

The Journey You're On

Our first family photo is the typical hospital snapshot that adorns many family albums. I'm lying in the hospital bed in a blue striped maternity gown cradling our newborn, while my husband stands over us smiling proudly into the camera. We had just welcomed our first child, a son who we named Samuel. He weighed 7 lbs., 11oz., and had dark brown hair and dimples in both cheeks. After nine months of following all the pregnancy do's and don'ts and receiving routine prenatal care with reassuring ultrasounds, I thought to myself, "We did it"! We have our healthy baby boy.

Those first hours with Sam were so sweet. However, they were also deceiving. Unbeknownst to us, Sam's heart was in the fight of its life. Nestled in my arms, he looked perfectly healthy. But beneath his chest, his heart struggled to pump oxygenated blood to his body. Luckily, our delivery nurse heard a murmur and doctors did further testing. An echocardiogram revealed Sam had a Congenital Heart Defect (CHD) called Critical Aortic Stenosis, a severe narrowing of the aortic valve. We were immediately transferred by ambulance to a children's specialty hospital, where Sam received a balloon valvuloplasty to widen the valve and allow for adequate blood flow. I remember it felt like a cruel irony—to instantly fall in love with your child with all of your heart, and for his to be broken.

We lived at the hospital for the first two weeks of Sam's life as he fought to stabilize and recover. It was a time of utter exhaustion, personal questioning, and rapid-fire education into all matters of the heart, from reviewing basic physiology to understanding the complex issues of congenital heart disease. We researched rates of incidence and mortality and were shocked to find CHD was the most common birth defect and the number one cause of all infant-related deaths. We became keenly aware that returning home with our son was not a "given" as we had once expected, but a blessing.

We tried to quickly tackle our new normal, which included a

routine of several medications, cardiac appointments and testing, occupational and physical therapy, new rules about what we could and couldn't do, and what Sam could and couldn't handle. But after two months, Sam's cardiologist informed us that his aortic valve was becoming stenotic again, and he would need open heart surgery at three months old.

On the morning of October 20, 2008 it was still dark as my husband packed our bags into the car and I bundled Sam into his car seat. We made the one-hour drive back to the hospital where Sam was scheduled for a Ross procedure. Surgery involved placing Sam under anesthesia, connecting him to the heart-lung machine, and stopping his heart. The surgeon would then replace Sam's aortic valve with his own healthy pulmonary valve, and replace his pulmonary valve with a donor's. It was an innovative procedure that we weighed against a standard mechanical valve replacement. If it worked, Sam would receive the benefit of having one of his own valves grow with him.

We met with the surgeon at 7:00 a.m. to ask any last questions: "How long before we hear something?" I asked. He told us someone would update us every couple of hours. We hugged and kissed our son and handed him over to the surgical team. Our only job then was to wait. My husband and I walked the hospital halls for a long time that morning. It was seven hours later when we finally heard the news we had been waiting for: "Sam is out of surgery and doing well. Would you like to see him?"

It can be a process to accept and embrace the journey you're on, especially if you hadn't expected to be there. But with every appointment, procedure, setback, and victory, we acquire a bit more knowledge to help us navigate our way—like being able to gauge the severity of Sam's symptoms, knowing when and how to intervene, and exchanging experiences with other families impacted by CHD.



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President's Message

by Tammy Thomas, CHF President



Congenital Heart Walks



As the new National President for The Children's Heart Foundation, I look forward to working with a dynamic and committed team of terrific individuals. Our goal of funding the most promising research for the treatment of congenital heart disease is one close to all of our hearts. As the most common birth defect, CHDs are complex and numerous. We have a team of State Chapter volunteers that work hard to raise funds for research. Our National team is dedicated to being the most efficient and productive foundation to put those funds to the best use. Thank you for supporting the The Children's Heart Foundation in its effort to provide health, hope and happiness to those with congenital heart disease. ♥

Our Congenital Heart Walk (CHW) program is a national initiative that was created in 2010 to unite the congenital heart defect (CHD) community in the fight against CHDs while raising much needed funds for our mission. This year, at 27 CHWs around the country, CHD patients of all ages, families, friends, colleagues, healthcare providers, and other caring community members join together to honor those affected with CHD, as well as, to remember those who have lost their lives due to congenital heart disease. Each walk is co-chaired by dedicated and inspiring volunteers, who plan for 6-12 months to prepare for their CHW day. One highlight of the walks is the moment when the Walk co-chairs, CHF and our partnering organization, the Adult Congenital Heart Association, address the walkers about the significance of the national program.



tlarson@childrensheartfoundation.org

"Change My Heart" is a fun and easy way to raise much needed funds and awareness for Congenital Heart Defects (CHDs)! This fundraising event is designed to be a week long fundraiser dedicated to collecting donations in your school, classroom, workplace, community etc. This fundraising event can be as simple or creative as you'd like to make it. For more information, please contact Tina at tlarson@childrensheartfoundation.org. ♥



Last year, with the unwavering efforts of our 26 Walk Committees, CHF funded an additional \$350,000 of CHD research. And, the momentum continues to grow with every walk season. Please check www.CongenitalHeartWalk.org for a walk near you. If you do not currently have a walk in your community and would like to help this year, consider participating in a virtual walk where you create your own event to benefit the CHW program.

If you would like to bring a walk to your community or would like more information, please contact our Congenital Heart Walk national office at 855-CHD-WALK or email Mike@CongenitalHeartWalk.org. ♥

emerging genetics and heart regeneration to fetal intervention and detection for newborns. For us, research provides hope, not just for Sam's future, but for every child who will receive a CHD diagnosis.

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Part of embracing our journey also meant thinking about how we could take something broken and turn it into something meaningful. We knew that CHD research was disproportionately underfunded, but that research was the key to advancing diagnosis, treatment and prevention of the disease. So we turned to The Children's Heart Foundation (CHF) and asked how we could help support the organization's mission to fund the most promising CHD research. With the help of some amazing families, we launched the CHF Michigan Chapter in 2010 and the Southeast Michigan Congenital Heart Walk in 2011.

Today Sam is five. He had a second open-heart surgery at three years old, and he will need more surgeries in his lifetime. Thanks to innovations in valve replacement, his next one may be less invasive. We know that with Sam's CHD, there will always be a set of unknowns. But we're thankful that there's also been birthday parties, T-ball and soccer games, learning to ride a bike, and his first day of kindergarten. Sam is an energetic, determined and curious kid, who's beginning to try and make sense out of this journey himself.

It's been rewarding to work with other families to help fund projects that have the potential to improve how we fight CHD. And it's always promising to hear about the advancements being made in congenital heart disease, from research into

Recently when he was flipping through his baby book (the one with our first family photo), he saw a picture of himself lying in a hospital crib, his chest bandaged with Steri-Strips. "Mom, was I good as a baby in the hospital?" he asked. I hugged him close and told him, "You were so strong, you amazed us all."

— Sally Powers ♥



The Medical Advisory Board Update



Carl L. Backer, M.D., Chairperson

The Medical Advisory Board of The Children’s Heart Foundation met at the Hotel Sax, 333 N. Dearborn, Chicago, Illinois on Saturday, November 16, 2013. There were



33 members of the Medical Advisory Board and chapter presidents from all over the United States. Members of the Medical Advisory Board besides myself included Dr. Tom Weigel, Dr. Bettina Cuneo, Dr. D. Woodrow Benson, Dr. Marla Mendelson, and Dr. Jennifer Hirsch-Romano. We discussed and recommended funding and no cost extensions for the following grants based on their first year progress report.

Second Year Funding			
Title of Research Proposal	Principal Investigator	Institution	Funding
Transcriptional Profiling of Pediatric Cardiac Stem Cells	Conrad Epting, M.D.	Northwestern University	\$ 100,000

The other second year funding that was discussed and recommended no cost extensions were:

No Cost Extensions			
Title of Research Proposal	Principal Investigator	Institution	Funding
Efficacy and durability of embolization of systemic-to-pulmonary collateral vessels in superior cavo-pulmonary connection patients prior to Fontan completion	Andrew C. Glatz, M.D.	The Children’s Hospital of Philadelphia	\$ 72,719
Late Functional Status of a cohort of Survivors with Critical Aortic Stenosis: A Congenital Heart Surgeons Society Study	Brian W. McCrindle, M.D., MPH	The Hospital for Sick Children, Toronto	\$ 96,829
Development of a Cell-based therapy for Congenital Complete Heart Block	Douglas Cowan, B.Sc., M.Sc., Ph.D	Children’s Hospital Boston	\$ 100,000

In 2013, we received a new all-time high number of grant applications, 55 grant proposals. All grants were reviewed and scored by the Medical Advisory Board prior to the meeting. Because of the large number of submissions, like last year, the grants were divided into 3 groups: Basic Science, Surgical, and Clinical Cardiology. The Medical Advisory Board, as many of you know, has also been divided into 3 categories of reviewers: Basic Science Reviewers, Surgical Reviewers, and Clinical Cardiology Reviewers. The appropriate grants were sent to the appropriate reviewers. In addition, the cur-

rent Chair of the Medical Advisory Board and the previous Chairs along with the Medical Advisory Board Liaison of the Board of Directors (Dr. Thomas Weigel) reviewed all of the grants. The grants were reviewed prior to the meeting by the members of the Medical Advisory Board and the mean scores were tabulated and ranked. The top 15 scoring grants out of 55 were reviewed at the meeting. After peer review, the Medical Advisory Board recommended to the Executive Committee, who approved, funding of grants in the following order:

First Year Funding			
Title of Research Proposal	Principal Investigator	Institution	Funding
Understanding Right Ventricular Physiology in Tetralogy of Fallot	Christopher Caldarone, M.D.	The Hospital for Sick Children, Toronto	\$ 71,000
Oxidative Damage to Bioprosthetic Heart Valves—Mechanisms and Prevention	Robert J. Levy, M.D.	The Children’s Hospital of Philadelphia	\$ 91,000
Genetic Analysis of Tbx1 in Disorders involving the Great Vessels of the Heart	Caroline E. Burns, Ph.D	Massachusetts General Hospital, Charlestown, MA	\$ 100,000
Development in Children with Congenital Heart Disease: From Fetus through Childhood	Lisa Paquette, M.D.	Children’s Hospital of Los Angeles	\$ 68,000
A Self-regenerative Hybrid Heart Valve	Arash Kheradvar, M.D.	University of California – Irvine	\$ 100,000

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Following grant review there was a discussion of the process of reviewing grant proposals. A priority would be to recruit more physicians who have basic science background because of the increased number of basic science proposals. A second point that was raised was to make the request for proposals more specific relating to the vision and mission of The Children's Heart Foundation. We also reviewed the current members of the Medical Advisory Board and recommendations for new members were made. The following members will be rotat-

ing off of the Medical Advisory Board: Dr. Joseph Amato, Dr. Susan Crawford, Dr. James Huhta, and Dr. Kent Thornburg. We thank them for their dedicated years of contribution to the Medical Advisory Board.

New additions to the Medical Advisory Board include: Dr. Joe Forbess (Surgeon), Dallas, TX, Dr. Peter Mohler, Columbus, OH, Dr. Brad Marino (Critical Care Intensivist), Cincinnati, OH, and Dr. Patrick Jay (Basic Scientist), St. Louis, MO. ♥

Chapter Development

♥ Chapters play a critical role in The Children's Heart Foundation's mission raising much needed funds and creating awareness for congenital heart defects (CHDs). Our statewide chapters are developed so that we have a perpetual structure in place to fight CHDs for the long term. All chapters are managed completely by a dedicated team of volunteer board members who are committed to the



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CHF mission. In the past several months, we have welcomed California and Nebraska as newly developing Chapters. California Chapter President, Sarah Ortiz and Nebraska Chapter President, Kristi Unick have assembled talented boards and held fundraising events including walks and golf tournaments. We are thrilled and grateful to have both Sarah and Kristi along with their dedicated volunteer leaders as part of the CHF Chapter team.

Several passionate CHF volunteers are also working hard to establish chapters in many states such as Alabama, Kentucky and Maryland. If you would like to get involved with an existing or developing CHF Chapter or would like more information on holding a fundraising or awareness event, please email Ellen Weiss at eweiss@childrensheartfoundation.org.

You can also join us at one of our upcoming Introductory Seminars. Each seminar is a one hour conference call where we learn more about your interest while explaining CHF's organization, financials, research, and volunteer opportunities. All upcoming seminars are on Wednesdays at 1 p.m. ET and 8 p.m. ET on the following dates:

August 13, September 17, October 15, November 12, and December 10.

We encourage all interested volunteers to contact Ellen Weiss at eweiss@childrensheartfoundation.org for more information. ♥



Arizona Chapter



arizona.childrensheartfoundation.org

The Arizona Chapter is getting ready for its two fall events. The first event is the 5th Annual Congenital Heart Walk, which will take place on November 9, 2014 at Tempe Diablo Stadium. This walk brings together families in their fight against congenital heart defects. The 2nd event is the 6th Annual “Valley of the Sun Golf Outing” at Grayhawk Golf Club on December 12, 2014. Anyone interested in this golf event, please contact Andy McKeague at a_mckeague@hotmail.com. The Arizona Chapter is currently rebuilding its board. Anyone interested in taking an active role in this chapter, please contact Ellen Weiss at eweiss@childrensheartfoundation.org ♥



Colorado Chapter



colorado.childrensheartfoundation.org

The CHF Colorado Chapter was impacted by the once-in-a-lifetime flood of 2013 and sadly we had to cancel our Congenital Heart Walk. However; the event itself, raised more than \$20,000 for us and our partners at the Adult Congenital Heart Foundation. We’re looking forward to a successful walk in September 2014.

Local families and our friends at Markely Motors and Wilbur’s Total Beverage rode in the Fort Collins, CO Saint Patrick’s Day parade for the second year in a row. They toughed out some more crazy Colorado weather, and thousands of spectators received CHF postcards with chapter information.

Finally, 2014 is a transitional year for our chapter. New members Derek and Kelly Patton are infusing our chapter with great new energy. President Amanda Adams will be handing the reigns over to our new president, Joy Gross, at the end of the year. We’re looking forward to more great news in 2015. ♥



Florida Chapter



florida.childrensheartfoundation.org

The Florida Chapter kicked off the year, with its 2nd Annual Congenital Heart Walk (CHW) in Jacksonville, FL. A month later, the 5th Annual CHW took place in Tampa. Both walks exceeded their goals. The Florida Chapter is currently in a rebuilding phase. Anyone interested in taking an active role in this chapter, please contact Ellen at chfl@childrensheartfoundation.org. ♥



Georgia Chapter



georgia.childrensheartfoundation.org

2013 was an amazing inaugural year for the Georgia chapter. Our premier event, Costume Ball 2013, was a great success. Sponsored by Colby Red Wine and hosted by Olympic Gold medalist Dwight Phillips, this event raised over \$8,000 for CHD research. We are looking forward to making the Costume Ball an annual event.

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Use the links below to Connect with CHF on Facebook, Twitter and/or YouTube. ♥



facebook.com/TheCHF



youtube.com/CHFnational



[@TheCHF](https://twitter.com/TheCHF)



and running a successful event.

Illinois' 3rd Annual Congenital Heart Walk in the Chicago area was held on June 7, 2014, at the Lincoln Park Rowing Lagoon in Chicago. There were two family-friendly routes: 1 mile or 3.1 miles (5K) through the park. We owe a ton of gratitude to Jaymi Griesmeyer and Jennifer Mowen for continuing this benefit in support of CHF.



Mia's Merry Monsters

We've met some awesome new friends this past year and as a result, we've teamed up with our local Adult Congenital Heart Association (ACHA) and planned our inaugural congenital heart walk. Sponsored by Emory, Children's Healthcare of Atlanta, Pediatric Cardiology Services, and WGST over 70 teams united in the fight for CHD, Saturday, May 10th at Stone Mountain Park in Stone Mountain, Georgia. Over \$70,000 was raised for our first walk!

The Sibley Heart Center's—Kids at Heart program has welcomed us with open arms as well. They have graciously allowed us to raise awareness and spread the word of our local CHF chapter at all of their events including "The Parenting Your Heart Child Conference".

We recently welcomed Kristen Vicknair as our Vice President. Kristen is full of positive energy and ideas, and we are very thankful for her service.

We appreciate all of our board members, community partners and volunteers! As our chapter continues to grow, we welcome volunteers and board members interested in supporting CHF's mission and commitment to CHD research and awareness. We look forward to an awesome year. For more information on our chapter visit: georgia.childrens-heartfoundation.org. ♥

The 15th Annual CHF Golf Outing was held on Monday, July 28, 2014, at Conway Farms Golf Club in Lake Forest. Participant's enjoyed a wonderful day of sunshine, golf, dinner and auctions on the site of the 2015 BMW Championship. Additionally, a Founder's Award was presented to Megan Van Pelt, Immediate Past President of our National Board by Betsy Peterson for her stellar performance for her years of involvement with CHF.

We're excited about an inaugural event for CHF IL in 2014 to be called the "Red Tie Ball". Please save the date of Saturday, November 15th, 2014 as it will be held in Cathedral Hall at the University Club of Chicago. Our first formal (black or red tie optional) event will include dinner and dancing, along with live and silent auctions. Our Co-Chairs Martha Hauber and Darlene Buenzow are always looking for sponsors, auction items or volunteers. Please contact Martha at martha@childrensheartfoundation.org or Darlene at darlene@childrensheartfoundation.org for more information on this event. More information on our chapter and events can be found on our website: <http://illinois.childrensheartfoundation.org>. ♥



Illinois Chapter

illinois.childrensheartfoundation.org



♥ The Illinois Chapter held its annual family benefit, *Hearts at Play*, on February 23rd, 2014 at Pinstripes in Northbrook, IL. It was a special evening to celebrate, enjoy and be inspired by the many CHD children in attendance. The event raised approximately \$10,000 for The Children's Heart Foundation. A special thank you to event chairs Martha Hauber and Darlene Buenzow.

CHF IL had its 2nd Chicago Urban Race – a scavenger hunt in the heart of Chicago on Saturday, April 26th. In just a few short hours, we were able to raise money for research and create awareness among a younger demographic. Kudos to Byron Yip and AnnaLisa Daniele for bringing the idea to us



Michigan Chapter

michigan.childrensheartfoundation.org



♥ The Michigan Chapter concluded 2013 with its most successful Congenital Heart Walk to date. Held every September in Clarkston, the 3rd Annual Congenital Heart Walk of SE Michigan united over 1,000 participants in Depot Park and raised \$108,000 in the fight against CHD. We thank the Walk Committee for their outstanding work; our many partners and sponsors for their support; our impassioned volunteers; and all the walkers who raised funds and came out to support the CHD community. Thank you for helping make 2013 a banner year!



To kick-off 2014, the Michigan Chapter launched the state's first "Change My Heart" fundraisers at local schools, raising over \$4,400 for CHD research. A special thank you to the families and students who organized and participated at Barnard and University Hills Elementary Schools and Southgate Anderson High School. We are also grateful to the companies who supported us during Heart Month, including ITC Holdings Corp for their "Casual for a Cause" program, which raised \$3,200, and Middlebelt KinderCare Learning Center's "Bowling & Healing Hearts" event, which raised \$2,208. And we extend our thanks to Whole Foods Markets in Oakland County for supporting CHF Michigan with their "One Dime at a Time" program during the months of April through June.

Looking ahead, the Chapter is planning its 5th Annual "Scoop for Hearts" fundraiser with co-sponsors Culver's of Clarkston and Oakland County Parks and Recreation. We also look forward to the 4th Annual Congenital Heart Walk of SE Michigan, which will take place on September 28, 2014. For more information, please visit <http://michigan.childrensheartfoundation.org>.

The Michigan Chapter is able to support the CHF mission thanks to the year-round service of our amazing board members, volunteers and family. We would like to welcome our new Advocacy Chair, Rachel Kain. The Michigan Chapter is always looking for new recruits—please contact us if you're interested in serving on the board or volunteering. We also thank our MAB members Dr. Jennifer Romano, Dr. Nancy Cutler and Dr. Carlen Fifer, as well as Mott Children's Hospital, Children's Hospital of Michigan and Beaumont Hospitals for their support. ♥

Plans are underway for our 2014 walk on August 17th. We've already secured \$5,000 in sponsorships—thank you St. Louis Children's Hospital! We have moved the walk to Forest Park in order that we have access to a more expansive space to hold the growth that we've experienced in the number of walk participants. It truly will be a fun event!

Before we get to the walk, however, we had a number of events, including a golf tournament on June 7th and our 1st Annual 5k race on June 20th. We also just held our 4th Annual Trivia Night for Hearts on April 12, 2014, raising close to \$20,000 for congenital heart research. Over 500 people participated in an evening filled with laughter, music, door prizes, and fabulous auction items. The generosity of St. Louis Children's Hospital, ITC for the Audio/Visual set up, Kräftig, Colby Red Wine, McAlister's Deli, and Pretzel Boys, along with an impressive list of auction items added to our success. This event was made possible by the strategic planning of a dedicated group of volunteers and Board members.



Trivia Night

Another huge success from 2013 was the 1st Annual Ollie Hinkle I ♥ Food and Wine Benefit, which raised over \$35,000. The benefit was hosted by our Board Members Jenn and Mark Hinkle in honor of their fallen heart warrior, Ollie. It featured food, wine, and beer from some of St. Louis' most renowned establishments. We're already looking forward to this event again in November 2014.

For more information about the Missouri Chapter and our events, please visit missouri.childrensheartfoundation.org, follow us on Facebook, or follow us on Twitter @TheCHF_MO. ♥



The Missouri Chapter continues to grow! For 2014, we've added new faces to our Board, new events, and are implementing a strategic initiative to expand our presence into Kansas City and Springfield, Missouri. So, these are exciting times!

Do you receive our new monthly ENewsletters?

If you are not currently receiving our newsletters with the latest information on CHF, please sign up at: <http://weblink.donorperfect.com/signupforenewsletter>. We would love to connect with you electronically.



New York Chapter

newyork.childrensheartfoundation.org



Ohio Chapter

ohio.childrensheartfoundation.org



Bittersweet is the word to describe what's been going on in the New York Chapter. The 2014 New Year started off with the loss of a newborn named Henry. There's no way around it... loss of a heart angel affects everyone in the chapter in some way. But we persevered and had our famous Cardio Challenge for the third year in a row. It was a huge success and Henry's parents managed to meet with other families that they could share their experiences.



Cardo Challenge

We were beneficiary of the following fundraisers: The Work of Heart Preschool in Huntington, the Agora Gallery in Manhattan, Barbara Skoblow Leivent's State of the Heart Art Show and Brandon Buie's Zumbathon. Then in March, our chapter suffered a serious blow with the loss of another heart angel, Brandon. His mom's words were "My son flew away last night". The CHFNY Facebook page overflowed with loving support for his family and again... the chapter pulled together to fundraise with a NY Yankees game and the Congenital Heart Walk—LI in May. We'll be looking for more events toward the end of the year but the big one will be the Congenital Heart Walk—NYC in November.

Like all of our children, the New York Chapter is going through a growth spurt. Keep a lookout on our website, facebook page and eblasts for a CHD Summit, perhaps in the late summer or early fall, where we'll discuss the direction of our chapter and ways you can become more involved. There will be board positions, committee positions and volunteer opportunities available where you can make a difference and save a life, one child at a time.

Our chapter is resilient... our New York families, friends and supporters know the importance of the mission and we are all determined to continue funding vital chd research and spread awareness. ♥

Looking back, 2013 was a fun filled, exciting and successful year. Once again we participated in events of the Davis Heart and Lung Research Institute at the Ohio State University. We were invited to attend the Hospitality House in Murfield Village for the Memorial Tournament and Presidents Cup. Two rival volleyball teams, Madison Plains Middle School and London Middle School joined forces to raise money on behalf of the CHF. Each team sold t-shirts, raffle tickets and held a silent auction at their match to donate over \$3100.00. CHD survivor Kennedy Clifton played for the home team of Madison Plains. The Hills Market in Columbus put our President Tammy Thomas and her husband to work as servers during their charity happy hour night where proceeds benefited CHF.



Madison Plains Middle School and London Middle School joined forces to raise money on behalf of the CHF.

2014 promises to be a year of change for our chapter. As our long time President, Tammy Thomas accepted the nomination of and position of National CHF President. We appreciate all of Tammy's hard work and although we will miss having her at the reins here in Ohio, we are extremely excited to get to work alongside her as she begins this new journey with CHF. Congratulations Tammy! Bobbie Sue Jacobs is now our President and we welcomed new board member Kristin Goessl as our new Vice President!

With all the changes, things here in Ohio haven't slowed down much. So far this year, we had the opportunity to participate in the Ross Heart Hospital 5K in February. In March we were selected as one of the charities to benefit from the proceeds of the Columbus Auto Dealers Auto Show Charity Gala. The Memorial Tournament, The Hills Market and the Congenital Heart Walks are all on our agenda to participate in this year along with a Crew Golf Tournament. ♥



Oregon Chapter

oregon.childrensheartfoundation.org



2014 has brought some excitement to the Oregon Chapter! It is our 10th year as a chapter of CHF. We are celebrating!

To kick off our year, we hosted Vinolympics in February at Davis Street Tavern in downtown Portland. 100 people competed in wine-focused games, like wine and food pairings and blind tasting.

Throughout the year, to help celebrate our anniversary, we are asking our friends and supporters to host their own private events to raise money for research. This is everyone's opportunity to lend a hand: host a dinner party, have a lemonade stand, or have friends and family sponsor you or your child on a run. We have a great online tool to make publicizing and collecting money for the event easy and fun! Take a look at the link below.

<http://oregon.childrensheartfoundation.org/10-year-fundraising-your-own-event/>

Again this year CHF-OR along with Bike Gallery will be hosting two wine rides in beautiful Oregon wine country. The second ride will be held on September 21 at Vista Ridge Winery. The events will consist of a supported bike ride through rolling hills that begins and ends at the wineries and finishes with a delicious catered lunch, and wine! These are truly great events and we look forward to seeing everyone again this summer.

Lion Heart was held again at the Portland Children's Museum on June 7th, and it was another great year of reconnecting with heart families and our community.

Our 10th year celebration will culminate in February 2015, with Vinolympics, with a Roar! This larger scale event will cap off our busy year. Stay tuned for more details, but mark your calendars now! ♥



Pennsylvania Chapter

pennsylvania.childrensheartfoundation.org

♥ Our chapter continues to prosper with new volunteers and fundraisers across the state! We were thrilled to add Melissa Torrissi to our board. Melissa is heart mom

to two-year old Lux and will be hosting her second "Keep the Beat" fundraiser this September in Philadelphia, which benefits our chapter. Welcome, Melissa!

Last July, our chapter president, Lori Jones, was awarded the Philadelphia Eagles Community Quarterback award in a ceremony at the Eagles training facility. Sponsored by Teva Pharmaceuticals, The Children's Heart Foundation was awarded a check for \$50,000! Thank you, Eagles & Teva!



Please save the date for a special chapter event that you won't want to miss. Our chapter is hosting a formal Heart Gala on February 6, 2015 at the Racquet Club in Philadelphia. We hope to raise much needed life-saving funds and celebrate our chapter!

We held three walks in Pennsylvania this year. The 1st walk of the year was held in Hershey on May 3, raising over \$35,000. The Philadelphia/Delaware Valley walk took place on June 8th. This was the 5th year for this walk, and exceeded their goal by raising over \$90,000. The 3rd walk was held on June 29th in Pittsburgh at the Boathouse at North Park, raising over \$80,000. This was Pittsburgh's 3rd walk. Over \$200,000 was raised for all three walks.

OTHER SUCCESSFUL PA EVENTS: Remember an Angel/Swing for a Survivor Golf Outing was another huge success, raising over \$33,000 for CHF in memory of AJ Kahler, son of PA Board member Denise Kahler. To date this event has raised over \$100,000. This year will mark the 6th Annual Golf Outing in memory of AJ Kahler. The golf outing will take place on August 10, 2014.

In September, the Annual Philly Hearts event proved once again successful as friends of CHF gathered at the Merion Tribute House in a family-fun party. The Loving Heart Award was given to Ady Dorsett. In honor of her son who lost his battle with CHD, Ady founded Hayden's Heart, an organization doing amazing things for heart families. The Smart Heart Award was given to Dr. Jack Rychik who is the Director of the Single Ventricle Survivorship Program and the Director of the Fetal Heart Program at CHOP. Both winners were more than deserving of these awards.

We are continuing to grow our family of volunteers around the state and are anxious to see what this year brings in our fight against CHD! ♥



Texas Chapter

texas.childrensheartfoundation.org



The Texas Chapter celebrated their first birthday in November 2013. Looking back, I can say it's been a terrific year. We've put in place strong Medical and Chapter Boards to help make Texas a very strong chapter. In our first year, along with laying some groundwork for growth, we raised over \$50,000 to help fund CHD Research! Our Board of Directors includes Sarah Berg, President; Anna Jaworski, Vice President; Heather Roell Oshman, Treasurer; Christie Salazar, Secretary; Ashley Forbes, Director of Fundraising; Erin Cord, Volunteer Coordinator; Katie Cataldo, Junior Board President and Carl Wolford, general board member.

We kicked off our *Hearts for Hearts Campaign*, a paper heart icon to spread CHD Awareness. Volunteers served a meal at two *Ronald McDonald Houses* as a way to give back and let families know about The Children's Heart Foundation – Texas Chapter.

In DFW: Volunteer Jennifer Reed put on *Olivia's 2nd Annual CHD Week Balloon Release* and volunteered at The Gallery at MIDTOWN's *Little Art for Little Hearts* art show.

In Central Texas: Around 30 volunteers helped with a runner gear check and thirteen runners (including Sarah Berg, Chapter President) ran the *Austin Marathon & Half Marathon*. Thanks to volunteer Lani DeGuire, we were the beneficiaries of *Hops for Hearts*, a coffee and beer afternoon.

In the Rio Grande Valley: Former Board Member, Heather Silva, put on *The Heart Games: Calling All Super Heroes* where kids got to dress up like and meet superheroes.

In March we had our *4th Annual Central Texas Congenital Heart Walk*. This was our biggest year yet with 60 teams and over \$92,000 raised! We participated in *Amplify Austin* "Day of Giving" and The Rancho Viejo Golf Club put their *First Annual Charity Golf Tournament* where CHF TX was one of the featured charities!



On the horizon, we have baseball games, hockey games, skydiving, kids fun days, Congenital Heart Walks and more.

Some upcoming events:

September 2014 "Spin A Thon" in Austin

February 10, 2015 CHF TX Awards Ceremony/Cocktail Reception in Austin

February 2015 "Hearts for Hearts Paper Icon Campaign"

February 15, 2015 Austin Marathon

March 7, 2015 Congenital Heart Walk - Central Texas in Round Rock

March 2015 Amplify Austin

April/May 2015 The "3rd Annual SJRA Jump for Charity" in Rosharon

May 2015 CHD Night with The Round Rock Express in Round Rock

For details about all of our events visit our website: <http://texas.childrensheartfoundation.org>

As Chapter President, I am grateful and humbled by the volunteers on the Board of Directors and all of the volunteers that make our events prosperous. Without your help, we can't be successful.

We are looking for volunteers like you to help with our annual events and to host new ones, if you have ideas or just want to be a helping hand please contact us at CHFTX@childrensheartfoundation.org for more information. We can't be successful without volunteers and donors like you. Texas is going to be the biggest and best chapter. That's just what we do here. Will you join us? ♥



Virginia Chapter

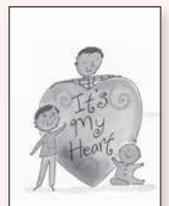
virginia.childrensheartfoundation.org



The Virginia Chapter has gone through a rebuilding stage. They have new board members and are looking forward to continuing with the Congenital Heart Walks in 2015. Anyone interested in being part of this board, please contact Candice at chfva@childrensheartfoundation.org. ♥

"It's My Heart Book"

The second edition of "It's My Heart" is now available two ways. You can order a paperback version or purchase an e-book by visiting www.childrensheartfoundation.org/publications/its-my-heart. Shipping charges will occur for orders of three copies or more and the e-book can be purchased for \$9.99. ♥





Upcoming Events



Please join us at the events listed below.

August 10, 2014 – Elizabeth PA

The 6th Annual “Remember an Angel, Swing for a Survivor” Golf Tournament in memory of AJ Kahler will be held on Sunday, August 10, 2014. For more information, contact Denise Kahler: littlegepk@aol.com

August 10, 2014 – Whispering Springs, WI

The 4th Annual Kuhnz Family CHF Golf Outing will be held on Sunday, August 10, 2014 at the Whispering Springs Golf Course in Fond du Lac, WI. For more information contact Daniel Kuhnz at drkuhnz@gmail.com

August 17, 2014 – Forest Park, MO

The Congenital Heart Walk for the Greater St. Louis area will take place on Sunday, August 17, 2014 at Forest Park, Upper Muny Lot. Registration starts at 9:00 a.m.

August 23, 2014 – Memphis, TN

Grant’s Gala will be held Saturday, August 23, 2014 at The Teton Trek in the Memphis Zoo. Grant’s Gala was created to honor the memory of Grant Michael Goughnour who passed away suddenly 17 days after his birth. For more information on Grants Gala, visit: www.grantsgala.com

September 13, 2014 – Aurora, CO

The Congenital Heart Walk for the Rocky Mountain Area will take place on Saturday, September 13, 2014 at General’s Park. Registration begins at 8:30 a.m.

September 13, 2014 – Portland, OR

The Congenital Heart Walk for the Portland Metro area will take place on Saturday September 13, 2014 at Laurelhurst Park. Registration begins at 9:00 a.m.

September 13, 2014 – Little Rock, AK

The Congenital Heart Walk for the Little Rock area will take place on Saturday September 13, 2014 at Two Rivers Park. Registration begins at 9:00 a.m.

September 15, 2014 – Bolton, MA

The 5th Annual Jasper Johnson Golf Outing will be held at International Golf Club on Monday, September 15, 2014. Starting time: 12:00 p.m.. For more information visit www.jaspersheart.org.

September 20, 2014 – Cleveland, OH

The Congenital Heart Walk for the Northern Ohio area will take place on Saturday, September 20, 2014 at Wade Oval, University Circle. Registration begins at 9:30 a.m.

September 20, 2014 – Plymouth, MN

The Congenital Heart Walk for the Twin Cities area will take place on Saturday, September 20, 2014 at Clifton French Regional Park. Registration begins at 9:00 a.m.

September 21, 2014 – Vista Hills Winery, OR

Rides are approximately 30 miles of rolling terrain. With activities such as bike poker, these intimate rides are all about fun and merriment and there is no shame in catching the “sag wagon” up an occasional hill! 100% of the profits will be donated to the Oregon Chapter of The Children’s Heart Foundation. Register now at: <http://www.bikegallery.com/about/wine-rides-pg75.htm>

September 28, 2014 – Clarkston, MI

The Congenital Heart Walk for the Southeastern Michigan area will take place on Sunday, September 28, 2014 at Depot Park. Registration begins at 9:00 a.m.

October 11, 2014 – Cincinnati, OH

The Congenital Heart Walk for the Greater Cincinnati area will take place on October 11, 2014 at Eden Park, Mirror Lake. Registration begins at 8:30 a.m.

October 12, 2014 – Westerville, OH

The Congenital Heart Walk for the Central Ohio Area will take place on Sunday, October 12, 2014 at Westerville Sports Complex. Registration begins at 8:00 a.m.

November 9, 2014 – St. Louis, MO

Ollie Hinkle Food & Wine Benefit will take place at The Cheshire St. Louis from 2:00 p.m. – 5:00 p.m. For more information, please visit: Missouri.childrens-heartfoundation.org

November 9, 2014 – Tempe, AZ

The Congenital Heart Walk for the Phoenix Metro area will take place on Sunday, November 9, 2014 at Tempe Diablo Stadium. Registration begins at 9:00 a.m.

November 15 – Chicago, IL

Red Tie Ball is The Children’s Heart Foundation of Illinois first ever Chicago Gala. This will be held in Cathedral Hall at the University Club of Chicago. This event will honor Chicago’s Leaders in Children’s Heart Care.

December 12, 2014 – Scottsdale, AZ

The 6th Annual Valley of the Sun Golf outing will take place at the Grayhawk Golf Club. For more information, please contact Any McKeague at amckeague@hotmail.com

For more information on all the Congenital Heart Walks, please visit: www.congenitalheartwalk.org ♥

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The Children's Heart Foundation™

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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 more than \$6.3 million through 58 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 ♥