

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Summer 2004

Dear Friends,

During a recent family trip to [REDACTED], we had the opportunity to meet with [REDACTED], whose daughter [REDACTED] passed away from ACD in February 2003. [REDACTED], [REDACTED], big sister [REDACTED] and newborn baby brother, [REDACTED], graciously invited us into their home and into their hearts as we shared memories of our babies. We are thankful to them for sharing [REDACTED] with us, and we understand they had plans to share [REDACTED] with another family they visited while vacationing in Florida.

Over the last seven years, we have had the opportunity to meet a few families from the ACDA and have found that talking to other families that have experienced the same tragedy is sad but healing. We hope that during your travels, you will have the occasion to meet with other families in the ACDA and share your family with them. The ACDA directory is the best resource for finding families in the area you plan on traveling to.

Fondly,

Donna & Steve Hanson
ACDA Executive Directors
sdhanson@flash.net

Family and Friends Contribute to the Success of Cookbook Fundraiser

Recipes from the Heart, the cookbook that the Durand family of New York designed and published in memory of their daughter, Olivia, is already a successful fundraiser for ACD research. Because of the efforts of many friends and family, they have sold over 400 cookbooks and the Durands sent their first check for \$2,265 to NORD. There are a few people that the ACDA would like to recognize for their efforts in selling these cookbooks and helping to raise awareness of ACD.

- Steve Lake (brother of Donna Hanson) and Jeffrey Bradley bought 30 cookbooks and sent them as gifts to other family members, friends and co-workers. In a beautiful note they included with the cookbook, they wrote about ACD, the short life of Steve's nephew, Eric, and the purpose of the fundraiser. Not only did Steve and Jeffrey support the Durand's fundraiser, but they helped remind others close to them that Eric is still alive in our hearts and that we are working to find a cure for ACD.
- [REDACTED] mother, [REDACTED], has sold 35 cookbooks and [REDACTED] aunt, [REDACTED], has sold 10 at her office.
- [REDACTED], [REDACTED] and [REDACTED] are members of the Durand's gym called *Olivia's Circle*. These three women graciously took cookbooks to their offices and left them with a note asking their co-workers to support this cause. [REDACTED] has sold 28 and [REDACTED] and [REDACTED] have each sold 20.
- [REDACTED], a friend of *Olivia's Circle* and who donated more recipes than anyone else, has sold over 20 recipe books.
- [REDACTED], who owns Giuseppina's Boutique next to *Olivia's Circle* and who was Olivia's godmother, has sold 15 books.
- [REDACTED], ACDA member in England, purchased several cookbooks to sell to friends and family.

ACDA also sends a special thanks to Tina at *Olivia's Circle*. She has been instrumental in setting up displays and e-mails to improve the cookbook sales.

There are still many cookbooks left. For only \$8.00, they make great stocking stuffers and gifts during the upcoming holidays. We bought some and intend to give them as teacher gifts this holiday season. It costs only \$3 to mail any amount of cookbooks because of a generous offer made by a member of *Olivia's Circle*. If you haven't bought your copy yet or if you would like to sell some cookbooks, please e-mail Lisa Durand at casper119@aol.com or call Olivia's Circle at (518) 456-2187. Credit cards and checks are accepted. 8

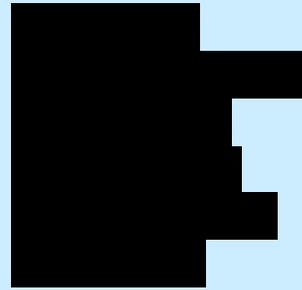
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In Memory Of

We have created a new section of ACDA Notes dedicated to remembering the birth dates of our members' babies who are not here to share our lives. Please pause to remember them.



October 17
October 28
November 2
November 7
November 13
November 26

Please let us know if we have inadvertently omitted your baby's name or if you do not wish to have your baby's name included in this section. You can email us at sdhanson@flash.net. 8

ACD Research Account Keeps Growing!!!!!!

THANK YOU!!!

It was so encouraging and heartwarming to recently learn that the ACD Research Account at The National Organization for Rare Disorders (NORD) was closing in on the \$35,000 required to issue a grant (\$32,900 as of August 31). One year ago, there was approximately \$13,000 in the ACD research account; so in one year, the amount has more than doubled!!! In addition to the [redacted] [redacted] major fundraiser in Belgium and the cookbook fundraiser by the Durand family in New York, there have been some recent contributions made to NORD that we would like to recognize.

- When Steve Lake (brother of Donna Hanson) and Jeffrey Bradley heard that that the ACD research account was close to \$35,000, they sent a \$1,000 donation to NORD to help the ACDA get even closer to their goal.
- Wonderland Nursery School in Albany, New York had a bike-a-thon again this year and donated \$897.50 to NORD in memory of Olivia Durand. This was the second year that Wonderland, the preschool that Olivia's older brother, [redacted], attended, raised money for ACD research. Thank you to all the children, teachers and parents who made this wonderful gesture!
- *Olivia's Circle* sent NORD a check for \$530 from membership donations from January to July. For each and every membership paid monthly, \$1 is donated to the ACD Restricted Research Account in Olivia's memory.

Many, many thanks to these family members and friends and to all of you who have contributed to this successful campaign to raise money for ACD research.

As most of you probably realize, it takes a lot of funding to make meaningful progress in the medical research arena. While it will be a significant milestone for our small group of families to raise \$35,000 in two years, it is our hope that our fundraising efforts will continue and expand so that we can further contribute to research until a cause and cure for ACD are found. 8

We Think of You In Silence

We think of you in silence
And often speak your name,
But all that's left to answer
Is your picture in a frame.

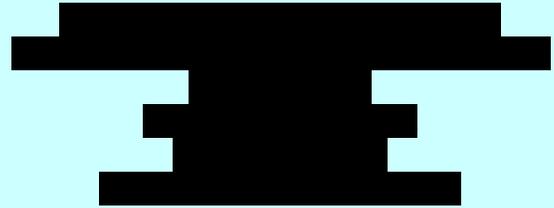
If we could have one lifetime wish
One dream that would come true
We would pray to God with all our hearts
For yesterday and you.

If tears could build a stairway
And heartaches make a lane
We could walk our way to Heaven
To be with you again.

- Author Unknown

New Families

Please take some time to introduce
yourself to our new family:



Announcements

- We have been experiencing some problems with the guestbook on the ACDA website. We apologize and hope to have it corrected soon.
- There is \$32,900 in the ACD research fund at NORD as of August 31, 2004. Thanks to everyone who is helping us reach our goal of \$35,000!!!
- The ACD Study at Baylor College of Medicine would like to include blood samples from all the healthy siblings. Contact Bassem Bejjani at Office Phone: (509) 368-6717, Fax: (509) 358-7627, or E-Mail: bejjani@wsu.edu for more information.
- If you would like to contribute to ACD research, you can do that by mail or on-line. Since the ACDA is *not* a non-profit organization, we have set up a fund specifically designated for ACD research at NORD (National Organization for Rare Disorders). You can make a tax deductible donation to the ACD fund by sending a check to the following address. **Please make your check payable to "ACD Restricted Research Fund of NORD" to earmark your donation for ACD research.** Many employers have a Matching Gifts Program. Please check with your Human Resources department to see if they will match your contribution.

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***ACD Study Team Article
Accepted for Publication***

The Baylor ACD Study Team of Partha Sen, PhD, Nivedita Thakur, BA, David W. Stockton, MD, Claire Langston, MD and Bassem A. Bejjani, MD notified the ACDA that their article on the phenotype of ACD has been accepted by the *Journal of Pediatrics*. Their work to define the characteristics of ACD was supported in part by a grant from the National Institute of Health and by participation of ACDA members. Baylor projects that the article will be published later this year. Baylor has requested that the article not be published on the ACDA website since the article belongs to the *Journal of Pediatrics*; however, you can obtain a copy from us via e-mail. Baylor expressed its appreciation for all those families who have supported their research with blood and tissue samples and other information. Without ACDA member participation, this research would not be possible. 8

Just Say "I'm Sorry"

*You don't know how I feel; please don't tell me that you do
There's just one way to know--have you lost a child too?
"You'll have another child"--must I hear this every day?
Can I get another mother, too, if mine should pass away?
Don't say it was "God's will"--that's not the God I know.
Would God, on purpose, break my heart, then watch as my tears flow?
"You have an angel in heaven--a precious child above."
But tell me, to whom here on earth shall I give this love?
"Aren't you better yet?" Is that what I heard you say?
No! A part of my heart aches and I'll always feel some pain.
You think that silence is kind, but it hurts me even more.
I want to talk about my child who has gone through death's door.
Don't say these things to me, although you do mean well.
They do not take my pain away; I must go through this hell.
I will get better, slow but sure--and it helps to have you near.
But a simple "I'm sorry you lost your child" is all I need to hear.*

--Gail Fasolo--

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