

## Coming Events and Reminders

Mark your calendars for the following events in 2003:

- ♥ Hershey Hearts Picnic Saturday, July 19, 2003 at Hoffer Park in Middletown with entertainment by Steven Courtney.
- ♥ Reading Phillies Game on Sunday, August 24, 2003.
- ♥ Hershey Hearts Support Group Meeting Saturday, October 18, 2003, from 1:00 - 3:00 PM.
- ♥ Board Meetings are held the third Monday of every month.
- ♥ If you have any questions, suggestions, or entries for the newsletter please send them to Hershey Hearts, P.O. Box 163, Hershey, PA 17033-0163.
- ♥ If you know of a family that would like to receive this newsletter or would like to be removed from the mailing list, please call 1-800-864-2349, mailbox #3388.
- ♥ If you are moving or have an address change, please call Hershey Hearts at 1-800-864-2349, mailbox #3388 to give the correct address.



## Directions to the Hershey Hearts Picnic

Saturday July 19, 2003 — 11:00 AM - 4:00 PM

### Hoffer Park in Middletown, PA

#### From Harrisburg

Take 322 East toward Hershey to the "Hummelstown / Middletown" Exit  
At the traffic light off the exit, turn right onto Middletown Road  
Follow Middletown Road for about 5 miles into Middletown  
Use the "\*\*\*\*\*Inside Middletown Boro\*\*\*\*\*" directions

#### From York

Take 83 North to the PA Turnpike East (76) toward Philadelphia  
Continue on the Turnpike to Exit 19 - Harrisburg east  
Take 283 East - Exit 2E toward Lancaster  
Get off at the "Middletown / Hummelstown" Exit  
Bare right off the exit, follow signs toward Middletown  
Follow Middletown Road for about 1 miles into Middletown Boro  
Use the "\*\*\*\*\*Inside Middletown Boro\*\*\*\*\*" directions

#### From Lancaster

Take 283 West to the "Middletown / Hummelstown" Exit  
At the stop sign off the exit, turn left toward Middletown  
Follow Middletown Road for about 1 miles into Middletown Boro  
Use the "\*\*\*\*\*Inside Middletown Boro\*\*\*\*\*" directions

#### From Hershey Medical Center

Take 322 West toward Harrisburg to the "Middletown / Hummelstown" Exit  
At the stop sign off the exit, turn left toward Middletown  
At the first traffic light, turn right, following signs toward Middletown  
At the next traffic light, turn left onto Middletown Road  
Follow Middletown Road for about 5 miles into Middletown Boro

#### \*\*\*\*\*Inside Middletown Boro\*\*\*\*\*

Middletown Road becomes Vine Street inside Middletown Boro  
Follow Vine Street until the traffic light (about 1.5 miles)  
At the traffic light, turn right onto Main street (Route 230)  
Turn left at the next street "NORTH RACE STREET"  
(J&J Pizza Family Restaurant is on the south / west corner)  
Follow North Race Street until the fifth stop sign.  
Turn left at the fifth stop sign into Hoffer Park

# Hershey Hearts Newsletter



Hershey Hearts is committed to supporting, helping and educating families of children with congenital heart disease. This is achieved through meetings, newsletters and a visitation program. Our aim is to strengthen families during their long journey from despair to hope.

Vol. 7 Number 2

June 2003

## Hershey Hearts Picnic

By Paul Sipe

The 7th annual **Hershey Hearts Picnic** will be held on **Saturday, July 19th from 11:00 a.m. until 4:00 p.m.** The picnic will be at Hoffer Park in Middletown. Please use the directions included. Please bring a covered dish and/or a dessert. Bar-b-que, hot dogs, silverware, plates, napkins, cups, and drinks will be provided. We will eat at 12:00 noon.

This year's activities will include clowns, Tony the Tiger and a special appearance by singer, songwriter and funny guy "**Steven Courtney**" at 1:00 p.m. After the concert we will have a brief meeting and announce the winner our special raffle.

The picnic shelter is enclosed, therefore the picnic will be held rain or shine. The picnic shelter is handicap accessible (Handicap parking at the shelter with macadam walkway up to the shelter). Everyone is welcome! Please come and join in on the fun and fellowship! **WE HOPE TO SEE YOU THERE !!!**

## A Meeting of the Hearts

By Rachel Hilker

It was a cool Saturday afternoon when I heard the sound of children laughing. I made my way down some old steps within the Fishburn United Methodist Church. There I found an energetic youth group awaiting the arrival of Hershey Hearts children. They were prepared to show them a good time while the adults got together to chat. Their smiles lit up the room. Darn, I wish I had brought my son after all. He would have enjoyed playing with the other children.

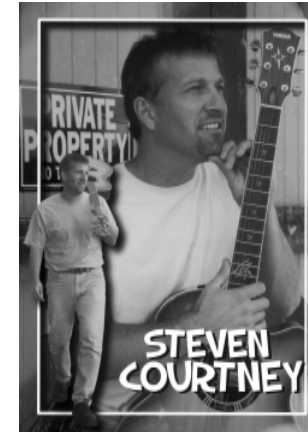
I had never been to this church before, nor had I been to a support group meeting before, but I felt at home when I was greeted by familiar faces and some smiling new ones. Maybe the words "support group meeting" put an idea in my head about what this gathering would be like, or maybe it was just my nervousness about sharing feelings with people that I have not known for very long, but as I was driving out to the meeting, I got butterflies about what to expect. Was it going to be sad? Would hearing about the pain that each

family has been through make me relive too many scary memories? I wasn't sure, but I knew that talking to others about their children and my own would help heal some of those feelings.

Our faithful president, Paul Sipe, started the meeting out. He talked about the empty chair, and how it represented a family out there who has not yet been touched by congenital heart disease. I thought to myself, "Wouldn't it be great if we could find that family now and let them know that we are here to help them out when it is their time to fill that seat? I'm sure you can remember back in the days when you were just going about your life and suddenly you were hit with that pain in your stomach as a doctor tells you that something is wrong with your child's heart. Your own heart sinks into the pit of your stomach, and it is all you can do to keep the tears from coming. What if at that moment a group of Hershey Hearts families came rushing through the door and hugged you? Wouldn't it have felt nice to know that there were so many loving parents nearby who had been there before and were willing to help you feel less alone?" Well, that's pretty much impossible to do at that pivotal moment, but that doesn't mean it's too late to do now. I looked around the room quickly and wondered if someone needed that hug. Then I thought, "Uh-oh. This is the part where it gets sad, right?" To my surprise, nobody looked sad. Nobody looked like they needed a hug.

So where is the family that needs a hug? Why aren't they here? If they are sad, why can't they just come out to a meeting and collect their hugs? Isn't that why we are here? The meeting continued on with some current news and upcoming events. Still I looked around and nobody was crying yet. Then the pizza arrived. It sure smelled good. Would anybody want to eat now at a time when we were supposed to be sitting around reliving painful memories?

Everyone got up and helped themselves to good food and soft drinks. I timidly picked up a plate and served myself some lunch. Soon everyone was chatting together around the tables of food, and I quietly just listened in here and there to try to fit in somewhere. It seemed to come so naturally that others were sharing funny stories about what their kids had done the other day at school, or how they were playing sports this year, or simply just what was new with them. Soon a child or two wandered into the room, and we got to hear about what they were doing these days. They would run back out with a slice of pizza to join in on the fun upstairs. The



longer I stayed, the more I felt just like I was at a family get together. We were all so different, but yet we had so much in common. I met a friendly husband and wife who had just come over from the medical center after doing visitation. They shared how some of the patients were doing there today. It was nice to hear their own story too, and how they felt after seeing the kids in the PICU and NICU. Healing was happening right before my eyes without anybody really getting deep into painful memories. So much was shared without any formality whatsoever. Pride, hope, concern, love, faith — it all filled the room without a tear in sight!

I left there that day feeling very alive. I made some new friends. I caught up with a couple more familiar ones. I saw the smiles on the children that have braved surgeries and testing, but still knew how to be a kid. I felt hopeful about my two little heart patients too! What a great feeling to be part of a group that is filled with so many caring people and inspiring children. I had nothing to be scared of at all by attending this meeting, and I happily look forward to the next one. My only sadness came from looking around the room and seeing that there was plenty of room for more Hershey Hearts families, but they just weren't there. That meant there were that many more people that I didn't get a chance to meet, and that many more people that didn't get to experience what I did that day, and that many more children that didn't get to play with other heart patients and have fun. I hope that maybe next time their busy schedules will allow them to be able to join us for a few hours of friendship and good food. Then maybe they can feel what it is like to get a big hug from the group without having to feel sad first. Hey, the picnic is coming! It's another wonderful opportunity for you to get that hug, just in case you missed it at the last meeting. There will be more food, more smiling faces, and more children to play and laugh with! I hope we get to see you there!

### President's Message

By Paul Sipe

It is the time of year for the annual Hershey Hearts picnic and that means that it is also the time for election of officers. This year we will be holding elections for the **Vice President, Treasurer and Member-at-Large** (odd years). We are also looking for several individuals to fill the vacant **Member-at-Large** (even years) and **Communication Chair**. The Member-at-Large is an elected position with a term of two years. The duties of this position include attending board meetings and acting as the voice for the general membership. The Communication Chair is appointed by the Board and is responsible for managing the Hershey Hearts voice mail and web page. My hope is that we can find several individuals to volunteer a couple of hours a month to help fill these positions. With the help of volunteers Hershey Hearts can continue to fulfill its mission statement of supporting, helping and educating families of children with congenital heart disease. If anyone is interested in any of these positions please feel free to contact me personally.

### Reading Phillies

By Paul Sipe

Hershey Hearts will once again be sponsoring a day at the Reading Phillies on **Sunday, August 24, 2003**. There will be a picnic buffet from 12:00 p.m. until 2:00 p.m. that will feature Bar-b-que, hot dogs, chicken, pasta and potato salad, chips, pretzels, iced tea, lemonade and soda. The game begins at 1:05 p.m. This event is sponsored by Hershey Hearts and is free to support group members. Children under the age of four do not need a ticket. There are a limited number of tickets available. If you have any questions, or would like to reserve tickets, please contact Judy Byrne. Tickets will be distributed at the picnic, but can be mailed if you are unable to attend the picnic. In the event of inclement weather, call (800) 864-2349 mailbox #3388 for more information.



### Treasurer's Report

By Jill Hester

In the last newsletter, it was reported that the total balance in both our savings and checking accounts as of December 31, 2002 was \$15,545.49. For the five months between January and May 2003, our receipts totaled \$7,670.89. The amount of \$4,209.55 was from our Basket Bingo Fundraiser (sponsors and ticket sales), \$30.00 designated for the "For Hearts" Fund, \$120.00 in Survival Kit Sponsors, \$2,711.38 in various cash donations, and \$575.00 to sponsor prizes for the Heart Beat Auction. The savings account earned \$24.96 in interest.

Disbursements totaled \$7,189.53 from January through May. They included; \$799.81 in Basket Bingo expenses, \$2,340.81 for the Heart Beat Auction (to purchase prizes), \$625.68 for the February newsletter printing and mailing, \$443.80 in membership meeting expenses (March support group meeting), \$217.76 for the Family Meal Program, \$801.48 for Survival Kits, \$160.19 in miscellaneous expenses, and \$1,800.00 for the Reading Phillies outing coming up in August (see related newsletter article).

The total balance in both our savings and checking accounts as of May 31, 2003 is **\$16,026.85**.

Thank you to Terisa Johnson for her dedication in running the Basket Bingo Fundraiser, and to all of those who supported it.

As always, if anyone would like to make a donation, or contact us for any reason, our mailing address is:

**Hershey Hearts  
P.O. Box 163  
Hershey, PA 17033-0163**

### 4th Annual Basket Bingo

By Terisa Johnson

Hershey Hearts held its 4th Annual Basket Bingo event on April 27<sup>th</sup> at the Loyal Moose Lodge in York. We had a successful turnout. The baskets were filled with extra surprises, and participants were also able to join in on raffles and special games. Everyone had a great time. I wanted to say an extra "thank you" to Colleen Fiddler for letting us use their facility, and also to Denny for calling his first bingo.

The people I want to thank are: Chris Yohe, Paul Sipe, Dawn Snyder, Jill & Jim Hester, Michelle Frey, Jackie Kohr, Wendy Nafziger, Gail Garrett, Tammy Woods, Memo and Lora Raineri, Stacie Perkins-Smith, Rachel Hilker, Sharon Winters, Samantha Winters, Doris Fry, Doug, Camie, Joy and Husband, Heather Wallick, Jan Miller, and my husband Eric. Without these special people, this wouldn't have been another great success. I want to also thank all the businesses and individuals who donated prizes or gift certificates.



"Just a few of the lovely baskets that were up for grabs"



"Terisa Johnson, taking a quick last minute break to ensure everything is ready to go."

### Editor's note:

I believe that it would be agreed upon that a very special "thank you" should be extended to Terisa for the many hours she devoted to making the basket bingo possible. The sound of everyone cheering and laughing within the Moose Lodge was a definite affirmation that the bingo was a great success. It was also a great opportunity to meet or reunite with other Hershey Hearts members. Thank you, again, Terisa!

### Helpful Pre-Surgery Tips

By Rachel Hilker

If you received the last newsletter, then you may recall an article that featured some helpful advice from Myra Popernack, RN, CCRN, who is a key leader of the nursing staff in the PICU at Hershey Medical Center. She took the time to share with us a few strategies to help make a child's stay in the PICU a little more comfortable for everybody. Being as helpful as she is, she offered a few more suggestions that we would like to share with you now.

In preparation for your child's open-heart surgery, there are a couple of techniques you can help them practice at home. If your child is old enough, they can try blowing bubbles and blowing through a straw into a glass of water. Let them know that while this doesn't hurt now, it may be a little painful to perform after their surgery. During recovery, deep breathing and coughing play an important role in expanding the lungs after surgery. One way to help reduce the pain at the surgical site is to hold a pillow, doll, or favorite stuffed friend tightly while performing these exercises. Myra suggests, "Practice hugging a favorite stuffed animal, (hopefully a nice sized one in relation to the chest size) and coughing after taking three deep breaths in and not letting them out. It automatically makes you cough. Try it!"

If you have a child that is facing an upcoming surgery, we hope that these ideas will help make the experience a little more comfortable. As always, we wish your family all the best on your journey towards a happier, healthier heart!

### Visitation Committee

By Kimberly Yearick

The visitation committee is always asking for more individuals who are willing to take time to share in the cardiology journey with those who are heart patients and families at Hershey Medical Center. Each visitor is scheduled for approximately two or three visits per year. The visits are appreciated. Will you please consider joining? For more information on the program and *becoming a volunteer*, please contact Kimberly Yearick or Sherry Noel. Thank you.

## WE NEED YOUR HELP!

**Please consider volunteering for the following positions in Hershey Hearts:**

- ♥ Member -at- Large
- ♥ Picnic Chairperson
- ♥ Communication Chairperson

## **My Name is Lindsey Patricia Edwards**

*As lovingly told by her father, Ken Edwards*

The doctors said I was going to come into the world on November 7, 1999, but that was not my plan. It was warm and comfy in my mommy's belly, and I was going to stay in there as long as possible. I knew something was up on Tuesday morning. I think my mommy had enough of me kicking her and carrying me around in her belly. She must have wanted me out more than I wanted to stay in because at 9:56 p.m. on Tuesday, November 16, 1999, I was out and in my daddy's arms. I came into the world 20 inches long, and weighing seven pounds. My mom's name is Wendy Sue, and my dad's name is B. Kenneth, and my name is Lindsey Patricia Edwards.



**Lindsey Edwards  
in September of 2002**

I hung out in my dad's arms for a little while before I went on to my mommy. They were trying to get me to eat from my mommy's breast. Yeah right, you try and eat for the first time after being pushed, pulled, smacked, and tubes being stuck in you. Then the nice nurse took me away to another room where they wiped me down and cleaned me up. Something must not have been quite right because the doctors and nurses were giving me a lot of attention and looking very concerned. The next thing I knew, I was in a room they called the ICU, and they were hooking me up to all kinds of wires and tubes. They were real worried about my oxygen sats. I could hear the pediatrician and cardiologist talking about something called pulmonary stenosis. They also said something about having a hole in my heart. All this time I am wondering where my mommy and daddy were.

Mommy, Daddy, and Grammy Krueger came into my room. They were not looking too good. Their eyes were leaking all over me. I was glad to see them, but they were getting me all wet. They were talking about the helicopter ride I was going to take to Hershey Medical Center. They said that the doctors are top notch, and they were going to take good care of me. A lady came into the room. She was very nice, and she comforted Mommy, Daddy, and Grammy. They all held hands and said a prayer for me. It made me feel much better.

All of a sudden these people all dressed in blue came into my room and made my mommy and daddy move away from me. The one man was not very nice to me. He grabbed my head and started shoving a long tube down my throat. Then he hooked a pump up to the hose. I did not have to breathe on my own anymore because the machine was doing

it for me. What is this? No, no more tubes. There are too many tubes in me now. I did not want them to put anything more on me or in me. I did not like it so much that I reached down and ripped the one right out of my belly button. I must have done a bad thing because everyone started rushing around trying to put that thing back inside me. The doctor from Hershey was getting frustrated because everything she needed to fix me, including a nurse, was not in the ICU. She did a great job fixing me up and getting me ready for my helicopter ride. As they were putting me in a box, I looked over and saw Mommy and Grammy hanging on to my daddy. They all looked very sad and scared. The last thing I remember from Pocono Medical Center is my mommy and daddy holding my hand and telling me that Daddy would see me soon in Hershey. Oh yeah, I also remember those cool yellow ear cups they put on me for the ride.

Where is my mommy? Where is my daddy? Where am I? There were many strange people and strange things all around me. People were poking me, sticking me, and talking about me. I heard something about an echocardiogram. The doctor said that I had two holes in my heart to go along with the pulmonary stenosis. I think he called it Tetralogy of Fallot.

There is my daddy! He does not look so good. He came in and sat with me for what seemed like hours. The doctors and nurses told him all about the things they were doing to me while he was on his way to be with me. He left for a while and returned with a woman whose eyes were leaking. This was my Mommom. She held my hand and sat with me for quite a while. They left when I was sleeping. I could not wait until they got back.

When I woke up I was in some kind of a bubble. I could feel warm moist air swirling all around me. My daddy, Mommom, and another lady were by my side. Who is this other lady? I know her. It's MOMMY!!! I sure did miss her! Mommy did not look so good. I wanted her to touch me, hold my hand, something. Why didn't she try to hold me? Everyone just sat around me and talked for some time, then left.

When my mommy and daddy came back, my bubble was gone, and I had tubes in my nose that helped me breathe. The nurse bundled me up and gave me to my mommy. She hugged and kissed me, then put this thing with warm stuff in it into my mouth. It was pretty good, and everyone was glad that it was going into my belly. After that, Mommy gave me to my daddy, and he started smacking me on my back. I did not know what was going on until I let out a big burp. That is what everyone called it, and I could not have any more warm stuff until I did it. When all my eating and burping was over, I settled into Daddy's arms and went to sleep. I was hooked. I knew everything was going to be okay now because my mommy and daddy were here.

\*\*This story was written while Lindsey was in the hospital. Wendy Edwards currently works for the Children's

Heart Center of Northeast Pennsylvania with Dr. Hansrote, who was the cardiologist that referred Lindsey to Hershey. Lindsey was able to return home with her family when she was two and a half weeks old. She is now three years old. Wendy mentions, "She is your usual pre-schooler and wears us out daily. She will need more surgery down the road, but we are confident the Hershey staff will take the best care of her. Thank you for the Hershey Heart program, and we enjoy our time with other families during visitation."

## **Survival Kits "Thank You"**

*By Jill Hester*

I would like to extend an extra thank you to those who have sponsored Survival Kits by making a donation to Hershey Hearts, or by donating Wish List items for the tote bags. To date, we have had 24 Survival Kits sponsored, and have received many bags of Wish List items. An extra special thank you also goes to the Saint Joan of Arc School in Hershey, PA for making the Survival Kits their Catholic Schools Week Service Project this past spring and filling 25 totes, with items left over to help fill even more bags!



The Survival Kits are an on-going project that continues to be well received and appreciated by the families that receive them while their child is being treated at Hershey Medical Center. They are an important way for Hershey Hearts to support and help families of children with heart disease. You can sponsor a Survival Kit and dedicate it to anyone's honor for a \$20.00 donation to Hershey Hearts. Your donation will be acknowledged with a post card recognizing the donation, which is placed in the Survival Kit tote bag.

### **Our Wish List items include the following:**

- \* **60 minute phone cards**
- \* **Individually wrapped snacks**
- \* **Mints or hard candy**
- \* **Toothbrushes and toothpaste**
- \* **Purse-size packs of tissues**
- \* **Travel or personal size toiletries**

If you can donate any of these items, or have any questions about the Survival Kit program, please contact me by calling the Hershey Hearts voice mail number at **1-800-864-2349 mailbox #3388**.

## **Summer Safety Tips for Children with Heart Problems**

Summer is here, so just a few tips to make your summer safe and enjoyable.

Children with heart rhythm problems and pacemakers:

-Avoid spinning amusement rides and rides that have sudden drop-off like the flume or roller coasters. These can aggravate the rhythm problem.

-Children with pacemakers should avoid contact sports where the pacemaker site could be injured - Example: goalie in soccer, catcher in baseball, diving from high boards or "belly-flopping". Injury to the pacemaker site could cause fracture of the pacemaker leads. Also, rides that have safety belts that may press heavily over the pacer site and cause injury should be avoided.

-Drink extra fluids during very warm weather to avoid dehydration and dizziness.

Children with unrepaired or partially repaired heart defects; children who still have "blue" episodes - Example: Hypoplastic Left Heart, Hemi-Fontan, Fontan, Shunts, 3 chambered hearts:

-Drink plenty of water or fluids to avoid dehydration. The heart needs extra fluid to pump efficiently.

-"Stay Cool"- avoid direct exposure to sun and severe heat. Wear hats, loose, light clothing; use fans or light air conditioning. Increased heat can make the heart work harder to try and cool the body.

-Take frequent rest periods - avoid over-exerting.

**Have a Safe and fun summer!!**

## **What's On Your Mind?**

We are continually looking for ways to improve the quality of the Hershey Hearts newsletter. One way that you can help us make this publication more enjoyable is to share what is on your mind. Do you have an inspirational story to share? Do you know a person who is making a difference in the lives of our little heart patients that you think should be recognized? Speak up, and don't be afraid to let those creative juices flow! This is your newsletter, and we would like to make sure that you get the most out of each issue.

One topic we are still working on exploring are the challenges that school-aged heart patients face, and ways that they overcome them. If you have some input, please send it our way!

If you would like to *submit an article, an idea, a photo or a even just a question that maybe other parents can answer*, please contact Rachel Hilker by mail at **Hershey Hearts, P.O. Box 163, Hershey, Pennsylvania 17033-0163**. We look forward to hearing what's on your mind!

