

# Unity



2014 Vision Report



DownSyndromeAchieves

REIMAGINE THE POSSIBLE.

# Unity



## **DownSyndrome Achieves is a national, nonprofit organization**

committed to improving the quality of life and maximizing the potential of every individual with Down syndrome by fostering innovative research partnerships that accelerate breakthrough discoveries.

# THE TIME TO ACT IS NOW.

“It’s not a roll of the dice. Among my three daughters, at least one of them will get dementia. There’s no way we’re going to beat the odds.”

## SANDRA SAVAGE

Mother of three children  
with Down syndrome

## TO SOLVE A MYSTERY.

The link between dementia and Down syndrome (DS) is as mysterious as it is destructive. As a person with DS ages, the likelihood of developing dementia or Alzheimer’s disease increases. In fact, more than 75% of people aged 65 and older who have DS also have Alzheimer’s. That’s nearly six times higher than for people in the same age group who don’t have DS.\*

“All of our kids go through so much. Then, to face dementia—it just breaks my heart. They deserve a more peaceful, pleasurable life. If DS research can help make that possible, I’m behind it,” Savage said.

## TO SUPPORT NEW RESEARCH.

Research is the key to unraveling the mysteries of Down syndrome. It is critical not only for understanding the connection to dementia, but also for the many other conditions people with DS develop—including congenital heart defects, childhood leukemia, diabetes, high blood pressure, hyperthyroidism and celiac disease. Remarkably, new research can help not only those with DS—but everyone with these conditions.

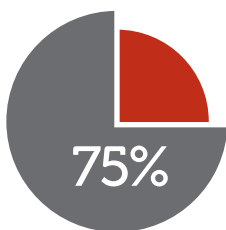
## TO IMAGINE WHAT WE CAN DO WITH MORE.

DS research has already come so far, with so little. For example, The Down Syndrome Research Initiative (DSRI) connects leading medical directors, researchers and clinicians to share information, knowledge, expertise and human resources in ways that have never been attempted before.

As a result, the DSRI has moved Down syndrome research forward in new and exciting ways. On the horizon:

- New pharmaceuticals that can potentially improve memory and learning, helping people with DS live more independently.
- New gene therapies that may one day repair congenital heart defects in the womb—avoiding the need for invasive surgery.

New treatments and therapies that may halt the progression of plaque build-up in the brain, which leads to early onset dementia.



of people aged 65 and older who  
have DS also have Alzheimer’s.

# TOGETHER, WE CAN

## REIMAGINE THE POSSIBLE.

At DownSyndrome Achieves, we are uniting with others in the DS community as never before to proactively meet the urgent challenges that lie ahead.

We follow a legacy of parents and other advocates who banded together 30 years ago to give DS a new voice. They knew the only way to create change was to seize the opportunity themselves. So they demanded that people with DS live not in institutions, but at home with their families. They insisted their children have access to the same schools as everyone else, as well as early intervention services to help improve quality of life.

Today, the cause is just as challenging—and just as critical to the lives of those living with DS. We must demand more resources for DS research, so we can shorten the path from new discoveries to longer, healthier and more vibrant lives.

It's time for us all to reimagine what's possible and come together as a community to advance DS research. Because united, we achieve more.

2013 set the stage for a breakthrough year in 2014 with the launch of the ONE21<sup>SM</sup> campaign, a new, community-wide initiative of parents, researchers and advocates for Down syndrome. We're coming together for the first time to give DS research the support—and the voice—that it so urgently needs.

Scientifically, we still know very little about DS. Compared to other conditions—such as cystic fibrosis (CF) or autism—DS has comparatively little funding for research. There are a lot of resources dedicated to the eradication of Down syndrome, but little going to improve the quality of life of those who already have DS. Improving health and maximizing quality of life is what DownSyndrome Achieves is all about. We need to do this now for our generation; for our children.

## More questions than answers.

100

PERCENT OF PEOPLE WITH DS AFFECTED BY CHALLENGES IN SPEECH AND COMMUNICATION. WHAT IF WE COULD FIND OUT WHY?

4 months

AGE BRAIN PLAQUE DIRECTLY LINKED TO DEMENTIA CAN BEGIN GROWING IN CHILDREN WITH DS. WHAT IF WE COULD PREVENT COGNITIVE DECLINE?

47

PERCENT OF INFANTS WITH DS BORN WITH A CONGENITAL HEART DEFECT REQUIRING INVASIVE SURGERY. WHAT IF IT DIDN'T HAVE TO BE THIS WAY?

ONE21<sup>SM</sup>

A COMMUNITY UNITED WILL  
ACHIEVE GREAT THINGS.

# A COMMUNITY UNITED WILL ACHIEVE GREAT THINGS

## COMING TO LIFE.

A critical goal for our community is to create the nation's first dedicated, standardized and sustainable DS biobank. In 2014, researchers from across the country gathered together to begin its planning and development. This centralized biobank is open to all DS researchers, regardless of institutional affiliation, and goes a long way toward advancing the science of DS, so therapies and best practices can be available sooner.



## What is a biobank?

A biobank is a large medical-grade refrigeration unit used to store high-quality samples of blood, tissue, DNA and other specimens that researchers need to build a more thorough understanding of DS. It is a critical tool in advancing research in speech and communications, congenital heart defects, childhood leukemia, early cognitive decline, thyroid issues and other conditions.

Biobanks have been in use since the late 1990's and are already commonplace in other research areas, such as autism, cystic fibrosis, Duchenne muscular dystrophy and psoriasis.

## GETTING CONNECTED.

As DS and Alzheimer's research becomes more and more interconnected, ONE21 is garnering the support of two of the most respected health institutions in the United States, the National Institutes of Health (NIH) and the Alzheimer's Association. This partnership further legitimizes and accelerates the mission of ONE21, as together we seek to unravel the connection between DS, dementia, leukemia and other conditions.

## GAINING MOMENTUM.

Many of the world's leading DS researchers are pledging their support to ONE21. These visionary thinkers are coming together from Harvard University, Johns Hopkins University, Massachusetts General Hospital, University of California-Berkeley and many other major institutions across the country. They're adding their voices to our cause, and through ONE21 we've made it easy to add yours.

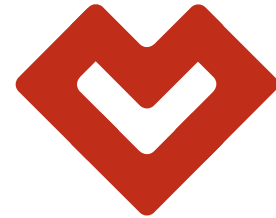
21

# ONE21

A COMMUNITY  
UNITED WILL ACHIEVE  
GREAT THINGS.



# THE HEART OF CHANGE.



Understanding the link between DS, dementia and other conditions is critical.

The time for leadership is now.

## IMPROVING QUALITY OF LIFE.

ONE21 unites advocates everywhere to improve the quality of life for people with Down syndrome. Understanding the link between DS, dementia and other conditions is critical to accelerating our progress—and there's no time to lose. For every one of the 400,000 Americans living with DS today, the potential for dementia and early cognitive decline is real. The time for leadership is now.

## JOINING TOGETHER.

Our ONE21 community is growing, and the first DS biobank is an unprecedented leap toward finding new answers and treatments. With the support of parents, researchers and advocates everywhere, the future has never looked brighter.

But, we can't rest yet. We must continue to look ahead, and fight for a future where quality of life is no longer an issue—and people with DS can have the same opportunities as everyone else to reimagine the possible.

How you can support

## DownSyndrome Achieves & ONE21:

- > Join ONE21 by visiting [www.ONE21.org](http://www.ONE21.org).
- > Sponsor or participate in a DownSyndrome Achieves event.
- > Join our corporate sponsors or your 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).

All ONE21-directed donations are allocated exclusively to ONE21.

**ONE21**<sup>SM</sup>

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one21.org  
e: help@ONE21.org



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DownSyndrome Achieves  
PO Box 1596  
Dublin, OH 43017

e: help@dsAchieves.org  
866.568.8949  
Federal 501(c)(3) Tax ID#: 30-0542477