

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Spring 2004

Dear Friends,

We are so grateful for the continuing efforts of our ACDA families to raise money for ACD research. In this newsletter, you will read about the amazing energy, creativity and dedication of the Durand and [REDACTED] families. Along with their own commitment to remember their babies, they have been blessed with very generous friends and family who have been dedicated to helping them with their fundraisers. We hope their stories will inspire you.

ACDA families, their relatives and friends have been the driving force behind the funding being collected at NORD that is restricted for ACD research. Because of you, over \$15,000 has been raised since the account was established just two years ago. It is because of you that we will soon be able to contribute financially to the research being done on ACD. We are so grateful to all of you and hope that your efforts will continue to raise awareness of ACD.

Fondly,

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

[REDACTED] AGILITY Trophy A RESOUNDING success!

On April 24, the most successful fundraising effort for ACD research took place in Belgium in memory of [REDACTED], who died from ACD in July 2003. [REDACTED]'s parents, [REDACTED] and [REDACTED], organized a dog agility competition that raised \$11,500 (US dollars (9500 euros). Over 120 dogs participated in the competition and over 200 people attended. With the help of many generous friends, family, community members and sponsors, the event was a remarkable success! There were five agility courses and prizes for the winner of each course in each category (small-medium-large dog).

In order to raise money from other sources besides the traditional registration fees and concessions, the [REDACTED]'s became creative. On the day of the competition, participants were offered a chance to run an obstacle course with their dog for an additional charge. By the end of the day, \$237 dollars had been raised! [REDACTED] and [REDACTED] were touched by the generous spirit of the participants on the day of the competition. In addition to the obstacle course, money was raised on the day of the event by a raffle called a tombola. [REDACTED]'s niece, [REDACTED] and [REDACTED], a friend of the [REDACTED] family, sold tickets during the competition and two winners were selected to receive gifts donated by Suzanne and Guido Bruynseels-Wensel.

The competition truly became a community event when [REDACTED]'s, [REDACTED]'s twelve year old nephew, asked his schoolmates from St. Cordula in Schoten, Belgium to help him raise money for ACD research. Two classes of 12-year old students held a walk-a-thon and raised \$1,200 that they donated

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to the [REDACTED]'s event. The amount of money these students contributed was the highest ever raised in the history of their school.

All the proceeds received from the registration fees, snacks, beverages, event activities and sponsors will be donated to NORD and earmarked for the ACD Restricted Research Fund.

This event was a labor of love by [REDACTED] and [REDACTED], and ACDA is overwhelmed by their efforts on behalf of ACD research. The [REDACTED]s want to sincerely thank their families, their friends, and the competitors. [REDACTED] and [REDACTED] wanted to especially thank the members of Hondenschool De Roedel Brecht who showed them what real friendship means by pulling more than their weight by volunteering the entire day of the competition to ensure that everything went smoothly. Special thanks also to the following friends and sponsors:

- Jan De Laet, a local butcher who donated 200 hamburgers;
- Guido Van Campenhout, the administrator and bookkeeper for the event;
- The competition judges, Jef Van Eester, Wilfried Claes, Guy Lenaerts and Willy Simons;
- Herman Faes, who donated the event venue, and [REDACTED]
- Bento who donated a bag of dog food to each dog that entered the competition.

Photo May 2003

The ACD Association sends it heartfelt and sincere thanks to the [REDACTED]s and all the generous people who contributed to the success of [REDACTED]'s *Agility Trophy*!!

Thank you also to all the additional sponsors and contributor's to *Nick's Agility Trophy* (and anyone else whose name may have accidentally been omitted).

Accountantskantoor Lingier
Antwerps Beroepskrediet
Autovak N.V.
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Baert Gerrit
Boden-Sommen
Bruynseels - Vochten
Cafe De Gulden Coppe
Caralinda
Claes - Van Loo
Collega's Nancy
Colorpa bvba
Comm. V. Dired
David Wakman
De Hoon Walter
De Keyzer Diane
Deweert-Janssens
D'Haene Jan
Dignef Jozef
DP verzekeringen
Gabriels - Maes
General Safety Coordination

Goolaerts Jan
Groover International
Grosso Laura
Haerbos Jacobs
Heyvaert Hubert
Hondenkapsalon Fiocco
Jenny Vandenhole
KBC - Ranst
Kenis Franky
Kets Rudy
Kolum verzekering
Lippeveld Patrick
Masamo
Meert Anne
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Oma & Opa Debucquoy-Van Gaever
Pastoor LO
Quintens - Ceunen

S.D.S.
Sagam
SCA Grafhic paper
Sint Cordula
Smet - Macouter
Spoelders
Sun Chemicals
Teurfs Franciscus
Thienpondt Katia
Tips Luc
Van Ammel
Van de Perre Paul
Van Der Auwera
Van Doninck-Mothrath
Van Geel - Quisquater
Van Herck
Vanoevelen Anna
Verpoorten
Voets
Wagemans Jules

"Recipes from the Heart" Now Available

The loving efforts of the Durand family and numerous friends have resulted in the publication of "*Recipes from the Heart*", a tribute to Olivia Leona Durand, who died of ACD in 2002. This cookbook contains over 400 recipes from around the world and is being sold for \$8.00 (US) plus shipping. Thanks to a special deal with Fedex, shipping is only \$3.00 per order to anywhere in the US. There were 1,000 cookbooks printed and they are going fast – 200 were sold in the first week. When all the cookbooks are sold, at least \$4,000 will be donated to NORD for ACD research. To receive a copy of the cookbook or to obtain copies to sell, either e-mail Lisa Durand at casper119@aol.com or call Olivia's Circle at (518) 456-2187. Credit cards and checks are accepted.

The ACDA would like to thank Lisa and Harry Durand and all the generous family, friends and businesses who contributed to this wonderful tribute to Olivia. Special thanks to Tina, at Olivia's Circle, who was instrumental in the compilation of recipes and the shipment of the cookbooks.

Dreams

Is it possible, tell me, to hold onto dreams
When they've crumbled to ashes, and nothing it seems.
Remains but the memories of happier days
When tomorrow held promise in infinite ways.

Can you hold onto hope after losing a child?
When nothing makes sense, and nothing's worthwhile?
When the days and the nights all roll into one,
and though moving's an effort, it's easy to run...

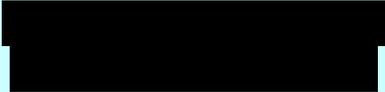
But no matter how fast there appears no escape
From the pain and heartache that follow and shape
the efforts we make to hold onto our dreams.
That have crumbled to ashes, that are haunted, it seems
By our constant companions of guilt and despair;
horror and grief tag along everywhere.

Where are our answers, where does pain end?
I search and I suffer - I ask you again.
Can you hold onto hope after losing a child?
When nothing makes sense,
and nothing's worthwhile?

-Sally Migliaccio

Safe Arrival


Born April 29, 2004
To


Congratulations!!!

Status of ACD Article in *Journal of Pediatrics*

As mentioned in the Winter 2004 "ACDA Notes," the ACD study team at Baylor College of Medicine has written an article on the clinical data from their ACD study. The article was submitted to the *Journal of Pediatrics* in February for initial review. After making some requested changes, it was resubmitted in May and Baylor is awaiting final decision from the *Journal of Pediatrics*. Baylor will provide a copy of the manuscript to ACDA as soon as it is formally accepted by the *Journal*.

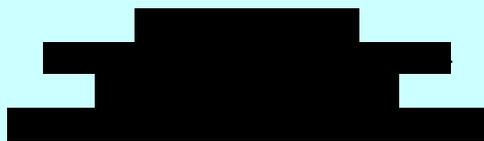
Announcements

- There is \$15,937 in the ACD research fund at NORD as of May 25, 2004.
- 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 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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New Families

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



How very softly you tiptoed into
my world

Almost silently

Only a moment you stayed

But what an imprint

Your footprints have left

Upon my heart.

-Dorothy Ferguson