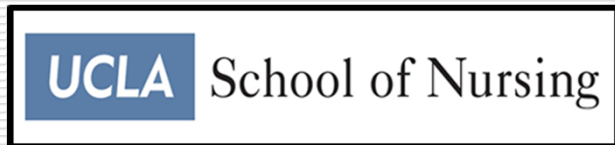


# Mental Health and Quality of Life after the Fontan

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## What We **Believe** We Know

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# Disclosures

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✓ None

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# Post-Fontan: What We Know....

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- ✓ Survival is **EXPECTED** after surgery – focus now is to reduce morbidity and improve quality of life (QoL)
- ✓ The Fontan procedure is **NOT** perfect and comes with uncertain longevity with advanced age.
- ✓ Along with medical sequelae there is the potential for **behavioral and psychosocial challenges**.
- ✓ Despite some limitations, most find a way to manage their chronic medical condition in order to get the **"best out of life"**.<sup>1</sup>

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<sup>1</sup>Berghammer MC et al. *Cong Heart Dis.*, 2015

# Quality of Life

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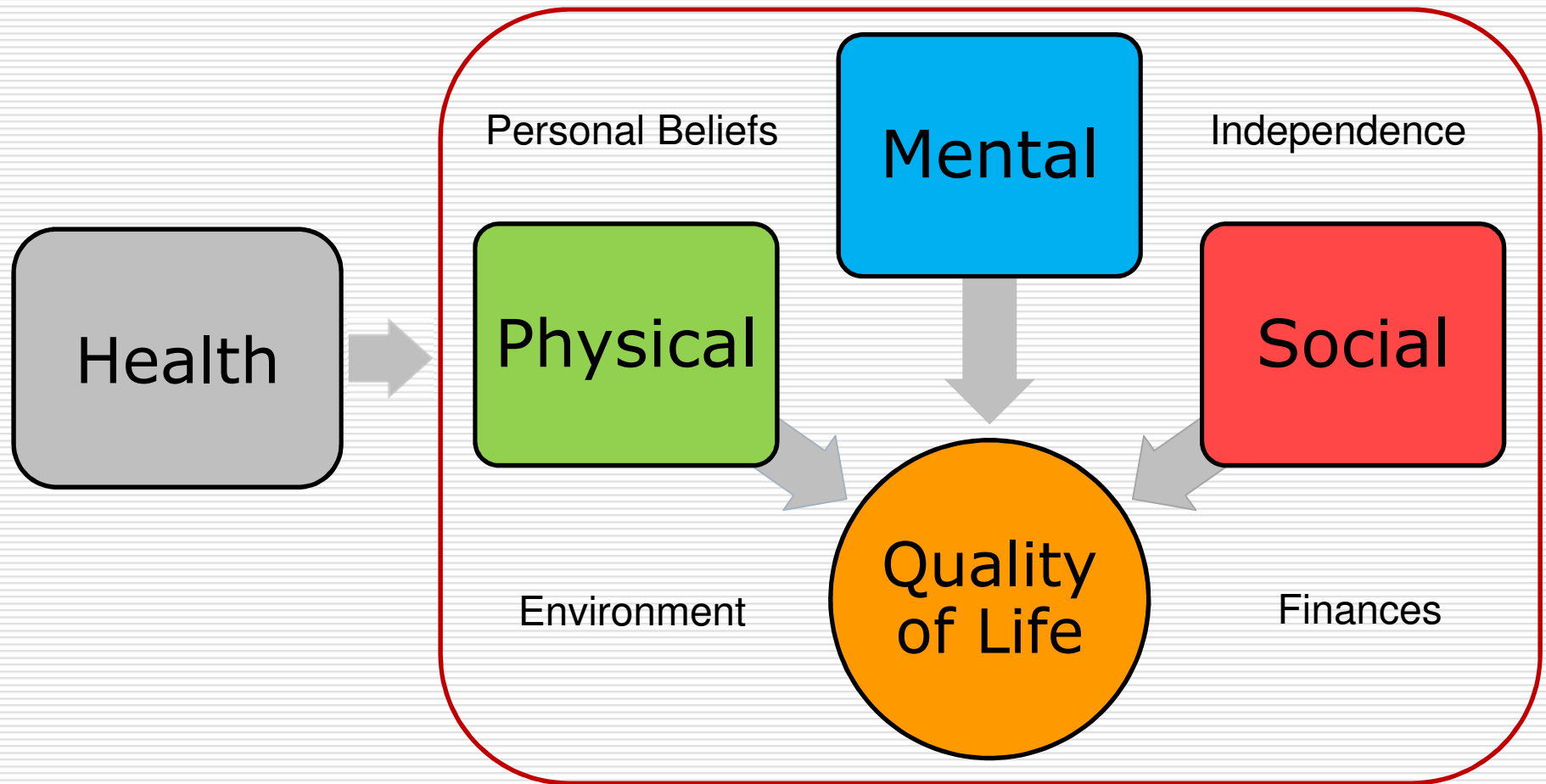
- ✓ Many QoL studies in the larger heterogeneous group of CHD
- ✓ Methodologic Limitations
  - ✓ Small, single center studies
  - ✓ Variety of measures used
  - ✓ Wide age ranges
  - ✓ Proxy response (parent-report) and / or self-report<sup>1</sup>
- ✓ Inconsistent or conflicting findings across countries
- ✓ Difficult to draw firm conclusions
- ✓ Over the past 5 years, more mental health and QoL research in the single ventricle subgroup of CHD

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<sup>1</sup>Lambert LM et al. *Pediatrics*, 2009

# Quality of Life: Individual Perception

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# Clinical Profile Post-Fontan Worries / Symptoms

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## Adolescent / Adults Post-Fontan N=54

Worries	N %	Symptoms	N %
Current Health	45 (83)	SOB walking > ½ mile	37 (68)
Job / Future Job	37 (68)	Palpitations	33 (61)
Working Life	33 (61)	Dizziness	33 (61)
Living Independently	29 (54)	Nocturia	26 (48)
Exertion / Sports	26 (48)	SOB walking < 100 yd	23 (43)

# Predictors of QoL Post-Fontan

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Scale	Variable	Beta	R <sup>2</sup>	Adjusted R <sup>2</sup>	F	P Value
<b>SWLS</b>	NYHA Class	-.292*	.085	.067	22.599	<.001
	Depression	-.641†	.411	.400		
	Social Support	.323*	.576	.550		

SWLS = satisfaction with life scale, NYHA class = New York Heart Association classification

\*p < .05

†p < .001

# Mental Health and Psychosocial Concerns

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- ✓ Children and adults have an increased risk of behavioral, mental health and social concerns.<sup>1</sup>
  - ✓ Anxiety or heart-focused anxiety
  - ✓ Depression
  - ✓ Post-Traumatic Stress
- ✓ Large Pediatric Heart Network Fontan study, **parents reported > 50%** of children with problems related to anxiety, depression and behavior.<sup>2</sup>
- ✓ **1/3 of adults** with CHD met diagnostic criteria for at least one life-time mood or anxiety disorder.<sup>3</sup>

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<sup>1</sup>Marino BS et al., *Circulation*, 2012; <sup>2</sup>McCrindle BW et al., *Circulation*, 2006;

<sup>3</sup>Kovacs AH et al., *Int J Cardiol*, 2009



# Mental Health Post-Fontan

## Psychiatric Disorders in Adolescents With Single Ventricle Congenital Heart Disease

David R. DeMaso, MD,<sup>a,b,c</sup> Johanna Calderon, PhD,<sup>a,c</sup> George A. Taylor, BA,<sup>a</sup> Jennifer E. Holland, BA,<sup>a</sup> Christian Stopp, MS,<sup>b</sup> Matthew T. White, PhD,<sup>a,c</sup> David C. Bellinger, PhD, MSc,<sup>a,c,d,e</sup> Michael J. Rivkin, MD,<sup>a,d,e</sup> David Wypij, PhD,<sup>b,f</sup> Jane W. Newburger, MD, MPH<sup>b,g</sup>

- ✓ 156 adolescents post-Fontan compared to controls [mean age 15]
- ✓ Higher rates of lifetime psychiatric diagnosis (**65%** vs.22%;  $p<.001$ ) - assessed by clinical interview

“Adolescents post-Fontan displayed a high risk of psychiatric morbidity, particularly **anxiety disorders and ADHD.**”

# Predictors Mental Health and Quality of Life

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- ✓ **Social adjustment** and perceived **health status** were more predictive of **anxiety** than medical variables (Kovacs AH et al. *Int J Cardiol*, 2009; Muller J et al. *Int J Cardiol*. 2011)
  - ✓ Worse **NYHA class** or **functional health status** were more predictive of **worse physical and psychosocial QOL** (Moon JR et al. *Heart Lung* 2009; Popelova J et al. *Cardiol Young* 2001; Dulfer K et al., *Cardio Young*, 2016)
  - ✓ Feeling of **optimism**, positive **sense of coherence** and good **social support** were protective factors for **anxiety / depression** (Wang Q et al. *J Pediatr.*, 2012)
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# Quality of Life Post-Fontan

## ORIGINAL ARTICLES

www.jpeds.com • THE JOURNAL OF PEDIATRICS



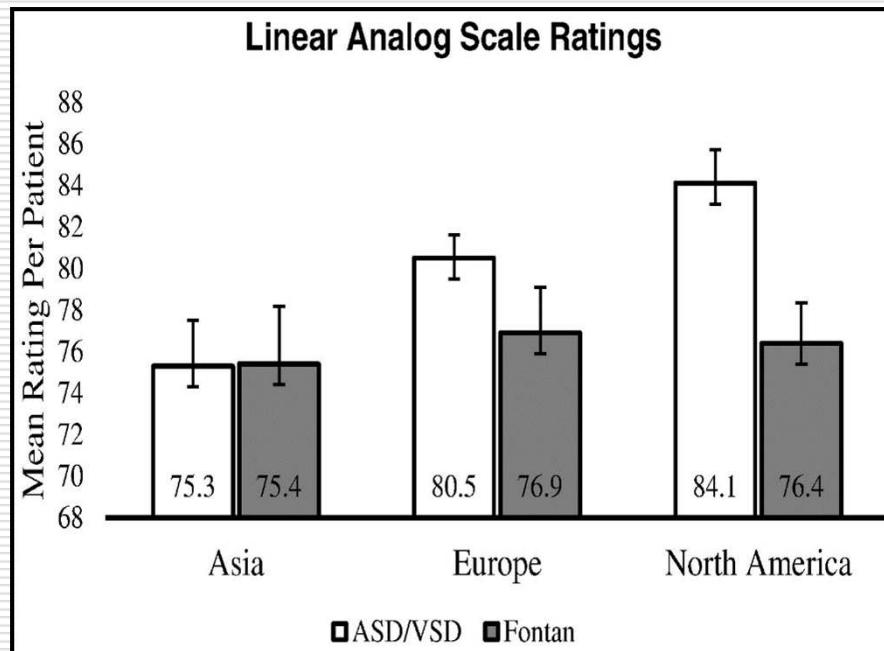
### Assessment of Quality of Life in Young Patients with Single Ventricle after the Fontan Operation

Karen Uzark, PhD, CPNP<sup>1</sup>, Victor Zak, PhD<sup>2</sup>, Peter Shrader, MA<sup>2</sup>, Brian W. McCrindle, MD, MPH<sup>3</sup>, Elizabeth Radojewski, RN<sup>3</sup>, James W. Varni, PhD<sup>4</sup>, Kaitlyn Daniels, BSN, RN<sup>5</sup>, Jill Handisides, BSN<sup>6</sup>, Kevin D. Hill, MD, MS<sup>7</sup>, Linda M. Lambert, MSN, FNP<sup>8</sup>, Renee Margossian, MD<sup>6</sup>, Victoria L. Pemberton, RNC, MS, CCRC<sup>9</sup>, Wyman W. Lai, MD<sup>10</sup>, and Andrew M. Atz, MD<sup>11</sup>, on behalf of the Pediatric Heart Network Investigators\*

- ✓ Cross-sectional, 408 Post-Fontan, age **13-25** years
- ✓ Enrolled in Pediatric Heart Network Fontan Follow-up Study
- ✓ PedsQL and SF-36

“Post-Fontan participants had significantly **worse physical (45%)** and **psychosocial (30%) QOL** than controls ( $p < .001$ ); potential for decline in QOL with aging’

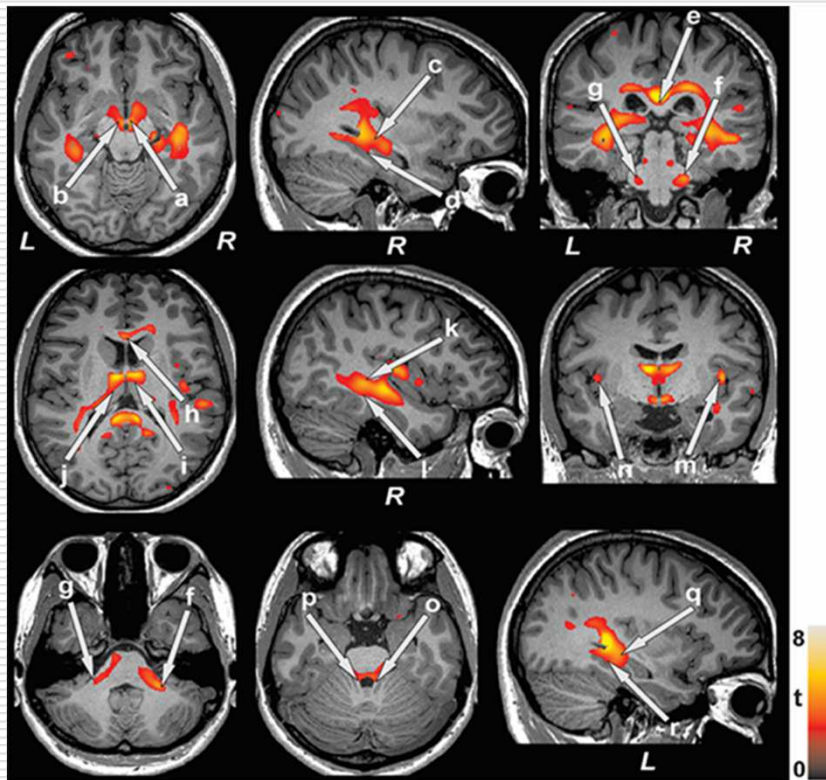
# Regional Variation in QoL Post-Fontan



- ✓ 163 Fontan participants, mean age 27.4, ASD/VSD controls
- ✓ International **APPROACH-IS** consortium
- ✓ Fontan group had **lower** QOL, greater medical complications and **30%** documented mood / anxiety disorders
- ✓ **NO** regional variations were identified in the Fontan group

“Regional differences in QOL are lost with greater disease complexity”  
“When specific medical complications and mood / anxiety disorders co-exist”

# Brain Changes in Anxiety and Depression Regulatory Regions



- ✓ Brain regions with higher T2-relaxation [more free water] values in adolescents Post-Fontan group over controls.
- ✓ Changes in areas of the **Limbic System** - emotional brain.
- ✓ **Areas:** hypothalamus, hippocampus / parahippocampal, amygdala, insula, and cingulate

All images are in neurological convention (L = Left; R = Right). Color bar indicates t-statistic values.

There could be a biologic or intrinsic component for anxiety and depression

# Experiences with Living Life: Post Fontan Qualitative Studies

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- ✓ Open-ended interviews
- ✓ Some negative experiences but felt strong and healthy
- ✓ Three Themes:
  - ✓ Happiness over being me
  - ✓ Focusing on possibilities
  - ✓ Being committed to life
- ✓ **Strong appreciation of having survived**
- ✓ Semi-structured interviews
- ✓ Three Themes:
  - ✓ Family network
  - ✓ Coping with physical limitations and finding “**ones own pace**”
  - ✓ Life perspective
- ✓ Need for friends and resource persons outside of the family to provide “**normal**” life experiences

Berghammer MC et al. *Cong Heart Dis.*, 2015

Overgaard DJ et al. *J Cardiovasc Nurs.*, 2012

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# Summary:

## What We **Believe** We Know

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- ✓ Physical limitations and psychosocial challenges for **some** children and adults Post-Fontan that can impact mental health and a person's individual perception of QoL.

### What We Need to Know...

- ✓ Does mental health and QoL **change overtime** in with aging? Need for longitudinal studies.
  - ✓ Interventional studies are needed to improve **modifiable** predictors of mental health and QoL.
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# Clinical Implications

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- ✓ **BE PROACTIVE.** Start **EARLY** with preventive screening for anxiety, depression, and social maladjustment in the pediatric setting at every visit.
  - ✓ Collaborate with **mental health professionals** or have them part of your specialized care teams
  - ✓ Developing family-based approaches to foster healthy mental well-being and **psychosocial adjustment** to living life with a chronic condition.
    - ✓ Encourage normal life experiences
    - ✓ Improve coping and adaptive abilities
    - ✓ Expanding social support networks
    - ✓ Foster a positive self-perception
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# Thank You

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