

FON Virtual Learning Session

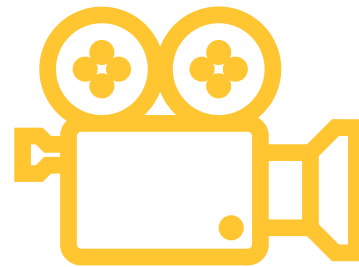
Fall 2021

Welcome and thank you for being here! We will begin shortly.



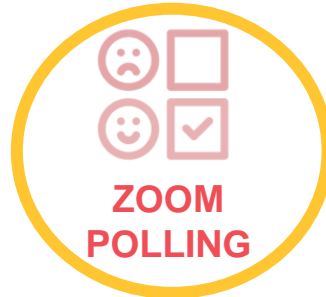
Recording

Please be aware that this meeting is being recorded. All presentations will be posted to Microsoft Teams following the event and recordings will be sent to all participants.





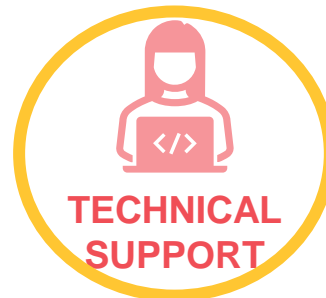
IF JOINING AS A TEAM, TYPE THE NAMES OF EACH OF YOUR PARTICIPANTS IN THE CHAT TO LOG ATTENDANCE



WE'LL USE ZOOM POLLING THROUGHOUT THE DAY



USE THE ZOOM **CHAT** FEATURE OR JOIN THE CONVERSATION ON TWITTER AT **@FONTANOUTCOMES** AND **#FONVLS**

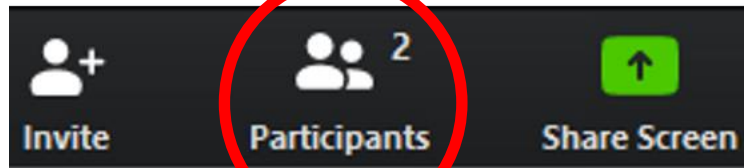


IF YOU NEED TECHNICAL SUPPORT, DIRECT MESSAGE **TECH SUPPORT – RYAN** IN THE CHAT

Please Update Your Name to Include Your Care Center

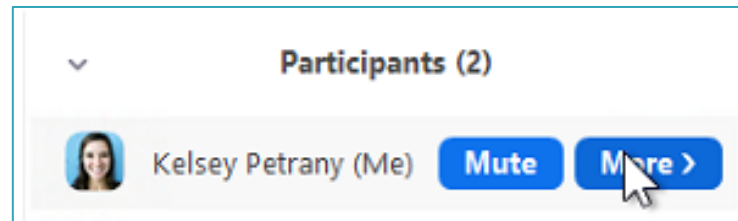
STEP 1:

Click on the Participants icon located on the bottom of the black tool bar.



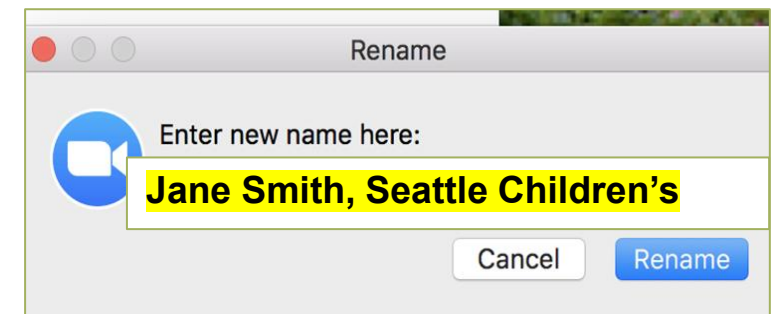
STEP 2:

Hover over your name
Click More → Rename.



STEP 3:

Type your name & Care Center.



Learning Session Program

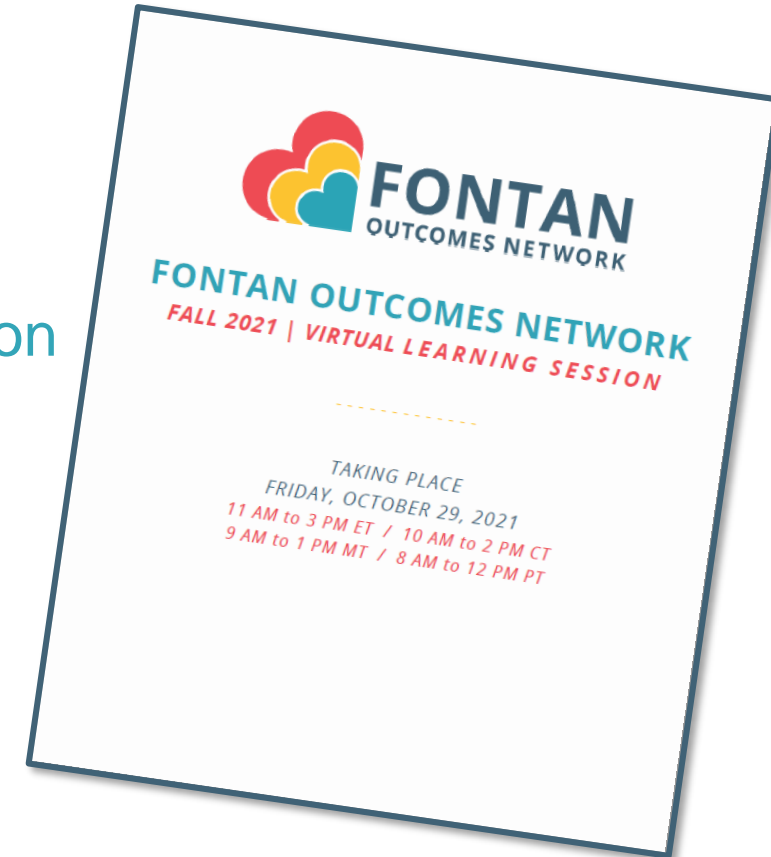
Make sure to look at the event program.

You will find the event program in your pre-event email.

From: FON info@npcqic.org

Subject: Your Guide to Our Fall 2021 Virtual Learning Session

- Agenda and zoom links for the day
- Headshots of our leadership team
- Zoom Tips and other resources!



Fontan Outcomes Network: State of the Network

Jack Rychik



The state of the Fontan Outcomes Network is...

- **Organized & Expanding**
- **Transformative**
- **Inspiring**

Our Purpose: The Fontan Outcomes Network will...

- **Develop a registry that will catalogue clinical data and accurately map the clinical trajectory of individuals with single ventricle disease throughout the lifespan;**
- **Apply quality improvement science and create a collaborative learning platform;**
- **Provide a rich foundation of clinical information/phenotypic data to partner with genotypic/biorepository effort;**
- **Conduct investigation, exploratory research and clinical trials.**



Data Collection & Registry

LEARNING NETWORK

Optimize Physical Health & Functioning

Optimize Surveillance & Support of Neurodevelopmental Needs

Optimize Resilience & Emotional Health

CLINICAL REGISTRY

Map clinical trajectory

Deep phenotyping to partner with genotype data

Foundation to conduct research & clinical trials

Working Groups

**Engagement
& Community
Building**

**Quality
Improvement**

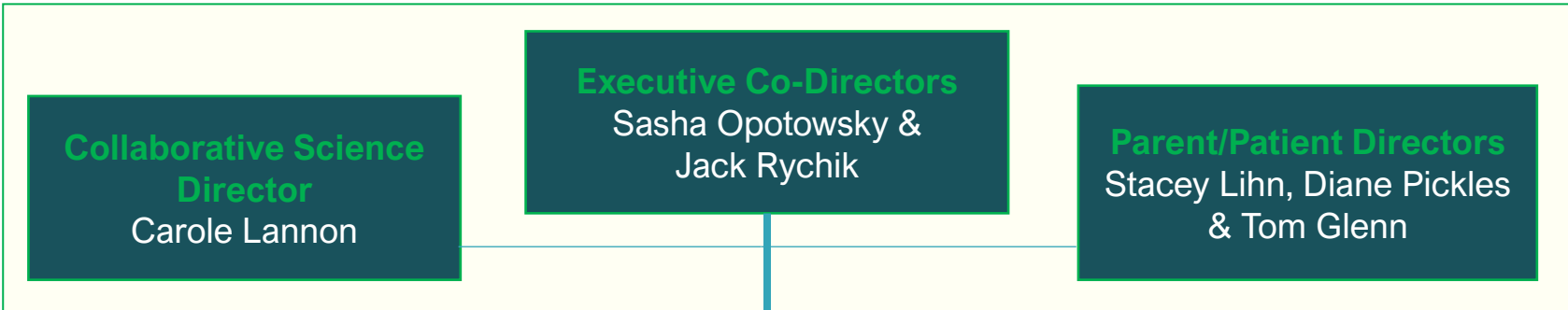
**Data &
Analytics**

Research

FON Governance

Executive Leadership Team

Oversight & communication



Strategic Advisory Committee

Stacey Lihn (Chair)
M Gaies, K Keller, T Geva, D Penny,
J Rossano, K Bates, D Brown,
T Karageorges, M Jacobs, A John,
K Eyler, Y d’Udekem, S Timmons,
R Shaddy, others

Coordination & Implementation Team
ELT, Workgroup representative*, SAC Chair

Working groups

Engagement & Community Building
Meg Didier, Kurt Schumacher*, Michelle Steltzer, Fred Wu

Quality Improvement
Kiona Allen*, Katie Dodds, Sal Ginde, Alicia Wilmoth

Data & Analytics
Mike DiMaria, Erin Hoffmann, Adam Lubert*, Rahul Rathod

Research
David Goldberg*, Richard James, Nadine Kasparian, Nancy Pike

Activity

Individual Initiatives

QI Projects

Connections to other initiatives (ACTION, FORCE, Project SINGULAR, NPC-QIC, CNU)

Scientific initiatives, data use & publications committees

Biobanking/genomics

Operations & support

Anderson Center & Heart Institute Research Core
Project Management, Quality Improvement, Data/Stats, Regulatory, Communications, Network Operations

DATA



How are we going to collect the data?

- Prospective enrollment with informed consent of people of all ages living with Fontan circulation
- Central IRB with data use agreements between centers
- Enrollment through a participating care center
- Longitudinal data collection

**Goal: 1,000 individuals
within first year**



How best to characterize individuals?

AHA SCIENTIFIC STATEMENT

Evaluation and Management of the Child and Adult With Fontan Circulation: A Scientific Statement From the American Heart Association

Jack Rychik, MD, Chair, Andrew M. Atz, MD, FAHA, David S. Celermajer, MBBS, PhD, Barbara J. Deal, MD, Michael A. Gatzoulis, MD, PhD, Marc H. Gewillig, MD, PhD, Tain-Yen Hsia, MD, Daphne T. Hsu, MD, FAHA, Adrienne H. Kovacs, PhD, Brian W. McCrindle, MD, MPH, FAHA, Jane W. Newburger, MD, MPH, FAHA, Nancy A. Pike, PhD, FAHA, Mark Rodefeld, MD, David N. Rosenthal, MD, Kurt R. Schumacher, MD, MS, Bradley S. Marino, MD, MPP, MSCE, FAHA, Karen Stout, MD, Gruschen Veldtman, MBChB, FRCP, Adel K. Younoszai, MD, Yves d'Udekem, MD, PhD, Co-Chair, and On behalf of the American Heart Association Council on Cardiovascular Disease in the Young and Council on Cardiovascular and Stroke Nursing



Circulation

Volume 140, Issue 6, 6 August 2019; Pages e234-e284
<https://doi.org/10.1161/CIR.0000000000000696>

Table 16. Proposed Adult* Organ System Surveillance Testing Toolkit (Table view)

Organ System	Basic	In-Depth	Investigational
Liver	CMP	Serum FibroSure biomarkers	Liver biopsy
	Platelet count	Serum α -fetoprotein	
	Serum GGT	Liver imaging via CT or MRI	
	PT/INR	Liver elastography (ultrasound or MRI)	
	Total serum cholesterol		
Kidney	Abdominal (liver) ultrasound		
	Serum BUN, creatinine	Urinalysis albumin/creatinine ratio	Nuclear scan GFR
Lymph	Serum cystatin C	Renal ultrasound with Doppler	
	Serum albumin, total protein	Serum IgG	T2-weighted MRI lymphatic imaging
Endocrine/metabolic	Absolute lymphocyte count	Fecal α -1 antitrypsin level	Lymphatic angiography
	Serum calcium	Parathyroid hormone	Serum insulin-like growth factor
	Vitamin D	Bone densitometry/DXA scan	
Heme	Nutritional evaluation and consultation		
	CBC, Hgb, Hct	Serum iron	Coagulation factors
		TIBC	
Lungs		Ferritin	
	Pulmonary function testing	Chest x-ray	
Neurological/psychological	Psychological evaluation and consultation	Neurodevelopmental/cognitive testing†	Brain MRI scanning

Patient Enrollment Strategy

Initial enrollment of patients at time of
Fontan surgery

AND

Enrollment of those receiving regular care
at Fontan specialty or general cardiology
clinic (pediatrics and ACHD) at care
center (this will include children,
adolescents, and adults)



[HOME](#) » [ABOUT US](#)

THIS IS BROAD

We seek to better understand the roots of disease and narrow the gap between new biological insights and impact for patients.



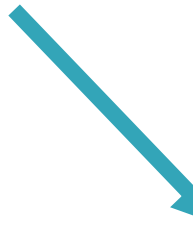
The Broad Institute of MIT and Harvard is a research organization that convenes a community of researchers from across many disciplines and partner institutions—MIT, Harvard, and Harvard-affiliated hospitals.

ABOUT US

- [This is Broad](#)
- [History](#)

INPUT

Care Centers
collecting
specific data
at specific
intervals
uploading to
BROAD



OUTPUT

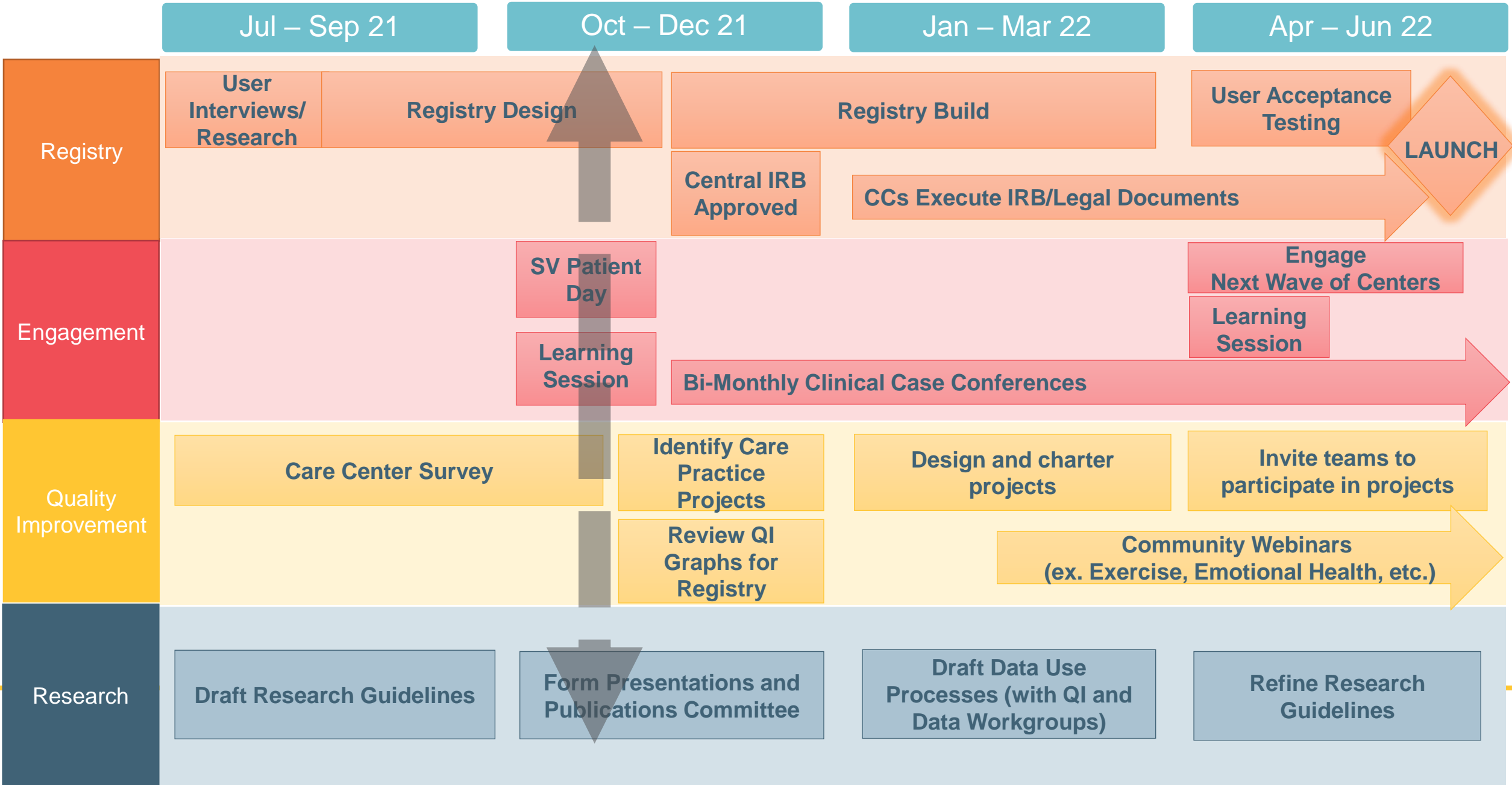
Analytics for QI
process charts
& ongoing
learning

Registry data
available for
research, QI
work, new
knowledge



12 Founding Care Centers

FON Year 1 Timeline



LIFESPAN TRAJECTORY





Supported by:

ADDITIONAL
VENTURES



CONGENITAL
HEART
ALLIANCE
OF CINCINNATI



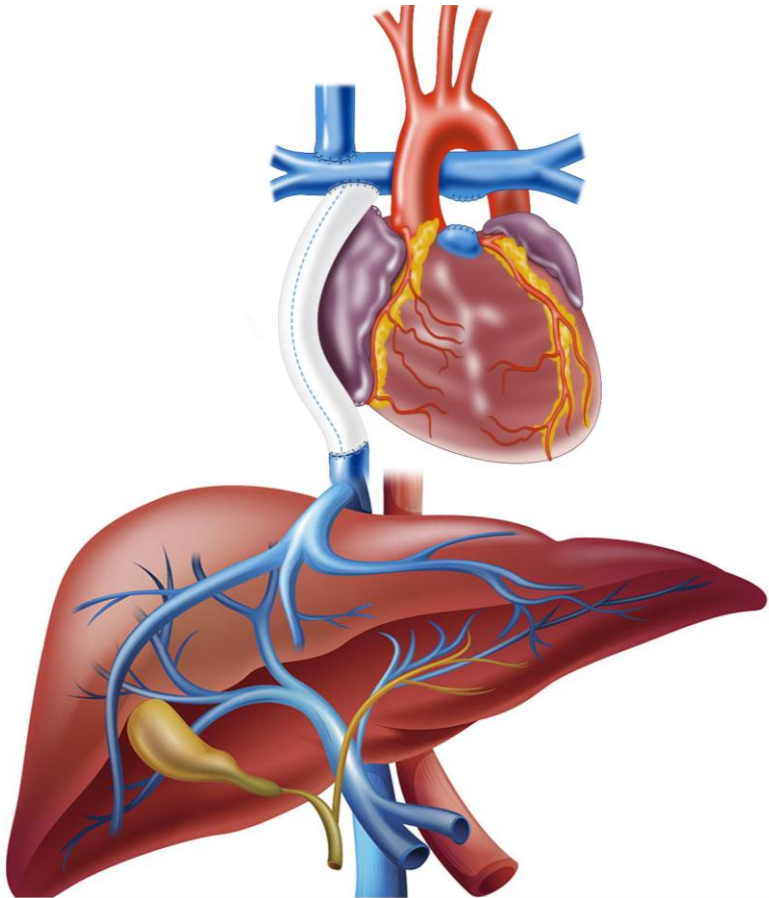
Fontan Outcomes Network: Ignite Talk

Kathryn M. Dodds



Why Do This?

This Is Not “Normal” Physiology



- Blood is “routed” to and through lungs...
- Passive flow, not pumped there
- Elevation in systemic and central venous pressure
- Impact on ventricular filling and function
- Liver congestion
- Elevated hepatic venous pressure
- Increased lymphatic production but impedance to forward lymphatic flow

Not “Fixed” Or “Corrected”

“This procedure is **not an anatomical correction**, which would require the creation of a right ventricle, but a procedure of **physiological pulmonary blood flow restoration, with suppression of right and left blood flow mixing**”

Fontan and Baudet – Thorax 1971;26:240

Inpatient and Surgical Focus and Key Drivers

- Databases/National Cooperation

- STS
- European Congenital Heart Surgeons Association Database
- The World Database for Pediatric and Congenital Heart Surgery
- United Network for Organ Sharing (UNOS)
- Pediatric Heart Network's Single Ventricle Reconstruction trial
- Pediatric Cardiac Critical Care Consortium (PC4)
- National Pediatric Cardiac Quality Improvement Collaborative (NPC-QIC)
- The Australian and New Zealand Fontan Registry

- Time

- CPB
- Days on ventilator
- Days in ICU
- LOS
- "Stage"

- Age

- Gestational Age
- Age at BDG
- Age at Fontan

- Survival

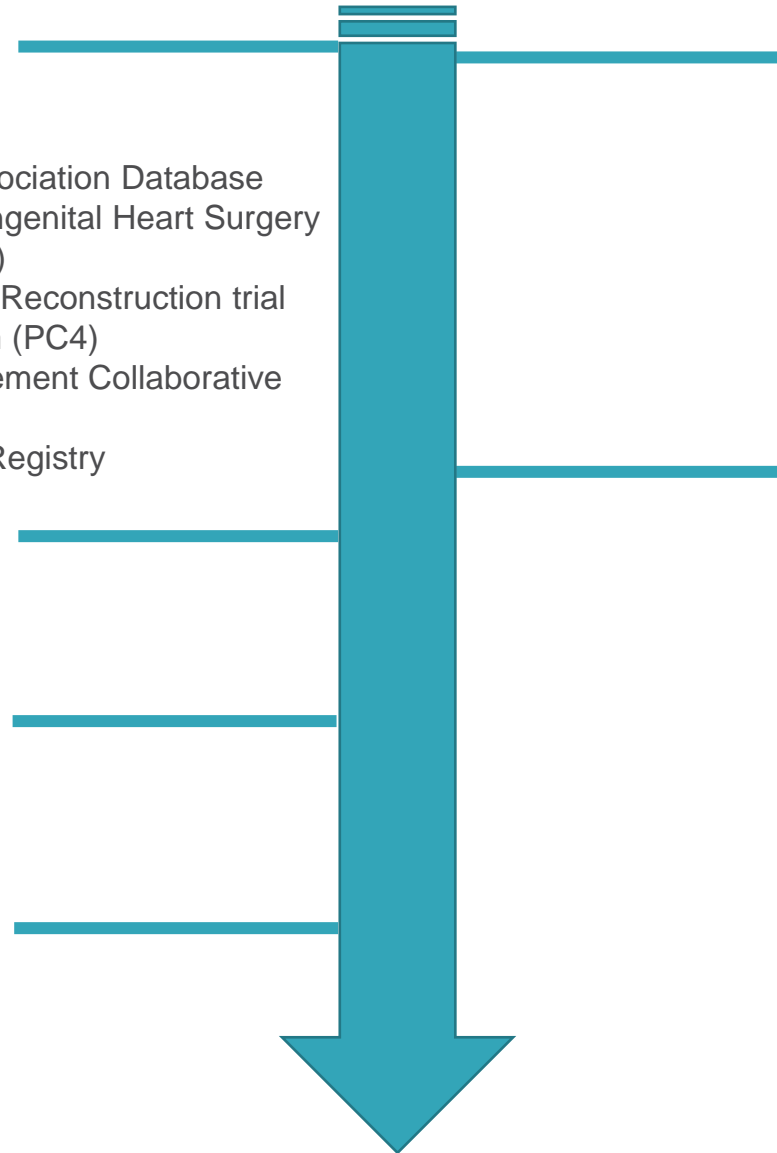
- Interstage
- Takedown
- Transplant free

- Risk Factors

- Gestational Age
- Birth Weight
- Genetic abnormalities/syndromes
- Post natal diagnosis
- Anatomy

- Teams

- Fetal
- Surgery
- Anesthesia
- Critical Care
- Cardiology
- Interstage Team
- PT/OT/Speech
- Dietician
- Psychology
- Child Life
- Inpatient Nursing/Outpatient Nursing
- Parents



Survival to Fontan

After the Fontan?

no defined or agreed upon “routines/protocols”

no “stages”

no “scripts”

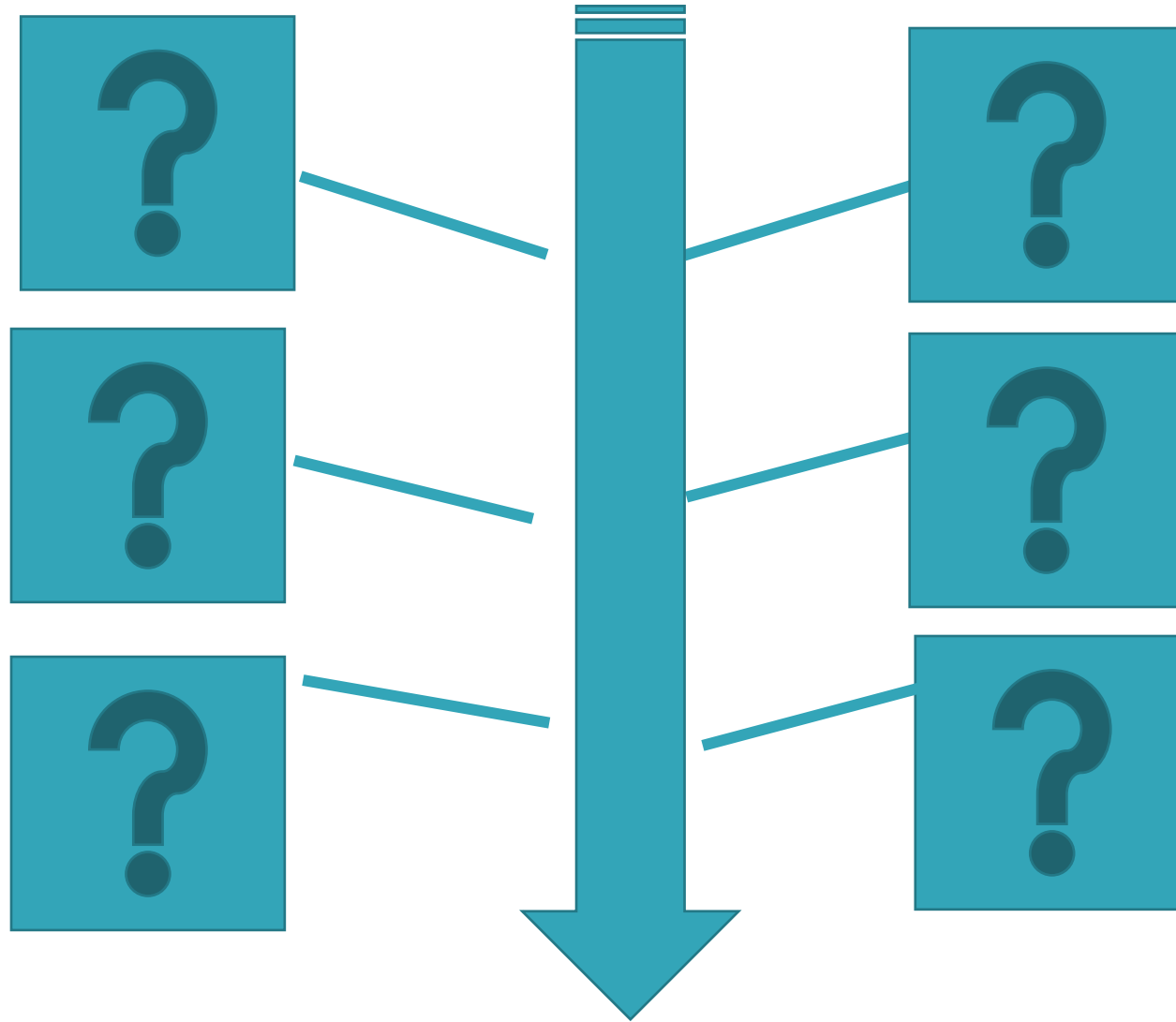
no “databases”

no “pathways”

no “interdisciplinary teams”

but there should be

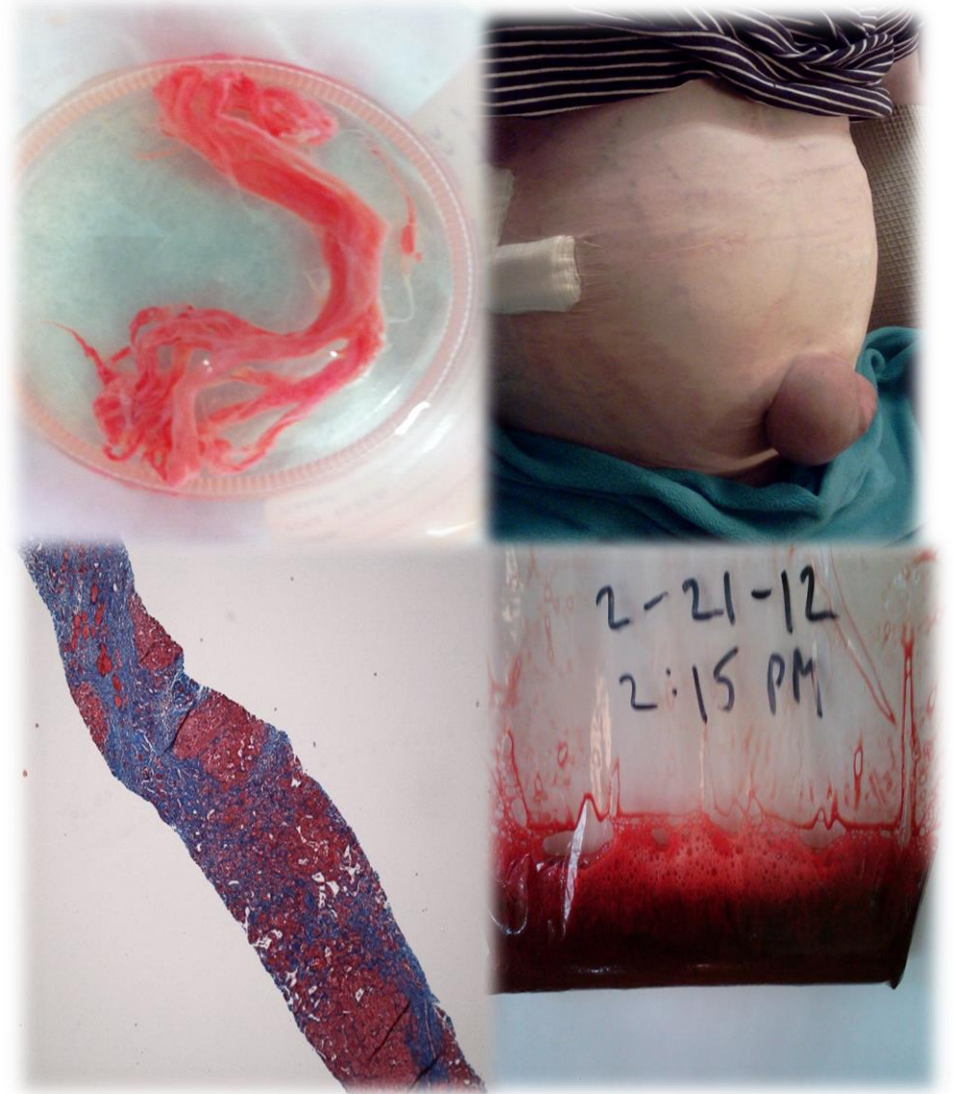
What are the “Key Drivers?”



Improved outcomes and lifetime care for Fontan patients

There Can Be Significant Challenges

- Lymphatic issues:
 - Protein Losing Enteropathy/Plastic Bronchitis
- Hepatic fibrosis, cirrhosis, carcinoma
- Hemoptysis
- Thromboembolism
- Systolic and Diastolic Dysfunction
- Valve issues: Regurgitation/Root dilation
- Rhythm issues
- Immune Issues
- Growth and Bone Issues
- Cognitive and Behavioral Issues
- Mental Health Issues
- Need for transplant...but not just the heart...but when VAD first?
- Need for palliative care
- Financial cost and burden



Impact & Burden Over Time

Stress

Fear

Depression/Anxiety

Diminished Quality of Life

Financial concerns

Insurance concerns

Family/sibling impact

Uncertain future

Increasing morbidity

Mortality



What Do We Know?

- Fontans have a health condition that is persistent and long lasting in nature
- Fontans have a *disease* that lasts longer than three months
- It may get slowly worse over time...
- It may lead to death...
- It may cause permanent changes to the body...
- It may impact their quality of life...

This Defines A Chronic Illness

The World Health Organization: Chronic Diseases
www.who.int/topics/chronic_diseases/en/

Mandate For Chronic Illness Care

“Encourage the ***coordination of medical care*** with the ***development of patient centered medical homes*** and accountable care organizations”

Robert Wood Johnson Foundation

Chronic Conditions: Making the Case for Ongoing Care (2004)

We have a responsibility to create “medical homes” for our Fontan patients

We have a responsibility to improve outcomes and lifetime care for Fontan patients

What are the “Key Drivers?”



Starts with the development of structured, interdisciplinary teams that follow Fontan patients...

Build expertise, knowledge, breadth, and depth

Capture the data and track patient outcomes

Cardiology
Hepatology
Endocrinology
Immunology
Refer as needed:

- Lymphatics
- Pulmonary
- Psychology
- Neurology
- Hematology



A UNIQUE
PROGRAM

FOR YOUR SINGLE
VENTRICLE SURVIVORS

 Children's Hospital
of Philadelphia®

Single Ventricle Survivorship Program (SVSP)

~Started in 2011

Surveillance of all Fontan survivors through comprehensive and multidisciplinary evaluations at determined touchpoints in time in a single clinic setting with a multidisciplinary team

The focus was on complications...

The focus was on surveillance...

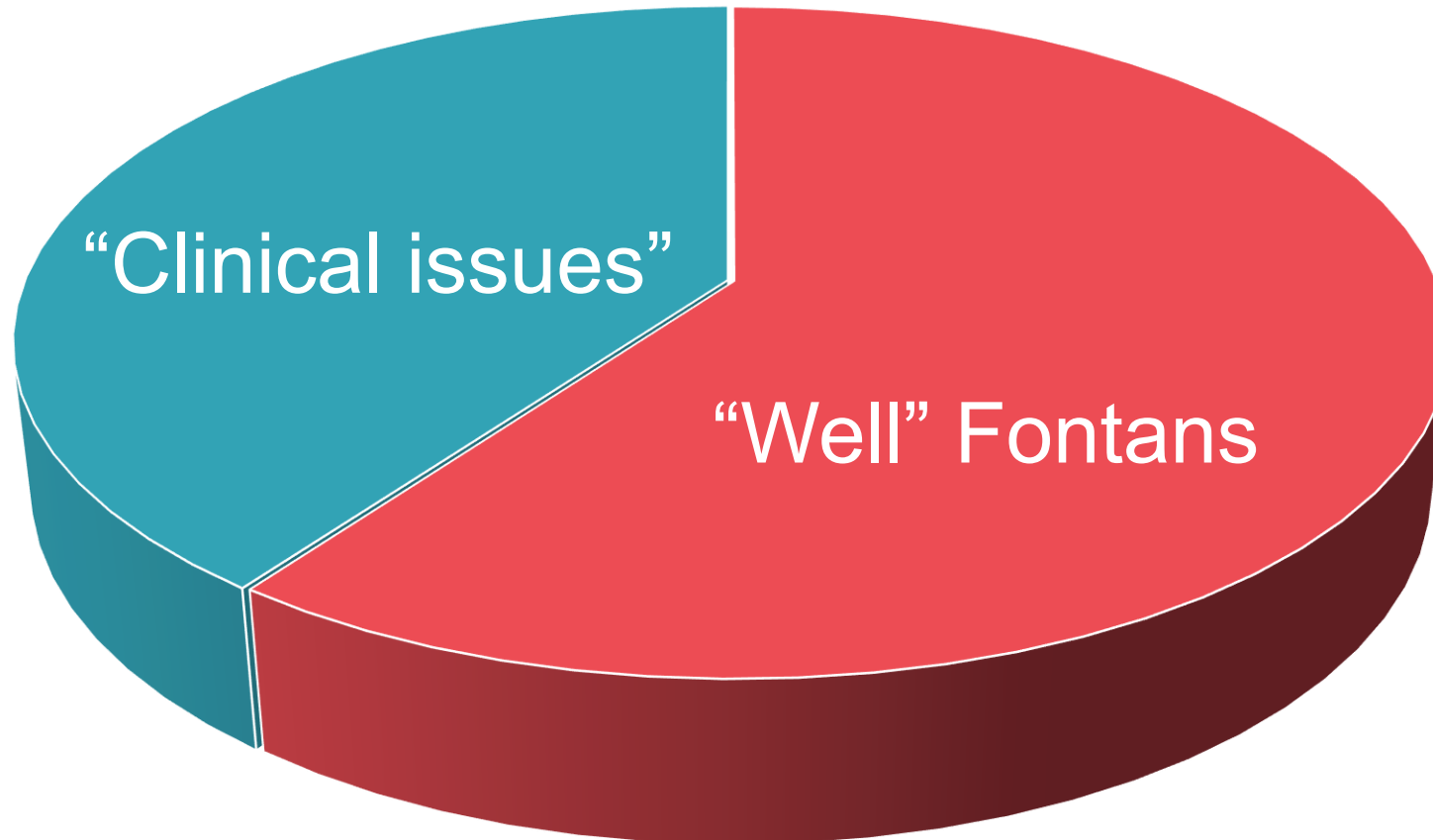
Illness Model

If you build it...

they will come

- Close to 600 patient visits over 10 years
- Patients with multiple follow up visits (2-5)
- We have learned about the liver, lymphatic issues, growth, immune function
 - We have created a team of Fontan “experts”
 - We have some breadth and depth
 - We have some data, we are learning about “key drivers”

Many Patients are “Well”...

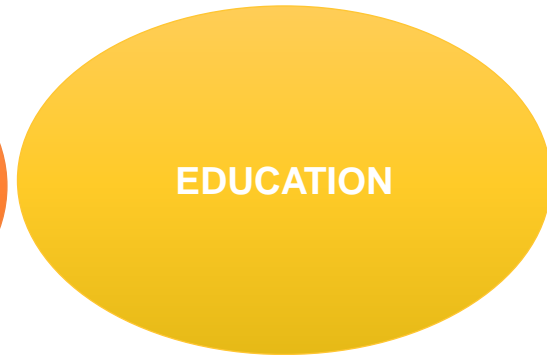


“Surveillance” is not the only “key driver”

The Fontan *FORWARD* Program at CHOP

January 2019

Fontan
Rehabilitation,
Wellness,
Activity and
Resilience
Development Project



Focus on Survivorship & Wellness Promotion & Resilience Building

Cardiology
Nursing
Hepatology
Endocrinology
Immunology
Psychology
Dietician
Social work
Exercise Trainer

The **FORWARD** Project

Fontan
Rehabilitation,
Wellness,
Activity and
Resilience
Development
Project



chop.edu/forward

Focus on Survivorship & Wellness Promotion & Resilience Building

January 2019-Present: Fontan *FORWARD*

- Increased the team
- Added clinics
- SVSP surveillance plus~
 - Evaluation with Psychologist
 - Evaluation with Dietician
 - Meet with Exercise Trainer
 - Meet with Social Worker



The Glass is Half Full

- **Make the Fontan the best it can be for each patient**
- Continue surveillance but include a health/wellness promotion model
- Optimize tolerance of this physiology past age 20-30 years
- Identify complications early and try to rescue failing Fontan's
 - PLE, Plastic Bronchitis, Hemoptysis, Function, Neoaortic valve dilation, Elevated Fontan pressures
 - Stabilize, Reverse, and Buy good quality time
- Identify complications early and determine when to timely refer for transplant
- Develop assessment tools to assess wellness and disease burden
- Promote a wellness lifestyle
 - Encourage healthy diets and intentional physical activity
 - Provide education about avoidance of risky behaviors
 - Assist patients to embrace their health potential/self care
 - Recognize that mental health is as important as clinical health
- Improve the scope, depth, and breadth of the teams caring for patients and their families
- Collaborate! THIS IS BIGGER THAN A SINGLE CENTER
- Collect the data!

Opportunities

“DATA IS POWER”

Timing is Everything!

Need National & International EFFORT

Circulation

AHA SCIENTIFIC STATEMENT

Evaluation and Management of the Child and Adult With Fontan Circulation





A Scientific Statement From the American Heart Association

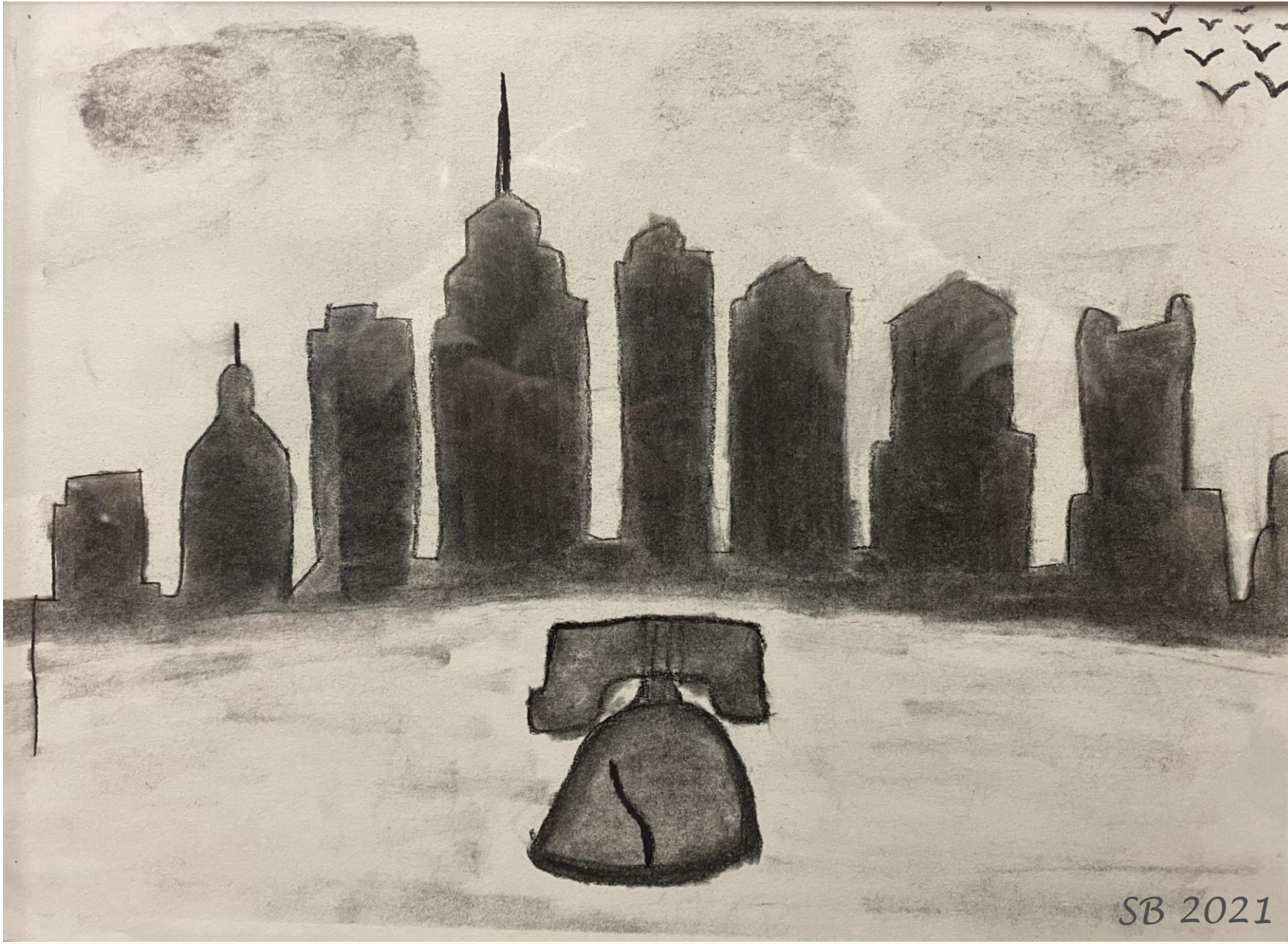
ABSTRACT: It has been 50 years since Francis Fontan pioneered the operation that today bears his name. Initially designed for patients with tricuspid atresia, this procedure is now offered for a vast array of congenital cardiac lesions when a circulation with 2 ventricles cannot be achieved. As a result of technical advances and improvements in patient selection and perioperative management, survival has steadily increased, and it is estimated that patients operated on today may hope for a 30-year survival of >80%. Up to 70 000 patients may be alive worldwide today with Fontan circulation, and this population is expected to double in the next 20 years. In the absence of a subpulmonary ventricle, Fontan circulation is characterized by chronically elevated systemic venous pressures and decreased cardiac output. The addition of this acquired abnormal circulation to innate abnormalities associated with single-ventricle congenital heart disease exposes these patients to a variety of complications. Circulatory failure, ventricular dysfunction, atrioventricular valve regurgitation, arrhythmia, protein-losing enteropathy, and plastic bronchitis are potential complications of the Fontan circulation. Abnormalities in body composition, bone structure, and growth have been detected. Liver fibrosis and renal dysfunction are common and may progress over time. Cognitive, neuropsychological, and behavioral deficits are highly prevalent. As a testimony to the success of the current strategy of care, the proportion of adults with Fontan circulation is increasing. Healthcare providers are ill-prepared to tackle these challenges, as well as specific needs such as contraception and pregnancy in female patients. The role of therapies such as cardiovascular drugs to prevent and treat complications, heart transplantation, and mechanical circulatory support remains undetermined. There is a clear need for consensus on how best to follow up patients with Fontan circulation and to treat their complications. This American Heart Association statement summarizes the current state of knowledge on the Fontan circulation and its consequences. A proposed surveillance testing toolkit provides recommendations for a range of acceptable approaches to follow-up care for the patient with Fontan circulation. Gaps in knowledge and areas for future focus of investigation are highlighted, with the objective of laying the groundwork for creating a normal quality and duration of life for these unique individuals.

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On behalf of the American Heart Association Council on Cardiovascular Disease in the Young and Council on Cardiovascular and Stroke Nursing

Key Words: AHA Scientific Statements
congenital heart defects • Fontan procedure • quality of life

© 2019 American Heart Association, Inc.
<https://www.ahajournals.org/journal/circ>

- AHA guidelines for care
 - Circulation July 2019
 - <https://doi.org/10.1161/CIR.0000000000000696>
- Multiple centers in US have outstanding programs
 - Issues and questions are bigger than a single center!!
- Parent and patient involvement   sistersbyheart
- International Fontan Interest Group(IFIG)
- National Pediatric Cardiology-Quality Improvement Collaborative (NPC-QIC)  National Pediatric Cardiology Quality Improvement Collaborative
- Fontan Outcomes Network  FONTAN OUTCOMES NETWORK
 - Working towards development of a national database, and standardization of care and follow-up



Thank You!

Fontan Outcomes Network: Ignite Talk

Taylor Hartzel Houlihan



Introduction



1997



2021

Early Exercise



“She may never be an Olympian, but she can do whatever she wants to do.”

- Dr. Thomas Spray



Empowered to Dance

Good Habits for Life



Exercise is so important not just for my physical health, but for my mental and emotional health as well.

Why We Need FON



1. Create a unified message of guidance and support
2. Ensure proper exercise testing and annual exams
3. Empower current and future generations of patients with Fontan circulation to pursue physical activity

Engagement Opportunities

Stacey Lihn

Carole Lannon



Objectives: Share Upcoming Engagement Opportunities

- Blogs/communications
- 2022 Educational opportunities
 - Developing care center/patient and family resources
 - Hosting webinars on key topics
- Late 2022/2023
 - Participate as a FON center with access to data for research and QI



Building Strength Through Numbers

Awareness

- #HearHero Campaign
- Blog Posts
- Social Media
 - Facebook
 - Twitter
 - Instagram
 - YouTube
- Website:
fontanoutcomesnetwork.org

Communication

- Monthly Newsletter to SV Community
- Weekly Newsletter to Care Center Key Contacts
- Clinical Vignettes from Case Review Conferences*

Engagement

- SV Patient Day
- Social Media Takeover*
- QI Education Spring 2022 through Cardiac Networks United*
- Future opportunities for FON Workgroup participation:
 - Data & Analytics
 - Quality Improvement
 - Research
 - Community Building & Engagement

Community Building & Engagement Workgroup Priorities

1. Awareness
2. Communication
3. Engagement

**coming soon*

#HeartHero Spotlight

Nominate a heart hero:

- nurse
- patient
- physician
- family member
- therapist
- anyone who's impacted the SV journey



FON #HeartHero Spotlight: Ayden Cazares

The Fontan Outcomes Network is a community of patients, family members, caregivers, clinicians, researchers, and supporters, dedicated to improving the quality of life and health outcomes for individuals with single ventricle circulation. Each month, we feature a member of the community who goes "above and beyond" in service of this mission as our #HeartHero.

<https://www.fontanoutcomesnetwork.org/nominate-a-hearthero>

Future Opportunities 2022/2023

- 2022: Developing Resources and Educational Webinars for the Community
- Late 2022/2023: Participate as a FON Center
 - Access to data for Improvement and Research
 - All Teach, All Learn
 - Contribute to changing the outcome

2021

Gathering Information for FON: What is Important, Where are Gaps

- Survey of the 12 Founding Care Centers

Question: Please share at least three areas where practice standardization would be most likely to improve long-term patient care and outcomes.

- Single Ventricle Patient Day Survey

Question: Please indicate topics of interest



Liver Health



Exercise/Physical Activity



Emotional Health



Transplant



Birth Control & Pregnancy

**PATIENT &
CARE CENTER
SURVEY:**

**FIVE THEMES
EMERGED**

2021/2022 Next Steps

- Identify 1-2 projects to start
- Workgroups from 12 founding centers to synthesize consensus best practices
- Identify, and if needed, develop practical resources
 - Care practice plans
 - Patient and family materials
- Share openly with the community, e.g. webinars, website
- May serve as basis for improvement efforts

Example Resources from other networks: Care Practice Plans & Patient Materials

NATIONAL PEDIATRIC CARDIOLOGY
Quality Improvement Collaborative | a JCCHD initiative

This Red Flag Action Plan template was designed by NPC QIC teams and parents, as a way to facilitate clear communication between families and their cardiologist regarding recognition of interstage warning signs ("red flags") and what to do about them.

Families (and clinical teams) are encouraged to review and complete this form with their cardiologist, and to modify the form freely.

RED FLAG ACTION PLAN for PARENTS

This document is intended to help you and your cardiologist clarify the appropriate responses to any "Red Flags" or significant changes in your baby's health. We encourage you to:

- ✓ Review and complete this document carefully with your Cardiologist. Modify it as much or as little as you like.
- ✓ Determine with your cardiologist what important health indicators you should track and record.
- ✓ Fill in any missing phone numbers below, insert helpful notes, and read all materials provided by the hospital and physicians
- ✓ Make several copies of important documents to share with babysitters, neighbors etc. and store additional copies in convenient places like diaper bags, strollers, or the car
- ✓ Go to all medical appointments
- ✓ Respond to calls and other communications from your healthcare providers
- ✓ **Cardiologist Name and Phone Number**

You know your baby best! We encourage you to report any changes that are of concern to you.

RED FLAGS	ACTIONS (What to do)
Any behavior or bodily change that worries you	
Irritability/won't calm, or decreased response to you	
Temperature over ___ °F	
Increased work of breathing or stopping to breathe during feeding	
Feeding difficulty, increased sweating during feeds, or excessive spitting up	
Does not gain an average of ___ grams over ___ days	
Vomiting or diarrhea (more than ___ episodes in ___ hours)	
Fewer than ___ wet diapers per day	
Low oxygen saturations (less than ___ %)	
Feeding pump or pulse ox monitor problems	

Pediatrician Phone Number:

Other Important Phone Numbers and Notes:

Moving Toward a Heart-Healthy Life

action
ADVANCED CARDIAC THERAPIES
IMPROVING OUTCOMES NETWORK

YOUR BODY WAS MADE TO MOVE!

All children should get **at least 60 minutes** of physical activity every day.

the good news:



Most young patients with heart disease can exercise safely because most fun activities are noncompetitive, low-moderate intensity, and use just body-weight. You don't have to do all your exercise at once; small bursts of activity count too.

WAYS TO BE ACTIVE

MOVING AND PLAYING

at home, school, or work



Take the stairs, play at recess

RECREATIONAL SPORTS

no pressure to perform, can take breaks



Walk, jog, bike, work out at gym

COMPETITIVE SPORTS

pressure to train and perform at a high level



Playing for school or college teams

TYPES OF EXERCISE

AEROBIC

exercise makes you breathe fast and sweat

Light intensity | Can easily sing | Walking
Moderate intensity | Can talk in sentences | Jogging
High intensity | Can't speak full sentences | Running

STRENGTHENING

exercise makes you pull or push using your muscles

Light weight | jumping, push-ups, sit-ups
Moderate weights | squats, bench-press

EXERCISING RIGHT

It's **OK** to sweat, feel a little breathless, and have mild soreness in your muscles.

It's **important** to drink water, avoid excessive heat, and take breaks.

WARNING SIGNS



You should **never** feel squeezing chest pain, dizzy, or pass out. This means you need to stop.

Stay safe!

Check with your health care team before participating in competitive sports, moderate-high intensity exercise, or lifting heavy weights. Your care team might restrict you or recommend certain precautions.

actionlearningnetwork.org | info@actionlearningnetwork.org | Action-Learning-Network | @Action4HF

A Parent's Guide to HLHS: Preparing for Fontan

The Pre-Fontan stage can be both exciting and scary for patients and families. This bulletin was designed by parents of children with single ventricle diagnosis, in collaboration with mental health and healthcare professionals, to provide information and useful resources for your family as you prepare for the Fontan surgery. Consider the following ideas in conjunction with your child's likes, dislikes, coping style, age and preferences.

Preparing Your Child

- Encourage familiarity with the medical experience through medical play, books, TV shows, and apps to increase your child's and family's comfort level. (See resources below.)
- Utilize mindfulness apps to help your child identify emotions and learn coping strategies. (See resources below.)
- Discuss the surgery with your child no more than one week before; recommended 1 day per year of age (ex: 3 days before if 3 years old).
- Consult with your hospital's child life specialist or social worker on specific language to use with your child.
- Emphasize surgery is not punishment because your child did anything wrong. Avoid words such as "sick" or "broken," instead, use words like "help" or "make stronger."
- Reinforce that the Fontan is part of growing up with single ventricle and means he/she is getting stronger and may allow increased activity (ex: run without getting winded, take swim lessons).
- Remember it's okay to not have all the answers, "I'm not sure, but I can find out for you" or "let's ask the doctor together" are good responses.
- Ask, non-judgmentally listen, and support how your child is feeling about the upcoming surgery.
 - Children often express emotions through their play so watch for this in various ways.
 - Reach out to your child's care team if you have any concerns.
- Feeling a loss of control is common. Try to give your child a sense of control. Ideas include: packing a bag and choosing books/activities for the hospital stay, choosing comfort items like a blanket or stuffed animal.
- Pre-surgery hospital consultation is recommended and often available including a hospital tour, room pictures and information on hospital resources



"I was anxious and nervous about my son's Fontan now that he was three years old and able to voice fear, pain, and other emotions. The last time he was hospitalized he was five months old and obviously didn't remember it."

Kristen, Heart Mom

Child-Focused Resources

Websites: Anesthesia: Visit kidshealth.org/en/parents, search for "Preparing your child for anesthesia" | Surgery: Visit kidshealth.org/en/parents, search for "Preparing your child for surgery"

Books: *At the Hospital* by Carron Brown (A Shine-A-Light book), *My Brother Needs an Operation* by Anna Marie Jaworski, *Super Heart Hero* by Samantha Kelly

TV: Doc McStuffins, popular children's show about medical care

Mindfulness Apps: For younger children: Breathe, Think, Do with Sesame Street

For older children: Stop, Breathe & Think Kids

National Pediatric Cardiology
Quality Improvement Collaborative

sistersbyheart

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FON Year 1 Timeline

Jul – Sep 21

Oct – Dec 21

Jan – Mar 22

Apr – Jun 22

Registry

User Interviews/
Research

Registry Design

Registry Build

User Acceptance
Testing

LAUNCH

Central IRB
Approved

CCs Execute IRB/Legal Documents

Engagement

SV Patient
Day

Engage
Next Wave of Centers

Learning
Session

Learning
Session

Quality
Improvement

Care Center Survey

Identify Care
Practice
Projects

Design and charter
projects

Invite teams to
participate in projects

Review QI
Graphs for
Registry

Community Webinars
(ex. Exercise, Emotional Health, etc.)

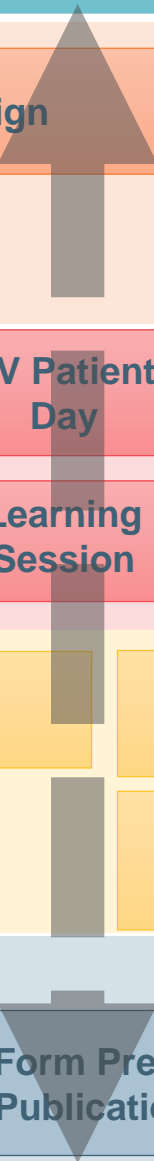
Research

Draft Research Guidelines

Form Presentations and
Publications Committee

Draft Data Use
Processes (with QI and
Data Workgroups)

Refine Research
Guidelines



Q & A with the FON ELT

Please enter any questions for the FON Executive Leadership Team in the chat.



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Parent/Patient Director

Single Ventricle Community:

- Thank you for attending!
- Please complete the event evaluation in the chat.
- We hope to see you again soon!

FON Founding Care Centers:

- Please join us for the second session in 15 minutes.
- Please check your email or event program for the second Zoom link.

Questions? Message us in the chat or email
info@fontanoutcomesnetwork.org