



CARDIOLOGY
2024



Building a Multi-Disciplinary Fontan clinic Challenges and Opportunities

Deepti P Bhat, MD, FACC

Co-director, Multi-disciplinary Pediatric Fontan Clinic,

Medical Director, Echocardiography

Assistant Professor, University of Arizona

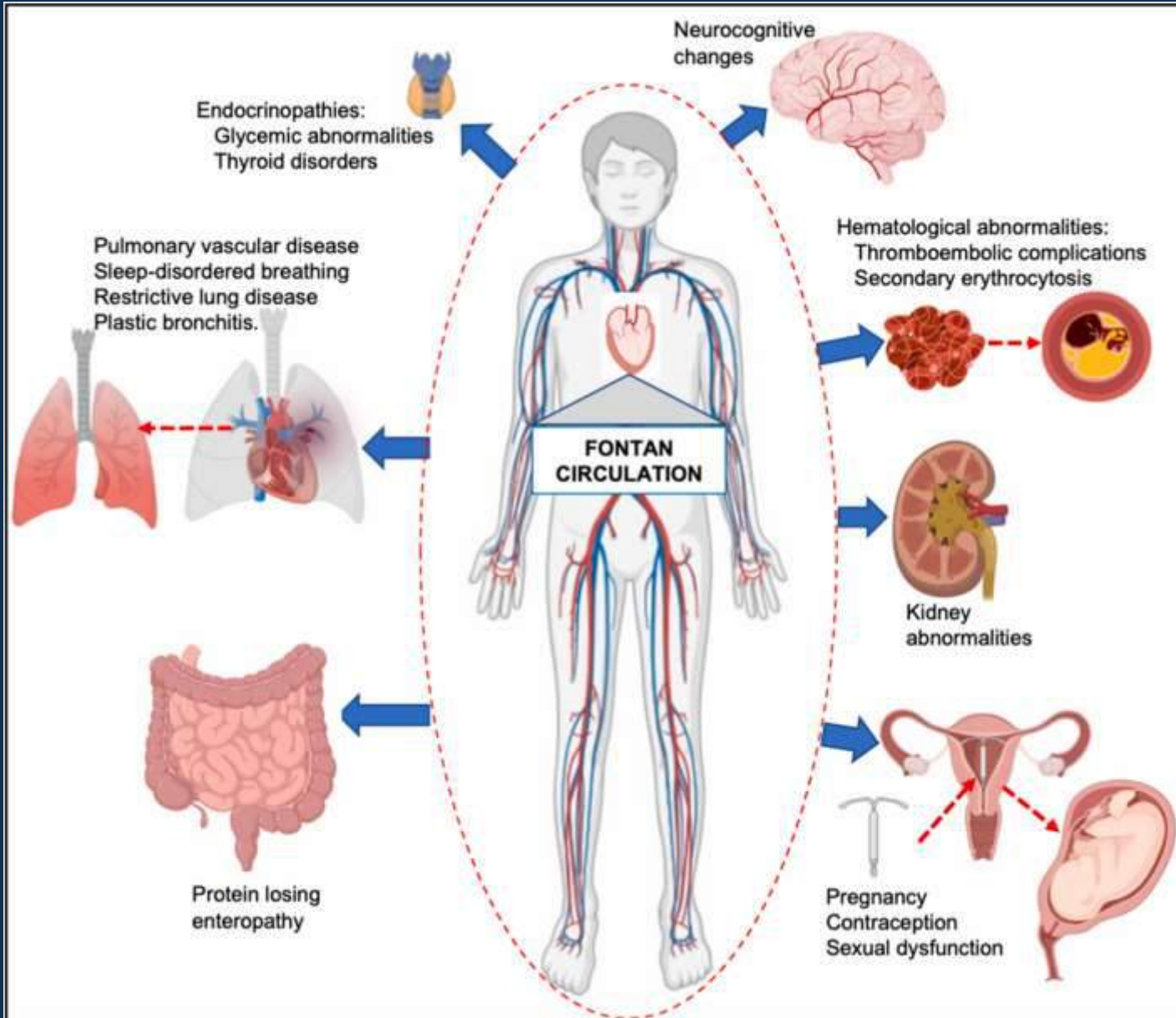
Center for Heart Care, Phoenix Children's

Arizona

PHOENIX CHILDREN'S *Hospital*

I have no financial disclosures.

Fontan patients need multi-disciplinary care because Fontan is a multi-system disease



MDC Fontan care may include:

- Congenital cardiology
- Pulmonology
- Hepatology
- Endocrinology
- Nephrology
- ENT
- Immunology
- Psychology
- Psychiatry
- Nutrition
- Social Work
- Exercise physiology
- Obstetrics/ Gynecology
- Developmental pediatrics
- Lymphatic specialists
- General surgery
- Plastic surgery
- CT surgery
- Transplant teams



Fontan Clinic

Center for Heart Care

At one time, babies born with single-ventricular heart defects had low chances for recovery and a healthy future. The [Fontan procedure](#), developed in 1971, changed that. Now, after decades of improvements to the procedure, most children survive to adulthood and enjoy a good quality of life.

But building a multi-disciplinary Fontan clinic can be challenging !

The team of specialists at the Fontan Clinic at Phoenix Children's know what to look for and how to respond effectively. No matter where the procedure was performed, we can provide follow-up testing and care, now and into the future.

If you or your child have had a Fontan procedure to correct a single-ventricle heart defect, you are invited to visit this multispecialty clinic. We accept patients from across the nation. No matter where the procedure was performed, our clinic can evaluate your needs and provide experienced, specialized care and monitoring. We can help anticipate and identify any changes or complications — so you can get the most effective treatment as quickly as possible.

Your doctor or cardiologist can refer you to the Fontan Clinic. We'll work with your cardiologist and other healthcare providers to make sure you get all the care you need.

And often feels like this:



Challenge: Balancing needs of your patients with your resources

Demand

Volume of single ventricle patients cared for?

Adult Fontan patients?

Referring providers?

Surgical volumes for Fontan?



Supply

Time, funds, support staff?

Pediatric specialists?

Adult specialists including OB?

Heart transplant availability?

Multi-organ transplant?



Challenge: Finding the right MDC model that fits your needs

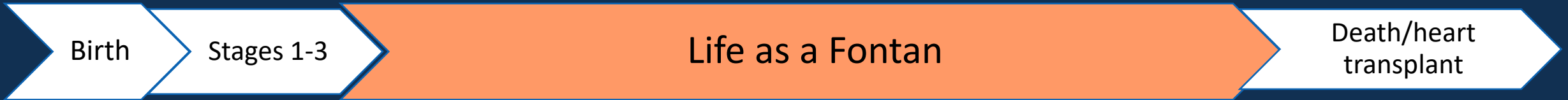
One size does not fit all

- Study the existing models of care
- Study what has worked and not worked at your institute
- Discuss with the other Fontan teams



Image courtesy: Arunya 3rd grade

Select the care model that works for your program



Comprehensive SV program: SV team manages all SV patients after Stage 1 surgery

Continuity, staff experience, coordinated care; but requires enormous resources

Fontan clinic takes over the care after Stage 3 surgery

Continuity, uniform standardized Surveillance and management Needs resources

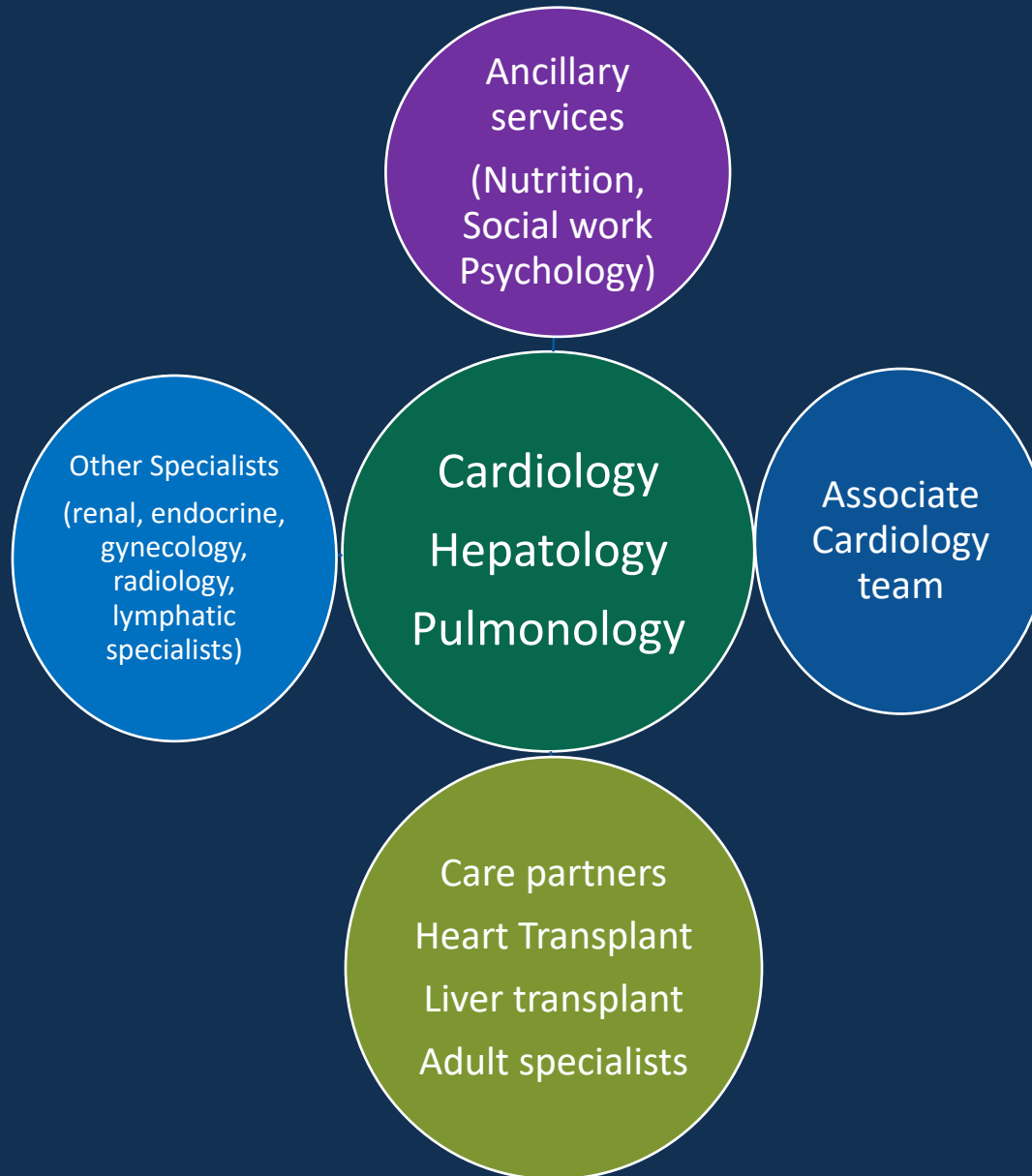
Fontan clinic coordinates multi-disciplinary care and assists the primary cardiologist

Practical, can be started with limited resources; requires strong communication and coordination with referring cardiologist

Challenge: Defining the goals of the Fontan clinic

- Surveillance
- Comprehensive follow up care
- Optimizing care, including referral to organ transplant
- Other functions of the Fontan clinic:
 - Inpatient consultations for failing Fontan patients
 - Developing outpatient and inpatient management protocols
 - Develop educational resources for the providers and patients
 - Participate in multi-center networks, research

Challenge: Building a multi-disciplinary team



Core Cardiology team members:

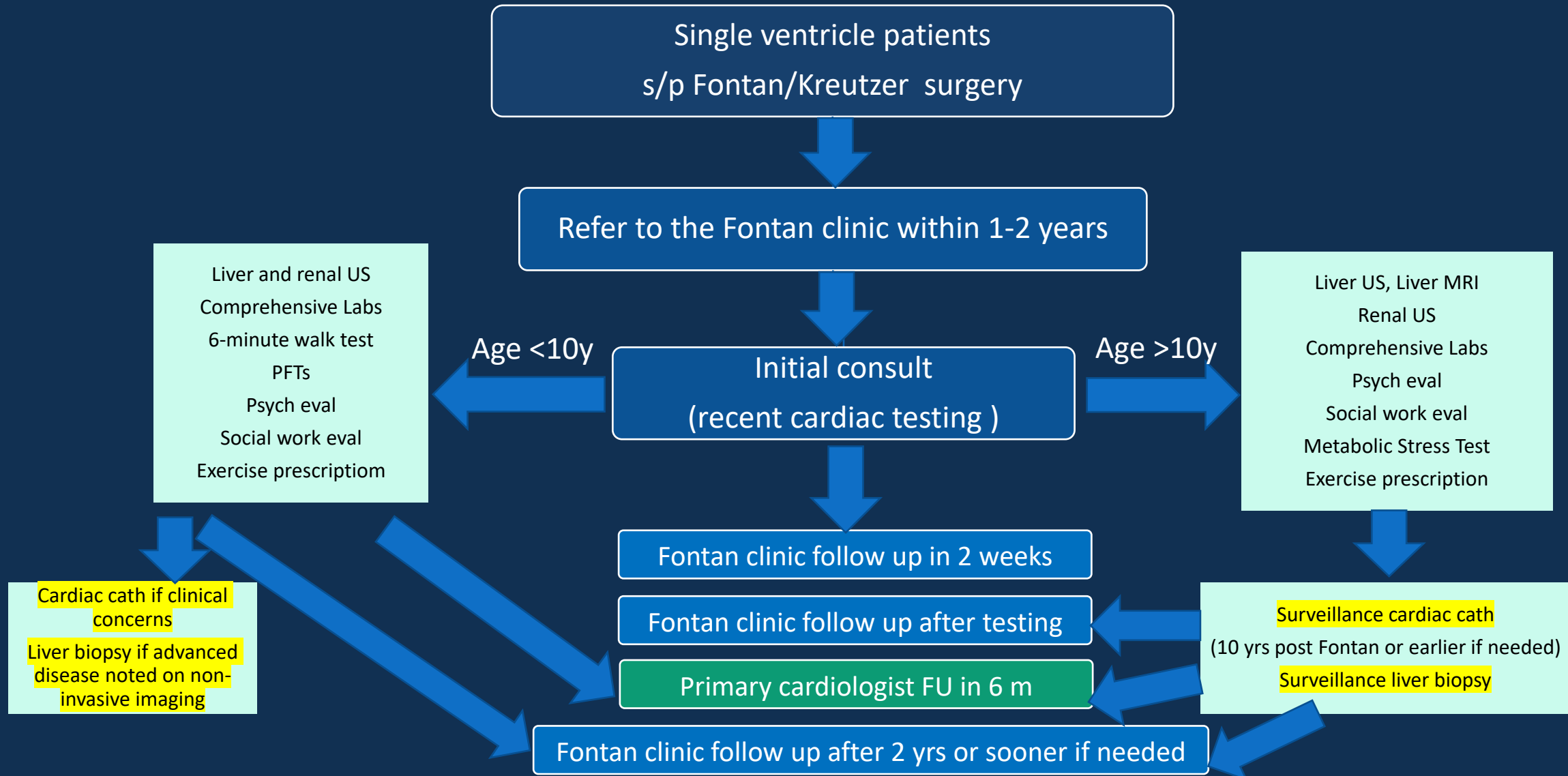
- Cardiologist (pediatric and ACHD)
- Fontan clinic coordinator
- Fontan medical assistant
- Fontan advanced care practitioner

Associate Cardiology team:

- Cardiac interventionalists
- Electrophysiology
- Exercise Physiology
- Cardiothoracic surgeon

Challenge: Creating a smooth workflow and clinic operations

Our model



Challenge: Working Together As A Team

- Common goal
- Clear task delegation
- Clear workflow
- Communicate

Team Huddle:

- Before the clinic
- During the clinic
- After the clinic
- When test results arrive
- When patient status changes



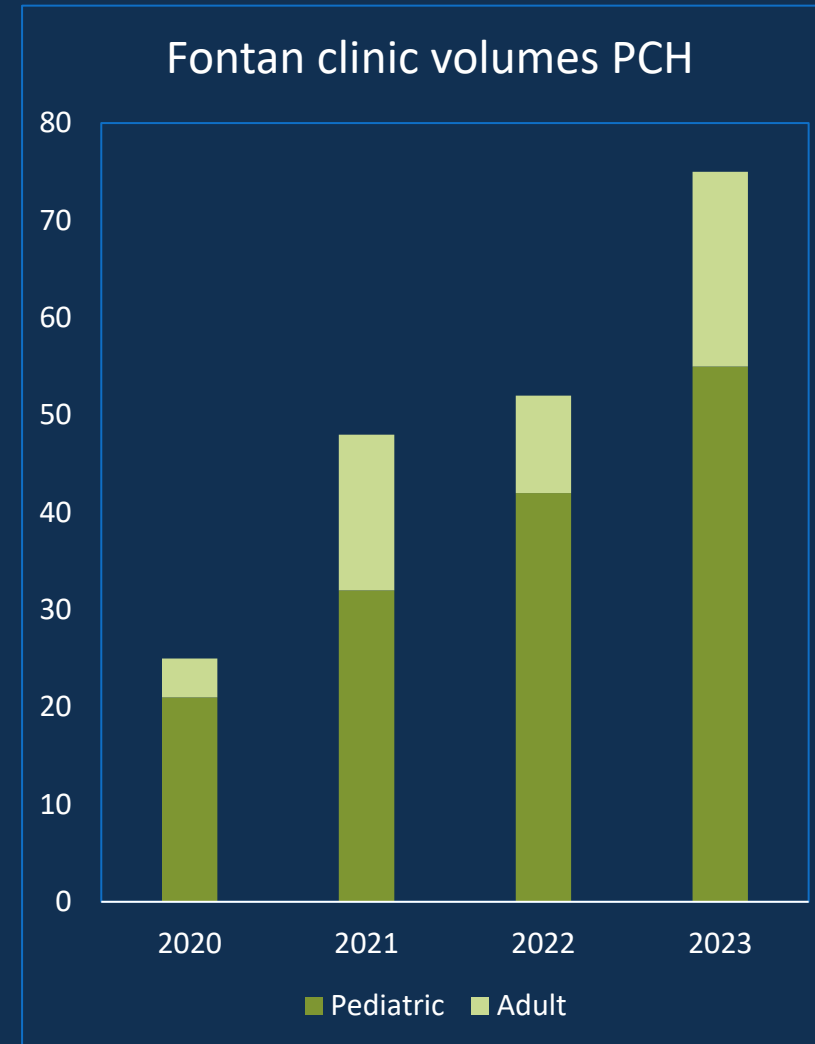
- Present a united face to the patients and providers.
- Avoid conflicting recommendations.
- Talk as a team not as individuals.
- Educate each other.
- Respect each other.

Challenge: Gaining trust

- Gaining trust of the referring cardiologists
- Gaining trust of the families (parents and caregivers)
- Gaining trust of your patient

Gaining trust of the referring cardiologist

- Show them how the Fontan clinic will benefit their patients
- Show them how your clinic functions
- Communicate : the referring provider should get clear recommendations from the team
- Expect resistance to some recommendations
- Respect the differences in opinion
- Use the primary cardiologist to gain patient trust



200% increase
over 3 years

Gaining trust of the parents

- Acknowledge their anxiety and stress.
- Deliver bad news honestly but with compassion.
- Try to be the **problem solver**, not just a “problem finder”.
- **Expect denial, shock and resistance : many of them never knew that the Fontan surgery could cause liver/lung/kidney damage.**
- Communicate clearly.
- Allow time to process.
- Summarize at the end of the visit.
- Use **social worker** to gauge their support system.
- Provide **educational resources**, evidence-based research findings
- **Schedule a follow up visit to answer their questions.**

Gaining trust of the patients

Meeting several specialists at the same time can be intimidating and stressful for children and young adults



Image courtesy: Arunya, 9 yrs



Image courtesy: Arushi, 12 yrs

Talk to your patient directly, no matter how young they are !

Ask what they know
Ask how they feel
Ask what they want

Respect their opinion
and desires

Educate
Be honest
Empower
Give hope



Image courtesy: Arunya, 9 yrs

Expect shock,
depression
Use psychologist

Be a cheerleader
Be a friend

Give them time
Keep them involved
Connect them with
peers

Engage in research, network building

1. **Safety and utility of CardioMEMS device for remote pulmonary artery monitoring in pediatric Fontan patients: a case series.** Bhat DP, Graziano JN, Garn BJ, Franklin WJ. Eur Heart J Case Rep. 2023 Aug 30;7(9):ytad422
2. **Utility Of CardioMems Device In Assessing Changes To Fontan Hemodynamics With Exercise In Pediatric Fontan Patients.** Sabati A, Chesney B, Montachal J, Bhat DP. Abstract presented at Cardiology 2024.
3. **Accuracy of Elastography vs Biopsy in Assessing Severity of Liver Fibrosis in Young Fontan Patients.** Bulut O, Bailey S, Bhat DP. Manuscript submitted.
4. **The Pandemic Effect: Did Limited Access to Care During the COVID-19 Pandemic Effect Newborns with Single Ventricle Congenital Heart Disease?** Maenchen M, Lindblade C, **Bhat DP** J Am Soc Echocardiography 2023
5. **Pre-Glenn Hemodynamic and Echocardiographic Risk Factors affecting One-Year transplant-free survival in HLHS.** Ramanathan R, Graziano J, Bhat DP. Manuscript in progress.
6. **Short and medium-term outcomes of patients with Hypoplastic Right Heart syndrome: a 12-year single center retrospective review.** Matney Chelsea et al. Abstract presented at Cardiology 2024.
7. **Interstage growth failure prolongs duration to Stage II palliation: a 10-year single center experience.** Bates Kaitlyn et al. Abstract presented at Cardiology 2024.

Fontan Outcomes Network

ACTION/Fontan Network

NPC-QIC

Summary

- MDC Fontan clinic requires strategic planning, well defined goals, clear delegation of tasks and responsibilities, and effective communication to be successful.
- Most importantly, it requires a team of dedicated, committed and compassionate health care staff who truly want to work with this complex population.
- Despite the challenges, the Fontan clinic provides a great opportunity to improve the quality of care for these fragile, complex patients.
- Build slow, take your time-----its worth it!

Thank you to our wonderful Fontan team at PCH



Deepti P. Bhat,
MD

Director,
Pediatric
Fontan clinic



Wayne J.
Franklin, MD,
FACC

Director, Adult
Fontan clinic



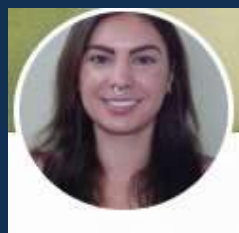
Ozlem Pinar
Bulut, MD

Fontan
Hepatologist

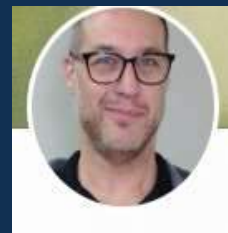


Sophia N.
Williams, MD

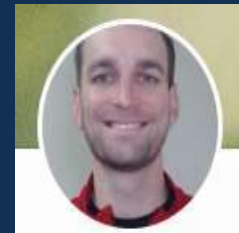
Fontan
Pulmonologist



Kat Wingate
Fontan Dietician



Jake Wilks
Social worker



Jake Montchal
Exercise
Physiologist



Sarah A Mejia
Psychologist

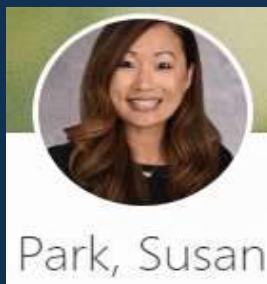


Karen Papez
Nephrologist



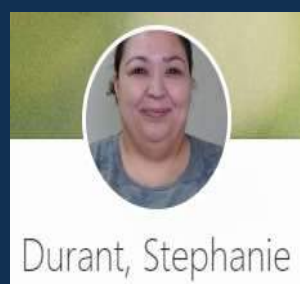
Chesney, Bill

Fontan clinic
coordinator



Park, Susan

Fontan NP



Durant, Stephanie

Fontan clinic MA



Arash A.
Sabati, MD

Director, Stress
lab

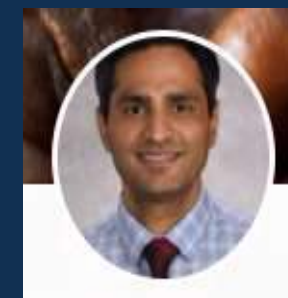


Joseph N.
Graziano, MD

Director, Cath
Lab, IMP



Mohamad
Alaeddine, MD
Cardiothoracic
surgeon, SV
Lymph team



Vasu Gooty
MD
Cardiac
imaging, SV
lymph team

Fontan radiology lymph group:

Scott Willard, Carrie Schaeffer, Sudhen Desai, Josh Pohlman

Thankyou
Feel free to contact me with any questions:
Email: dbhat@phoenixchildrens.com

