



CHD Awareness **Tried and True**

MLH groups should do what they can to raise awareness about congenital heart defects and their impact. This is important because the more awareness we raise, the more likely it is that people will give money to CHD research, which could improve the lives of our children and adults living with CHD. In February of each year, The Congenital Heart Information Network (www.tchin.org) sponsors CHD Awareness Week, February 7-14. MLH supports this and is actively involved. In addition to CHD Awareness Week, groups should try to plan activities and events that create awareness throughout the year. This Tried and True will provide ideas for creating CHD awareness in your area.

CHD Awareness Week (February 7-14)

Sponsored by The Congenital Heart Information Network www.tchin.org

MLH groups can participate in small ways or big ways, depending on the time you have to plan and implement activities, the number of people you have who can help you, and the amount of money your group has for CHD Awareness activities.

Some general tips for conducting any CHD activity or event during CHD Awareness Week (most can be used during the rest of year as well) are:

1. **Coordinate Efforts if Possible.** When planning your publicity efforts, a good idea is to coordinate your efforts with other organizations. This can increase the visibility of your efforts and also provide you with additional help and resources. You can collaborate with others such as:
 - Your local Mended Hearts chapter if there is one in your vicinity.
 - Congenital Heart Information Network (www.tchin.org)
 - The local American Heart Association (www.americanheart.org) who support Heart Month during the month of February.
 - Children's Heart Foundation
 - Hospitals are often our most valuable allies in the community and our partners in delivering the MLH program. The hospital's communications, public relations or marketing staff can be extremely helpful resources in executing an awareness effort. If the hospital is already planning an event, MLH may be able to offer that all-important patient perspective or "voice" in their media efforts.

Coordination with other groups ideally helps to maximize visibility for the issue and leverages the strengths of the organizations. Remember, the goal should be to create awareness of the issues first and foremost rather than focusing on organizational positioning. Much can be gained by approaching efforts in a cooperative, coordinated and unified manner. To do otherwise dilutes the collective effectiveness, power and passion of all involved.

2. Use Existing Materials and Localize/Customize. MLH has a wealth of materials already in existence for groups to customize and use in their areas. Refer to the coordinators' section of the MLH website for CHD Awareness materials. If you don't see something you would like, contact the National Awareness Chair. If possible, we will try to create or locate these materials for you.

Please don't use fill-in-the-blank news releases, proclamation request letters, letters to the editor, and other materials that need to be customized as is and send to newspaper, radio and TV outlets in the community. Items that need to be customized in these materials are either in bold, underlined or in red. If you have questions, be sure to ask the national office.

3. Use Media Resources

- Radio Stations—Many Mended *Little* Hearts groups have the opportunity to talk about CHD, their family's story and/or MLH on a local radio station. Family stories are incredibly powerful in creating awareness. If you get a spot on the radio, be sure to review the MLH Fact Sheet and CHD Awareness materials before the interview. It is very important that you quote and are quoted correctly so that accurate and consistent messaging is happening in the public. MLH has Approved Public Service Announcements (PSA's). ***Be sure to provide contact information for your group during the interview so those listening can get in touch with you. Be sure to share a recording of the PSA on your Facebook if possible.***
- Newspapers—There are many ways to use local newspapers to create CHD awareness. Perhaps the easiest is posting about your awareness event in the health section of the paper. This is typically free, and you can put the information about your meetings in there each month.

You may also be able to obtain print media by writing a letter or op-ed piece to the editor/publication about CHD and your group.

Finally, many papers, particularly smaller papers, will do public interest stories about people in their area. CHD families have very compelling stories, and newspaper editors are often willing to print them before a big group event like a CHD Awareness event or a

major fundraising event. Be sure to give contact information for your group in the article.

- Television—Some television stations will want to do a story on a MLH family or on CHD, particularly during February. This is a wonderful opportunity to spread awareness about CHD and to let people in your community know about your group. This is another instance in which you will want to ensure that you are using correct facts as distributed in the CHD Awareness Toolkit. Also, please be sure to notify the Awareness Chair and/or National Program Director.
 - Newsletters—There may be other groups in your area related to health or youth that would put something about MLH in their newsletters free of charge, particularly during February because it is heart month. If there is a Mended Hearts in your area, they are very likely willing to put something in their newsletter. Other non-profits, particularly dealing with parents and children, might be willing to put something in their newsletter about MLH as well.
 - Bulletin Boards—Some hospitals, doctors' offices, local grocery stores, pharmacies, schools, libraries, etc. have bulletin boards where people can put information about CHD, local groups and events. Be sure to ask if you can put CHD Awareness and MLH information on these bulletin boards around town.
 - Web sites—Some organizations, hospitals, blogs and businesses will put MLH information and a hyperlink to the MLH website (national or local) on their website; be sure that your awareness activities are highlighted. It is a good idea to reciprocate the hyperlink and can sometimes signify the beginning of a partnership. Also, you can contact The Congenital Heart Information Network (www.tchin.org) and ask that your CHD events be included on their website.
4. Prepare for Events. Before any CHD Awareness event, be sure to have spokespersons identified in advance prepared to discuss the event and the issue(s) with any media present and with those who attend the event. You want to let people know about CHD and why this is important. Have these spokespersons review materials and CHD facts in advance. Also, you want to be sure to have any handouts, visual aids, displays and materials prepared in advance of the event.

Share Your Successes (including any pictures). We would love to hear what worked for you so that we can build on the success of others – that's what our sharing network is all about. Think of it as if we are a large corporation creating a portfolio. If we collect all of our successes and place them in an easily shared format it will be more effective for grant requests, proposals and furthering our cause. Whether your event is in February, or any

time of the year – let us hear from you. There are two very easy ways to share this info-post them to your group Facebook page or email them to the Awareness Chair.

5. Purchase Awareness Merchandise. Before your event, you can order some items for CHD Awareness, like t-shirts, hoodies, bracelets, lollipops or other items to help make CHD more visible. We have some items on the MLH website under Market Place. If you want to order in bulk, you can find reduced prices for MLH coordinators only at <http://mlh.leeannhunt.com/home/>. Wearing a t-shirt or hoodie, alone, can be a good way to spread awareness. Often people will ask what MLH is, and this is a good time to educate them that CHD is the number one birth defect in the U.S. and a life-long chronic disease that affects millions.

CHD Awareness Week Activities

The following is a list of activities and ideas that our MLH groups have done for CHD Awareness Week (and can be done all throughout the year):

Proclamations—Each year, many groups ask their governor, mayor or local official to sign a proclamation, which is an official statement about a particular matter, declaring that February 7-14 is Congenital Heart Defect Awareness Week. Often the best way to contact your government official is through the official website. If you don't know who to contact in your state you can check here, <http://thomas.loc.gov/home/state-legislatures.html> to find your state website. On that site, there is often an address to mail requests to and/or an email address. MLH has samples of proclamations and letters asking for proclamations for you to customize. Groups are usually provided with a copy of the proclamation after it is signed. In some instances, groups may be able to get a photo op (request FAR in advance) with the government official signing the proclamation. If this is the case, be sure to invite as many people from your state or town as possible to the event and send a media advisory to your local media.

Booths or Tables at Events—There are many events that groups can participate in by having a booth or a table. **Using red decorations will help reinforce the I See Red campaign.** At these events, you want to have information and materials available about CHD and MLH. The national office has a nice, professional display you can use for events. They will ship it to you free of charge, but you will need to ship it back. Some groups make their own displays using pictures and stories of the children and adults in their group. You will want to include the MLH Fact Sheet at your booth, along with other materials that will help people learn about CHD and MLH. Some events groups participate in are:

- Health Fairs

- Baby and/or Child Expo's
- Carnivals/Fairs
- Heart Walks
- Sporting Events
- Heart Camps
- Other local events (co-host a table with your MHI chapter)

Speaking Engagements—Group members, and even some of the older CHD children and young adults, should speak about CHD and MLH wherever possible, i.e., to Rotary or Kiwanis groups, local service organizations, schools, police and firefighters, local businesses, and at other events where there will be speakers. Be sure to customize your speech for the audience and occasion. Also remember that people want to hear stories more than facts. They might forget facts, but they will remember stories. Practice telling your story in a compelling way without acronyms and cater to your audience. If you want to practice, use fellow MLH leaders or Steering Committee Members as a resource. Speaking can also help with fundraising for your group.

Murals, Logos, Displays, Bulletin Boards—Many groups have the opportunity to put displays, murals, bulletin boards or logos out around their local community. Some examples of locations for these items are:

- Local Hospitals—For example, the San Antonio, TX was able to put up a mural in their local hospital
- Malls—some malls may let you decorate a storefront/window display that is currently vacant
- Stores—One group was allowed to put up a display at BabiesRUs. Other child-related stores might welcome displays
- Fire Stations

MLH Clothing, Accessories and Merchandise—People who wear MLH merchandise are often stopped by others and asked about the organization. This is the perfect opportunity to briefly educate them about CHD and MLH. Also, if you give away items with the MLH logo on it, people may contact our organization to learn more about CHD and what we do. Remember the more that these items are worn, displayed, etc. the greater our reach and therefore awareness.

- School Activities—Some groups have members go into the schools to talk about hearts and heart defects in an age-appropriate way. For younger children, members may want to take in crafts or pictures to color.
-ask to speak to your child's class and use the "Our Heart" worksheet to explain heart defects to the students. **Depending on the grade level you could discuss the color red, identify some red objects and explain that red is the color for CHD.**

-Some schools have clubs that need to accumulate volunteer hours. They can collect and/or create carebags for your group. Be sure to get approval for any activities with the school principal or administrator.

-ask classrooms to participate in “penny wars” for the week leading up to or CHDAW. **The students can design the jars or you can provide one for them using the I See Red collateral.**

Jump Rope for Hearts—The American Heart Association plans many Jump Rope for Hearts activities throughout the nation. Sometimes, the purpose of this event is to raise money and awareness for childhood obesity. There are, however, some Jump Rope for Hearts events that raise money for CHD research and raise awareness about CHD’s. You will want to explore this if there is an event in your area and determine what is best for your group in terms of time and resources.

Parties and Events—Groups can have parties or CHD Awareness events to help raise awareness. Groups, if possible, should celebrate CHD Awareness Week in some way. Some examples are Valentine’s parties, bowling parties, parties at a Children’s Museum, parties at an Inflation Nation or other inflatable playground (find out age limits though to be sure not to exclude older CHD kids), and parties at local restaurants. Be sure to have an opportunity for people to meet each other (introduction time) at your event. You may be able to get much of your event and the food for your event donated. Chik-fil-A is often wonderful at helping our groups. If you can get media coverage for your event, that will increase awareness. **Have a contest and see who can wear the most red, the most creative use of red, etc. When people see a gathering of people all wearing red it can make quite a statement and impression.**

Valentine’s Cards and Items—Everyone likes to get a Valentine card or item. MLH members can make and distribute Valentines. Children in the hospital, especially, LOVE to receive them. CHDAW is also a good time to thank your doctors and nurses for their care.

Selling Paper Hearts—This is a fundraiser, but also creates awareness if you put a CHD fact or statistic on the hearts. Local businesses and restaurants will often sell the hearts for MLH groups. We do have a template for the hearts.

Care Bag Drives—Ask your members and anyone that will attend your awareness event to collect carebag items and bring them to the event. When you make care packages, include general information about CHD. There is a Family Information Pack on the Coordinators’ Web site that includes materials to use to help parents and families of children in the hospital.

Parades—If you have an opportunity to have a float in a parade, this can be a good way to spread awareness. Be sure to have website or contact information somewhere on your float. If your group has funds, you could throw lollipops or other candy with the MLH logo on it so people will be able to contact you. Dixie Varns of Sturgis, SD is a good person to ask about floats (SturgisSD@mendedlittlehearts.org).

National Donor Day is February 14th. Partner with your local organ donation organization to raise awareness for both causes. This is a great opportunity to educate the public that some defects require transplant.

Sponsor or Host a Blood Drive-Most blood organizations will allow you to be present at the drive and hand out your information or create a display. It is an opportunity for the blood donors to make a direct connection to someone (or like someone) their donation will help. **You can also tie the color of blood (red as it fills up the donor bag) to I See Red.**

Social Media-Make a goal of at least one Facebook post a day during CHDAW. Five suggested posts have been given to you. Have fun with it and remember the more people that share the greater the reach. Don't forget you can share items from other groups, the national page and the CHD Awareness page.

Twitter-MLH will be kicking off CHDAW with a Twitter party on February 7th, 1pm EST. This party is open to the public and it is easy to participate. Simply "tweet" a post about CHD using the (hashtag) #CHDAWARE. More information will follow as we get closer to the date.