



**CHERUBS - The Association of Congenital  
Diaphragmatic Hernia Research, Awareness,  
and Support**

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Support  
Congenital Diaphragmatic Hernia  
Public Awareness



## *CHERUBS Volunteer Roles and Duties*

Date of Creation: August 17, 2009

### I. Roles of Officers and Volunteers

#### A. President

1. Oversee all activities, officers, volunteers, and board members
2. Represent CHERUBS at events, fundraisers, conferences, interviews, etc.
3. Create and maintain website
4. Compose all written materials including:
  - a. Newsletter
  - b. Parent Reference Guide
  - c. Pamphlets
  - d. Form Letters
  - e. Press Releases
  - f. Business Cards
5. Tabulate and publish CDH Research Survey Results
6. Research CDH Survey Results against medical journal articles
7. Make sure all New Member Packets are created and mailed
8. Make sure all Inquiring Packets are created and mailed
9. Update all databases:
  - a. Newsletter Mailing List
  - b. Complete Mailing List
  - c. Volunteer Lists
  - d. Member Files
  - e. Inquiry Files
  - f. Regional Files
  - g. Parent Matches
  - h. Research Library
  - i. E-Mail Address Book
10. Answer organization e-mails
11. Create annual financial statement
12. File necessary government paperwork
13. Balance accounts

14. Pay all bills
15. Apply for grants
16. Oversee all fund-raisers
17. Answer and return organization telephone calls
18. Monitor monthly member chats
19. Monitor listserv
20. Monitor forums
21. Monitor and update accounts on other sites (Facebook, Myspace, Twitter, etc)
22. Update organization blog
23. Check on families
24. Answer questions
25. Answer postal mail
26. Listen to families
27. File paperwork
28. Purchase supplies and equipment
29. Write receipts
30. Update CDH Research Library Files
31. Print off all documents sent by e-mail such as Membership Forms, Information Requests, Research Articles and follow proper filing and database procedures
32. Referee all disagreements between members, volunteers, and board members when it causes problems within CHERUBS
33. Research all new medical advances
34. Make sure all duties of volunteers, officers, and board members are being followed through.
35. Make sure all rules set by CHERUBS for all volunteers, officers, board members, activities, and services are being followed.
36. Think of new fundraiser
37. Think of new activities
38. Keep records of all activities, expenses, fund-raisers, projects
39. Help Volunteer Coordinator
40. Plan annual conference
41. Lead voting on Advisory Committee
42. Maintain volunteer software
43. Register domain names
44. Update legal team
45. Represent CHERUBS in all legal actions
46. Represent CHERUBS at all medical conferences
47. Ensure that all organization decisions are made with the best interests of the whole CDH community at heart.

#### B. Vice-President

1. Serve as our ambassador in the medical community
2. Help to spread the word about CDH
3. Notify CHERUBS of any medical advances that come to his/her attention
4. Refer families of children with CDH to CHERUBS
5. In the case of the death or dismissal of the president, make sure that CHERUBS continues on and a new president is appointed

#### C. Secretary

1. Follow assigned duties as given by the president
2. Help with new member work-ups and databases, as assigned by the president
3. Serve on the local Board of Directors
4. Serve on all committees
5. Advise the president of problems, deadlines, and volunteer activities
6. Help think of new fundraisers, activities, and projects
7. Help plan new fundraisers, activities, and projects
8. Oversee all volunteers
9. Help create and proofread all printed materials
10. Listen to parents
11. Learn all of the duties of the president, but not conduct them
12. Step in for the president when the president is ill or otherwise unable to fulfill duties
13. In case of the death or dismissal of the president, step in as temporary president until a meeting of the Vice-President and local Board of Directors appoints a new president- of which the secretary is automatically nominated.

#### D. Research Coordinator

1. Research all new medical information on CDH and the complications that commonly occur with CDH patients
2. Update and maintain the Congenital Diaphragmatic Hernia Research Library inventory list
3. Oversee all Research Volunteers
4. Help maintain About CDH and Recent News webpages
5. Write a “New Research and Procedures” article for The Silver Lining

#### E. Local Board Members

1. Attend quarterly meetings
2. Oversee the activities, officers, fundraisers, and projects of CHERUBS

#### F. Advisors

1. Vote on all major financial, legal and organization decisions at CHERUBS
2. Support services, volunteers and the President
3. Monitor forums
4. Vote to ban members if necessary
5. Vote on new services
6. Represent CHERUBS on all legal, state and federal forms
7. Hold quarterly meetings in person or on-line
8. Respond in a timely fashion to all issues
9. Help enforce organization rules
10. Represent CHERUBS at functions, conferences and other events in the absence of the President
11. Ensure that all organization decisions are made with the best interests of the whole CDH community at heart

#### G. Medical Advisors

1. Help to spread the word about CDH
2. Notify CHERUBS of any medical advantages that come to his/her attention
3. Refer families of children with CDH to CHERUBS

4. Send CHERUBS copies of any medical journal article involving CDH that you have authored/co-authored

#### H. Memorial/Birthday Volunteer Director

1. Oversee all Memorial/Birthday PM Volunteers
2. Update the Secretary quarterly on progress
3. Make sure all memorial/birthday PM's are sent on time
4. Make sure that all days of the week have a volunteer to send PM's

#### I. Birthday / Memorial Day PM Volunteers

1. Make sure all PM's are sent on time
2. Notify committee that PM's are sent
3. Check in with your card director at least monthly

#### J. Research Volunteers

1. Research medical journal articles on-line and/or in medical libraries for articles on:
  - a. Congenital Diaphragmatic Hernia (CDH) – including all types of CDH
  - b. Extracorporeal Membrane Oxygenation (ECMO)
  - c. Nitric Oxide (NO)
  - d. Tracheal Ligation & Occlusion
  - e. In Utero Surgery
  - f. Feeding Problems
  - g. Lung Hypoplasia
  - h. All types of CDH repair
  - i. All genetic studies and epidemiology studies involving CDH
  - j. All syndromes involving CDH
  - k. All other research involving the cause, treatment and prevention of CDH
3. Send on-line material to the Research Coordinator
4. Mail printed material to the President
5. Report progress quarterly to the Research Coordinator
6. Report printing and postage costs for reimbursement or receipt to the Research Coordinator at least annually

#### K. On-Call Volunteers

1. Listen to families needing to talk
2. Do NOT give out medical advice
3. Do NOT answer medical questions
4. Refer all families to CHERUBS main office for membership, medical questions and referrals
5. Notify Secretary of all calls

#### L. State/International Representatives

1. Welcoming new families in your state/country, listening to them and helping them with information about CDH.
2. Checking up on families to make sure their doing ok. If you haven't heard from them in over two months, just drop them a line to see how they are doing.
3. Encourage non-members to fill out membership form and members to join our services:

matching, sending in their stories and pictures and joining our on-line services.

4. Represent CHERUBS at your state/national parent conferences.
5. Up-dating the Volunteer Coordinator on your progress once a month.
6. have local get-togethers. (optional)
7. Send out small newsletters within your area, with approval. (optional)
8. Create a web site or blog for your state / country. (optional)
9. Post and encourage posting on your state / country's forum on our site.
10. Notify the President and secretary of all functions, get-togethers, projects, published materail, chats, conference attendance and other activities in advance.

## II. All Volunteers Must Also:

1. Report to the Volunteer Coordinator or Committee Leader(s) at least once a month
2. Meet volunteer software milestones in a timely fashion
3. Record hours volunteered on our volunteer software
4. Be an active member of CHERUBS and our forums
5. Check and respond to volunteer mail at least once a week
6. Follow all rules and guidelines set in the CHERUBS Volunteer Rules signed agreement