

Annual Report 2016

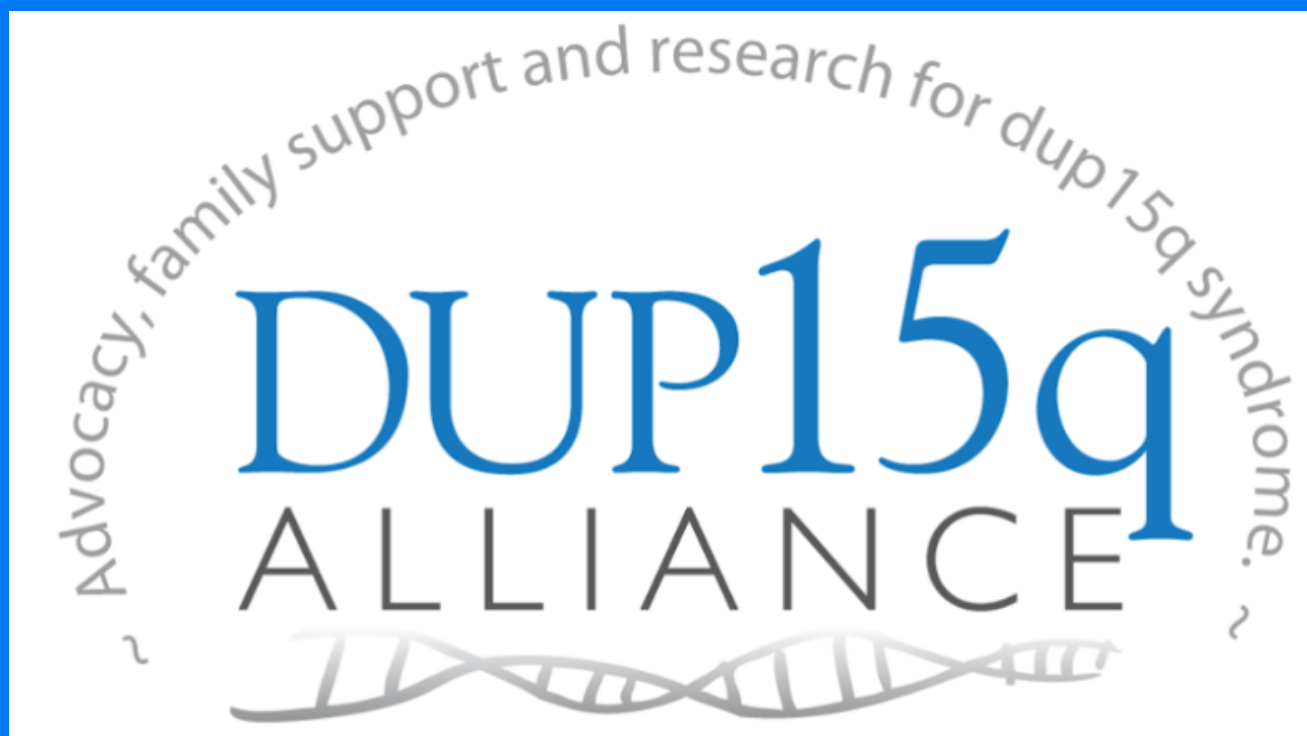


Table of Contents

page 3	Board of Directors & Staff
page 4	Professional Advisory Committee
page 5	New Executive Director
page 6	Financials
page 7	Highlights
page 8	Grant Fellowships
page 9	Thank You



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.

Board of Directors

Tom Doyle	Board Chair
Kadi Luchsinger	Executive Director
Elaine Lowell	Secretary
Donna Bennett	Cofounder and Board Member
Guy Calvert	Board Member
Adrienne Campolmi	Board Member
David Gifford	Board Member
Fernando Gomez	Board Member
Jane Kim	Board Member
Rylie McHam	Board Member
Mike Porath	Board Member
Tessa Quinlan	Board Member

Staff

Vanessa Vogel-Farley	Executive Director
Kadie Luchsinger	Executive Director thru 6-30-16
Kim Maring	Operations Manager
Deirdre Popp	Administrator
Adrienne Felterman	Treasurer



Professional Advisory Committee

Dmitrios Arkilo, MD

Minnesota Epilepsy Group, MN

Stormy Chamberlain, Ph.D.

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 Comprehensive Epilepsy Center

NYU Langone Medical Center, New York, NY

Scott Dindot, PhD

Department of Pathobiology and Department of Molecular and Cellular Medicine

Texas A & M University, College Station, TX

Brenda Finucane, MS, CGC

Autism & Developmental Medicine Institute Geisinger Health System, Lewisburg,
PA

Shafali Jeste, MD

Semel Institute for Neuroscience and Human Behavior UCLA Health Systems

School of Medicine, Los Angeles, CA

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, MA

Ron Thibert, DO, MsPH

Pediatric Epilepsy Program

Massachusetts General Hospital, Boston, MA

Meet our new Executive Director Vanessa Vogel-Farley



I am excited to get the chance to introduce myself as the new Executive Director of Dup15q Alliance!

I come to the Alliance with a decade plus of experience in genetic disorders and child development research experience, as well as more than eight years of establishing and managing a non-profit organization.

Growing up on a dairy farm in rural Wisconsin, I learned the value of hard work and family immediate or extended, and the Dup15q Alliance is an amazing example of that. Every day I reflect on what your "family" (parents, families, caregivers and supporters of someone with dup15q syndrome) has created in the Alliance, and I am humbled to be able to serve you.

I have hit the ground running in my first couple of months, and while I was lucky enough to attend the 2015 conference as a researcher and met many of you and your children in person, I now have had the opportunity to spend some time each day talking to dup15q families. I am learning their stories, their concerns, their triumphs, and what they want and need from the Dup15q Alliance as we grow this organization together. This has been a truly wonderful experience and I look forward to speaking with many more of you in this way. Please feel free to call (1-855-387-1572) or email me at vanessa.vogelfarley@dup15q.org.

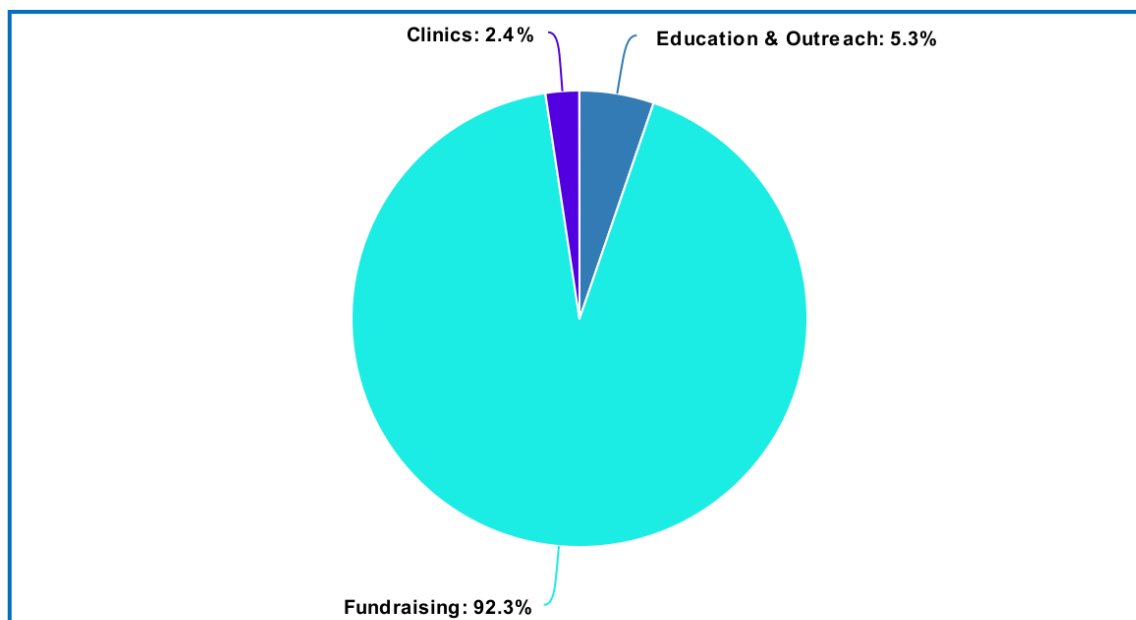
You all have great ideas, comments and questions. The question that I have heard the most in these recent conversations is "do you have a child with dup15q syndrome?". The short answer is "no, I do not". The long answer is "no, I do not, but, I know that is an advantage to every family in the Dup15q Alliance. Since I don't have a child with dup15q syndrome, I am able to take all of the information that I get from every parent and every child I meet and combine it into goals/directions/research ideas/fundraisers that everyone in the Alliance can benefit from, with no concern about my own experiences and biases."

The Dup15q Alliance has brought together world-class physicians and researchers all who are dedicating their time and knowledge to helping characterize dup15q syndrome and exploring new treatments. The interest in dup15q syndrome is constantly growing!

I look forward to using all of my experience and knowledge that I have gained from every aspect of my career in order to grow and develop Dup15q Alliance and work with you to bring us all to the next level.

2016 Financials

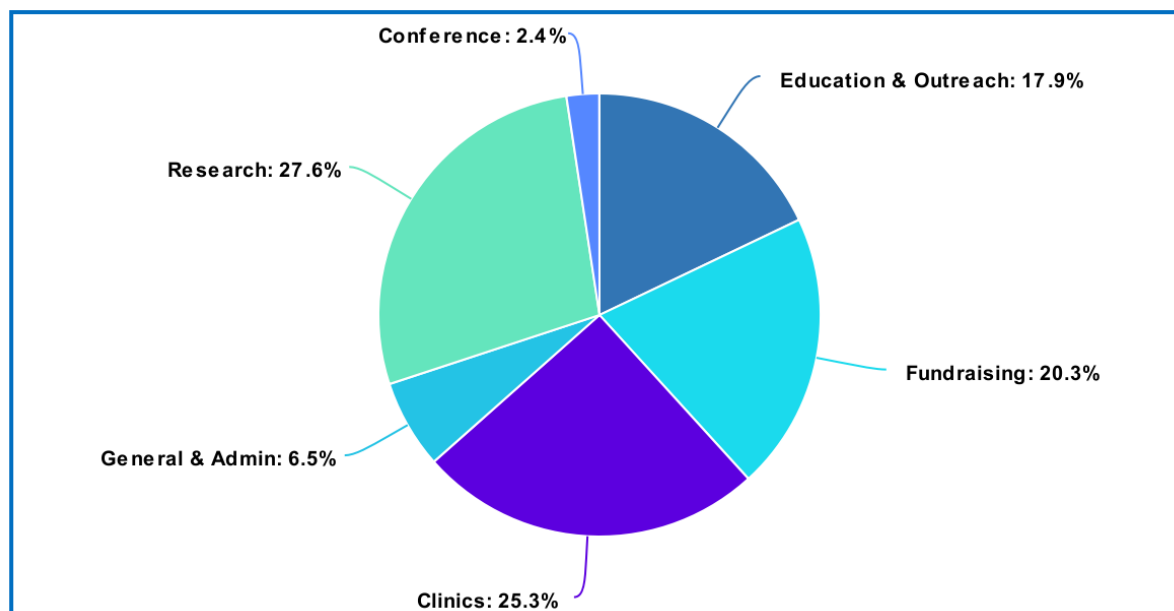
2016 Income



■ Education & Outreach ■ Fundraising ■ Clinics

meta-chart.com

2016 Expenses



■ Education & Outreach ■ Fundraising ■ Clinics ■ General & Admin
■ Research ■ Conference

2016 Highlights

Clinics Caravan

Miles traveled: 105

Miles to go: 5279

15,000 in 15 days

\$43,382.00 around Rare Disease Day

200 donors

NORD Rare Summit

SFARI Grant

Science Meeting

Little Miss Sunshine Walk

Wabasha, MN

Believe Walks

Atlanta, GA

Evansville, TN

Honolulu, HI

Indianapolis, IN

Medford, NJ

Miami, FL

Seattle, WA

Syracuse, NY



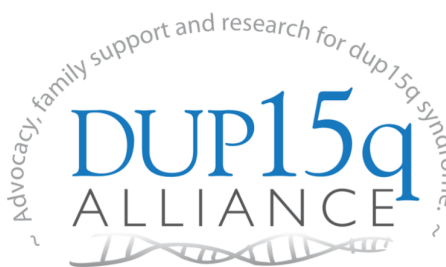
2016 Grants

Grant Fellowships

Dup15q Alliance received eleven proposals, awarding fellowships totaling \$175,000 to two promising young scientists:

JAMES FINK received \$25,000 for three years to study
“Hyperexcitability In Human Stem Cell- Derived Neurons From
15q Duplication Syndrome Patients”

KEVIN HOPE received \$25,000 for four years for his project
“Investigation of Synergistic Interactions Among Genes in the 15q
Duplication Syndrome”



Thank you

A very key ingredient to growth in our Alliance is increasing awareness of our condition in the scientific field and promoting research. Of course our bold mission requires funding to make it possible. We have some phenomenal energetic and generous families whose dedication to fundraising is completely amazing. This past September the first annual national Walk for Dup15q Alliance was held at eight locations across the country. These 'Believe Walks' were tremendously successful and next year's date is already set for October 1. The Alliance is very grateful to all our fundraising families for enabling our support of science, our highly beneficial conferences, and so many other Alliance activities. Cheers to each and every one of you awesome fundraisers!

Another sign of strong growth in our alliance is that conferences are now being held in other countries around the globe. Including the latest European conference held earlier this fall in Milan, Italy. Of course our greatest source of strength in Dup15q Alliance is our wonderful families. There is power in sharing our stories and learning about one another's journeys.

In the words of Tom Doyle, Board Chair, "We are grateful to all those engaged in research, those treating our children, those who participate so strongly in our Registry, and those who so generously donate to the Dup15q Alliance to help advance the cause of supporting our families

and promoting the awareness and research that will one day lead to targeted treatments.

Thank you for your support!"

