

Lucy's Dance

When our daughter, Lucy, was two weeks old, her pediatrician heard a heart murmur and referred us to a local cardiology group. We light heartedly took the card, not knowing what to expect. The pediatrician looked me in the eye and said, "Waiting one week will be waiting too long". Based on the gravity of his words, we called immediately from the hospital parking lot. The next day we were seen by Dr. Marc Le Gras at Emanuel Children's Hospital. After the echo, Dr. Le Gras met us back in the exam room with a drawing of the heart and said, "It's a little more than a heart murmur." He then drew a diagram explaining Tetralogy of Fallot, a right aortic arch, and an isolated left pulmonary artery. I heard his words but absorbed nothing except "Your daughter needs surgery in the next week." Thus began our education in the anatomy of the human heart.



At three weeks of age, we handed our baby over to the anesthesiologist. It was the most terrifying and heart wrenching moments in our lives. (We would repeat this parental torture 11 more times in the next seven years and it never got easier.) Her first surgery was on her left pulmonary artery. Her ductus was still open so Dr. Starr decided to use it and attach it to her left lung. Lucy sailed through the surgery, but unfortunately 6 hours later, she coded.

By the grace of God, Dr. Le Gras was still in his office and ran to Lucy's room in the PICU. He cracked her chest and began CPR, manually massaging her tiny, precious walnut sized heart. She was in very critical condition and she was placed on ECMO (Extracorporeal Membrane Oxygenation). This is a complex, dangerous hi-tech machine that does the work of the heart & lungs. Her sternum was open and her heart covered by a transparent membrane (we could see her beating heart). Her life support included a respirator, a peritoneal dialysis catheter, two chest tubes, an external pacemaker, and several IV lines. Lucy had multiple transfusions and was on many drugs. She weighed 7.5

lbs prior to surgery and had an extra 5 lbs of fluid. I counted 28 tubes coming out of her tiny little body. These tubes pumped her blood, cleaned her blood, fed her, digested her food, eliminated her waste, breathed for her, fed her drugs and kept her alive.

We were told to say our goodbyes because the chance of Lucy making it through the next critical 48 hours was less than 3%. We were surrounded by our loving family, and held vigil next to Lucy, telling her stories, blowing her kisses and gently touching her on the few centimeters of skin that was safe to touch. After a few days, it was time to trial her off ECMO. It took a few attempts, as Lucy crashed during one of them, but she made it through the difficult transition and began to slowly make steps in the right direction.

A week later, when stable enough to endure, Lucy had another five hour surgery to remove a clot from her left pulmonary artery and insert a BT shunt in to the left lung. She came back to the PICU with her chest still open. It had been two weeks since Lucy had been held. Every day, we celebrated small milestones with the wiggle of a toe or finger. A month and six surgeries later, we were able to take Lucy home.

During that time, I became introduced to other heart moms over the internet. Connecting with other heart moms was essential to re-gaining my sanity. It provided me with education, comfort, and even company. Two years later, we became involved in the Oregon Chapter of The Children's Heart Foundation and were so impressed with the grass roots effort to raise as much money as possible for the prevention, treatment and diagnosis of congenital heart defects. The friends that we have met through the "heart parent" networks are friends for life. We feel each other's stresses and celebrate each other's victories. Over the last 7 years, we have witnessed many miracles and also suffered some devastating losses in our heart community.

Lucy's cardiac future is uncertain but we have so much hope in the research that is happening. The fact that pulmonary valves eventually will be replaced in the cath lab gives us hope that Lucy may never need another open heart surgery.



Lucy has already surpassed the limits of modern medicine. Lucy is a dancing, singing, brilliant, sensitive, adorable, and very vocal little girl. If it is true "that what doesn't kill you makes you stronger", Lucy will be able to leap tall buildings in a single bound! ♥



President's Message

by Megan Van Pelt, CHF President



Heartfelt Thanks



As the days continue to pass in 2009, we are embarking in new areas of research funding, starting new chapters in Pennsylvania, Arizona, and Illinois and creating new relationships with families and other organizations. The year has been filled with new opportunities and changes. What has not changed is that CHF continues to be a leader in the field of congenital heart defect research and providing much needed funding to young investigators.

One of the greatest experiences in my time as a volunteer for CHF (& most definitely during my tenure as Board President) was a recent trip to Washington, DC for the National Congenital Heart Coalition Lobby Day 2009. I joined approximately twenty other CHF volunteers and staff to discuss the recently introduced Congenital Heart Futures Act. This bill, which calls for research, surveillance, and education in congenital heart disease, gives me hope as a parent and as one of the leaders of this organization. This legislation will further enhance the research we fund by providing information for researchers and physicians to help patients who face high risks of developing additional heart problems as they age, and lead to better treatment strategies. A very special thank you to one of our own, Ellen Weiss, for her leadership and tireless efforts in creation of the bill as well as facilitation of our Washington, DC endeavors.

"...CHF continues to be a leader in the field of congenital heart defect research and providing much needed funding to young investigators."

In closing, I would like to thank our incredibly dedicated volunteers on the chapter and national levels, as well as, our event sponsors and donors who continue to support our efforts during these trying economic times. Each of you makes a difference and brings health, hope and happiness to children impacted by congenital heart defects. ♥

ProFlowers

Brighten someone's day and benefit CHF at the same time. The Children's Heart Foundation has teamed with **ProFlowers**, the online fresh flower marketplace, to raise awareness and funding for the leading birth defect in America. Celebrate birthdays, anniversaries, and special occasions, say thank you to someone or just brighten someone's day, visit <http://www.proflowers.com/CHF> and choose from a variety of beautiful arrangements. Ten dollars from each purchase will benefit CHF! ♥

- ♥ **Joanna and Mike Agne and Family** for hosting the 5th Annual "Forever in our Hearts" Gala. Once again, the Agne Family and Committee made this event a terrific success. This year they are replacing the November event with a "Forever in our Hearts" Summer Luau to be held on July 17, 2009 at the Oak Brook Bath & Tennis Club. For more information visit: www.foreverinourheartsgala.org.
- ♥ **Alpine Children's Charity** (ACC) created by a group of 14 cousins to have "kids helping kids". Many thanks to all the dedicated children and families for their efforts to raise awareness and funding for childhood diseases.
- ♥ **St. Jude Medical:** to date has sponsored the 2009 "Hearts at Play" Family Benefit, the 5th Annual Arizona Golf Outing, the "Share your Heart" event, and the Phoenix Golf Outing.
- ♥ **The Kluth Family Foundation** and **Luke Kisielewski** chose CHF to receive their unrestricted gift.
- ♥ **Huffy Bicycle Co., Four Seasons Heating and Air Conditioning, St. Jude Medical, LifeSource** and **The Pickell Family Foundation** for sponsoring the 2009 "Hearts at Play" Family Benefit, Chicago, IL.
- ♥ Hearts at Play Co-Chairs, **Charles and Jackie Tillman** for their support and generosity.
- ♥ Over 40 students and adults from Glenbard East High School, St Francis Xavier Quest Group of LaGrange and Northwestern Memorial Hospital volunteered at "Hearts at Play" Family Benefit.
- ♥ The Louisiana State Chapter of **Pi Sigma Epsilon** hosted the 3rd Annual "Art for the Heart" Gala in Baton Rouge, LA to benefit The Children's Heart Foundation.
- ♥ **Ginn Resorts**, Palm Coast, FL; **Edwin Hancock Engineering Co.**, Westchester, IL; **Holi and Patrick Heffron**, Plymouth, PA; **Infinium Capital Management**, Chicago, IL; **Westfield Hawthorn Mall**, Vernon Hills, IL; **New Franklin Elementary School**, Marion, PA; **5th Grade Class from Westside Elementary School**, West Fargo, ND; **Lyndwood Elementary School**, Lyndwood, PA; **Mended Little Hearts**, Jacksonville, FL; **Schaumburg High School Band Boosters**, Schaumburg, IL; **Little Star Preschool**, Nanticoke, PA. CHF was chosen as their beneficiary for their various fundraising events.
- ♥ **To all our donors and volunteers for their generosity and support. We appreciate all your efforts to support research and spread awareness. THANK YOU!** ♥



The Medical Advisory Board Update



Carl L. Backer, M.D., Chairperson

The Medical Advisory Board of The Children’s Heart Foundation met on October 25, 2008. At this all day meeting, the Board reviewed 28 proposals for funding to The Children’s Heart Foundation. In attendance were: Drs. Joseph Amato,



Carl L. Backer, Roger Cole, David Cooper, Nancy Ghanayem, Andrew Griffin, Marla Mendelson, David Sahn, Robert Stewart, Catherine Webb, and Thomas Weigel. The grant proposals were reviewed in detail and ranked for presentation to The Children’s Heart Foundation Executive Board. This Board met on November, 3, 2008 and based on the scoring of the grants and funding available, the following three new grants were approved for funding:

First Year Funding			
Title of Research Proposal	Principal Investigator	Institution	Funding
Computationally Guided Design of Biodegradable Drug Eluting Stents for the Treatment and Reversal of Vascular stenoses in Children with Congenital Heart Defects	Marlene Rabinovitch , Professor of Pediatric Cardiology	Stanford University School of Medicine	\$ 100,000
Determining the Natural and “Unnatural” History of Anomalous Aortic Origin of a Coronary Artery with an Interarterial Course (AAOCA): A multi-institutional study	Julie Brothers, M.D. , Assistant Professor	Division of Cardiology, The Children’s Hospital of Philadelphia	\$ 50,000
Cell Based Therapy for Congenital Cardiomyopathy using Endogenous Cardiac Stem Cells	Sunjay Kaushal, M.D., Ph.D. , Assistant Professor of Surgery	Northwestern University Feinberg School of Medicine <i>(This grant is funded by the Tiana Tillman Research Fund from The Children’s Heart Foundation)</i>	\$100,000
Total			\$250,000

Second Year Funding Was Approved for the Following Grants			
Title of Research Proposal	Principal Investigator	Institution	Funding
Genetics of Hypoplastic Left Heart Syndrome	Vidu Garg, M.D.	University of Texas Southwestern)	\$ 70,000
Preconditioning Against Periventricular Leukomalacia Associated with Neonatal Cardiac Surgery	Edward Hickey, M.D.	The Hospital for Sick Children, Toronto, Ontario, Canada	\$ 38,891
Human Factors and Patient Safety during Congenital Heart Surgery	Emil Bacha, M.D. , Senior Associate in Cardiac Surgery	Children’s Hospital, Boston	\$ 36,750
Total			\$ 145,641
Grand Total			\$ 395,641

Several members of the Medical Advisory Board who have contributed immensely for many years are stepping down from the Board. Our thanks for the generous gift of your time and expertise to The Children’s Heart Foundation. These individuals include: Drs. Scott Bradley, Frank Cetta, Timothy Cordes and Constantine Mavroudis.

New members of the Medical Advisory Board are: Drs. Todd Camenisch, Betina Cuneo, Kathy Jenkins, and James Tweddell.

Dr. Todd Camenisch is an Associate Professor at the University of Arizona in Tucson, Arizona in the Department of Pharmacology and Toxicology. Dr. Camenisch will be the Medical Advisory Board Chairman for the Arizona Chapter of The Children’s Heart Foundation. He is a scientist who is involved in the study of cardiac embryology, particularly examining developmental processes and their application to congenital heart disease in a mouse model.



Dr. Todd Camenisch

Dr. Betina Cuneo is an Associate Professor of Pediatrics and Obstetrics at the Heart Institute for Children, Hope Children’s Hospital, Chicago, Illinois. She is the Director of Perinatal Cardiology at Advocate Health Care and the Heart Institute for Children. Her special interest is in fetal echocardiography and the fetal evaluation of babies with congenital heart disease.



Dr. Betina Cuneo



Dr. Kathy Jenkins

Dr. Kathy Jenkins is an Associate Professor in Pediatrics at the Harvard Medical School in Boston, Massachusetts. She is a senior associate in cardiology at the Children’s Hospital, Boston. Dr. Jenkins is also Senior Vice President and Chief Patient’s Safety

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Advocacy



some steps to follow in creating your email:

1. Go to <http://www.senate.gov> and <http://www.house.gov/> to look up your representatives and their email addresses
2. Draft your email – Go to www.childrensheartfoundation.org and click on ‘Advocacy’ for an email template.
3. Send your email. Remember to include your full mailing address as well as your email address. Don’t use US mail, as snail mail goes through lengthy security clearance and takes weeks to arrive in Congress.

And lastly, if you are a constituent of Senators Durbin or Cochran or Representatives Space and Bilirakis, we encourage you to email or call their office and let them know how much you appreciate their leadership of this effort.

For the full text of the Congenital Heart Futures Act, see <http://thomas.loc.gov> and search for bill number *S.621* or *H.R. 1570*. If you have any additional questions on Advocacy, please contact Ellen Weiss at Eweiss@ChildrensHeartFoundation.org. ♥

These are certainly extraordinary times for The Children’s Heart Foundation Advocacy.

Thanks to the efforts of many CHF volunteer leaders along with the National Congenital Heart Coalition, we have successfully introduced unprecedented legislation, the **Congenital Heart Futures Act** (*S.621; H.R.1570*) in Congress. Just over a year ago, the CHF began collaborative talks with the Adult Congenital Heart Association (ACHA), the only CHD organization focused on adult congenital heart disease. The CHF realized the potential for all CHD patients of working in Coalition: one united voice, less duplication, increased research, increased awareness and better health outcomes. In 2007, the CHF and the ACHA as well as the Congenital Heart Information Network (CHIN) formed the National Congenital Heart Coalition (NCHC) with the mission to improve and prolong the lives of all those affected with congenital heart disease, as well as, to prevent CHDs. After the NCHC was formed, the group decided to create federal legislation which will, when passed into law, increase public funding of CHD research, create a national patient registry and fund CHD education and awareness. Along with the invaluable support of the American College of Cardiology, two other national CHD organizations, It’s My Heart and Mended Little Hearts, joined the NCHC advocacy effort creating an incredibly powerful, united voice for congenital heart disease.

The CHF is very grateful to Senator Richard Durbin (IL), Senator Thad Cochran (MS), Congressman Zack Space (OH) and Congressman Gus Bilirakis (FL) who have all decided to be lead sponsors of the legislation. After the congressional leaders introduced the ground-breaking CHD legislation on March 17th in the Senate and the House, they are each working tirelessly to obtain co-sponsors necessary to vote the Act into law. As of April 1st, four additional co-sponsors have supported the bill: Congresswomen Betty Sutton (OH), Congressman Charles Wilson (OH), Congresswoman Sheila Jackson-Lee (TX), and Congressman Todd Russell Platts (PA). Along with the ongoing support from the American College of Cardiology, the American Heart Association has formally endorsed the objectives of the Act.

Thank you to all the CHF volunteers who lobbied this past summer in their home states as well as those who travelled to DC to lobby for the introduction of the bill. CHF needs everyone’s continued support to pass the Act into a Law.

What you can do now to help pass the Congenital Heart Futures Act into Law...

The Congenital Heart Futures Act, like any other legislation, needs majority support in both the House and Senate in order to be passed into law. Anyone interested in helping is encouraged to email their US Senators and Congress people today to ask them to become a co-sponsor of the legislation, which is bill *S. 621* in the Senate and *H.R. 1570* in the House. Here are



Family Benefit



On Saturday, Feb 21, 2009, the Annual Family Benefit, “Hearts at Play” was held at Chicago’s renown Field Museum. The infamous Chicago weather didn’t hold back and despite a rather blustery and snowy evening, over 780 people gathered to raise \$70,000 for CHD research. The celebration included doctors, professionals, parents and, most notably, children and young adults who continue their brave battles with America’s #1 birth defect.

Charles “Peanut” Tillman, cornerback for the Chicago Bears and his wife, Jackie, joined “Hearts at Play” this year as honorary co-chairs in honor of their infant daughter, Tiana, who underwent a successful heart transplant in 2008 as a result of a



Charles “Peanut” Tillman and the kids.

congenital heart defect called cardiomyopathy. Charles and Jackie highlighted the event with a \$100,000 grant presentation to Dr. Sunjay Kaushal, of Children’s Memorial Hospital, to support his research in the area of cardiomyopathy. Charles signed autographs and graciously posed for pictures with his many fans— both kids and adults alike.

The generosity afforded to us by all of our guests, donors and sponsors continues to help to fund the much needed research that will one day, we hope, lead to the cure and subsequent prevention of congenital heart defects in children. ♥



Save the Date



Please join us at the activities below. For additional information, please visit our web site at www.childrensheart-foundation.org

June 28th – Portland, OR

Four wine bike riding tours benefitting CHF-Oregon. The other dates are: July 26, August 2nd and September 27th. To learn more and register, go to <http://www.bikegallery.com/wine-rides.php>.

July 11, 2009 – Blue Lake Park, OR

Inaugural Heart Family Picnic. For more information, go to www.chforegon.org.

July 17, 2009 – Oak Brook, IL

Forever in our Hearts "Summer Luau" will take place at The Oak Brook Bath and Tennis Club. This event will replace the November event this year. For more information visit www.foreverinourheartsgala.org.

August 2009 – Ocean County, NJ

Fourth Annual Caden Dudt Memorial Basketball Tournament.

August 2009 – Columbus, OH

CHF Ohio – Night with the MLS Columbus Crew. Contact: mpierce@chfohio.org for more information.

August 8, 2009 – Memphis, TN

Grant's Gala will hold its third annual event Saturday, August 8th at 7pm at Central Train Station located at 545 South Main Street, Memphis, TN 38103. For more information visit: www.grantsgala.com.

August 23, 2009 – Belle, Vernon, PA

"Remember an Angel, Swing for A Survivor": A Pennsylvania Golf Outing in memory of Alec James Kahler to be held at Cedarbrook Golf Course in Belle Vernon, PA. For more information, visit www.rememberanangel.weebly.com.

September 2, 2009 – Silvas, IL

CHF-Iowa will hold its 2nd Annual Golf Outing at TPC at Deere Run in Silvas, IL. For more information contact: Mick Landauer at mlandauer@childrens-heartfoundation.org.

September 21, 2009 – Lake Forest, IL

The 10th Annual Chicago Golf Outing will be held at Conway Farms Golf Club in Lake Forest, IL. For more information contact: CHF Office.

October 10, 2009 – Safety Harbor, FL

3rd Annual 'Change A Heart' Walk in Phillippe Park. For more information, contact CindyHepp313@aol.com or 727-772-5579. ♥

Medical Advisory Board..., continued from page 3

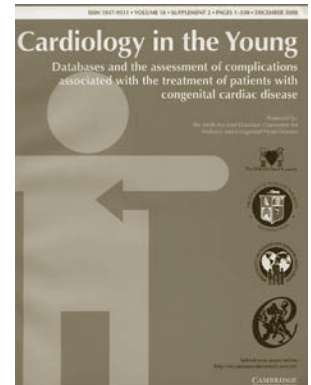
and Quality Officer. She serves on several national committees that are leading efforts to define and measure quality of care for pediatric cardiology patients.

Dr. James Tweddell is Professor of Surgery and Pediatrics at the Medical College of Wisconsin, Milwaukee, Wisconsin. He is the Director of Pediatric Cardiothoracic Surgery at Children's Hospital of Wisconsin in Milwaukee. Dr. Tweddell is widely known for his use of an extensive and detailed clinical database to improve the outcomes of children undergoing congenital heart surgery.



Dr. James Tweddell

I would like to provide some follow-up on previously funded grants that have now completed their funding course. In both 2007 and 2008 principal investigator, Jeffrey P. Jacobs, M.D., received \$50,000 per year for a project which was developed by the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. This has resulted in a 530-page supplement to *Cardiology in the Young* entitled, "Databases and the Assessment of Complications associated with the Treatment of Patients with Congenital Cardiac Disease." This was published as a separate volume in December of 2008. The front cover of the supplement features The Children's Heart Foundation logo as one of four primary sponsors for this project. Also, every manuscript published within this supplement gives thanks to the support of The Children's Heart Foundation. This supplement includes 29 manuscripts and both a long list of complications and a short list of complications, with consensus-based definitions provided in each list. This is a landmark accomplishment in formalizing the way that congenital heart surgeons classify, catalog, and track complications after treatment of patients with congenital heart disease.



The research cycle moves on and the current call for research proposals for 2009 has been submitted. The deadline for clinical research proposals is: June 5, 2009. These proposals will be reviewed by the Medical Advisory Board of The Children's Heart Foundation in the fall of 2009 and those recommended for funding will receive funding in December of 2009. ♥

Good Search

Remember to use GoodSearch.com, the Yahoo-powered search engine, for all of your web searches and we'll receive a penny every time you do a search!

Hundreds of great stores including Amazon, Best Buy, Staples, eBay, Apple and others have teamed up with GoodShop. Every time you place an order, you'll be supporting CHF! Visit www.goodshop.com enter **The Children's Heart Foundation, Lincolnshire** as the organization and then search all the shops. It is that easy! ♥



Chapter Development Update



VP of Chapter Development, Tom McKeough

PA News

With the ongoing success of Chapters in Florida, Iowa, Indiana, Ohio, and Oregon, The Children's Heart Foundation recently established its newest Chapter, in Pennsylvania. Patty Cheshire, President of the PA Chapter, has been planning and organizing fundraisers for CHF for three years. Along with the support and dedication of a group of volunteers, Patty established the chapter and planned a special evening held on Saturday May 9th called "Share Your Heart". It was a huge success! Welcome aboard Pennsylvania Chapter!

AZ News

CHF has had wonderful support in Arizona for many years thanks to the commitment of Todd Camenisch, PhD, who has spearheaded the Annual Golf Outing in the Tucson area since 2005. Dr. Camenisch, who is a Heart Development Researcher at University of Arizona, understands first hand the overwhelming need for increased congenital heart disease research funding. In the 5th Annual Swing Fore Their Hearts, Todd and his team gathered nearly a full field of golfers to the Omni Tucson National on Saturday, February 21st. Complemented by spectacular weather, dedicated sponsors and golfers contributed \$15,000 to CHF by the end of the day.

Just two hours away in Phoenix, Janeen Kokodynski, President of the soon-to-be Arizona Chapter, organized her 2nd Annual Heartfelt Affair on Saturday, February 28th. Held at the National Restaurant Supply Company, Janeen and her committee brought together 175 people who contributed \$17,000 during an evening of wine tasting and amazing cuisine. One of the evening's highlights was the appearance of Chef Eddie Matney, who is a highly regarded Executive Chef, and graciously volunteered his time and incredible talent to CHF!



Heartfelt Affair welcoming table.

If you are interested in volunteering in any capacity in Arizona, please contact Janeen Kokodynski at janeen.kokodynski@dcranch.com.

IL News

Since 1996, when CHF was founded, the Foundation has been headquartered in and around Chicago. With the tremendous growth of CHF across the country, CHF is pleased to announce the formation of an Illinois Chapter under the leadership of Todd Ford, former Chair of the Chicago Golf Outings. The creation of an Illinois Chapter will bring together a team of volunteer

leaders in the state focused on fundraising and awareness of CHDs. For their first event, the IL Chapter will be hosting the 10th Annual CHF's Golf Outing presented by the Exchange to be held on September 21, 2009 at Conway Farms. Brian Chandler, a longtime CHF supporter will chair the event. As in the past, the golf outing will include lunch, golf, dinner, player gifts and a silent and live auction. For more information on the event, please visit www.childrensheartfoundation.org.

Chapter Development News

Are you interested in learning more about CHF, the critically needed research that CHF funds, volunteering, advocating, building awareness, or speaking with the CHF national staff? Then, stay tuned for our next Chapter Development Seminar to take place Wednesday, July 15th at 12PM CST and Thursday, July 16th at 6PM CST. This is a one hour conference call available toll free. If interested, please contact Ellen at EWeiss@ChildrensHeartFoundation.org. ♥



Florida Chapter



The The Florida Chapter is springing into action with a number of events.

The Carson Alan Swingle 2nd Annual Helping Heart Memorial Benefit was held in St. Cloud on April 17th at the Royal St. Cloud Golf Links. The evening included poker, black jack, a silent auction, dinner and more.

Our annual Walmart fundraiser and community outreach event, run by our Junior Board, was rained out and will be rescheduled for September. That timing should work out well, because we will be able to promote our October walk event at the same time. Our 3rd Annual Walk, Healing Hearts, will be held on October 10th at Safety Harbor's Phillippe Park. For more information on Walmart or the walk, contact Cindy at CindyHepp313@aol.com or 727-422-0912.

Do you live in Florida or know someone who does who would like to become more involved with The Children's Heart Foundation? While most of our members and activities are located in and around Pinellas and Hillsborough County, we really hope to expand our active membership to cover more of the state. To find out how you can become more involved, contact our new president, Mark, at MJHepp@aol.com or 727-422-0912.



Dr. Mark Hepp

Information and updates on all of these events can be found at our website, www.chfflorida.org. ♥



Ohio Chapter



fter a quiet winter, The Ohio Chapter is actively preparing for what hopes to be a successful second year in existence.

On April 18th, we had a small fundraiser at the home of Scott and Tammy Thomas in Lancaster, Ohio. Tammy is the Ohio Chapter Vice President and Scott is our VP Legal. The event consisted of a wonderful dinner of homemade pizza with gourmet toppings accompanied by heart-healthy Mediterranean side dishes. We finished up dinner with some great chocolate desserts. Along with this, a fine assortment of Italian proscos was on hand to sample and savor. The remaining Chapter officers and Board members are begging Scott and Tammy to make this a regular event. The meeting started at 3 p.m. with the event beginning shortly after at around 6 p.m.

Marketing Director Angela Wrather is actively working with the Columbus Crew to organize our second annual Heat Day with the Crew. We are looking at a date in either June or July. After a successful first year, we are anxious to improve and grow the event this year and establish an expanded working relationship with the Crew. Please watch our website as this continues to develop (www.chfohio.org).

The Ohio Chapter would like to recognize Congressman Zack Space (D-OH) for helping to introduce legislation to expand Congenital Heart Disease Research. The Ohio Chapter is writing a letter to Congressman Space to thank him for his support of our cause. We encourage everyone to continue to write your local Congressional Representatives and Senators to help pass this vitally important legislation.

As always, if anyone is interested in being a part of the Ohio Chapter or would like information about hosting a fundraiser, please contact President Matt Pierce at mpierce@chfohio.org. ♥



Iowa Chapter



he Iowa Chapter is currently working on their 2nd Annual Golf Outing. This outing will be held on September 2, 2009 at TPC at Deere Run in Silvas, IL. This is the same golf course the John Deere Classic is played every year. It is a magnificent course and will test any level of golfer. The event will include lunch, dinner, and raffles. For more information on this golf event, or if anyone is interested in hosting a fundraiser; please contact Mick Landauer at mlandauer@childrensheartfoundation.org. ♥



Oregon Chapter



he Oregon Chapter of The Children's Heart Foundation had a great year in 2008. Our two events, LionHeart and PULSE, together with the support of our community, raised \$105,000 for research. These events hosted over 900 attendees whom our cause and organization inspired. In addition, we formed partnerships with local businesses including the Bike Gallery, KINK FM, and Comcast. From the Journey of Courage at LionHeart to the 100 amazing pieces of art created for and auctioned off during PULSE – we could not be more proud of our Chapter and the dedicated volunteers who have brought our events to life.

The Oregon Chapter's focus in 2009 is a "Year of Connection." Given the current economic climate, we are focused on deepening our connections with the community. These efforts will optimize our fundraising capabilities for 2010 and will drive the future success of our organization. In order to concentrate on this mission, CHF-OC will forego holding LionHeart and PULSE in 2009.

Our inaugural Heart Family Picnic will be a centerpiece of our community-building efforts this year. Staged at beautiful Blue Lake Park on July 11th, the Picnic will provide a chance for heart families in the Northwest to connect and share their stories of courage and hope. For more information, or to RSVP for this event, go to www.chforegon.org.

In addition, thanks to CHF-OC board member Kelly Aicher, we are proud to once again welcome the generous contributions of a wonderful Oregon business and dedicated sponsor. The Bike Gallery has organized The Children's Heart Foundation Wine Rides, which feature quiet rural roads through the acclaimed Northern Willamette Valley wineries, with 100% of the proceeds benefiting CHF-OC. Riders may choose between four rides, starting and ending at three different wineries: Penner-Ash, Vista Hills, and Stoller Vineyards. Ride dates are June 28, July 26, August 2, and September 27. To learn more, and register, go to: <http://www.bikegallery.com/wine-rides.php>.

We are honored to work with such exceptional volunteers, and we are grateful for the opportunity to help children born with congenital heart disease. ♥



Indiana Chapter



he Indiana Chapter is in the beginning stages of planning a Black Tie Dinner in October. Keep checking the website for more information. If anyone is interested in being part of the Indiana Chapter or would like information about hosting a fundraiser, please contact Brian Velez at bvelez1980@comcast.net. ♥

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About CHF



The Children's Heart Foundation was established in 1996 by Betsy and Steve Peterson to honor the memory of their son, Sam, who died from congenital heart disease at age eight. Today, the Foundation is a national organization with local chapters and a network of volunteers working to eradicate congenital heart disease as America's number one birth defect. To date, CHF has distributed \$3.4 million through 37 research grants. ♥



Our Goal



The goal of The Children's Heart Foundation is to bring health, hope and happiness to children impacted with congenital heart defects, the number one birth defect in the United States. We accomplish this goal by funding the most promising research to advance the diagnosis, treatment and prevention of congenital heart defects in children.

Saving Children's Lives – One Heart at a Time ♥