

dsachieves.org

More attention.  
More achievement.  
It's time for more.

Are you ready? Here's what you can do:

- Sponsor or participate in a DownSyndrome Achieves event
- Join our corporate sponsors, or encourage your company to do so
- Make DownSyndrome Achieves part of your company's matched charitable giving program
- Make a tax-deductible donation online at [www.dsAchieves.org](http://www.dsAchieves.org)

DownSyndrome  
**Achieves**  
*Reimagine the possible.*

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Federal 501(c)(3) Tax ID#: 30-0542477

Reimagine  
the  
**POSSIBLE.**

DownSyndrome  
**Achieves**

# A Promise *of Change*

DownSyndrome Achieves is a unique research and legislative advocacy group formed around these simple ideas:

*Every child* is born with a unique heart, spirit, personality and potential. **Each enriches the world with new possibilities.**

*We are determined* to see that **each child receives what the world has to offer**, and that the world receives what each child has to offer in return.

*By driving innovations* in research and political advocacy, we can **enable those living with Down syndrome to lead meaningful and fulfilling lives** unhindered by preconceived limitations.

*A non-profit can raise more than money* and awareness. By **operating like a business** with aggressive goals, **a non-profit can raise the level of achievement in research and advocacy.**

*From birth through adulthood*, we can **level the playing field for those living with Down syndrome.**

*Expanding the horizons* for those living with Down syndrome begins with **expanding our own conception of what can be achieved.**

*It's time for us all to* **reimagine the possible.**

This is no time  
for institutional  
thinking.

As recently as 20 years ago, people with Down syndrome (DS) were shuttered away in institutions. Today, they're growing up at home with their families, and living as vibrant members of the community. More than a promise of hope, this is a story of achievement.

Down syndrome research has come so far, with so little. Imagine what we can do with more.



*"By working cooperatively, we can shorten the path to discoveries that can one day improve the quality of life for every individual living with Down syndrome."*

**Dan Coury, MD,**  
Chief of Developmental and Behavioral Pediatrics  
Nationwide Children's Hospital

# The harsh truth.

Consider this: The first clinical description of Down syndrome was published in 1866, just after the Civil War.

More than 145 years later, scientists have yet to completely understand what happens specifically at the cellular, molecular or biological level to cause the condition.

Compare that with Cystic Fibrosis (CF), which was first described clinically in 1938. Less than 50 years later, researchers discovered the gene that causes the disorder. As a result, there are now more than 30 gene therapies to treat CF.

The harsh truth is that Down syndrome research is astonishingly underfunded by the federal government. In fact, DS is one of the least-funded programs at the National Institutes of Health—and the financial commitment is falling. Between 2010 and 2011 alone, there was a nearly a 30% drop in funding for DS research.

On a *per capita* basis, the 2011 federal investment amounts to **just \$50 for every person living with Down syndrome** in the U.S. (currently, about 400,000). Because there's little funding, there's no real incentive for the best and brightest scientists and clinicians to commit to DS research. And that may be the harshest truth of all.

# The business *of more.*



DownSyndrome Achieves founder & CEO, Lito Ramirez, with Congresswoman Cathy McMorris-Rodgers, chair of the House Down Syndrome Caucus.



Lito Ramirez with Congressman Pat Tiberi, House Ways & Means Committee and key member of the House Down Syndrome Caucus.

DownSyndrome Achieves is a national organization committed to accelerating research and scientific discovery through effective state and federal legislative advocacy.

DownSyndrome  
 Achieves

We may be a non-profit organization, but we think and function like a business—with a social mission. We plan strategically to meet short- and long-term goals and understand that we are accountable to our donors, who are our investors. We subscribe to the best practices of for-profit and not-for-profit industries, including transparency, fiscal accountability and risk management.

We're also committed to collaborating and partnering with all DS advocacy groups, recognizing that each brings unique talents and skills to serve the greater good. We're stronger together than each of us would be on our own.

Above all, we're here to be the catalyst for more frequent discoveries, faster—because DS research has lagged behind for far too long.

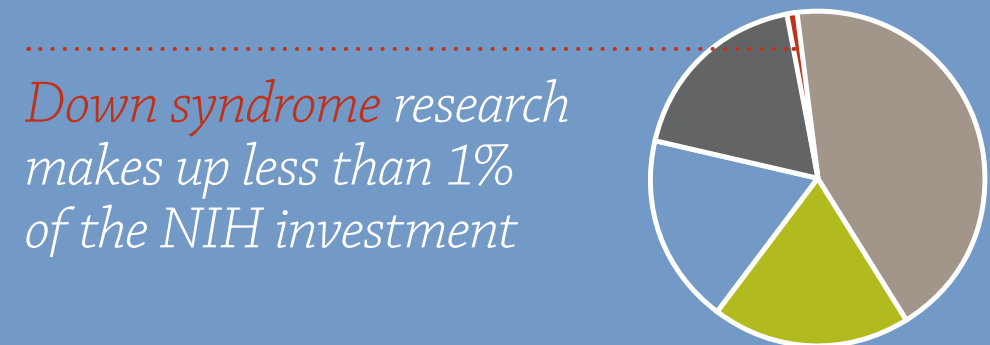
# Why your support matters

The NIH continues to underfund DS research:

	Total NIH Investment	Per Capita Spend
Autism	\$169 million	\$338
Cystic Fibrosis	\$79 million	\$2,633
Duchenne MD	\$75 million	\$1,666
Crohn's Disease	\$67 million	\$168
<b>Down syndrome</b>	<b>\$20 million</b>	<b>\$50</b>

Source: NIH Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) - February 2011

Down syndrome is one of the least-funded programs at the National Institutes of Health—and the financial commitment is falling.



*Down syndrome research makes up less than 1% of the NIH investment*

# The Down Syndrome Research Initiative (DSRI)

*The nation's first DS research consortium*

- Childrens Hospital of Pittsburgh
- Cincinnati Children's Hospital Medical Center
- Cleveland Clinic
- Nationwide Children's Hospital
- The Ohio State University
- Riley Hospital for Children
- University Hospitals / Rainbow Babies & Children's Hospital
- University of Pittsburgh

*"Thank you for spearheading this important initiative... Very little has been done in both the basic sciences and the clinical sciences of Down syndrome. But it is never too late. The Cleveland Clinic is committed to helping establish this consortium and see that it continues to function as a model Down syndrome consortium in the country."*

**Manikum Moodley, MD**

Director, Pediatric MS and Demyelinating Disorders  
Program Director, Neurofibromatosis Program  
Cleveland Clinic

## The difference *we make.*

As a business with a social mission, we thoughtfully examine the challenges and barriers that inhibit DS research, and work aggressively to develop solutions that drive innovation and scientific discovery.



In June, 2010, our approach led to an agreement among eight pediatric and academic institutions to form the nation's first DS research consortium. The Down Syndrome Research Initiative (DSRI) brings together leading medical directors, researchers and clinicians to share information, knowledge, expertise and human resources. Together we are moving DS research forward in ways that have never been attempted.

While mainstream research focuses on cognition, the DSRI studies other areas, such as chronic illnesses and behavioral conditions. By filling this research 'gap,' we're working in parallel with mainstream researchers to create a more thorough understanding of DS as a whole.

For example, no one knows (yet) why individuals with Down syndrome are predisposed to congenital heart defects, childhood leukemia, Alzheimer's disease, diabetes, high blood pressure, hyperthyroidism and celiac disease, among others. Imagine how solving these puzzles could help not only individuals with Down syndrome—but everyone?



# The Promise *of Research*



Michael was born with a congenital heart defect, a 'hole in his heart.' Down syndrome created it, and no one understands how. When he was just four months old, Michael endured more than 8-hours of open heart, lung bypass surgery to close the hole.

*Today, he's a healthy, happy kid.*

But what if that heart defect could have been repaired in the womb, before he was ever born? Imagine if a new gene therapy made it possible. It's not science fiction; it's the future. We already know that children with DS are missing certain proteins, a condition which creates the 'hole in the heart.' With more funding, we'll learn even more. So someday, the Michael's of the world won't have to undergo surgery. With your help, we can make it happen faster.

## Imagine what's possible.

The faster we accelerate research, the more we'll empower people with Down syndrome to achieve what they want most: better jobs, more independence—and most important of all, more acceptance. Individuals with Down syndrome don't want to be a burden on the community. They want to be part of it, just like everyone else.

