

Dear Friends of RDS,

There is much to celebrate and much happening! In this Fall issue of the Research Down Syndrome newsletter, I am pleased to provide details of recent news on the research front

- Roche Pharmaceuticals announcement of a clinical trial to evaluate a compound designed to address the cognitive issues associated with Down syndrome.
- 2011-12 Grants Awards Announcement
- Update on the formation of Down Syndrome Research Consortium

YOU are responsible for making this happen. We are constantly working to make it easier for everyone to participate. You can learn more by reading about:

- Recent Research Down Syndrome Events
- The Research Down Syndrome Runners Program
- The Research Down Syndrome Ambassadors Program

All of us at Research Down Syndrome are grateful for your support and remain committed to our Founding Principles of Research, Respect, Results. We appreciate your continuing involvement and look forward to hearing from you as, together, we work to EMPOWER THE EXTRAORDINARY!

Best wishes,
Bob Schoen
President, Research Down Syndrome

Roche Phase 1 Clinical Trial of Molecule to Treat Down Syndrome Cognitive Difficulties Announced

The announcement by Roche of a Phase 1 clinical trial to investigate the safety and tolerability of a molecule designed to address the cognitive and behavioral deficits associated with Down syndrome represents a landmark step in research addressing the memory, learning and communication challenges of those with Down syndrome. Specific information regarding this trial is linked on the RDS website. The initiation of this clinical trial provides tangible indication of progress in the rapidly advancing area of Down syndrome cognitive research that has received significant non-profit foundation support over the last several years. Research Down Syndrome is proud to be a leading contributor to this effort.

Your continued support helps assure the continued progress of research such as this.

Thank You!



**Roche Phase 1
Clinical Trial**
Page 1

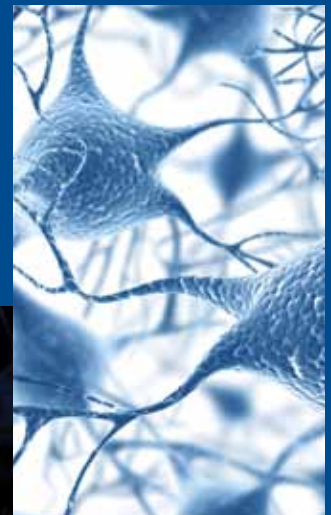
**RDS Research Grants
Announced**
Page 2

**Race for the
Extraordinary**
Page 3

**A Day of Learning
with America's Top
Golf Instructors**
Page 4

**RDS Ambassadors
Update**
Page 4

Research Update
Page 4



RDS Research Grants Announced

Research Down Syndrome is providing funding to six Down syndrome cognitive research projects. RDS is pleased to be able to support such research that has seen tremendous progress in recent years, including the September 2011 announcement by Roche of a human clinical trial to investigate the safety and tolerability of a molecule designed to address the cognitive and behavioral deficits associated with Down syndrome.

Research Down Syndrome is a leading source of private funding for Down syndrome related cognitive research. Your continued support is so greatly appreciated!

Johns Hopkins University School of Medicine:

RDS Research Center Grant entitled *"A Down Syndrome Virtual Center for Basic and Translational Studies-Cognition and Therapy in Down Syndrome"*.

These studies include continued investigations of a single dose treatment, early in the life of a Down syndrome model, of a growth factor that completely restores brain function involving learning and memory in adults that may lead to significant new therapeutic therapies. Additional studies are investigating abnormalities in brain cell signaling that might identify potential therapeutic drug targets. Finally, the RDS grant will assist clinical studies that will help establish support for a clinical trials network.

University of California, San Diego School of Medicine:

RDS Research Center Grant entitled *"Deciphering the Genetic and Mechanistic Bases for Cognitive Deficits in People with Down Syndrome: Pursuing High Priority Projects to Accelerate Development of Effective Treatments"*.

A continuation of studies examining the roles of brain cell receptors and channels in imbalances of nerve cell transmission in mouse Down syndrome models.

Another funded study continues to investigate the connections between Down syndrome and Alzheimer's disease as related to cognitive dysfunction, specifically the role of excess amyloid precursor protein (APP).

University of Arizona:

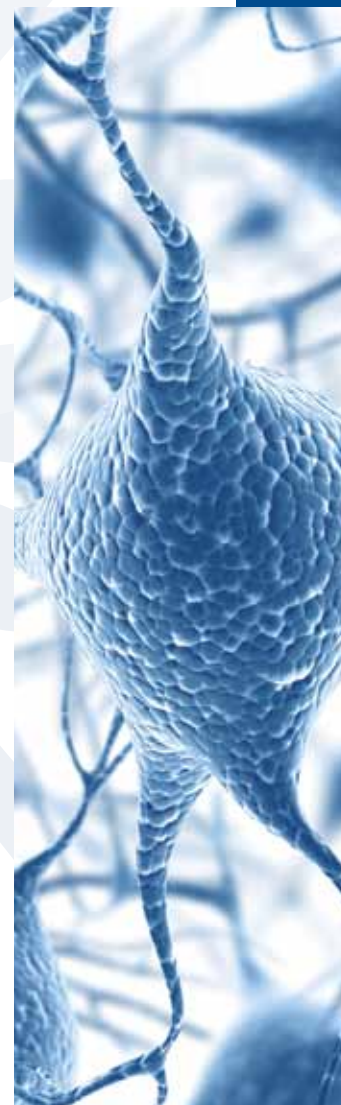
RDS Innovation Research Grant entitled *"The Neuropsychology of Down Syndrome"*.

This grant supports continued development of the Arizona Cognitive Test Battery (ACTB). The ACTB provides neurocognitive assessment in individuals with intellectual disabilities, an important advance as Down syndrome cognitive research approaches clinical trials in humans. Further developments of the ACTB include expanding the test to wider ranges of age and ability, the application of this test battery to Down syndrome sleep studies, and the development of other biological markers that might provide additional efficacy testing.

Stanford University School of Medicine:

RDS Innovation Research Grant entitled *"Reducing Cognitive Disability in Down Syndrome- Exploration of the Mechanisms of Hippocampal Dysfunction and Pharmacotherapy"*.

These studies include continued investigation of drugs that address brain cell receptor dysfunction and that may lead to potential therapeutic strategies to improve memory and sleep in Down syndrome. These studies will also continue to address in the mouse model the correlations between abnormal sleep mechanisms and memory dysfunction, again, to identify potential therapeutic strategies for improvement.



University of Texas, Austin:

RDS Innovation Research Pilot Grant entitled “Molecular analysis of proneurogenic, neuroprotective drugs on prevention of APP-induced neurodegeneration in a model of Down syndrome”.

These investigations employ the *C. elegans* nematode model to study drugs that prevent amyloid precursor protein (APP) induced nerve cell degeneration, and identify the impact of over-expression of human chromosome 21 equivalent genes in neural dysfunction. These innovative studies will provide a model that allows rapid analyses for Down syndrome research.

VA Palo Alto Health Care System: RDS Innovation Research Pilot Grant entitled “Improving Beta-adrenergic Signaling in the Treatment of Cognitive Dysfunction, an in vivo Study in the Ts65Dn Mouse Model of Down Syndrome”.

This pilot grant will support a continued evaluation of an FDA approved neurotransmitter inhibitor, Atomoxetine, to improve learning and memory in a mouse model for Down syndrome. This study could provide the basis for an accelerated clinical trial for this drug in individuals with Down syndrome. An additional investigation centers around the role of brain cell receptor subtypes in restoring cognitive function and preventing age-related nerve cell degeneration in the mouse model for Down syndrome.

Additional detail on these grants, including a listing of the research institution and the primary investigators, as well as additional information on the grant programs, can be found on our website www.researchds.org

Race for the Extraordinary

The RDS Runners Team is closing out a fantastic first year. To support the RDS mission of cognitive research to improve memory, learning and communication in persons with Down syndrome, RDS runners have participated and received support from marathons across the country, from New York City to San Diego. RDS Runners recently competed in the Bank of America Chicago Marathon. Thank you Runners!

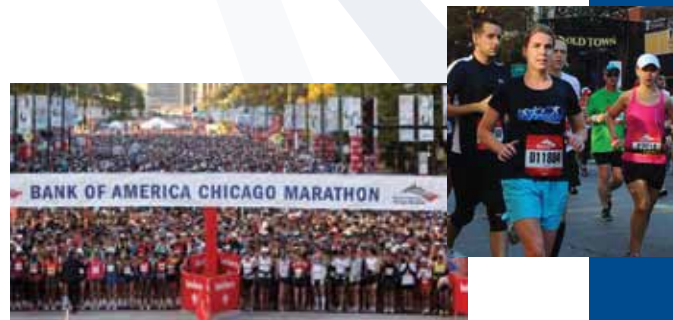
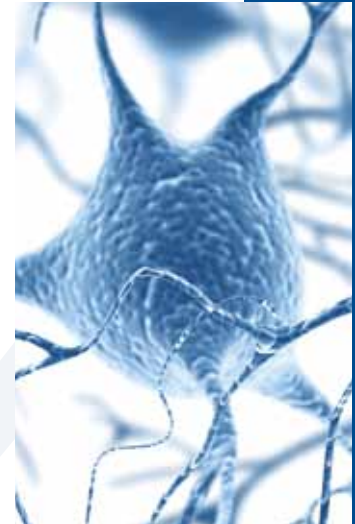
RDS is extremely excited about 2012, and our goal to fundraise in races across the country. RDS has already been accepted in 15 marathons across the country, and is now planning RDS Fun Runs as well.

RDS Runners has become **the** national charity running program to greatly expand public support for Down syndrome research. We ask our readers to consider joining our 2012 Runners team, or informing others of our racing program. Compete as an RDS Runner to support Down syndrome research that will be assisting persons have increased life opportunities thru pharmacological therapies to treat the cognitive difficulties associated with Down syndrome.

NOT A RUNNER? You can still help by:

- Planning a RDS Runner Fun Run
- Volunteering at an event or forming a cheering section
- Hosting pre-race dinners

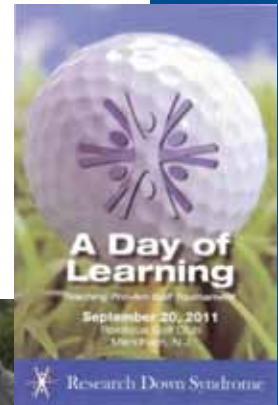
Contact us at info@researchds.org to help or learn more about the RDS Runners Program.



A Day of Learning with America's Top Golf Instructors

Karen and Rick Shea organized and hosted a Teaching Pro-Am Golf Tournament on September 20, 2011 at Roxiticus Golf Club in Mendham, New Jersey to benefit Research Down Syndrome. "A Day of Learning" was a unique event with a clinic led by PGA Tour coach Mike Bender, who Golf Digest calls "One of America's Top 10 Greatest Teachers". Participants in the event included Brad Hennefer, a young man with Down syndrome who started the Golf for Life Foundation. 24 Teaching Pros from around the country were included in each foursome. The teaching pros included PGA National Teachers of the Year, as well as LPGA National Teachers of the Year. The round of golf was followed by dinner, prizes and fun.

RDS thanks special guests Mike Bender and Brad Hennefer, as well as Lorin and Cheryl Anderson, and all the teaching professionals. Their participation made this a truly memorable day. RDS also thanks all of the sponsors, donors, and golfers who contributed to the success of this event. We are particularly thankful to Karen and Rick Shea. We are deeply moved by their devotion to this cause. Their support of Research Down Syndrome has been invaluable.



RDS Ambassadors Update

RDS would like to recognize and thank our Ambassadors, who act as representatives of RDS and support our mission of Down syndrome cognitive research awareness and financial support. Our Ambassadors continue their support by representing RDS at Down syndrome association meetings, by attending Down syndrome community events and organizing fundraisers.

THANK YOU, RDS AMBASSADORS:

Beth McKenna	Janet Caramello	Romney Croft
Steve McKenna	Julie Otto	Suzanne O'Neill
Christine DeSilva	Mike Mannor	Tamara White
Christy Sanchez	Patty Watson	Lara Font
Jack Dean	Paul Watson	



RDS Ambassador Christine DeSilva represents RDS at Tucson Buddy Walk

Research Update

Down Syndrome Research Consortium Established

The National Institutes of Health has joined with organizations interested in Down syndrome to form a consortium that will foster the exchange of information on biomedical and biobehavioral research on the chromosomal condition.

Per Dr. Yvonne Maddox, Deputy Director, NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), "A single, comprehensive forum will make the research effort to address Down syndrome more effective, minimizing duplication of effort and capitalizing on the knowledge of those with the greatest experience in the field".

RDS will participate as a consortium member. The establishment of a Contact Registry is the first order of business.

AMBASSADOR  Research Down Syndrome