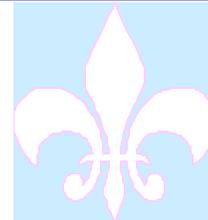


# ACDA Notes



From the Alveolar Capillary Dysplasia Association

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

Summer 2003

Dear Friends,

It was six years ago this summer that our son, Eric, died in our arms of some rare disease called ACD. He would have been starting first grade this year, and oh, how our lives would be so different if he were here with us now. While our hearts still ache with missing him, we have been so blessed to have had two beautiful little girls since Eric's death. As many of you can attest, having another baby after losing a baby to a potentially hereditary disorder can be unnerving and frightening. Having another baby is a personal decision and one that many of us will face. We wish you peace and strength as you come to terms with your choices and your decision. We are grateful to our friends in the ACDA who provided us with information and support to help us make our decision. We hope that the article on page 1 is beneficial to you as you consider or embark on a subsequent pregnancy.

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

## New ACDA Logo

We are proud to announce that the ACDA has an official logo! Madonna's long time dream of having an ACDA logo has come to fruition thanks to [REDACTED].

As mentioned in the last newsletter, [REDACTED] own an advertising agency, and they offered their expertise to design a logo. The logo, shown here, will be incorporated into a new brochure, letterhead and the newsletter. ∞



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## Your Subsequent Pregnancy

Deciding if and when to have another baby after losing a child to ACD, forces all of us to face many issues. It is unfortunate that we do not have any guarantees about the health of another child.

In the book "**Empty Cradle, Broken Heart, Surviving the Death of Your Baby,**" author Deborah L. Davis, Ph.D.,

Continued on page 2

discusses some relevant points to keep in mind as you come to terms with your loss and decide how to proceed with a subsequent pregnancy. The book contains a chapter on Trying Again and a chapter on Coping During Subsequent Pregnancy and Birth. Some key points from these chapters:

### **On Trying Again:**

- For many parents, the decision to try again is a difficult one. Give yourself a few months to think about the timing, even if you know you want to try again.
- In deciding when to get pregnant, there are many physical, emotional and logistical factors to consider.
- There are advantages to waiting and there are advantages to getting pregnant fairly soon. Weigh these advantages according to your unique situation and needs.
  - Advantages of getting pregnant soon include having the feeling that you are moving on toward more joyful times, overcoming feelings of failure, overcoming feelings of emptiness and beating the biological clock.
  - Advantages of waiting include healing physically, healing emotionally, keeping the babies separate in your mind and being able to enjoy the new baby more because you are grieving less.
- When trying to get pregnant, you may feel anxious, angry, obsessed, ambivalent or mechanical, but many parents also feel more hopeful about the future.
- It is important to have a supportive doctor or midwife who is considerate of you anxieties and needs for attentive care.
- Whether to do prenatal testing is a personal decision. Some mothers find it reassuring; others find it invasive and nerve-wracking.

"Your doctor and your friends may express concern about your physical or emotional recovery or how you would cope with another loss. But remember it's not their decision to make. It's your recovery, your body, your pregnancy, your children, and your life. It's also your decision."

### **On Coping during Subsequent Pregnancy:**

- It is normal to have fears about the baby's health and feel anxious or hesitant.
- Talk about your fears to someone who can listen and offer reassurance.
- Many mothers find therapeutic value in keeping a journal to help express and deal with their feelings.
- After birth it is normal for you to grieve deeply, as having another baby can act as a catalyst for your emotions about the baby that died. Make room for your grief and joy. Finding a balance rather than trying to suppress emotions will benefit you and your baby. ∞

Reprinted with permission from "*Empty Cradle, Broken Heart, Surviving the Death of Your Baby*" which is available direct from the publisher by calling (800) 992-2908. The book is also available through your favorite bookstore or online retailer.

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

# Thank You!!

The ACDA exists and continues to exist because of the efforts of parents throughout the world who want to make a difference in memory of their baby. As the organization grows, it is necessary for us to call on you to help us with various projects that will enhance the support and services that ACDA provides. Just recently, two of our families have volunteered to assist us with some of these efforts. We want to recognize their efforts and thank them for assisting us.

- [REDACTED] are in the process of creating a bibliography of books that will help parents, siblings and other family and friends in their time of grief. This list will be included on the website for all to reference. If you have any suggestions on books that you found helpful, please forward them to us at [sdhanson@flash.net](mailto:sdhanson@flash.net).
- [REDACTED] are reviewing and providing comments on a list of "Frequently Asked Questions" that we want to post on the ACDA website. We believe such an addition will assist families in finding some answers to many of their questions.

These are just two of the current on-going efforts here at ACDA. While acknowledging such efforts, we don't want to overlook the continuing efforts of the [REDACTED] family in raising money for ACD and the [REDACTED] for their design contributions.

If you would like to assist us in our efforts, please contact us at [sdhanson@flash.net](mailto:sdhanson@flash.net). ∞

## Announcements

- 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](mailto:sdhanson@flash.net).
- There is approximately \$13,207 in the ACD research fund at NORD as of July 31, 2003.
- 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](mailto: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:

Sue Larkins ([Larkins.Family@ntlworld.com](mailto:Larkins.Family@ntlworld.com))

or

Jackie Woodward ([jackie.woodward1@btopenworld.com](mailto:jackie.woodward1@btopenworld.com))

## Silent Child

By Kelly Lancor

My silent child  
Our precious baby,  
Close to my heart  
I'll keep you with me.

An important job  
God has for you  
There is love to give,  
And work to do.

He needs an angel,  
Strong but small,  
To shine light on many  
And give love to all.

Before you go  
I give you this,  
Half my heart  
And one last kiss.

We miss you dearly  
That we know,  
But by God you were chosen  
So to heaven, you must go.

# Safe Arrival

## New Families

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

[REDACTED]  
[REDACTED]  
[kellyboyajian@yahoo.com](mailto:kellyboyajian@yahoo.com)

\*\*\*\*\*

[REDACTED]  
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[heatherr@interlexusa.com](mailto:heatherr@interlexusa.com)

*Searching for Answers, Hoping for a Cure . . .*



## Friends of Olivia

Olivia Durand of Rotterdam, New York, left behind many wonderful family and friends when she passed away from ACD in May 2002, just one week from her seven month birthday. Earlier articles in ACDA Notes told the story of Olivia's parents who founded *Olivia's Circle*, a circuit training gym to memorialize Olivia's life. Many wonderful stories about the generosity of family and friends have evolved since then.



Olivia at 4 months

Most recently, the preschool that Olivia's older brother, Joseph, attended made a large donation to *Olivia's Circle*. Wonderland School held their annual bike-a-thon for which the three and four year old children asked their family and friends to pledge a certain amount of money for their fundraiser or for each lap. The school then donates the money to a worthy cause. This year their bike-a-thon was so successful that they split the earnings between *Olivia's Circle* and another family who has two ill children. The Durand's had no idea that Wonderland had earmarked their fundraising for *Olivia's Circle* and only learned of this wonderful act of kindness when the President of the Co-op showed up at their door with a card and a check. The Durand's were overwhelmed with the generosity of the parents and children of Wonderland Co-op. Lisa Durand, Olivia's mother, said, "They all had very big hearts and we thank them."

The Durand's have also received a donation from a church who heard about Olivia's story and from many other private contributors. Additionally, on the anniversary of Olivia's death, all of the staff at *Olivia's Circle*, Albany Funding, & Cleopatras Salon contributed money to create "Olivia's Garden", which is a spot in the gym with flowers, statues, pictures, etc. for her anniversary (you can see it on the website at [www.oliviascircle.com](http://www.oliviascircle.com)). The additional money left over was donated to NORD. The Durand's thought that was another great tribute to Olivia, and they are grateful to all the friends and family who are always trying to raise more money for NORD. They hope to help reach the goal of \$35,000 to fund a research grant through NORD in the near future. Many thanks from ACDA to all of Olivia's wonderful family and friends who are helping to make a difference in Olivia's memory. ∞