Mark your Calendar:

November 19, 2010 – Deadline for Photo submission for 2011 Annual Calendar
February 2011 – CHD Awareness Month
June 5, 2011 – 15th Annual Picnic
June 20, 2011 – 2nd Annual Golf Tournament

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All our newsletters are linked to SERVICES page www.littlehearts.org

Share our newsletter with family, friends and your favorite PC and surgeon

BOARD OF DIRECTORS
Megan McDonnell Busenbark
Lenore Cameron
Tim Cameron
Kelly Molloy
Rita Pardee

Have a question for LITTLE HEARTS, INC?
Email us at INFO@littlehearts.org

Toll Free: 866-435-HOPE
Phone/Fax: 860-635-0006
MAILING ADDRESS
P.O. Box 171
Cromwell, CT 06416

PHYSICAL LOCATION
110 Court Street, Suite 3A
Cromwell, CT 06416

 Quarterly
 NEWSLETTER

2011 Annual PHOTO Calendar

Every year, we put together a photo calendar – a favorite for many families! Members mail in a photo of their heart child along with the permission and order form. Photos are then placed in the month that they were born, with their first name, CHD and the year they were born underneath it. Just like you see in the above photo. Do we have good-looking kids, or what?

Interested in having your precious heart child in our 2011 calendar? Are you an adult member with a CHD and interested in participating? In addition to receiving membership forms from adults born with a CHD over the years, quite a few of our “heart-kids” are now grown ups! Photos of those born with a CHD of any age are welcome!

It’s so easy. All you have to do is complete the permission form (page 2 of the newsletter) and send it with your favorite photo to us by the deadline of Friday, November 19. With our growing membership of 2,000, we recommend you get it to us sooner than later to guarantee a spot. Permission forms received with an order for the calendar will be added before non-orders due to space limitations.

You can place your order ($24.00 which includes shipping cost) when you send in your photo or place it online by visiting the PRODUCTS page of www.littlehearts.org. All orders will be mailed out around the second week of December, just in time for the holidays!
Little Hearts, Inc. 2011 Annual Photo Calendar

PERMISSION FORM

I ______________________________________ (name of heart child’s parent or self if adult with a CHD) give Little Hearts, Inc. permission to use the enclosed photo of ______________________________ (name of heart-child) in the Little Hearts 2011 Annual Photo Calendar. I understand that my child’s (or your) first name, year of birth and diagnosis will be underneath the photo. My heart child was born the Month of ________________, on ______ (Date), in the Year of ____________ and his/her (or my) heart defect(s) at birth was ____________________________________________________________ ____________________________________________________________ ____________________________________________________________ __________________________ __________________________

Signature of Parent/Guardian (Required) Date (Required)

DEADLINE: Photo of your heart child and permission form must be received by Little Hearts by Friday, November 19 as the calendar will go to print the following work day. Permission forms received with orders will be added before non-orders due to space limitations.

ORDER INFORMATION

METHOD OF PAYMENT: (pre-pay to guarantee a spot in the calendar by November 19, 2010)
1) Check (payable to Little Hearts, Inc.) 2) PRODUCTS page of www.littlehearts.org 3) This Form

Credit Card # __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ ___

Please send ____________ ( # of calendars) at $24.00, totaling $_______________ (shipping included) to _______________________________________________________ (leave blank if same as cardholder).

MAILING ADDRESS: P.O. Box 171, Cromwell, CT 06416  FAX: 860-635-0006 *51. If you want to make sure we received your form and order, provide us with your email address________________________

PICTURE INFORMATION

• Send in either a 2X3, 4X5, 5X7 color photo of your heart child.
• If you prefer to use a JPG, email it to us and mail/fax in your registration form separately.
• Mail only original photos and not copies as print quality in the calendar will be poor.
• All photos mailed to us will be returned with your calendar order.
• Photos emailed to us aren’t added to the calendar until your registration form is received.
• Photos may be cropped by Little Hearts due to size limitation.
• Do not paper clip your photo to form or write on back of photo.
UNIVERSAL PULSE OX SCREENING

How many of you have a child who was diagnosed with a CHD after being discharged from the hospital? How many of you have been whisked away in the ambulance to a Children’s Hospital and had to do a crash course in heart defects? How many parents have lost their baby because their CHD wasn’t diagnosed until it was too late? Why aren’t babies checked for heart defects before they leave the hospital? Wouldn’t a simple test that is painless and inexpensive save some of our heart kids and the heartaches of many?

On September 17, 2010, the Secretary’s Advisory Committee for Heritable Disorders in Newborns and Children (SACHDNC) unanimously agreed to recommend the additional screening for Critical Cyanotic Congenital Heart Disease to the core panel for universal screening of all newborns in the United States.

Based on SACHDNC’s vote, a letter of recommendation will be sent to the US Secretary of Health and Human Services, Kathleen Sebelius, with recommendations and the process that was used to reach the decision. She then has 180 days to either adopt or reject the recommendations and to publicize the determination.

It is then up to individual states to determine whether to adopt their panels and type of adoption (i.e., universally required, universally offered but not required, offer to select populations by request, etc.) and timeline for doing so.

While implementation and technique issues still need to be addressed, pulse oximetry is the primary method to be implemented. We’ll share updates as they come are way.

This is a HUGE milestone for the CHD community. We’re not there yet but we’re a lot closer than we ever have been! Many thanks to all of the CHD advocates. We’ve linked a recent article on our website pertaining to screening by one of our Medical Advisory Board Members, Darshak Sanghavi, MD. Visit the homepage of www.littlehearts.org and scroll down to visit our MAB and enjoy Darshak’s article.

FEBRUARY 2011 - CHD AWARENESS MONTH

Looking to bring awareness to the #1 birth defect? For over a decade now, an international coalition of families, individuals, non-profit organizations, support groups, and health professionals participate in a campaign to increase public awareness for CHDs. What can you do to help?

If you’re interested in sharing your story with the media, use our PR Toolkit to help you get your story out there. If you work, organize a “Jeans” Dress down fundraiser. If you have kids in school, you could organize a Loose Change fundraiser. These are the three that are the most used by members.

On the News & Events section of our website, our PR Toolkit, flyers for fundraisers, and more are linked for you to print off and use. If you’d like a flyer designed for your specific fundraiser, contact us! Don’t forget to share your accomplishments with us so we can show you off with fellow members! If applicable, take photos as well. Email your accomplishments to the Little Hearts email address: info@littlehearts.org.
Accomplishments of CHD Awareness 2010 by Members & Friends

Loose Change School Fundraisers
ECS Elementary Loose Change – Laurie Cantwell
Dwight D. Eisenhower – Hagy Family
Merriamack Middle School – Burke Family
P.S. 104Q The Bays Water School
Portland High School – Joanne Grant, Chemistry Teacher
Resurrection Grammar School
Toms River Intermediate School North – Aimee Kwityn

Work Fundraisers
Allstar Marketing Group - Rita Pardee
CIGNA – Munterich Family
Dell Perot Systems
Warnaco, Inc. “Valentine” Bake Sale

Blood Drives
“Give Blood Play Hockey” – Cari Darminio
“Have a Heart” blood drive – Adria Giordano

MOMS Club Fundraisers
MOMS Club of East Northport NY – Sarrit Haik
MOMS Club of East Brunswick NJ – Val Guerin

Radio Show
Shared CHD facts on talk show – Patti Dalon

Proclamation Requests
Florida – Michele Villanucci
Massachusetts – Podworski family
Mississippi – Kristi Pena
New York, Town of Greenburgh – Tom Reilly

News Articles:
Born with a Broken Heart, NJ – Jacqueline Bergrin
Newspaper article Boone, NC – Teesa Klear
Newspaper article, MD – Melanie Letzer

Jewelry Sales
Heart Garden Necklaces – Samantha Hunt

Mount Washington Summit Climb: PHOTO TO LEFT

Maine Air Soft Team, Ghost Team, Wolf Pack: Taryn Allen

PR TOOLKIT AND FLYERS AVAILABLE ONLINE
A Message from your President

Dear Members of Little Hearts,

I answered the phone one recent morning to the anxious voice of a mother-to-be in a desperate search for support. Her unborn child was just diagnosed, with a rare CHD, pulmonary atresia with impact ventricular septum (IVS). So rare, she was told, that it would be nearly impossible to find another parent in her shoes to talk to. But on our call, I told this mom we could connect her with dozens of parents with a child living with this CHD. I heard the relief in her voice – and the smile on her face.

I know you understand this mother’s story all too well. We all do. That’s because we are all on the same journey – having a child with a congenital heart defect. And the beauty of Little Hearts is that we can all take this journey together and never feel alone.

For the last 13 years, Little Hearts has strived to provide services that meet your needs – from email support and parent matching to our online picnic slideshows and member stories. Today, I am thrilled to tell you that we are taking our organization to an entirely new level – and that means we will serve you even better.

You may remember the member survey we emailed to you back in February in conjunction with CHD Awareness Week. In it, we asked for your input on our services. Well, we heard you – and we have been working these past months to put several new programs in place.

- **CHD Research** – Beginning in 2011, Little Hearts will fund CHD research by contributing to The Children’s Heart Foundation. This is a very important milestone for our organization as we now will play a role in advancing the diagnosis, treatment and prevention of CHDs. We will update you about the various research projects we support. We are very excited about this new, important component of the Little Hearts mission.

- **Public Awareness** – We launched a public relations program early this year to secure media coverage of CHDs. More than 200 news outlets – from Forbes.com and CNBC.com to local newspapers and TV news stations nationwide – have covered our member survey and fundraising events. We also created Facebook and Twitter pages. Now, we are mapping our 2011 communications strategy, which is designed to raise awareness of CHDs through the news media and among the medical community, legislators and parents.

- **Community Forum** – We know so many of you rely on our email support group when you have questions and seek insights from other parents. Soon, we will also be connecting you in an interactive way through the Little Hearts website. In just a few months, we will launch a community forum, where you can connect and chat with the parents who can help you most, when you need it most.

*Continued on Page 6*
These Little Hearts programs are designed to help you get the most of your membership with Little Hearts. We strive to give you exactly the kind of support you need. And to make your journey with your heart child just a little bit easier.

To continue providing the support and services you want and need, we need your help. Please consider making a contribution to Little Hearts. The more donations we secure, the more we can invest in CHD research, and the more we can help you and our other 2,000 families around the country. You know first-hand the real difference Little Hearts can make. Please help us continue to make it.

To donate online, go to www.littlehearts.org or mail a check to Little Hearts, Inc. PO Box 171, Cromwell CT, 06416.

From all of us at Little Hearts, we want to thank you in advance for your support – and, as always, for your membership. Our organization would not be what it is today without you.

Sincerely,
Lenore M. Cameron
President and Executive Director

Supporting Little Hearts through donations and fundraisers

Does your child have an upcoming birthday? Is your husband or wife having a milestone birthday? Is your child having a Bat Mitzvah or Bar Mitzvah? Members in the past have contacted their friends and family and have asked for donations to be made to Little Hearts in their honor.

Did you recently lose a loved one? A grandmother, a father, a sister? Ask friends to make a donation in their memory to Little Hearts. Donations in memory and in honor of are added to our website annually.

LOOKING TO ORGANIZE A FUNDRAISER FOR LITTLE HEARTS?
LOOKING FOR SUGGESTIONS ON BRINGING CHD AWARENESS IN FEBRUARY?

Here are a few suggestions that members have done for us in the past –

- Organize a Jeans Day fundraiser at work or at school
- Organize a loose change fundraiser at work or at school
- Do you play golf? Organize a golf outing
- Are you a runner? Organize a 5 mile run
- Are you in a band? Organize a concert to benefit Little Hearts
- Is your child in high school? Clubs do fundraising as well as utilize their media club to bring awareness to their community
- Payroll deduction programs (i.e. United Way, Big Y, etc.)

We have flyers and promotional items to help you with your fundraisers. On the NEWS/EVENTS page of our website, we have flyers to print off – CHD FACTS SHEET, CHD AWARENESS FLYER, and a LOOSE CHANGE FUNDRAISER FLYER. If you need anything tailored for your event, contact us and we would be happy to make adjustments especially for you!
Board of Directors Position Openings

We are looking for members who have the interest and time in serving as Little Hearts Board Member. Do you have the skills to oversee Little Hearts functions, plan our future and meet our mission? Do you have fundraising skills and experience in organizing events? If you’re interested in applying for a position, email us at Board@littlehearts.org.

Little Hearts LISTING OF RESOURCES

We have recently updated our Listing of Resources, which now includes a listing of Heart Camps and financial assistance websites. If you haven’t checked it out lately, please do so! It’s online on the CHD FACTS page of our website. If you have resources you’d like us to share with others, email us at info@littlehearts.org.

Medic Alert Foundation

One of the resources we share in our Listing of Resources is www.medicalert.org - the Medic Alert Foundation. Have you ever had an emergency where EMTs, nurses or doctors were asking for medical information, names of prescriptions and dosages, etc.? Who can remember all of these while going through a crisis?

By becoming a member of this organization, you provide them with the necessary medical information and if there is ever an emergency, it can be obtained by phoning the toll free number and ID # listed on the back of the bracelet or necklace worn by your heart child or yourself. You can also print off the medical information that you’ve provided from their website and keep it with if you’d like. They are always adding new kids styles too and we see many of the heart kids at our annual picnics wearing them as well.

RESEARCH STUDY: Brain Structure and Function after the Fontan

If you are between 12 to 19 years old and have had the Fontan Operation, you might be eligible to participate in an important research study at Children’s Hospital Boston on neurologic (brain) and developmental outcome in teenagers who have undergone the Fontan Operation. If you are interested in being a part of this research study or want additional information, please contact Lisa Jean Buckley at Lisajean.buckley@cardio.chboston.org or Janice Burnett at Janice.burnett@cardio.chboston.org or phone 617-355-5421. We have also linked additional information about their study on the homepage of our website. This study is funded by the National Heart, Lung, and Blood Institute, NIH.

Little Hearts Services

We currently provide parent matching, email support group for parents, email support group for the heart kids, NEWS email group, quarterly newsletter, member stories, awareness products, annual photo calendar, recommended resources, picnic slideshows, Pictures of HOPE, Facebook Page for Parents and Teens, and Twitter. If you weren’t aware of some of these services and would like to know more, email us!
C.H.O.G.’s Annual Daena’s Run 2010

Daena’s Run 2010 was another success! Many thanks to the Columbia Harley Owners Group of Connecticut and Committee who organize this yearly for us!

DAENA’S RUN 2010
COMMITTEE
CHOG Members

Roger Avery
Jackie Bean
Chip Bean
Bob Bourey
Kathy Bourey
Don Casone
Juanita DeMarchi
Tony DeMarchi
Mark Gluck
Marsha Hawkins
Kathy Jolie
Glen Jolie
Cindy Paggioli
Scott Paggioli
Jackie Papineau
Ray Pittman
Phl Shine
Brian Spillane
Donna Spillane
Carl Sypher
George Sypher
Keith Udal
Greg Vincek
Rob Wirtz

Member Nick Duva with his family
Dave Parmenter & CasualMoose.com

David Wert, Chip Bean & Carl Sypher
Cool shot!

Megan Busenbark & David Wert
Jeffrey & Tim Cameron
Happy Raffle Winner
Juanita & Tony DeMarchi

Guess who this special young lady is? You’re right! Daena!