



GLOBAL
DOWN SYNDROME
FOUNDATION®

How to Establish a Medical Care Center for Down syndrome

*DS AIA Leadership Conference
Thursday, February 22, 2018 • Denver, CO*

Presenter: Michelle Sie Whitten, President & CEO

Global Down Syndrome Foundation

A Unique Affiliate Model!

The Global Down Syndrome Foundation is part of a network of affiliate organizations that work closely together on a daily basis to deliver on our mission, vision, values, and goals:

Global & Affiliates



❖ **Global:** was established as a 501(c)3 in 2009 and is “Dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education, and Advocacy”

❖ **Affiliates are:**

- Established with a lead gift from Anna & John J. Sie Foundation
- Must work closely together to benefit people with Down syndrome
- Must be self-sustaining financially

Global Affiliates at a Glance

Sie Center for Down Syndrome

- ❖ **Over 1,400 unique patients from 27 states, 1 US territory and 10 countries**
 - Nationally renowned experts such as Dr. Fran Hickey, Patricia C. Winders and mentees for future generations
 - 14 Full-time equivalents providing multi-disciplinary care
- ❖ **Clinical Research Core competencies – DS and Aspiration, DS and Infantile Spasms, DS and Autism, DS and Sleep Apnea**
 - Other competencies – Physical Therapy, Behavior, Educational Influences, Speech, Feeding and more
- ❖ **Specialty Clinics Offered - 8**
 - Mental Wellness Clinic
 - Medical Clinic
 - ENT Clinic
 - Sleep Clinic
 - Feeding & Swallowing Clinic
 - Infant Clinic
 - Telemedicine Clinic
 - School age Clinic



Global Affiliates at a Glance

34 Labs and over 120 Scientists

Alzheimer's Disease



Bettcher



Dell'Acqua



Hoeffer



Kennedy



Potter



Xue

Cognition, Autism and Brain Function



Chen



Maclean



Jones



Maier



Mueller



Santos



Shaikh



Stitzel

Immunology



Lenz



Hsieh



Shen



Spritz



Sullivan



Yeager

Stem Cells and Development



Bilousova



Klymkowsky



Link



Old



Olwin



Pearson

Advanced Genetics and Genomics



Blumenthal



D'Alessandro



Dowell



Johnson



Liu



O'Connor

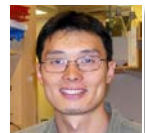
Leukemia



DeGregori



Espinosa



My personal story



Anna and John J. Sie



Patrick & Sophia Whitten

Our medical journey

Amnio, Birth, Open Heart Surgery

- ❖ Prenatal Diagnosis via amnio at 19 weeks
- ❖ Complete atrial ventricular septal defect diagnosed at 32 weeks
- ❖ Open-heart surgery at 3 ½ months old



Our medical journey

A Great Heart Team in CO



Quest for the Best

Thomas Center for DS in Cincinnati



Quest for the Best

Thomas Center for DS in Cincinnati



Quest for the Best

Thomas Center for DS in Cincinnati




Our Timeline

- ❖ **2003 Sophia was born**
 - Linda Crnic organizes a “state of the union” day for me and two other parents in DC in conjunction with her T21 research conference
- ❖ **2004 Visit with Dr. Elias Zerhouni, the then Director of the National Institutes of Health (NIH) – advises us to build an “academic home” for Down syndrome research and medical care**
- ❖ **2006 First visit to Thomas Center for Down Syndrome at Cincinnati Children’s Hospital**
- ❖ **2006-2007 Visited Kennedy Krieger Institute/Johns Hopkins, Stanford/Lucille Packard Children’s Hospital, Down Syndrome Center of Children’s Hospital of Pittsburgh, Down Syndrome Program at Boston Children’s Hospital**
- ❖ **2008 Organized a Scientific Summit to ascertain if Down syndrome research could produce any results in our lifetime**
 - Signed agreement with Children’s Hospital Colorado to establish a medical center for Down syndrome starting with Patricia C. Winders; Dr. William I. Cohen consulting
 - Signed the agreement to establish the Crnic Institute for Down syndrome
- ❖ **2009 Established the Global Down Syndrome Foundation**
- ❖ **2010 NOVEMBER – fortunate to have Dr. Stephen Daniels recruit Dr. Francis Hickey to lead our clinic**

Importance of Research and Medical Care

We decided to go with our home court advantage and build the academic home here in Colorado...

DS Clinic	Great Science	Great Medical Care	Did they work together?
Down Syndrome Center at Children's Hospital of Pittsburgh	--	+	
Thomas Center for Down Syndrome at Cincinnati Children's Hospital	--	+	
Down Syndrome Program at Boston Children's Hospital	--	+	
Lucile Packard Children's Hospital	+	- / +	
Down Syndrome Clinic and Research Center at Kennedy Krieger Institute	+	+	

Two Important Fellows



Dennis Matthews, MD

- Fischahs Chair Pediatric Rehabilitation Medicine
Chairman
- Chair and Professor of Physical Medicine and Rehabilitation
- Medical Director Rehabilitation Center
- PPAARDI-in-chief
Pathology, Psychiatry/Behavioral Sciences, Anesthesiology,
Audiology, Speech Pathology and Learning Services,
Rehabilitation Medicine and Diagnostic Imaging

Stephen R. Daniels, MD, PhD

- Chairman, Department of Pediatrics
University of Colorado School of Medicine
- Pediatrician-in-Chief
- L. Joseph Butterfield Chair in Pediatrics
Children's Hospital Colorado
- Professor of Pediatrics

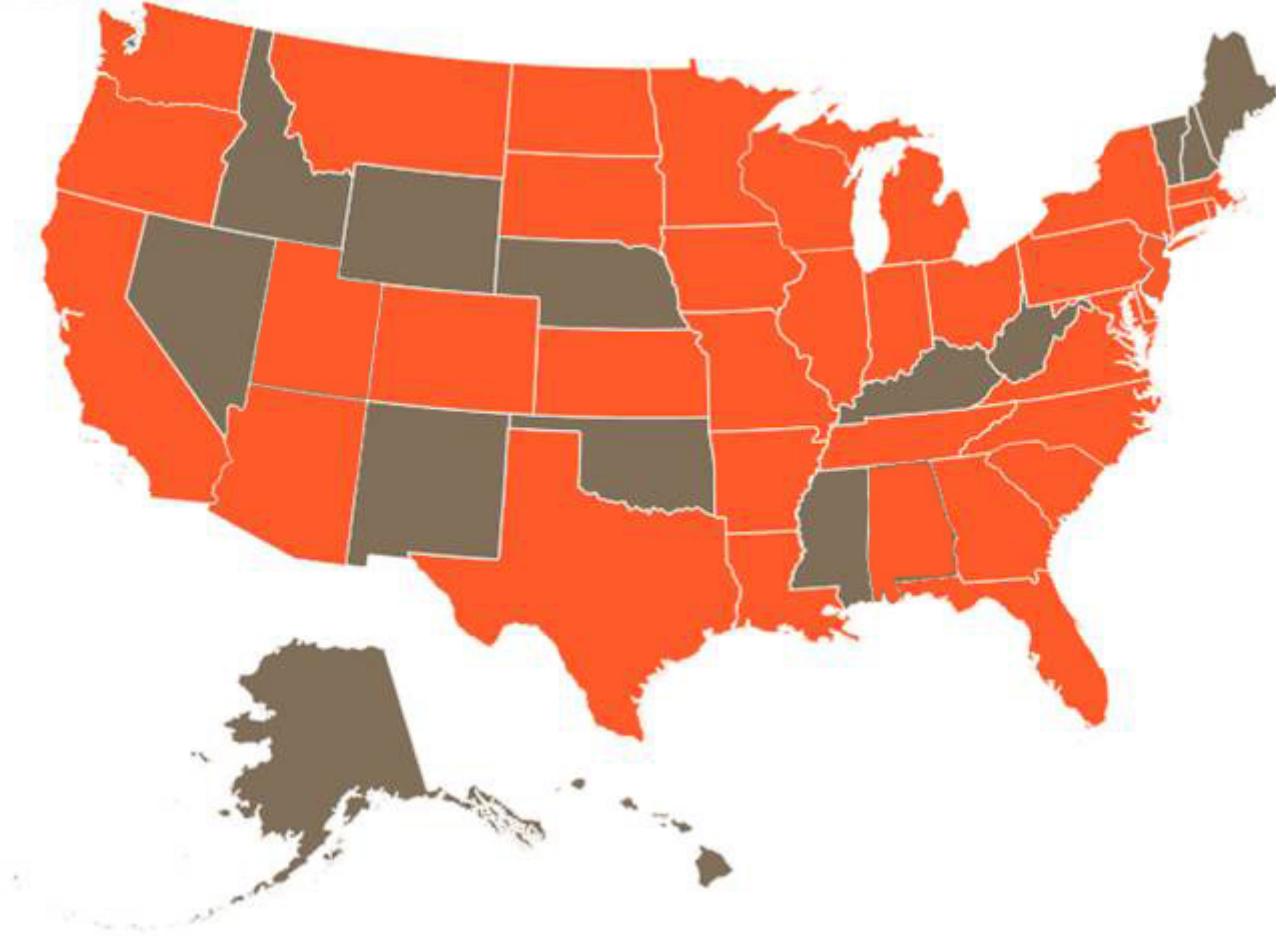


So what did we learn that could be useful to you?

- ❖ Find out what Down syndrome program or clinic exists near you
– there are specialty clinics throughout the nation and as far as we can tell, only 12 states that do not
- ❖ A program or clinic that exists may not be what you are interested in building (e.g. it is only a half day once a month versus once a week, it does not have strong speech or physical therapy, it does not have a feeding clinic, it is too far for the majority of your constituents, it may only service children)
 - Consider building upon what already exists
 - Consider becoming a partner that provides referrals, feedback and fundraising – become a Community Advisory Board member

There are “Down Syndrome Clinics” All Across the US

States in orange have at least one Down syndrome medical care center, while states in brown currently have none.



Most Clinics are Pediatric

- ❖ Over the 9 years since the Sie Center began seeing patients we've learned about so many other DS Clinics across the US...

Waisman Center-University of Wisconsin Madison
 UAMS Adult Medical Genetics & Down Syndrome Clinic
 Down Syndrome Program, Providence
 Sie Center for Down Syndrome at Children's Hospital Colorado
 Arkansas Children's Hospital Down Syndrome Clinic
 Rady Children's Hospital San Diego Down Syndrome Center
 Down Syndrome Clinic at Nemours
 Emory University Down Syndrome Clinic
 Deaconess Riley Children's Specialty Center - Down Syndrome
 Adults with Down Syndrome Specialty Clinic
 Center for Disabilities & Development
 Down Syndrome Clinic & Research Center
 Euro-Peds National Center for Intensive PT
 Boston Children's Hospital Down Syndrome Program
 MassGeneral Hospital Down Syndrome Program
 Children's Hospital of New Orleans Down Syndrome Clinic
 Greenwood Genetic Center
 Albert Pujols Wellness Center for Adults with Down Syndrome
 Down Syndrome Center St. Louis Children's Hospital
 Children's Mercy Down Syndrome Clinic
 Down Syndrome Clinic, Columbus OH
 Blick Clinic
 Down Syndrome Center, Charlotte NC
 Down Syndrome Center of Western Pennsylvania
 Adult Down Syndrome Clinic, Columbus OH
 Rainbow Child Development Center/Down Syndrome Clinic
 Judy Center for Down Syndrome

Baylor Transition Medicine Clinic
 Akron Children's Down Syndrome Program
 Down Syndrome Clinic, Dallas TX
 Down Syndrome Clinic of Houston
 Developmental Pediatrics
 Down Syndrome Clinic of Wisconsin
 Down Syndrome Center at Hope Haven Children's Clinic
 Trisomy 21 Program at The Children's Hospital of Philadelphia
 Aging & Developmental Disabilities Program
 AHRC New York City
 Behavioral Development Clinic & NICU Follow Up Clinic
 CDRC Down Syndrome Program
 Center for Down Syndrome, Palo Alto CA
 CHOC Children's Down Syndrome Program
 Comprehensive Down Syndrome Program
 Coordinated Treatment Center
 Developmental and Behavioral Pediatrics
 Down Syndrome Assessment Center
 Down Syndrome Clinic, IN
 Down Syndrome Clinic, MN
 Down Syndrome Clinic at Vanderbilt
 Down Syndrome Program, WA
 Jane & Richard Thomas Center for Down Syndrome
 Mailman Center for Child Development
 Medical University of South Carolina
 Palmetto Health Down Syndrome Clinic

Pediatric Down Syndrome Clinic, AZ
 Robert Warner MD Center for Children with Special Needs
 Sanford Children's Down Syndrome Clinic
 Shodair Children's Hospital
 UC Irvine Adult Down Syndrome Clinic
 UCSD Adult Down Syndrome Clinic
 Duke Children's Comprehensive Down Syndrome Program
 Down Syndrome Clinic - Lacrosse
 Children's Mercy Down Syndrome Clinic - Kansas City
 Down Syndrome Clinic, Alabama
 Care of Children with Down Syndrome, DC

White = All Ages/Adult (19)
 Gray = Pediatric (46)

Important Considerations

Location

- ❖ There are many advantages of being embedded in a hospital
 - Referrals to audiology, sleep, ENT, GI, heart, etc
 - Systems change – the other divisions of the hospital suddenly start using people first language and refer patients that come in through ER or other departments to the specialty clinic
 - Systems change rotations – depending on the type of hospital there can be training for new generations of medical professionals
 - CLINICAL RESEARCH IS SO IMPORTANT
 - No need to spend funds on bricks and mortar
- ❖ HOWEVER, if a large donor wants a stand alone building that can be affiliated with a hospital or satellite of a hospital that is something to consider...generally follow the key donors lead

Important Considerations

Referral Strength & Constituent Knowledge

- ❖ What percentage of your constituents are children versus adults (over 18)? This may help you understand if your interests are in pediatric care or adult care or both.
 - How many children could you be referring to the such a center each year?
How many adults?
 - How would you refer and promote? How would you measure success?
 - Understand from the hospital's side, what insurance can be accepted and take that into account if you use a survey of your constituents to help answer these questions
- ❖ What services/clinics would you want the center to provide?
 - A survey of your constituents will help answer this question
 - There is a fairly standard list of services/clinics that could be important to a Down syndrome medical center or program (Doctor, Nurse, Physical Therapist, Speech Language Pathologist, Occupational Therapist, Feeding Specialist, Psychologist, etc)

Important Considerations

Assisting to Fund the Center

- ❖ From our experience we have found that \$200K a year is a “magic number” to help launch a weekly medical care center for patients with Down syndrome providing at least three expertise (e.g. MD, Behavioral expert, Speech Therapist)
- ❖ What key donors are determined to help establish a specialty medical clinic or could be easily convinced of this priority?
 - Do any of your donors have the capacity to fund an endowed chair? Generally hospitals offer such named chairs starting at \$2 million (this can usually be paid over many years); ask for multi-year commitments.
- ❖ What advisory board can be created to help fund or fundraise for this center each year?
- ❖ Incorporate the expectation of feedback from the beginning
 - Timely programmatic updates and financial updates empower you to continue fundraising from existing donors and expand your donor base

Important Considerations

Be Prepared & Create a Financial Model

- ❖ Identify an advocate at the hospital to help navigate the negotiation/process
- ❖ Know what you are funding
 - Have the hospital provide you with the salary or salary range of all the types of medical professionals you could envision at your center
 - Hospitals will have an admin/overhead allocation per staff that is quite high (could be 35%) so make sure that is factored in
 - Model out five years of the center expenses
- ❖ Ideally have access to a model within the hospital for another specialty clinic
- ❖ Understand what spacing issues there may be and what specialty clinics you may share space with
- ❖ Incorporate the desire for clinical research, research grant activity, and publications for the future

Catalyzing Your Belief & Resolve

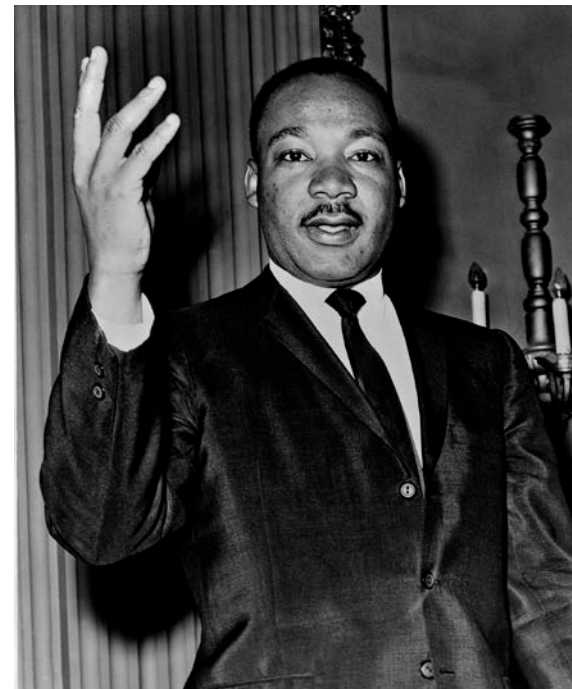


Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

~ Margaret Mead

Of all the forms of inequality, injustice in health care is the most shocking and inhumane.

~ Martin Luther King Jr.



The Global Dream

A United & Coordinated Future

- ❖ **One day...to assist local medical care centers to launch or become more robust**
- ❖ **To have the medical records coordinated across centers**
- ❖ **To have natural history research projects through thousands of patients with Down syndrome**
- ❖ **To have a state of the art biobank that is contributed to by the coordinated centers and shared for basic and clinical research**
- ❖ **To have clinical research published and influencing medical guidelines that then significantly improve the health of people with Down syndrome**

THANK YOU from the Global Family!

Happy to Take Questions

