ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Dear Friends and Family,

Beginning with this newsletter, we are starting a new feature in *ACDA Notes.* Like us, you may often long to talk about your baby so he/she is never forgotten, but as time passes, the opportunity comes along less and less. Therefore, we would love for all of you to share your child with all our friends and family in the ACDA. We will start the feature with the story of our son, Eric, and hope that all of you will find it comforting to share your story with other families that have experienced the tragedy of this disorder. What you write is totally up to you – you can include a picture, a poem, or other memories of your child. We know it is a very emotional look back at our child's short life, but those few precious days we had with Eric will live forever in our hearts. Please submit your story via email (sdesj@verizon.net) at any time.

On another note, the current balance of our ACD Research account at NORD is $14,115. In order to support ACD research, we need to raise a total of $35,000, at which point NORD can issue another research grant. If any of you have any fundraising ideas or have undertaken a fundraising activity, please share it with us. It will take all of us to find a cause and cure for ACD.

Fondly,

Donna & Steve Hanson
ACDA Executive Directors

INSIDE

Eric's Story

Eric was our first child. We were so thrilled to be having a boy to carry on the Hanson name! Steve's dad, who is of Scandinavian heritage, suggested the name Eric, which seemed like the perfect name for our baby boy. He was going to be a special addition to our lives that we had waited so long to start together.

Little did we know that our otherwise perfect life would come crashing to a halt when Eric was born. When Eric arrived in the world, we got to hold him for a few short moments before the pediatrician whisked him away for an exam. He was a big baby, with a cute little dimple in his chin and a broken collar bone! I will never forget watching Steve hold his son for the first time. Those few moments that we got to hold him without any tubes or equipment would end up being so much more precious then we could have imagined. Oh, how we wish we would have taken so many more pictures during those few minutes!

The next 11 days were a like a roller coaster ride. Within an hour of his birth, Eric presented with problems. The hospital had

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Inspiration for Helping Yourself Heal

An article in the February 4th edition of PARADE magazine entitled "The Courage to Move On" by Ann Hood caught our eye. Ms. Hood lost her 5-year old daughter from a virulent form of strep in 2002. After her death, she struggled with her grief and how to define her life. We received permission from Ms. Hood to reprint some excerpts from her article that we thought were particularly relevant for those of us who have lost a baby to ACD. We share them with you in hopes that you will know that you are not alone in your grief and that you will find purpose in your life.

"After the death of someone we love, we are forced to figure out who we are now. It is difficult to reach the point where you realize that moving forward doesn't mean leaving behind the person you've lost."

"Part of the work of grieving is to channel our emotions and energy into activities that help us redefine ourselves. Some people turn to creative pursuits. Some people reach out and help others by volunteering. And some, recognizing that life is precious and short, fulfill their dreams."

"To help yourself heal, do what moves you. Or do what matters. And in each new activity, remember the loved one who brought you there. Then, take those first tentative steps into the rest of your life."

It is our wish that your baby or babies that have been so tragically taken from you will lead you to fulfilling your dreams.

Note: Reprinted with permission from Ann Hood, the author of "The Knitting Circle" just published this year.

Memorial Garden

Please take a moment to remember these sweet babies who will live in our hearts forever.

Be sure 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.

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Welcome New Families

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[redacted]

Please feel free to contact them and share your experiences.

SAFE ARRIVALS

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Congratulations to both families!

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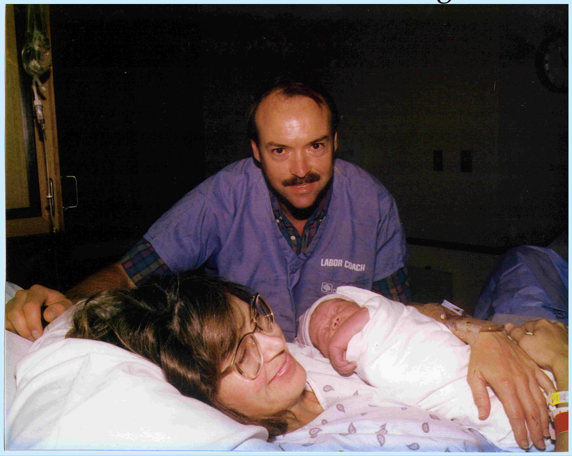
convenient accommodations for us so we were able to stay by Eric's side as the doctors tried to figure out what was wrong with him. It was agonizing to see Eric and not hold him, touch him or talk to him. It was frustrating not knowing what was wrong with him, and it was heartbreaking wondering if he was in pain.

On the sixth night, the doctor took us to the NICU nursing room for some privacy. She told us that she suspected Eric had ACD, a disorder that we had never heard of. She recommended that Eric be transferred to another local hospital for an experimental treatment of nitric oxide. However, the doctor warned us that Eric might not survive the transport. That shook us to the core but we wanted to give Eric every chance. Eric survived the transport and initially, Eric responded to the nitric oxide. During those few days, we watched, hoped and waited with other families, slept in a community bunk room and agonized over our suffering little boy. Father's Day came and went but it was a sad day for Steve. Eventually, Eric did not respond to the nitric oxide. After discussions with the doctors and three long hours of agonizing discussion between ourselves, we made the most difficult decision of our lives.

Finally, late that night, we got to hold Eric again – for the last time. We sat and rocked him, giving him kisses and hugs to last a lifetime. We called our parents who came to say good bye to Eric. We took more pictures, got a lock of his hair and made a print of his tiny little foot. We walked out of the hospital in the wee hours of the morning with such heavy hearts and without the little baby boy we had dreamed about for months. The days that followed are a blur.

Oh, how we wish we had different memories of our time with Eric but it's all we have. We don't think those 11 days will ever fade in our memories as other memories have. Eric has been gone almost 10 years now. We have two beautiful daughters who will learn and understand more about Eric as they grow older. Despite the short time that Eric was with us, he has changed our lives. He is forever in our hearts.

Donna & Steve
Parents of Eric Stephen
June 7-17, 1997



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Our hearts still ache in sadness,
and secret tears still flow,
what it meant to lose you,
no one will ever know.