# **Annual Report**

Fiscal Year Ending September 30, 2014







# **President's Message**

# Hello to our donors, supporters, and valued volunteers,

The year of 2014 was full of changes – a new name, new staff - but our dedication to our mission remains the same. We remain focused on funding the most promising lines of discovery in Down syndrome cognition research.

We celebrated our ten year anniversary with a new look and new name. In March 2014, we changed our name from the Down Syndrome Research and Treatment Foundation (DSRTF) to LuMind Foundation to reflect the hope we feel about the future for people with Down syndrome. The name LuMind is derived by combining the word "lumen" – a measure of light – with "mind" to reinforce our focus on cognition.



We hope you agree that our name stands out from the crowd and reinforces our commitment to pushing the boundaries of cognition research.

A new identity was also the first step in our new bold operational plan, also developed in 2014. Beginning in 2015, we are inviting our supporters on a quest to leverage the discoveries over the past decade to ignite a new level of possibilities.

Our five year plan has a goal of awarding \$25 million in grants to push the boundaries of cognition research, leading to a better quality of life for the more than 250,000 people with Down syndrome. This isn't just a dream; it's a near-term reality.

Operationally, we continue to be wise stewards of your donations. We awarded \$1,250,000 in grants to researchers at leading institutions, so they could continue to make significant breakthroughs unraveling the mysteries of Down syndrome.

We are honored to be opening the door to a future bright with promise and opportunity for people with Down syndrome and those who love them. Won't you join us?

Sincerely,

Carolyn Cronin

President and CEO, LuMind Foundation





# **Our Mission**

LuMind Foundation'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.







# **Leadership Team**

The volunteer leadership of LuMind Foundation 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.

### **Board of Directors**

Ryan M. Hartman, Chairman, Hood River, Oregon
Ann Margaret Chrisney, Treasurer, Los Angeles, California
Anthony Providenti, Interim Secretary, New York, New York
Amy Allison, Kansas City, Missouri
Terry W. AnCel, Chicago, Illinois
Shon Christy, Akron, Ohio
Margie Doyle, Chicago, Illinois
Hampus Hillerstrom, Boston, Massachusetts
Todd Kinsella, Ph.D., Palo Alto, California
Sohail Masood, Phar.D., Boston, Massachusetts
Deborah Morris, New York, New York

### **Scientific Advisory Board**

Michael M. Harpold, Ph.D., Chief Scientific Officer, LuMind 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 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.



This approach has generated results that are recognized as unprecedented in this field: clinical trials initiated by a major pharmaceutical company just a few short years since our founding.

Key results of LuMind Foundation-funded research that set the stage for clinical trials:

- Identified nine potential therapeutic drug targets.
- Advanced three potential therapeutic compounds into the pre-clinical phase.
- Increased the number of LuMind Foundation-supported Principal Investigators focused on Ds research from four in 2007 to more than 20 in 2014.
- Enabled investigators to achieve sufficiently strong research results to successfully apply for over \$12 million in follow-on grant funding from NIH and other foundations.
- Proactively invested in core capacities and infrastructure necessary to support clinical trials:
  - DS Cognition Project establishing a consortium of investigators and institutions ready to recruit patients.
  - A battery of tests tailored to the Ds population to evaluate the efficacy of potential drug treatments on cognition.
  - Relationships with pharmaceutical and biopharmaceutical companies to identify proprietary drug development candidates and support clinical trials.

### **The Research Grants**

LuMind Foundation 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 Foundation actively engages with investigators seeking and receiving awards.

During the grant award cycle which ended in May of 2014, LuMind Foundation awarded grants totaling more than \$1.05 million to support research initiatives led by respected scientific investigators at five outstanding academic institutions.

In June 2014, LuMind Foundation committed another \$1.1 million in grants to support exceptional investigators and their research at the six institutions listed below which will significantly further progress to advance results-driven cognition research and build on the promise of the future.



#### JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

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



#### **EMORY UNIVERSITY SCHOOL OF MEDICINE**

LuMind Research Center Grant: The Down Syndrome Cognition Project

https://www.youtube.com/ watch?v=IeYwinLWiCo&feature=youtu.be





# **Education and Outreach**



### **UNIVERSITY OF CALIFORNIA, SAN DIEGO SCHOOL OF MEDICINE**

Research Center Grant: Defining the genes and mechanisms and treatments for neurodevelopmental and neurodegenerative causes of cognitive dysfunction in Down syndrome



### THE UNIVERSITY UNIVERSITY OF ARIZONA

Innovation Research Grant: The Neuropsychology of Down Syndrome



### STANFORD UNIVERSITY

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



Veterans Alfairs Palo Alto Health Care System Innovation Research Pilot Grant: Improving Adrenergic Signaling for the Treatment of Cognitive Dysfunction in Down Syndrome

For more information on our research grants, please see please visit the research center on our website: www.LuMindFoundation.org/Down-Syndrome-Cognition-Research.

In addition to funding research to find treatments to improve cognition, LuMind Foundation invests in educating the community of individuals with Down syndrome and their families and friends about research progress and opportunities to provide input to national research initiatives and participate in clinical trials. Many channels are utilized to inform and galvanize the community.

The LuMind Foundation website (www.LuMindFoundation.org) offers a window into the specific research investments LuMind Foundation has made and how they fit into the Research Strategy, R&D pipeline and the broader landscape of Ds research. Our newly rebranded website was visited more than 99,000 times during the last fiscal year, serving over 39,000 unique users.

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 8,000 constituents.

As an essential component of our community outreach, LuMind Foundation maintains an active presence in online social media. Our Facebook page, frequently updated, has been "Liked" by more than 11,000 people by the end of FY 14. On Twitter we had more than 800 followers, and participate actively in one-on-one and group discussions. Our blog boasts more than 800 readers, offering perspectives on research and Ds in the news.

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







Some of the LuMind Foundation webinars and presentations in FY2014 included:

- A DS Cognition Research Update in the Bay Area, CA where Drs. Craig Garner, Craig Heller, and Ahmad Salehi, all of Stanford University, spoke during this informative, accessible presentation.
- In honor of mothers and caregivers, Dr. Jamie Edgin from the University of Arizona provide an update on the current state of work on memory formation and sleep-dependent learning in children and young adults with Down syndrome.
- An invitation-only webinar to announce our 2015 Grants to our major donors and supporters.

LuMind Foundation also actively pursues the opportunity to participate in educational events to inform the public about the possibilities and promise of Ds cognition research. Some of these events during FY2014 included:

- DADS of Southeast Michigan Research 101: Dramatic Progress in Down Syndrome Cognition Research: Mind to Lab Bench to Bedside where Dr. Harpold presented the latest advances on cognition development research.
- Down Syndrome Louisville Research 101: Research Matters.....and Right NOW is a Game Changer: Dramatic Progress in Translating Biomedical Down Syndrome Cognition Research by Dr. Michael Harpold.
- Down Syndrome Association of Greater Richmond Dramatic Progress in Translating Biomedical Down Syndrome Cognition Research Discoveries into New Therapies by Dr. Harpold.
- Down Syndrome Association of Greater Charlotte DS Cognition Research Update as part of our kick-off the inaugural Race for Research.
- In celebration of Down syndrome Awareness Month, Dr. Jamie Edgin presented at a DSAIA webinar on The Research Landscape: Update on Ds Cognition Research and Ongoing Clinical Trials Sleep and Cognition Webinar.
- Dr. Harpold spoke at a Down syndrome Awareness Month event in Plainview, Long Island, New York about LuMind's current research investments and the clinical trials now underway.

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 our messages into special events through inspirational speakers, mission moments, and awareness opportunities, so participants understand the amazing progress their donations fuel. Here are highlights of our signature events where we combined fun, fundraising, and mission.

- We kicked off FY 2014 with the 8th annual ROMP for Research, a family fun day at New York City's Asphalt Green and one of LuMind's most popular events. The ROMP has raised almost \$7 million dollars for cognition research.
- Funding Futures Chicago continues to entertain and raise money for cognition research at the fun Goose Island Brewery. Thank you to all who help fund futures, made even brighter by the promise of Ds cognition research.
- Long-time LuMind Foundation supporter, Hayes
   Mechanical expanded their golf tournaments from
   one in Chicago to three additional locations in Omaha,
   Nebraska, Belleville, Illinois (outside St. Louis, MO), and
   Freeland, Michigan.
- Celebrating its 8th year, Southern California's One Xtra Reason to Live, Love, and Hope, enjoyed an unforgettable evening to benefit research.
- We created a NASCAR-themed event, the Race for Research, a three-day scavenger hunt road rally where teams visit places of NASCAR significance, meet racing celebrities (like our honorary co-chair NASCAR Driver David Ragan) and spread awareness about the importance of Down syndrome research. The event also exceeded its fundraising goal by 50% in its inaugural year.













# **Financial Health**

LuMind 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, 2013 through September 30, 2014, 90% of expenses went directly to research grants and education and outreach. General Management and Fundraising expenses were kept to 10% of total expenses.

<b>Total Revenues</b>	\$2,203,494	
Expenses		
<b>Research Grants Program</b>	\$1,250,000	62%
<b>Education &amp; Outreach</b>	\$552,375	28%
General Management & Admin	\$34,042	2%
Fundraising	\$169,763	8%
<b>Total Expenses</b>	\$2,006,180	
<b>Change in Net Assets</b>	\$197,314	

Net assets at the end of FY 2014 totaled \$723,607.

# **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, with help from generous corporate sponsors, helped raise more than \$700,000 each year for cognition research.

We appreciate the hard work and the heart that go into these efforts — thank you for all you do to help propel research!

























We are grateful for all of our donors. For a longer list of our friends who support us, please visit our website: www.LuMindFoundation.org/down-syndrome-friends.









LuMind Foundation
225 Cedar Hill Street
Suite 200
Marlborough, MA 01752
508.630.2177
LuMind@LuMindFoundation.org
www.LuMindFoundation.org