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
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
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

Establishing A Down Syndrome Medical Center
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…

<table>
<thead>
<tr>
<th>DS Clinic</th>
<th>Great Science</th>
<th>Great Medical Care</th>
<th>Did they work together?</th>
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<tr>
<td>Down Syndrome Center at Children’s Hospital of Pittsburg</td>
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<td>Thomas Center for Down Syndrome at Cincinnati Children’s Hospital</td>
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<td>Down Syndrome Program at Boston Children’s Hospital</td>
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<td>Down Syndrome Clinic and Research Center at Kennedy Krieger Institute</td>
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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
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
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...

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<thead>
<tr>
<th>White = All Ages/Adult (19)</th>
<th>Gray = Pediatric (46)</th>
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<tbody>
<tr>
<td>Baylor Transition Medicine Clinic</td>
<td>Pediatric Down Syndrome Clinic, AZ</td>
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<td>Akron Children’s Down Syndrome Program</td>
<td>Robert Warner MD Center for Children with Special Needs</td>
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<td>Down Syndrome Clinic, Dallas TX</td>
<td>Sanford Children’s Down Syndrome Clinic</td>
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<td>Down Syndrome Clinic of Houston</td>
<td>Shodair Children’s Hospital</td>
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<td>Developmental Pediatrics</td>
<td>UC Irvine Adult Down Syndrome Clinic</td>
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<td>Down Syndrome Clinic of Wisconsin</td>
<td>UCSD Adult Down Syndrome Clinic</td>
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<td>Down Syndrome Center at Hope Haven Children’s Clinic</td>
<td>Duke Children’s Comprehensive Down Syndrome Program</td>
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<td>Trisomy 21 Program at The Children’s Hospital of Philadelphia</td>
<td>Down Syndrome Clinic - Lacrosse</td>
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<td>Aging &amp; Developmental Disabilities Program</td>
<td>Children’s Mercy Down Syndrome Clinic - Kansas City</td>
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<td>AHRC New York City</td>
<td>Down Syndrome Clinic, Alabama</td>
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<td>Behavioral Development Clinic &amp; NICU Follow Up Clinic</td>
<td>Care of Children with Down Syndrome, DC</td>
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<td>CDRC Down Syndrome Program</td>
<td>Greenwood Genetic Center</td>
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<td>Center for Down Syndrome, Palo Alto CA</td>
<td>Albert Pujols Wellness Center for Adults with Down Syndrome</td>
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<td>CHOC Children’s Down Syndrome Program</td>
<td>Down Syndrome Center, St. Louis Children’s Hospital</td>
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<td>Rainbow Child Development Center/Down Syndrome Clinic</td>
<td>Judy Center for Down Syndrome</td>
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<td>Waisman Center-University of Wisconsin Madison</td>
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<td>UAMS Adult Medical Genetics &amp; Down Syndrome Clinic</td>
<td>Down Syndrome Program, Providence</td>
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<td>Rady Children’s Hospital San Diego Down Syndrome Center</td>
<td>Down Syndrome Clinic at Nemours</td>
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<td>Emory University Down Syndrome Clinic</td>
<td>Deaconess Riley Children’s Specialty Center - Down Syndrome</td>
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<td>Euro-Peds National Center for Intensive PT</td>
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<td>Mass General Hospital Down Syndrome Program</td>
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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 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
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