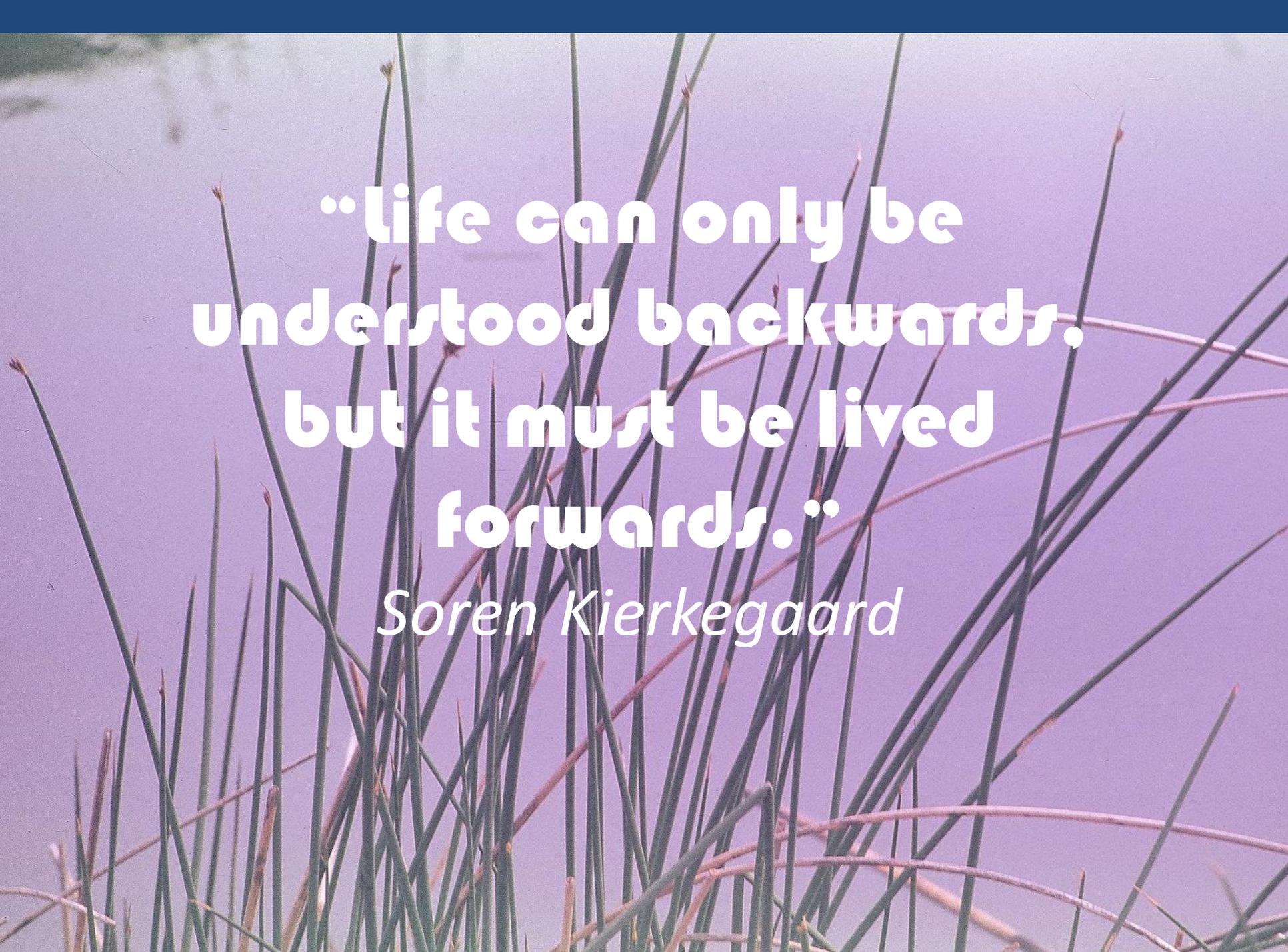


ACHD: How bright is the future?

NO



Conflict of **interest**



**“life can only be
understood backwards,
but it must be lived
forwards.”**

Soren Kierkegaard



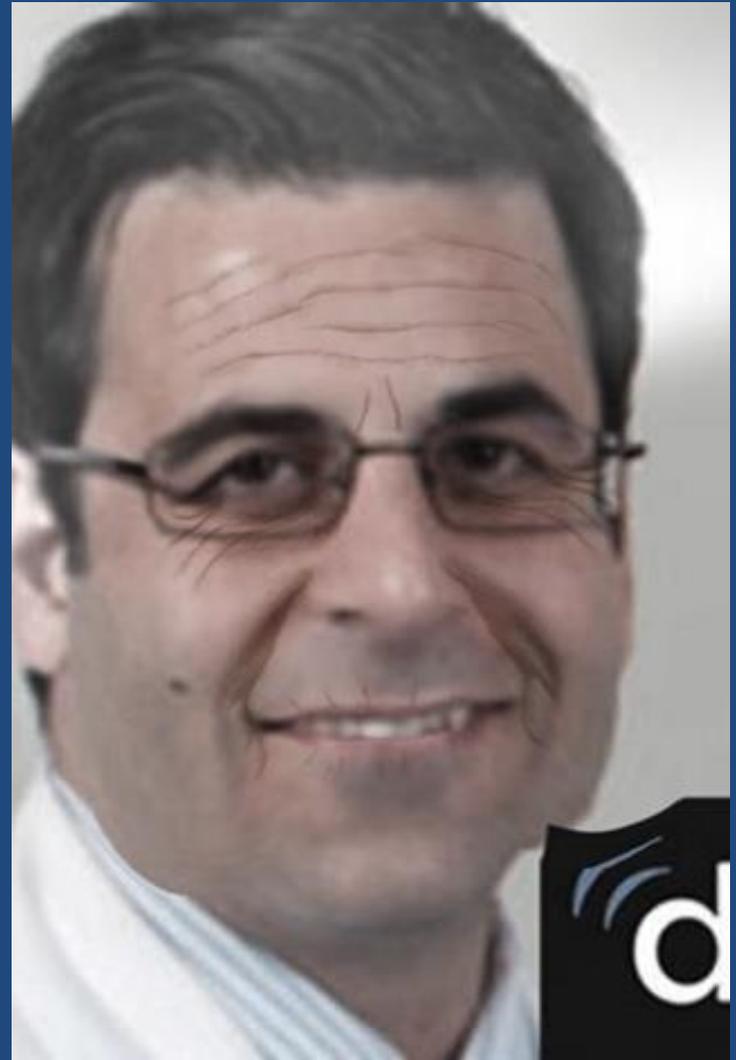
What do I know about the future?

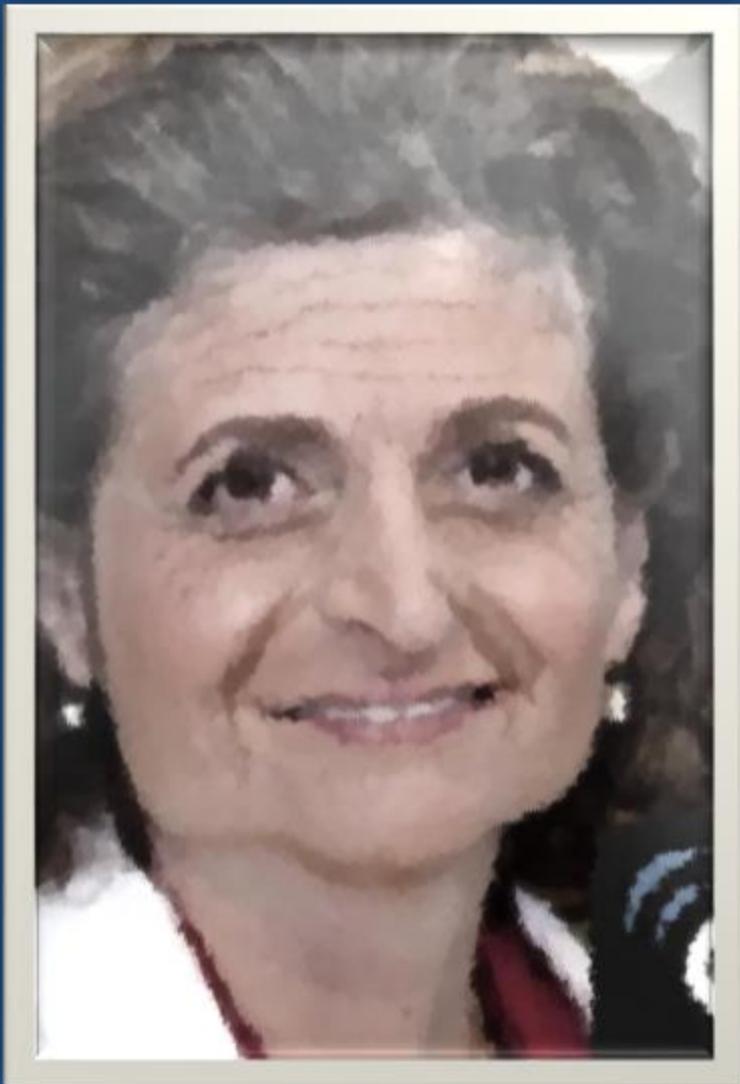


Curt Daniels, MD
Chancellor of Ohio State
Led expedition of ACHD
patients to Antarctica



Jamil Abouhosn
Noted vintner
Sports columnist
Artist/Musician
Owns KD winner
Placed first Melody
Valve on the ISS





Arwa Saidi
Secretary HHS
Established a single
payer system with
universal EMR, linked
to ACHD center
network with virtual
navigation and clinical
trials



Ariane Marelli
Director General WHO
Combining ayurvedic
medicine with
epidemiologic studies



Mikey: Beloved internet performer
Visits former colleagues in their nursing homes

Mug shot
Hot-wired
self driving car for a
joy ride on the
Angeles Crest
Highway



What Would You Like To See?



I would like to be as healthy
as I was at 8 years old

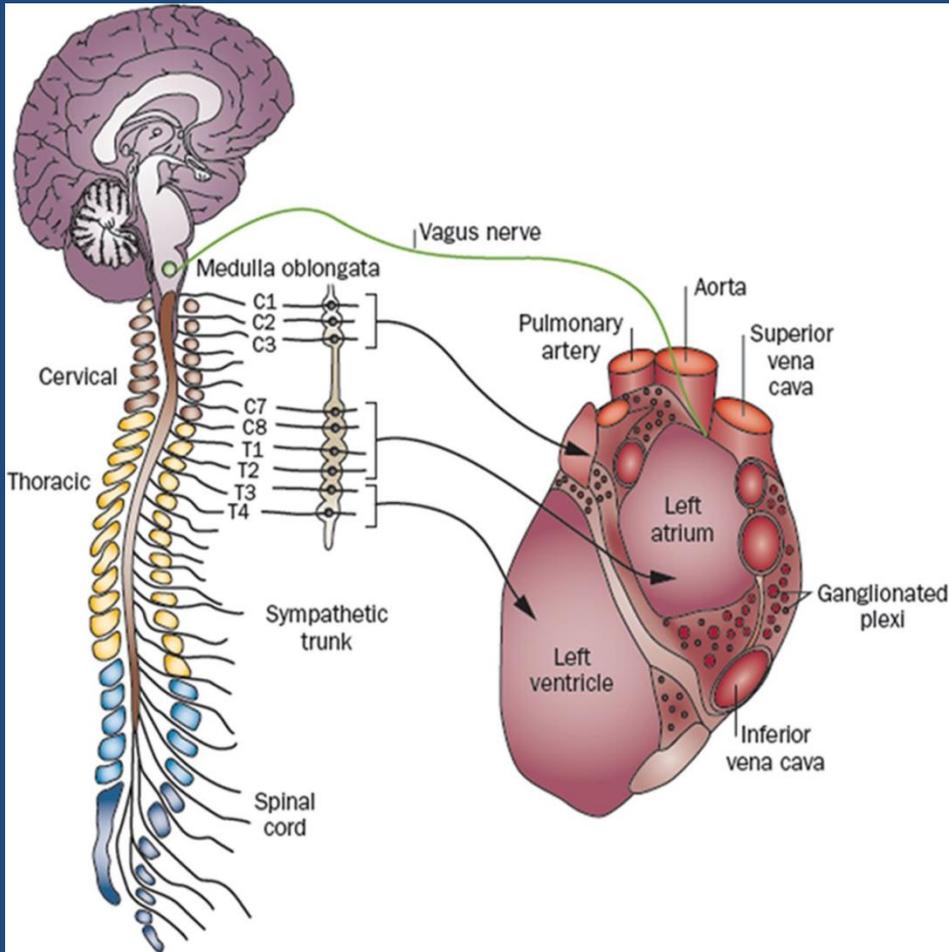
**Normal rhythm
without shocks**

Employment,
access to health
care, housing,
relationships

Good News: Quality of Life

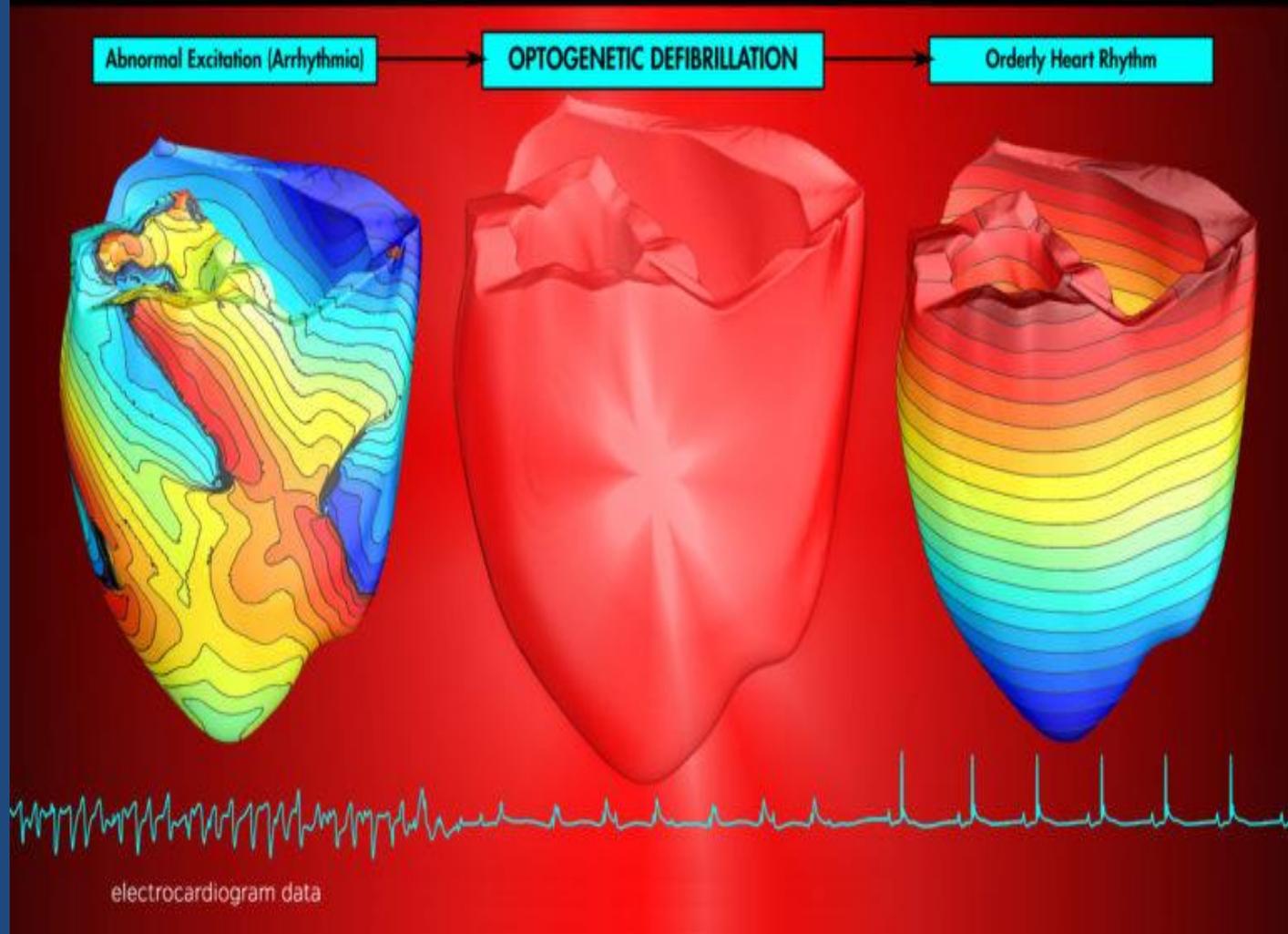
- Studies in Switzerland, US, Canada
- QOL similar to age and gender matched population except for the most severe disease
- Patients with moderately severe lesions better than general population
- Some specific psychosocial issues - insurance, marriage, depression, anxiety, employment
 - Need emphasis on whole life management, job coaching, independent living

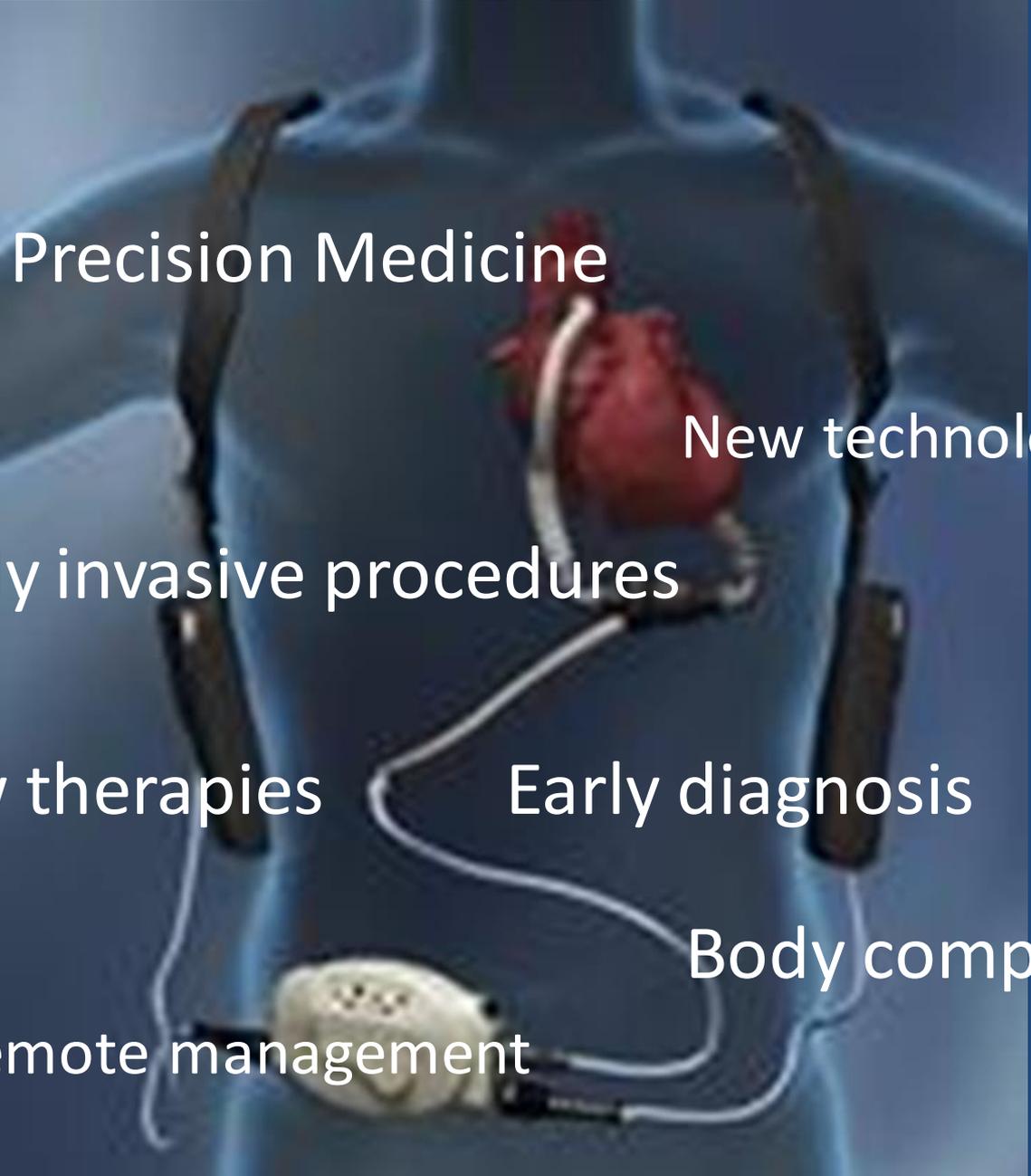
Managing Arrhythmias



- Treatment of atrial and ventricular arrhythmias through autonomic modulation
- Newer techniques to image autonomic nervous system.
- Ablating or stimulating ganglionic plexuses or vagus nerve

Using Light to Restore a Healthy Heartbeat





Precision Medicine

New technology

Minimally invasive procedures

New therapies

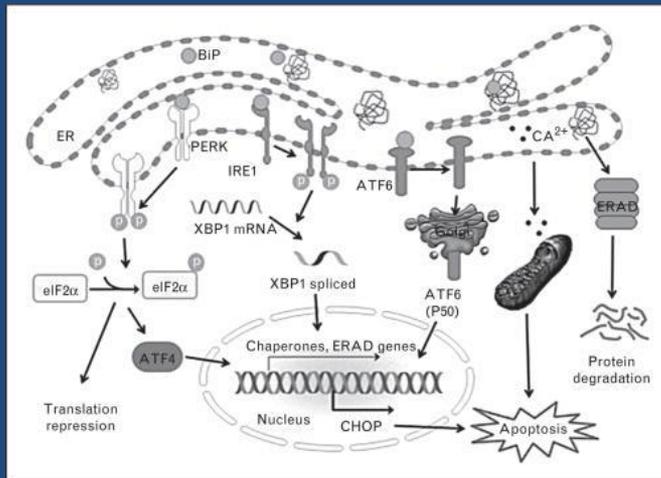
Early diagnosis

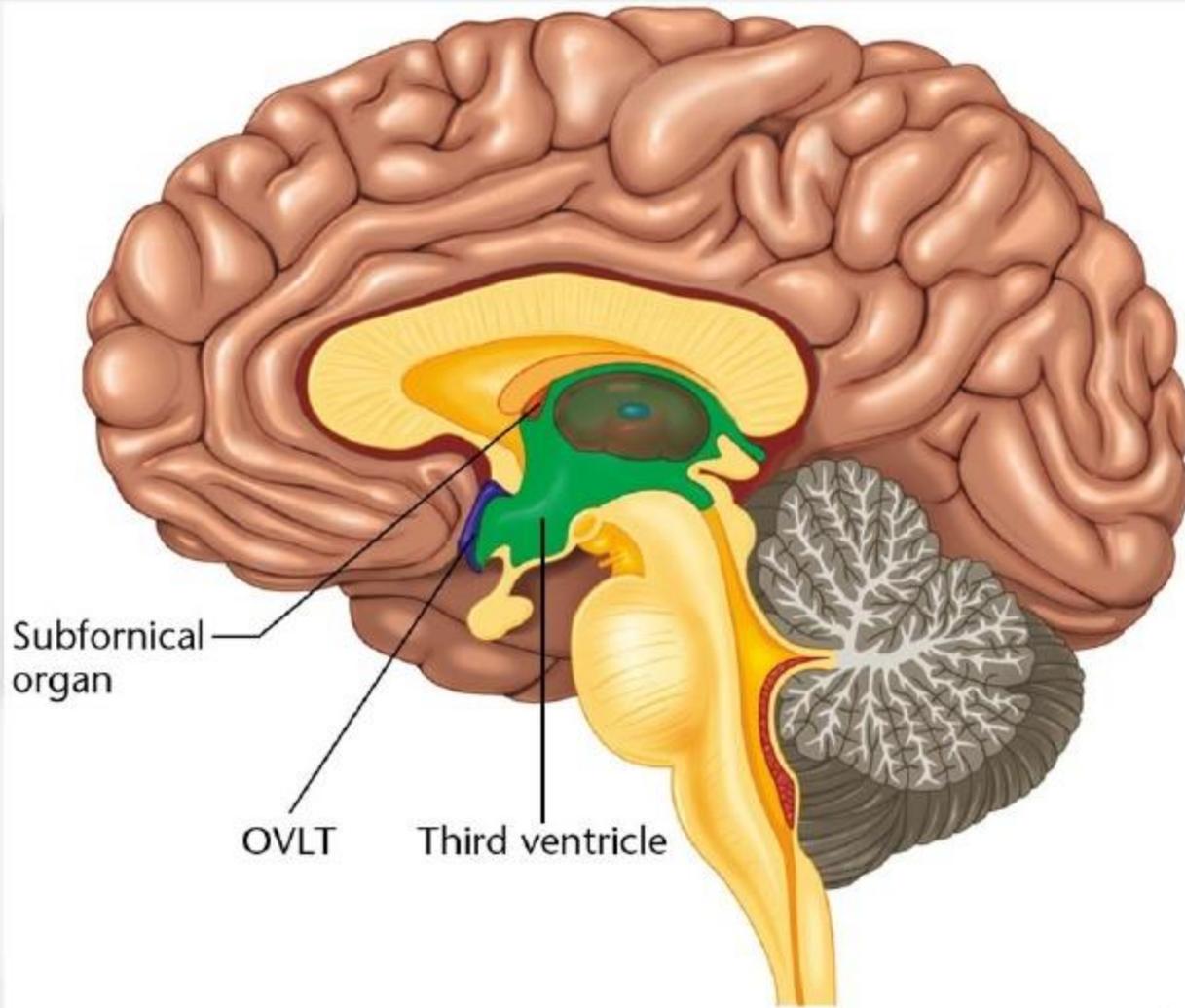
Body computing

Remote management

Keeping Your Heart in Shape

Molecular chaperone networks – heat shock proteins prevent accumulation of damaged proteins – Control folding of proteins to activate or deactivate signaling proteins. Protect against ischemic injury. Prevent maladaptive remodeling/fibrosis, PAH and delay congestive failure/arrhythmias





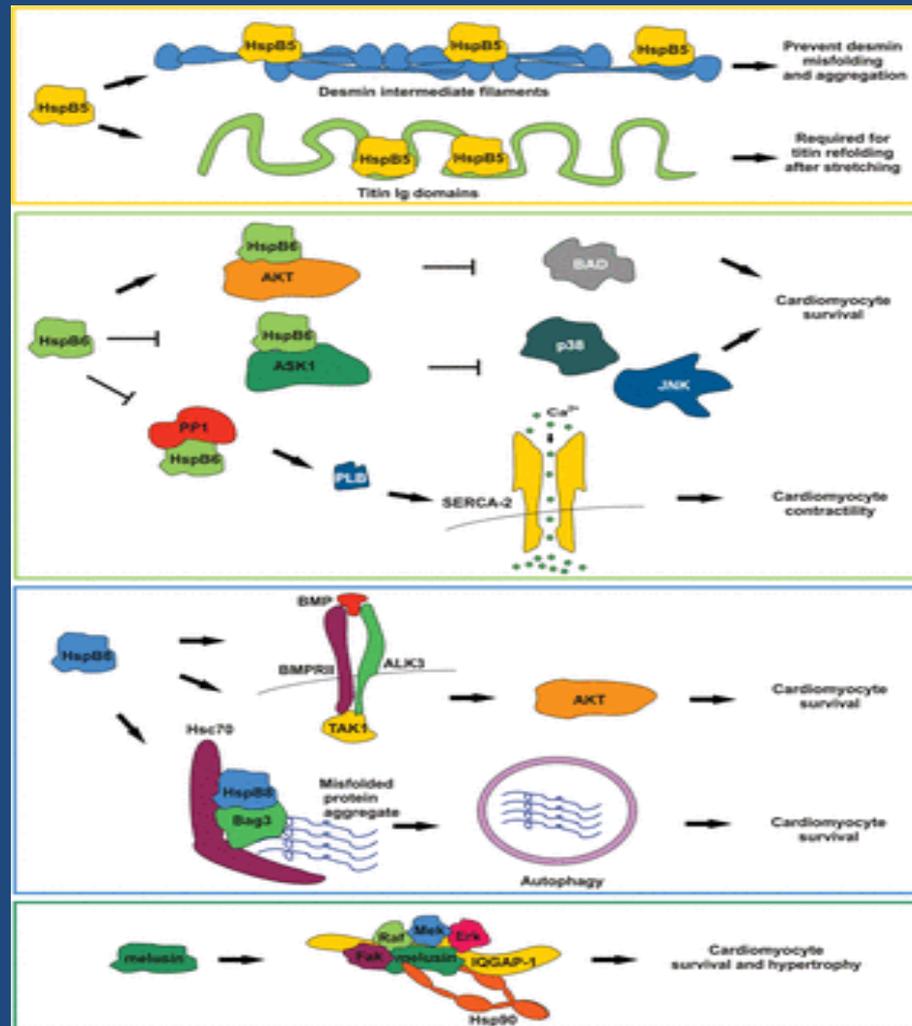
Subfornical organ

OVLT

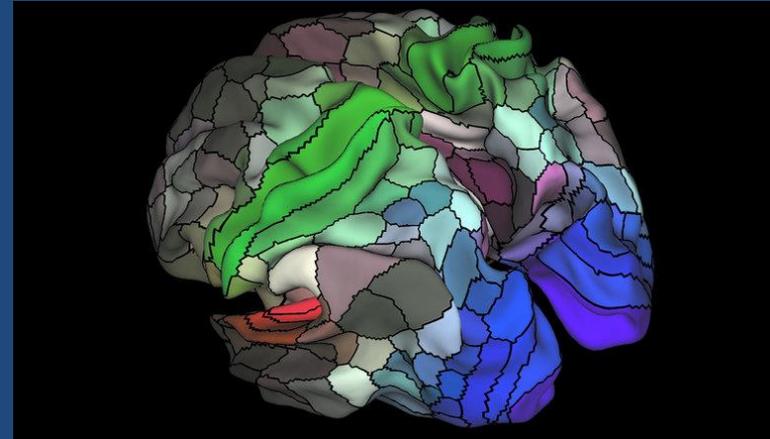
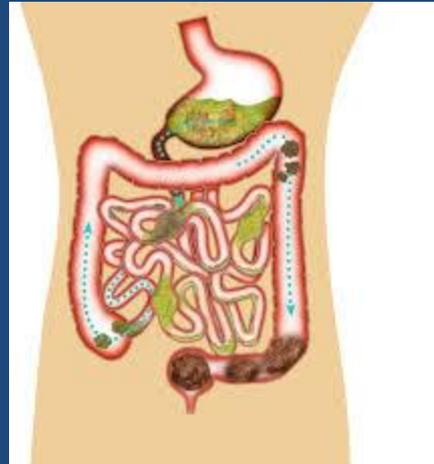
Third ventricle

Future Improvements

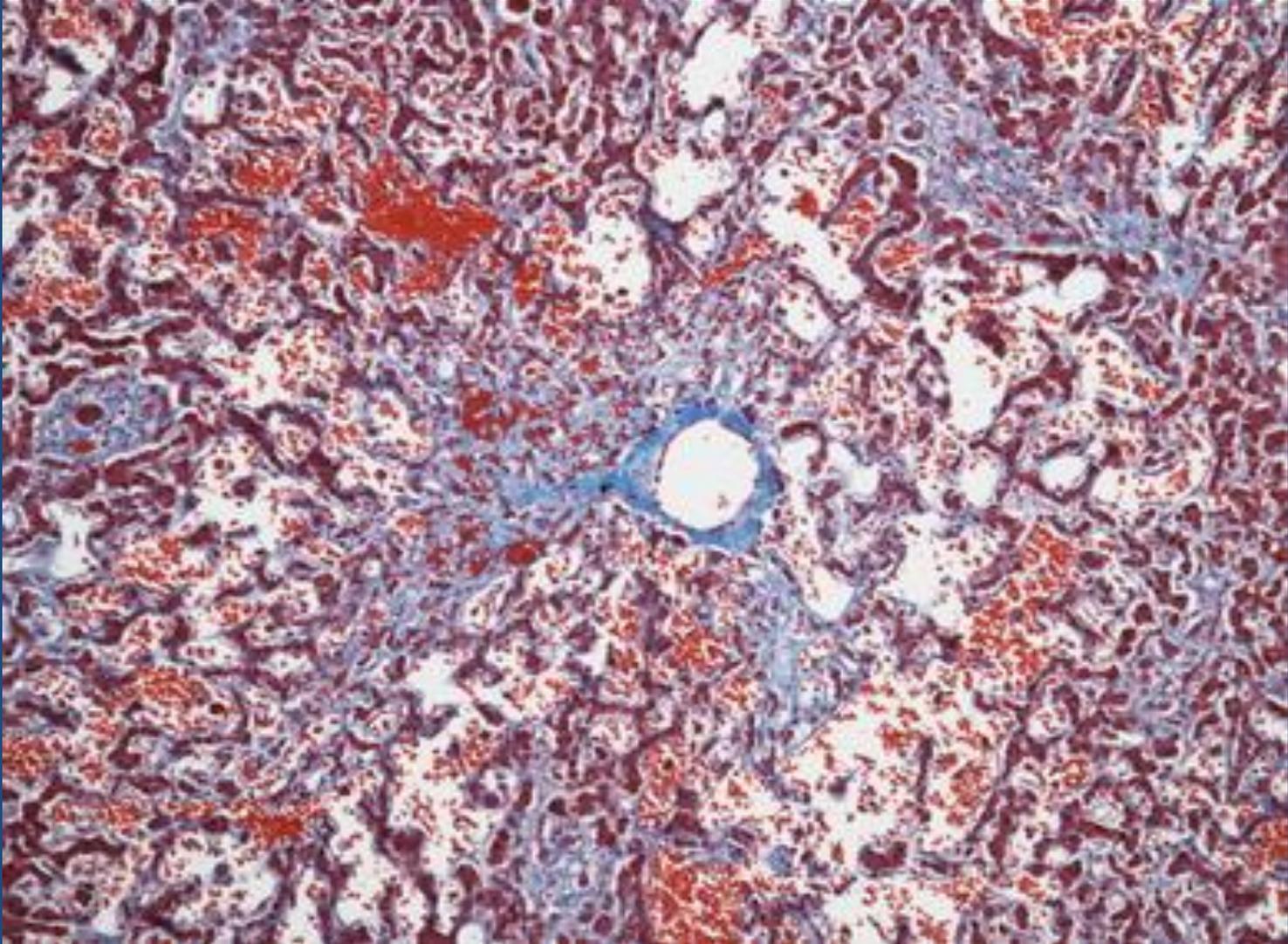
Chaperone Function in Cardioprotection



The heart is only a part of the story of adult congenital heart disease



Liver of 20 year old man with chronic venous congestion



Risk Factors for Fontan Patients

- 44 patients, mean age 29.5 years (18-55) followed at Yale (Sikand et al)
- Less than 1/3 had healthy BMI
- 54% were overweight or obese

Preventive Measures for the Liver

- Lifestyle to promote healthy BMI and reduce risk of diabetes
- Education about alcohol risk, viral hepatitis
- Avoidance of acetaminophen, NSAIDS
- Non-selective beta blockers?
- Immunize for hepatitis A and B?

Cautionary Tale

- Substance abuse among YCMC more likely to engage in any and heavier substance use. Transition years and early adulthood were periods of peak risk compared with healthy peers.
- Wisk and Weitzman: Substance Use Patterns Through Early Adulthood: Results for Youth With and Without chronic Conditions Am J of Preventive Med 2016:51(1):33-45

Atherosclerosis lifestyle risk factors in children with CHD

MASSIN EUR J CARDIOVASC PREV REHABIL 2007

OBJECTIVE:

To assess lifestyle risk factors for atherosclerotic cardiovascular disease in children with congenital heart disease.

MATERIALS AND METHODS:

Surveys were distributed to 329 unselected cardiac children.

RESULTS:

Many patients were taking an unhealthy diet and did not eat fruit (68%), vegetables (60%) or low-fat milk products (60%) every day, whereas 41% drank sweetened beverages and 89% ate foods high in fats at least three times a week. Only 15% spent half an hour daily involved in after-school physical activity, whereas 7.6% were overweight, 4.3% had arterial hypertension, 50% were passive smokers and 12% of teenagers were active smokers.

Geriatric CHD

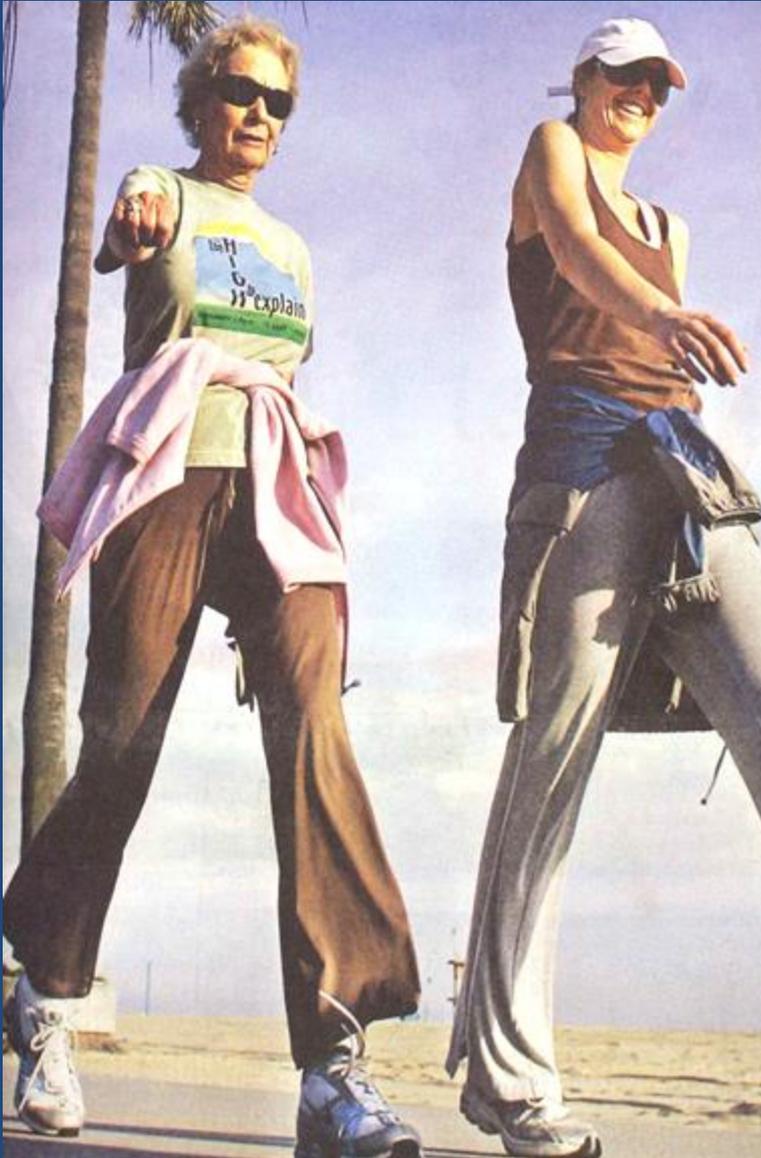
- Cancer
- Diabetes
- Acquired cardiovascular disease
- Alzheimer's Disease
- Osteoporosis

Exercise after the Fontan Procedure?

“The results in the over 200 **Fontan participants** in the literature convincingly demonstrates that **cardiac rehabilitation is safe** in this population and further, they **deeply benefit** from an exercise program with **improved exercise tolerance, muscle strength, activity levels and quality of life.**

Therefore, we believe that a cardiac rehabilitation program should become **standard of care** within this population. The program must incorporate **lower limb resistance training** to augment the **muscle pump and aerobic exercise.**”

Sutherland, Jones, d’Udekem Heart, Lung and Circulation (2015)



EARLY IDENTIFICATION OF CHILDREN PREDISPOSED TO LOW PEAK BONE MASS AND OSTEOPOROSIS LATER IN LIFE

M. Loro, J. Sayre, T. F. Roe, M.I. Goran, F.R. Kaufman, V. Gilsanz

The Journal of Clinical Endocrinology and Metabolism
85:3908-3918, 2000

B6 THE WALL STREET JOURNAL THURSDAY, JULY 10, 1997

Osteoporosis Study Shows Early Start Of Disease in Girls

By RHONDA L. RUNDLE

Staff Reporter of THE WALL STREET JOURNAL

A new study of genetic variations in young girls provides evidence that osteoporosis starts early in life.

Prepubescent girls with certain variations in the Vitamin D receptor gene accumulate less bone mass than other girls and thus are likely to be at higher risk for fractures later in life, said Vicente Gilsanz, principal investigator of the study, in this week's New England Journal of Medicine.

Despite the findings, "we can't predict

Reducing risk of superimposed CVD

Role of lifestyle reduction

Alegria et al

- 15 patients mean age 39 years followed for 5.5 months with **plant-based diet**
- BMI 30.7 to 27.7
- NHYA Class 2.5 to 1.5
- Higher exercise tolerance, better digestion, reduced anxiety, improved sleep, lower diuretic doses, clearer thinking



The Future is in Your Hands



ACHD -Present and Future Issues

Physical Health and Ability

Mental Health

Technological
Advances

Employment

Reproductive
Health

Housing

Medical
Therapies

Healthy Living

Geriatric CHD

