From The Alveolar Capillary Dysplasia Association

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Winter 2005

#### Dear Friends.

We were overwhelmed by the response we received in December to our request for donations to the National Organization for Rare Diseases. We are so excited to report that through many generous contributions, we not only exceeded the \$35,000 threshold but we exceeded it by over \$5,000!! There were a few people that contacted us and ensured us that the account would exceed the required \$35,000 by year end as they would personally make up any shortfall. Employers made extremely generous donations, families contributed and our wonderful family members and friends donated to the account.

On behalf of the ACDA members, we thank all of you for supporting this effort. We feel extremely fortunate to be able to contribute to ACD research after establishing an account with NORD less than three years ago. We hope that our efforts will help to provide us with the answers we all seek.

#### Fondly,

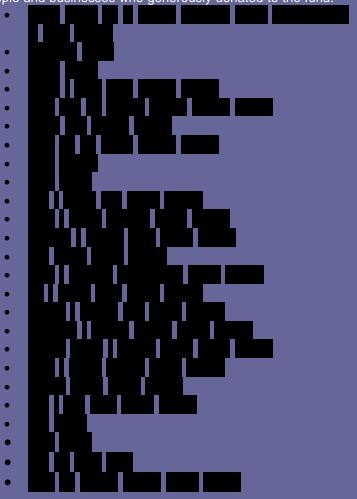
Donna & Steve Hanson ACDA Executive Directors sdesj@verizon.net

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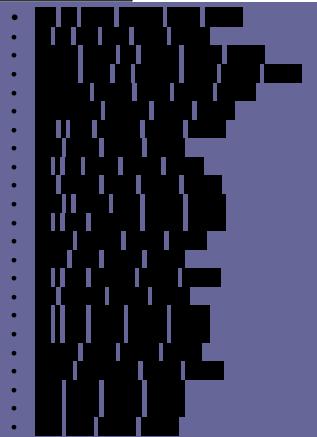
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### ACD Research Account Exceeds \$35,000; Research Grant from NORD is Initiated

In December 2004, the National Organization for Rare Diseases (NORD) notified the ACDA that if the ACD Restricted Research Account exceeded \$35,000 by the end of the year, NORD would be able to award a grant for ACD research in 2005. The ACDA is extremely grateful for the tremendous response it received to it's request to exceed this threshold. Our ACDA families, extended family members, friends and even employers generously donated to the account to ensure that the account exceeded \$35,000 by the end of the year. Because of so many generous people, the balance of the ACD fund as of December 31, 2004 was \$40,455.00!!! The ACDA would like to extend a heartfelt thank you to the following people and businesses who generously donated to the fund:



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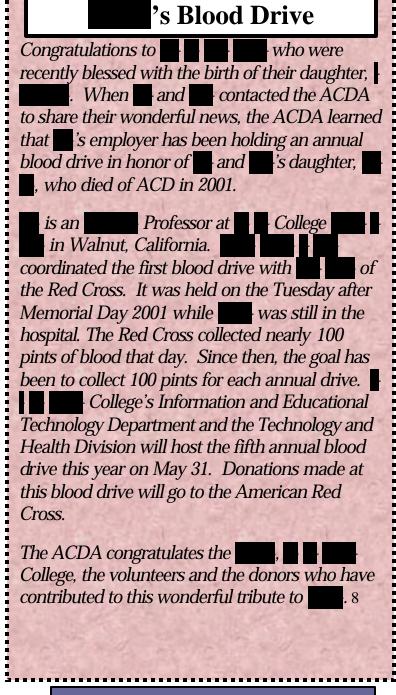


We made an attempt to get the names of everyone who made a contribution. Please accept our apology if you made a donation and your name is not included.

As a result of exceeding the \$35,000 threshold, NORD informed the ACDA that they have begun the announcement process for the ACD research grant. On January 31, 2005, the Request for Proposal (RFP) was posted on the NORD website at

<u>www.rarediseases.org/research/requests</u>. Proposals for "the one year grant for clinical research studies related to the early detection, diagnosis, or treatment of patients with Alveolar Capillary Dysplasia" are due to NORD on April 13, 2005. NORD will announce the grant recipient on September 30, 2005.

We will keep you posted on the grant process in upcoming newsletters.  $\boldsymbol{8}$ 



# New Families

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

Parents of January 20 – March 2, 2004

Australia

# Second Annual 's Trophy to Be Held in April

and of Belgium have announced that the second annual 's's Trophy will be held on April 23, 2005. This highly successful dog agility competition was established last year by and in memory of their son, who died of ACD in 2003. The spassion for dogs was turned into a fundraiser for ACD research and last year's event raised \$11,500 (9500 euros) for the ACD Restricted Research Account at NORD.

They are expecting the same competition format as last year with agility and obstacle courses but are expecting about 175 dogs to compete (versus 120 in 2004). The dog school that the are involved with, Hondenschool De Roedel Brecht, are again supporting this fundraiser with their time and effort. This year, all the money donated by sponsors will be donated to NORD for the Restricted ACD Fund.

The ACDA extends a heartfelt thank you to the sand all their sponsors, volunteers and participants who are supporting this wonderful tribute to supporting the sand participants.

## Memorial Garden

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 <a href="mailto:section.">sdesj@verizon.net</a>.

# **Announcements**

- Olivia's Circle donated \$4,483 in 2004 to the ACD research fund at NORD. This includes contributions from membership and from sales of "Recipes from the Heart" cookbook. Thank you to the Durand family for their efforts on behalf of ACD.
- Recipes from the Heart, the cookbook that the Durand family developed in memory of their daughter, is still available for \$8.00. They can be purchased by e-mailing Lisa Durand at <a href="mailto:casper119@aol.com">casper119@aol.com</a> or calling Olivia's Circle at (518) 456-2187. Credit cards and checks are accepted.

