



Children's Heart Center

THE HEART BEAT

Goryeb Children's Hospital
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100 Madison Ave.
Morristown, NJ 07962

Goryeb Children's Center
Overlook Medical Center
99 Beauvoir Ave.
Summit, NJ 07901

Newton Medical Center
175 High Street
Newton, NJ 07860

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Flemington, NJ 08822

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Margaret Micchelli & Stuart Kaufman

THE DIRECTOR'S CUT CHRISTINE DONNELLY, MD

Heart History: Pioneers in Pediatric Cardiology-The Collaboration of Helen Taussig, Alfred Blalock and Vivien Thomas "to seek a newer world" – the 70th year anniversary

This year is the 70th anniversary of the first palliative operation to help children born with severe cyanotic congenital heart defects. There is no other procedure in the history of pediatric cardiology that changed the lives of so many and so quickly than what is now known as the Blalock-Taussig shunt. In honor of this landmark event, we are reprinting the story of this achievement from our first issue of *The Heart Beat*. Blalock, Taussig and Thomas were true pioneers and the world of pediatric cardiology will be forever indebted to this remarkable team.

Today, there are as many adults living with congenital heart disease as there are children. This speaks to the advances and successes in pediatric cardiovascular medicine that have occurred over the past decades. It is hard to imagine, therefore, a time in the not too distant past when children born with congenital heart disease, especially those defects resulting in cyanosis causing the "blue babies" rarely survived past childhood. And yet such was the case in the 1940s when a remarkable collaboration resulted not only in a revolutionary change in the

world of children born with cyanotic heart defects but in the birth of pediatric cardiovascular medicine.

Helen Taussig obtained her doctor of medicine degree from Johns Hopkins University in 1927, a time when few women were physicians and some medical schools did not even accept women as students. Under the mentorship of Dr. Edward Park, she was placed in charge of the cardiac unit at the Harriet Lane Home for Invalid Children at Johns Hopkins Hospital and began her life's work in the care of patients with congenital heart disease. After a decade of observations and care of her "blue babies" she determined that most of her patients were blue because of insufficient blood to the lungs. What is truly remarkable is that she was able to determine this through her clinical skills and armed with rather rudimentary diagnostic tools of a stethoscope (an amplified one since Dr. Taussig was nearly deaf), fluoroscopy (X-ray) and a crude electrocardiogram. (There were no echocardiogram machines or cardiac catheterization laboratories at that time). She observed that her patients with critical pulmonic stenosis which limited blood flow to the lungs did better if their ductus arteriosus (a naturally occurring vessel that connects the aorta and pulmonary artery before birth) remained patent, since this



vessel was able to bypass the area of obstruction and provide blood to the lungs. She was convinced that most of her cyanotic patients could be helped by creation of an "artificial ductus." She needed, however, to convince a potential "creator" of such.

Dr. Taussig approached Dr. Alfred Blalock, the newly appointed Chief of Surgery at Hopkins with her idea. Dr. Blalock with the aid of his surgical assistant Vivien Thomas had previous experience with creating this artificial ductus but for a different indication. Over the next year, Vivien Thomas was able to create an animal model of "cyanotic heart disease" and tested the new operation in his laboratory. Sooner than anticipated, the operation was performed on one of Dr. Taussig's patients because of her rapidly deteriorating condition. On November 29, 1944, Dr. Alfred Blalock with Vivien Thomas standing behind him for guidance, "created" the first "artificial ductus" shunt in 15 month old Eileen Saxon and history was made. After

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NURSES' NOTES

**All You Need to Know
About Sports
Clearance**

Andrea Winner, RN, BSN

- ♥ Even if your child has no activity restrictions from a cardiac perspective, the school may still need a sports clearance form.
- ♥ Please familiarize yourself ahead of time with your school's specific requirements and forms.
- ♥ The best time to request sports clearance is at your regularly scheduled pediatric cardiology appointment.
- ♥ Think ahead! If your appointment is in the spring, you can still request the form for fall or winter sports.
- ♥ Due to high volume at the beginning of the school year, we may be unable to respond immediately to your sports clearance request.
- ♥ An RN answers phone messages on Monday-Friday from 9am-4pm. Calls are returned in order of medical urgency (chest pain, Rx refills, etc.) with sports clearance as a lower priority.
- ♥ **OUR NEW PROCEDURE:** Please submit a stamped, self-addressed envelope with the form and it will be mailed back within 10 days.
- ♥ Thanks for working with the nursing team to make this a smooth process for all!



STAFF HIGHLIGHT

MARIA LAWTON, RN, BSN
PEDIATRIC NURSE

I began working in the division of pediatric cardiology in February of 2006. Many of you know me from encounters during office visits or perhaps from dialogue on the phone. In either case, it's a privilege to work for this department and be part of a team to which you entrust your most cherished gem, your children.

I attended nursing school at Seton Hall University and after graduation my journey in healthcare began. Working in various areas and trying to find what it was that would bring me satisfaction and a sense of accomplishment was my goal. One afternoon, I met a family whose child had significant heart disease and I recall being very curious and intrigued. For weeks afterwards, it consumed my thoughts and I found myself reading about cardiac anomalies. It was then I realized I had to pursue this interest in pediatric cardiology.

When I'm not working, my time is spent with my husband and two children. I enjoy time outdoors at sporting events, gardening, swimming, bike riding, jogging, cooking and entertaining my family and friends. My absolute favorite pastime is sitting back with my husband as we watch and listen to the sound of our children's laughter and happiness. I relish these times and hope that my involvement in any child's life will allow many parents to treasure similar moments.

CARDIOLOGY AND GENETICS DARIUS J. ADAMS, MD

Over the past decade, numerous discoveries have provided evidence about the genetic etiologies of congenital heart defects and the roles that these genes play. Although there is still much to be learned, these advances point to better care for pediatric cardiology families.

When cardiac defects are seen in junction with other anomalies, rather than presenting as a single medical problem, the etiology is often easier to identify. However, such syndromes account for less than 20% of congenital heart defects identified.

Chromosome analysis, by blood test or cheek swab, can identify numerous chromosomal abnormalities and sometimes provide information about deletions and duplications of large amounts of genetic material. We have been testing for syndromic conditions involving heart defects, such as DiGeorge syndrome (22q deletion) and Williams syndrome, by this method for years.

However, there are a large number of single gene disorders that have cardiac involvement. Specific gene panels are available to test for Marfan's or thoracic aneurysm-related disorders or Noonan syndrome which is genetically heterogeneous. Recent technology, such as whole exome sequencing, has identified mutations that play a role in congenital heart disease that have not been included in these panels before.

Cardiomyopathy and Long QT syndrome are heart conditions, not immediately identifiable at birth or in early childhood, that also have a genetic etiology. Therefore, testing earlier in a child's lifetime due to a family history of these conditions may provide better opportunities to proactively manage these diseases.

Overall, genetics plays a much greater role in the field of cardiology than was previously thought. It's important that as we proceed with genetic testing that we take part in collaborative databases to better understand the role that genetics plays and how to best help affected families. Clinical and research laboratories are encouraged to share identified mutations and a description of the patient's symptoms in order to better understand the genetic basis of cardiac conditions.

In this new arena for care, Atlantic Health now has the benefit of the Jacobs Levy Equity Management Personalized Genomic Medicine program staffed by myself, a board-certified genetics physician, and a genetic counselor. Genetic testing and post-test counseling are provided on matters related to DNA health and wellness.



DIRECTOR'S CUT (CONT'D)

publication of the results of the first 3 operations in JAMA in 1945, Dr. Taussig's clinic was engulfed by patients, and over the next 4 years, over 700 operations were performed which became known as the Blalock-Taussig shunt. Physicians came from all over the world to learn the technique of the operation from Dr. Blalock and Vivien Thomas and the world of children born with congenital heart disease was changed forever. The impact of this operation was tremendous, if not miraculous, but is most poignantly summarized in a letter that Dr. Taussig

received from a 12-year old French patient, Jean Pierre Cablan which she kept framed on her mantelpiece: "Je suis maintenant un tout autre petit garçon..je vais pouvoir aller jouer avec mes petits comrades." ("I am now a completely different little boy... I can now play with my friends") - a new world indeed!

For a dramatized account of the first Blalock-Taussig shunt, see the TV movie "Something the Lord Made."

FAMILY CONNECTION

You know the look. The one that other parents give you when you say your baby had emergency open-heart surgery when he was born. That sympathetic, but "Thank God it's not me" look. Before we had Tyler, I probably was one of those moms who gave the look without realizing it.

It's so tough to explain to someone else what goes through your mind everyday about your heart baby. It's hard to explain that when I hear that particular song on the radio, the one that was playing in the NICU when he was recovering with tubes & wires sticking out of him, how it brings me right back to that hospital room and hits me like a ton of bricks. Like it happened yesterday.

We have a 4 year old daughter, Julianna, who wasn't born with a CHD and a 1 1/2 year old son, Tyler, who was born with infra-diaphragmatic TAPVR (total anomalous pulmonary venous return). His defect was successfully repaired at 8 days old at Columbia CHONY.

So far, at 18 months old, he runs and plays like any other child. But anytime I see him run around, I can't help but think "Is today going to be the day that he has a heart-related issue?" When I put Tyler to bed at night, I give him just a little longer of a kiss, and a little longer of a nose-nuzzle on his fuzzy head. I talk very softly to him, telling him how much we love him and feel so incredibly blessed to have him in our lives. He is such an extraordinary little boy and is absolutely in our lives for a reason.

Here comes the weird part. There is a fine line as to how I feel about Tyler's CHD. Sometimes people say that we are *lucky* because he only had to have one open-heart surgery. Only *one* surgery - Are we *really* lucky? Yes, he is alive and healthy now, but I don't feel *lucky* every day when I see his little scar. I touch it and feel his beautiful heart



pumping and I thank God he is alive. And in the same thought, I don't feel lucky when I think about everything we endured as parents not knowing if he was going to live when his chest was being cut open. I don't feel lucky knowing all that he went through after he was born. I don't feel lucky when I know one day I will need to explain what he went through as a newborn.

The upside is that every minute of every day, I feel exceptionally blessed to have him as our son. His scar is who he is. He wouldn't be Tyler without his scar (which Julianna says is his belly button). He is so incredibly happy and full of life, so innocent and perfect, and I could hold him in my arms until the end of time. I want to protect him from everything in the world because I feel like he has been through so much already. I know there are other CHD babies who do not live very long and/or have multiple surgeries in their lifetime. Every situation is different. So, yes, we *are* lucky & blessed that Tyler is with us and he is healthy, however I do not feel lucky for going through what we went through.

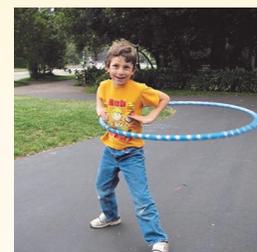
As time goes on, we tend to put the 'heart defect' on the back burner of our thoughts, even though his scar is a daily reminder of how our little boy is so unique.

When we were first going through this, our family & friends offered great support. Then we were told about the CHD support group at the hospital where we talked to other CHD parents. It was the mental relief that we needed, listening to other CHD parents who felt the same way we did and were going through the same thing we were. The meetings really allowed us to express our feelings and helped us to feel not so alone.

Skye, mother of a 1 1/2 year old son

Did you know??

- ♥ Jumping rope involves almost every muscle in your body.
- ♥ Using free weights builds muscle mass faster than using weight machines.
- ♥ More than 80% of teenagers don't meet the recommended guidelines for aerobic activity.
- ♥ Underwater swimming is the only time you should hold your breath while exercising.
- ♥ Being dehydrated reduces exercise performance.
- ♥ Hula hooping for 30 minutes burns about 210 calories.
- ♥ Watching TV for 30 minutes burns about 23 calories.
- ♥ Doing karate for 30 minutes burns about 300 calories.
- ♥ Skateboarding improves balance, as well as coordination between your eyes, legs, feet and arms.
- ♥ How was Zumba invented?



Answer: Alberto Perez, a fitness instructor, forgot to bring music for his group aerobics class. So, he improvised with his salsa and merengue tapes.

AMERICAN ACADEMY OF PEDIATRICS: PARENT RESOURCES

The Internet is overloaded with information. In fact, there is so much information available to parents that it may be difficult to distinguish between what's reliable and what's not. (And that's not including the varying quality of blogs.) If you have questions about parenting, where do you turn to get guidance and ideas?

The American Academy of Pediatrics is a resource for current, accurate and helpful information on topics of interest to parents. Check out some of the book titles that are available through their website: <http://www.aap.org/en-us/aap-store/parent-resources/Pages/parent-resources.aspx>.

- Building Resilience in Children and Teens
- CyberSafe: Protecting & Empowering Kids in the Digital World of Texting, Gaming and Social Media
- Sleep: What Every Parent Needs to Know
- Sports Success Rx! Your Child's Prescription for the Best Experience
- Food Fights: Winning the Nutritional Challenges of Parenthood Armed with a Bottle of Ketchup
- Dad to Dad: Parenting Like a Pro



SUMMER CAMP FOR CHILDREN WITH CHD

Would you like your child to have the experience of overnight camp with the reassurance that qualified staff can address your child's cardiac needs? Some of our youngsters have attended these specialized camps and have great things to say about it. They have met new friends, developed more independence and had lots of fun. Please feel free to contact the camps to get more information and to see if it's right for your child.

The Edward J. Madden Open Hearts Camp
 Ages 8 to 16
 Great Barrington, MA
 (413) 528-2229
www.openheartscamp.org

Hope with Heart Camp
 Ages 7 to 17
 Harriman, NY
 (973) 728-3854
www.hopewithheart.org



CHD COALITION WALK A SUCCESS

Over 1,000 people attended the CHD Awareness Walk and Family Fun Day on 9/21/14 at Darlington Park in Mahwah. The AHS pediatric cardiology team members of the "The Heart Throbs" were joined by many of our families to show support and increase awareness of congenital heart defects. It's also a fun day for children with crafts, games, snacks and live music.

The CHD Coalition, a non-profit parent organization, offers support to families, donates to CHD research, provides scholarships to high school seniors and distributes heart bags for children having surgery. To find out more, please call (973) 291-4676.

