

# ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 6, Issue 4

<http://www.acd-association.com>

Fall 2004

Dear Friends,

The holiday season is here, and it is sometimes difficult to be joyful when the loss of your baby has left such a void in your life. This feeling can be made worse by others not wanting to talk about the child (for fear of hurting your feelings) or you not wanting to talk about it because other people just don't understand.

Many ACDA members have described a similar feeling, and we also experience this. If this feeling hits you, try contacting another ACDA member via phone, e-mail, letter, or even coordinate a meeting if your travels take you near another member. The ACDA directory contains all the key contact information. Several members communicate periodically and others have formed relationships with other ACDA members. Support is what ACDA is all about, and it's good to have someone else that really understands and can personally relate to your experiences. This communication only takes a few minutes and will not only help you, but the other person as well.

Remember, a friend is the best gift you can give yourself anytime and particularly this holiday season. Best wishes for a joyous holiday.

Fondly,

Donna & Steve Hanson  
ACDA Executive Directors  
[sdesj@verizon.net](mailto:sdesj@verizon.net)

## ACD Fund Nearing \$35,000

The ACD Restricted Research Fund at the National Organization for Rare Disorders (NORD) is close to the \$35,000 minimum required for NORD to fund a Clinical Research Grant. At the end of October, NORD reported that the ACD fund was at \$33,900. This is a remarkable achievement for our small group of family and friends in a two year period. It is heartwarming to have had so many generous donations that memorialize our babies.

In order for NORD to initiate a Request for Proposal (RFP) to medical researchers next year, our fund must have a minimum of \$35,000 by December 31, 2004. NORD only issues RFPs once a year so we need everyone to help us achieve this goal so that a research grant for ACD can be awarded in 2005.

Here is the necessary information if you, your family and friends would like to make a contribution to ensuring an ACD research grant award in 2005:

### Contributions from within the United States

- Please make your tax deductible check payable to "Alveolar Capillary Dysplasia Restricted Research Fund of NORD" to earmark your

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### IMPORTANT ANNOUNCEMENT

Please note that effective immediately, the e-mail address to contact the ACDA is changing to:

[sdesj@verizon.net](mailto:sdesj@verizon.net)

Likewise, if your e-mail address changes, please let us know.

donation for ACD research.

- To make a donation in memory of a loved one, please include “In memory of *baby's name*” in the memo section of the check.
- If you would like your contribution acknowledged to the parents of the baby, please include the name and address of the parents to be notified.
- Many employers have a Matching Gifts Program. Please check with your Human Resources Department to see if they will match your contribution.
- Send your contribution to:

**National Organization for Rare Disorders**  
**P.O. Box 1968**  
**Danbury, CT 06813-1968 USA**

### International Donations

- NORD recommends that families living outside of the United States use a credit card to make a donation since it costs less to convert international currency when using a credit card.
- Tax deductibility of this donation varies by country. Check your tax code.
- Contact Cindy Thayer [cthayer@rarediseases.org](mailto:cthayer@rarediseases.org) with the authorization amount, type of credit card (Master card, Visa), name on the card and the expiration date on the card.
- Indicate the donation is for “Alveolar Capillary Dysplasia Restricted Research Fund of NORD”
- Provide the “In Memory of” and acknowledgment information as described above.

Do not contribute through the NORD website at this time because it is not possible to designate the contribution for a restricted fund and it will go to the general NORD (not ACD) fund.

We feel confident that together we can reach this milestone and create the first of many ACD research grants.

## Research News

### ACD Paper Published

“Expanding the Phenotype of Alveolar Capillary Dysplasia (ACD),” authored by the ACD research team at Baylor College of Medicine in Houston Texas, has been published in the November 2004 edition of the *Journal of Pediatrics*. Baylor provided the ACDA with reprints of this journal article. Copies were e-mailed to ACDA members but if anyone else would like to obtain a reprint, please e-mail us at [sdesj@verizon.net](mailto:sdesj@verizon.net). The article will not be posted on the ACDA website due to the *Journal of Pediatrics* copyright restrictions.

Baylor thanks all the families that have participated in and supported their research and who made the publication of this article possible. The ACDA would like to acknowledge and extend thanks to Drs. Bassem Bejjani, Partha Sen, Claire Langston, and David Stockton and their staff of doctors and researchers who are working towards finding answers for those of us who have lost a baby to this disorder.

### Additional Baylor Grant application

Baylor submitted a grant application to the National Institutes of Health (NIH) for research funding to understand the molecular genetics of Alveolar Capillary Dysplasia. If awarded, the grant will be used to continue their research and create a database. The database will keep all the family tracking, clinical, and genetic analysis data for the research team's internal use. It will hopefully have an interface for families to see and submit information about their family without being able to see or access other families data, and it will have a public view that shows aggregate information similar to what was published in the recent paper.

A letter of support for this grant application was sent by the ACDA in late September. The letter emphasized the strong relationship and support between the Baylor research team and the ACDA membership. The application was submitted on September 30th and the research team expects to receive scoring results next spring. If the NIH decides to fund this project, support would be expected around July 2005.

# Fundraising Opportunity

David Stockton, MD, from the ACD research team at Baylor, notified the ACDA of a unique fundraising opportunity for our members. The following contest is a great way to raise money for the ACD research account at NORD and to acknowledge your family's efforts for a very personal cause. Take a look and let us know if you submit an entry!!!

Does your family volunteer together? FamilyFun, in partnership with DisneyHand, which does worldwide outreach for The Walt Disney Company, would like you to tell them about what it is you do -- and why!

If you are one of five Grand Prize winners, DisneyHand will donate \$5,000 to the 501(c)3 charity or public school of your choice, and your family will win a deluxe gift package of FamilyFun books and kits; and if you are one of 25 First Prize families, DisneyHand will donate \$1,000 to the charity of your choice, and you will win a gift package of FamilyFun books and kits. All families participating in the contest will receive a FamilyFun Volunteers' certificate.

As part of the entry process, you'll be asked to answer the following questions:

- What project and organization did you volunteer for?
- Which family members participated?
- When in 2004 did this take place?
- How many total hours did you volunteer as a family?
- What was special about the way you volunteered together?
- How did your work benefit others or improve the community or world you live in?
- How did volunteering strengthen your family relationships?

You'll probably want to take a moment to get your answers ready before entering, since all entry fields will have to be completed in one session.

So **enter the FamilyFun Volunteers Contest now!** To enter, all you need to do is go to the Family Fun website:

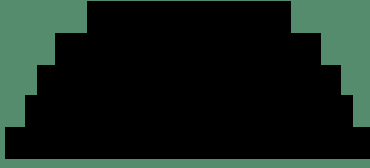
(<http://familyfun.go.com/parenting/learn/activities/feature/volunteers-contest/>) and submit an entry by signing in (you must be a registered visitor).

## Announcements

- ***Recipes from the Heart***, the cookbooks that the Durand family developed in memory of their daughter, is still available for \$8.00. They make great holiday gifts and can be purchased by e-mailing Lisa Durand at [casper119@aol.com](mailto:casper119@aol.com) or calling Olivia's Circle at (518) 456-2187. Credit cards and checks are accepted.
- Thank you to the short mat bowling club of Barnstaple, England who donated £25.00 (~\$50 USD) in memory of [REDACTED] [REDACTED].
- 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](mailto:bejjani@wsu.edu) for more information.

## New Families

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



## Silent Footprints

We never had the chance to play, to laugh, to rock, to wiggle.  
We long to hold you, touch you now and listen to you giggle.

I'll always be your mother. He'll always be your dad.  
You will always be our child, The child we never had.

But now you're gone.. but yet you're here. We'll sense you everywhere.  
You are our sorrow and our joy. There's love in every tear.

Just know our love goes deep and strong; We'll forget you never.  
The child we had, but never had, And yet will have forever.

(c) Christie Michael All Rights Reserved

## Safe Arrival

[Redacted]  
To Proud Parents  
[Redacted]  
Congratulations!

## In Memory Of

We are dedicated to remembering the birth dates of our members' babies who are not here to share our lives.  
Please pause to remember them.

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 [sdesj@verizon.net](mailto:sdesj@verizon.net).

<http://www.acd-association.com>