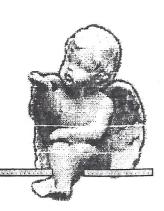


## CHERUBS

## The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support

A Non-Profit Organization



June 15, 1996

## Dear Members:

Because we write our newsletters a month in advance (to give the printers time to print them), I thought that we might add a page to each newsletter to update them to our mailing time. First let me say, I know this newsletter is short compared to past newsletters but to try to save some postage cost, we cut out 4 pages this time. Hopefully, the next newsletter will be 12 pages.

Since we wrote this newsletter, we have added 2 new members to our list of medical advisors. Claudine P. Torfs, PhD, from the California Birth Defects Monitoring Program and Wendy Barkley, a registered dietician, have graciously agreed to become Honorary Medical Advisors. Claudine Torfs is an epidemiologist, which means she studies the trends of birth defects, cancer, and other diseases and disorders in California. Wendy Barkley is also the mother of a son, Jack, who was born with CDH. They are both wonderful additions to our professional membership.

We also attended the American Pediatric Surgical Association's annual convention in San Diego. There were quite a few exhibits and speeches about congenital diaphragmatic hernia. We will printing the summaries of these reports in our next newsletter.

In the newsletter I talked about the episode of Chicago Hope that involved a baby with CDH. Well, wouldn't you know it, it aired already before we could get this newsletter to you, but maybe it will rerun again this summer.

The June issue of Reader's Digest has a short story about a family who underwent in utero surgery, "The Baby Who Was Born Twice". One of our medical advisors, Dr. Michael Harrison, is included in this story.

I'd like to say thank you to Glaxo Wellcome for donating a used computer. It is sincerely appreciated, but unfortunately it quit on us just a few weeks after we got it. So we still need a computer!

Some of you may have missed the section "Questions and Answers". Well, we just didn't have any questions this time, but keep them coming in if you do! I'd also like to start a "new additions" sections for new babies of our members. We'd like to include those babies with CDH and their little brothers and sisters. I think by also printing the names of healthy new siblings, they will be inspirations to other parents who are thinking about having more children after a child with CDH. So let us know if you've had any new additions!

For those of you who sent pictures for the conference: If you stated that you wanted them returned after the conference, they should be inclosed with this newsletter. If you didn't get them back, but do want them returned, just let me know and I'll mail them out. If you don't request that they be returned, they will put up on our bulletin board and used at future conferences.

Finally, we going to put together a library of research for our members, so that when you call for specific information we will have it on hand to make copies of for you. This goal will be a major undertaking and we need your help! Enclosed with this newsletter, you will also find information about this project.

I hope you all have great summers!

Sincerely,

Dawn M. Torrence President and Founder

Mrs. Dawn M. Torrence, President and Founder