

ACDA NOTES

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Dear Friends,

As we approach the holiday season, we give thanks to all of you who have crossed our path and have given us a reason to do meaningful work in our son's memory. The holidays are difficult for most of us as we mourn the loss of our children who should be sharing in the wondrous spirit of the season. We hope you find some small comfort in doing something special in memory of your sons and daughters. As in every year past, we will choose an "angel" from the Salvation Army Angel Tree who is the same age our son, Eric, would have been this year. We hope our small but meaningful gift will bring some joy to a young boy's holiday in memory of Eric.

We wish you the best during this holiday season and much peace and happiness in the New Year. Please tell all your loved ones how much they mean to you as we all know how quickly and unexpectedly they can be taken from us.

*Happy Holidays to you and Your Family,
Steve and Donna Hanson
sdhanson@flash.net*

NORD Report on ACD Now Available

The Rare Disease Database for patients and family members at the National Organization of Rare Disorders (NORD) now includes a report on ACD thanks to the efforts of Robin Steinhorn, M.D. and Mr. Edward Gruson, Medical Editor at NORD. Mr. Gruson drafted the initial report and Dr. Steinhorn conducted the necessary medical review.

Dr. Steinhorn, the Head of Neonatology and Associate Chair of Pediatrics at Children's Memorial Hospital and Northwestern University, previously assisted ACDA by writing a definition of ACD for *The NORD Guide to Rare Disorders* that was published in December 2002.

A summary of the ACD report is on-line at <http://rarediseases.org/search/rdbsearch.html> and the full-text report can be purchased from NORD for \$7.50.

We are grateful to both Dr. Steinhorn and Mr. Gruson for their efforts on behalf of ACDA. We feel that this report will provide both families and the medical community with a vital source of information on ACD. ∞

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Olivia's Circle Cookbook Fundraiser a Worldwide Success

Lisa & Harry Durand, founders of Olivia's Circle, are continuing their inspiring fundraising activities in memory of their daughter, Olivia. Olivia's Circle has started a cookbook fundraiser to raise money for NORD to find a cure for ACD. They created a cookbook with recipes donated by members of ACDA and other friends and family of Olivia that will be professionally bound and published and then sold for a profit. All proceeds

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will go the Restricted Research Fund for ACD at NORD. To date, over 400 recipes have been submitted for the cookbook, to be titled "Recipes from the Heart." Family members, friends and businesses were given an opportunity to also purchase a memory page or advertisement in the cookbook. The deadline for advertisements is December 15, 2003 if you still are interested.

These cookbooks are a great gift idea. If you are interested in helping to sell the cookbook once it is published, please contact Lisa at 800-869-2757 x307 or at info@oliviascircle.com. We will keep you posted on when the cookbook will be available to purchase. Many thanks to the Durand's and Olivia's Circle for their continuing fundraising activities. ∞

Carrying On - A Mother's New Hope

For some grieving parents, journal writing is a therapeutic means for grieving, healing and growth. It can provide a place to affirm their experience, express innermost feelings, share their thoughts, organize feelings to deal with them effectively, and share their emotions with others.

██████████ of San Antonio, mother of ██████████, has found such comfort in writing a journal. She wanted to share her thoughts with us as she embarks on a subsequent pregnancy. ██████████ provided this journal excerpt that will be the first in a series of three articles as we follow ██████████ on her journey.

Hello to everyone. My name is ██████████. My story is very similar to many of yours. After a very normal second pregnancy, ██████████ was born. She passed away in my arms five weeks later. After she passed, we visited my doctor to find out when we could begin trying again. My biggest fear was that we would have to wait a year due to the c-section. However, I was not prepared for her graphs and charts about percentages and probabilities, thus we left her office with more heartache and fear than before. We met with a geneticist who sadly to say, knew less about ACD than we did. He just handed us a card for an adoption agency his wife oversaw. Our sadness and utter confusion swallowed us whole.

For months, my husband and I sought the advice of family and friends. Should we adopt? Or risk the possible pain and nine months of fear? No one could tell us what we already knew we truly wanted to do. We were going to try again. After three months of trying, I gave up. I wanted to go back to thinking about adoption. The fear was beginning to creep in. Three weeks later, on the day of my husband's big birthday party, I took a pregnancy test. That night, surrounded by friends and family, I handed him his gift. Wrapped in a jewelry case, was the promise of a new life, a positive test.

It took me a few weeks to get up the nerve to go to the doctor. It pained me so to go back to the place I had been just a few months before. When we finally went, I walked into the room for the first sonogram, and I fell apart. This was the same place I saw into ██████████'s little world, where they had told me she looked healthy. I slid up onto the table, and within a few moments, there it was - yet another small life. Another life growing in

the same place its sisters had been nurtured before. After taking measurements, they told us the due date would be May 6, 2004. My husband and I looked at each other and began to cry. May 6th will be my 30th birthday.

Visits to my doctor have been very strange. She has allowed me to come in every two weeks to hear the heartbeat. However, the last few times that we have gone, it has taken quite a while to find, and the icy chill that travels down my spine until I hear the fast flutter is paralyzing. We have been offered all of the genetic tests and the amnio. My only fear is ACD; anything else, I can deal with. Just give me a baby I can bring home.

The person who has helped me to stay above the tide is my daughter, [REDACTED]. At the beginning of this pregnancy, I felt that I wanted to keep her sheltered. I was not sure I wanted her to know. But the truth is, I love being pregnant, and at only 4 months, I have quite the stomach! For [REDACTED] more than anyone, I want this child to be healthy. I worry about her and the toll it would have on her if ACD were to occur once again.

My younger sister had her first child a couple of months after [REDACTED] was born, and it took finding out that I was pregnant again to even be able to see him. But still, sometimes I just hold him, never wanting to let go. The pain still comes in waves.

A few days ago, I found myself complaining to my mother that I had no idea what was at the end of the next five months, and she reminded me that we never know what tomorrow holds for us. With that said, all we can do is love the today we are given. Thank you for reading. Please do keep us in your thoughts over the coming months.

[REDACTED]
[REDACTED]

Thank You!!

We received the Autumn 2003 *Orphan Disease Update* from the National Organization for Rare Disorders recently. We were thrilled to see that so many of our ACDA members and their friends and families are remembering our children who are no longer with us. We wanted to say thank you to those families and to everyone who is helping to raise funds through NORD so that we can support ACD research. We may be a small group, but we believe that we can make a difference. Thank you to the families and friends of the following children who made recent donations to NORD:

[REDACTED]

Announcements

- Check out the ACDA website! [REDACTED] has updated the site to include Frequently Asked Questions and a copy of the Baylor presentation to American Society of Human Genetics held in Baltimore, Maryland on October 15-19, 2002. Thank you [REDACTED]!!
- Thanks to [REDACTED] for creating the new masthead for our newsletter that incorporates the attributes of the logo and provides a more consistent ACDA identity.
- There is approximately \$14,057 in the ACD research fund at NORD as of November 10, 2003.
- We have heard many heartbreaking but wonderful stories about your babies since we joined ACDA. If you would like to share a story of your baby's life in the ACDA newsletter, please forward it to us at sdhanson@flash.net.
- Did you know that 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 live in the UK and are interested in joining an ACD support group in that country, please contact:

[REDACTED]
or
[REDACTED]

This poem was on a card that was given to the [REDACTED] family at the funeral of their daughter, [REDACTED]. It was so perfect for them that they later had it engraved on [REDACTED]'s headstone.

Journey's Just Begun

Don't think of her as gone away...
Her journey's just begun.
Life holds so many facets...
This earth is only one.

Just think of her as resting
From the sorrow and the tears
In a place of warmth and comfort
Where there are no days and years.
Think how she must be wishing that we could
Know, today, how nothing but our sadness
Can really pass away.

And think of her as living
In the hearts of those she touched...
For nothing loved is ever lost...
And she was loved so much.

Submitted by [REDACTED] in memory of her daughter, [REDACTED],
May 31, 1996 to July 3, 1996

Here is a tribute to [REDACTED]
[REDACTED] who was born on July 27,
1998 and died long before her time
on August 8, 1998.

[REDACTED]

He loaned you a little while, a child of His
for you to love while she was here and
mourn for in her death.

She brought her charm to gladden you
and though her stay was brief,
you'll have her lovely memory
as solace for your grief.

You sheltered her with tenderness, you
loved her each new day,
and for the happiness she gave,
forever grateful stay.

She is not gone forever, she's waiting
there for you
with Jesus where the angels sing
and time is ever new.

So put your trust in Jesus,
st follow in His way,
and when God calls His children home,
you'll see her that sweet day.

Written by [REDACTED],
Grandmother of [REDACTED]

Submitted by [REDACTED], Mother
of [REDACTED]

Safe Arrival

[REDACTED] and big sister, [REDACTED],
are proud to announce the arrival of

[REDACTED]
Born on September 8, 2003
Congratulations!!!

Check out [REDACTED]'s Website at
[REDACTED]

New Families

Please take the time to say hello to our new
families, offer your support and share the story of
your baby.

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Searching for Answers, Hoping for a Cure . . .

