

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Fall 2008

Dear Friends and Family,

With the holiday season upon us, it is both a joyful and emotional season for all of us. We hope that you find some time to give of yourself in memory of your baby. It is up to us to leave a legacy for them as they cannot do it themselves. May you find a special way, in this season of giving, to honor your baby by giving of yourself. It may bring you peace and help in your healing process.

Warm wishes to you and your family for a wonderful holiday season and a prosperous new year. We are excited about the progress the ACD community has made in 2008 and are even more excited about the possibilities for 2009.

Fondly,

Steve & Donna Hanson

ACDA Executive Directors

Kick-off Meeting for CDC Grant

On November 14, 2008, the Steering Committee for the Centers for Disease Control grant convened its first meeting at Children's Hospital of Philadelphia. The grant, *Characterizing Alveolar Capillary Dysplasia to Increase Awareness among Health Care Providers*, was awarded to the 3 Angels Memorial Fund for ACD Research.

The objective of this grant is to develop educational materials for ACD and to determine the optimum way(s) to deliver this information to the medical community. A follow-up grant would disseminate the information to the medical practitioners. The major initiatives for the current year long project are:

- Assemble a multidisciplinary panel of experts that will serve at the Steering Committee – This has been completed and the Steering Committee members listed below will serve as the Scientific Advisory Board.
- Refine the current definition of ACD and develop diagnostic best practices
- Conduct a Scientific Workshop in Spring 2009.

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The Steering Committee Members are:

- Naomi B. Bishop, MD – Principal Investigator, Medical Director of 3 Angels and Asst. Professor of Pediatrics, Division of Pediatric Critical Care Medicine at Weill Cornell Medical College in New York
- Hakon Hakonarson, MD, PhD – Director, Center for Applied Genomics, The Children’s Hospital of Philadelphia and Associate Professor of Pediatrics, at Children’s Hospital of Philadelphia
- Claire Langston, MD – Professor of Pathology & Pediatrics, Baylor College of Medicine and Pathologist, Texas Children’s Hospital, Houston, Texas
- Craig Snyder – 3 Angels; Co-founder 3 Angels Memorial Fund for ACD Research, Arlington, Virginia and Managing Partner, IKON Public Affairs, Washington, D.C.
- Robin Steinhorn, MD – Raymond and Hazel Speck Berry Professor of Pediatrics; Head, Division of Neonatology, Associate Chair of Pediatrics at Children’s Memorial Hospital at Northwestern University, Chicago, Illinois
- Jeffrey Whitsett, MD – Chief, Section on Neonatology, Perinatal and Pulmonary Biology at Cincinnati Children’s Hospital Medical Center, Cincinnati, Ohio
- Stefan Worgall, MD, PhD – Chief of Pediatric Pulmonology, Allergy & Immunology, Associate Professor of Pediatrics and Genetic Medicine, Weill Cornell Medical College, New York, NY

In addition to ourselves, the following people were also in attendance at the initial meeting:

- Kevin Roy – Grant Coordinator, 3 Angels Memorial Fund for ACD Research, Arlington, VA and Associate, IKON Public Affairs
- Kristin Cappola, MPH – Research Coordinator, 3 Angels Memorial Fund for ACD Research, Arlington, VA.

The group concluded that until the gene is identified, the most accurate diagnostic procedure is to perform a lung biopsy, using a standardized protocol. Also:

- A “best practice” guideline for ACD should be published
- Experts in pulmonology, critical care and neonatology should agree on content
- Finding the gene is a top priority; therefore, samples are badly needed
- Once gene is identified, developing animal models and treatment can follow
- Only then can we begin to impact clinical practice.

We were very impressed with the mix of disciplines represented by the Steering Committee and the level of interest in ACD. We are grateful to the Committee members that have volunteered to lead this effort. We hope that some of you will be able to attend the conference scheduled for the Spring. We will let you know as soon as the date and location have been chosen.

Baylor Wins NORD Grant

*In November 2008, Partha Sen, PhD, from the Baylor College of Medicine, was chosen for a second time by the National Organization for Rare Disorders (NORD) Medical Advisory Committee to receive a \$30,000 grant. While there were other applicants, Dr. Sen's study was clearly the most outstanding, according to Stefanie Putkowski, the NORD Research Program Administrator. The title of Dr. Sen's study is: **Genotyping and VEGF188 Expression Study for Further Understanding of the Molecular Basis and Pathophysiology of ACD.***

Thank you to all our members, your family members and friends of the ACDA for raising these greatly needed research funds!!

You Are Invited - 3 Angels Fundraiser

Vanessa Else is the make-up artist for some of the biggest names in show business and for one evening only, she will give you the star treatment and benefit the 3 Angels Memorial Fund for ACD Research.

At this limited guest list event, Vanessa will be sharing her celebrity make-up tips as well as individual evening, daytime and "no make-up" make-up for each guest. In addition, everyone will receive a **Modern-Audrey Gift Bag sponsored by Oasis Day Spa**. Plus, there will be a silent auction for one-of-a-kind gifts.

Celebrity Make-up Artist Vanessa Else

Monday, February 2, 2009

5:00 - 9:30 PM

215 E. 96th Street, New York

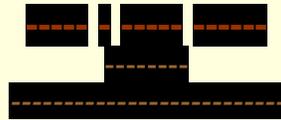
Tickets \$250 per person

Thanks to NiCole Robinson, mother of Lincoln, for her creative fundraising in support of ACD research. To get tickets for this event for you, your family and your friends, go to the 3 Angels website at http://www.3angelsfund.org/events/beauty_and_soul.php

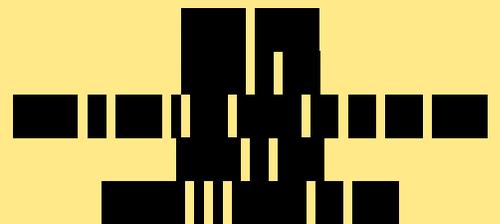
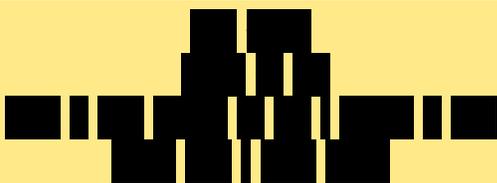
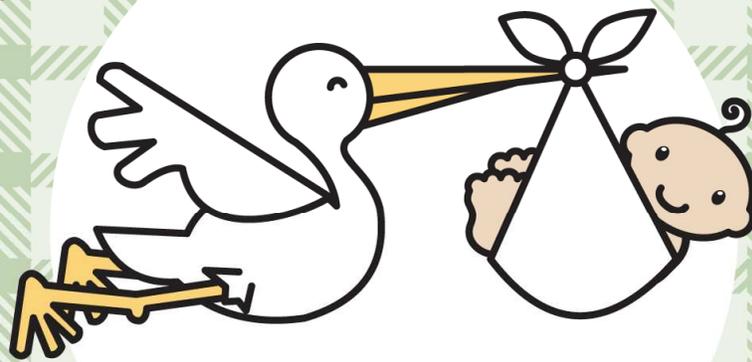
If you have an idea for a fundraiser or would like to host a fund raising event in your area, NiCole would like to help. Email her at info@3angelsfund.org.

New Family

Please reach out to the newest member of the ACDA Association. Send them an email and let them know they are not alone.



Safe Arrivals



Announcements

- If you have a fund raising idea or would like to host a fund raising event in your area, we would like to help. Email the 3 Angels at 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
PO Box 12251
Arlington, VA 22219

Contact Information

ACD Association

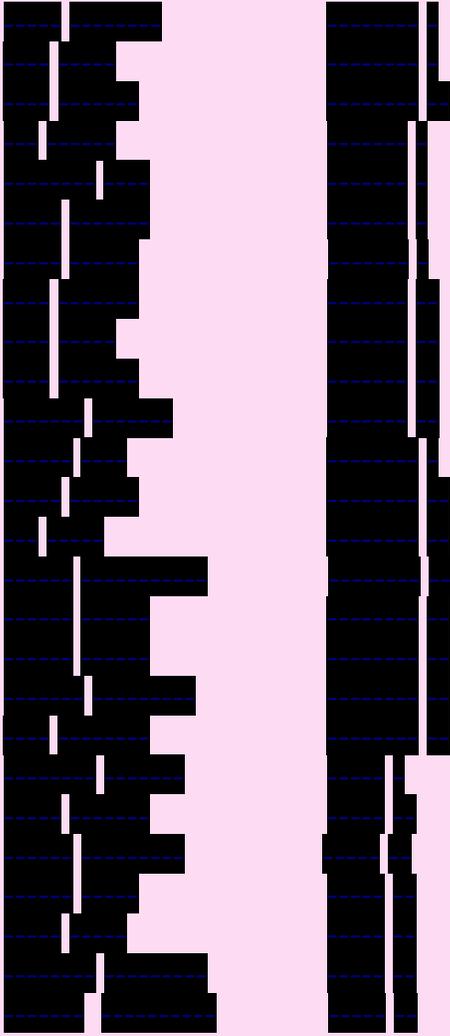
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Remembering Our Babies

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



A Candle for Your Child

*Today you will light a little white candle
and say aloud your child's name.
For one fateful day, your life was changed.
The holidays will never be the same.*

*Today you will light a little white candle
and hang an ornament on a special tree.
Who would have thought you would be in
this place?
Sharing your child as a memory.*

*Today you will light a little white candle,
a small gesture to some others.
Here we share the pain of our loss,
with mothers, fathers, sisters & brothers.*

*Today you will light a little white candle,
and as you gaze into the flame,
may comforting memories flood your mind,
as you proudly say your child's name.*

*Today you will light a little white candle,
With us your compassionate friends...
For all of us know that though they're not
here,
our love for them NEVER ends.*

Author Unknown