

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Summer 2008

Dear Friends and Family,

We are excited to announce that the Centers for Disease Control awarded a \$250,000 grant for ACD awareness to the 3 Angels Memorial Fund. This is the first year of a possible multi-year effort and a giant step towards increasing ACD recognition in the medical community. The details of the grant are summarized on page 1.

Also in the issue, you will see that two ACDA families submitted stories about their babies. Thank you to the [REDACTED] and [REDACTED] families who poured their hearts out in two different forms - one letter written at the time of their loss and one written nine years after losing their daughter. We know that you will be touched by their stories as we were.

Fondly,
Steve & Donna Hanson
ACDA Executive Directors

3 ANGELS MEMORIAL FUND AWARDED CDC GRANT

Earlier this month, the United States Centers for Disease Control (CDC) contacted the 3 Angels Memorial Fund for ACD Research to inform them that they were the recipients of a \$250,000 grant for ACD awareness.

Under this grant, the 3 Angels will:

- Identify recognized experts in pediatric pathology, neonatology and rare disorders to serve on an ad hoc committee;
- Organize and lead a scientific workshop and/or conference on ACD in early 2009;
- Evaluate the appropriate strategies to target and educate healthcare professionals; and
- Produce a plan to disseminate this information.

Naomi Bishop, MD is the Principal Investigator for this effort. She is a pediatric intensivist at Weill Cornell Medical College in New York City and the Medical Director of the 3 Angels Memorial Fund. She is responsible for overseeing the design and execution of the project. Dr. Bishop will be assisted by three other members of the team:

Continued on Page 2

INSIDE

- | | |
|---|-------------------------------------------------|
| 1 | <i>CDC Awards Grant</i> |
| 2 | <i>Safe Arrivals</i> |
| 3 | <i>Letter from the [REDACTED] Family</i> |
| 4 | <i>[REDACTED]'s Story</i> |
| 5 | <i>Announcements</i> |

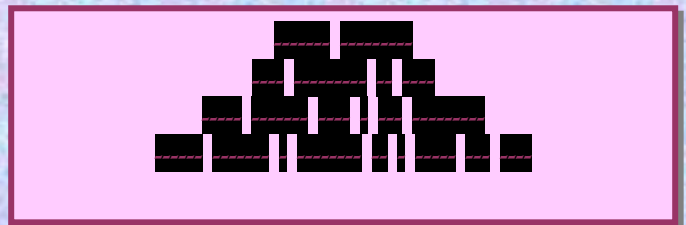
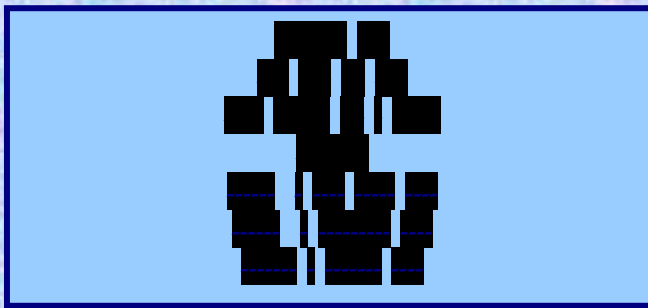
- Ann F. Brunswick, Ph.D., Special Research Scientist, Mailman School of Public Health of Columbia University who will be the Senior Project Consultant.
- Craig Snyder, the co-founder of the 3 Angels Memorial Fund and managing partner of IKON Public Affairs, a political and strategic communications consulting firm based in Washington, D.C., will act as the Communications Consultant.
- A graduate assistant from Weill Cornell Medical College will be assigned as the Administrative Assistant/Project Coordinator and will assist Dr. Bishop in the execution of the project.

This is an exciting opportunity for the ACD community to raise awareness of this rare disease. This project will insure the proper recognition and timely diagnosis of ACD by medical professionals. It will enable all medical professionals to assemble in order to define and describe the current state of ACD and associated conditions. A case definition for ACD will be developed for use in the educational materials and strategies to raise awareness of and educate healthcare providers on ACD will be determined.

In addition to this effort in FY 2009, the United States Senate Appropriations Committee has voted for an additional \$250,000 for ACD work by the CDC. There are a number of additional steps in the federal 2009 budget process, which probably will not be finalized until the beginning of next year, but we are very encouraged that these additional dollars for ACD will be funded in the final budget.

Thank you to Craig Snyder and NiCole Robinson for their efforts in continuing to press Congress for this funding. This grant is a major step toward increasing ACD awareness.

Safe Arrivals



I am writing this letter as ■■■'s father because I feel compelled to share with all of you how much ■■■ and I loved our son. We want to share the details of our 3 days with him. More than anything we want people to acknowledge ■■■'s short life and our roles as his father and mother. Most importantly, we want to celebrate ■■■'s existence and for all of you to help us keep his spirit alive.

On September 8, 2005 ■■■ and I became proud parents of ■■■ ■■■ ■■■. ■■■ was diagnosed with a rare condition called "Alveolar Capillary Dysplasia." Although ■■■ was born at 34 weeks he was still a big boy as he weighed 7 ¼ lbs and almost 20 inches long. He was a beautiful baby with soft pink skin and sharing all the best features of his mother and father. He had ■■■'s chin, lips, nose, and long fingers and he had my cheeks, eyes, and forehead.

Although losing a child is the worst thing a parent can experience, ■■■ and I feel very blessed by being given the time we had with him. ■■■'s desire to meet his mother and father was so strong he beat the odds by making it out of the delivery room. In the short time we got to spend with ■■■ in the neonatal unit he taught us many things about strength, courage, and bravery. What we learned most of all was that ■■■ was truly aware of who his Mommy and Daddy were. He fought off sedation and medication and was able to open his eyes and look at us when he heard voices. We were also blessed with being able to hold our son while he was still hooked up to the wires and tubes. And to the amazement of the doctors and nurses ■■■'s heart rate increased to normal levels while his Mom and Dad were holding him. My proudest moment as a Dad came when my son had enough strength to squeeze his mother's finger when she was upset. ■■■ was able to see some of his toys as we would bring different ones each time we went to see him. When we did need to get rest ■■■ was left with his "■■■ teddy bear" so that he wouldn't be lonely.

In 3 days we were able to tell ■■■ everything a parent would need to tell their child in a lifetime. He knew how much we loved him, how brave he was and how very proud we were of him. ■■■ knew how much everyone loved him. Even though our time with ■■■ was short, there will never be two more proud parents than ■■■ and myself. ■■■ showed us and taught us more in 3 days than anyone would be able to do in 50 years. We know that ■■■ is now with God as one of his angels. Please know that he is looking out for all of you,

especially his best friends: [REDACTED] [REDACTED] [REDACTED] [REDACTED] [REDACTED] and all the babies next to him in the neonatal unit.

We are going to a perinatal bereavement group at LIJ. Everyone asks what he or she could do to help so I am enclosing this article for you to read that we got at counseling which describes how we feel; the deep void and the emptiness and what you can do to help. Please bear with [REDACTED] and I as we try to find a "new normal" in our life. We are not the same as we were before. Our son took a huge piece of our hearts with him. We thank all of you for your love and support. We hope that [REDACTED] has touched all of your lives. We beg you to please never forget him as he will never forget you.

[REDACTED] and [REDACTED], New York
Parents of [REDACTED] - [REDACTED] [REDACTED] [REDACTED]

[REDACTED]'s Story

[REDACTED] was born in July 1999. Writing that down amazes me. It was more than 9 years ago. I can recall events of that time with clarity as if it was yesterday, but at times I panic because "have I thought about Megan today, will I ever forget her?" I know I will not.

We are an "average" Australian family. We looked forward to the birth of our second child. [REDACTED] was born to my husband and I, following an uneventful pregnancy. She has a big sister who was almost 3 when she was born. [REDACTED]'s birth was uneventful. Born at around 2 am, I had a (far too) brief cuddle and then she slept in the nursery for the night. I went to see her at around 7 am in the morning. As soon as she was disturbed, she became cyanotic (went blue). She was transferred to a major tertiary paediatric facility and was managed with the usual array of treatments-which many parents of children affected by ACD, would be familiar. Many highs and lows followed, and when her ECMO was withdrawn, she died at 6 days of age, comforted by her mum and dad, sister, an aunty and grandparents.

We agreed to limited autopsy- lung tissue samples were taken. Fortunately, the Pathologist was familiar with ACD, and we were told ACD was the cause of [REDACTED]'s death. This meant for us, there was no blame of hospitals or staff. As there was no known cause, we thought about what my husband and I had been exposed to during the pregnancy, and

whether anything else could have contributed. After some time, we were more able to accept that although there seemed no real reason for this to happen to our daughter, it did.

Our lives had taken an unexpected course, and we managed to live through it, finding strength in each other and for me, a resilience that I never knew I had.

We also have a son who is 8-(I got pregnant 5 months after [REDACTED] died- this was right for us). Every day family life seems to include [REDACTED]. I wonder what she would have enjoyed- sports, music, dance? What would she look like? Would she cause me to get frustrated and perplexed at times, like my other two children do? very probably! I considered having a fourth child, but admitted I was not brave enough. Having my son was 9 months of joy, anxiety and fear. Ultimately I felt joy, relief and appreciation at having a well child. Two living children were enough.

There are tears on Birthdays, Mother's day and Christmas, and at other times when I least expect it. I feel a strange mixture of sadness and joy when I hear another mother call her child by her name - [REDACTED], or when I am served by a shop assistant with a name badge- [REDACTED]. To have my [REDACTED] with us, would bring my biggest smile, but it cannot be. So I do my best to remember her and have her in our lives. We celebrate [REDACTED]'s birthday each year, with a simple family birthday party, with the four of us and [REDACTED]. Last year, my son cried when we lit the candles on the birthday cake. I think he realized that he truly missed his sister, although only ever seeing photos of her and our stories. We planted a tree for [REDACTED] at our children's school on the day she would have started school. My daughter tells most people she has a sister who died. This seems to make some adults uncomfortable, but other children seem to accept it much easier.

We took part in the research into ACD being conducted. My older daughter understood why blood samples needed to be taken. But my son had to be bribed by a large block of chocolate! I look forward to any findings being made. If it is found to have a genetic link, then our family will have to ensure that our children use this information to help them in their future choices.

[REDACTED] & [REDACTED], Australia
Parents of [REDACTED]

ACD in the News

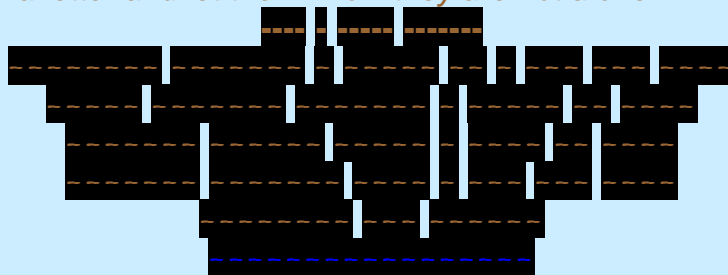
In the July 21, 2008 issue of *People Magazine*, NiCole Robinson and Craig Snyder shared their ACD experiences with writer Debra Lewis-Boothman. In a moving account of their devastating loss of their son, Lincoln, and Craig's loss of two other children to ACD in a previous marriage, you realize that NiCole and Craig are determined to make a difference in memory of their children.

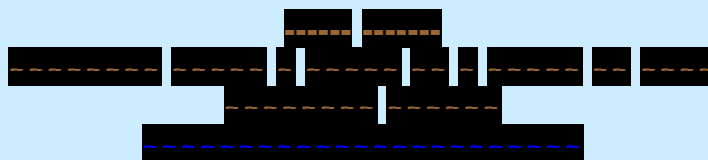
Thank you to Craig's nephew, Todd Barrish, Senior Vice President of Dukas Public Relations, who has volunteered his services to help with press relations for the 3 Angels Memorial Fund. Todd was responsible for facilitating the magazine's interest in this story that is so close to all of our hearts.

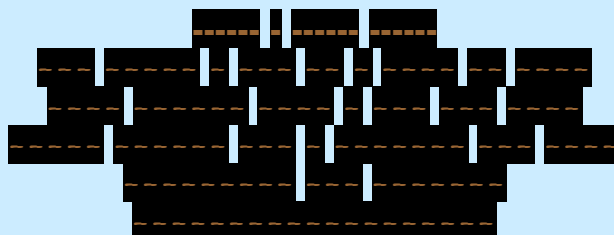
Follow this link to view the entire article -
<http://www.3angelsfund.org/news/PeopleMagazineACD-072108.pdf>

New Families

Please reach out to the newest members of the ACD Association. Give them a call, send them an email or write them a letter and let them know they are not alone.







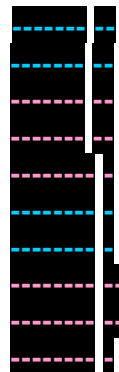
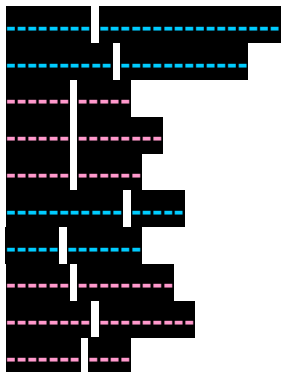
Announcements

- As we also mentioned in the previous issue of *ACD Notes*, the NORD Medical Advisory Committee (MAC) is in the process of scoring all the applications for a \$30,000 grant for ACD Research and determining which researchers are to be invited to submit full proposals. The final decisions on grant awards will be made by the MAC in early November 2008. This grant is based solely on generous contributions from our ACD families and friends!
- The [REDACTED] family of New York recently raised \$2,000 for ACD research in their third annual golf tournament in memory of their son, [REDACTED].
- Jackie Woodward, mother to Hannah, is the ACDA point of contact for families in the UK. Jackie has been instrumental in reaching out to families in England the last several years. You can reach her at jackie.woodward@homecall.co.uk. Thank you Jackie!
- The website for the 3 Angels Memorial Fund for ACD Research has a new on-line store. There are ACD Awareness bracelets, angel logo pins and angel note cards. Check it out at <http://www.3angelsfund.org/store.php>.
- Visit <http://www.3angelsfund.org/news.php> for “ACD in the News” including a press release announcing Steve and Donna Hanson joining the 3 Angels Board of Directors.
- Make a general or “In Memory Of” donation for ACD research on the 3 Angels website at <http://www.3angelsfund.org/contribute.php> or by mail:

Mail check or money order donations to:
3 Angels Memorial Fund
PO Box 12251
Arlington, VA 22219

Remembering Our Babies

We hope that you will find meaningful ways to celebrate the birth of your child.



Rare Diseases – What are they?



Well not exactly. It actually has a very specific legal definition. The term “Rare Disease” is actually defined through an Amendment to the Orphan Drug Act of 1983 (Orphan Drug Act, P.L. 97-414; Health Promotion and Disease Prevention Amendments, P.L. 98-551). It is defined as a condition affecting fewer than 200,000 Americans or a disease with a greater prevalence but for which no reasonable expectation exists that the costs of developing or distributing a drug can be recovered from the sale of the drug in the United States.

There are approximately 25 million people in the United States that are affected by an estimated 7,000 rare diseases or conditions leading to significant morbidity and mortality. Alveolar Capillary Dysplasia is classified as a rare disease and is listed in the National Organization of Rare Diseases (NORD) database of rare diseases.

You may be surprised to know that some relatively well known diseases like Cystic Fibrosis (approx 30,000 cases) and Hemophilia are classified as rare diseases. While these diseases have many more cases than ACD, they have a relatively low number of affected people, but have nonetheless achieved widespread recognition.

2008 is the 25th anniversary of the The Orphan Drug Act which was passed by Congress in 1982 and signed into law by President Ronald Reagan on January 4, 1983. It represents one of the most successful pieces of public health legislation in U.S. history. Before 1983, few approved drug treatments were available for those with rare disorders. Since the passage of the Act, more than 1,500 drugs and biological products have been designated by the FDA as orphan products and are in various stages of development. More than 300 of these products have been approved for marketing in the United States providing treatment opportunities for more than 11 million Americans.

Development of treatments for Orphan Diseases can be very expensive with limited payback opportunities for Drug companies. As incentive, they are given 7 years exclusivity for products that the FDA approves as “orphans” and approves for marketing. In addition, the Act provides 50% tax credit for clinical trial costs.

As members of the ACDA, we need to get the word out on ACD because the more well known diseases are, the more research attention and funding they receive.

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