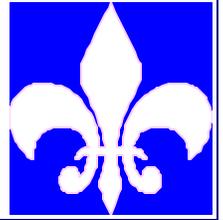


ACDA Notes

From the Alveolar Capillary Dysplasia Association



Volume 5, Issue 1

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

Winter 2003

Dear Friends,

Happy New Year everyone. We hope that 2003 will bring everyone peace, happiness and prosperity. We are really excited about the activity that is going on amongst our ACDA families. It is so heartwarming and inspiring to hear about fundraising activities that are taking place and support groups that are forming. Not only are these activities wonderful ways to deal with grief and memorialize our children, but we are encouraged that our own efforts on behalf of ACDA to honor our son, Eric, are not in vain.

We hope that this and other ACDA newsletters bring you new hope and inspire you to honor your own baby.

Fondly,

Steve and Donna Hanson

sdhanson@flash.net

NORD Supporting ACDA

You may be wondering why ACD is not listed in the rare disease database for patients and family members at the National Organization for Rare Disorders (NORD). Upon investigation, we found that NORD requires that a report be written on each disease listed in the database and that the ACD report had not been written. We contacted Mary Dunkle, the NORD Vice President of Communications, who offered to write the summary, adapting the entry Dr. Robin Steinhorn wrote last year for *The NORD Guide to Rare Disorders*. NORD requires that a physician review the database report before it is published, and Dr. Steinhorn has graciously agreed to review it on behalf of ACDA. Therefore, we hope to see ACD listed in the NORD rare disease database in the next few months. Thank you NORD and Dr. Steinhorn! ☺

More Fundraising News

We are so excited about the many fundraising activities that families from around the world have embarked on. Here are their stories:

From the [redacted] family in England...

[redacted] of Northampton, England, was recently inspired to raise some money for ACDA in honor of her daughter, [redacted]. She hoped to raise a small amount of money from her co-workers at the Northamptonshire Magistrates Courts. [redacted] simply sent an e-mail to her co-workers explaining the purpose of NORD and the reason that

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NORD is important to her and her husband, [REDACTED]. [REDACTED] was overwhelmed by the response she received when within a few days she had received about £105.00 !! [REDACTED]'s co-workers continued their generosity when it was decided that they make NORD/ACD the beneficiary of the Christmas raffle that raised an additional £150.00 for a total of £255.00 (approximately \$400 US). The [REDACTED] were amazed how generous people were for a worthy cause and it gave them comfort knowing that [REDACTED]'s short life may play a part in saving many others.

From the [REDACTED] family in New York...

In the last ACDA newsletter, [REDACTED] and [REDACTED] shared their plan of creating Olivia's Circle, a women's fitness center, named after their six month old daughter who died from ACD. The [REDACTED]s have now developed a website, www.oliviascircle.com, to publicize their venture and to let people know that they are raising money for NORD through Olivia's Circle. They linked their website to ACDA's website so people can learn more about ACD, and for each fitness center membership paid monthly, \$1 will be donated to NORD. To date, \$600 has been received! [REDACTED] and [REDACTED] hope that their efforts provide ideas for other families to raise money for research.

From the [REDACTED] family in Italy...

[REDACTED] and [REDACTED] found a wonderful way to honor their daughter, [REDACTED], who died in 1998. On the occasion of their son's first birthday in January, they asked friends and family to bring a donation for ACD to the party rather than a birthday present. They raised \$100! When [REDACTED] is old enough to understand the significance of this unique "birthday present," we know that he will be extremely proud.

From the [REDACTED] family in Texas...

[REDACTED] and [REDACTED] are holding an ACD fundraiser in honor of their son, [REDACTED], on March 28th from 6:30 to 8:30. It will be held at the Plano Arts Center and will include an auction of paintings and donated items. Plans that are being discussed include a wine and hors d'oeuvres reception with a guest speaker. Please contact [REDACTED] or [REDACTED] for more information.

Thanks to the [REDACTED], [REDACTED], [REDACTED] and [REDACTED] families for their fundraising efforts on behalf of ACD. With their help and yours, we can raise the \$35,000 needed for a NORD research grant to study ACD. If you are so inspired to join in the fundraising activities, please be sure to let us know so that we can include your efforts in an upcoming newsletter.

If you would like to make a financial donation to NORD, here is the information you need:

- Make the check payable to "NORD Restricted Research Fund - Alveolar Capillary Dysplasia"
- Send your check to:
National Organization of Rare Disorders
P.O. Box 1968
Danbury, CT 06813-1968

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

New ACD Articles

Two new ACD articles were recently found in the medical literature. The first article details four cases of ACD admitted to one hospital in France and the second article discusses six cases of ACD seen at an Australian hospital from 1982 to 2000. There are two ways to get copies of these articles: (1) you can find them at your local medical library or (2) you can contact us for a copy if you do not have access to a medical library.

"Alveolar capillary dysplasia: a cause of persistent pulmonary hypertension of the newborn" by Joumana Alameh, Ahmed Bachiri, Louise Devisme, Patrick Truffert, Thameur Rakza, Yvon Riou, Silvie Manouvrier, Pierre Lequien and Laurent Storme; *Journal of Pediatrics* (2002) 161: 262-266

"Incidence of alveolar capillary dysplasia in severe idiopathic persistent pulmonary hypertension of the newborn" by J. Gibbals and CW Chow; *Journal of Paediatrics and Children's Health* (2002) 38, 397-400

"Death of a Child"

Sorry I didn't get to stay.
To laugh and run and play.
To be there by your side.
I'm sorry that I had to die.
God sent me down to be with you,
to make your loving heart anew.
To help you look up and see
Both God and little me.
Mommy, I wish I could stay.
Just like I heard you pray.
But, all the angels did cry
when they told little me goodbye.
God didn't take me 'cause He's mad.
He didn't send me to make you sad.
But to give us both a chance to be
a love so precious .. don't you see?
Up here no trouble do I see
and the pretty angels sing to me.
The streets of gold is where I play
you'll come here too, mommy, someday.
Until the day you join me here,
I'll love you mommy, dear.
Each breeze you feel and see,
brings love and a kiss from me.

By Sandy Eakle

Safe Arrivals

Congratulations to the following families who have been blessed with another baby:

██████████
Born November 15, 2002

To ██████████

██████████
Born December 14, 2002

To ██████████

██████████
Born December 22, 2002

To ██████████



Subsequent Pregnancy

We have received many questions from families in the Association, but the following question about subsequent births is the most often asked:

After having a child with ACD, what special procedures/tests did you request from your OB/GYN during pregnancy and/or what special requests did you have for the hospital upon birth of your subsequent baby?

Many parents are anxious about the health of their baby during pregnancy and upon birth and request that their medical providers perform certain precautionary measures. We would like to include your comments in the next newsletter and develop a list of recommendations that we can give to families that are either expecting or considering a subsequent pregnancy. It is not our intent to "play doctor" but to share information and provide ways for you to be informed. Please send your comments to sdhanson@flash.net.

Please Welcome Our New Family

Please take the time to welcome a new family to ACDA, offer support and share the story of your child (children).



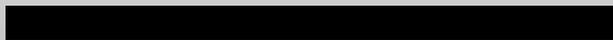
Remembering Your Baby

Here are some suggestions that you might consider to memorialize your child:

- Write a poem.
- Wear a piece of jewelry, perhaps an angel, that symbolizes your baby.
- Build a chest to hold memories and mementos.
- Write a song. ∞

Announcements

- There is approximately \$4,080 in the ACD research fund at NORD as of December 31, 2002. That's an increase of \$1,330 since September 30, 2002.
- If you live in the UK and are interested in joining an ACD support group in that country, please contact:



or



Searching for Answers, Hoping for a Cure . . .



ACD Technical Terms

Readers of this newsletter have probably also tried to read their child's autopsy and some of the ACD articles published in Medical Journals (for a current listing of Journal Articles, please see the ACD website at ACD-Association.com). This can be a daunting task with the confusing technical terms used in these documents, particularly when coupled with the emotional aspects of the subject. The list of brief definitions below is far from comprehensive, but hopefully will provide clarification of some medical terms that are not readily available in most standard dictionaries. If you come across some other medical terms you don't understand when reviewing your child's autopsy or some Journal Articles, please send them to us and we will attempt to get a definition. If you have your own list of terms to add to the list, please send them to us and we can compile them and post them on the website.

Acinar - pertaining to the acinus.

Acinus (pulmonary definition) - that part of the airway consisting of the respiratory bronchiole and all of its branches.

Alveolar - relating to a alveolus

Alveolus - a small cell, cavity, or socket.

Anoxia - Absence or almost complete absence of oxygen from inspired gases, arterial blood or tissue.

Apnea - absence of breathing

Calice - Plural of calix

Calix - One of the branches or recesses of the kidney into which the orifices of the malpighina renal pyramids project.

Cryptorchidism - failure of one or both of the testicles to descend.

Cyanosis - A dark bluish or purplish coloration of the skin and mucous membrane due to deficient oxygenation of the blood.

Distal - situated away from the center of the body, or from the point of origin.

Dysplasia - abnormal tissue development

Epithelial - relating to or consisting of epithelium.

Epithelium - the purely cellular avascular layer covering all the free surfaces, cutaneous, mucous, and serous, including the glands and other structures derived therefrom.

Hydronephrosis - dilation of the pelvis and calices of one or both of the kidneys resulting from obstruction to the flow of urine.

Hypertrophy - general increase in bulk of a part or organ not due to tumor formation.

Hypoxemia - Subnormal oxygenation of arterial blood, short of anoxia.

Hypoxia - Decrease below normal levels of oxygen in inspired gases, arterial blood, or tissue, short of anoxia.

Idiopathic - denoting a disease of unknown cause

Karyotype - the chromosome characteristics of the individual cell or of a cell line

Labile - unstable, unsteady, not fixed

Lumen - the space in the interior of a tubular structure, such as an artery or the intestines.

Necropsy - same as autopsy

Neonate - newborn

Parenchyma - A distinguishing or specific cells of a gland or organ, contained in and supported by the connective tissue framework.

Perfuse - to force blood or other fluid to flow from the artery to the vascular bed of a tissue or to flow through the lumen of a hollow structure.

Perinatal - Occurring during, or pertaining to the periods before, during or after the time of birth. I.e., before delivery from the 28th week of gestation through the first seven days after delivery.

Perioral - around the mouth

Phenotype - The appearance resulting from the interaction of the genetic makeup of a person with the environment.

Pleura - the serous membrane enveloping the lungs and lining the walls of the pleural cavity.

Pleural - relating to the pleura.

Pneumocytes - another name for an alveolar cell

Prostaglandin - Any of the class of physiologically active substances present in many tissues, with effects such as vasodilation, vasoconstriction, stimulation of intestinal or bronchial smooth muscle, uterine stimulation and antagonism to hormones influencing lipid metabolism.

Pulmonary alveolus - one of the thin-walled saclike terminal dilations of the respiratory bronchioles, alveolar ducts, and alveolar sacs across which gas exchange occurs between alveolar air and the alveolar capillaries.

Pulmonary hypertension - High blood pressure in the pulmonary arteries. Normally, the pressure in the pulmonary arteries is low (compared to that in the aorta). Pulmonary hypertension can irrevocably damage the lungs.

Sepsis - Presence of various puss-forming and other pathogenic organisms, or their toxins, in the blood or tissues.

Septa - plural for septum.

Septum - a thin wall dividing two cavities or masses of softer tissue.

Serous - relating to, containing, or producing serum or a substance having a watery consistency.

Tachypnea - rapid breathing