

# IDEAS

## IsoDicentric 15 Exchange, Advocacy & Support

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

<b>Leadership</b> <i>Announcing the 2010-2011 IDEAS Board of Directors and Scientific Advisory Board.</i> <b>Page 2</b>	<b>Membership</b> <i>The membership served by IDEAS is located throughout the world. IDEAS illustrates the distribution of this global membership network.</i> <b>Page 3</b>	<b>Scientific Meeting</b> <i>Part of the IDEAS mission is to convene a scientific meeting to bring scientists together to talk about their interests in dup15q and to promote research collaborations.</i> <b>Page 4</b>	<b>Events</b> <i>Several events and fundraisers were held in 2010 supporting the mission of IDEAS. They included a 5K/15K Run, a Golf Tournament, an Italian Conference, and several Regional Gatherings.</i> <b>Page 5</b>	<b>Financial Status</b> <i>IDEAS had a great fiscal year in 2010 thanks to the outstanding support of its' families, external donations, fundraising events and the direction of the board.</i> <b>Page 6</b>	<b>Communications</b> <i>IDEAS communicates both internally and externally using the MIRROR newsletter, a website, BigTent online community for members, Facebook and Twitter.</i> <b>Page 6</b>
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## Message from the Board Chair

Len Poore

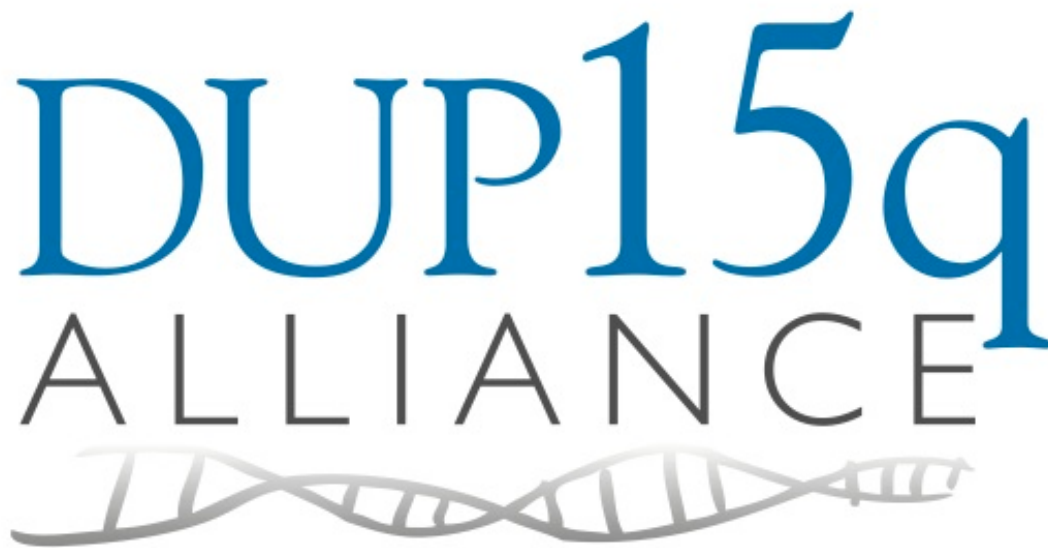
2010 was a year of change and achievement for IDEAS. We restructured the IDEAS board to provide board members greater involvement in multiple areas and also strengthened the board with the appointment of a Vice President of Communications and a Vice President of Finance. In June 2010 we established our 2010-2013 Strategic Plans and published those on our website for all to view. We completed several goals on that plan in 2010, several are currently in process and a few are just in the planning phase. This plan is a living document to be updated annually as the priorities of our organization and members change over time.

In 2010 we are happy that 90 families found and registered with IDEAS and join our existing members in making strides in making a better tomorrow for those with a diagnosis of dup15q. While the economy continued to struggle to recover in 2010 our families continued to organize fund raising events and make donations which led us to exceed our fundraising goals. At the same time the board worked diligently and closely managed how that money was spent. Overall our financial position improved in 2010. Major planning happened throughout 2010 on our June 2011 conference. I appreciate the efforts of all who have made a contribution and I believe this will be our most successful conference to date.

Looking toward the future, we will continue to focus on our strategic goals,

work to make IDEAS better known in the medical community, and to support our medical advisors in their research and developments. Most importantly we will continue to support new families looking for information when they receive their child's diagnosis and existing families looking for additional knowledge to provide the brightest future for their child.

On behalf of IDEAS I want to thank our Executive Director Kadi Luchsinger, Vice President of Communications Rachel Doucette, Vice President of Finance Tom Doyle, and the board members for their time in leading IDEAS in 2010 and for shaping IDEAS for a great future. We continue true to our mission statement; "IDEAS provides family support and promotes awareness, research and targeted treatments for chromosome 15q duplication syndrome".



## Board of Directors

The installation of the 2010-2011 IDEAS Board of Directors occurred in June 2010. After serving IDEAS since 1999, Nicole Cleary moved on from her board position as Board Chair. Nicole provided valuable leadership at key points in the development of IDEAS, including its incorporation. Paula Davis and Frank Kobuszewski also completed their service to the IDEAS Board of Directors. All three board members served the organization with distinguished dedication.

Dr. Ron Thibert from Massachusetts General Hospital's Pediatric Epilepsy Program and Dr. Sarah Spence from Children's Hospital Boston's Department of Neurology were elected members of the IDEAS Scientific Advisory Board by the Board of Directors.

IDEAS also introduced an updated organizational structure which included the addition of the position of Vice President of Communication.

Looking ahead, the Board of Directors has approved changing the organization name to Dup15q Alliance with the above logo. This decision was made to encompass all members served by this organization.

### 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  
Cindy Johnson (NJ)  
Lisa Lightner (PA)  
Rylie McHam (OH)  
Linda Meagher (TX)  
Mike Porath (CA)  
Patti Rubel (VA)

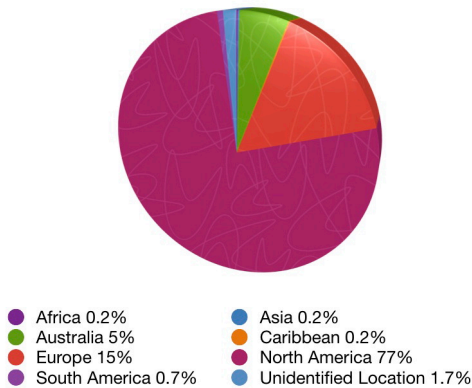
### Scientific Advisors:

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

## IDEAS Membership

IDEAS 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. IDEAS 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.

IDEAS dup15q Members International Distribution



The chart above illustrates the IDEAS immediate family membership by international distribution. The majority of the membership served by IDEAS is in North America, Europe and Australia.

The majority of the membership served by IDEAS is located within the United States. The chart below illustrates the IDEAS 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

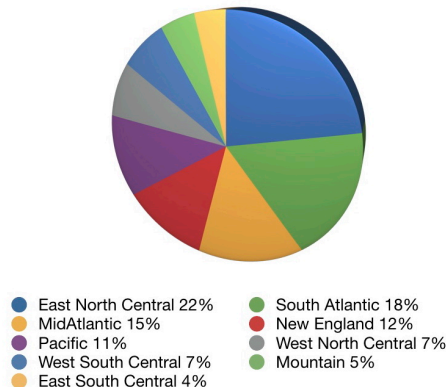
**Pacific:** Alaska, Washington, Oregon, California and Hawaii

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

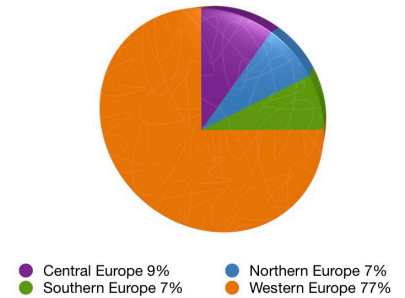
**Mountain:** Idaho, Montana, Wyoming, Nevada, Utah, Colorado, Arizona and New Mexico

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

IDEAS dup15q Members by US Geographical Division



IDEAS dup15q Members by European Geographical Division



Outside of the United States, a large portion of the remaining IDEAS membership is located in Europe, primarily in Western Europe. The chart above illustrates the IDEAS 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 and Netherlands

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





## IDEAS 2010 Scientific Meeting

*May 18, 2010 in Philadelphia, Pennsylvania.*

*Pictured Above: 2nd row left to right: Sarah Spence, Shin-ichi Horike, Jerzy Wegiel, Jane Pickett, Lawrence Reiter, James Sutcliffe, Edwin Cook, Randy Carpenter*

*1st row left to right: Janine LaSalle, Carolyn Schanen, Brenda Finucane, Nora Urracam, Julie Cleary*

*Pictured Below: 2nd row left to right: Sanjeev Kothare, Karen Sales, Daniel Lightfoot, Jane True, Rachel Doucette*

*1st row left to right: Paula Davis, Candace Tietsworth, Cindy Johnson, Carolyn Komich-Hare, Kadi Luchsinger*

As part of the IDEAS mission, a scientific meeting is convened to bring scientists together to talk about their interests in dup15q and to promote research collaborations. The 2010 meeting was the largest scientific meeting convened by IDEAS to date.

The 2010 IDEAS Scientific Meeting brought together top researchers in the area of chromosome 15q duplication syndrome. The agenda of the meeting was as follows:

### **Overview of dup15q syndrome**

Carolyn Schanen, MD, PhD

### **Mortality and dup15q**

Edwin Cook, Jr., MD

### **Overview of Neuropath Results**

Jerzy Wegiel, PhD

### **Epigenetic Alterations in idic15 Brain Samples**

Janine LaSalle, PhD

### **Homologous Pairing of Chromosome 15q11-13 is Associated with Significant Disruption of Gene Expression in Human Maternal Chromosome 15 Microcell Transferred Neurons**

Shin-ichi Horike, PhD

### **Breathing Abnormalities in dup15q**

Sanjeev Kothare, MD

### **Seizures in dup15q**

Agotino Battaglia, MD, DPed, DNeuro

### **Interstitial dup15q and Autism**

Lawrence Reiter, PhD

### **GABR3 Mutation and Autism**

James Sutcliffe, PhD

For a more detailed overview of the 2010 IDEAS Scientific Meeting please read the 2010 Spring/Summer MIRROR newsletter which can be found on the IDEAS website ([www.dup15q.org](http://www.dup15q.org))

The next IDEAS Scientific Meeting will be held on June 22, 2011 in Philadelphia, Pennsylvania.





## IDEAS Events

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

### Golf Tournament



On August 6, 2010 the 1st Annual Illinois Golf Outing at Poplar Creek Country Club in Hoffman Estates, Illinois was held to benefit IDEAS. The day brought together almost 100 golfers who participated in a Golf Scramble. The day was followed with a social event including dinner and a Silent Auction and Raffle.

This event was lead by Ember Burke and Shannon Rozovics and raised \$14,371. The Miller, Boyd, Horath, Kross, Burke, Rozovics, and Quinlan families as well as Kadi Luchsinger and Paul Karch attended the event.

### Vermont Run



On September 19, 2010 the 5th Annual Idic 15 5K/15K Run was held in Killington, Vermont to benefit IDEAS.

This event, chaired by Sarah Rasmussen, an IDEAS family member, was taken to a new level in 2010 by adding a 15K race to the existing 5K course.

This race raised \$16,634 to benefit IDEAS.

Eight IDEAS families including the Bopp, Davis, Doucette, Luchsinger, Poore, Rasmussen, Rivard, and True families participated in this event.

### Italian Conference

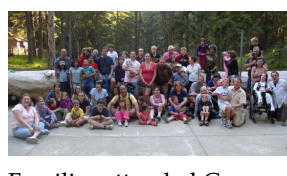


An Idic 15 Italian Conference was held September 8-11 in Prato, Italy (near Florence). Christina Cannugi coordinated the conference.

Fifteen families participated in presentations and workshops on topics including the family aspects of raising a child with special needs, Augmentative Alternative Communication, seizures (presented by Dr. Beghi from the Italian Epilepsy Association), siblings and Applied Behavioral Analysis (ABA).

IDEAS Board Member Patti Rubel joined the families at this event.

### Regional Gatherings



Families attended Camp Prime Time in Yakima, Washington in July, 2010.

Two Midwest Regional Gatherings were held in Columbus, Ohio in June and in Ankeny, Iowa in September 2010.

The Northwest Regional Gathering was held in Goldendale, Washington in September 2010.

The Florida Regional Gathering was held in Clearwater, Florida in November 2010.

"The regional get togethers are a wonderful place to get to know each other. No one ever wants to leave....," Deb Lindgren

### Other Fundraisers



IDEAS introduced a cause bracelet in 2010. The funds raised by the sale of these bracelets benefits IDEAS and increases awareness of dup15q.

While there were several fundraisers held in 2010, the list includes the Golf Tournament, the Vermont Run, a Basketball Pool, Christmas Card Sale, Dress Down for Work, and the Phantom Tea.

Online donations are made via the website and Facebook. These donation methods have raised over \$4000.



## Financial Status

*IDEAS is a financially thriving organization.*

IDEAS had a great fiscal year in 2010 thanks to the outstanding support of its' families, external donations, fundraising events and the direction of the board.

In 2010, IDEAS budgeted \$64K for income and \$61K for expenses. At the conclusion of the year, the actual figures were \$88K for income and \$43K for expenses.

The income was more than expected, primarily as a result of the Illinois Golf Tournament and the Vermont 5K/15K Run, as well as other member family organized fundraisers. Expenses were also less than projected.

IDEAS successfully passed a 2011 budget. Although financial growth is necessary,

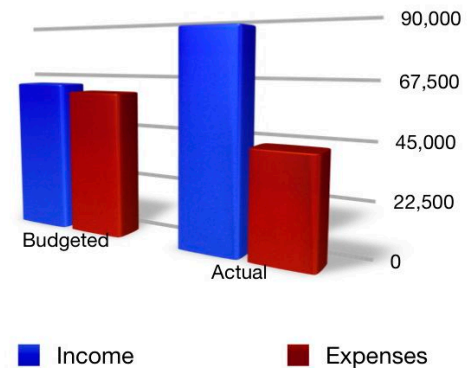
IDEAS is a financially thriving organization.

As a result of the past fundraising efforts, IDEAS was able to drastically reduce the registration fee for the 2011 conference directly benefitting the families affected by dup15q.

The Board of Directors takes the responsibility for IDEAS funds very seriously and strives to

continue to provide great support and services to affected

families, promote research and increase awareness of dup15q.



## Communication

*Believe In Our Kids!*



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

Member focused information is delivered via the quarterly newsletter, MIRROR. This publication is available on the IDEAS website, is emailed to members and is available by mail if necessary. IDEAS also

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

IDEAS 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 Facebook and Twitter. IDEAS 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 IDEAS' mission as well as significantly assisting in fundraising efforts.

## Contact Information

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[info@dup15q.org](mailto:info@dup15q.org)

## Public Relations

Rachel Doucette at [rachel.doucette@dup15q.org](mailto:rachel.doucette@dup15q.org)

## Social Media

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

**Facebook:** [www.facebook.com/pages/IDEAS/305990303151](https://www.facebook.com/pages/IDEAS/305990303151)

**Twitter:** [www.twitter.com/IDEASdup15q](https://www.twitter.com/IDEASdup15q)

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