# MENDED HEARTS / MENDED LITTLE HEARTS
# VISITING TRAINING COORDINATOR’S MANUAL
# TABLE OF CONTENTS

## SECTION 1 – About the MH/MLH Accredited Visiting Program

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Visiting Training Coordinator’s Duties</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Categories of Visits</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>TAVR Visiting Program</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>Working with Hospitals</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>Referrals of Patients</td>
<td>14</td>
</tr>
<tr>
<td>5</td>
<td>Privacy Act/HIPAA</td>
<td>15</td>
</tr>
<tr>
<td>6</td>
<td>Recruiting Accredited Visitors</td>
<td>21</td>
</tr>
<tr>
<td>7</td>
<td>Ongoing Monitoring</td>
<td>24</td>
</tr>
<tr>
<td>8</td>
<td>Physicians Notification and Patient Follow-Up</td>
<td>30</td>
</tr>
<tr>
<td>9</td>
<td>Starting a Non-Surgical Visiting Program</td>
<td>31</td>
</tr>
<tr>
<td>10</td>
<td>Telephone and Internet Visiting</td>
<td>33</td>
</tr>
<tr>
<td>11</td>
<td>Working with People</td>
<td>34</td>
</tr>
<tr>
<td>A</td>
<td>Chapter Annual Visiting Report</td>
<td>35</td>
</tr>
<tr>
<td>B</td>
<td>Monthly Report Tally</td>
<td>36</td>
</tr>
<tr>
<td>C</td>
<td>12-Month Reporting Spreadsheet Example</td>
<td>37</td>
</tr>
<tr>
<td>D</td>
<td>Consent Form</td>
<td>38</td>
</tr>
<tr>
<td>E</td>
<td>Confidentiality Form</td>
<td>39</td>
</tr>
<tr>
<td>F</td>
<td>Evaluation Form for Accredited Visitor</td>
<td>40</td>
</tr>
<tr>
<td>G</td>
<td>Family Visiting Record</td>
<td>41</td>
</tr>
</tbody>
</table>

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Chapter 1

VISITOR TRAINING CHAIR/COORDINATOR’S DUTIES

As the Visitor Training Chair/Coordinator (VTC), you have been chosen for a very important role. A good visiting program can make a Mended Hearts chapter or Mended Little Hearts group very strong, while a poor visiting program can greatly weaken a chapter or group. You will need to have certain qualifications for this position. First, you must be an experienced Accredited Visitor, except in new chapter or groups. You will also need good management skills and the ability to work well with people.

The duties and responsibilities of a VTC are:

A. The Visiting Training Chair/Coordinator must be an Accredited Visitor and visit patients, caregivers or families regularly.

B. Manage and monitor the chapter or group Accredited Visiting Program and Accredited Visitors.

C. Recruit potential Accredited Visitors. Not everyone can become a successful Accredited Visitor, but it is important to recruit people who have the potential for patient and family visiting. Encourage group Accredited Visitors to tell you about other potential visitors. Visitors MUST be:

   a. Mended Hearts: A heart patient or caregiver.
   b. Mended Little Hearts: An immediate family member or a direct caregiver of a child with a congenital heart defect/disease or an adult who has a congenital heart defect.

D. Visitor Training Chairs/Coordinators will be responsible for conducting accreditation and reaccrediting training workshops. The training can be delegated to a Visitor Co-Chair or Trainer who can assist with other Visitor Chair/Coordinator duties. As an alternative to, or in addition to, a live training workshop, the VTC can ensure ALL Accredited Visitors have gone through the online Accredited Visitor Training. Please note that the VTC must collect the Affidavits of Completion and Confidentiality Statements for all visitors who go through the training. Also, the Accredited Visitors must still conduct visits under observation to satisfy accreditation requirements.

E. Training for new and existing Accredited Visitors must be planned and scheduled at least once each year or the VTC must ensure all visitors go through the online training once a year to refresh their knowledge. When members are interested in becoming Accredited Visitors, it is important to train them as soon as possible so they don’t lose interest, and the online training provides a quick way for them to
get the training completed. It is up to the VTC whether the chapter or group will require additional training for its accredited visitors.

F. Maintain group visiting records and provide those numbers on the chapter or group’s annual report collected by the national organization. The number of patients, caregivers and/or families visited and the number of visits must be reported to the national organization each year. The tabulation of visiting data may be delegated to another group member, but the VTC is responsible for accurately reporting the data. Chapter or group visiting data should be tabulated monthly, and the VTC should prepare a monthly or quarterly report to his or her local chapter on visiting statistics. Examples of these reports are in Appendix A through C of this Manual.

G. Keep the National Visiting Chair informed of any chapter or group visiting problems, as well as successes.

H. The Visitor Training Chair or Coordinator may be removed by the National Visiting Chair or, for Mended Little Hearts, the MLH Board Director for cause.
Chapter 2

CATEGORIES OF VISITS AND REPORTING

As stated in Chapter 1, one of your duties is to report your chapter or group’s visiting numbers on your chapter or group’s annual report. Proper reporting is important because it allows us to gauge the effectiveness and impact of our Accredited Visiting Program and share that information with others. We can then determine the number of people being helped by Mended Hearts and Mended Little Hearts. These numbers also help us get sponsorship and support from other organizations. In order to report the different visits to national, the VTC needs to have a firm understanding of the different categories and types of visits.

Visitors for Mended Hearts will visit heart patients and their caregivers. Visitors for Mended Little Hearts will visit parents and other family members of a child with a heart defects/heart disease. Other family members are usually parents, grandparents, older siblings, or other relatives. The categories of visits is as follows:

1. **In-person Visits**—These visits are face-to-face visits with a patient or caregiver or with a parent or family member of a child with a heart defect/heart disease. These visits are usually done in the hospital, in the hospital’s waiting room or at a cardiac rehab facility.

2. **Telephone Visits**—These are visits, as the name suggests, made by telephone. These visits include an Accredited Visitor talking by telephone to:
   a. A patient about his or her condition
   b. A caregiver about a patient’s condition
   c. A parent or family members about child’s condition or procedures

   For these to count as visits, the main purpose of the call must be to discuss a heart disease or congenital heart defect diagnosis, the patient or child’s condition, or heart procedures, medical interventions and/or surgeries that the patient will have or has just had. Note: Texts count as telephone visits as they are done via mobile phones. (See more about text visits later in this Manual.)

3. **Online Visits**—These visits are typically done by e-mail, but today, they also might be done on chat groups or social media as well. As with telephone visits, the main purpose of the email or message on social media must be to discuss a heart disease or congenital heart defect diagnosis, the patient or child’s condition, or heart procedures, medical interventions and/or surgeries that the patient will have or has just had.
Transcatheter Aortic Valve Replacement (TAVR) Patient Visitors

As you know, Mended Hearts wants to support ALL heart patients and their families, regardless of condition, age, or where they live. Our goal is to live up to our motto, “It’s great to be alive...and to help others!” We want to grow Mended Hearts and expand the services we provide, even if it is not in person.

The TAVR Visiting Program addresses a unique need. People who are about to have a TAVR procedure are often scared and want to talk to someone who has had a TAVR. This is partly because the TAVR procedure is relatively new and because people want to know specifically about his procedure.

How Does the TAVR Visiting Program Work?

What Is the TAVR Visiting Program?
The TAVR Visiting Program is a telephone visiting program. People who have had a TAVR and are willing to call people who are about to have a TAVR go through a one-hour telephone visitor training, are provided with an Accredited Visitor Handbook, and are placed on a list so we can contact them if someone who is about to have a TAVR would like a call.

What Are the Requirements to Be A TAVR Visitor?
TAVR visitors are simply people willing to make phone calls to patients before their TAVR procedure. TAVR visitors do not need to be fully accredited visitors to make phone calls. However, they must attend a one-hour telephone visiting training chaired by Dr. Fredonia Williams, national visiting chair. They must also agree to confidentiality. A TAVR visitor does not have to be a member of a specific chapter, but we do let them know about chapters near them, if any, and encourage them to go to a meeting.

If a TAVR visitor would like to become a fully accredited Mended Hearts hospital visitor, he or she must be a member of a Mended Hearts chapter and go through the full training with observed visits. This visitor must work with the chapter Visiting Chair.

How Are TAVR Visitors Selected?
In many cases, we are counting on the Visiting Chair or other chapter leader to connect with the TAVR program in their area and to help us find TAVR patients who are willing to call other patients before a TAVR procedure. Also, if a TAVR patient is already in your chapter, or who joins your chapter, ask if he or she is willing to join the TAVR Telephone Visiting Program.

What Happens After We Find a TAVR Visitor?
If you find a TAVR visitor, please contact your National Resource Center at 1-888-HEART99 (1-888-432-7899) and let us know. We will let you know when the next telephone training is so the TAVR visitor can join the call. The chapter leader is welcome to join the call with the visitor, but we ask that the visitors only participate so we make sure we get all of their questions answered. If chapter leaders have questions, please don’t hesitate to contact us at any time.

**How Do We Track TAVR Visits?**

If you have TAVR visitors in your chapter, please count their visits the same way you would any telephone visits, but please also KEEP A SEPARATE TALLY of TAVR visits. We need this number.

**What is TAVR?**

**Overview of TAVR**

- Since its introduction in the U.S. in 2011, transcatheter valve replacement has reduced recovery times and shortened hospital stays (generally 1 or 2 hospital nights) as compared with open heart surgery.
- A TAVR procedure is performed by a specialized structural heart team—both an interventional cardiologist and cardiac surgeon are certified to do the procedure.
- Approximately 600 hospitals in US are qualified to perform TAVR procedures.
- The TAVR procedure is currently approved for patients who are at intermediate or greater surgical risk (note called a procedure, rather than surgery).
- There are ongoing clinical trials including those for low-risk surgical patients; it is anticipated that TAVR will be expanded to this low-risk patient population in late 2019.
- Currently two companies manufacture valve devices, Edwards Lifesciences and Medtronic, used in transcatheter aortic valve replacement.
- Mended Hearts supports ALL TAVR patients and raises awareness of this innovative valve therapy through patient support, during regional and national educational programs, and through our advocacy efforts.

**TAVR Educational Resources**

Mended Hearts has developed several aortic stenosis and valve education resources to support awareness and education on valve disease and less-invasive transcatheter treatment options.

1. **GoToGuide on Valve Disease**: [https://mendedhearts.org/gotoguide/the-gotoguide-on-valve-disease/](https://mendedhearts.org/gotoguide/the-gotoguide-on-valve-disease/)
• Valve disease explained
• Know the symptoms
• Understanding treatment options
• Recent FDA approval for expanded use of TAVR
• What to expect during treatment

2. *Heartbeat magazine*: (Nov./Dec 2016) article shared MH TAVR Patient Accredited Visitor, Larry Haffner’s personal journey:

3. TAVR Educational Videos and TAVR patient testimonials are available at:
http://NewHeartValve.com

**Steps to Starting a TAVR Visiting Program for Chapters**

1. Identify the Valve Clinic Coordinator (VCC) at your hospital valve clinic certified to perform the TAVR procedure and begin building that relationship. Also build a relationship with the interventional cardiologist who performs TAVR, and/or the hospital’s or clinic’s cardiology chair who oversees the TAVR team. Please enlist your national staff team if you need support identifying the appropriate people at your local hospitals so that we may facilitate these new contacts and introductions.

2. With help from the VCC, identify TAVR patients who would be capable and enthusiastic TAVR Visitors who is willing to call other TAVR patients before their procedure.

3. When a potential TAVR visitor is identified, please gather all contact information (name, mailing address, phone number and email address (if available) for Mended Hearts chapter and national member records.

4. All contact information should be sent to National Resource Center (info@mendedhearts.org) and to your local chapter officer, specifically the visiting chair.

5. Chapter leaders must follow-up with each potential TAVR visitor to discuss the requirement to participate in Mended Hearts monthly telephone training for TAVR visitors in advance of any visits.
6. Monthly TAVR Patient Visitor training teleconferences are being scheduled. The national office staff and chapter visiting chair can work with the potential TAVR visitor to sign them up for the next training call.

7. The Local chapter Visiting Chair or president should provide potential TAVR visitors with Mended Hearts Accréditator Visitor Training Handbook, if possible in advance of the training.

8. As all Accredited Visitors (whether phone, in-person or online) must be members of Mended Hearts. We do not want the $20 national member-at-large dues to be a financial barrier. Thus, when collecting the member info, TAVR member annual national dues may be waived for the first year, unless the chapter can provide the member dues. Send all contact information to Chapter officer and National Resource Center in Albany with “TAVR” complimentary written at the top of the member form.

**TAVR Telephone Visitor Training**

All TAVR visitors must go through a minimum of a one hour-long telephone training to become a TAVR visitor. Mended Hearts offers these training calls at least once a month. These calls cover:

- About Mended Hearts
- About Mended Hearts Accredited Visiting Program
- About the TAVR Visiting Program and how it is similar and different
- Rules of Conduct for Telephone Visiting
  - No medical advice
  - Visit only when you feel positive and well
  - Always be positive about a patient’s care and hospital
  - Never compare hospitals or doctors
  - Respect other people’s choices
  - Refer to the cardiologist for medical questions and to the social worker for mental health questions
- Diversity sensitivity
- Confidentiality
- Privacy and HIPAA
- Active Listening
- Visiting procedures including tracking
- Follow Up
We encourage the TAVR visitor to also take the next steps to complete the full visitor training online to become an Accredited Visitor through Mended Hearts and to take advantage of the local Mended Hearts support, meetings and resources. If in-person TAVR visits are desired, accredited training and additional hospital volunteer training will be required and coordinated through the local chapter and hospital.

Data Collection Requirements for Annual Reports

Data on Accredited Visiting should be collected regularly. It is up to the VTC to determine how the visiting numbers will be collected. Some require it to be sent via email or text. If the VTC has Visitors call in their data numbers, he or she will need to be sure to write it down and record it quickly so it does not get lost.

Accredited Visiting number are important to show how well your chapter or group is doing and so we can show how well we are doing supporting patients, caregivers and families as an organization.

The data that is required and should be maintained is as follows:

1. **Total In-Person Visits**
   a. Number of patients, caregivers or families visited in person. (One family may include one or several members.)
   b. Total number of in-person patient, caregiver or family visits. (Accredited Visitors might visit the same patient, caregivers or family more than once.)

2. **Total Number of Telephone Visits**
   a. Number of patients, caregivers or families visited by telephone
   b. Total number of telephone visits. (Accredited Visitors might visit the same patient, caregiver or family more than once.)

3. **Total Number of Online Visits**
   a. Number of patients, caregivers or families visited via email or through chat groups or social media venues
   b. Total number of online visits. (Accredited Visitors might visit the same patient, caregiver or family more than once.)

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Example 1
Mended Hearts Chapter 28 Annual Visiting Report

Let’s say for in-person visiting, the Accredited Visitors visited the John Doe twice, Colonel Sanders once, Earl Grey three times, and Clint Eastwood twice. The in-person visit numbers would be:

Total in person visits

   a. 4 patients visited in person
   b. 8 total in-person patient visits

Then, do the same thing for telephone visits and internet visits. Below is an example of numbers and reporting for these visits. The numbers below are not based on the above example.

Total Number of Telephone Visits

   a. 32 patients visited by telephone
   b. 65 total telephone visits

Total Number of Online Visits

   a. 25 families visited online
   b. 41 online visits

Example 2

Mended Little Hearts of Central VA Annual Visiting Report

Example: Let’s say for in-person visiting, the Accredited Visitors visited the Jones family twice, the Smith family once, the Davis family three times, and the Harris family twice. The in-person visit numbers would be:

Total in person visits

   a. 4 families visited in person
b. 8 total in-person family visits

Then, do the same thing for telephone visits and internet visits. Below is an example of numbers and reporting for these visits. The numbers below are not based on the above example.

Total Number of Telephone Visits

a. 45 families visited by telephone  
b. 52 total telephone visits

Total Number of Online Visits

a. 30 families visited online  
b. 49 online visits

When Most In-Person Visits Are Made

There are different times when Accredited Visitors might visit a patient, caregiver, parent or family member. The following is an explanation of when visits might take place:

1. Pre-op — When a patient or child is awaiting surgery or other medical procedures, they are often very anxious and so are caregivers, parents and/or family members. This may be a good time for the Accredited Visitor to contact them and try to reassure them. The Cath Lab waiting room can be a good place to visit with patients and the families of these patients.

2. Post-op — Most visits will be performed during this period while the patient or family is still in the hospital. The surgery or procedure is over, and the patient or family will likely have many questions about recovery, lifestyle and health.

3. Post procedure/post hospital stay — The patient or family is relieved that they are through the surgery or procedure, but they may feel anxious about the future. Accredited Visitors go a long way in demonstrating how the patient can improve recovery and lead a healthy life and how the family can assist the child in the road to recovery.

4. ICU/CCU — It is rare to be able to visit patients in the ICU or parents with a child in the ICU/CCU/CICU, but on occasion, visits may be requested in these areas by medical staff, the patient or a family member.
Chapter 3

WORKING WITH HOSPITAL(S)

One of the most important steps for Mended Hearts or Mended Little Hearts (MH/MLH) groups is establishing an Accredited Visiting Program at the hospital. The VTC plays an important role in this process. Because of Health Insurance Portability and Accountability Act (HIPAA), some hospitals are very guarded about allowing visiting programs, and you will need to be aware of this. The VTC should have knowledge about how the hospital works, and he or she will have to be very professional when dealing with the hospital. The following procedures can be used by new groups to establish a hospital Accredited Visiting Program. Established groups can also use these procedures to add hospitals to their Accredited Visiting Program.

Hospital/Physician Relations and Approvals:

- One of the best ways for groups to establish an Accredited Visiting Program in a hospital is through the Volunteer program or Auxiliary program established in the hospital. If Accredited Visitors are qualified hospital volunteers, then many of the HIPAA issues are avoided.

- Whether you are representing Mended Hearts or Mended Little Hearts, start by providing hospitals, physicians and medical staff with information about our organization to show that our Patient and Family Accredited Visiting Program is a qualified and respected form of adjunctive patient care. Let these people know about the comprehensive training program that MH/MLH Accredited Visitors are required to complete. Assure them that each Accredited Visitor is required to complete a re-accreditation program yearly.

- Seek a hospital employee to help you coordinate this process. This person could be a nurse involved with pediatric cardiac patients, an employee in social services, a Child Life Specialist, a nurse in the cath lab, etc. Ask for his or her assistance in speaking to a member of administration who would be in charge of a program such as MH/MLH in the hospital. Truism: The higher the rank of the administrator involved in the program, the more willing the complete staff is to fulfill the requests necessary for an effective Accredited Visiting Program.

  ➢ Work with the hospital coordinator to determine the most appropriate times for parent/caregiver/family visiting.

  ➢ If appropriate, establish a procedure for the Accredited Visitor to receive parents’ names and room numbers for the heart child.
If appropriate, request a SECURE area for MH/MLH to keep forms, such as the visiting records, and other materials. This area should not be accessible to anyone except Accredited Visitors and the necessary hospital staff.

Obtain permission from the hospital to establish a Mended Hearts / Mended Little Hearts patient and family visiting program from the hospitals and physicians.

Universal Precautions

Mended Hearts has Adapted Universal Precautions (see Handbook) that describe precautions that visitors should take. Mended Hearts has adapted these precautions from various hospital universal precautions. Hospital precautions can run from one to fifty pages in length. MHI has adopted precautions that should adhere to hospital precautions while not treating Accredited Visitors as medical staff.

You should ask the hospital’s permission to use Mended Hearts Adapted Universal Precautions. Bear in mind, however, that the hospital’s universal precautions supersede the Mended Hearts Universal Precautions anywhere the hospital precautions are more stringent.

If the hospital does not require volunteers to take an orientation course about the hospital’s rules, check to see how the hospital handles fire procedures, quarantine procedures, etc., to incorporate into your training.

Cooperation

For an Accredited Visiting Program to be successful, the continuing cooperation of individuals and groups outside of our organization, is required. They include the following:

A. Medical Professionals — Physicians, nurses and other medical professionals should be encouraged to join local Mended Hearts or Mended Little Hearts groups. They should also be encouraged to present programs to groups and to help train Accredited Visitors.

B. Hospital Administrations — Patient and family visiting requires the approval of hospital administrations, but cooperation does not stop there. Hospitals can provide many resources to MH/MLH, including office space, a voicemail line (to be monitored by an Accredited Visitor), assistance in publicity and public relations,
access to copying equipment, printing and mailing of meeting notices, meeting rooms for general meetings and training meetings, and refreshments. This type of cooperation is encouraged.

C. American Heart Association — Groups should establish a good working relationship with the local American Heart Association and work together on common goals. The local AHA office should be given a local contact telephone number to refer calls that come into the AHA concerning heart patients and the family. This contact, ideally, will be an Accredited Visitor. Such calls would be considered a telephone visit and reported in this category.

D. Other Agencies and Support Groups — Groups should look for opportunities to cooperate with nonprofit health agencies and other self-help groups. (Many communities have volunteer information centers that serve as a resource for families to use.) This type of cooperation can be a big help in Accredited Visitor training and a useful addition to Mended Hearts’ or Mended Little Hearts’ referral system.
Chapter 4

REFERRALS OF PATIENTS

The way in which families are referred to groups will vary from one group to another. In most groups, the hospital will assign a coordinator who will work out the details with the Visitor Training Coordinator. Because each group is different, there is no one correct way to have patients referred to the group. The following case examples can be used as a guide to help set up a group’s patient referral system.

Case 1 — The Visiting Training Coordinator obtains a list of names of children from the hospital pediatric nurse, Child Life Specialist or nurse in the Catheterization Lab. The names are then entered into a group’s Visitors’ Log at the desk where the group has been given space to keep materials. The Accredited Visitors check with the charge nurse on duty for new names of families listed for visiting and the condition of the child.

Case 2 — The Visiting Training Coordinator obtains a list of patients’ names from cardiologists and surgeons and calls the hospital to make sure a child has been transferred from ICU/CCU and the parents are ready for a visit. The VTC can also ascertain whether the family may need a visit during this time. Then, the VTC assigns families to Accredited Visitors. Accredited Visitors check with the nurses’ station before they visit.

Case 3 — Accredited Visitors may be assigned a specific day of the week and hours to visit by the Visiting Training Coordinator. Accredited Visitors obtain a list of families to be visited from the nurses’ station, volunteer office, cath lab or wherever the hospital has designated.

Case 4 — The group gives care packages to the hospital to give to patients from the group’s geographical area. The care packages contain the group’s information. Families receiving the care packages contact the group requesting a visit.

Case 5 — Cardiologists give information to families about the group and refer families to the group who request a visit.
Chapter 5

PRIVACY ACT — HIPAA

General Understanding

Each healthcare entity will have its own set of policies with regard to HIPAA and will have varying interpretations of HIPAA itself. Therefore, it is critical that groups work with their healthcare entity liaison including, where applicable, a privacy officer, to ensure that policies are being followed correctly.

HIPAA — Privacy Standards

Congress passed the Health Insurance Portability and Accountability Act (HIPAA) in 1996. As part of the Act, Congress called for regulations promoting administrative simplification of healthcare transactions as well as regulations ensuring the privacy and security of patient information (Department of Health and Human Services). The regulations apply to what are called “covered entities”:

- Healthcare providers
- Health plans
- Healthcare clearinghouses

Any transmittal of health information in electronic form in connection with a transaction is covered under HIPAA. The regulations are made up of three parts:

- Transactions standards
- Privacy
- Security

Mended Hearts, and therefore Mended Little Hearts, is affected by the Privacy regulations.

Privacy Regulations: The privacy rules govern the release of individually identifiable health information, specifying how health providers must:

- Provide notice of privacy policies and procedures to patients
- Obtain consent authorization for use of information
- Tell how information is generally shared
- Inform patients about how to access, inspect, copy and amend their medical records.
The privacy rules became effective in April 2001; their compliance deadline was April 14, 2003.

Steps Groups Can Implement

Be active in understanding your healthcare entity’s policy regarding HIPAA – Privacy Standards.

- As suggested above, require Accredited Visitor volunteers to join the healthcare entity’s volunteer organization or auxiliary organization. When Accredited Visitors are volunteers in the hospital system, many hospitals view them as part of the healthcare entity and/or the care coordination process. Therefore, volunteer Accredited Visitors are privy to limited patient information. This will help to avoid many of the problems that HIPAA creates for visiting programs. This is the best way to establish a successful Accredited Visiting Program with a hospital.

- Ask to meet with the healthcare entity privacy officer or liaison to discuss the healthcare entity’s HIPAA policy as it relates to MH/MLH visiting.

- Become familiar with the healthcare entity’s policy and follow its rules.

- Let the privacy officer know that the data being maintained is minimal and does not conflict with the Privacy Standards. (Please review National’s Data Requirements of the Visiting Program above.)

HIPAA PRIVACY TRAINING FOR ACCREDITED VISITORS

- All currently Accredited Visitors must participate in the MH/MLH HIPAA privacy-training program.

- If applicable, invite a representative from the healthcare entity to talk about HIPAA and its importance in his/her system.

- Groups will require that Accredited Visitors sign Mended Hearts’ confidentiality form.

- It is recommended that each Accredited Visiting Program develop a “check” system to ensure that Accredited Visitors adhere to the HIPAA–Privacy
standard and take appropriate measures against volunteers who fail to comply.

Response to Privacy Infractions

Please understand that the healthcare entity has the right to revoke the visiting privileges of a volunteer who has violated its privacy standards. The healthcare entity could even choose to close the entire visiting program if infractions occur. The Visiting Trainer Coordinator can also revoke visiting privileges of a volunteer who does not follow the rules.

The patients have confidentiality rights. Violating their identity and personal health information could result in a lawsuit.

Frequently Asked Questions/Common Situations

Hospital

Question: We have an Accredited Visiting Program that does not comply with our HIPAA – Privacy Standards. We discovered this when our Privacy Officer reviewed the visiting practices. How do we maintain the Accredited Visiting Program?

To maintain the visiting program, the Accredited Visitors have three options:

1. MH/MLH Accredited Visitors can become hospital volunteers. Again, when Accredited Visitors are volunteers in the hospital system, many hospitals view them as part of the healthcare entity and/or the care coordination process. Therefore, a consent form is not required and the volunteer Accredited Visitors are privy to limited patient information.

2. Contact the appropriate coordinator at the Mended Hearts National Office to discuss additional measures that can be implemented to maintain the group’s Accredited Visiting Program. An example is the recent recommendation offered by the Office of Civil Rights, a government entity charged with guiding healthcare entities on HIPAA. The Office of Civil Rights suggests that providers, such as Mended Hearts, sign an
agreement with the hospital allowing the hospital the right to provide patient information to Accredited Visitors. The agreement is called a Business Associate Contract. There are Mended Hearts chapters who could give you an example of this contract if you need one.

3. The Accredited Visitors can offer the consent form to the hospitals to give to patients at admission or discharge. **We do not recommend implementing the consent form method unless it is mandated by the healthcare entities because it can detrimentally impact visiting programs for chapters and groups. When consent forms are used, families are far less likely to request/allow for a visit.**

**Groups**

**Question 1: We have a wing dedicated to heart patients. Do we need to collect a patient’s name and room number?**

No. However, Accredited Visitors in healthcare entities that do not have such a wing will need to work with the healthcare liaison on how to be directed to families who would like a MH/MLH visit. National does not need to have names and room numbers of patients.

**Question 2: We send newsletters and conduct phone follow-up visits. How are we supposed to obtain patient information for these follow-up visits?**

If your healthcare entity provides you with a patient’s personal information, you still need to ask the patient (or for a child patient, the family) if they would like to receive a newsletter or a phone follow-up visit. If the healthcare entity offers you more information than name, address and phone number, shred those records regularly (typically every three months).

If the family gives this information to you, you must to be very clear about how you will use it. For example, “We will mail you our newsletter for three months, then your personal information will be destroyed unless you let us know you want to remain on our mailing list.”

Whether the healthcare entity offers you the patient’s personal information or not, National recommends that you maintain minimal information such as name, address and phone number for a limited time period (average of 3 months). Do not write down any health conditions.

**Question 3: Our visiting program has been discontinued at the hospital. As a result, our group is not gaining new members and current members are losing interest due to their
inability to visit patients or families. How can we attract new members? And, is there any way we can offer a visiting program?

Network with cardiologists or hospitals to set up displays of brochures, posters and Heartbeat magazines detailing Mended Hearts / Mended Little Hearts services. One MLH group convinced its hospital to display brochures as an FYI to families with a heart child at their hospital. The national office has posters that can be used to increase public awareness and establish community interest at your local level.

If there is a pediatric or adult cardiac practice(s) in your area, consider approaching them to offer a visiting program (phone and electronic visiting) and support group meetings.

Question 4: My hospital liaison told me that Accredited Visitors are part of the patient care process and so have access to patient information and do not need National’s consent form. Is this true?

Each hospital will view and implement HIPAA Privacy Standards differently. If your hospital allows you to access patient information, you need to follow its policies. National recommends that you do not maintain records of patients’ names and health conditions. About every three months, shred any records that you have been given that contain the patients’ names and health conditions.

It is still beneficial to educate the Accredited Visitors about HIPAA Privacy Standards and to implement a “check” system to ensure adherence to the policies.

Question 5: As an Accredited Visitor, I can’t make an intelligent visit without knowing the patient’s health conditions. How am I to visit?

With HIPAA, hospitals/health care entities may not release the patient’s health information. However, a successful visit does not require you to know the patients’ health conditions. The basic premise of a visit includes the visitor telling the family members:

1. Who you are and that you are with Mended Hearts / Mended Little Hearts.
2. Why you are there.
3. That you also have a child with a heart defect/heart disease, or you are a heart patient.
4. Then, listen to the patients and/or family members.
Remember that receiving health information that is volunteered by family or the patient is acceptable under HIPAA so long as it is kept private. Depending on the comfort level of the patients or family members, they may share their concerns with you.

**Consent Form**

Even if you try to avoid it, a few healthcare entities may require Mended *Little* Hearts Accredited Visiting Programs to provide them with a consent form that can be presented to the patient. This ensures that visits are consensual. The reason for this is that the Privacy Regulations established a federal requirement that most doctors, hospitals or other healthcare providers obtain a patient’s written consent before using or disclosing the patient’s personal health information to carry out treatment, payment, or healthcare operations to people who are not a part of the healthcare entity.

A consent form you can use is in Appendix D of this manual.

**Confidentiality Statement**

All Mended Hearts and Mended *Little* Hearts Accredited Visitors must sign a Confidentiality Statement. A copy of the Confidentiality Statement is in Appendix E of this manual. (There is also a copy on page 19, Appendix B, of the Handbook.) The VTC may make copies as necessary.
Chapter 6

RECRUITING ACCREDITED VISITORS

Recruiting Accredited Visitors is the Visiting Training Coordinator’s responsibility. The Visiting Training Coordinator is ultimately responsible for the actions of the Accredited Visitors and so must feel comfortable with the choice of candidates and the quality of their training.

Qualification of Candidates

The Visiting Training Coordinator has certain criteria to follow in searching for new candidates. The following information will help the Visiting Training Coordinator in this effort.

- Mended Little Hearts: An Accredited Visitor MUST be a member of Mended Little Hearts.

- For Mended Little Hearts, in order to conduct family visits, an Accredited Visitor must be a parent or a caregiver of a child with a heart defect/heart disease, or an adult with a congenital heart defect/heart disease that was discovered during childhood. The Accredited Visitor needs to be able to share experiences with the family and would be unable to do this if he or she was not a person with firsthand experience of caring for a child with a heart defect or growing up as a child with a heart defect. The true message to any family or caregiver is, “I have been there. Our family and child survived this event.” Hospitals offer many experts who can walk parents through a child’s recovery, but the support from people who have had these experiences can come from Mended Little Hearts Visitors.

- Many groups use husband-and-wife teams of Accredited Visitors. Visiting can be more enjoyable when sharing the time with a spouse. Both husband and wife must be Accredited Visitors.

- Training candidates who have no experience with a heart child undermines our uniqueness as MLH Accredited Visitors, and therefore is not allowed.

- When recruiting a candidate for visiting, the Visiting Training Coordinator must determine if the person appears healthy physically and emotionally and presents a positive image of a Mended Little Hearts member. Some people continue to be angry, frustrated and in denial when dealing with children with heart problems. These people are not good candidates. A
A healthy mental attitude is of utmost importance for the Mended Little Hearts Accredited Visitor.

- Mended Hearts: An Accredited Visitor MUST be a member of Mended Hearts.

- For Mended Hearts, in order to conduct patient visits, an Accredited Visitor must be an adult with a heart defect/heart disease. The Accredited Visitor needs to be able to share experiences with the patient, and would be unable to do this if he or she was not a person with firsthand experience of heart disease. The true message to any family or caregiver is, “I have been there. Hospitals offer many experts who can walk patients through their recovery, but the support from people who have had these experiences can come from Mended Hearts Visitors.

- Many groups use husband-and-wife teams of Accredited Visitors. Visiting can be more enjoyable when sharing the time with a spouse. Both husband and wife must be Accredited Visitors, and one of the two must be a heart patient.

- Training a candidate who has no experience as a heart patient is allowed only if the person accompanies another Accredited Visitor during the visits.

- When recruiting a candidate for visiting, the Visiting Training Coordinator must determine if the person appears healthy physically and emotionally and presents a positive image of a Mended Hearts member. Some people continue to be angry, frustrated and in denial when dealing with heart problems. These people are not good candidates. A healthy mental attitude is of utmost importance for the Mended Hearts Accredited Visitor.

**Qualities of Candidates/Visitors**

The continuing improvement in the quality of the Mended Little Hearts visiting program requires thoughtfully and tactfully monitoring and evaluating trainees and Accredited Visitors.

Candidates should demonstrate a:

1. **Positive Mental Attitude.** As stated above, all candidates should exhibit a positive mental attitude. This does not mean to suggest that Accredited Visitors can’t share some difficult journeys they have experienced and express sadness or anger about those, but the overall attitude MUST be positive and helpful to others who are scared, angry, sad or feel lost.
2. Desire to help others. Visitors must possess a desire to help others in an unselfish and caring manner, without expecting to receive a tangible reward. Family visiting must not be done to satisfy a person’s ego.

3. Once members become Accredited Visitors, they should also:

- Be willing to continually improve on their visiting skills.
- Recognize that family visiting is a team effort. Each visit to a patient or family is part of a larger Accredited Visiting Program designed to offer support and encouragement.
- Acknowledge that children and families are unique and should be treated with respect and dignity.
- Appreciate the quality of medical care that makes it possible for heart patients to lead useful lives.
- Be responsible for their own health style and lifestyle that promotes a rich and rewarding life following either the diagnosis of a child with a heart defect/heart disease or their own heart disease. By presenting a positive example, Accredited Visitors demonstrate that individual responsibility is an important ingredient in handling and getting through the experiences related to heart disease.
- Adhere to MHI/MLH standards and policies.
- Adhere to hospital policy.
- Attend local group meetings. These meetings serve as continuing education for the Accredited Visitor. If the Accredited Visitor invites the patient or family to attend a meeting, they are going to expect to see a familiar face there i.e., the Accredited Visitor who called upon them in the hospital.
Chapter 7

ONGOING MONITORING

The Visitor Training Coordinator has the ultimate responsibility to monitor and evaluate the Accredited Visiting Program. Visitor program monitoring usually includes building morale, recognizing Accredited Visitors, handling problems, and where necessary, canceling visiting privileges.

Building Morale

Morale is more than a word; it is the spirit of your working group. If your Accredited Visitors have good morale, they will be better visitors and more helpful to others. They will also feel satisfaction with what they are doing, which is good for everyone. Good morale makes a good Accredited Visiting Program, and ultimately helps the entire MH/MLH chapter or group.

How to build morale

*Set a good example—walk your talk.* People are more likely to have good morale if their leader exhibits positive leadership characteristics. The VTC must be well-informed and share that information with his or her Accredited Visitors.

*Know your Accredited Visitors.* Many people, when talking about leadership, say that people don’t care what you know until they know that you care. Get to know your Accredited Visitors and use the Accredited Visitor Recognition ideas below to show them that they are valued, and that you care about what they are doing.

*Communication.* Good communication is essential for good morale. Accredited Visitors need to be kept informed. If you have concerns, you should share these with your Accredited Visitors. Talk to each other about visiting experiences. Address concerns of Accredited Visitors. Also, sometimes Accredited Visitors might get overwhelmed with emotion, particularly if a child is suffering or dying, or an adult patient is struggling. Allow Visitors to express emotion in a safe environment. Allow Accredited Visitors to make suggestions about how to run the program more effectively. They will often have great ideas. If an idea cannot be implemented, explain why without putting down the idea.

*Express goals and give information.* Make sure all of your Accredited Visitors are aware of the goals of the Accredited Visiting Program. Also, make sure that all Accredited Visitors have the information and the resources they need to conduct their visits. When people don’t have information and/or resources, they get frustrated about what they are doing.
Accredited Visitor Recognition

“The key to developing people is to catch them doing something right.”
Ken Blanchard and Spencer Johnson
The One Minute Manager

Recognizing Accredited Visitors is important to the quality and success of the Mended Hearts and Mended Little Hearts Accredited Visiting Program. Accredited Visitor recognition can come in many forms. Some examples of things the VTC can do to recognize visitors are:

- Recognize individual Accredited Visitors and their accomplishments at group meetings.
- Send Accredited Visitors an email expressing appreciation for what they are doing.
- Send Accredited Visitors cards through the mail expressing thanks for a job well done.
- Allow Accredited Visitors to participate in the next Visitor Training Program.
- Explain to the group, at a group meeting, why what Accredited Visitors do is so valuable.
- Have the Accredited Visitors be the speakers at a meeting so they can talk about what they do, and they can answer questions the group might have. Remember that sharing other families’ or patients’ personal information is not permitted. Even discussing the details of a patient’s medical condition, without naming the individual, is not permitted, because others might recognize who it is from your account.
- If there is a family in your group who benefited from a visit and joined the group because of the visit, ask them if they would be willing to speak about what the visit meant to them.

Note: Certificates of achievement for visiting should be reserved for special circumstances or outstanding accomplishments. This type of award must remain a symbol of special recognition, not a routine way to acknowledge Accredited Visitor status.

Remember that it is important for Accredited Visitors to be involved in the exchange of information and in decision making regarding the Accredited Visiting Program. Also, Accredited Visitors need to be kept informed of matters affecting visiting.

Handling Problems

“People are okay, it’s their behavior that’s a problem sometimes.”
Ken Blanchard and Spencer Johnson
The One Minute Manager
Unfortunately, even in the best of Visiting Programs, problems may arise. It is the duty of the Visitor Training Coordinator to be aware of any problems that arise, and to handle them quickly and efficiently. Handling problems is difficult for many people, especially when the Accredited Visitors are friends in the chapter or group. However, remember that your group could suffer if there are problems with the Accredited Visiting Program, and you are doing no one any favors if you ignore those problems.

Certain common conditions will always require attention and possible action. They include:

**Over-Visiting** — Staying too long or visiting too often can be a problem. This problem requires tactful management; otherwise, a good visitor may be lost if he or she does not understand the problem. The VTC might explain to the Visitor that while families appreciate visits, the visits can become too much for people who are overcome with emotion and stress if they are too frequent or too long in length.

- **Length of Visit** — Good individual judgment must prevail when determining the length of a family visit. The Accredited Visitor must be careful to notice signals that a family is getting tired or overwhelmed and leave courteously and promptly at that time.
- **Frequency** — Too many patient and family visits can be worse than no visit at all. Daily visits, by the same or different Accredited Visitors, are excessive (unless there is a special request by the patient). Again, the Accredited Visitor must look for cues from the family regarding their need for subsequent visits.

**Misguided Accredited Visitors** — Sometimes an Accredited Visitor can become too involved in patient and family visiting, resulting in misguided behavior. The Accredited Visitor may become a nuisance to patients and families and to medical staff. He or she may be perceived as pushy, arrogant or inflexible, which leads to problems. Another form of misguided Accredited Visiting is a Visitor who gets too involved with the patient or family and does inappropriate things like buying them gifts from their personal funds, giving them money, etc. These situations need to be dealt with as soon as possible. In serious cases, it is up to the discretion of the Visiting Training Coordinator to ask this Accredited Visitor to cease visiting and to turn in his or her badge.

**Burnout** — An over-committed Accredited Visitor can easily suffer “burnout” resulting from too many patient and family visits over time. Accredited Visitors should be encouraged to take a break in their visiting routine; otherwise, they may become less effective visitors.

**Under-Visiting** — The Accredited Visitor may be spending far too little time with the patient or family, or he may be visiting too infrequently to keep his or her visiting skills up to standard.
Religious Motivation — See Section III, Group 3, Rule #11.

Disruptive Behavior — For reasons not always clearly understood, occasionally Accredited Visitors may become disruptive with medical staff. This is a serious problem that must be dealt with quickly and properly in order to maintain the respect of the medical staff. The Visitor Training Coordinator, Group Coordinator, or Chapter President have the authority to ask the visitor to stop visiting and to turn in his or her badge if necessary.

Unauthorized Visiting — Only fully trained and Accredited Visitors may represent the Mended Hearts or Mended Little Hearts Accredited Visiting Program and only with proper authorization. Unauthorized visiting, whatever the circumstances, is a serious matter and must never be permitted. It requires immediate action on the part of the group, and steps must be taken to prevent it. If it occurs, the Regional Director may need to ask the National Officers in charge of Accredited Visiting to deny membership privileges to such person.

How to handle problems

Good leadership skills are necessary to handle problems. The VTC should not deal with problems too lightly, nor should he or she react in a way that might belittle the Accredited Visitor. The best way to deal with any problem is to first check out the facts. After confirming the facts, if the person admits the mistake and says that he or she will correct it, then you just have to make sure that the person follows through. If not, when dealing with problems:

- Be sure to present the problem in a manner that is both firm and sensitive to the feelings of the Accredited Visitor. Tell the Accredited Visitor exactly what he or she did wrong, and also explain how that impacted, or might impact, the Accredited Visiting Program. You might also share how you feel about it.
- Listen to the Accredited Visitor’s version of the problem and try to gain an understanding of his or her point of view. Ask questions where necessary to gain a better understanding.
- Do not make statements or comments that are demeaning or insulting to the Accredited Visitor. Avoid extreme statements, i.e. “You always...” and “You never...”
- After both of you present your information, first, reaffirm you confidence in the Accredited Visitor. Then, if possible, work with the Accredited Visitor toward developing an acceptable solution to the problem. This can be done by brainstorming a list of possible solutions quickly, and then going through each to determine if they are workable solutions. Let the Accredited Visitor come up with solutions first, even if you already know
what solution you prefer. If needed add some ideas yourself. Sometimes you will be amazed at people’s ability to solve their own problem behavior.

*Remember:* The quality and success of the Accredited Visiting Program depends upon thoughtfully monitoring and evaluating the Accredited Visitors. Mended Hearts and Mended Little Hearts has earned — and must maintain — the respect of patients, families and medical professionals. Always recognize and encourage the strengths of each Accredited Visitor, and always be willing to help each Accredited Visitor to overcome any problems that arise.

**Canceling Visiting Privileges**

For serious problems that cannot be resolved in any other way, it may become necessary to cancel visiting privileges of an Accredited Visitor. If it is necessary to question the abilities of an Accredited Visitor or to cancel visiting privileges, do so with professionalism. Accusations or charges against an Accredited Visitor should be substantiated and verified, and any formal action must permit the Accredited Visitor to present his or her views and opinions.

Remember that before it gets to the point of canceling visiting privileges, the VTC should take all steps possible to deal with the problem, using the steps from the previous section about dealing with problems. If there is no way to resolve the issue without canceling privileges, the VTC can use the following steps to cancel privileges (using discretion about what would work in that specific situation):

A. For MLH, consult the Group Coordinator about the situation. For MH, contact the ARD or RD. Both the VTC and the Group Coordinator/ARD must agree that privileges should be cancelled.

B. Set up a face-to-face meeting with the Accredited Visitor.

C. Present the situation to the Accredited Visitor in a calm and objective manner. Explain clearly why visiting privileges must be cancelled. Be sure to avoid making personal comments about the Accredited Visitor.

   Example (for disruptive Accredited Visitor): “Our visiting program is vital to our group’s success. We have already discussed the fact that the families and doctors are finding your behaviors (be specific as possible) to be disruptive. Since this is continuing to happen, I have no choice but to cancel your visiting privileges. This means that you will not be permitted to visit patients/families until further notice.”

D. If possible, have the Accredited Visitor sign a paper stating that he/she understands that he/she does not have visiting privileges as a Mended Hearts or
Mended Little Hearts Accredited Visitor, and any visiting he or she does from here forth is in no way connected with Mended Hearts or Mended Little Hearts.

E. Notify the hospital(s) that the cancelled Accredited Visitor no longer has visiting privileges with Mended Hearts or Mended Little Hearts, and any visiting that he or she does is in no way connected to our organization.

When in doubt about how to deal with an Accredited Visitor problem, contact the National Program Coordinator as soon as possible. Time lost in dealing directly with a visiting problem can only produce greater problems and misunderstanding.

If necessary, the national officer in charge of visiting, or the National President of Mended Hearts, may act to resolve accredited visiting problems, but this is a last resort. Groups must be prepared to deal with their own Accredited Visitor problems. Only a small number of Accredited Visitors cause problems that require serious action. Mended Hearts and Mended Little Hearts exist to help others, and to help each other. This should be the spirit for problem solving within the Accredited Visiting Program.
Chapter 8

PHYSICIAN NOTIFICATION AND PATIENT FOLLOW-UP

Physician Notification

One suggestion for chapters or groups is to contact local cardiologists and cardiac surgeons by letter, asking them to tell their patients, or families of the children they treat, about the local groups available to them for support. Ask permission to leave a group newsletter, brochures, meeting schedules, local contact numbers and extra copies of Heartbeat (if available) in the physician’s waiting room.

Along with the letter to the physician, the group should include a letter to families of children with heart defects that the doctor can sign and give to his/her patients. Type Sample #2 on plain paper and attach it to the letter to the physician.

Family or Patient Follow-Up

Volunteers might follow-up their visits with a letter or card to patients or families, providing that the patient/family has given their address to the Accredited Visitor and specified that MH/MLH may contact them in this manner.

Let National know if you plan to incorporate these letters/cards into your Accredited Visiting Program. If your group already uses a similar program, please indicate this on your annual report form.

All groups must follow HIPAA guidelines. No family or caregiver can be contacted as follow-up unless that family has given its consent. You must specifically ask the family or caregiver if you may write or call them to see how their child is recovering or to send notices of group or chapter meetings.
Chapter 9

STARTING A NON-SURGICAL VISITING PROGRAM

Sometimes your group might want to start a non-surgical Accredited Visiting Program to either augment the current Accredited Visiting Program or as your only visiting program. You will need to follow these guidelines:

**Hospital Approval**

1. Meet with hospital contacts to discuss implementing a program to expand visiting to include visiting patients or families of children who are having non-surgical procedures.


3. Explain your feelings to the hospital contacts. Refer to your own feelings at the time you or you or your child had an echocardiogram, EKG, MRI or other procedure. Alternatively, have someone with you who has had (or whose child has had) one of these procedures.

4. Stress that Mended Hearts and Mended Little Hearts trains their Accredited Visitors, which includes understanding the feelings of heart patients and their families.

5. Explain the protocol of visiting patients and families of non-surgical patients, particularly if it will be done in another part of the hospital.

6. When you get hospital approval, tell the nursing staff that the Accredited Visiting Program is being expanded to include all heart patients. If non-surgical patients are cared for in another hospital location, be sure to contact staff there to acquaint them with Mended Hearts and Mended Little Hearts.

To start this type of non-surgical Accredited Visiting Program, you will want to get the approval and support of Accredited Visitors of your group. Ensure that everyone understands the purpose of the Accredited Visiting Program, and how this type of visiting enhances that purpose by helping patients and families deal with the emotions involved in being a heart patient or having a child with a heart defect or heart disease.
Training Accredited Visitors


2. Discuss the importance of understanding of the feelings of families whose child has had an echocardiogram, EKG, MRI, catheterization or other procedure.
   ➢ Accredited Visitors should not say or imply that children with heart defects might have to have surgery or other invasive procedures later. Point out that every child’s course of treatment is unique to him or her, and the family should discuss the options with the child’s doctor.

   ➢ Let the patient or parents/caregivers discuss whatever they wish. It is important that they communicate.

3. Plan a special training session asking someone in the medical profession to train your Accredited Visitors about the nuances of visiting patients or families in particular non-surgical circumstances. (This should be counted as reaccrediting for the Accredited Visitors.)

Chapter 10

TELEPHONE AND INTERNET VISITING

Telephone Visiting

Visiting families by telephone requires the same accreditation as visiting in-person. It is very important that anyone who is given a family’s personal information will handle that information with the sensitivity required. Telephone visitors must abide by HIPAA regulations and other procedures that guide the Mended Hearts/Mended Little Hearts Visiting Program.

Internet Visiting

Currently, Mended Hearts/Mended Little Hearts has no national internet-based visiting program. However, some Accredited Visitors may be given a family’s email address so that the Accredited Visitor can contact that patient or family. As visiting by telephone, to visit by email, an Accredited Visitor must first complete the regular accreditation/reaccreditation training given by the VTC. Again, this is done to ensure that the Accredited Visitor is aware of HIPAA issues and proper procedures to take when visiting families.
Chapter 11

WORKING WITH PEOPLE

As a Visitor Training Coordinator, you will be leading a group of Accredited Visitors. In order to lead any group, you need to have skills that help you work with others effectively. You will establish positive relationships with people when you:

Treat People Right

Effective leaders respect the dignity of others and have trust in the individuals they are working with. They act in a manner that expresses care and concern for people. These leaders recognize and encourage the strengths of others as well as being aware of areas of needed improvement. It is common for good leaders to frequently catch people doing things right and to praise them for it.

“Treat people as if they were what they ought to be and you may help them to become what they are capable of being.”

Johann Wolfgang von Goethe

Empower

A truly great leader empowers others, rather than dictating to others, so that his or her followers (in this case the Accredited Visitors) learn to make good decisions and become autonomous in what they do. These leaders learn as much from the people they lead as the people they lead learn from them.

‘The function of leadership is to produce more leaders, not more followers.”

Ralph Nader

Communicate

Two-way communication is essential when working with others. Good leaders share information realistically and truthfully about what can be done and what cannot be done. They also respond quickly to requests for needed information, resources, or help. If leaders don’t know an answer, they admit it and try to find the needed information.

To have two-way communication, leaders must be approachable. Leaders are approachable if they demonstrate characteristics like patience, acceptance of criticism, reliability, and concern for the feelings of others. It is also often helpful for leaders to display a sense of humor.
“People without information cannot act responsibly. People with information are compelled to act responsibly.”

Ken Blanchard, John P. Carlos, Alan Randolph
Empowerment Takes More Than a Minute

Remain open

Effective leaders are those who are good at working with others and remain open to new thoughts and ideas. These leaders don’t ever respond, “That’s just the way it’s done around here.” They recognize that people who are doing visiting will have good and creative ideas about how to improve the processes. These leaders will take the time to listen to the Accredited Visitors so that they feel heard and understood.

“We should not only use the brains that we have, but all that we can borrow.”

Woodrow Wilson

Give credit, take blame

Effective leaders are those who are quick to give credit and praise to the group as a whole, but they are not quick to assess blame to the group. Often these leaders accept the blame for problems themselves, as a reflection of a need for better leadership. It is destructive, when working with others, to point fingers at any individual for collective problems. This is not to say that individuals who are causing problems should not be dealt with, but if there are problems with the Accredited Visiting Program, the VTC should accept responsibility for those problems. On the other hand, if you have a great Accredited Visiting Program, give the credit to all of the Accredited Visitors.

“I praise loudly, I blame softly.”

Catherine the Great
APPENDIX A
MENDED HEARTS / MENDED LITTLE HEARTS ANNUAL VISITING REPORT
(note: this report is part of the complete annual report)

V. Visiting
A. Is the chapter/group visiting program ___ Active ___ Inactive ___ No Program
B. Number of Accredited Visitors: __________
C. Number of Training Seminars Held for New Visitors: __________
D. Number of Re-Accrediting Seminars: __________
E. List of Hospitals Served (Indicate Hospital, Clinic or Other)
   NAME OF FACILITY CITY and ZIP
   ____________________________________________ __________
   ____________________________________________ __________
   ____________________________________________ __________
F. Does your group distribute any form of care package? Y ___ N
   1. What does it include? ____________________________
   2. Where does the funding come from? ____________________________
H. Do you distribute literature/material other than MHI’s or AHA’s? Y ___ N
   NOTE: If yes, please include samples with this report.
I. Visiting Numbers
   NOTE: Odd numbered items should include only the number of families. Whether the visit is to one family member or several, it is counted as one family.
   Even numbered items should include total number of visits – there may be more than one visit to a particular family.
   1. Number of families visited face-to-face: __________
   2. Number of visits to families face-to-face: __________
   3. Number of families visited online: __________
   4. Number of visits to families online: __________
   5. Number of families visited on the telephone: __________
   6. Number of visits to families on the telephone: __________
   7. Total Number of families visited (Add items 1, 3, & 5): __________
   8. Total number of visits to families (Add items 2, 4, & 6): __________
APPENDIX B

MENDED HEARTS / MENDED LITTLE HEARTS
MONTHLY VISITING REPORT TALLY

This form is to help groups keep a tally of monthly Accredited Visiting numbers. Make copies of this form, and use one for each month. Then, at the end of the year, it is easier to calculate total visiting numbers.

Chapter/Group name: ___________________________________________________

Location: _____________________________________________________________

Hospital (name and address): __________________________________________

____________________________________________________________________

____________________________________________________________________

Month of: ___________________________________________________________________

In-person Visits

1. Number of families visited in-person _______
2. Total number of in-person visits _______

Telephone Visits

3. Number of families visited by telephone _______
4. Total number of telephone visits _______

Internet Visits

5. Number of families visited by internet _______
6. Total number of internet visits _______

Totals

Total families visited this month (add 1, 3 & 5) _______
Total number of visits this month (add 2, 4 & 6) _______

You can also post all of this numbers on a 12-month. Then it will be easy to calculate total for the end of the year reporting. This form does not need to be sent in to national. It is for your group’s personal use.
### APPENDIX C

**MENDED HEARTS / MENDED LITTLE HEARTS**

12-MONTH REPORTING SPREADSHEET EXAMPLE

<table>
<thead>
<tr>
<th>Month</th>
<th>Families Visited In-person</th>
<th>Total In-person Family Visits</th>
<th>Families Visited by Telephone</th>
<th>Total Telephone Visits</th>
<th>Families Visited by Internet</th>
<th>Total Internet Visits</th>
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*Transfer totals to Group Annual Visiting Report Form (Appendix A—Visitor Training Manual).*
Who We Are
Since 1951 Mended Hearts has been a national nonprofit organization with a history of offering support, encouragement and hope to heart patients, their families and caregivers during hospital visits and through support group meetings. Mended Little Hearts is a program of The Mended Hearts, Inc.

Our Mission
“To inspire hope and improve the quality of life of heart patients and their families through on-going peer-to-peer support, education, and advocacy”.

Our Members
We’re like the very people we serve — patients, parents, caregivers, and families of heart children — sharing our experiences as we offer hope. Healthcare professionals also join our mission by providing their expertise and support.

Our Method
We partner with hospitals and rehabilitation clinics across the nation to help patients, caregivers, and families who have children with heart defects/heart disease to have a positive patient-care experience.

Visiting Service
Mended Hearts/Mended Little Hearts Accredited Visitors serve families and caregivers of children with heart defects/heart disease by being there to listen, share their experiences, and offer encouragement to concerns.

I have read, understand, and agree to have a Mended Hearts/Mended Little Hearts visitor contact me.

Patient/Parent’s/Caregiver’s Signature: ____________________________________________________________

Printed Name: ________________________________________________________________________________

Date: ________________________________________________________________________________________

The Mended Hearts, Inc., and therefore Mended Little Hearts, honors patient confidentiality requirements. We recognize your medical information is confidential and protected by law. The Mended Hearts, Inc. does not maintain a national patient database. Your name will not be given or distributed to any other organization.
CONFIDENTIALITY STATEMENT

Mended Hearts and Mended Little Hearts honors patient confidentiality requirements. We recognize the fact that patient medical information is confidential and protected by law.

The Mended Hearts, Inc. National Office does not maintain a patient database. For three months, local groups, with the consent of the parents/caregivers, are allowed to keep the parent’s name, address and telephone number for the purpose of follow-up visits and/or newsletter mailing.

Exchange of visiting information between group members or officers must be conducted in a confidential setting.

ACCREDITED VISITORS ARE NOT ALLOWED TO RETAIN PATIENT HEALTH INFORMATION OR RECORDS. The child’s/parent’s/caregiver’s name, address or telephone number is not to be distributed to any other organization or used in any manner not initially revealed to the parent.

I have read, understand and agree to abide by the terms of this Agreement.

Accredited Visitor’s Signature: ________________________________

Printed Name: ______________________________________________

Date: ________________________________________________________

Chapter/Group Name: ________________________________________
| Name of Trainee | ____________________________________________________________ |
| Name of Observer | ____________________________________________________________ |
| Date of Visit | ____________________________________________________________ |
| Category of Visit | (in-person, telephone, internet) |

Observation of Visit

Trainee was
Friendly _____ yes _____ no  Comments: _______________________

Dressed appropriately _____ yes _____ no  Comments: ____________

Answered questions appropriately _____ yes _____ no
Comments: _____________________________________________________

Presented materials and chapter information to patient/family _____ yes _____ no
Comments: _____________________________________________________

Filled out report forms _____ yes _____ no
Other comments: ________________________________________________

| Other comments: | }
APPENDIX G

ACCREDITED VISITING RECORD

Chapter/Group __________________________________________________________

Hospital ____________________________________________________________

Address ____________________________________________________________

Name of Patient/Parent/Caregiver _______________________________________

Type of Visit

____ In-person    _____ Telephone    _____ Internet

Address of Patient/ Family _____________________________________________

Phone # of Family __________________________

Note: To record a phone number or address of a patient/family, the Accredited Visitor must ask the parent or caregiver’s permission to make a follow-up phone call or to send a newsletter or meeting reminder. This information CANNOT be used for any other purpose than explained to the patient. Furthermore, National does not collect any patient-specific data.

Name of Accredited Visitor ___________________________________________

Date(s) of Visit _____________________________________________________

Follow up:

Patient/Family agreed to _____ Phone Call    _____ Meeting Invitation    _____ Newsletter

Remember that all information and conversations with patient/child and/or family are confidential. Violation of confidential information may result in substantial fines under the HIPAA privacy mandates.