

**Living a “Normal” Life
with
Congenital Heart Disease:**

A Patient’s Perspective

Tom Grady

Discussion Summary

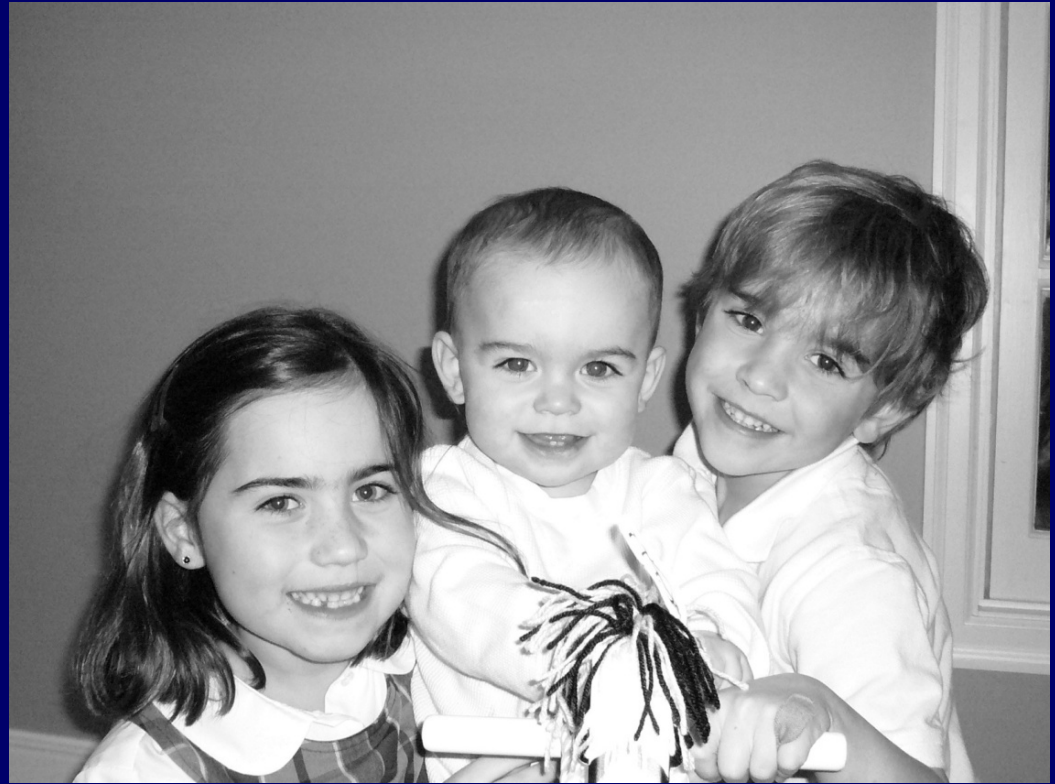
- Quick biography
- Facts about CHD
- Summary of my CHD
- Stories from 5 “Grand Openings”
- Athletics: Growing up and today
- Transition to adult cardiac care
- Adult Congenital Heart Association (ACHA)
- Q&A

Quick biography

- Born in St. Louis, MO in 1968
- Born with Tetralogy of Fallot (undiscovered at birth)
- Twin brother and two older brothers born healthy
- No family history of CHD
- Saint Louis University (English/Journalism major)
- Tulane University (M.B.A. – Finance/Marketing)

Quick biography - today

- Married
- 3 children
 - Maddix (8)
 - Patrick (6)
 - Auggie (18 months)
- Live in Minneapolis
- President of Palladium Capital
- Volunteer, ACHA



Facts about CHD

- Heart defects are the most common birth defect
 - 1 in 120 births
 - 3x more common than muscular dystrophy
 - 5x more common than childhood cancer
 - 30x more common than cystic fibrosis
- 35 defects
 - Simple
 - Moderate severity
 - Great complexity

Facts about CHD

- For the first time ever, there are more adults than children living with congenital heart defects in U.S.
 - 1 million adults
 - 800,000 children

Summary of my CHD

Tetralogy of Fallot (TOF)

- Four defects:
 - Ventricular Septal Defect (hole between ventricles)
 - Pulmonary Stenosis (narrowing of valve)
 - Right Ventricular Hypertrophy (wall thickening)
 - Overriding Aorta (AV too close to Right Vent.)

Summary of my congenital heart defect

Tetralogy of Fallot (TOF)

- First identified in 1888 by Dr. Etienne Fallot
- 1 in 1,500 babies are born with TOF
- 10% of all CHDs are TOF

Stories from 5 Grand Openings

- First open-heart surgery at 3 months:
 - “Blue as the sky” in a bathtub
 - Flatlined during catheterization
 - Creative plumbing saves the day (temporarily)
 - “Take him home to die”

Stories from 5 Grand Openings

- Second open-heart surgery: 6 years old
 - First of many corrections
 - “He’s fixed” (or so they thought back then)
 - Go home and live a normal life
 - 1975 Missouri Heart Fund Child
 - Lots and lots of unwanted attention

1975 Heart Fund Child



1975 Heart Fund Child



“The Money Shot”

Stories from 5 Grand Openings

- Third open-heart surgery: 18 years old
 - Falling asleep after school
 - Pediatric cardiologist dies
 - New cardiologist asks to check me over just in case
 - Only kid shaving on my floor
 - Fixed again! – go live a normal life
 - Start of college delayed a semester

Stories from 5 Grand Openings

- Fourth open-heart surgery: 23 years old
 - Living in New Orleans
 - No specialty care or congenital experts in town
 - Training for first 10k – routine EKG shows issues
 - Cardiologist has never seen anyone like me before
 - Family friend recommends NOLA native at UCLA
 - Finally, someone who knows what I have!!
 - Four-month insurance battle begins

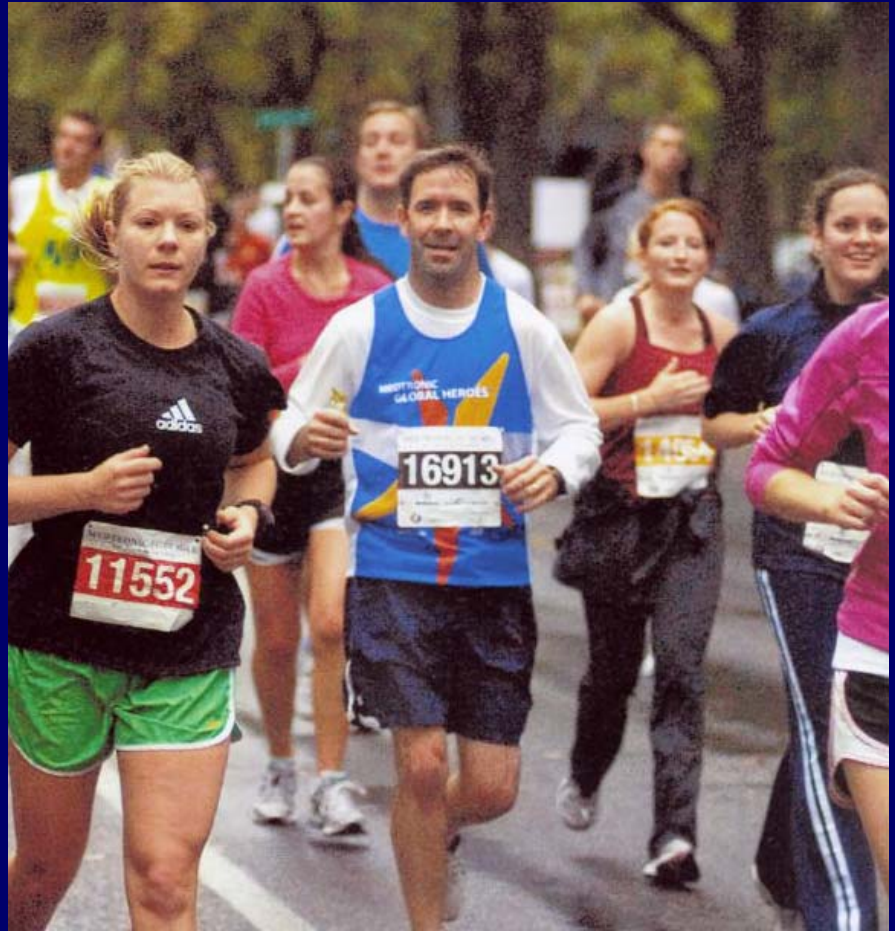
Stories from 5 Grand Openings

- Fifth open-heart surgery: 38 years old
 - Pig valve has to be replaced
 - First surgery as a parent
 - Same surgeon as 1993
 - No insurance issues this time
 - Four-day hospital stay

Athletics: Growing up and today

- Doing what most 40 year olds do:
 - golf, tennis, squash, racquetball
- Running has become a great activity
- Doctor-approved (treadmill stress test/Echo)
 - Two half marathons
 - One 10-mile race
 - A dozen 5k and 10k races

Medtronic Global Hero



Medtronic Global Hero



Exercise

- More than 90% of adults living with heart defects have no or only mild limitations
- Ask your cardiologist
- Get specific information about the risks
- Research suggests exercise key for all hearts
- For some, exercise is a prescription

Transition to adult cardiac care

- CHD means lifelong management and care
- Things change with time; new issues arise
- Need to be under care of trained CHD specialists
- The number of specialists in adult CHD is growing
- Our population is living longer – a new demographic

Adult Congenital Heart Association (ACHA)

The Adult Congenital Heart Association (ACHA) is a non-profit organization which seeks to improve the quality of life and extend the lives of congenital heart defect survivors. Through education, outreach, advocacy and promotion of research, ACHA serves and supports the more than 1.8 million individuals with congenital heart defects, their families and the medical community.

ACHA

- National clinic directory
- Message boards
- Annual conferences
- Newsletter
- Support networks
- Medical and insurance reference information

Adult Congenital Heart Association (ACHA)



www.achaheart.org

Final thoughts

- Everyone has challenges in life – we are no different
- With adversity comes resilience, empathy, perspective
- Parents have to walk a fine line:
 - Be attentive, careful and honest with your child
 - But let them be kids
 - They want to be treated like everyone else
- Your #1 Goal: Make them responsible for their care