

Colin Doyle (pictured) and his family continually support DS research. Colin was involved in a clinical trial and, like a champion, wore his EEG cap to help research advance for himself and others.



2016

Moving Cognition Research Forward



Dear friend,

2016 saw LuMind Research Down Syndrome celebrate its first anniversary since our merger. We continued to champion the efforts to increase funding and research dollars for Down syndrome cognition research. We want to thank you for your continued support, interest and passion to help ensure individuals with Down Syndrome:

- Participate more successfully in school;
- Lead more active and independent lives; and
- Avoid the early onset of Alzheimer's disease.

We continued to grow and learn as a foundation in 2016. Speaking through our One Voice we strengthened our existing donor relationships and cultivated new ones. Through the hard work of the staff, our board of directors, our scientific advisory board and our volunteers we held multiple successful fundraising events, grew our runners program and spread the word on the importance of cognition research whenever and wherever possible.

We awarded \$1.6 million in grants for 2016-2017 allowing researchers the opportunity to continue their work.

It is not only an honor and privilege to be the largest private source of Down Syndrome research funding; it is also a responsibility we take very seriously. We strive to keep our operational costs low. Only 11% of our expenses were spent on administrative costs, ensuring more of your donation goes to fund research.

As individuals with Ds are living longer lives, remains unopened. For this reason, we are as education, and funding to accelerate Down

President's Message

As our late friend and Chief Scientific Officer, Dr. Michael Harpold often said "Individuals with Down syndrome have the same right to research as any other population." For this reason, we are as committed and determined as ever to increase the awareness, education, and funding for cognition research.

Thank you once again for your support and belief in LuMind RDS. Together we can make a difference in the lives of individuals with Down syndrome through the advancement cognition research.

Sincerely,



Marla Murasko
Interim
Executive Director



Ryan Hartman
Chair,
Board of Directors



Stephanie Hartman
CATALYST
Performance Consulting
Owner

Sky's the Limit
Event Chair

Ryan Hartman
Insitu, Inc.
President & CEO

LuMind RDS Foundation
Chair, Board of Directors

it's our responsibility to ensure that no door determined as ever to increase the awareness, syndrome research to improve their lives.





Mission

LuMind Research Down Syndrome's mission, maintained since our inception, is to stimulate biomedical research that will accelerate the development of treatments to significantly improve cognition - including learning, memory and speech - for individuals with Down syndrome so they:

- Participate more successfully in school;
- Lead more active and independent lives; and
- Avoid the early onset of Alzheimer's disease.

Since our founding in 2004, we have become the leading private source of funding in the United States for Down syndrome cognition research, especially now with the merger between LuMind Foundation and Research Down Syndrome.

Vision

Recognized global leader in funding a comprehensive portfolio of research to meaningfully improve memory, cognition, and independence in individuals with Down syndrome.

The volunteer leadership of LuMind Research Directors consisting of members from around Board with representatives from the fields of basic

Mission & Leadership

2016 Board of Directors

Ryan M. Hartman, Chairman, Hood River, Oregon
Daniel Flatley, Vice Chair, New Vernon, New Jersey
Patrick Kannan, Treasurer, Executive Committee, Finance Committee Chair
Virginia Bennett Flynn, Audit Chair, Marshfield, Massachusetts
Michael J. Mannor, Ph.D., Secretary, Granger, Indiana
Amy Allison, Kansas City, Missouri
Terry W. AnCel, Chicago, Illinois
Margie Doyle, Chicago, Illinois
Lara Font, Sugar Land, Texas
Hampus Hillerstrom, Boston, Massachusetts
Christopher G. Lis, Ph.D., Libertyville, Illinois
Deborah Morris, New York, New York
Karen Shea, Morristown, New Jersey

2016 Scientific Advisory Board

Michael M. Harpold, Ph.D., Chief Scientific Officer, LuMind RDS Foundation
Ronald Evans, Ph.D., Salk Institute for Biological Studies
Leslie Leinwand, Ph.D., University of Colorado
Lynn Nadel, Ph.D., University of Arizona
Roger Reeves, Ph.D., Johns Hopkins University School of Medicine
Andre Strydom, MBChB, Ph.D, University College London

Down Syndrome includes a Board of
the United States and a Scientific Advisory
science, translational science, and medicine.



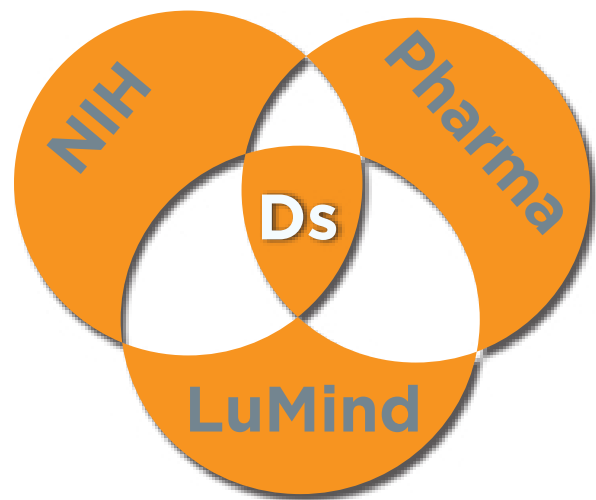


AC Immune/UC San Diego School of Medicine

→ University of California San Diego collaborates with AC Immune in World's First Clinical Trial for anti-Abeta Vaccine Targeting Alzheimer's Disease-like Characteristics in People with Down Syndrome with funding from the NIH and LuMind RDS.

→ AC Immune announced the publication of a ground-breaking scientific study on an anti-A-beta vaccine potentially signaling a way to treat cognitive deficits in people with Down syndrome (Ds). The study, entitled An anti-Abeta-Amyloid Vaccine for Treating Cognitive Deficits in a Mouse Model of Down Syndrome, was published in the scientific journal PLOS ONE.

→ AC Immune also announced the start of patient recruitment for the first clinical trial for this anti-Abeta vaccine (ACI-24) targeting Alzheimer's disease-like characteristics in those with Down syndrome. Announced earlier this year and being conducted in collaboration with the University of California San Diego (UC San Diego), the phase 1b trial is expected to include 24 patients with a 12 month treatment period followed by a 12 month follow up.



The LuMind RDS Foundation awards a record projects, 24 principal investigators, 9 potential

Research Grants

Emory University: The Down Syndrome Cognition Project

- Collaborating with Johns Hopkins, Kennedy Krieger Institute, University of Arizona, UC Davis/Mind Institute, U of Pittsburgh, Oregon Health and Science University, Children's National Medical Center Washington DC, U. of Pennsylvania/Children's Hospital of Philadelphia, Waisman Center/University of Wisconsin.
- Investigating how genes result in the variation of cognitive ability among individuals with Down syndrome.
- Develops and builds on components of critical importance for a Ds-specific phenotype and genotype research database and associated biorepository
- Advancing validation of the ACTB as specific new biomedical standard and critical efficacy assessment component in clinical trials

Johns Hopkins: A Down Syndrome Center for Fundamental Research-Cognition

- Can a single-dose treatment with a potential drug, early in life restores structure and function involving learning and memory in adults?
- How does a protein coding gene affect the development of AD pathology in humans and mouse model of Ds?
- Developing a tool to measure memory process dysfunction and drug-mediated changes related to cognition.

\$1,615,000 in grant funding for six research drug targets, and two clinical trials.





U. of Arizona: Brain Development, Sleep and Learning in Down Syndrome

- Validate Down syndrome-specific assessment — Arizona Cognitive Test Battery (ACTB)
- How does sleep disruption contribute to learning delays and formation of long-term memories in young children and adults with Ds?
- How does sleep disruption contribute to language acquisition in toddlers and pre-school aged children?

UC San Diego School of Medicine: Defining Genes, Mechanisms and Treatments for Neurodevelopmental and Neurodegenerative Causes of Cognitive Dysfunction in Down Syndrome

- How else does the APP gene affect impaired cognition and Alzheimer's disease (AD) neuropathology?
- Are there other genes on chromosome 21 that affect age-dependent development of AD?

LuMind RDS collaborates with the NIH, The AC
first public/private funding collaboration for a

Research Grants

VA Palo Alto Health Care System: Improving Adrenergic Signaling for the Treatment of Cognitive Dysfunction in Down Syndrome

- Build on previous discovery that drugs such as L-DOPS and formoterol, each developed and approved by FDA for other medical conditions, could restore contextual learning in a mouse model of Ds.
- Can lower therapeutic dosages of either L-DOPS or formoterol in synergy with physical exercise effectively restore contextual learning and memory, improve helper molecules signaling and neuron connections and also overcome the progression and effects of degeneration of neurons in the brain associated with the Alzheimer's disease neuropathology in Ds?
- Could these results could provide further evidence and a rationale for accelerated clinical evaluation of these drugs in individuals with Ds?



Immune/UCSD School of Medicine for the
clinical trial in Down syndrome research.



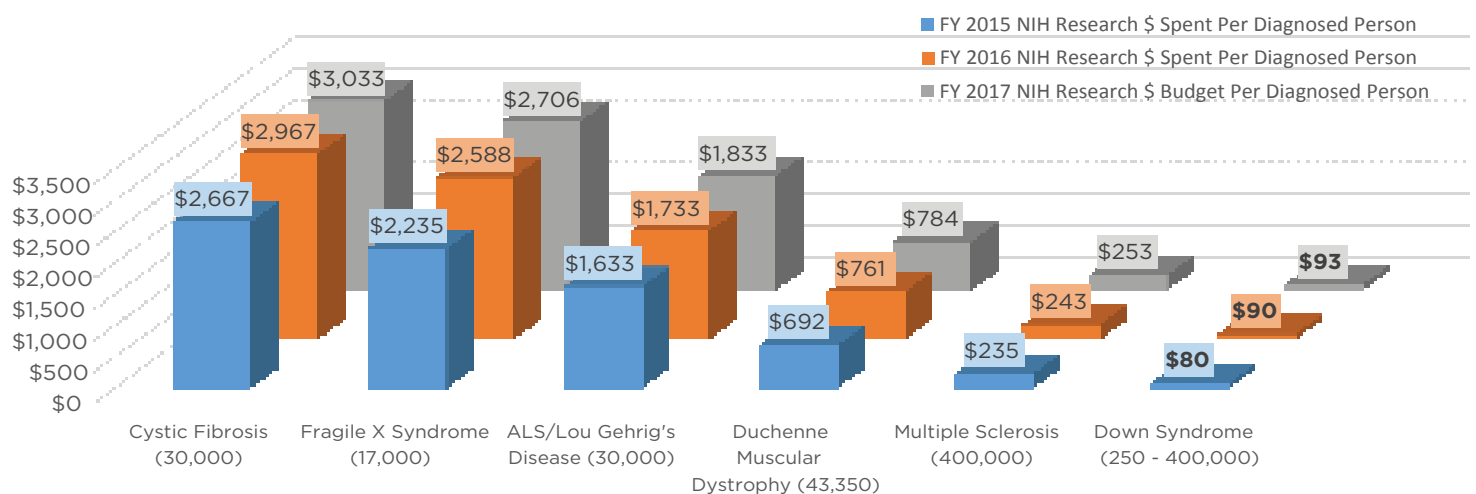


Connecting families with the opportunities Down syndrome research has to offer and the funding challenges that slow down progress is critical to the success of our mission. Communities and families play a significant role in the progress of translational research and patient outcomes. Support from communities and families help researchers conduct clinical trials, and donations accelerate promising and emerging research with early funding so they can attract public funds. All of this helps research discoveries move closer to becoming effective and applicable therapies and treatments for the individuals who could benefit from them the most.

The LuMind RDS Education and Outreach Initiative is led by LuMind RDS Board, staff and our funded researchers who volunteer their time to speak at various affiliate online and in-person conferences and scientific society meetings to share the results of their research

Down syndrome is the most commonly occurring genetic condition but remains one of the lowest funded conditions by the NIH.

NIH Funding History 2015 Actuals - 2017 Estimates



LuMind RDS shared the history, progress, and with more than 39,000 families, policy makers,

Education & Outreach

and what those could potentially mean for individuals with Down syndrome. Overall, we reached over 39,500 and engaged with more than 3,200 who shared our message, fundraised or donated in 2016.

LuMind RDS believes every person living with Ds deserves a bright future, filled with limitless possibilities and the ability to become more independent. It is our goal to make this vision a reality by continuously pushing the boundaries of cognitive research and delivering much-needed resources to the most innovative and committed professionals in the field. We collaborated with many small and large affiliates, organizations and groups to make sure Down syndrome research was always included in the conversation.

Down Syndrome Affiliates in Action

321 e-Conference webinar research presentation

International Society to Advance Alzheimer's Research and Treatment (ISTAART) Ds & AD Professional Interest Area (PIA) Meeting

Tufts New England Medical Center Board, CSO, & CEO

LuMind RDS Hosted Research 101 - Seattle, OR

NIH DS Consortium Mtg, Indianapolis

DSMIG Annual Conference, Orlando, FL

National Down Syndrome Congress Conference, Orlando, FL

Alzheimer's Talks Teleconference - USAgainstAlzheimers.org

Connecticut Down Syndrome Congress Convention

SANDS Buddy Walk - LuMind RDS/Research booth, Tucson, AZ

Combined Federated Campaign, Virginia

Keystone Research Symposia, Biology of Down Syndrome: Impacts Across the Biomedical Spectrum, Santa Fe, NM

Kansas City Down Syndrome Guild

LuMind RDS Hosted Research 101 Oro Valley, Arizona



value of Down syndrome cognition research
corporate leaders, researchers, and affiliates.





- At the 10th annual ROMP for Research, a family fun day at New York City's Asphalt Green and one of LuMind RDS's most popular events, participants had a ball while supporting Ds research!
- Funding Futures Chicago continues to entertain and educate about Ds cognition research. This year the evening of fun featured a pre-event Happy Hour welcoming the next generation of LuMind RDS supporters to the organization.
- Jackapalooza in Chicago was revamped from a student-led music performance to a May evening cocktail party with musical guests. The Villalobos family amazes us with their lyrical creativity as they support research!
- We hosted the second awards gala, Sky's the Limit, in Seattle to honor the best and brightest who have propelled Down syndrome cognition research.

Our inaugural honorees were:

- Founders' Award - Terry AnCel, Hayes Mechanical
- Dr. David Cox Rising Star Award - Presented to Dr. Mike Rafii, UC San Diego
- Dr. William Cohen Researcher of Distinction Award - Presented to Dr. Roger Reeves, Johns Hopkins
- Luminary Award - Presented to ROMP Co-Chairs, Steve & Mary Lazare and Anthony Providenti



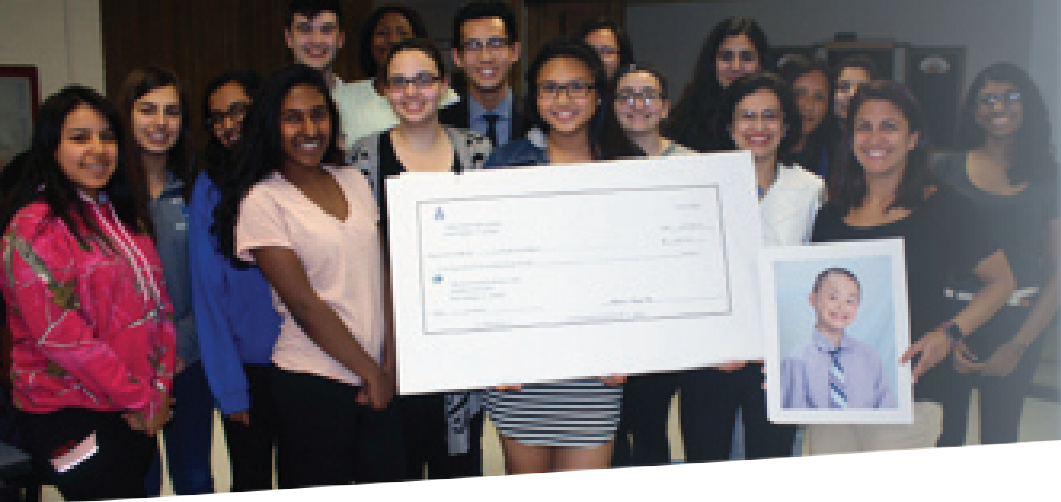
We reach even more with the help of ambassadors events where they connect the participants to the

Education & Outreach

- LuMind RDS Foundation was the beneficiary of the St. Charles, IL stop of the “Glitter and Glue for Good” tour led by New York Times best-selling author, Kelly Corrigan. Sarah and Mia Wuellner raised awareness at this event by sharing their story and why they support LuMind Research Down Syndrome Foundation.
- Four, golf tournaments in Chicago, Belleville, Illinois (outside St. Louis, MO), and Freeland, Michigan. and Omaha hosted by long-time friend, Hayes Mechanical Inc.
- The Brinks triple-threat event combined a golf outing, online auction and a carnival, raised dollars and awareness of the importance of Ds research.
- The Libretti golf outing celebrated 5 years of raising awareness and funds to support Down syndrome cognition research
- We celebrated Ds Awareness month with the annual Ashley Rose Golf tournament, attracting the DC crowd.
- We also held the second NASCAR-themed event, the Race for Research, a three-day scavenger hunt where teams visit places of NASCAR significance, answer questions about Ds, meet racing celebrities (like our honorary co-chair NASCAR Driver David Ragan) and spread awareness.
- Tribute 21 is an amazing evening of elegance in support of Ds research. The swanky DC event caps off Ds Awareness month with a celebration of people with Ds in honor of Flynn Fry.
- The 24 Hour Relay is a wonderful day and night - a full 24 hours of support for Ds research. Incredible perseverance and education from New Jersey!
- Our eXtraordinary LuMind RDS Runners were out in full and half marathons in New York, Chicago, Boston and in shorter and longer races around the country, including the WDSO 321 Virtual Run/Walk. We are so fortunate to have these dedicated people in our community. Strong body, strong mind!

who organize education and fundraising research supported by LuMind RDS.





LuMind Research Down Syndrome Foundation is committed to being a wise steward of the resources entrusted through donations from the public. In fiscal year 2016, which runs from October 1, 2015 through September 30, 2016, 89% of expenses went directly to research grants as well as education and outreach. General Management and Fundraising expenses were kept to 11% of total expenses. LuMind RDS thanks the many individuals and organizations for their continued support.

Total Revenue	\$2,534,675	
Expenses		
Research Grants Program	\$1,615,000	63%
Education & Outreach	\$668,536	26%
General Management & Admin	\$44,919	2%
Fundraising	\$256,431	9%
Total Expenses	\$2,584,886	
Net Assets	\$246,573	

LuMind RDS truly values your trust and fiscal
 In 2016, 89% of all donation revenue was used

Financial Health

We are humbled by the contributions of our friends and partners to advance Down syndrome cognition research. Thank you for your continued support, donations, and fundraising.

Individuals

Terry Ancel
Benno Ansbacher
Edward DeNoble
Roger & Dawn Kafker
Michael & Dorothea Kane
Christopher & Heather Lis
John & Ramona Mooney
Carl & Suzanne Shepherd
Sarah & Daniel Wernikoff
Jim & Patricia White
Laura & Said Ziouani

Organizations & Companies

Hayes Mechanical
Cancer Treatment Centers of America
Molly Lawson Foundation
Alexander's Angels
Northern NJ Down Syndrome Alliance
Down Syndrome Guild of Greater Kansas City
Buddy Walk of South Plainfield
Sonepar Management
Down Syndrome Association
Stanley & Marion Berman Family Fund
Lazare, Potter & Giacovas
Debbie & Andrew Morris Foundation
Frederick & Margaret L. Weyerhaeuser Foundation

Illinois Mechanical Sales
Henry Schein LIC Operations
Network Computing Group LLC
Wenatchee Valley Medical Center

Down Syndrome (DS) Affiliate Supporters

Alexander's Angels
DSA of Central Texas
Northern New Jersey DSA
DSG of Greater Kansas City
DSA of Greater St. Louis
Buddy Walk of South Plainfield
Michiana DS Family Support & Advocacy Group
Galveston-Houston Families Exploring DS
Heart of Illinois DSA
DSG of Dallas
DSA of Greater Charlotte
DS of Louisville
DSA of Greater Cincinnati
DSA of Western Kentucky
DS Connection of the Bay Area
KIIDS, Inc.
DS Connection of Long Island
Dads Appreciating DS of Southeast

responsibility is our highest priority.
for research, education and outreach.



LuMind Research Down Syndrome Foundation

225 Cedar Hill Street
Suite 200
Marlborough, MA 01752

508.630.2177
LuMindRDS@LuMindRDS.org

www.LuMindRDS.org



Through our past efforts we have entered a new era that years ago few imagined possible. By our continued efforts in cognition research we will open doors to countless opportunities for individuals with Down syndrome.