ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Dear Friends and Family,

We are so grateful to those of you that are helping the ACDA to raise awareness of ACD and to raise money for ACD research. In this edition of ACDA Notes, we highlight the efforts of the [redacted] [redacted] [redacted] [redacted] families that have recently been working with us on several projects. Even with our busy daily lives, it is easy for all of us to help raise awareness by just contacting the hospital and doctors that treated our babies. We will soon have brochures that you can mail to those medical professionals.

Thank you also to [redacted] and [redacted] [redacted] for sharing their daughter, [redacted], with us in this edition. They lost [redacted] to ACD in November of 2001, and we know their heartbreaking experience will sound so familiar to many of you.

Fondly,
Steve and Donna Hanson, Executive Directors

INSIDE

[redacted]'s Story

Written Christmas 2002

by [redacted] [redacted]

Although we had planned the pregnancy, it still came as a shock when the line on the test was positive. It had happened a lot quicker than I had originally thought. We were ecstatic. As the months went by and I got bigger, we started planning our new arrival. We decorated the nursery, bought lots of equipment, a few clothes, even went out to buy nappies on the advice of others saying we should buy them while we still had two wages. We were all ready.

On the evening of 26th October 2001, my waters broke. Bags packed, we arrived at the hospital on the 27th. The hospital were not at all worried; they sent me away and told me to come back the next day to be induced if nothing happened in the meantime. We went home. Nothing happened so we turned up at the hospital again at 11 a.m. on Sunday 28th October 2001.

By 7:09 p.m. we had a beautiful baby girl whom we named [redacted] [redacted]. She was perfect. Ten tiny toes, ten tiny fingers, button nose, rosy cheeks and a mass of black hair. She was a very quiet baby right from the start, I suppose I should have known that something was wrong – I guess I thought I was just lucky.

We both had a quiet night and got up the next morning to prepare for our mountains of visitors, my husband having gone home

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and rung round everybody to announce her arrival. At 11 a.m. our first visitors arrived. By 11:30, [redacted] was being rushed away. She had been turning a funny colour throughout the morning only to be pink again whenever any doctor managed to look at her. It just so happened that a midwife was with me when she did it again. They whisked her away and that was the start of our nightmare and the last time we held our daughter for real.

We were whisked from our local hospital through two further hospitals (where we nearly lost her) and then by helicopter to Glenfield Hospital in Leicester where she was put on ECMO to try and "put her back in the womb and start her up again" as she wasn't breathing properly. While on ECMO she appeared to improve but they couldn't get her off the machine. When they did manage to get her off she still remained on the ventilator. We were able to touch her and be by her bedside but only managed to hold her once with all her tubes around her.

It was such a mammoth task getting her off and back on the crib that we only did it once. She didn't take too kindly to being moved around and became very distressed. Her condition did not improve so by the third week they did a lung biopsy. We had to wait a whole week for the result but we were warned that it might be Alveolar Capillary Dysplasia (ACD) and that if it was, the condition was fatal.

Even though we were told this, we still clung on to every last stitch of hope that we could muster. You gather your inner strength and even though deep down you know something is seriously wrong you cling to that last thread until it is finally broken. We were told a week after the biopsy, 31 days after she was born, that she had ACD and that life support would need to be discontinued. It was so unfair, although she was very sick she had come so far. I was still clinging on to that hope… what if… is it really… why?

The hospital staff were very good. They let us do everything the way that we wanted to. I carried her down a corridor to the "quiet room" where her daddy held her until she died. She looked at me with wide eyes when I picked her up, almost for one last time, and then she did the same with her daddy when I passed her to him. She closed her eyes and after a while was gone. We washed and dressed her, did hand and foot prints and took a lock of her hair. We laid her in a crib and left her.

No-one can explain the emotions of losing a child; the only people who understand are those who have had a similar experience. Your life is over. The nursery is empty. Your heart is broken and your inside feels hollow. You go into the hospital to have a baby, your whole life is geared up for this little person and you come home with nothing but a few memories.

We have just passed her first birthday and the day that she died one year ago. I thought that things would get a little easier but they haven't. I don't cry so much on the outside now but inside I am crying all the time. The pain is always there, it never goes away, gnaws away at you inside constantly, coming to the forefront in waves.

You feel empty inside like part of you has been taken away. I can't imagine ever feeling whole again. How can life be so cruel we ask ourselves? No-one will ever know the answer why.

And to add: I wrote this back at Christmas 2002 when I was at an all-time low. You never think that things are going to get any better but they have. The pain never goes away and I cry as I write this still but we have since been blessed with two beautiful children [redacted] aged 4 and [redacted] aged 2 for which we are eternally grateful. Never give up hope. Cling on to every last shred. The impossible is achievable.

ACDA Members Make A Difference

We want to thank some of our ACDA members that are working behind the scenes to support current efforts of our organization. As a volunteer organization, we rely on our members to help us raise awareness of ACD and to raise money.

[redacted] [redacted], mother of [redacted], offered the services of her family's printing company to develop and print a new brochure and letterhead. We have been working with [redacted]'s brother, [redacted] [redacted] [redacted] [redacted] [redacted] [redacted] [redacted] and hope to publish a brochure this fall.

[redacted] [redacted], mother to [redacted], is spearheading the ACDA letter writing campaign. She is drafting a letter we can all use to solicit support from our friends and families, and she will coordinate the donations we receive for our research account at NORD. Stay tuned for more information! In addition to this, this energetic mom is planning a fundraiser in her hometown of Jacksonville, Florida on [redacted]'s "Angelversary" of December 17.

Thanks to these two families for their support of the ACDA!

Family Party Turned Fundraiser

[redacted] [redacted], mother of [redacted], recently had a birthday party for her niece, [redacted] and her nephew, [redacted], who turned one and three years old. Instead of presents, the party guests made donations in [redacted]'s memory. In addition, [redacted]'s sister-in-laws father, [redacted] [redacted], works for [redacted] [redacted] [redacted] and they matched the donation 100%. [redacted], her family and friends collected over $1,100 for the ACD Research Fund at NORD! Thank you for such a generous way to remember [redacted]!

WELCOME TO OUR NEW FAMILY

[redacted]

Essex, England

[redacted]

[redacted]

Brother [redacted] – December 15, 2004

Please feel free to contact the Singletons and share your story.

Family Establishes Fund in Daughter's Name

One of our newest families, [redacted] [redacted] [redacted] [redacted] of England, have established "[redacted]'s Fund" in memory of their daughter. They raised nearly £6,000 (approx $12,000 US) from donations at her funeral and have subsequently set up the fund to continue to raise money. They plan to split the money between their local hospital special baby care unit and for research to find a cause and cure for this terrible disease. [redacted] wrote "My little girl put up such a fight and I cannot let her battle be in vain; so although she may not live on, her name and memory always will." We are in awe that the [redacted] [redacted] [redacted] can find such strength and focus in a time of overwhelming grief. Thank you!

Announcements

- *Steve Lake, uncle of Eric Hanson, recently made a $1,000 donation to NORD in memory of Eric's 10th birthday. In a letter that accompanied this generous donation, Steve said, "NORD has played a pivotal role in bringing awareness to the Alveolar Capillary Dysplasia fight - may a cure be found for this rare and often fatal disorder." Thank you Steve!*
- *Thanks to continued donations from families and friends, the current balance of the ACDA Restricted Research Fund at NORD is $18,620.*
- *Some of you may have received an email recently from [redacted] [redacted]r requesting donations to a fund that he has established in memory of his children that died from ACD. We are communicating with [redacted] and will keep the ACDA members posted on our discussions.*

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