

Cardiology 2018

**The Challenges of the Fontan Circulation — Where We Are,
Where We Need to Be**

*Patient and Family-centered Advocacy Goals: Where Are We with
Influencing the Healthcare Community and Other Societal Agencies?*

*Scott Leezer
February 25, 2018*



Personal History

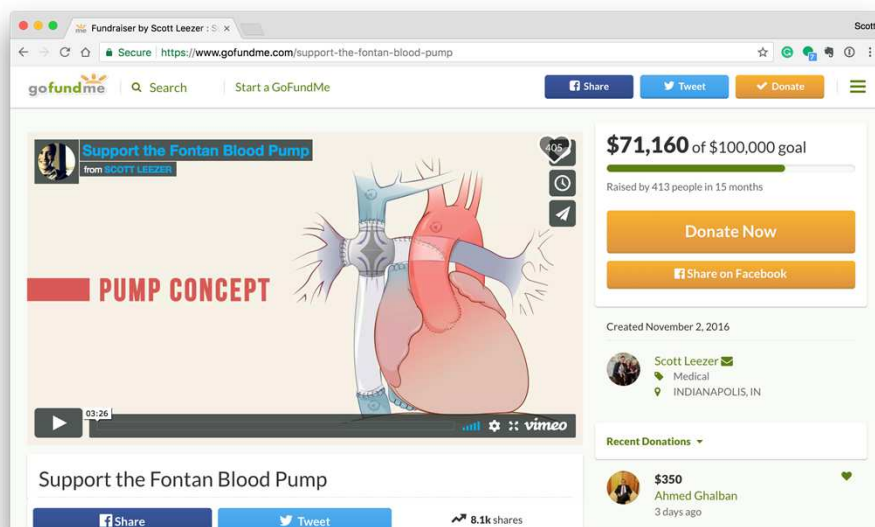
- Single Ventricle, Double Inlet Left with Transposition of the Great Arteries
- Modified Fontan, 1989 (Puga)
- Fontan conversion to extracardiac conduit, 2010 (Dearani)
- Pacemaker 1989, six months after Fontan



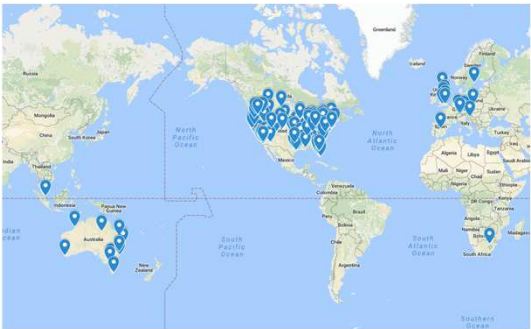
Professional History



- Served as an aide to Senator Dick Durbin (D-IL), assisted with health care policy
- Currently, VP at CURA Strategies, a strategic communications and government relations consulting firm in Washington, D.C.
- Worked with various congenital heart disease organizations on advocacy initiatives.

Patients & families desire opportunities to be involved in efforts to improve outcomes.

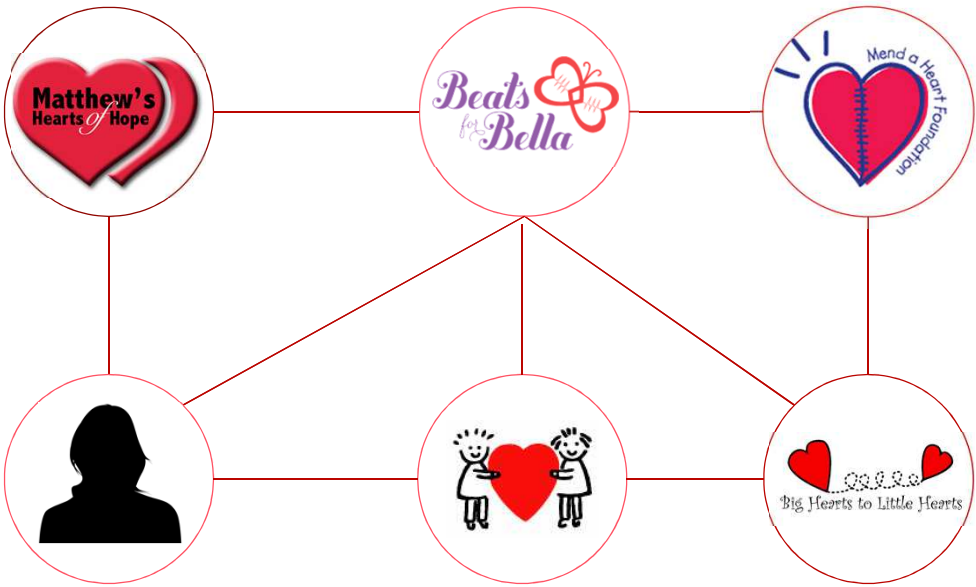


Donors from 5 continents



 650,335 Impressions	 17,010 Engagements
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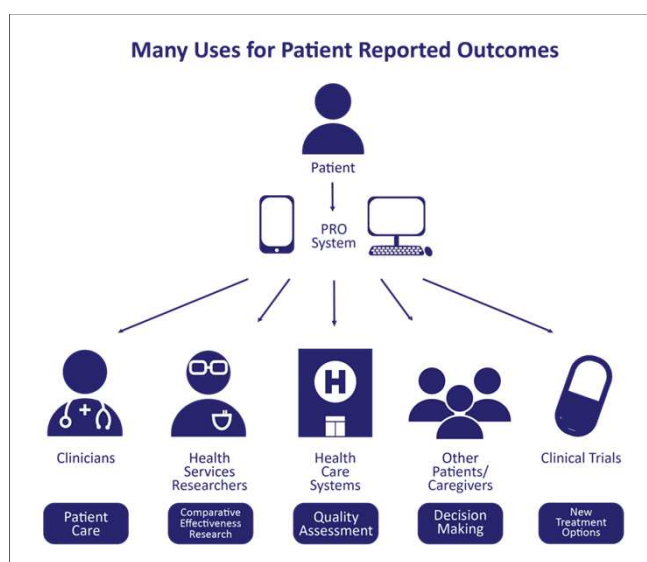
\$410,000+

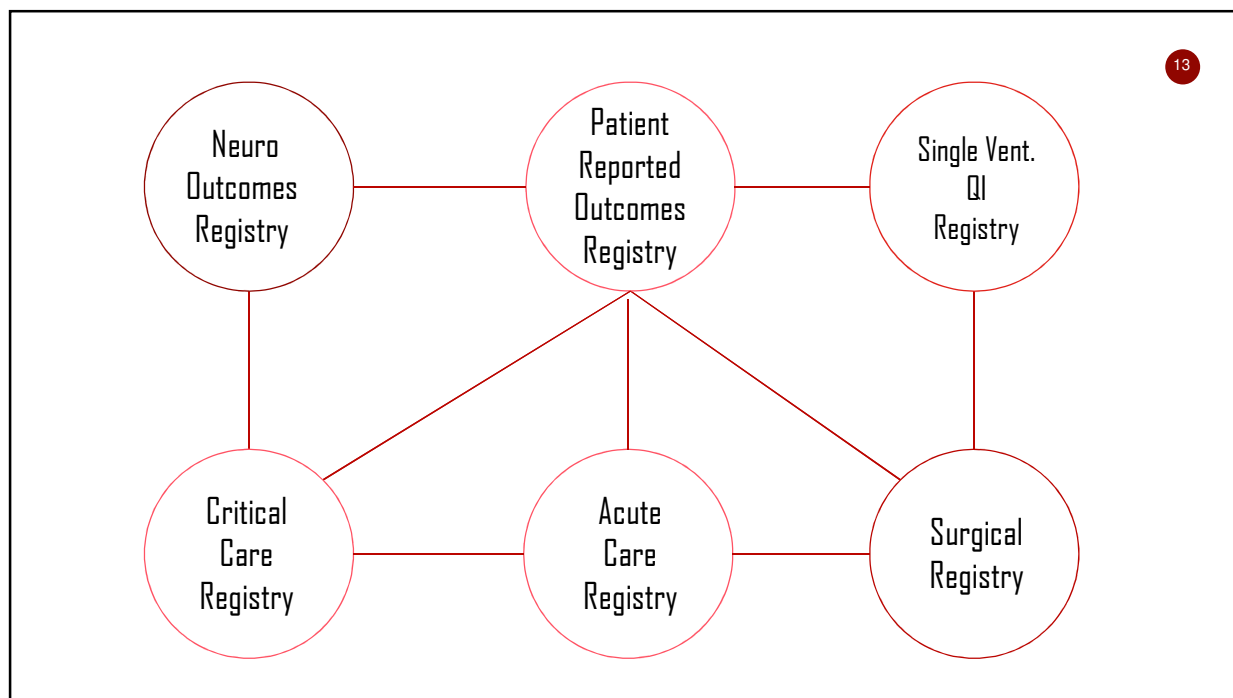


Patients and families have an increasing desire for the data and trends necessary to make informed decisions about their child's care.

“Expand the Team”

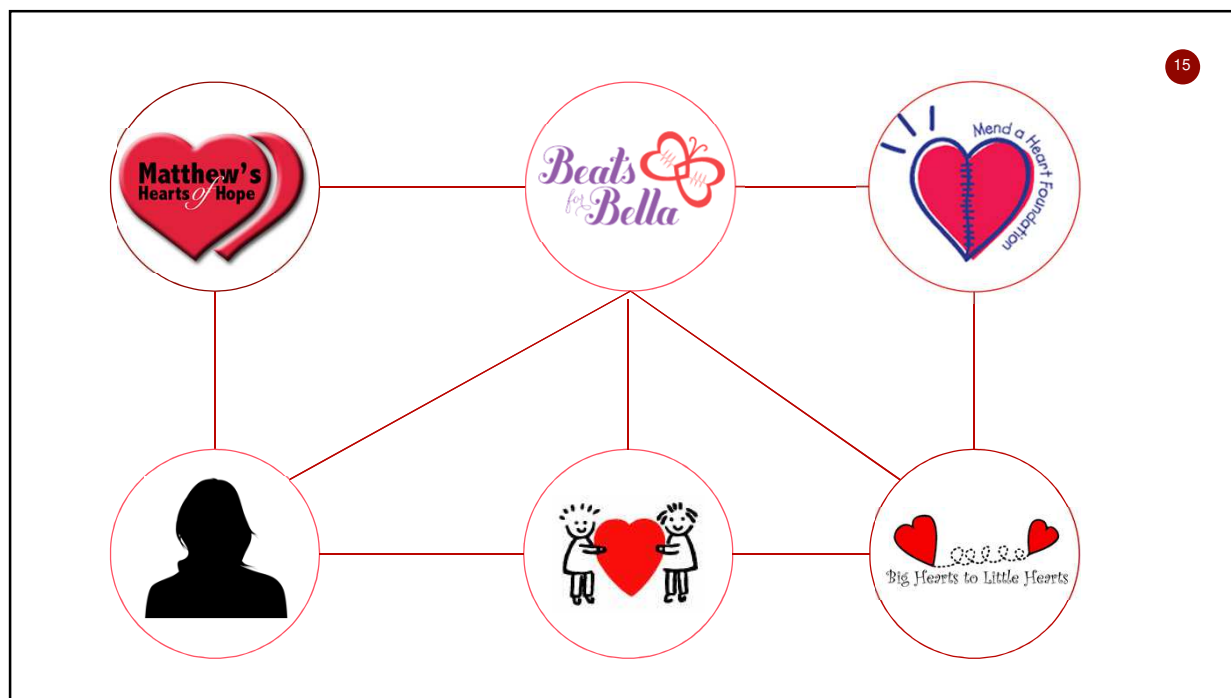
POTENTIAL ELEMENTS OF PRO SURVEY QUESTIONS	
Quality of Life	Patient Satisfaction
Activities of Daily Living	Physical Functioning (Sleep, Mobility, Fatigue)
Need for Therapies (Physical, Occupational, Feeding and Speech)	Mental Health (Depression, Anxiety, ADHD)
Employment Status	Disability Status
Need for Gastrostomy Tube	Educational Achievement
Family Stress and Financial Impact	Developmental Milestones and Neurodevelopmental Challenges





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*Increase the Impact of CHD Research
Funding Organizations*



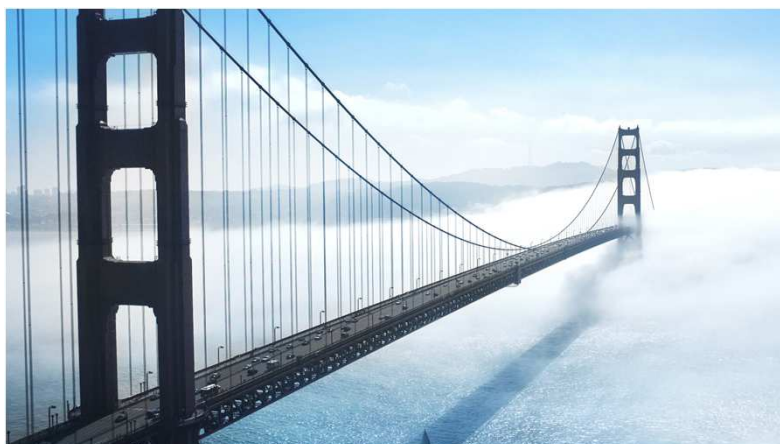
List of Congenital Heart Disease Organizations

335 Foundation
Mooresville, NC
Adult Congenital Heart Association
Philadelphia, PA
Alliance for Adult Research in
Congenital Cardiology
Pittsburgh, PA
American Heart Association
Atlanta, GA
Asher James Congenital Heart
Disease and Thrombosis
Foundation
Schaumburg, IL
Baby Heart Press
Temple, TX
Beats for Bella
Plymouth Meeting, PA
Big Heart for Little Hearts
Spring Lake, NJ
Broken Hearts of Florida
Tallahassee, FL
California Heart Connections
Irvine, CA
Children's Heart Association of
Cincinnati
Cincinnati, OH

Children's Cardiomyopathy
Foundation
Tenafly, NJ
Children's Heart Foundation
Lincolnshire, IL
Congenital Heart Defect
Awareness Quilt Project, Inc.
Taneytown, MD
Congenital Heart Defect Coalition
Butler, NJ
Congenital Heart Defects Families
Association
Kansas City, MO
Congenital Heart Information
Network
Margate City, NJ
Cora's Story
Indianapolis, IN
Erika Kate Hope Alliance
Muscatine, IA
Ethan Lindberg Foundation
Rockford, IL
God's Special Little Hearts, Inc.
Sparta, KY
Heart Heros
Omaha, NE

Hearts of Hope
Rochester Hills, MI
Hearts Unite the Globe
Temple, TX
Help-A-Heart
Des Moines, IA
Hopeful Hearts
Costa Mesa, CA
Jumping for Jeffery
Little Rock, AR
Kari's Heart Foundation
Johnson City, TN
Kids With Heart NACHD
Green Bay, WI
Little Hearts Fighting for Life
Houghton, LA
Little Hearts, Inc.
Cromwell, CT
Littles Hearts for Life, Inc.
Oconto Falls, WI
Louisiana Pediatric
Cardiology Foundation
Baton Rouge, LA
Mend-A-Heart
Clarendon Hills, IL
Mended Little Hearts
Dallas, TX

National Birth Defects Prevention
Network
Houston, TX
Matthew's Hearts of Hope
Sherman, CT
Pediatric Congenital Heart
Association
Madison, WI
Pediatric Stroke Network
Leesport, PA
Pulse Oximetry Advocacy
Indianapolis, IN
Saving Little Hearts
Knoxville, TN
Saving Tiny Hearts
Deerfield, IL
Sisters By Heart
El Segundo, CA
The Greg Olsen Foundation, Inc.
Boca Raton, FL
The Newborn Coalition
Washington, DC
The Organization for
Understanding Children's Hearts
Peoria, IL
Whole Hearts Foundation
Perrysburg, OH



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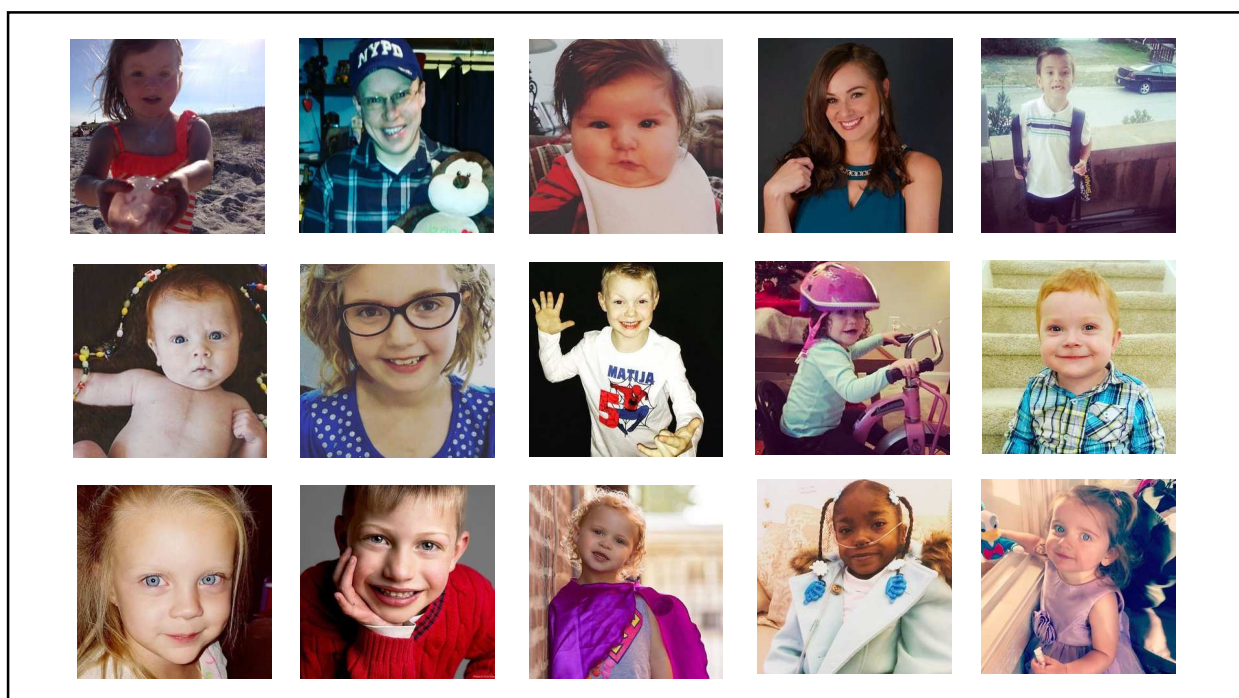
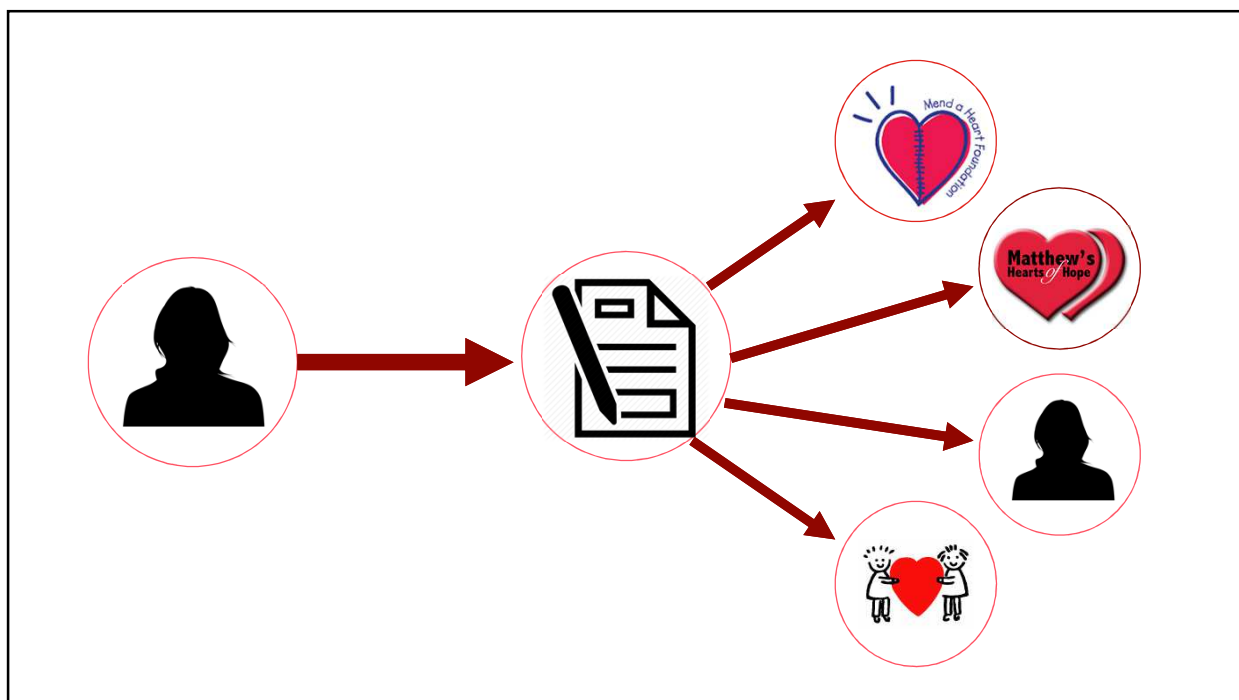
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SKIDMORE COLLEGE

JOHN J. DREW UNIVERSITY





"I can't help but get emotional knowing how far so many amazing doctors have come in their research to prolong the lives of so many kids and adults who aren't given much of a chance. We look forward to the wonderful advancements in medicine that will allow a whole new generation of people a chance to walk this earth for a very long time."

- Christopher about his son, Beckett, who was born with HLHS



