



Children's Heart Center

THE HEART BEAT

Goryeb Children's Hospital
Morristown Medical Center
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Morristown, NJ 07962

Goryeb Children's Center
Overlook Medical Center
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Summit, NJ 07901

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Newton, NJ 07860

Flemington Specialty Pediatric Care
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Aparna Prasad, MD
Leonardo Liberman, MD-EP Consult.

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Andrea Winner, RN

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PE,FE, Lead Clinician
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Edited by:

Margaret Micchelli & Stuart Kaufman

THE DIRECTOR'S CUT CHRISTINE DONNELLY, MD

The Transition Process: "The time has come", the walrus said, "to talk of many things..."

-Lewis Carrol

With the tremendous advances in diagnosis and treatment over the past several decades, today over 95% of children born with congenital heart defects (CHD) are living into adulthood. With this magnificent achievement resulting in a growing number of adults with CHD, our aims in pediatric cardiology have broadened to be sure that our young adult patients, many of whom we have known and cared for from before birth, are fully prepared to enter the world of adult healthcare. This process is called "transition."

In 2011, the American Heart Association emphasized the need for developing a transition process for CHD patients by issuing a policy statement of Best Practices. Although initiation of this process may vary from patient to patient, in most cases, the process begins in early adolescence and continues until the eventual transfer of cardiac care to adult healthcare providers. Our ultimate aim is to equip our patients with the necessary information and resources to become self-confident advocates for their health management. Like the developmental transition from adolescence to adulthood, it involves the gradual assumption of more responsibility for one's self and actions and continual education is key.

Through individual physician and staff instruction during visits, our biannual health fairs, written material and web-based programs, we aim not only to have teens and young adults learn about their specific heart defect, medications and surgical procedures, but also learn about insurance issues, lifestyle effects on the heart, Adult Congenital Heart Disease Centers (ACHD) and support groups so that at the end of this process, "graduation" to the world of adult medicine will not be a cause for concern, but rather one for celebration.



Teen Health Fair: The Cardiac Game of Life



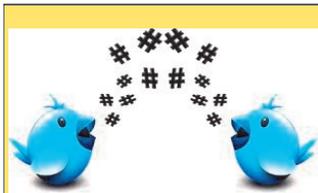
Do you ever wonder about what comes next when you "outgrow" pediatric services? Maybe you've never filled your own medication prescription or you don't really understand how your insurance coverage works. Perhaps you've been thinking about what it will be like to see another doctor instead of the same pediatric cardiologist who knows you since birth. These are just some of the issues that will be addressed at our teen health fair on **Sunday, October 25, 2015 at 1 pm** in the hospital auditorium.

Young people, age 13 and over, and their parents are invited to attend. There will be pediatric cardiology staff to answer questions, as well as written materials on a broad range of topics. Ideally, the transition to adult healthcare should occur over time, with ample opportunities to ask questions and get the information you need to make good life style decisions. It's a process that parents, as well as the young person with CHD, will have to negotiate. The Teen Health Fair is a chance to start the conversation! For information, please contact Margaret Micchelli, LCSW at (973) 971-8689 or margaret.micchelli@atlanticealth.org.



Save the Date: CHD Coalition Walk September 20, 2015

NURSES' NOTES



#healthyhearts

Megan Dickinson, RN, BSN

- ♥ #riskforheartdisease About 1/3 of people, age 10 to 19, have high cholesterol levels.
- ♥ #happyheartdiet Eat low-fat foods like fruits, vegetables, beans, whole grains.
- ♥ #runforestrun Get 30 minutes of physical activity a day.
- ♥ #gotmilk Switch to drinking no fat, skim or 1% milk.
- ♥ #highbloodpressure #obesity #heredity #smoking Know the causes of heart disease.
- ♥ #stayhydrated Drink plenty of fluids daily.
- ♥ #staycool Summer is here! Avoid long periods in the heat.
- ♥ #stickysituation Avoid caffeinated energy drinks, such as Red Bull or Monster, because of the risk of low water absorption, kidney failure or heart attack.
- ♥ #callmecrazy Over 15% of teens send more than 6,000 text messages a month. Phones down and enjoy the outside.

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STAFF HIGHLIGHT

BHAVISHA PANDYA, RDCS-PE, FE
ECHO TECHNOLOGIST

I've been working as a Pediatric Cardiac Sonographer for fifteen years, and from the very beginning, I found my niche working with children and their families.

I was born and raised in London, England. My family and I emigrated to the United States in 1996 and moved to the "Sunshine State," Florida. I spent the next several years there, attending school and finishing my education in Cardiovascular Technology in Tampa, FL. Shortly after graduating from the program, I was very fortunate to have been taken under the wing of a Pediatric Cardiologist in an office setting. I came to the realization that this was the career I wanted to pursue.

I joined the Goryeb Children's Hospital in 2003 after relocating once again after getting married. I found myself being welcomed by a wonderful team of people who are all very compassionate and caring. I feel blessed and consider the people with whom I work to be part of my family also. We work together very closely and have one ultimate goal: to provide the best care to our patients and their families.

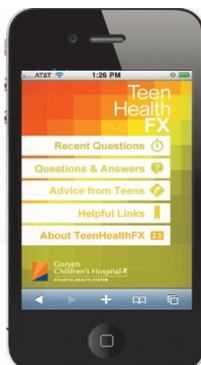
Today, I have a ten year daughter, a six year old son, and another baby due in December. I give credit to these amazing people in my life, including my wonderful husband who brings out the very best in me each and every day and gives me purpose to continue doing the best when I am at work, too. When I'm not at work, my family and I enjoy traveling and exploring new places.



SCHOLARSHIPS FOR H.S.SENIORS

The Congenital Heart Defect Coalition, a local parent organization, is offering two \$2,000 scholarships to high school seniors who have a congenital heart defect or acquired heart disease. As part of the application, the student is asked to write a short essay about his/her experience with heart disease. Please see the CHD Coalition website for information and an application form: <http://chdcoalition.org>.

TEENHEALTHFX.COM—YOU CAN ASK US ANYTHING



Did you know that Atlantic Health sponsors a popular website for teenagers and young adults to get factual health and medical information? Starting in 1999, it has had over 40 million users and received over 50,000 anonymous questions to date. This interactive website features:

- FX Answers** – previously posted questions and answers that allows visitors to search through categorized subject areas
- Teen Tips** – teens give guidance to other teens on important health and emotional issues
- TeenHealthFX Quizzes** – a fun way for teens to test their knowledge
- Hot Topics** – explore hot topics in-depth
- Facts** – surprising facts about teens and their world
- AskFX** – teens can post their questions at any time. To ensure confidentiality, TeenHealthFX does not get email addresses and could never email anyone back or even know who they are.

This resource helps teenagers and young adults get information in a non-threatening environment, clarify rumors or second-hand information and generally learn how to take good care of themselves, both physically and emotionally. Especially for those young people who have a heart condition and need life-long medical monitoring, it's one of many tools that can be used to make good decisions in maintaining a healthy lifestyle.

KAWASAKI DISEASE - FOCUS OF POSTER SESSION

Kawasaki disease, a cause of acquired heart disease in children, was presented at the poster session of the 19th annual AHS Research Day on June 11, 2015. Third year medical student Ryan Peretz, along with infectious disease specialist Dr. Elizabeth Baorto and pediatric cardiologist Dr. Donna Marie Timchak shared their findings of an unusual case in a 14 year old boy. They compared the data to the literature available in this age group, acknowledging its rarity, because it is more frequent in younger children.



All our pediatric cardiologists enjoy teaching the Goryeb residents, as well as medical students from various institutions, in addition to their full clinical practice. Ryan Peretz, who will be applying to pediatric residency programs, was influenced in his career decision by his positive experiences at the Goryeb Children's Hospital.

TEEN RECEIVES GOLD AWARD FOR CHD PROJECT



Randolph H.S. student Christine Padula, age 17, earned girl scouting's highest award for her project on congenital heart defects. The Gold Award requirements involve investigating, planning and implementing a community project that will have a lasting impact.

Christine, who knows about CHD first hand, researched and developed a fact sheet geared towards teenagers. Printed on neon green paper and written in a manner appealing to teens, the one page handout covers relevant issues: drugs, tattoos/piercing, sexuality, exercise, smoking. It points out areas where a teen with a congenital heart defect needs to be extra careful, encouraging open discussion about these topics with his/her pediatric cardiologist.

FAMILY CONNECTION



On the day our son was born, it turned out to be anything but a typical day, as Dr. Kaufman entered the room and diagnosed him with Tricuspid Atresia. Mark was sent to CHONY to await the first of the procedures that would successfully rebuild his heart. I'll never forget the strong grip that little baby in the NICU had on my finger, which was a good indication of the strength he would show in the years to come. Eighteen years later, we found ourselves helping Mark pack up for his freshman year at Penn State University, the college at the top of his list.

The fact that Mark was going off to live at college brought about many emotions. It was incredible to believe how far he had come since being born with a heart defect. Mark has done extremely well and we felt confident that he would excel in that environment. But we also worried because it was the first time he was going to be totally on his own, managing both his schedule and his health. Over the years, we did the best we could to impress on him how he needs to treat his body, especially because of his heart condition. Like all par-

ents with children in college, we worried about the social scene and the challenging issues that young people face.

Mark is a responsible young man, but would he remember to take his daily pills, and would he advocate properly for himself if he got the flu or fell ill? Even though his medical records were sent in advance, he did have to speak up when the infirmary wanted to give him medicine for a cough that he's not supposed to have. Fortunately, he called home to confirm his thoughts, and then let them know his condition and that he could not take what they suggested. It showed the importance of Mark having to take responsibility for managing his own health.

Mark has completed his freshman year and it was a very good one for him. He got excellent grades while at the same time going through the process of joining a fraternity. From the time that we shed tears when dropping him off, through the ups and downs of a first year of college, it is clear that our son has taken the next step in maturing as a young, independent adult. And we have all grown in the process of letting go.

Karl & Donna, parents of a 19 yr. old son

Did you know??

♥ There are now more adults with congenital heart defects (CHD) than children. In the United States, there are about 1 million adults and 800,000 children living with CHD.

♥ The number of adults with CHD increases each year by about 5%.

♥ In the U.S., CHD is now the most common form of heart disease encountered during a woman's pregnancy.

♥ At least 10% of all congenital heart defects are first found in adulthood.

♥ There are more than 40 different types of congenital heart defects.

♥ It is important for adults living with CHD to see a specialized health care provider for cardiac care regularly throughout their lives.

♥ It is estimated that only 50% of adults with congenital heart defects receive ongoing cardiovascular care.

♥ The Adult Congenital Heart Association (ACHA) is a non-profit organization dedicated to education, outreach and advocacy for adults with CHD and their families.

♥ What is the cost of membership in the ACHA?



Answer: Membership is free!

SOCIAL WORK CORNER MARGARET MICCHELLI, LCSW



HEALTH INSURANCE: BASICS FOR YOUNG ADULTS

Do you know the details of your health insurance coverage? And do you have a plan for when you're no longer covered under your parent's insurance at age 26? In the U.S., health insurance is most often offered through one's employer or through government programs with financial eligibility rules. Also, there are now more opportunities to purchase health insurance yourself since the full implementation of the Affordable Care Act (aka Obamacare) in 2014. Under this health care reform, there are no longer penalties for a pre-existing condition, such as a congenital heart defect, and there's no life-time cap on expenses if you need surgeries or expensive procedures in the future. On the other hand, it requires, with few exceptions, all Americans to have health insurance or else pay a yearly penalty.

When you're job searching, ask about health insurance. (If there are less than 50 employees, the company is not required to offer it.) Such group plans are generally less expensive than an individual plan. However, don't just sign up for or buy the cheapest plan. Make sure the services you'll need are sufficiently covered, such as echocardiograms, EKGs, cardiac catheterizations, MRIs and visits to specialists. Also, find out if you're allowed to see an out-of-state provider, such as NY/Presbyterian Columbia Medical Center where you may have been before.

Costs also vary depending on the type of managed care plan you choose. Here's a very brief overview. An HMO (health maintenance organization) requires you to use only providers/hospitals within that network, usually without a deductible or co-pay. A PPO (preferred provider organization) is more flexible, allowing some coverage for out-of-network providers, and doesn't require a referral to see a specialist. An EPO (exclusive provider organization) is the most restrictive plan, but it may also be the least expensive. Be sure to check if your cardiologist accepts the insurance plan you choose!

A premium is what you pay each month to have the coverage. It comes out of your paycheck for employer group coverage or you pay the insurance company if you're buying it privately. The premium cost is independent of whether or not you actually use the insurance. A deductible is what you pay out of pocket for medical costs each year before the insurance starts to cover its share. (Cheaper plans often have a higher deductible. Can you afford this deductible?) A co-payment is your financial responsibility for certain services, such as \$50 for each doctor visit. Co-insurance is your percentage of a healthcare cost, after you've paid the required deductible or co-pay, such as 30% paid by you and 70% paid by insurance. Finally, the maximum out-of-pocket cost is the upper limit you're required to pay in a given year before insurance pays the full amount for further services in that year.

Sources you may want to check for more information, such as financial eligibility requirements for government programs, include: www.njfamilycare.org, www.usa.gov/health-insurance, www.healthcare.gov.

Valentine's Day 2015: National Congenital Heart Defect Awareness Day

For the 6th year in a row, the division of pediatric cardiology celebrated National Congenital Heart Defect Awareness Day with a Valentine's party for children and families. On February 15th, the hospital auditorium was filled with food, fun and activities, even in the face of threatening weather that day. After all, one of the most important functions of our family events is to provide a chance for families to meet and socialize with others

who understand their experience with CHD.

Through the generosity of the Schmidt family, children had lots of fun decorating their own cupcakes. And we had a special appearance from the volunteer Fire Chief of Midland Park, Mark McCombs, who both educated and delighted the crowd with handouts and real firefighting gear to try on.

We look forward to seeing you at our next Valentine party, so please put Sunday, February 7, 2016 on your calendar!

