Dear Friends,

Recently, we learned of an ACDA family who has been holding a memorial event for their daughter every year since her death. This family reminded us that there are other families in the ACDA that may also be finding ways to memorialize their baby(ies). We want to thank those of you who have already shared your memorials with us and encourage others to share your story. No effort is too small to mention and to share with other families, for we believe that all these stories inspire others. In fact, we have had a few parents tell us so. In this issue of ACDA Notes, new ACDA mom, [Name], tells us about finding comfort in making quilts in memory of her son, [Name].

Please let us know if you have found a meaningful and comforting way to remember your child.

Fondly,

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

Quilt Fundraiser Provides Comfort for ACDA Mom

[Name], mother of [Name] who died in 2004 of ACD, is an artist who found a productive way to channel her grief and raise money for the ACDA research fund at NORD. When [Name] lost her son last year and was experiencing overwhelming grief, she found that she needed to do something in [Name]'s memory that did not require complex intellectual thinking. So, she thought it would be so appropriate to put her artistic abilities to work making quilts; especially since she made her first quilt while pregnant with [Name]. [Name] found comfort in the idea of giving warmth to other babies and found that her efforts have given her a sense of serenity about [Name].

To date, [Name]’s quilts have raised about $265 (Canadian) for ACD research and she has seven more orders to fill. The quilts sell for $50 - $150 (Canadian), depending on the complexity and take one to two months to complete. Two of her quilts are pictured below. If you are interested in purchasing a quilt from [Name], please contact her at [Contact Information].

The ACDA recognizes [Name] for finding a way to memorialize her son, [Name], even while trying to make sense of her painful loss. Thank you, [Name].
**New Families**

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

- **ACDA**
  - April 28 – May 15, 1998
  - July 24, 1992
  - June 5, 1996
  - May 8, 1999

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  - July 9 – 21, 2004

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**Update on ACD Research at Baylor College of Medicine**

Partha Sen, Ph.D. at the Baylor College of Medicine in Houston provided an update on the recent developments and near term research for the ACD study team. Here is a synopsis:

- Several new families have joined the Baylor ACD study in the recent months.
- Baylor submitted a Request For Proposal to NORD to fund a clinical/pathological study of patients’ lung tissue. This study will be done with Dr. Claire Langston, the lead pathologist on the team.
- They are planning to embark upon a microarray analysis project. This project compares the gene expression pattern in the lungs of ACD patients to that of a "normal" lung. The work for this project will be done in Dr. Bassem Bejjani’s laboratory at Washington State University.

All families are urged to participate in the ACD study underway at Baylor. Please contact Partha Sen at (713)798-7184 or e-mail: psen@bcm.tmc.edu if you would like to participate. This study is an opportunity for all of us to help find a cause and cure for ACD.
Awakening
Written for Abigail's second birthday in heaven

Watching my children in awe
Marveling at their innocence,
their love, their laughter.
Drinking in each moment for the miracle it is.

Their precious lives - given to my care,
Paralyze me with emotion,
Awash in gratefulness, love, joy.

The immensity of the gift of life
Lost on so many,
Overlooking the moments that make up a lifetime.

Every moment a gift.
Every moment a lifetime.
Every moment a treasure.

Thank you, Abigail, for my awakening.

Mindy Wilsford
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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.

Announcements

- Recipes from the Heart, the cookbook that the Durand family developed in memory of their daughter, is still available for $8.00. They can be purchased by e-mailing Lisa Durand at casper119@aol.com or calling Olivia’s Circle at (518) 456-2187. Credit cards and checks are accepted.

http://www.acd-association.com