



One Voice



ANNUAL REPORT

Fiscal Year Ending September 30, 2015

2015

PRESIDENT'S MESSAGE

Hello friends!

In 2015 we continued to change and adapt so we can propel Down syndrome cognition research to new levels. Thank you for coming along for the ride!

The biggest change in 2015 was the merger between LuMind Foundation and Research Down Syndrome Foundation. Together, we now speak with **One Voice** on Down syndrome cognition research - as LuMind Research Down Syndrome Foundation.

Using One Voice to propel cognition research represents more than a merger of two like-minded organizations. One Voice represents our continued focus as the largest private source of Down syndrome cognition research, It also underscores our dedication to improving speech, learning, memory in people with Down syndrome, as well as preventing or delaying the losses from early onset Alzheimer's disease in people with Down syndrome.

"People with Down syndrome have the same right to research as any other population."

**- Dr. Michael Harpold
LuMind RDS Chief
Scientific Officer**

Thanks to your help, we awarded \$1.3 million in grants for 2015-2016 to researchers at leading institutions, so they could continue to make significant breakthroughs unraveling the mysteries of Down syndrome.

We kicked off 2015 by inviting our supporters on a quest to leverage the laboratory discoveries and ignite new levels of possibilities. We are now one year into our ambitious five year plan to award \$25 million in grants over five years. To push the boundaries of cognition research, leading to a better quality of life for the more than 250,000 people with Down syndrome.

One of the most exciting aspects of the merger has been the wonderful LuMind RDS Runner's Program. We are so happy to be part of this amazing



community of Runners who race for the eXtraordinary. If you haven't already joined the LuMind RDS Runners Facebook group, I encourage you to check it out. Whether you run marathons or just have a desire to complete a local 5K you'll find supportive friends who also support Down syndrome research.

Operationally, we continue to be wise stewards of your donations. Only 11% of our expenses were spent on administrative costs, meaning that more of your donation goes directly to research.

So, thank you, we are honored to have your support and trust as together we strive for new opportunities for independence, success, and happiness for people with Down syndrome through the promise of cognition research discoveries.



Carolyn Cronin
Carolyn Cronin

President and CEO, LuMind Research Down Syndrome Foundation



OUR 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.



LEADERSHIP TEAM

The volunteer leadership of LuMind Research Down Syndrome includes a Board of Directors consisting of members from around the United States and a Scientific Advisory Board with representatives from the fields of basic science, translational science, and medicine.

2015 Board of Directors

Ryan M. Hartman, Chairman, Hood River, Oregon
Daniel Flatley, Vice Chair, New Vernon, New Jersey
Ann Margaret Chrisney, Treasurer, Pasadena, California
Michael J. Mannor, Ph.D., Secretary, Granger, Indiana
Amy Allison, Kansas City, Missouri
Terry W. AnCel, Chicago, Illinois
Shon Christy, Akron, Ohio
Margie Doyle, Chicago, Illinois
Lara Font, Sugar Land, Texas
Hampus Hillerstrom, Boston, Massachusetts
Todd Kinsella, Ph.D., Palo Alto, California
Sohail Masood, Phar.D., Boston, Massachusetts
Deborah Morris, New York, New York
Anthony Providenti, New York, New York
Karen Shea, Morristown, New Jersey

2015 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



RESEARCH GRANT PROGRAM

Our Approach

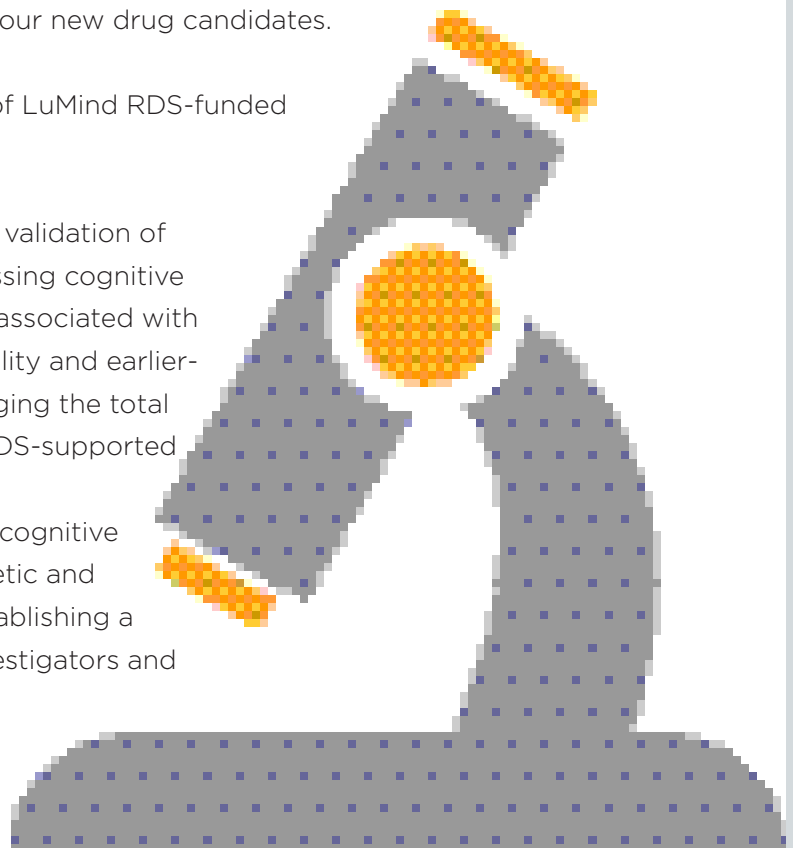
LuMind Research Down Syndrome Foundation takes a robust strategic approach to identifying and supporting projects across the research and development pipeline that have the greatest promise for accelerating discovery and translation to effective new therapies for people with Down syndrome.

LuMind RDS sustains productive levels of funding to researchers who are making significant strides toward the reality of drug therapies to improve cognition. We are proud to provide meaningful financial support to exceptionally productive researchers as they make advances, commence new projects, and most importantly yield high-impact results.

Through the achievements and steady support from us, the LuMind RDS-supported researchers have made discoveries that beginning in 2011 have rapidly led to multiple clinical trials for four new drug candidates.

Selected key investigations and results of LuMind RDS-funded research in 2015:

- Advancing further identification and validation of new therapeutic drug targets addressing cognitive impairment and neurodegeneration associated with the developmental intellectual disability and earlier-onset Alzheimer's disease in Ds bringing the total to 10 new targets through LuMind RDS-supported research.
- DS Cognition project - Investigating cognitive variability and correlations with genetic and comorbidity variability in Ds and establishing a consortium of clinical trial-ready investigators and institutions.



- Advancing further development and refinement of assessment test batteries tailored to the Ds population to evaluate the efficacy of potential drug treatments on cognition.
- Identification of new potential biomarkers that may help to accelerate new drug discovery and development to ameliorate the cognitive impairment associated with the developmental intellectual disability in Ds.
- Identification of new potential biomarker for cognitive decline associated with the earlier-onset Alzheimer’s disease in Ds and which might be useful to support clinical studies and trials.
- Establishment of correlation between sleep problems, including sleep apnea, and cognitive dysfunction in Ds.
- Continuing establishment of relationships with pharmaceutical and biopharmaceutical companies to identify proprietary drug development candidates and support clinical trials.
- Increased the number of LuMind RDS-supported Principal Investigators focused on Ds research from four in 2007 to more than 35 research investigators in 2015.
- Increased the number of LuMind RDS-supported Principal Investigators focused on Ds research from four in 2007 to more than 35 research investigators in 2015, and with a total of 78 scientific publications in prestigious biomedical research journals by LuMind RDS-supported researchers between 2004-2015
- Enabled LuMind RDS-supported investigators to achieve sufficiently strong research results to successfully secure over \$18 million in follow-on research support from NIH, other foundations, and universities through 2015.

Research by the Numbers

10

research targets

35

investigators in the field

\$18m

in leveraged support

\$1.3m

awarded in research grants

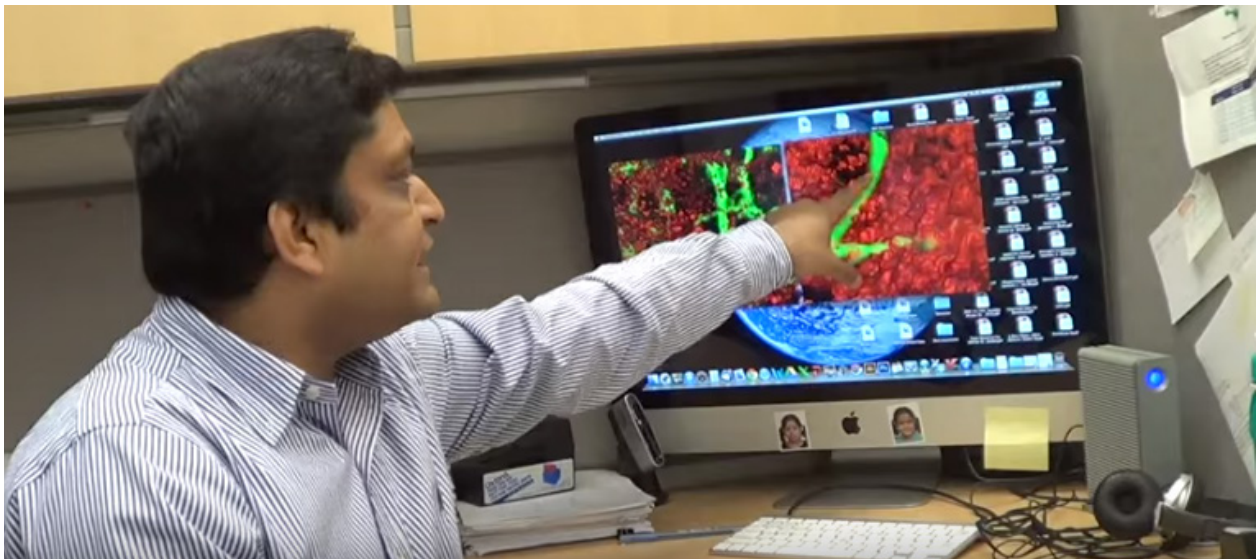


The Research Grants

LuMind Research Down Syndrome developed Research Grants Policies and Procedures to specify the governing criteria for the research we fund. These criteria include collaboration, integration of interdisciplinary approaches, open and prompt sharing of project information and results with each other and with other qualified researchers.

The Scientific Advisory Board (SAB) reviews research grant application submissions, with final approval and decision on awards by the Board of Directors. To track progress and evaluate future funding, the strategic scientific leadership of LuMind RDS actively engages with investigators seeking and receiving awards.

In June 2015, LuMind RDS committed \$1.3 million in grants to support exceptional investigators and their research at the six listed institutions which will significantly further progress to advance results-driven cognition research and build on the promise of the future.



For more information on our research grants, please visit the research hub on our website: www.LuMindRDS.org.



Johns Hopkins University School of Medicine

Research Center Grant: A Down Syndrome Center for Fundamental Research-Cognition



Emory University School of Medicine

LuMind Research Center Grant: The Down Syndrome Cognition Project



EMORY
UNIVERSITY

University of California, San Diego School of Medicine

Research Center Grant: Defining Genes, Mechanisms and Treatments for Neurodevelopmental and Neurodegenerative Causes of Cognitive Dysfunction in Down Syndrome

UC San Diego

University of Arizona

Innovation Research Grant: Brain Development, Sleep and Learning in Down Syndrome



Stanford University

Innovation Research Grant: Mechanisms Underlying the Roles of Sleep and Circadian Rhythms in the Learning Disability of Down Syndrome



VA Palo Alto Healthcare System

Innovation Research Pilot Grant: Improving Adrenergic Signaling for the Treatment of Cognitive Dysfunction in Down Syndrome



EDUCATION & OUTREACH

According to the Centers for Disease Control, each year approximately 6000 babies are born with Down syndrome, making it the most common chromosomal disorder. And thanks to advances in medical care, people with Down syndrome are living longer with an average life span of 47 years.

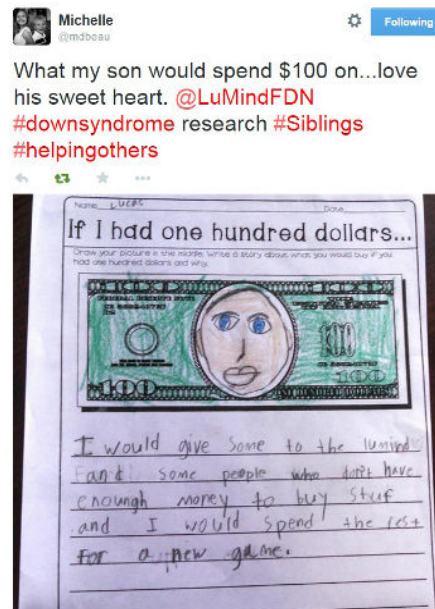
When you extend out to the thousands of people who love and care for a person with Down syndrome, there is a broad community of people interested in research. In addition to funding research to find treatments to improve cognition, LuMind RDS educates individuals with Down syndrome and their families and friends about research progress, opportunities to provide input to national research initiatives, and information on participating in clinical trials.

The LuMind Research Down Syndrome website (www.LuMindRDS.org) offers a window into the specific research investments we've made thanks to the generosity of our donors and how they fit into the Research Strategy, R&D pipeline and the broader landscape of Ds research.

Monthly Newsflash e-mails help keep our community up to date with local Ds events and national DS research progress. Each monthly Newsflash and special e-blasts reach 23,500 constituents.

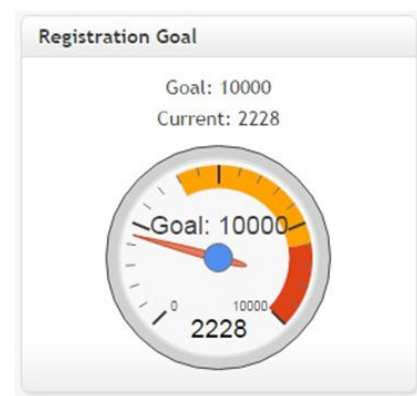
As an essential component of our community outreach, LuMind RDS maintains an active presence in social media, combining the communities of LuMind and RDS. Our Facebook page almost doubled it's "Likes" growing from 11,000 to 20,000. Twitter, Instagram, LinkedIn and other social platforms grew as well, allowing us to interact with a variety of people and organizations in the Down syndrome community.

LuMind Research Down Syndrome Foundation hosts free webinars and made presentations where Dr. Michael Harpold, LuMind RDS's chief scientific officer and Principal Investigators who receive LuMind RDS



funding explain their research to the interested public. We've worked with many Down syndrome organizations, both national and local, to educate their members on the importance of Down syndrome cognition research and share the exciting progress we've made, thanks to funding support.

- Researchers Dr. Craig Heller and Dr. Ahmed Salehi at Stanford hosted the Silicon Valley DSA with a research update and lab tour.
- Down Syndrome Association of Greater Cincinnati invited LuMind RDS and Dr. Michael Harpold to their Health Awareness Fair.
- As part of our inaugural Sky's the Limit Gala in Seattle, Washington, we held a research presentation where Dr. Harpold was joined by award honorees Dr. William Mobley and Dr. Jamie Edgin.
- Research 101 Presentation held at Proskauer Rose in New York City. At a private reception hosted by a board member at law firm, Board member Hampus Hillerstrom provided an overview of current funded research projects as well as five year, \$25 million strategic research plan
- It was standing room only at the National Down Syndrome Congress convention in NDSC Conference, Phoenix where more than 200 attendees heard from CSO Dr. Harpold and University of Arizona cognition researcher Jamie Edgin.
- The MODS Squad and DADS Group in Elmhurst, Illinois hosted Dr. Robert Schoen (former president/CEO of Research Down Syndrome).
- Hosted by Down Syndrome Association of Central Texas, this event featured presentations by Dr. Jon Pierce-Shimomura, Ds researcher at University of Texas, Austin, and Dr. Harpold.
- We kicked off Down Syndrome Awareness month in October 2014 with a webinar talking about DS-Connect featuring Dr. Harpold, Dr. Melissa Parisi from the National Institute of Health, and Diana Merzweiler from Down Syndrome Association of Greater Louisville. The webinar was part of our successful campaign to inspire new registrants to join DS-Connect.
- We presented webinars to announce our 2015-2016 Grants to our major donors, affiliate organizations and supporters.



Together we can move the needle on the gauge
We'll update the DS-Connect* graphic throughout the month of October to track the progress.

We also take advantage of the opportunities afforded at our fundraising events to raise awareness of our mission and engage with people to cultivate their interest in our work. We weave messages into special events through inspirational speakers, mission moments, and awareness opportunities, so participants understand the amazing progress their donations fuel.



- At the 9th 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.
- We were so happy to get back to our roots with the annual Southern California benefit gala: "One eXtra Reason to Live ... Love ... Hope."
- We hosted our inaugural 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 - Presented to Jim White and Patty O'Brien White on behalf of all those who were a part of the creation of the organization**
 - **Dr. David Cox Rising Star Award - Presented to Dr. Jamie Edgin, University of Arizona**
 - **Dr. William Cohen Researcher of Distinction Award - Presented to Dr. William Mobley, University of California, San Diego**
 - **Luminary Award - Presented to Sarah Wernikoff, former Chairperson, LuMind Research Down Syndrome Foundation**
- 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!



- Golf events continue to offer opportunities to introduce our mission to a wide range of supporters:
 - Long-time LuMind RDS supporter, Hayes Mechanical held four, yes, four, golf tournaments in Chicago, Omaha, Belleville, Illinois (outside St. Louis, MO), and Freeland, Michigan. Hayes Mechanical President and LuMind RDS Board Member Terry AnCel was on hand at all the events to relate the importance of Down syndrome research.
 - The annual Brinks Gold Tournament was once again a Texas-sized success! Combining a golf outing, online auction and a carnival, the Brinks event raised dollars and awareness of the importance of Ds research.
 - The Libretti golf outing continued their support of research, a tradition since 2011! Thank you!
 - 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 dedication 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 WSDS 321 Virtual Run/Walk. We are so fortunate to have these dedicated people in our community. **Strong body, strong mind!**



FINANCIAL HEALTH

LuMind Research Down Syndrome Foundation is committed to being a wise steward of the resources entrusted through donations from the public. In fiscal year 2014, which runs from October 1, 2014 through September 30, 2015, 89% of expenses went directly to research grants and education and outreach. General Management and Fundraising expenses were kept to 11% of total expenses.

Total Revenue	\$2,228,911	
Expenses		
Research Grants Program	\$1,427,500	61%
Education & Outreach	\$651,338	28%
General Management & Admin	\$98,274	4%
Fundraising	\$169,861	7%
Total Expenses	\$2,346,973	
Net Assets from the RDS Merger	\$246,573	
Change in Net Assets	\$128,511	

Net assets at the end of FY 2015 totaled \$852,119.



OUR FRIENDS

We extend our heartfelt thanks to the volunteers, affiliate organizations, and corporate sponsors who share our passion and commitment. From events such as golf tournaments to our signature Romp for Research as well as direct donations, affiliate organizations and volunteers all over the country support our cause. Here is a listing of our most generous affiliate and corporate supporters.

Thank you also to those many who made significant gifts and wish to remain anonymous.



Major Down Syndrome Affiliate Supporters

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

Major Corporate Supporters

Hayes Mechanical
Genentech
Lazare Potter & Giacovas, LLC
Illinois Mechanical Sales
Estee Lauder
Trianz, Inc.
APAX Partners
Pipe Fitting Council of Greater Chicago
Above the Tracks
AT&T
Brinks, Inc.
Denali Advanced Integration
Descartes Systems (USA) LLC
IBM
IT Convergence
Henry Schein
Stevenson Crane Services, Inc.
Behrmann Company
Darby Group
Fulton Street Brewery
Network Computing Group LLC
Wenatchee Valley Medical Center

We are grateful for all of the believers - donors, volunteers, and supporters.

Thank you.



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The future, in mind.

Through funding to the institutions and talent that are pushing the boundaries of cognitive research, the world is opening up for people with Down Syndrome, and we are honored to help hold the door.