

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 7, Issue 3

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

Summer 2005

Dear Friends,

As we write this newsletter, the proposals for our first ACD research grant are being reviewed by the NORD Medical Advisory Committee. This grant will be for \$30,000 and is the direct result of the personal and financial contributions of ACDA members, their families and friends. We realistically have a long way to go to find the cause and ultimately the cure for ACD, but this is a significant first step to funding additional research specifically focused on ACD. This is only the start, but we have some momentum because we are already almost half way to meeting the minimum funding for the next annual NORD Research Grant (even after the Research Grant is awarded this October). It would be wonderful to make yearly grants through NORD that could provide some continuity for this year's award or fund other research that could be even more promising.

As unique as ACD is, we are not alone in our grief because almost 1 in 100 babies die before one month of age. Many communities and organizations observe October as the National Pregnancy and Infant Loss Month. See page two for ways you can raise the awareness and understanding of ACD.

Fondly,

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

Update on ACD Research Grant

Nicole Woodage is the new Research Grant Administrator at the National Organization for Rare Disorders (NORD) replacing Linda Cataldo. Nicole recently informed the ACDA that the proposals submitted in response to the ACD grant were sent to the NORD Medical Advisory Committee for review in mid-August. The recipient of the \$30,000 grant will be announced and posted for the public in early October.

Update on Olivia's Circle

We first learned of *Olivia's Circle* in the Fall of 2002. This 30-minute circuit gym for women was a labor of love for Lisa and Harry Durand of New York in honor of their daughter, Olivia, who died from ACD in May 2002. It is with much sadness that the Durands were forced to close *Olivia's Circle* on August 31, 2005. During its existence, *Olivia's Circle* contributed \$9,312.90 to the ACD Restricted Research Fund at NORD. For every monthly membership paid they donated \$1 to NORD. The Durands also posted information in the gym that encouraged members to donate additional funds to ACD research. Their cookbook, *Recipes from the Heart*, continues to provide funding for ACD research.

The Durands have several hundred cookbooks from their ACD fundraiser that they are selling. If you would like to purchase the cookbook, *Recipes from the Heart*, (they make great gifts at the holidays), please contact Lisa at casper119@aol.com. Credit cards and checks are accepted. The Durands are also selling their circuit gym equipment from *Olivia's Circle* if anyone is interested in opening a gym in their child's memory.

INSIDE

1	<i>ACD Research Update</i>
1	<i>Olivia's Circle</i>
2	<i>Infant Loss Awareness Month</i>
2	<i>Safe Arrival</i>
3	<i>New Family</i>
3	<i>Memorial Garden</i>
3	<i>Announcements</i>

Pregnancy and Infant Loss Awareness Month

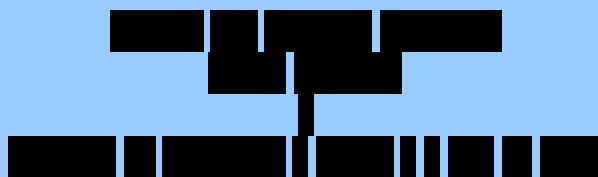
Each year, approximately one million pregnancies in the United States end in miscarriage, stillbirth or the death of the newborn child. Almost 1 in 100 births results in infant death before one month of age. These are statistics we are all too familiar with.

In 1988, the United States Congress designated the month of October as "Pregnancy and Infant Loss

Continued on Page 3

New Families

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



Wishes

My memory fails me,
I no longer see you in my mind.
But for the pictures
I can't remember your face.
I wish I could.

Your faint, kitten cry
So cute, a part of you
I hear it sometimes in another's.
But not often
I wish I did.

Your peaceful slumber,
Tiny breaths, gained with such effort.
I loved watching you sleep,
But no more
I wish it were.

I miss you, everything about you.
I want to see you, to hear you,
To watch you, to love you.
Up close, not from afar.
I wish I could.

All these things I miss
But I have one greater wish,
One unending ache
What I wish for most of all
Is one more touch.

Mindy Wilsford

Copyright © 2003 Mindy Wilsford

Safe Arrivals

Congratulations to [redacted]
[redacted] and big sis, [redacted]
[redacted], on the arrival
of
[redacted]

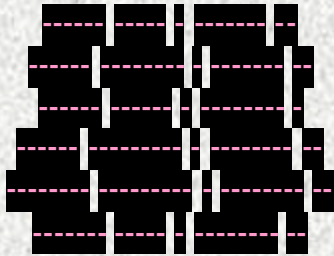
Born on [redacted]
Weighing in at 8 lb. 1 oz.



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 sdesj@verizon.net.



Example of
Pregnancy and
Infant Loss
Awareness Pin



Announcements

- As of August 23, 2005, the balance of the ACD Restricted Research Account at NORD was \$43,880.00. \$30,000 of that amount will be used for the research grant to be awarded in October 2005.
- Thank you to Phil Tenney of England for his recent updates to the ACDA website and for paying the renewal subscription to keep the site hosted and domain (www.acd-association.com) registered for another two years. Drop by and take a look.

Awareness Month." Observance of Pregnancy and Infant Loss Awareness Month offers us the opportunity to increase our communities' understanding of the great tragedy involved in the deaths of our newborn babies. It also enables us to consider how, as individuals and communities, we can meet the needs of other bereaved parents and family members and work to prevent causes of these problems.

Here are some ways for you to participate in this observance that has affected us all:

- Participate in a Loss Walk that your local hospital or church is having.
- Hold or participate in a memorial service to remember your baby (ies).
- Light a candle on October 15 at 7:00 P.M. (all Time Zones) in honor of all angel babies.
- Create and wear a ribbon to wear so that all may remember the babies we have lost. Whenever someone asks you about the ribbon, you may find they become embarrassed or try to change the subject. Take advantage of the opportunity to let them know that you are not wearing the ribbon just as a memorial, but also as a way for them to talk to you and ask questions. To create a Pregnancy and Infant Loss Ribbon, simply take one blue and one pink and attach them together with glue or stitch them together. Loop as shown in picture. Pins, like the one at left, can be purchased at <http://www.stockpins.com/pregnancy-infant-loss-awareness-pin.html>.

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