

Dear Friends,

As a new year begins, we thought it was an appropriate time to reflect back on the significant events of 2003.

- Through the efforts and support of Dr. Robin Steinhorn, NORD officially listed ACD in their rare disease database.
- Thanks to many generous families and friends, contributions to NORD reached 40% of our goal of \$35,000, the minimum required for a study grant to be awarded.
- The Genetic Study at Baylor continued with emphasis on families with multiple incidents of ACD.
- Thanks to the [redacted] family, an ACDA "identity" was completed with a new logo, newsletter masthead and letterhead.
- Three new families joined the Association. It is encouraging to know that our efforts are helping others, even though it is very sad to realize this means additional children had ACD.

Thank you to all the members, their friends and families that have supported ACDA's efforts.

Steve and Donna Hanson  
[sdhanson@flash.net](mailto:sdhanson@flash.net)

## [redacted]'s Trophy

*In memory of their son, [redacted] of Belgium are organizing a dog agility competition to raise money for ACD research. [redacted] and [redacted] have been involved in dog competitions for years as a hobby and thought that a competition was a wonderful way to honor [redacted] who passed away in May 2003 from ACD.*

Continued on page 3

## Update on the ACD Study

From Bassem A. Bejjani, M.D., F.A.C.M.G.

This month the ACD study team at Baylor College of Medicine submitted a manuscript to the *Journal of Pediatrics* that summarizes the clinical data on 23 babies who had ACD. Dr. Bejjani has offered to provide ACDA with a pre-publication proof of the manuscript as soon as they have an indication that the manuscript is accepted for publication (this may take about 6-8 weeks).

At the same time, Baylor has continued the whole genome screen to look for a gene for ACD. To date, they have run and analyzed 217 Markers (57% completed). They have 165 markers left to run (43% not completed) from a total of 382 markers in the set. In other words, they are more than half way done with trying to map the gene. So far, there are not any significant findings, but they are pushing forward and hope to complete the whole genome screen by the summer. The DNA from the deceased babies has been difficult to work with because they are extracting it from paraffin blocks. So, the quality of the DNA is poor and requires many repeats of the experiments.

Dr. Bejjani indicated that he will keep ACDA apprised of their progress. ∞

INSIDE

|   |                                   |
|---|-----------------------------------|
| 1 | [redacted]'s Trophy               |
| 1 | Update on the ACD Study           |
| 2 | A Mother's New Hope by [redacted] |
| 3 | New Families                      |
| 4 | Talking to Children About Death   |
| 4 | Remembering Your Baby             |

# Carrying On - A Mother's New Hope

## Part 2 of 3

In the Fall 2003 *ACDA Notes*, we introduced a new series of articles by [REDACTED] of San Antonio, mother of [REDACTED]. [REDACTED] is pregnant and wants to share her thoughts with us as she deals with the emotional issues of carrying another child after losing her precious [REDACTED]. Here is Part 2 of 3.

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As the days grow nearer to [REDACTED]'s birth, I find myself growing increasingly calm. The last few months have been easier to deal with than I had expected. I have chosen to trust that all will be well, and that in a few months time our family will be complete. January 3rd was probably the hardest day in several months. [REDACTED] would have been one year old. I again felt the physical pain, which had threatened to undo me months before. I truly believed I was going to spiral into a deep depression. But, as a new day arose, I again was comforted by the growing life inside me. I had to remain positive. Being pregnant has also led to the constant question, "Is this your first?" I almost always find myself having to go through the whole story. For me, I have three children, regardless of her physical presence.

Now, February 7th will mark the day of her passing. I am sure my mind will torture me with remembering every last detail of the four days that followed. I can only hope with every cell of my being that these types of memories will remain just that...memories. My mother and sister have asked if I want them to buy clothes or baby things for [REDACTED]. Although my eye has been caught by so many beautiful bobbles, I have yet to purchase anything. Hopefully the moment he is declared healthy, we can empty the stores [REDACTED] is due to become part of this world, May 6th. This is the day of my 30th birthday. I am hoping that it will be the best birthday ever.

[REDACTED]

From [REDACTED], Mother of [REDACTED]  
Written the day of [REDACTED]'s Memorial Service

As many of us sit here, we are full of thoughts of sadness, grief, and even anger. We all are mourning the loss of a beautiful child who will never experience life.

But, what is our definition of life? [REDACTED] was chosen to live out her life in eternal greatness. Right now she is in Heaven, looking down on us. No parent ever wants to cope with the death of a child, and when I asked why [REDACTED] and why so soon, I was given some advice that I think about every day. One of [REDACTED]'s doctors stated that sometimes God creates a child so beautiful that he needs to call that child home to be with him. I believe that [REDACTED] was chosen not only to live life eternally with God but to also watch over us.

[REDACTED] is now an Angel. She was asked to come home to God and she went with open arms. I now know that not only is [REDACTED] being watched over, but so are the many infants [REDACTED] was with in the hospital and every one of us here today. As much as I miss [REDACTED], I can still find comfort in knowing that she is in God's arms and that one day I will again be with her.

I love you [REDACTED],  
Mommy

# Announcements

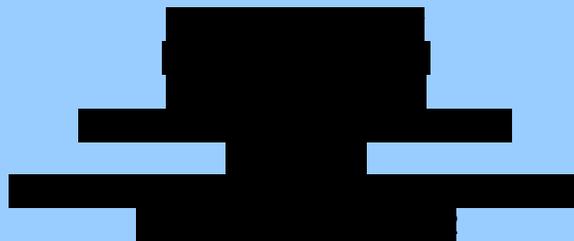
- There is \$15,862 in the ACD research fund at NORD as of February 11, 2004.
- *Recipes from the Heart*, the cookbook being developed by the [REDACTED] family of New York to raise money for ACD research, is in its final stages. By the time you receive this, the cookbook should be at the printer. [REDACTED] and [REDACTED], parents of [REDACTED], have told us that the cookbook will probably be ready for sale by June.
- [REDACTED], founded by the family of [REDACTED], donated \$3,241 to the ACD Research fund at NORD for the year 2003. Many thanks to the [REDACTED], [REDACTED], and their wonderful family and friends!
- Did you know that ACDA has over 50 members worldwide from Canada, Australia, New Zealand, the UK, Italy, Belgium as well as the US?
- 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.

Continued from page 1

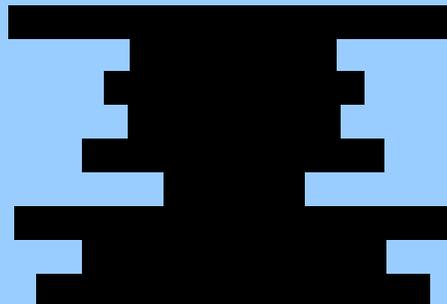
*The competition will take place on Saturday, April 24 and [REDACTED] and [REDACTED] are expecting between 150 and 200 dogs to participate. All of the admission fees and the proceeds on beverages and snacks will be donated to NORD for ACD research. They have been soliciting sponsorships to help defray the cost of the event and to date, two local businesses have generously agreed to help with the concessions. A local butcher is sponsoring the hamburger meat and a local bakery is sponsoring the hamburger buns. Having collected about \$1,500 so far, [REDACTED] and [REDACTED] are well on their way to not only staging a successful competition but raising a lot of money for ACD research. Our heartfelt thanks to [REDACTED] and [REDACTED]! ∞*

## New Families

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



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# How to Talk to a Child About Death

From your **Death and Dying Guide**

( <http://dying.about.com> )

A child's understanding of death varies with their age and their individual abilities. However, here are some guidelines that will help you talk to any child about death.

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## Here's How:

1. Do not avoid discussion of death if the child brings it up.
2. Be willing to share your feelings of grief with the child. Some adults try to hide feelings for the benefit of the child.
3. Be honest in answering any questions the child may have. Keep explanations simple.
4. Prepare children for the funeral by telling them what to expect. Let them know that there will be crying and sadness.
5. Share your feelings about spirituality and the circle of life with the child.
6. Allow them to talk about their feelings. Children often respond to the loss of a loved one with feelings of guilt.
7. Allow the child to be silent. The moment may not be right for them to open up.
8. Be patient and loving. Children may express their grief in tantrums, dependency or regression to an earlier age.
9. Give the child a chance to express his/her grief creatively. Writing, pictures, or claywork can help.
10. Be prepared. A child may ask more questions about death as they grow older.
11. Remember that sometimes all a child needs is a touch or a hug.
12. Consider researching grief support groups for children in your area.
13. Seek medical assistance if the child becomes depressed, withdrawn for an extended period of time, or makes any type of suicidal statements.

## Tips:

1. Avoid trite phrases like: 'Grandpa went to sleep.' or 'Aunt Betty went away.'
2. In general, children should be allowed to attend funerals. If they are reluctant, don't push.
3. Do not be surprised if the child repeats the same questions. ∞

## Remembering Your Baby



Memorials and mementos help us express our feelings and also honor our baby's importance. Here are some suggestions that you might consider to memorialize your child:

- Create a website about your baby
- Wear a piece of jewelry that symbolizes your baby. For example, place a wisp of your baby's hair in a heart locket that you wear around your neck.
- Create a memory book or box of your baby's mementos

If you have found a unique way to celebrate your child's life and would like to share it with the ACDA, please e-mail us at [sdhanson@flash.net](mailto:sdhanson@flash.net). ∞