,424.54
True Family Restricted	10,799.45
Total Assets	\$ 287,718.89

Liabilities and Equity

Opening Balance Equity	\$ 303,840.52
Net Income/Loss	(16,121.63)
Total Liabilities and Equity	\$ 287,718.89

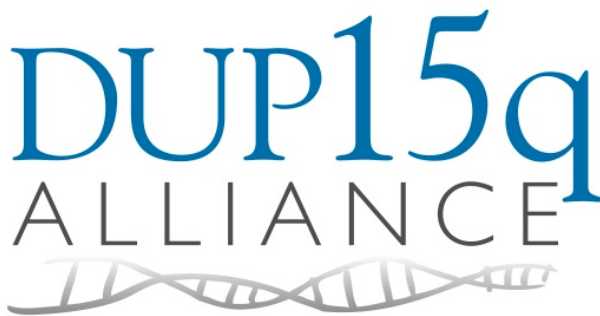
2 0 1 2
B U D G E T

Income

Fundraising	\$ 120,300.00
Grants/Memorials	2,500.00
Interest	600.00
Store	2,700.00
Total	\$ 126,100.00

Expenses

Independent Contractors	\$ 28,800.00
Administration	2,200.00
Education and Outreach	3,000.00
Fundraising	20,000.00
General Administration	5,000.00
<i>The Mirror</i>	3,800.00
PR and Marketing	10,300.00
Registry	36,000.00
Research Grants	3,000.00
Research Roundtable	10,000.00
Store	2,500.00
Website	1,500.00
Total	\$ 126,100.00



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*. This publication is available on the Dup15q Alliance 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. Other online social networks include Facebook and Twitter. 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 has increased awareness of the Alliance’s mission as well as significantly assisting in fundraising efforts.

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
- Facebook:** www.facebook.com/pages/IDEAS/305990303151
- Twitter:** www.twitter.com/IDEASdup15q
- BigTent:** www.bigtent.com/groups/dup15q