

State of the Networks & One Org Updates

David Brown, Richard James



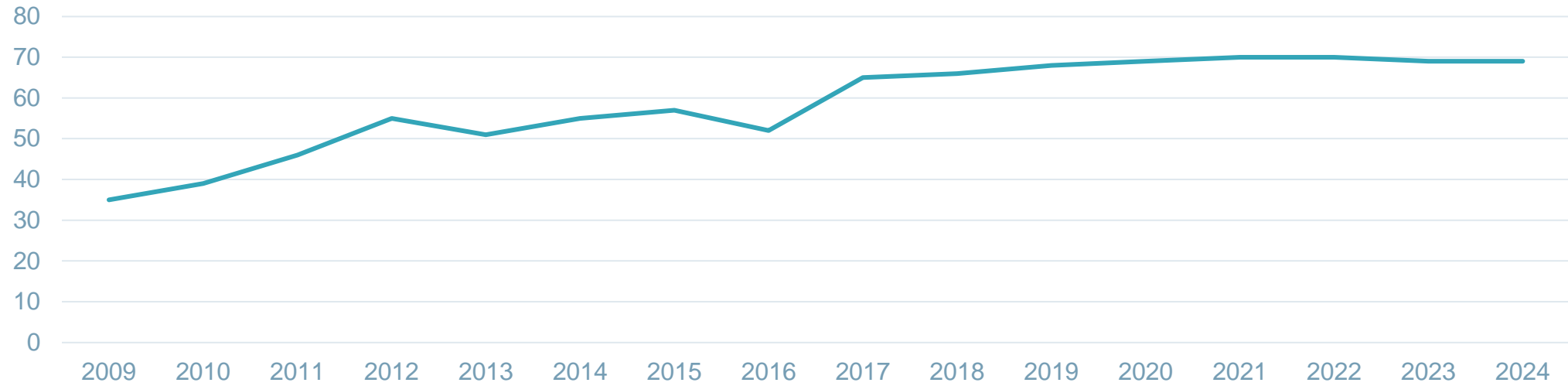
National Pediatric Cardiology
Quality Improvement Collaborative



Celebrate & Sustain the Work of NPC

David Brown

NPC-QIC Care Centers Over Time



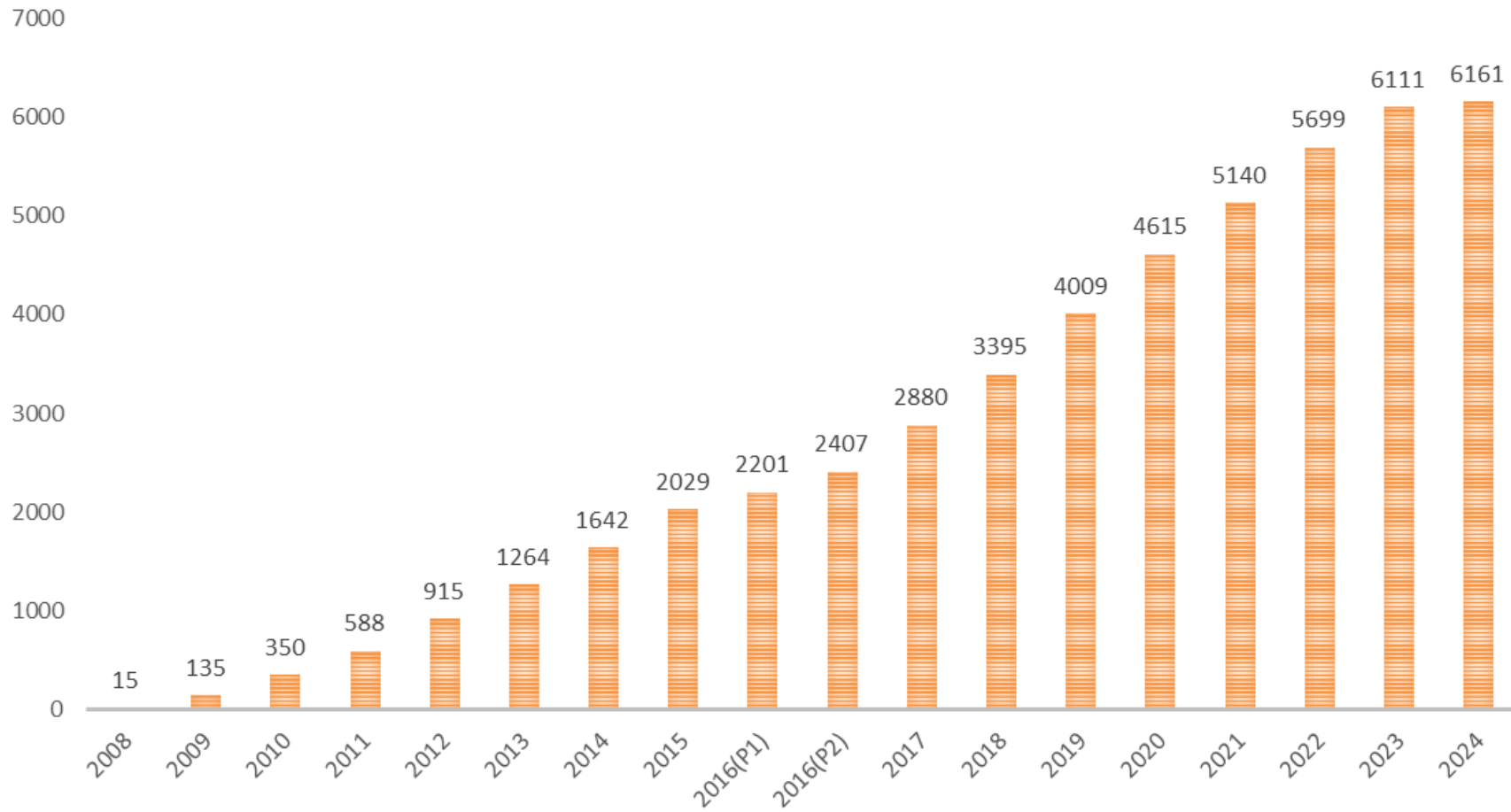
2009: 35 Centers



2024: 69 Centers



CUMULATIVE REGISTRY GROWTH BY BIRTH YEAR





Shining Stars

- Since Fall of 2017, 67 centers participating
- Determined with [Funnel Plots](#)
- Identify high performers across the network




- With over 6000 patients in registry we can now detect center improvements
- Determined at center level Patient Between Charts (aka G-charts).
- Identifies center level improvement (special cause)



Center Team Celebrations

On the Center Connect Guide for Team Time...

 indicates Shining Stars
 indicates Improvers

Interested in Learning More: Selecting Improvers & Shining Stars – G-Charts & Funnel Plots on April 16th - 4:30 EST

Shining Stars



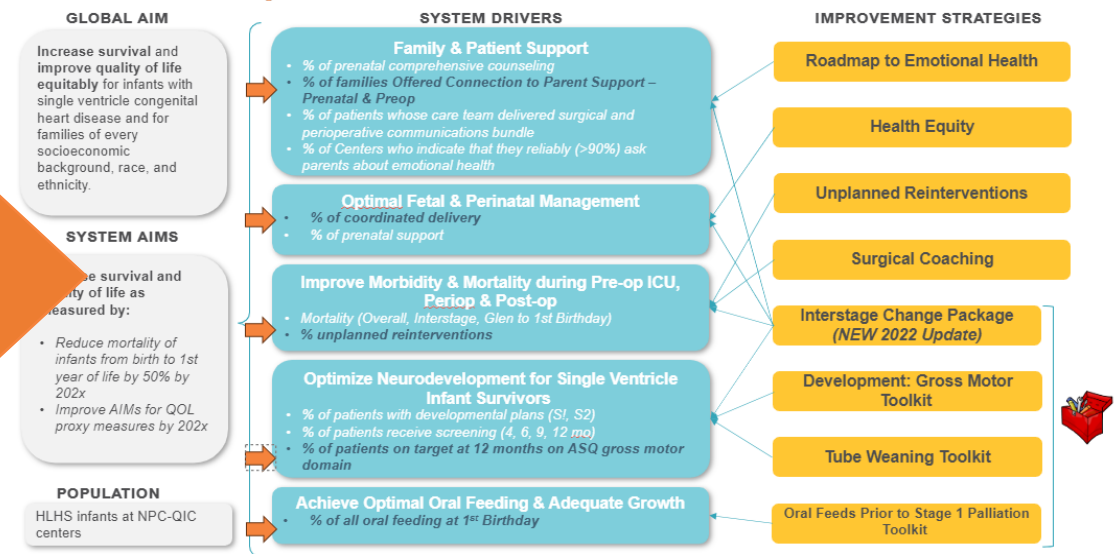
5 Measures

- 1) Families offered connection to Parent Support (Pre-Op),
- 2) Coordinated Delivery,
- 3) Unplanned Reinterventions,
- 4) Patients on target at 12 months on ASQ gross motor domain,
- 5) All Oral Feeds at First Birthday.

1 per driver

NPC-QIC PHASE II: SYSTEM LEVEL DIAGRAM

Revision Date: 12/6/2023



Get Involved: During Team Time – Identify centers to connect with post learning Session



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Shining Stars



Unplanned Reinterventions

- University of Florida, UF Health

All Oral Feeding at 1st Birthday

- Children's Healthcare of Atlanta

Offered Connection to Parental Support

- Children's Hospitals and Clinics of Minnesota
- Monroe Carrell Jr Children's Hospital at Vanderbilt
- Cincinnati Children's Hospital and Medical Center
- Boston Children's Hospital



Raise Hand

Raise your hand(s) when I say team name



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Shining Stars



Gross Motor Development Scores from 6-12 Months

- Cincinnati Children's Hospital and Medical Center

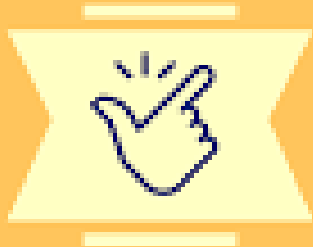
Coordinated Delivery

- Children's Mercy Hospitals and Clinics - Kansas City
- Primary Children's Hospital
- Riley Hospital for Children
- Children's Hospital of Wisconsin
- Children's Health/UT Southwestern
- University of Florida , UFHealth
- Boston Children's Hospital
- Cincinnati Children's Hospital and Medical Center
- Children's Hospital of Philadelphia - CHOP
- University of Wisconsin, American Family Children's



Raise Hand

Raise your hand(s) when I say team name



IMPROVERS

Coordinated Delivery

- University of Michigan
- Children's National
- Lurie Children's
- Riley Hospital for Children
- Nicklaus Children's Hospital
- Levine Children's Hospital
- SSM Health Cardinal Glennon Children's Hospital
- Doernbecher Children's
- Johns Hopkins All Children's Hospital

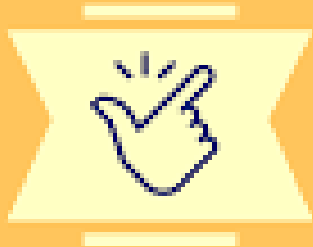
Gross Motor Development Scores from 6-12 Months

- Boston Children's



Raise Hand

Raise your hand(s) when I say team name



IMPROVERS

All Oral Feeding at 1st Birthday

- Medical University of South Carolina
- Children's Mercy Hospitals and Clinics Kansas City
- Texas Children's Hospital
- Children's Hospital of Wisconsin
- Seattle Children's Hospital
- Children's Hospital of Pittsburgh

Unplanned Reinterventions

- Boston Children's
- Colorado Children's
- Duke
- Boston Children's
- University of Maryland Children's Hospital



Raise Hand

Raise your hand(s) when I say team name

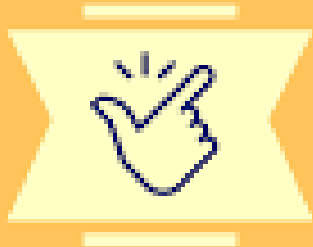


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Offered Connection to Prenatal Support

- UVA Children's Hospital
- Primary Children's
- CHOP
- Colorado Children's
- Riley Hospital for Children
- Duke
- Norton Children's
- SSM Health Cardinal Glennon Children's Hospital
- Children's Hospital of Pittsburgh
- Ochsner Hospital for Children



IMPROVERS



Raise Hand

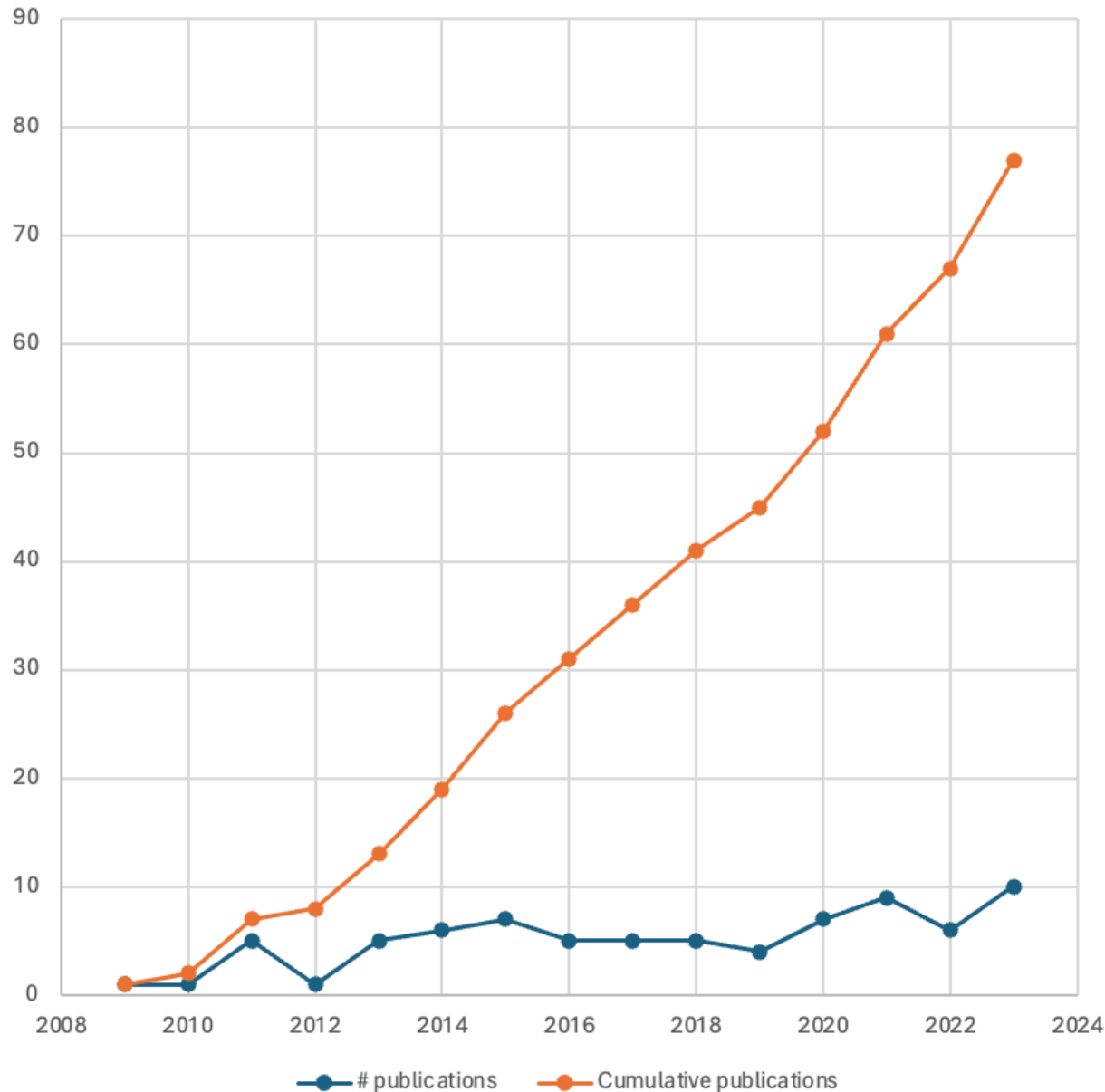
Raise your hand(s) when I say team name



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NPC Publications 2009-2023



NPC-QIC Publications

NPC-QIC publications have been cited more than 1,500 times in other works in more than 150 separate journals.

Risk Factors for Death or Transplant After Stage 2 Palliation for Single Ventricle Heart Disease

AUTHORS:

Emily M. Bucholz, MD, PHD, MPH, Minmin Lu, MS, Lynn Sleeper, SCD, Jeffrey Vergales, MD, MS, Michael A. Bingler, MD, Christina Ronai, MD, MSED, Jeffrey B. Anderson, MD, MPH, MBA, Katherine E. Bates, MD, MSHP, Carole Lannon, MD, Lindsey Reynolds, BS, David W. Brown, MD

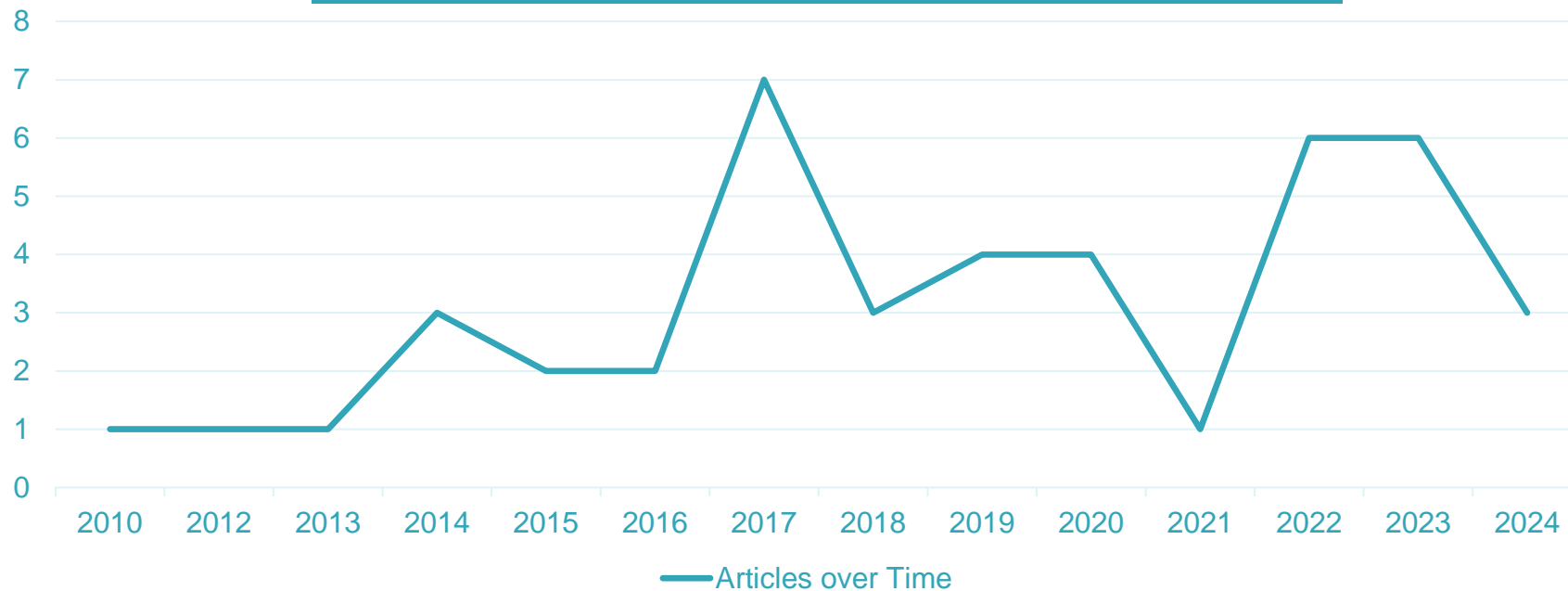
Risks Factors presence of a known genetic syndrome,

- shunt type at stage 1 procedure (S1P),
- tricuspid valve repair at S1P,
- longer time to extubation and reintubation after S1P,
- \geq moderate tricuspid regurgitation
- Extracorporeal membrane oxygenation after S1P and longer S2P cardiopulmonary bypass time without extracorporeal membrane oxygenation



Research Explained

NPC Research Explained 2010-2024



Parent members of the Research and Publications Committee help identify appropriate manuscripts that are of interest to parents for creation of a “Research Explained” summary.

The Research Explained summaries explain medical research in straightforward lay terms and discuss the significance of research findings.

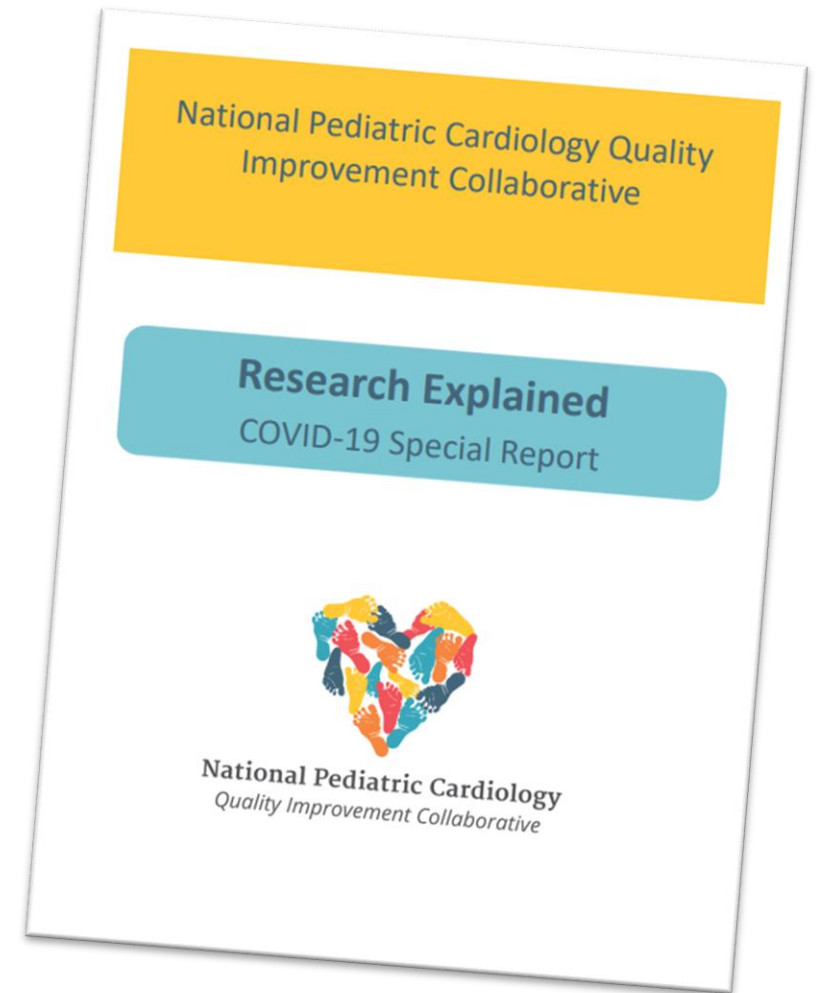
44 articles total

Research Explained & COVID Response

Research Explained: COVID-19 Special Report

Clifford Cua MD (physician), Richard James (parent), Thomas M Zellers MD (physician), Dawn Mazzanti (parent), Tavenner Dibert MD (physician), Jennifer Co-Vu MD (physician), Sarah Plummer MD (physician), Colleen Melchiorre (parent), Ryan Boggs MD (physician), Nicole Fenix (parent)

The Research Explained Committee worked to find research articles (5) with the most valuable information on COVID-19 and produce Research Explained summary pieces for the community.





POLL

How have you used Research Explained? Select all that apply.

- 1) I'm a clinician and I've read one or more
- 2) I'm a clinician and I've recommended these in general to families
- 3) I'm a clinician and I've shared one or more directly with patients/families
- 4) I'm a patient/family member and I've read one or more of these
- 5) I'm a family member and I've shared one or more of these with my online community
- 6) I'm with a support/advocacy organization and we've shared these with our membership online or via email.



Gathering NPC Successes & Tools

- "One Stop" Visualization to keep these rich resources and our journey from almost 15 years at our fingertips
- Short documents that share the milestones, successes and most importantly links to the prenatal through 1st Birthday tools, publications and resources



135

More HLHS Babies
Living & Celebrating
Birthdays

Since 2013



FON Progress

Richard James

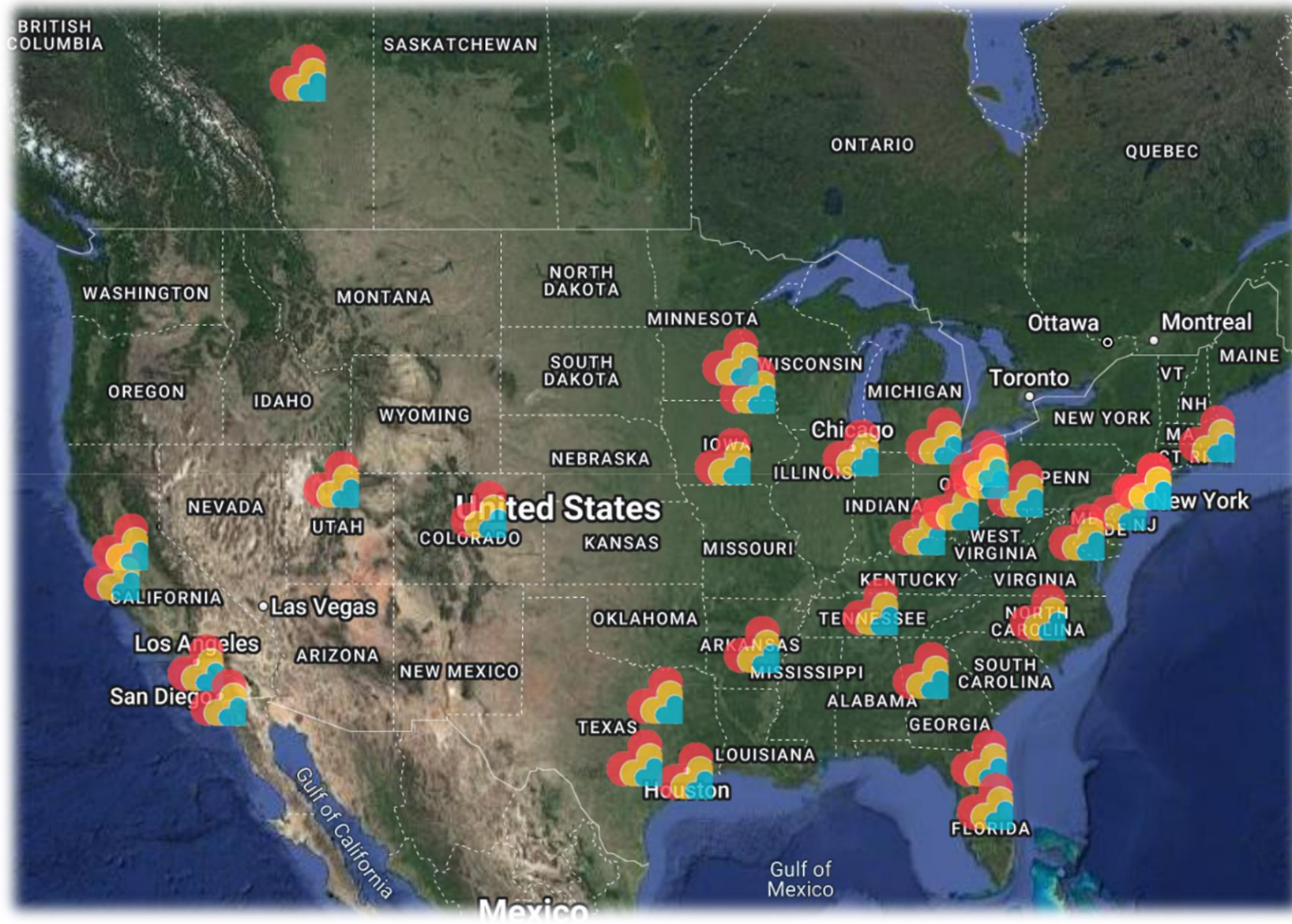
FON Membership

2021: Launched with 12 founding sites

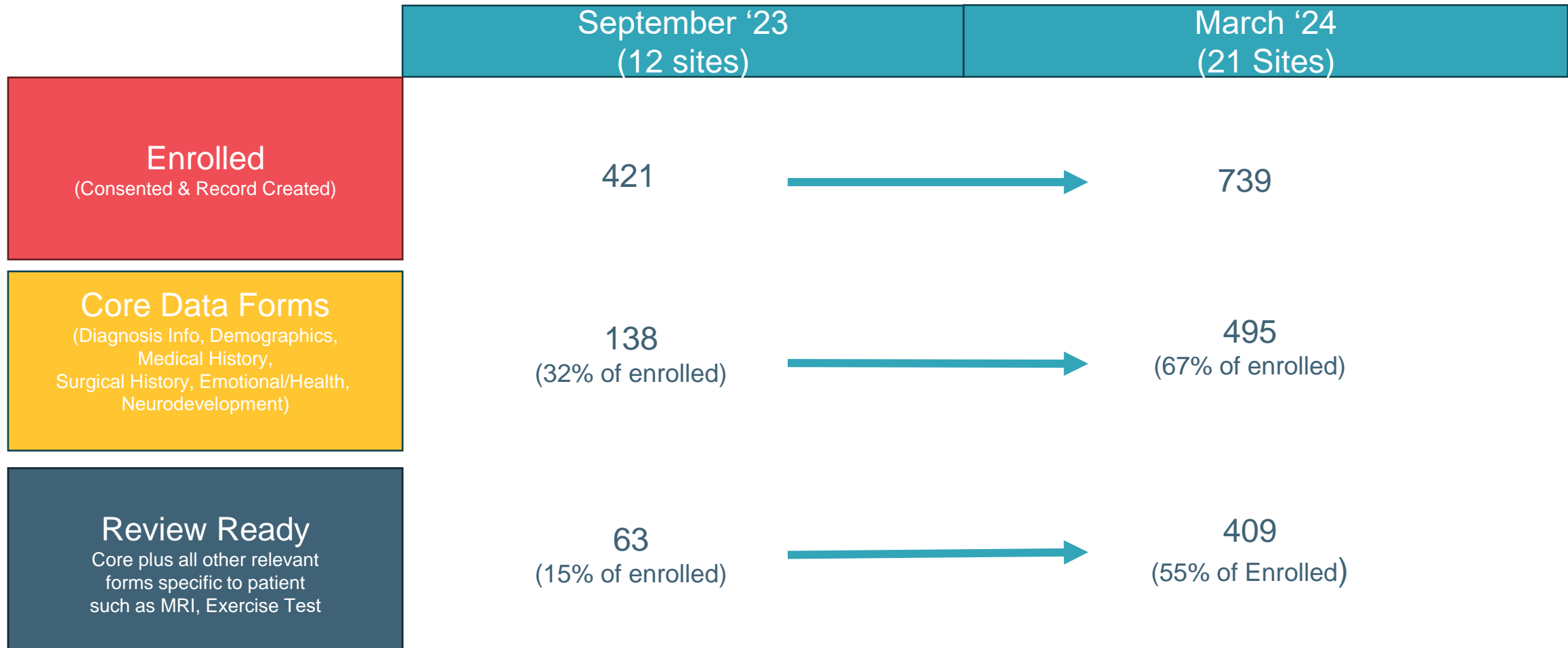
2022: 18 new sites

2023: 6 new sites

- American Family Children's Hospital
- CHOC Children's Hospital
- Children's Mercy Hospital Kansas City
- Ochsner Hospital for Children
- Phoenix Children's
- Sunrise Children's Hospital



FON Registry Enrollment progress



Harvest Date – 3/31/24

Physical Activity & Exercise Toolkit

- Special thanks to the community for invaluable feedback at our Fall 2023 Learning Session and to our new parent and patient members of the Toolkit team for their in-depth feedback.
- Grade school tools are undergoing graphic design and Spanish translation.
- **Roll-out of finalized grade school tools to the FON website by end of May 2024**
- Upcoming focus: Adapting tools and creating new tools for adolescents and adults.

Active Living With Fontan Circulation

Pre-K
Grade School

DRAFT

Building Your Motor Skills Step by Step

Every child's journey to a fun and active life is unique. Sometimes, hospital stays, health issues, and what your child likes might change the way you play and learn new things. The picture below shows just one way a child might learn to move, play, and join in sports and community fun. Your path will be different, but the picture will give you some ideas on what type of play will help your child grow and thrive.

One Path Through Foundational Motor Development

- Pedal a tricycle
- Balance bike or training wheels
- Beginner swimming
- Ride a standing scooter
- Jump on two feet
- Climb stairs with alternating feet
- One foot balance (short time)
- One foot single hop
- Kick a ball
- Gallop
- Skip
- One foot balance (longer time)
- Multiple 1-foot hops
- Catch a ball
- Pedal bike without training wheels
- Roller skate
- Pedal bike without training wheels
- Roller skate
- Run and kick a ball
- Dribble a basketball while running
- Hit a moving ball (tennis, baseball)
- Rollerblade
- Swimming strokes
- Organized sports
- Jump rope
- Cartwheel
- Dribble a basketball



Get Involved: Keep an eye out for grade school tools on the FON website! They will be announced in an upcoming newsletter.



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Physical Activity & Exercise Toolkit

- **ELT Sponsor:** Carole Lannon
- **QI Workgroup Sponsor:** Katie Dodds
- **Project Leaders:** Michael Danduran, Jesse Hansen
- **Project Team Members:** Jared Hershenson, Meagan Houpt, Christina Garcia, Roni Jacobsen, Meg Olson, Whitney Pierce, Phoebe Proctor, Rachael Satake, Casey Vogel, Lisette Wylie
- **Literature & Review Members:** Jana Norris, Genevieve Levin, Seda Tierney, Jolie Britt, Tam Dan Pham
- **Network Support:** Leann Stallard, Shari Wooton

Physical Activity & Exercise Improvement Project

Global Aim

- Support physical activity and wellbeing for individuals living with Fontan circulation

AIM

- Increase/Maintain Physical Activity Score

Population

- Individuals with Fontan circulation in the FON Registry

Family of Measures

- Max VO2
- Physical Activity Pediatric PROMIS Score & Adult TBD
- Individuals who receive age-appropriate information tools
- Individuals with completed fitness assessment at clinic visit or within 12 months prior

Interventions

- Testing FON Physical Activity & Exercise Tools



Get Involved: Launching for FON center team sign-up in early Summer!



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Liver Health

Global Aim

Optimize the liver health, quality of life and longevity of individuals living with Fontan circulation

Key Drivers

Ensure reliable assessment and surveillance of FALD at Care Centers

Promote consistent education of patients/families and clinicians about FALD

Consider multidisciplinary care models with dedicated hepatologists to address FALD

Initial Interventions

Recognize and support the use of evidence-informed strategies to support liver health surveillance

Incorporate patient preferences, risk factors, & constraints into liver health surveillance strategies

Develop & deliver materials leveraging existing resources for care centers to provide necessary information/education to patients and families

Preview and provide feedback on educational content at today's breakout session on liver health



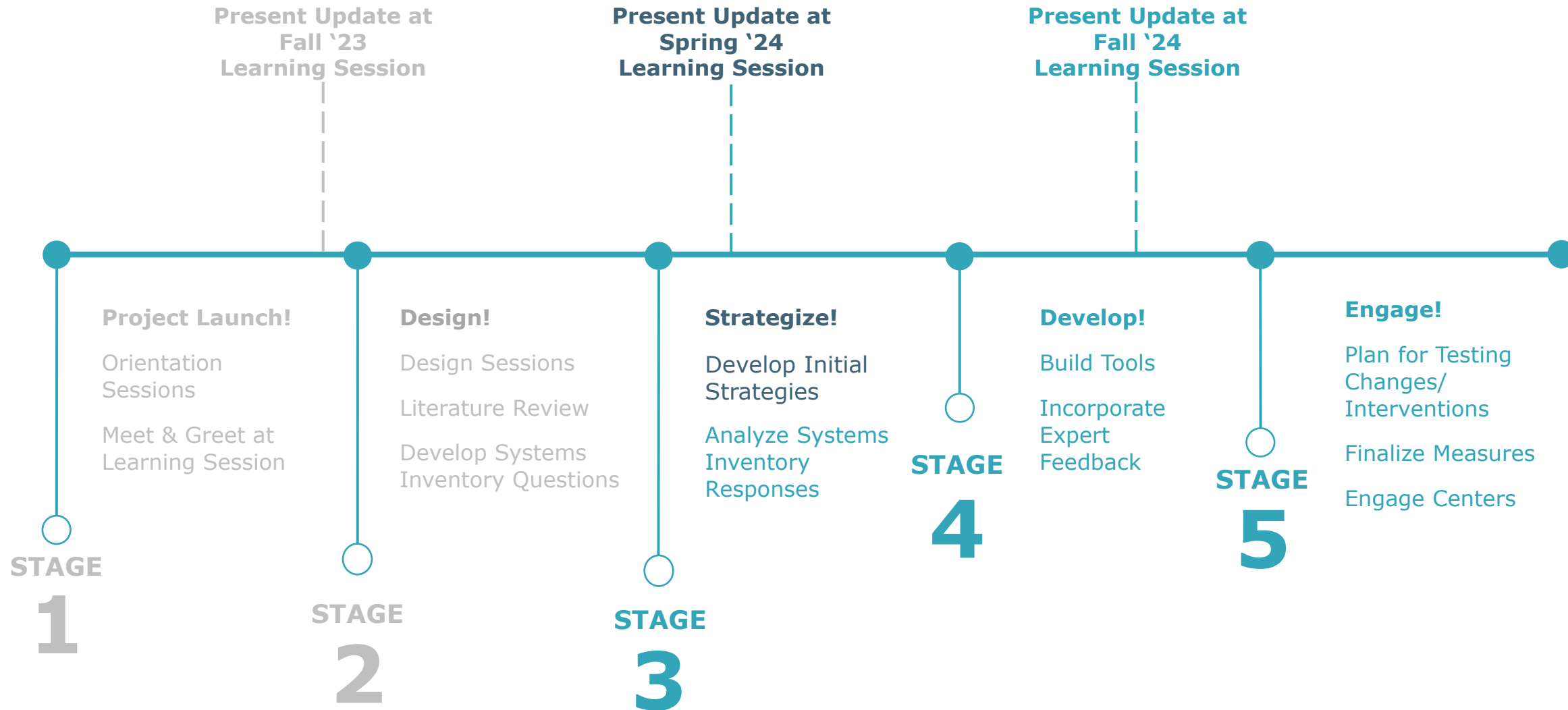
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FONTAN
OUTCOMES NETWORK

Liver Health Project Team Members

- **ELT Sponsor:** Carole Lannon
- **QI Workgroup Sponsor:** Sal Ginde
- **Project Development Workgroup:** Andrew Cheng, Jennifer Conway, Daniel Ganger, Alexis Gumm, Autumn Jones, Jana McClymonds, Cara Morin, Anita Pai, Mary Rouzer, Jack Rychik, Anita Saraf
- **Expert Feedback Workgroup:** Letitia Aloysius, Shahnawaz Amdani, Adrian Dantzer, Noelle Ebel, Greg Fleming, Amber Hildreth, Taylor Houlihan, Katherin Madigan, Mandi McCormick, Nadia Naz, Melanie Parent, Elizabeth Rand, Suren Reddy, Rusty Rodriguez, Jose Silva Sepulveda, Rachael Suddarth, Divya Suthar, Milly Weisert, Kerry Wong
- **Network Support:** Becky Collins, Adriana Ley-Chavez



Liver Health Project Timeline

FON Research

Added 9 new members!

Started the Publications and Presentations Subcommittee

Will open for Research Proposals Summer, 2024!

-Attend the breakout for more information & watch the newsletter



Get Involved: Plan a research proposal for Summer '24



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Research Members

- **ELT Sponsor:** Jack Rychik
- **Research Co-Chairs:** Shahnawaz Amandi, Nadine Kasparian,
- **Research Co-Leads:** Jennifer Conway, Stephen Dolgner, David Leone, Sandra McCormick, Sasha Opotowsky, Nancy Pike, Suren Reddy, David Renaud, Scott Salvaggio, Kurt Schumacher, Sumeet Vaikunth
- **Publications and Presentations Subcommittee Co-Chairs:** Jennifer Conway
- **Publications and Presentations Subcommittee Co-Leads:** Humera Ahmed, Ryan Fischer, Sunil Ghelani, Mauna Kareti, Trudy Pierick, Brandy Troisi, Adel Younoszai
- **Network Support:** Becky Collins



Community Building & Engagement

NPC-QIC & FON

BIG WIN!

Spanish translation coming
soon on both the FON & NPC-
QIC Websites!

www.npcqic.org

www.fontanoutcomesnetwork.org



Get Involved: Once available, share network sites as resources with your Spanish-speaking patients and families! We will announce in the FON & NPC-QIC newsletters.



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Lifespan Data Bridge

David Brown

Lifespan Data Bridge Workgroup

Guiding Principles

- Expand to all single ventricle patients
- Ensure continuity of data elements from NPC to FON
Streamline existing data collection
- Keep the best of NPC to carry forward and determine what should be removed
- Align to outside registries

Data Form Structure Subcommittees

North Star

- Develop structure/Framework for 1 year to Fontan content
- Consider measures and outcomes for research & improvement
- Outline key research questions

Streamline & Align

- Identify NPC data used most/least
- Consider external registries to which we should align
- Determine what from these external registries to use
- Identify FON and NPC overlap

Health Equity

- Review NPC and FON for gaps
- Explore areas for expansion
- Document known disparities
- Form questions developed in a separate, content group in January

BRIDGE AIMS & DRIVERS

GLOBAL AIM

Our vision is to equitably optimize survival and quality of life across the lifespan for single ventricle individuals and their families.

SYSTEM AIM

To design and implement an integrative and equitable system for data and knowledge sharing that allows individuals with SV to maximize their potential in growth, development, physical activity and to build emotional health and resilience of individuals and families with SV

KEY DRIVERS

Promote wellbeing & support family goals

Encourage & participate in physical activity

Identify & mitigate known structural, functional & QOL high risk factors

Positive oral feeding experiences

Equitable health access

Support early childhood growth & development

Health Equity Subcommittee

Purpose

- Review NPC and FON for gaps
- Explore areas for expansion
- Document known disparities
- Form questions developed in a separate, content group

DRAFT

Keep Collecting - Effective

NPC & FON

- Zip at Birth
- Race
- Ethnicity
- Primary Insurance
- Sex at Birth

FON

- Gender Identity
- Full address @ enrollment & updated at clinic visit

Note: Enables measure of Socio-Economic Status (Deprivation Index, Child Opportunity Index) or Distance from Care.

Investigate Adding or Keeping Impact is Worth Effort

Keep

- Language – primary language spoken in patient's household
(Action: talk to FON team how is this going so far)

Add

- Employment
(co-linear maternal education with patient education with education/income)

Considered But Don't Add Now

Low Effort

- Maternal Education
(could learn in future from CNOC)
- Maternal Age

Medium Effort

- Marital Status
- Access to Transportation

High Effort

- Health Literacy
- Immigration Status (legal/risk to families)
- Access to Childcare
- Patient Education

Streamline & Align Subcommittee

Purpose

- FON & NPC Overlap
- Determine data used most/least for NPC-QIC
- Consider external registries to which we should align
- Determine what from these external registries to use

Least-Used Measures

Surveyed NPC-QIC centers to determine most and least utilized measures (54 responses across 43 centers)

Time from Delivery to ICU Admission,
Stage I Surgery Delayed,
Patient/Family Pre-Operative Prep

Most-Used Measures

Surveyed NPC-QIC centers to determine most and least utilized measures (54 responses across 43 centers)

Mortality, Nutrition & Growth

External Registry Alignment

Pros:

- Used by significant approximately 20% of our centers
- Data is relatively easy to access
- Will reduce data entry burden
- Common definitions for fields

Cons:

- Only looking at time in CICU and would limit to reduce data entry burden to only events in this time frame
- Likely going to be encounters with patients that will not have data collected for PC4, resulting in needs for manual data entry. (No matter what registry we align to, unlikely to eliminate need for manual data entry in some areas)

Lifespan Data Bridge Workgroup & Subcommittees

- **ELT Sponsors:** David Brown, Jack Rychik
- **Workgroup Members:** Titus Chan, Mike DiMaria, Courtney Giese, Jessica Haley, Omar Khalid, Aparna Kulkarni, Linda Lambert, Mehul Patel, Amanda Picart, Ben Reinking, Neeta Sethi, Rachel Shustak, Sherry Smith, Alyson Stagg, Eileen Stewart, Ryann Treadwell, Hilary Voigt, Melissa Wiggins
- **North Star Subcommittee:** David Brown, Mike DiMaria, Courtney Giese, Jessica Haley, Linda Lambert, Aparna Kulkarni, Mehul Patel, Ben Reinking, Jack Rychik, Rachel Shustak, Alyson Stagg
- **Streamline & Align Subcommittee:** Alicia Chaves, Jessica Haley, Omar Khalid, Amanda Picart, Sherry Smith, Alyson Stagg, Ryann Treadwell, Hilary Voigt, Melissa Wiggins
- **Health Equity Subcommittee:** Titus Chan, Courtney Giese, Aparna Kulkarni, Nelangi Pinto, Neeta Sethi, Rachel Shustak, Eileen Stewart
- **Network Support:** David Carlson, Michelle Eversole, Emily Kuhnell, Leann Stallard, Jeff Theobald, Shari Wooton



Identify & launch an improvement project in the Glenn through Fontan Surgery (aka Bridge) space

One Org Progress Update

David Brown, Richard James

Success! (Continue Doing)



Joint Community Building & Engagement Workgroup

Case Conference offered to both Networks

Joint Learning Sessions

Lifespan Data Bridge work (Glenn through Fontan Surgery)

Change

~ goodbye ~

One Org Name

With over 2400
votes, we have
our official name





Single Ventricle Outcomes Network

SV-ONE



National Pediatric Cardiology
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Up Next

- NPC Teams invited to participate in Physical Activity & Exercise Improvement Project (a FON & CNU sponsored project)
- Bridge Improvement Project (Glenn through Fontan Surgery)
- Mission & Vision for SV-ONE (Community Input)
- IRB/DUA - Thinking of using the FON IRB proposal as a skeleton
- Leadership team for SV-ONE
- Integrating workgroups from NPC and FON (similar to CBE)

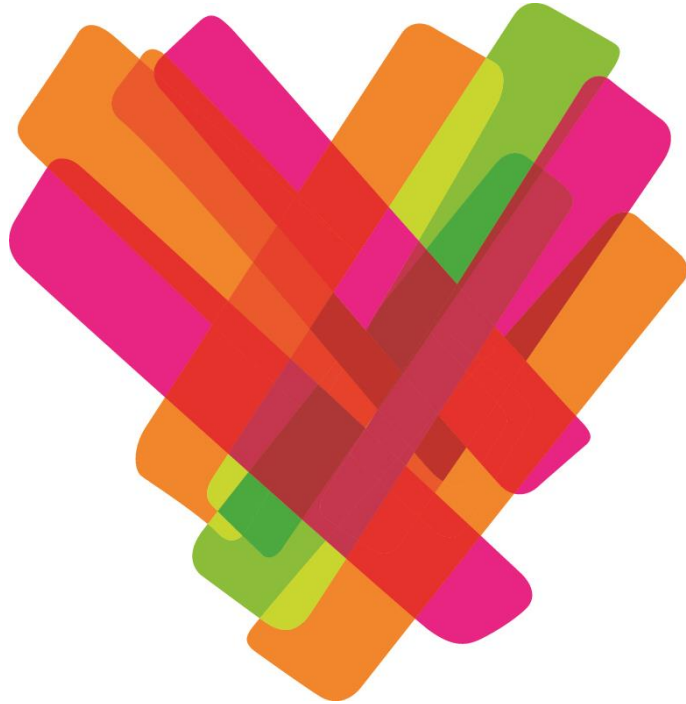
Soon is not a time. (Don Berwick)

By July 2025, we will be formally merged into SV-ONE.

ONE network, ONE fee, ONE IRB, ONE DUA.

Scratch Golf

Spencer Timmel



CONGENITAL
HEART
ALLIANCE



CONGENITAL
HEART
ALLIANCE

PROVIDING

Heartfelt Hope


Since 1940

OUR MISSION

To inspire heartfelt hope in patients and families impacted by congenital heart defects, as well as medical practitioners that care for them, through the funding of ground breaking research, global collaboration, and holistic well-being initiatives.

chaoc.org

WELLNESS INVESTMENT | 2004 - Ongoing



Camp Joyful Hearts and Family Camp at Camp Joy in Clarksville, OH
(Dr. N. Madsen)

2005

RESEARCH FUNDING

Normal Cardiac MRI Value Study in Children Ages 5-10 Years
CCHMC
(Dr. W. Gottliebson)

RESEARCH FUNDING | 2005 - 2007

HARP to Study RV Strain in Tetralogy of Fallot
CCHMC
(Dr. W. Gottliebson)

2006


EQUIPMENT ENDOWMENT

Endo-PAT 2000 to Measure Premature Arterial Damage in Children
CCHMC
(Dr. Urbina)

RESEARCH FUNDING


Cardiac Exercise Rehabilitation Study in Children with CHD
CCHMC
(Dr. W. Border)

EQUIPMENT ENDOWMENT | 2006 - 2009



Vascular Ultrasound Research Imaging System
CCHMC
(Dr. T. Kimball)

WELLNESS INVESTMENT | 2006 - Ongoing



WE'VE INVESTED OVER 80 YEARS Getting to the Heart of the Matter

CONGENITAL HEART ALLIANCE
OF CINCINNATI

Timeline Highlights
Getting to the Heart of the Matter Since

Our work to fund groundbreaking research, global collaborations, important... In the U.S. alone, our investments in research and development of children with CHDs by 37%. With an effort to provide generous funding increase that percentage even more!

1940

HISTORIC BEGINNING



With an initial bequest of \$200, Children's Heart Association of Cincinnati (CHAoC) is established with the help of pioneering pediatricians, Dr. R. Lyons and Dr. L. Rauh.

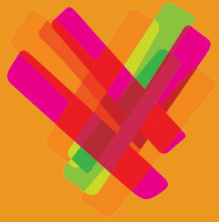


NPC-QIC & Fontan Outcome Network



CONNECTION & COLLABORATION

CHAOc supports the initiatives of both networks, as they align with our commitment to improve the outcomes for patients with congenital heart defects.



CONGENITAL
HEART
ALLIANCE

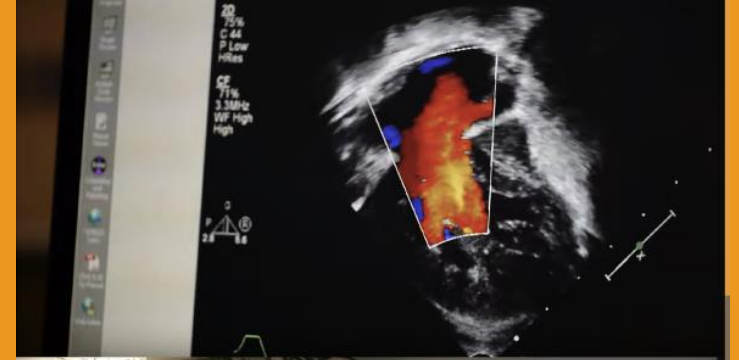
DOCUMENTARY

Building the Field

Lifelong Care for CHD

BY MICHAEL KATCHMAN

CHAoC BOARD TRUSTEE | VOLUNTEER SINCE 2001





SCRATCH
GOLF



OUR MISSION

Help children with Congenital Heart Disease (CHDs) — and children identified as at risk for future heart disease — socially, emotionally, and physically, through golf.

The Scratch Golf program allows kids to take a mental-health break from medical issues, while meeting new friends and learning the game of golf — an activity they can play for a lifetime.

DRIVING
OPTIMAL
WELL-BEING



1,697 FIRST TEE AFFILIATED
GOLF COURSES

#9

EXPANSION POTENTIAL

SCRATCH GOLF PROGRAMS ESTABLISHED IN

CINCINNATI
PHOENIX 
NEW ORLEANS

150+

SCRATCH GOLF KIDS
SERVED & COUNTING

250+

CHILDREN'S HOSPITALS IN USA

100s of
1,000s

USA CHILDREN LIVING WITH A CHD

150
FIRST
TEE
CHAPTERS

88%

OF PARENTS OF FIRST TEE PARTICIPANTS AGREE
PLAYING GOLF HELPS CHILDREN BUILD CHARACTER

REGIONAL ADVOCACY

With the common goal of providing safe activities for heart kids to lead healthy lives, Scratch Golf works nationally, **IN PARTNERSHIP WITH LOCALIZED, CHILDREN'S HOSPITALS,** to bolster hope for families across the USA.

Scratch Golf also shares helpful program resources for doctors and care providers to share with their patients.

As a precaution, patients must obtain clearance from their doctor in order to participate in the program.



SCRATCH
GOLF





CONGENITAL
HEART
ALLIANCE

Contact us to learn more!

Let's work together to
bring these impactful
programs to your
community.



Closing Statements

Richard

