Patient and Family Mental Health in CHD

Dr. Nadine Kasparian
Professor of Pediatrics
Director, Heart & Mind Wellbeing Center
Cincinnati Children's Hospital
www.cincinnatichildrens.org/heart-mind
nadine.kasparian@cchmc.org
@NKasparian

Cincinnati Children's
changing the outcome together

Mary

VSD repair at age 6 years.

Mary

VSD repair at age 6 years. **In 1957**.

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Our ACHD team met Mary only recently.
She had been lost to follow-up care.
Led a pretty ‘normal’ life.

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VSD repair at age 6 years. **In 1957**. She is now 72 years old.

Our ACHD team met Mary only recently.
She had been lost to follow-up care.
Led a pretty ‘normal’ life.

A few months ago-
Referred to a community-based cardiologist to assess for coronary blockages.
Cardiologist was concerned Mary may have pulmonary hypertension.
Connected her with our ACHD team.

Good News!

- Elevated right ventricular pressure was not due to pulmonary hypertension.
- There was hypertrophic muscle causing mild RV outflow obstruction.

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The team figured this would put Mary's mind at ease.
But that isn't what happened.

During her visit

Mary was tearful and visibly shaking.
It became clear she carried an enormous post-traumatic burden.

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It became clear she carried an enormous post-traumatic burden.

Mary had been living with anxiety since childhood.
Vivid memories of early medical experiences.
Worried intensely about her health.
Panic attacks and insomnia.
She avoided healthcare.
Had great difficulty even walking into the hospital.
During medical visits, her mind would go blank.
Rarely remembered what doctors told her.

Benefits of integrated psychological care

Cardiologist who referred Mary to our program, a really caring doctor, had no sense of her PTSD

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Cardiologist who referred Mary to our program, a really caring doctor, had no sense of her PTSD ➡ **under-recognized and under-treated**

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Ability to quickly connect Mary with a psychologist who has expertise in CHD, **who works side-by-side with our cardiac care team**, allowed her to have the medical care she needed.

And to start living with her heart disease, rather than in fear of it.

Psychological effects begin early. And can last a lifetime.

Ways traumatic stress can impact our patients across their lives:

- Being lost to follow-up cardiac care
- Having difficulty processing medical information
- Not adhering to clinical recommendations
- Ongoing guilt and fear associated with knowing your heart health is not being taken care of

Another aspect of Mary’s story

Another aspect of Mary's story

Medically, everything went well during her pediatric care.

Another aspect of Mary's story

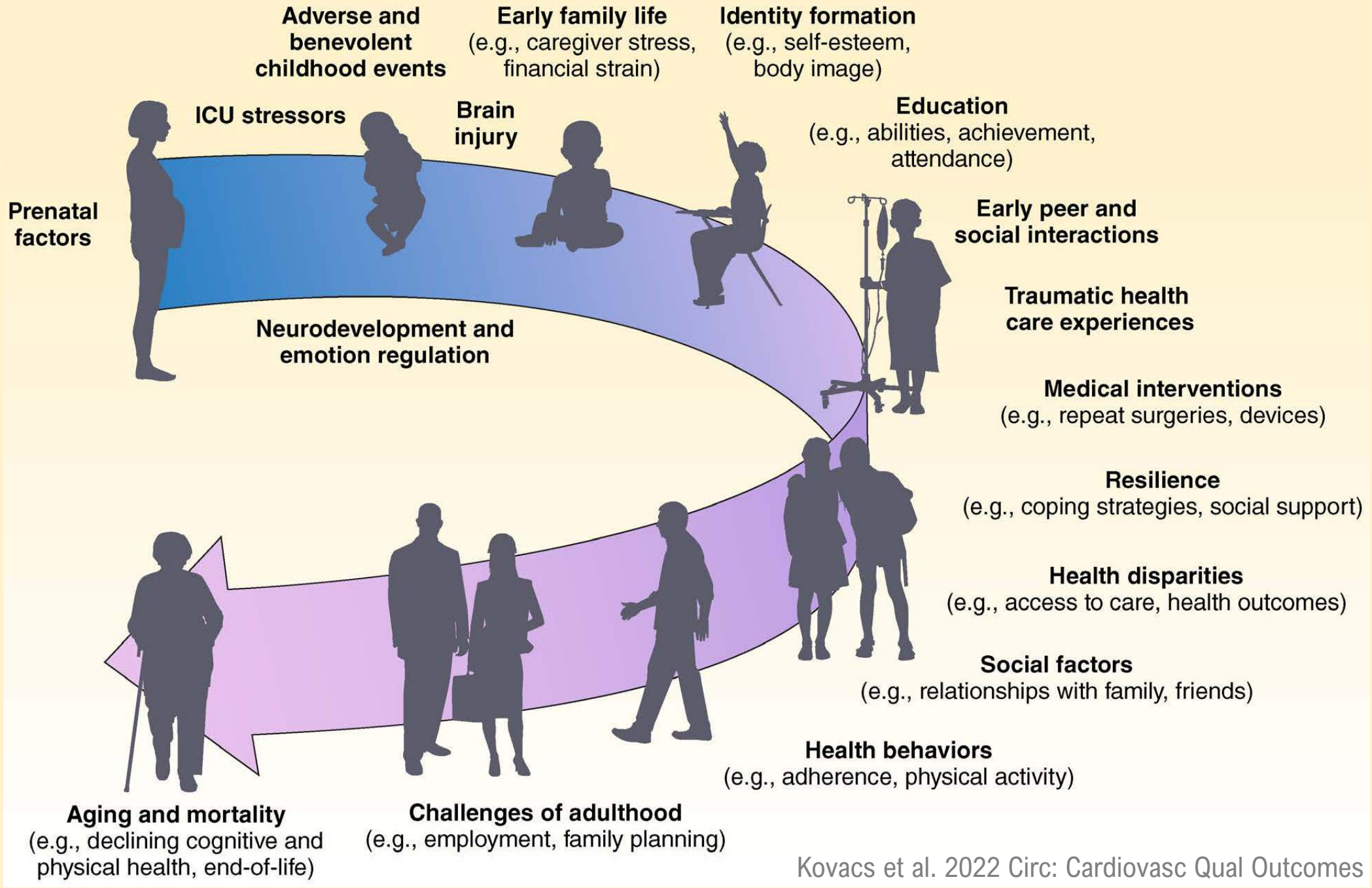
Medically, everything went well during her pediatric care.

Mary remembered her pediatric cardiologist as a kind and caring man – and speaks of him with great fondness.
She described a loving, supportive family.
She suffered no physical complications.
Heart disease hadn't limited her participation in typical childhood.

Her CHD was mild, but to a child's mind there's no such thing as 'minor' heart surgery.

From Cincinnati Children's Archives, taken in 1959

Reunion of children who had open-heart surgery, gathered around the heart-lung machine



Kovacs et al. 2022 Circ: Cardiovasc Qual Outcomes

Mental health in adolescents with single-ventricle CHD

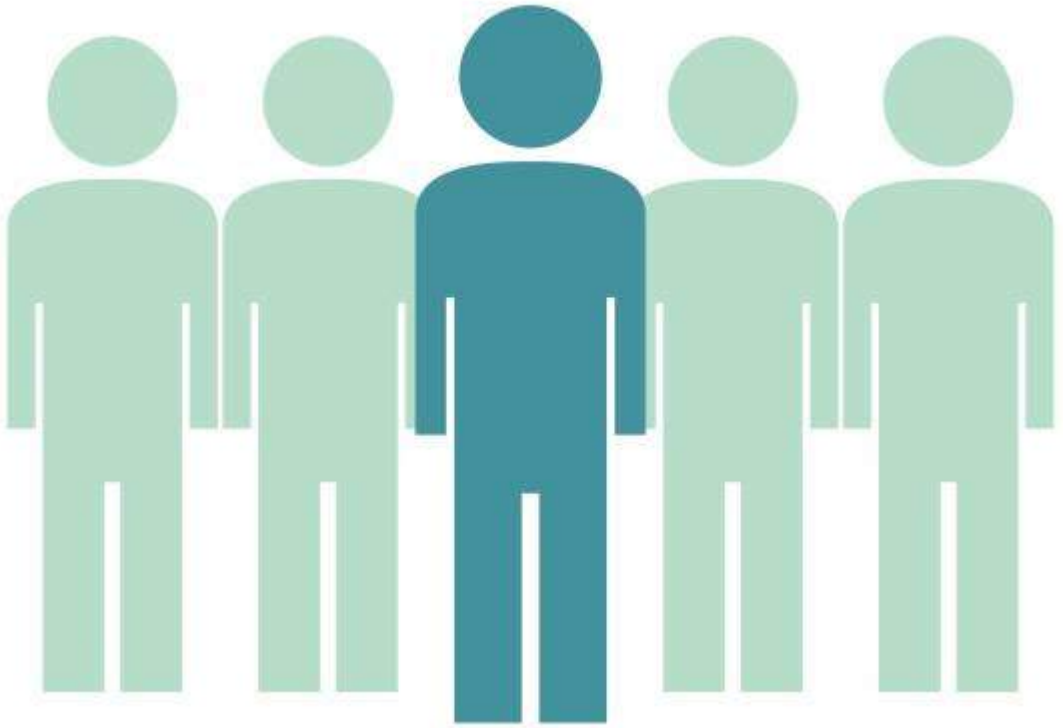
5X Higher rate of anxiety

6X Higher rate of ADHD

65% Lifetime prevalence of any psychiatric disorder

compared with 22% among healthy peers

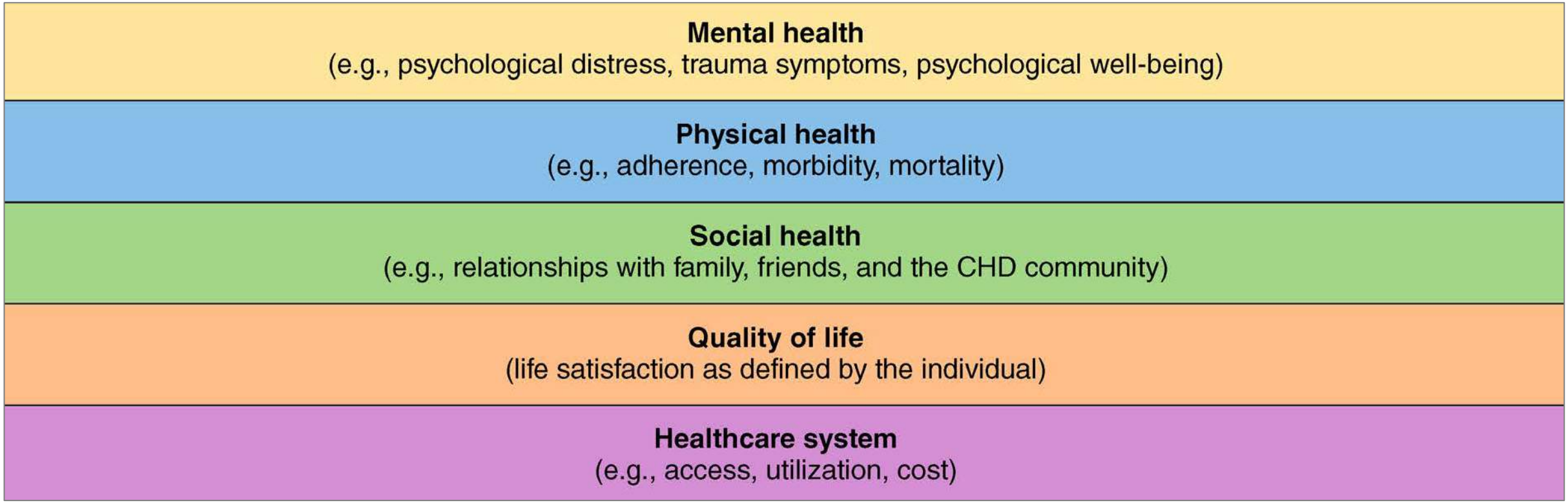
DeMaso et al. 2017 Pediatrics



1 in 5 adults with CHD meet criteria for PTSD

Deng et al. 2016 Am J Cardiol

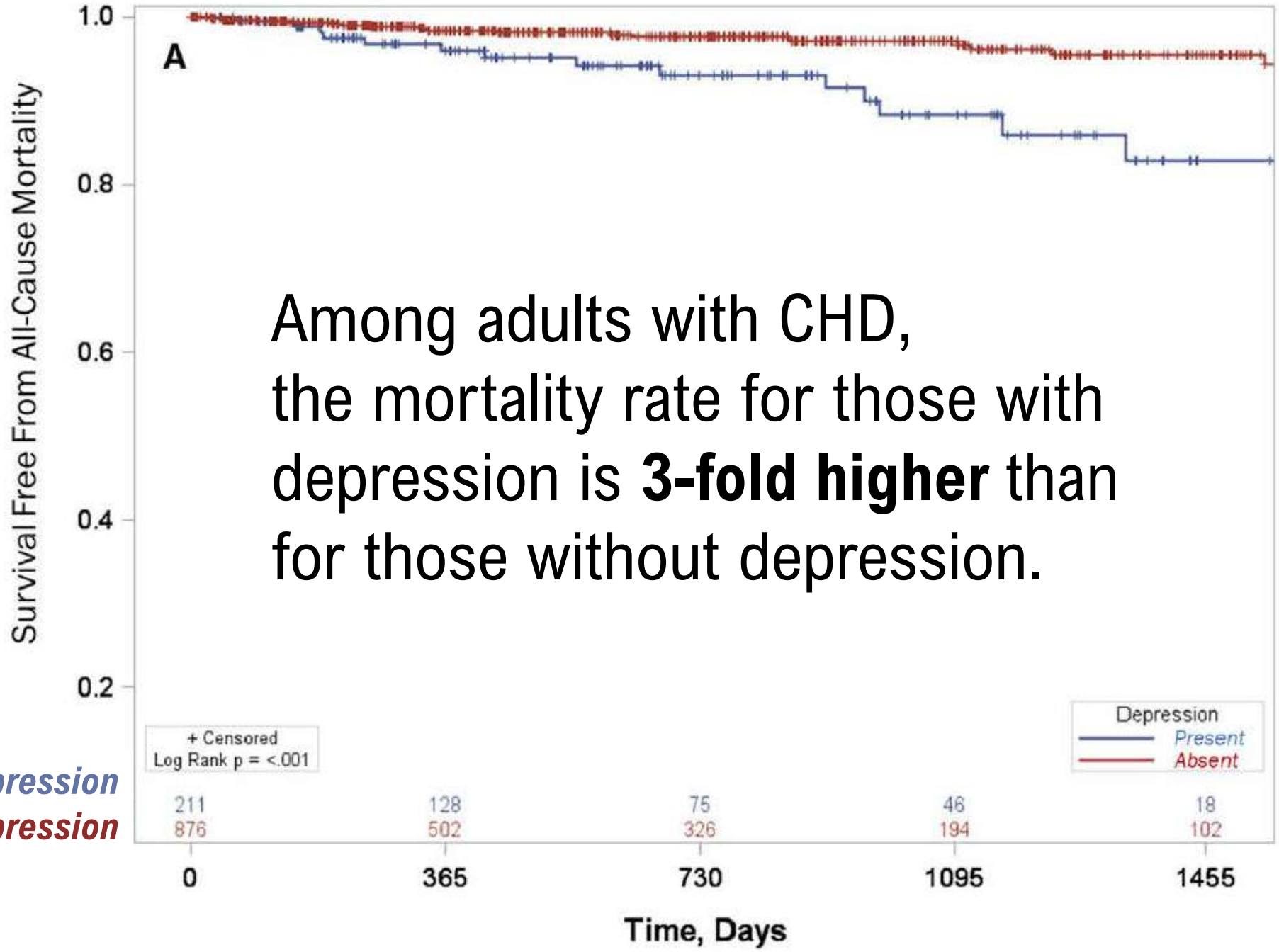
Why This Matters



Kovacs et al. 2022 Circ: Cardiovasc Qual Outcomes; Marshall et al. 2020 J Am Heart Assoc.

N=1,146 adults
39±14 years old
50% men

- High-sensitivity C-reactive protein
- N-terminal pro-B-type natriuretic peptide



Among adults with CHD, the mortality rate for those with depression is **3-fold higher** than for those without depression.

Carazo et al. 2020 JAHA

Parent Mental Health After CHD Diagnosis

Among parents of children with CHD requiring surgery in infancy:

- **Over 80%** report severe distress at some point in their child's medical trajectory
- **30%** report symptoms consistent with PTSD
- **50%** report clinical symptoms of anxiety and/or depression

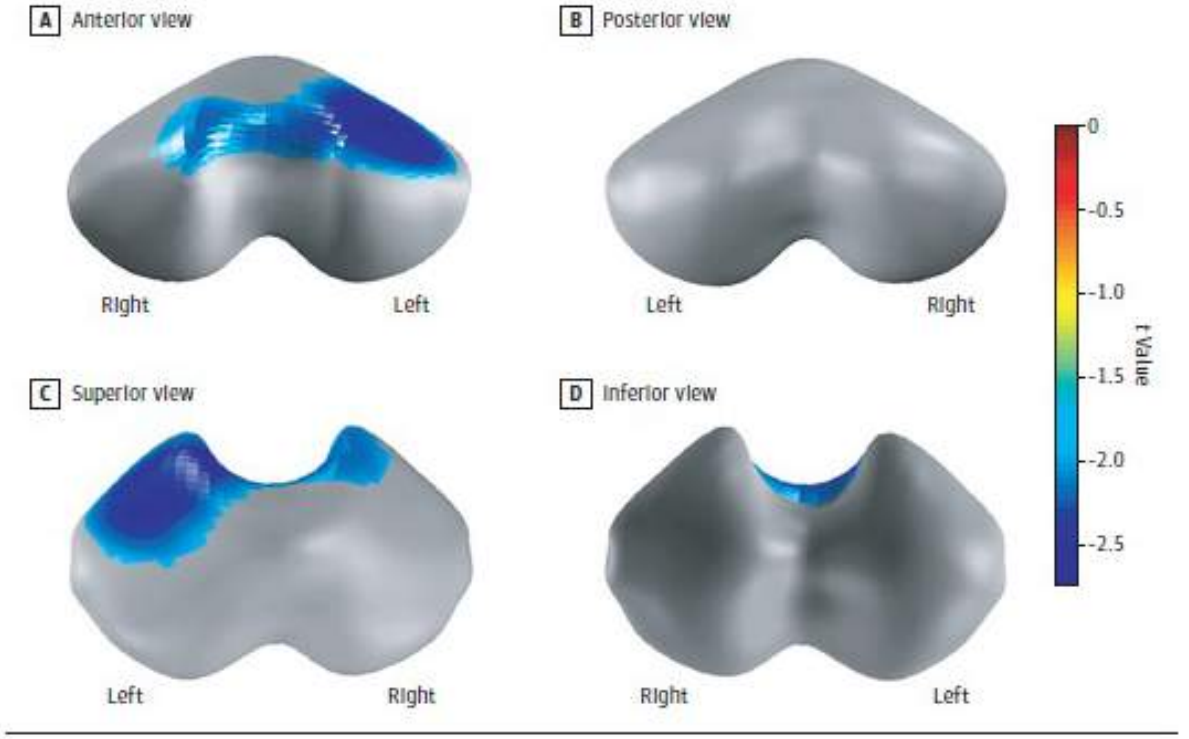
Woolf-King et al. 2017 JAHA; Kasparian et al. 2016 Med J Aust; Kasparian et al. 2019 Early Human Dev; McWhorter et al. 2021 Cardiol Young

JAMA Pediatrics | Original Investigation

Association of Maternal Psychological Distress With In Utero Brain Development in Fetuses With Congenital Heart Disease

Yao Wu, PhD; Kushal Kapse, MS; Marni Jacobs, PhD; Nickie Niforatos-Andescavage, MD; Mary T. Donofrio, MD; Anita Krishnan, MD; Gilbert Vezina, MD; David Wessel, MD; Adré du Plessis, MBChB; Catherine Limperopoulos, PhD

Figure 3. Differences in the Cerebellum of Fetuses With Congenital Heart Disease Positive vs Negative for Maternal Psychological Distress



Regions with negative *t* values (blue color) signify where the group positive for maternal psychological distress is significantly smaller than the group negative for maternal psychological distress. Regions with no color overlay indicate no significant difference between the 2 groups.

Early indications that higher psychological stress and anxiety among women carrying fetuses with CHD is associated with smaller fetal hippocampal and cerebellar volumes.

Parent mental health is often a stronger predictor of child mental health outcomes than medical and surgical factors (e.g., bypass strategies, length of stay, and post-operative complications)

McCusker et al., 2007;Bellinger et al, 2009; DeMaso et al., 2014; Denniss et al, 2019
Ernst et al, 2018, 2020; Golfenshtein et al, 2020; Wu et al, 2020; Roberts et al, 2021

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

and its consequences. A proposed surveillance testing toolkit provides

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

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POSITION STATEMENT

Management of People With a Fontan Circulation: a Cardiac Society of Australia and New Zealand Position Statement

Dominica Zentner, MBBS, FRACP, PhD [a,b,c,l*1],
David S. Celermajer, MBBS, FRACP, PhD [d,e,2],
Thomas Gentles, MBChB, FRACP [f,2],
Yves d'Udekem, MD, PhD, FRACS [b,g,h,2], Julian Ayer, MBBS, FRACP, PhD [i,j,3],
Gillian M. Blue, MSc, PhD [i,j,3], Cameron Bridgman, MBChB, FRACP [k,3],
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Rachael Cordina, MBBS, FRACP, PhD [d,j,3], Evelyn Culnane, BEd [n,3],
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Mark McGuire, MBBS, FRACP, PhD [d,j,3],
Paul Monagle, MD, MSc, FRACP [b,h,y,3]

Several statements on the care of people with CHD have highlighted the connection between physical and mental health outcomes

"People with Fontan circulation have higher rates of anxiety and behavioral disorders, and there needs to be a **low threshold** for the provision of mental health care."

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Clare O'Donnell, MBChB, FRACP [f,3],
Andreas Pflaumer, MD, FRACP, FCSANZ [b,h,m,3],
Kathryn Rice, MBChB, FRACP [f,3],
Gary Sholler, MBBS, FRACP, FCSANZ [i,j,3],

"People with Fontan circulation have higher rates of anxiety and behavioral disorders, and there needs to be a **low threshold** for the provision of mental health care."

Less than one-third

of those who meet criteria for a mood or anxiety disorder receive mental health treatment.

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Circulation: Cardiovascular Quality and Outcomes

July 14, 2022

AHA SCIENTIFIC STATEMENT

Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association

Adrienne H. Kovacs, PhD, Chair; Judith Brouillette, MD, PhD; Patricia Ibeziako, MD; Jamie L. Jackson, PhD; Nadine A. Kasparian, PhD; Yuli Y. Kim, MD; Tracy Livecchi, LCSW; Christina Sillman, MSN; Lazaros K. Kochilas, MD, MS, FAHA, Vice Chair; on behalf of the American Heart Association Council on Lifelong Congenital Heart Disease and Heart Health in the Young; and Stroke Council

Authors:
pediatric and adult psychologists, pediatric and adult psychiatrists, social worker, pediatric and ACHD cardiologists, nurse practitioner, and individuals with CHD.

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"Despite strong advocacy by patients, families and healthcare professionals, initiatives have been **slow to move forward** in the clinical setting."

Reasons we advocate for integrating mental health care within CHD teams

PATIENT PERSPECTIVE	CHD TEAM PERSPECTIVE
• Timely psychological care grounded in an understanding of CHD. • Greater opportunities for access to care, regardless of socioeconomic status. • Optimize healthcare coordination across clinicians from different disciplines.	• Facilitate training for all team members regarding important psychological and social factors. • Increase confidence discussing psychological health, given the presence of colleagues to refer to. • Increase interdisciplinary QI and research collaborations.

Kovacs et al. 2022 Circ: Cardiovasc Qual Outcomes; Marshall et al Kasparian. 2022 Psychol & Health

Heart and Mind Wellbeing Center

Goal: Integrated mental health care from fetus to adult as an ordinary, routine, and expected part of CHD care

- Tailored information
- Psychosocial screening
- Prevention and early intervention
- Mental health care rounds
- Clear pathways to peer support
- Staff debriefing and support
- Care that is trauma-informed

Recognizing and addressing the widespread impact of stress and trauma on patient and family resilience, recovery, and wellbeing.

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Next Steps: HeartGPS Trial

GPS for the heart journey

Cincinnati Children's
changing the outcome together

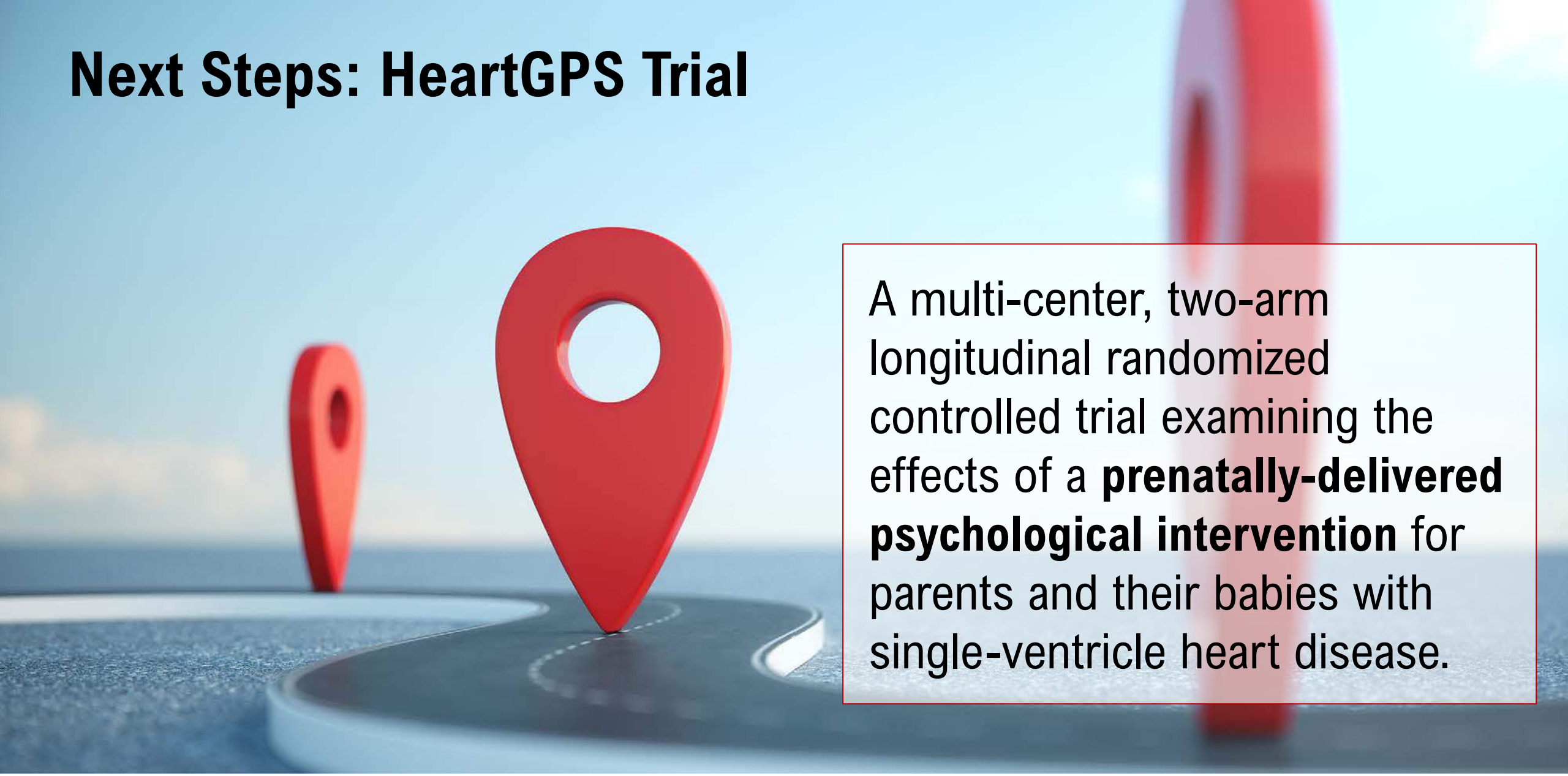
Children's Hospital LOS ANGELES

Monroe Carell Jr. Children's Hospital at Vanderbilt

The Sydney children's Hospitals Network

PI: Kasparian
PI: Cnota

Next Steps: HeartGPS Trial



A multi-center, two-arm longitudinal randomized controlled trial examining the effects of a **prenatally-delivered psychological intervention** for parents and their babies with single-ventricle heart disease.

GPS for the heart journey

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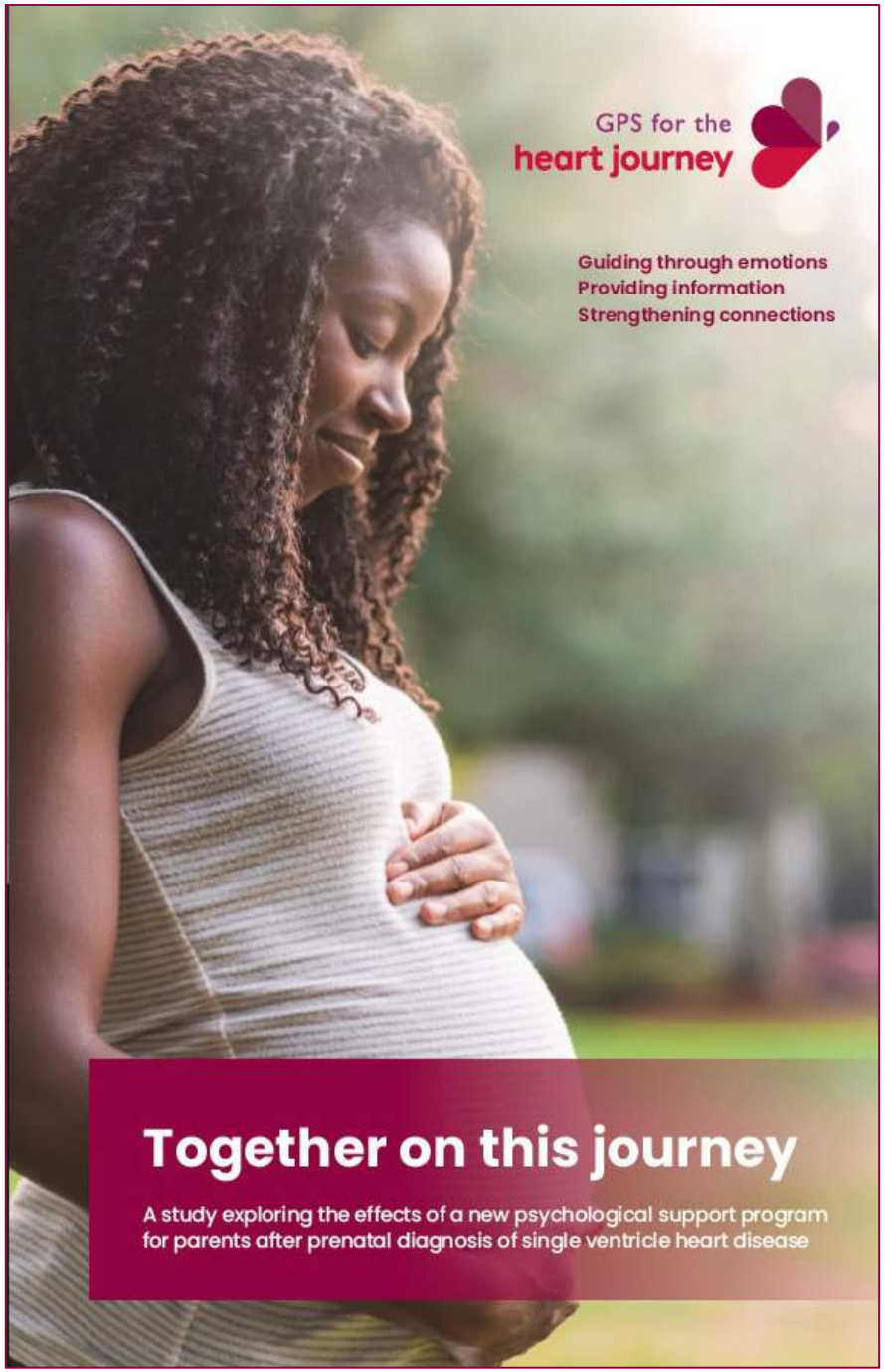

HeartGPS Intervention

Guiding through emotions
Providing information and education
Strengthening connections

Three Key Components

1. Tailored educational resources
2. Sessions with a HeartGPS-trained psychologist
3. Personalized mental health and wellbeing care plan

Two-generational approach to intervention

PRENATAL

POSTNATAL

HeartGPS Psychological Intervention

Fetal SVCHD Diagnosis

Psychosocial Assessment

Biospecimens Collection

GPS for the heart journey

or Usual Fetal Cardiac Care

35-weeks Gestation

Psychosocial Assessment

Fetal Brain Imaging

Biospecimens

Infant Age 30-days

Psychosocial Assessment

Infant Brain Imaging Neurobehavior Biospecimens

Infant Age 6-months

Psychosocial Assessment

Infant Age 12-months

Psychosocial Assessment

Mother-Infant Bonding

Infant Neurodevelopment

Two-generational approach to intervention




PRENATAL | **POSTNATAL**

HeartGPS Psychological Intervention

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Infant Brain Imaging
Neurobehavior
Biospecimens

Infant Age 6-months

Psychosocial Assessment

Infant Age 12-months

Psychosocial Assessment

Mother-Infant Bonding

Infant Neurodevelopment

Summary

- We've known for 60 years that CHD can have a psychological impact.
- Patients and families face unique stressors and are at risk for anxiety and depression.
- Our healthcare systems often fall short of identifying and treating psychological distress among those with CHD.
- We have an opportunity and responsibility to ensure comprehensive CHD care includes mental health care.
- **It's never too early (or too late!) to intervene to improve mental health.**

thank you!

ADDITIONAL VENTURES

THE BRETT BOYER FOUNDATION

Heart Foundation

The Commonwealth Fund

Australian Government National Health and Medical Research Council NHMRC

HeartKids

Cincinnati Children's changing the outcome together

FNSNF Swiss National Science Foundation

My Team

Michelle Ernst
Stacey Morrison
Emily Jones
Sela Shannon
Jennifer Smith
Katherine Bedard-Thomas
Lisa Bailey
Amanda Sammons
Devan Vaughn
Olivia Cleary
Emily Offenbacker
Chloe Hicks
Rebecca Henderson
Madeleine Pidcock
Dianne Swinsburg
Stephanie Tesson
Jacob Bird
Rachel Knight
Farah Akram
Katelyn Phillips
Kate Marshall
Sara Cibralic
Corey Lieneman
Julia Baenziger

HeartGPS partners

Co-PI: James Cnota – Cincinnati
Allison Divanovic – Cincinnati
Beth Kline-Fath – Cincinnati
James Peugh - Cincinnati
Sasha Opotowsky – Cincinnati
David Winlaw – Cincinnati
Kathy Meyer – Cincinnati
Jodie Votava-Smith – CHLA
Jay Pruetz – CHLA
Vidya Rajagopalan – CHLA
Eliza Harley – CHLA
Nhu Tran – CHLA
Sheila Perez – CHLA
Ann Kavanaugh-McHugh – Vanderbilt
Scott Baldwin – Vanderbilt
Allie Wroblewski – Vanderbilt
Neill Broderick – Vanderbilt
Sumit Pruthi – Vanderbilt
Elizabeth Snyder – Vanderbilt
Erica Sood – Nemours
Ashok Panigrahy – Pittsburgh
Gary Sholler – Sydney
Nadia Badawi – Sydney
Sheryl Foster – Sydney
Karen Leclair – Sydney