

# ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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

Winter 2009

Dear Friends and Family,

Because of the efforts of many of you, we have so much to celebrate in this newsletter! First is the safe arrival of so many babies! Knowing the risks, it is not easy to decide to have another baby, but we celebrate your special deliveries. Second, a conference to develop ACD awareness materials was held this month in Aurora, Colorado. Lastly, three states declared February 28 Rare Disease Day due to the letters written to state governors by ACDA members. Thank you to all of you that give us a reason to celebrate. Read on for all the details.

Fondly,

*Steve & Donna Hanson*

ACDA Executive Directors

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

## ACD Conference Convened

As part of the Centers for Disease Control (CDC) grant awarded last year, an ACD conference was convened at Children's Hospital in Aurora, Colorado on March 18 & 19 by the 3 Angels Memorial Fund for ACD Research. As you recall, the CDC grant is for development of ACD educational and awareness materials.

After considering the available options, and, in part, at the suggestion of Claire Langston, M.D., the conference was held jointly with the spring meeting of the Childrens Interstitial Lung Disease Research Network (chILD). Much of this meeting focused on the International ILD Web-based Registry that *chILD* has been developing, but an afternoon session on March 18 was devoted to a discussion of the work of the Steering Committee formed for the CDC grant. Attended by doctors and researchers from both the ACD community and the interstitial lung disease community, this afternoon session was an important step in the goal of developing awareness materials for ACD.

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The Steering Committee, led by the 3 Angels Medical Director Naomi Bishop, MD, developed and distributed a series of documents geared for Health Care Providers (HCPs) that will serve to improve diagnosis and confirmation of an ACD case. The “ACD Diagnostic Protocol,” an “ACD Biopsy Protocol” and an “ACD Fact Sheet” were distributed for comment. Craig Snyder then introduced the “Breath of Life” awareness campaign that will provide a cohesive look to the ACD awareness materials for HCPs. The campaign includes a new website that will be the vehicle by which awareness materials will be published. Craig facilitated a focus group to gather suggestions on the most effective ways to insure that HCPs will find this new website that will contain ACD-related resources targeted specifically for them.

In the words of 3 Angels founder, Craig Snyder, “I couldn't be more delighted with the way things went (at the meeting). We are moving dramatically towards an unraveling of the genetic puzzle of ACD and with that towards a broader understanding of the phenotype.” The ACDA would like to thank Naomi Bishop, Craig, Kristin Cappola, the ACD Awareness Project Research Coordinator and the other Steering Committee members who have committed their time to help us find the cause and cure for ACD.

# Announcements

- If you have recently moved or changed your email address, be sure to let us know. If you have approved release of your information, we share your contact information with new families so they have others to reach out to for support and understanding.
- If you are interested in conducting your own personal letter writing campaign, we have ACDA letterhead and brochures that we would be glad to send you. This is an easy fundraiser that doesn't take much time but the rewards are significant. We have a sample letter that we can send you that you can modify for your family.
- If you have a fund raising idea or would like to host a fund raising event in your area, the 3 Angels would like to help. Email the 3 Angels at [info@3angelsfund.org](mailto:info@3angelsfund.org).
- 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 for ACD Research  
PO Box 12251  
Arlington, VA 22219*



Rare Disease Day Rare Disease Day Rare Disease Day Rare Disease Day Rare Disease Day

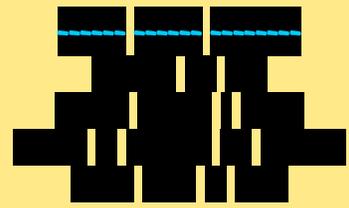
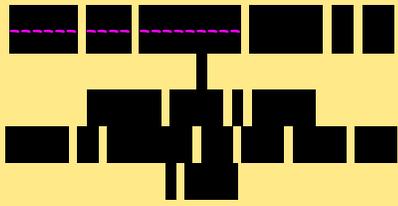
## **ACDA MEMBERS CELEBRATE RARE DISEASE DAY**

On February 28, 2009, the National Organization for Rare Disorders, along with 220 organizations in the US and Europe, including the ACDA, promoted awareness of rare diseases. Individuals across the US asked their governors to proclaim February 28 Rare Disease Day (RDD) in their states and 36 governors issued proclamations. Awareness was raised via special events, letters to editors, videos, news stories and press releases. We pass along NORD's gratitude to the following ACDA members who participated in this event:

- [REDACTED], parents of [REDACTED], got Governor Kathleen Sebelius to proclaim RDD in Kansas. [REDACTED] wrote us, "we will be honoring her ([REDACTED]) and all of our angels on this day."
- [REDACTED], parents of [REDACTED], got Governor Mark Sanford to proclaim RDD in South Carolina.
- Steve and I got Governor Rick Perry of Texas to proclaim RDD in memory of our son, Eric.
- Madonna & Jeff Myers, parents to Shelby, established a group in Facebook called "Alveolar Capillary Dysplasia." Madonna wrote us, "I thought it would be beneficial to get the word out though this highly visible medium."
- [REDACTED], parents of [REDACTED], distributed pins and bracelets around her school where she works to raise awareness.
- [REDACTED], parents of [REDACTED], ordered some pins and bracelets from NORD to wear.
- [REDACTED], mother to [REDACTED], mailed a letter to the Governor of her state, Indiana, and bought some pins and bracelets. [REDACTED] wrote, "My family and hubby's family would proudly wear them. Thanks again and I'm very happy to be apart of something for our little Angels."
- [REDACTED], grandmother to [REDACTED], set up a Facebook profile.
- [REDACTED] developed a display board to display at Wolfson's Children's Hospital in Jacksonville, Florida.

Thanks again to all the families that participated in this awareness campaign in memory of their baby.

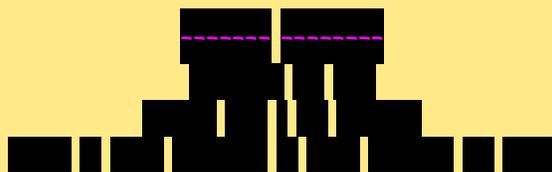
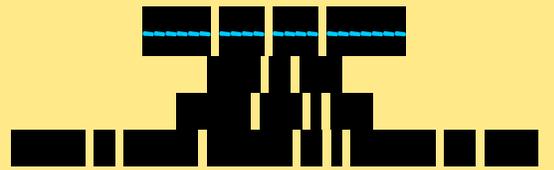
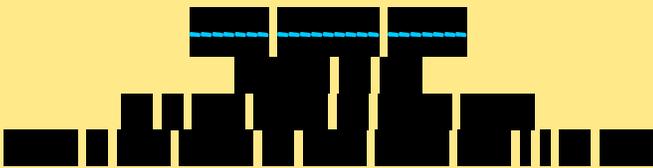
# Congratulations!



Safe



Arrivals

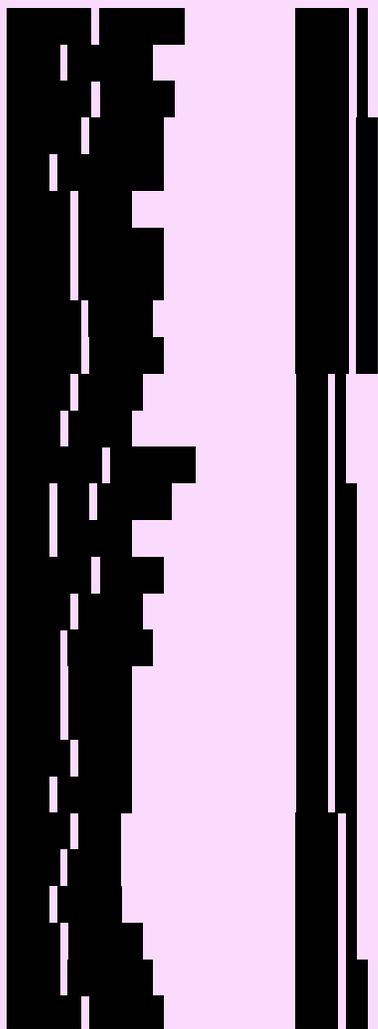


## ACDA Member to Present Lecture on ACD

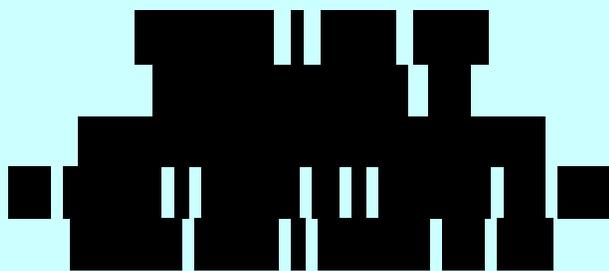
■■■■, mom to ■■■■, and a nurse, has been selected to present a lecture about ACD to approximately 100 first year medical students at the University of Florida in Gainesville on May 21. This is a great opportunity to educate our young doctors about this terrible disease – especially since there are so many of our members whose doctors didn't recognize ACD in their baby. ■■■■ is working on posters and a slideshow of pictures for her lecture. She is asking other ACDA members to send her a brief story and a picture of their baby that she could use in her presentation. If you haven't sent ■■■■ any information yet and would like to do so, email her at ■■■■. In addition, this lecture, being presented through the Genetics Department of the University, is in a lecture hall that can accommodate any parents that would like to come. If you would like to participate, contact ■■■■. Thank you ■■■■ for helping raise awareness of ACD!!

## Remembering Our Babies

*It breaks our hearts to see this list grow so long. Consider sending an email to a family to honor their baby.*



## New ACDA Family



### Contact Information

#### ACD Association

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#### 3 Angels Memorial Fund for ACD Research

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