BANKING ON BREAKTHROUGHS

The DSA biobank is helping researchers improve the health and well-being of those with Down syndrome by decoding links to common ailments that affect us all.





Our mission: to rewrite the future

By age 40, most every person living with Down syndrome will develop the pathology for Alzheimer's Disease, including the neurofibrillary brain tangles and beta amyloid brain plaque that make it the sixth leading cause of death in the United States.

People with Down syndrome also face significant risk for severe congenital heart defects, childhood leukemia, and epilepsy. In addition, autism, autoimmune disease, and numerous other chronic illnesses and diseases are all too common occurrences.

At DownSyndrome Achieves, we believe people with Down syndrome should have the ability to fulfill their full potential, free from challenging health conditions that can negatively impact quality of life.

Medical Problems

common in Down Syndrome



DownSyndrome Achieves is a unique research advocacy group that focuses exclusively on accelerating research through improvements in research infrastructure.

About DownSyndrome Achieves

We are creating the critical tools researchers need to make life healthier for people with Down syndrome.

Since our founding in 2011, DownSyndrome Achieves has had an impressive start. In just a few short years, we **formed a national Down syndrome research consortium,** advanced plans for a national DS biobank, formed strategic partnerships with top tier research institutes and developed a national campaign for parents and caregivers to encourage their involvement and interest in research.

We envision a future when Down syndrome comes without health complications. When people with Down syndrome can maximize their potential and lead healthier, more active, and independent lives. It is widely recognized that biobanks are a critical tool in translating biomedical research into improved health outcomes.

Biobanks have been in use since the 1990s. While there are dedicated biobanks for almost every common and serious health condition—such as cancer, autism, Parkinson's Disease, cystic fibrosis, spina bifida, and others—no national biobank has existed for Down syndrome.



Lito Ramirez | TEDxColumbuS

DownSyndrome Achieves CEO, Lito Ramirez, gives a powerful TEDx talk on the "joy, love and beauty" of raising a child with DS. Watch it here: dsachieves.org/tedx A biobank is a collection of biospecimens such as blood, hair, tissue, and DNA, which are used for medical research in the development of new treatment regimens for chronic illnesses and diseases. Today, they are a key resource for many academic, commercial, governmental, and pharmaceutical institutions.

Turning vision into reality, hope into action

In December 2015, DownSyndrome Achieves launched an effort to develop a national, dedicated biobank for Down syndrome. The DSA Biobank, located at Cincinnati Children's Hospital Medical Center, serves as a national central repository for biospecimens donated by individuals with DS and their immediate families.

High quality human biospecimens such as blood, plasma, DNA, RNA, and others) are the fuels that drive clinical and translational research. These biospecimens and associated patient health data are required to define both the biology of patients and the biology of their health condition. They must be collected and processed following rigorous standards that safeguard quality, and they must be annotated with appropriate patient-related and biospecimenspecific information. Only a dedicated biobank can do such intricate work.

High-quality, well-annotated biospecimens are in very high demand for research but extremely limited in availability. This lack of biospecimens and annotated data has hobbled the pace of scientific discovery in Down syndrome research in the U.S. and globally. In fact, ClinicalTrials.gov, an online registry of publicly and privately supported human clinical studies conducted worldwide, shows less than 50 active clinical studies in Down syndrome. This trails far behind other research categories, compared with the 270 studies in Cystic Fibrosis and the 351 active studies in autism. The DSA Biobank can help close that gap.

The DSA Biobank is a powerful resource for biomedical researchers to elevate the standard of care for health conditions that cooccur with Down syndrome. The biospecimens we collect enable researchers to increase scientific understanding of the biology, etiology, and pathophysiology of DS. They are available to any investigator seeking to answer important questions on health and disease in Down syndrome through research initiatives that are consistent with the philosophical vision and ethical standards of the DSA Biobank. This will facilitate the discovery of new therapeutics and diagnostics that will ultimately improve the health and wellbeing of people with DS and others.



Today, there are less than 50 active clinical studies in Down syndrome The DSA Biobank is going to change that, making more—and better research a reality. Our 5-year goal is to collect up to 500 blood samples from individuals with DS and their immediate families.





we now have access to the critical samples we need to continue our work.

–DR. DIMITRIOS KARAMICHOS, PHD UNIVERSITY OF NORTH TEXAS HEALTH SCIENCE CENTER

500

These samples are crucial to advancing translational research that will yield improved diagnostics and therapies for people with Down syndrome—delivered in years rather than decades.

Leadership Team

Lito Ramirez

President & CEO DownSyndrome Achieves

Lito Ramirez is president & CEO of DownSyndrome Achieves, the DSA Biobank's sponsor. Lito has more than 20 years of senior level experience in brand

development, strategic marketing, and product development specializing in B2B health care. Lito previously served as press secretary to Ohio Lieutenant Governor Nancy P. Hollister, and as Account Director for an oncology advertising agency where he helped manage the brand launch and strategic marketing initiatives for \$2.2B oncology biotech client. Lito also served as a Consultant, Sr. Product/Marketing Manager for Cardinal Health Specialty Solutions, where he directed strategic brand and marketing initiatives for a \$1.5B specialty pharmaceuticals division with an emphasis in health care technology, and rheumatology, urology, and nephrology therapeutic areas. He is TEDxColumbus speaker, and a published author, whose work has appeared in national health care journals, including the Journal of Medical Practice Management and Health Care Marketing Report. He is the father of a 10yr old son with Down syndrome.

William C. Nichols, PhD

Professor of Human Genetics Associate Director of Research Cincinnati Children's Hospital Medical Center

William C. Nichols, PhD obtained his BS with Distinction in Genetics & Development from the

University of Illinois and his PhD in Medical Genetics from Indiana University. He is principal investigator for the DSA Biobank at Cincinnati Children's Hospital Medical Center (CCHMC). He is Associate Director of Research, Division of Human Genetics, at CCHMC, and Professor of Human Genetics, Department of Pediatrics, at the University of Cincinnati College of Medicine. Dr. Nichols is additionally Director of the National Biological Sample and Data Repository for pulmonary arterial hypertension (PAH), which is an effort that has banked biological samples, clinical, and genetic data for close to 3,000 PAH patients. His lab was instrumental in identifying the first gene associated with the disorder. Dr. Nichols' ongoing research interests include genetic analysis of murine pulmonary hypertension, Down syndrome, and Parkinson disease.



Nicole White

DSA Biobank Coordinator

Nicole White is Biobank Coordinator for the DSA Biobank, and brings strong expertise, technical insight, and strategic design to the project. Nicole has



more than 18 years of research experience, specializing in the creation of new research core facilities. She currently serves as Research Shared Facilities Administrator at Cincinnati Children's Hospital Medical Center where she oversees 28 different research facilities including biobanks, bioinformatics and translational research, among others. Nicole has four children, including a daughter with Down syndrome.

Michael W. Pauciulo, MBA

Assistant Professor of Human Genetics Director, Discover Together Biobank Cincinnati Children's Hospital Medical Center

Michael Pauciulo is Director of the CAP accredited Discover Together Biobank at CCHMC, which



facilitates the acquisition, processing, storage, and distribution of biospecimens/data for the DSA Biobank. The Discover Together Biobank houses repositories and cohorts for a wide variety of investigators both internal and external to CCHMC. Additionally, the Discover Together Biobank is home to the institutional sample collection of over 95,000 individuals that is a request governed resource for research and discovery at CCHMC. He obtained his BS in Cell & Structural Biology from the University of Illinois and his MBA in Operations and Management from the University of Cincinnati. He is Assistant Professor of Human Genetics, at CCHMC, and Assistant Professor of Pediatrics, Department of Pediatrics, at the University of Cincinnati College of Medicine.

Jason Widmer

Board Chair Jason Widmer is a Chief Engineer at Honda R&D Americas, Inc. He is also father to Brooke, his young daughter who has Down syndrome.

Mark Weitzel

Treasurer

Mark Weitzel is a Vice President of Commercial Lending at JP Morgan Chase Bank.

Elizebeth Maag, JD

Secretary Elizebeth Maag is Senior Legal Counsel for Aware, an Al solutions company.

David Bastulli

David Bastulli is a Strategic Account Manager for Delta Medical Systems/Siemans Heathineers.

Rebecca Bowman

Rebecca Bowman is Director, Customer Operations, North America, for the Clorox Company.

Moti Bycel

Moti Bycel is a Senior Enterprise Customer Success Manager for LinkedIn Sales Solutions. He is also father to Ayala, his young daughter who has Down syndrome.

Steven Fields

Steven Fields is a senior consultant at Cramer & Associates.

Kevin Fox

Kevin Fox is the Founder of Foxwerx Group, a marketing & communications agency based in Columbus, OH.

Jillian Froment

Jillian Froment is Executive Vice President and General Counsel for the American Council of Life Insurers.

Joe Garber, JD, CPA Joe Garber is Senior Deputy Counsel at Root Insurance.

Gregory Moraski

Gregory Moraski is Vice President of Claims at Security First Insurance.

Cara Ryan

Cara Ryan is Senior Manager, Retail Media & eCommerce at Abbott Nutrition.

Michael Vaccaro

Michael is Director of eCommerce Sales & Marketing at The Scotts Miracle-Gro Company. He is the older brother of Daniel, who has Down syndrome.

Benefits

What are the Benefits of Participating in Research

- To take an active role in society by furthering our understanding of social, health, and behavioral challenges that families living with DS may face daily. You have the power to help turn those challenges into positives for other families.
- To contribute to the advancement of research that can make life healthier for people with DS, and accelerate the timeline for scientific discoveries in years rather than decades.
- To improve the well-being or quality of life of your loved one with DS by arming you with more information and treatment options

What are your Rights if You Participate in Research?

If you or a loved one with DS chooses to participate in research, you have the legal right:

- To give your consent or permission to participate in the research study
- To be told the purpose of the research study
- To be told of the possible risks or discomforts you may experience if you decide to participate
- To understand how your personal information will be kept private
- To withdraw from the study at any time

If you have questions, concerns, suggestions about research, a research-related injury, or questions about your rights as a research participant, please email us at dsabiobank@dsachieves.org.



Our Partners







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BREAKTHROUGHS BEGIN WITH YOU

You can help us rewrite the future.

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