

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 12, Issue 1

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

Winter 2010

Dear Friends and Family,

Just a few months into the new year and we have already been contacted by several new families. This is a double-edged sword as we are grateful that families are finding our organization but it also means that more babies are being lost to this dreadful disease. Please reach out to these new families and offer your support.

It has been a busy time for the ACDA with new families and creating a new ACDA database. There are tributes and fundraisers being planned, major donations made to NORD and awareness being raised. This may be a long newsletter but we know that you will be inspired as well as shed some tears like we did.

Fondly,

Steve & Donna Hanson
ACDA Executive Directors
sdesj@verizon.net

Support from Friends & Family

As many of us know, our family and friends can be a wonderful resource for support during time of overwhelming grief. Two new ACDA members have told us of how their families and friends have supported them in various ways. We want to share those with you.

Family

■■■■ of Charles Town, West Virginia, lost their daughter, ■■■, to ACD in January 2010. ■■■'s sister, ■■■, and her cousin, ■■■, began thinking of ways that ■■■ would be a part of their lives forever, carry on her name (which means beauty), and help search for answers on her cause of death.

■■■■ is planning a benefit in memory of ■■■ tentatively scheduled for June 2010 in West Virginia. A portion of the proceeds will help with medical bills and a portion will be donated for ACD research. Other family members will be working behind the scenes to make this fundraising event possible and working together they feel like they can make a difference in memory of ■■■. We will keep you updated as their plans firm up on these wonderful tributes to ■■■.

■■■■'s cousin, ■■■, and her husband ■■■, own ■■■, an audio/video production company in the North Texas area. They work for some well-known artists such as musician and archaeologist ■■■ from ■■■. In addition, they are the audio/video vendor for the ■■■ Independent School District. They were about to release a compilation CD of music they had recorded when ■■■ died from ACD. They decided that some proceeds from this CD would be contributed to ACD research. The CD will encourage other people to donate to NORD as well. The CD will be entitled:

Kids Helping Kids for Alveolar Capillary Dysplasia (ACD)

"Searching for answers. . .hoping for a cure"

Continued on Page 2

INSIDE

- | | |
|----|-------------------------------------|
| 1 | <i>Friends & Family Support</i> |
| 2 | <i>New ACDA Database</i> |
| 6 | <i>■■■■'s Story</i> |
| 8 | <i>Helpful Books for Children</i> |
| 10 | <i>Safe Arrivals</i> |
| 11 | <i>Rare Disease Day 2010</i> |
| 12 | <i>Donate for Research</i> |

One of the songs on the CD has received some airplay and another song on the CD has been chosen by a producer for a special video for the new Ft. Worth Ronald McDonald House. ■ and ■ have a lot of ideas on producing and marketing the CD which they will complete before ■'s tribute in West Virginia. In addition to the CD, ■ is making a video of one of the songs entitled "The Answer," which will include pictures of ■, information on ACD, and how to make a donation to NORD for ACD research.

During her spring break from college, ■ and ■'s daughter, ■, created a Public Service Announcement (PSA) video on ACD. The PSA explains what ACD is and asks people to help find answers by donating to NORD. The music that accompanies the PSA is sung by Rebekah Jordan and is one of the songs from the compilation CD that ■ and ■ are producing. The video PSA is on the ACDA website, MySpace and YouTube, and will soon be broadcast all over the world via internet-radio through a broadcaster than ■ knows. ■ is currently working to get someone to do the voice-over for that audio PSA.

■ Family

■ died of ACD on January 10, 2010 after a course of treatment that is all too familiar to all of us. His parents, ■ and ■, shared with us that over 30 friends and family members have made donations to NORD in memory of ■. As of March 17, the total donated was over \$5,000. The ACDA also received two checks which will be used to pay for hosting the ACDA website. Be sure and read more about ■'s life on page 6.

Our condolences to the ■ and ■ families for their tragic losses and may thanks to them for their support of ACD research. If you have a special fundraiser or awareness event that you spearheaded or attended or if you want to write a tribute to your child, please let us know. Send us your information at sdesj@verizon.net.

New ACDA Database

With close to 100 ACDA members, we have too many lists and paper files in various places. We realized that we needed to become more efficient and so we created a database of the ACDA membership data. In addition to keeping most of the information in one location, the database will help us keep track of members, make it easier to update information, generate reports (like the directory), and help automate some tasks that were previously manual. Another advantage of the database is it allows a faster review of the data to answer questions and enables a charting capability to look for trends.

One of the reasons we have a registration form for new members is to receive permission to share information with other members and researchers. We are respectful of members' privacy, and if you have requested that certain information not be shared, we will suppress it in any data shared with other people (e.g. the ACDA membership directory). We do use all of the data to generate reports and charts where that information is not uniquely identifiable to a specific family (see examples below).

The following summarized data and graphs are based on information provided by ACDA members and is accurate to the best of our knowledge. We suspect, however, that the data is not totally complete and current because we have lost contact with some members, others may have moved, and some had additional children that we are not aware of, but it the best information that we have. However, we believe it is reasonably representative of ACDA membership. Several reports attempt to answer some common questions that we receive from families and provide insight into ACD. We hope you find this information interesting.

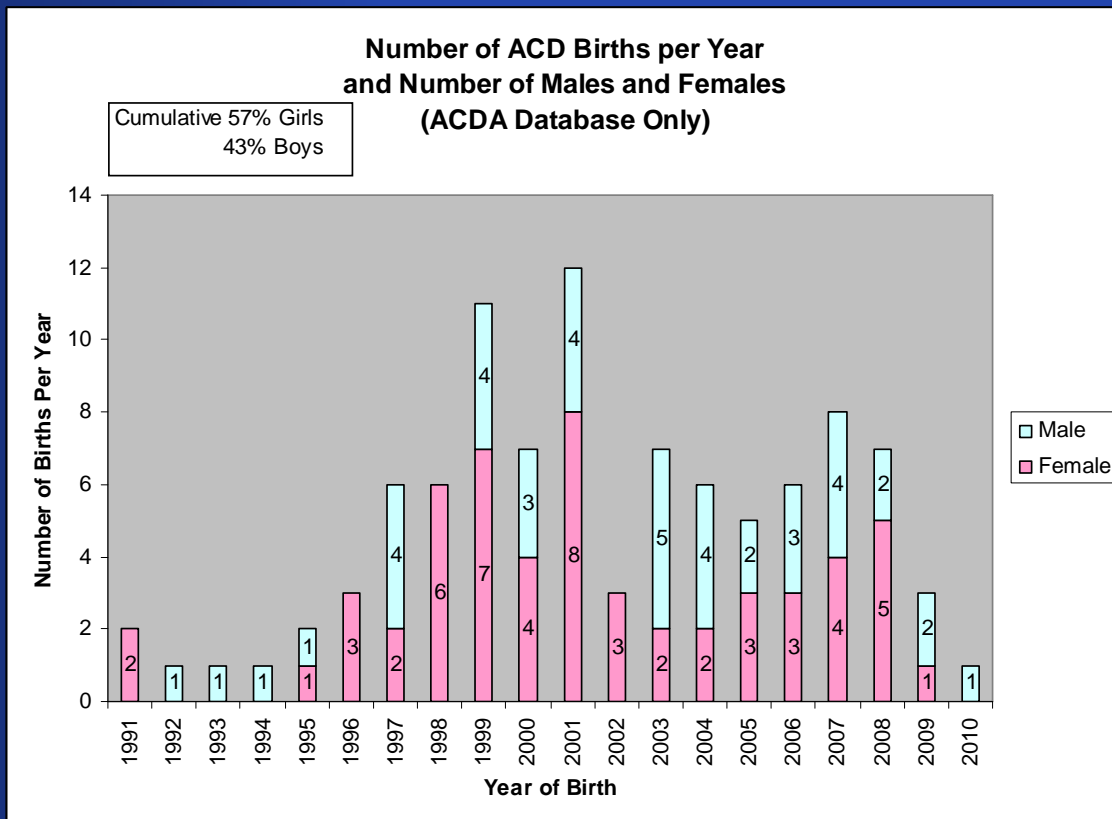
Continued on Page 3

1. **What are the chances that our next child will have ACD?** This is the most common question we receive and it is a difficult question to answer as no one knows the cause(s) of ACD. All we can present is the data from the ACDA members which shows the following:

Families with one child born with ACD	92
Families with two children born with ACD	3
Families that had a healthy child after an ACD baby *	61
Families who have not had another child (or not known to us)	35

* One of the three families that had two ACD babies went on to have a healthy child. The other two families with two ACD babies have not had another child together.

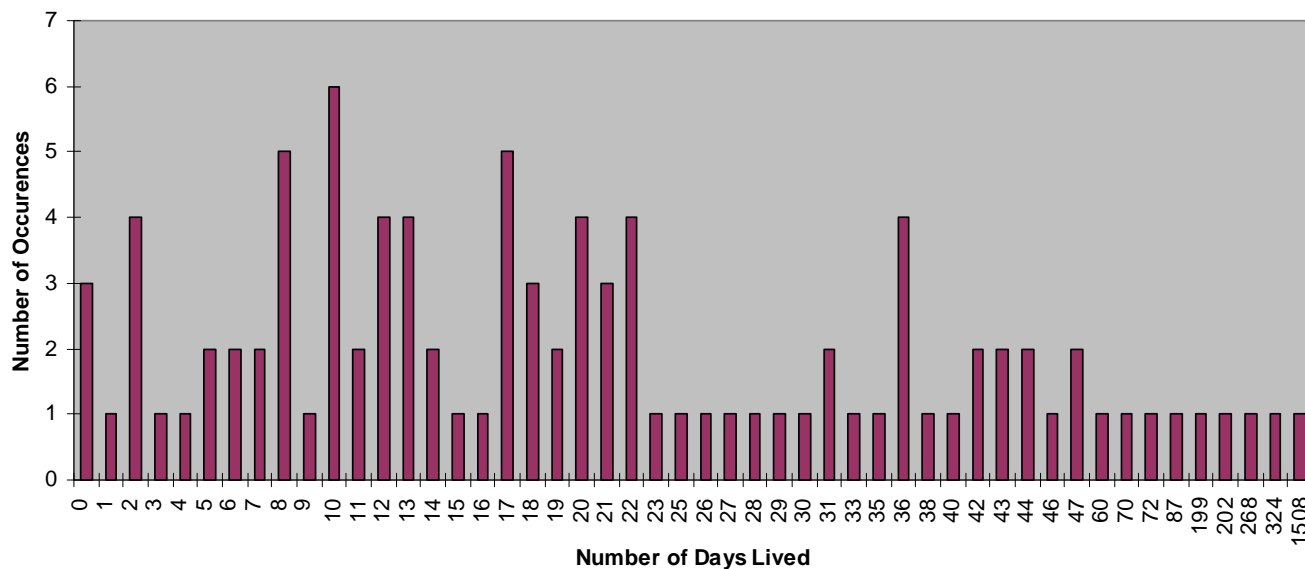
2. **Does ACD affect males and females equally?** The research papers we have seen indicate that ACD affects males and females equally. The data from the ACDA membership generally supports this with 57% female and 43% male, although this is a relatively small sample size,. We will monitor this ratio.



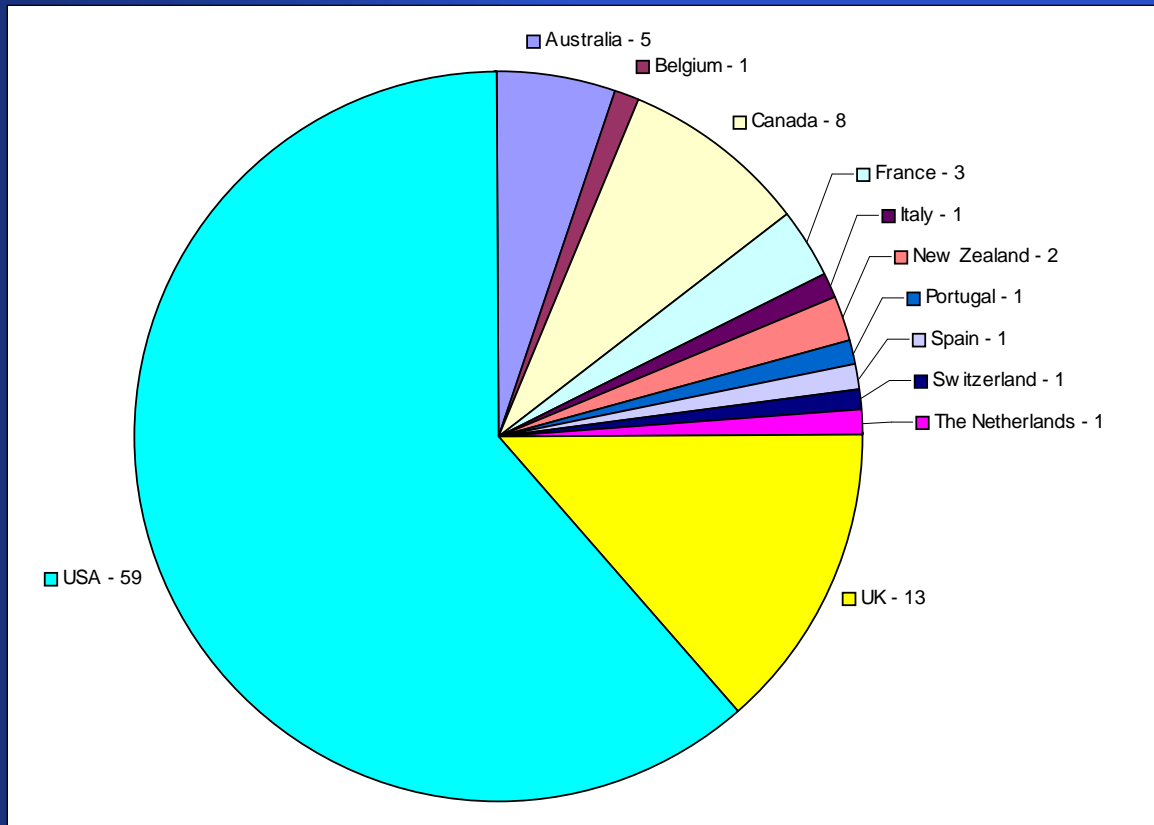
3. **How long do babies with ACD live?** ACD is a fatal disorder unless heart/lung transplant surgery is performed. Transplants are limited by the short time frame available, limited pool of donor organs and need for matching. However, we have been told that two such transplants have occurred, but they are not ACDA members and we are not aware of the outcome. ACD often presents itself within a few hours or days while the baby is still in the hospital, but in several cases it has not presented until weeks later. When the symptoms present and the level of care available to an ACD baby affect how long they live. We

don't have specific data on when babies presented with ACD or what levels of care were provided, but the following chart shows that babies live from less than a day to more than a year in one case.

Length of Time ACD Babies Lived

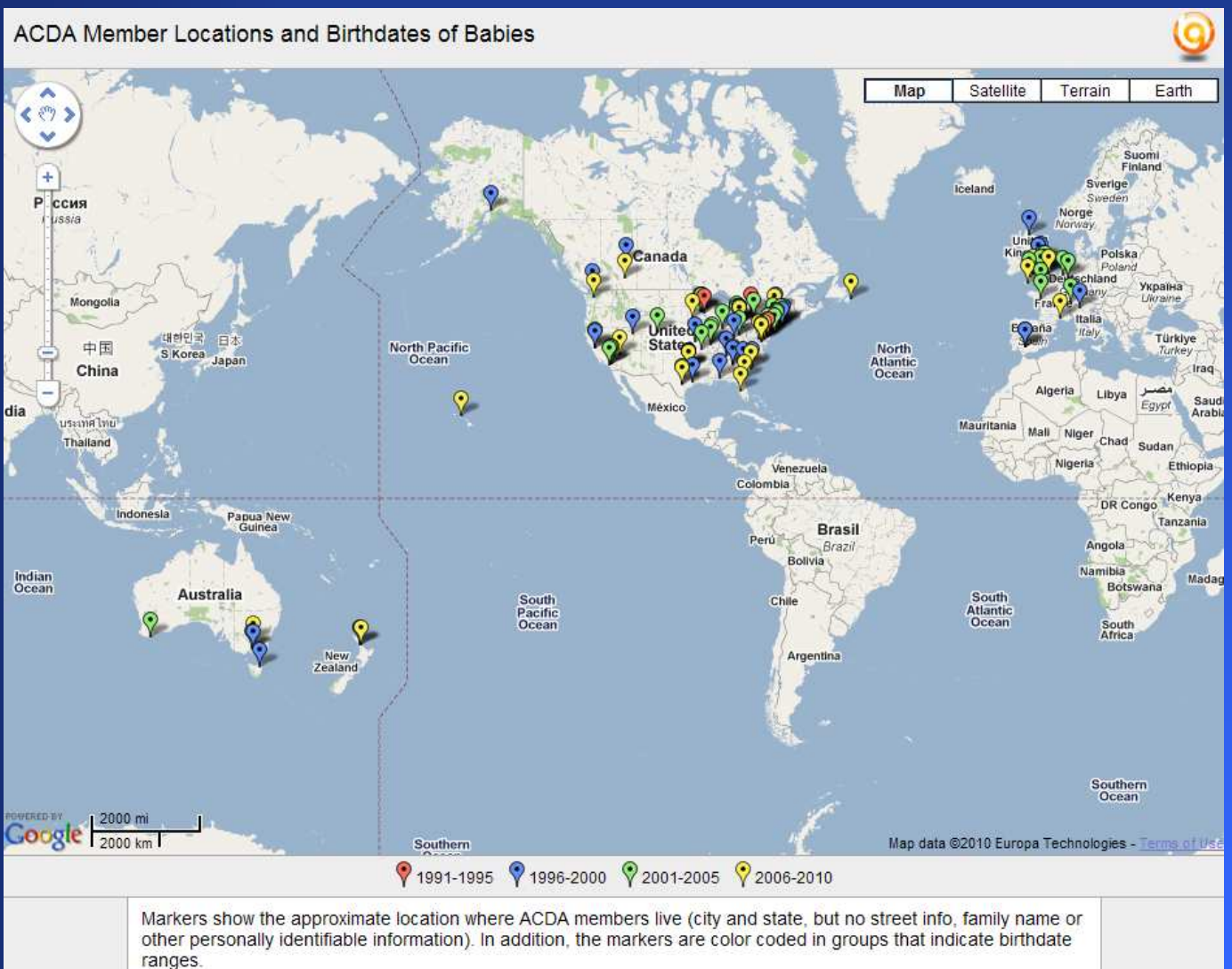


4. **Where do ACDA members live?** ACDA Members are currently located in 12 countries throughout the world. The two largest groups consist of approximately 60% in the USA and 20% in the UK.



5. **Are there any ACDA members that live near me?** One of the main benefits of being an ACDA member is being able to connect with others that have also experienced the loss of a child to ACD. When you feel all alone and like no one really knows what you've been through, talking with other members one on one can be very healing. Clicking on the link below will take you to an interactive version of the map that shows ACDA member locations. This will allow you to zoom in and see if anyone lives near you to allow more interaction for support or collaboration on a fundraiser. Consult the ACDA directory for more specific contact information.

<http://www.batchgeocode.com/map/64a676e8a9698163b7fec4efed040ebc>



■'s *Story*

Thank you to ■ and ■ for sharing this wonderful story of their son.

■ joined our family on January 10, 2010, weighing 7 lbs. and measuring 21 inches. He was bathed and examined, and then placed in my arms to snuggle. ■ and I took turns holding him and called our families to announce his arrival. Shortly after moving to our room on the maternity ward, ■'s coloring appeared to be purple. We called for the nurse who said she'd bring ■ down to the nursery. His oxygen levels were low, so he was taken to NICU for examination as a precaution. ■ went with ■ and I waited in my room for the epidural to wear off. When they didn't return, I changed out of my hospital gown and joined ■ and ■ in NICU. He was on oxygen, but we were able to hold him Sunday night and Monday morning.

Throughout Monday, his care team tried oxygen, a ventilator, and nitric oxide. ■ would respond to treatment for a little bit, but then his post SATs would drop dramatically and they were having difficulty keeping him stable. He was diagnosed with persistent pulmonary hypertension of the newborn. Monday evening, the neonatologist met with us and recommended placing ■ on ECMO. We met with the surgeon, signed the consents, and waited. His surgery went well, and we were very hopeful that ECMO would give him the time he needed to cure the hypertension. I was discharged from the hospital on Tuesday. It was difficult to leave the hospital without ■, but we were certain that he would soon join mom, dad, and two-year brother, ■, at home.

Throughout the first week, ■'s care team looked for possible causes to explain the hypertension. They asked questions of both ■ and me and spoke to my obstetrician. The neonatologist said that the longer the hypertension persisted, the greater the concern, but everyone seemed very optimistic that he would improve. We set up a page at ■■■■■ ■■■■■te on his progress. We were overwhelmed by the prayers and encouragement that we received not only from those we knew, but from friends of friends and others who had heard our story. There were so many people praying for our little ■.

The next week was similar to many of the stories that we've read on the ACDA website. They tried a variety of medications and more nitric. However, his echos showed little improvement. On Wednesday of the second week, they recommended a biopsy of his lung. They warned us of the risks of a lung biopsy while on ECMO, but the biopsy would give us answers as to how to proceed with treatment. We received special permission from the head nurse to bring his brother to meet him. (They had restrictions in place for anyone under 18 because of the H1N1 virus.) ■'s mom, my parents, my sister and ■'s sister waited at the hospital with us through the surgery. We were relieved that he made it through the surgery, but were disappointed to learn from the surgeon that the lung tissue did not look normal.

Friday was a long day. We were supposed to receive the results later in the afternoon, but the lab advised that the results would not be available until Saturday. ■ was more alert on Friday. He squeezed our hands and opened his eyes and seemed to be telling us how much he loved us and how hard he was trying to get better.

On Saturday, we arrived at the hospital before rounds. We sat with ■■■ and told him stories and enjoyed our time. At noon, the doctor told us that he should have the pathology report in half an hour. The nurse commented that the next half hour would probably feel long. It was both the longest, and the shortest half hour of my life. I wanted to know what was wrong with my baby, but also knew that it was probably the last half hour that I could pretend that he was going to come home. The pathology report confirmed ACD. We made the decision to remove him from ECMO, not wanting him to die attached to machines. We asked the hospital about donating his organs and they called LifeSource, while we informed our family about ■■■'s diagnosis. LifeSource was not able to find a match for ■■■'s kidney or liver, but they were able to use his heart valves.

The hospital arranged for a professional photographer who volunteers his services to come and take family photos Saturday night. My parents and sister brought ■■■ and we all had the opportunity to hold ■■■. It was a very emotional night. After they left, ■■■ and I sat with ■■■ for a little while and then ■■■ was taken off of ECMO. The nurse wrapped him in a receiving blanket that he'd received for Christmas and placed him in my arms. ■■■ and I held him and told him that we loved him and that it was okay for him to go. We told him that we would see him again someday and that we knew what a fighter he'd been and that if it had been possible to fight this disease he would have. Not long after he was taken off of ECMO, he passed away peacefully in his sleep, while ■■■ and I held him.

We know our little angel is watching over us. Our friends and family have been an amazing source of strength, support and encouragement throughout our journey and continue to be as we search for answers to this terrible disease. We also continue to meet so many wonderful people through this organization and feel truly blessed to have found such a supportive group.



■■■, big brother ■■■, ■■■ and ■■■

Helpful Books for Discussing Death with Young Children

Are you looking for a way to talk to your young son or daughter about the death of his/her sibling? Here are some books recommended by other ACDA members. If you know of other books that you have found helpful, please share them as we keep a file on grief resources.

- *"Mommy, Please Don't Cry, There Are No Tears in Heaven"* by Linda DeYmaz
- *"We Were Gonna Have A Baby, But We Had An Angel Instead"* by Pat Schwiebert
- *"Where do People Go When they Die?"* by Mindy Avra Portnoy
- *"What's Heaven?"* by Maria Shriver



Update on 3 Angels

In March 2008, we became Directors for the 3 Angels Memorial Fund for ACD Research to provide a unified voice in the ACD community. On January 6, 2010, 3 Angels convened its first Board of Directors Meeting since it's inception in late 2007. The purpose of the meeting was to vote us (Steve and Donna Hanson) off the Board. The motion passed 3 to 2. As mentioned previously, 3 Angels had told us that it was "neither practical nor desirable to make the day-to-day operational decision-making process more complicated, by involving you and Steve" and the "two organizations provide equally important but fundamentally different services to the small ACD community."

In the Board meeting, Craig Snyder indicated that the financial questions that we had submitted while Board Members, would be addressed later. We subsequently received a letter from the 3 Angels accountant that addressed, but did not really answer, most of our questions. Accordingly, we still believe it is in the best interest of the ACDA community to make tax deductible donations to NORD.

Announcements

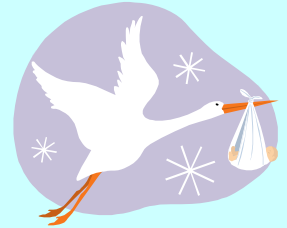
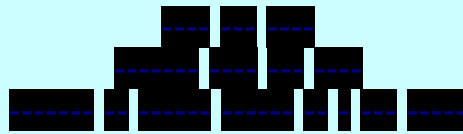
- The balance of the ACD Restricted Research Account at NORD is \$6,652 as of February 17, 2010. We need to raise \$35,000 for our next research grant.
 - [redacted], mom to [redacted], just received another invitation to go to the University of Florida in May to present information on ACD to a genetics class. Way to go [redacted], for raising awareness for doctors of the future!
 - [redacted], mom to [redacted], is walking in the March of Dimes March for Babies on April 25, 2010 in Plattsburgh, New York. Her team name is [redacted]'s ACD Angels.
 - Check out <http://www.breathoflifeproject.com/index.html> for the website developed by 3 Angels under their grant from the Centers for Disease Control. The Breath of Life Project is information on ACD targeted for medical professionals.
- 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.
- The ACDA has approximately \$100 remaining from donations that we have received over the years. We have used donations for travel expenses to Baylor and postage and plan to use the remaining funds to renew the website hosting later this year.

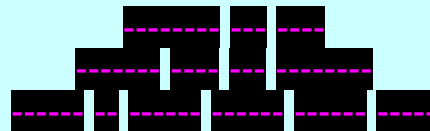
May you find a meaningful way to celebrate the precious life of
your baby.

Remembering Our Babies



Safe Arrivals

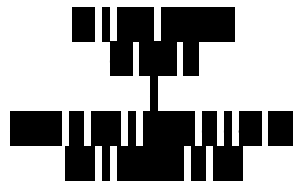


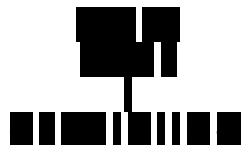


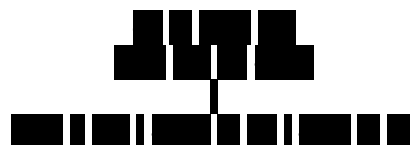
Please join us in congratulating the
[redacted] and the [redacted] families.

welcome.....

Please introduce yourself and share the story of your family with our new ACDA members.







Rare Disease Day 2010

The annual Rare Disease Day is a grass roots event that is celebrated on the last day of February by people around the world. This is a day to raise awareness of diseases and the special challenges encountered by those affected. The National Organization of Rare Disorders (NORD) encouraged families to contact the governors of their state to request a proclamation. The [REDACTED] family of South Carolina wrote to Governor Sanford and asked him to do just that. Below is a copy of the proclamation that the [REDACTED]s received for Rare Disease Day 2010. This was the second year that the [REDACTED]'s helped raise awareness of ACD and other rare diseases in South Carolina.

State of South Carolina Governor's Proclamation

- WHEREAS, a rare disease is a disease or condition that affects fewer than 200,000 individuals in the United States; and
- WHEREAS, there are nearly 7,000 such diseases in the United States affecting a total of nearly 30 million Americans; and
- WHEREAS, because many rare diseases are genetic, it is estimated that half of the people affected by rare diseases in the United States are children; and
- WHEREAS, individuals and families affected by rare diseases can experience a sense of isolation and hopelessness due to difficulties in obtaining timely, accurate diagnoses and problems in finding and receiving effective medical care; and
- WHEREAS, thousands of residents of the Palmetto State, including patients, friends and family, caregivers, medical professionals, social workers, and researchers seeking to develop safe, effective treatments, are impacted by rare diseases.

NOW, THEREFORE, I, Mark Sanford, Governor of the Great State of South Carolina, do hereby proclaim February 28, 2010, as

RARE DISEASE DAY

throughout the state and encourage all South Carolinians to recognize the need for research into the causes and cures for the many rare diseases affecting fellow residents of the Palmetto State.



A handwritten signature in black ink, appearing to read "Mark Sanford".

MARK SANFORD
GOVERNOR
STATE OF SOUTH CAROLINA

Make a Tax-deductible Contribution for ACD Research

The National Organization of Rare Diseases is a non-profit organization in the United States who is "dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. For the sixth consecutive year, NORD has been awarded the top rating for sound fiscal management by Charity Navigator, a leading evaluator of charities. Less than four cents of every dollar donated to NORD goes to administrative and fundraising costs. The ACDA has had a restricted research account at NORD since 2002 which allows our members to make tax deductible contributions for ACD research. Once this account reaches \$35,000 NORD will initiate the process to award a research grant. Previously, two such grants have been awarded to Baylor because of the generous donations of our members, friends and family. As evidenced by past grants, we are confident that our donations will be used for research. Therefore, please follow these steps when making a contribution to NORD:

- Please make your check payable to "NORD - Alveolar Capillary Dysplasia Restricted Research Fund" to earmark your donation for ACD research.
- In the memo section of the check or on a separate note attached to the check, state that the donation is "in memory of (name of child)."
- Your family and friends can attach a note to their check with your name and address and NORD will notify you of their gift.
- Send your check to the following address:

National Organization for Rare Disorders, Inc.
P.O. Box 1968
Danbury, CT 06813-1968 USA

The most critical part of this process is ensuring that your check is made out to "NORD - Alveolar Capillary Dysplasia Restricted Research Fund" to ensure that your donation is earmarked for our ACD Research Account.

You may also make a donation on the NORD website at <http://www.rarediseases.org/helping/donate>. When filling out the section entitled "You may enter the name of the person you wish to honor with your gift here" type in the name of the baby followed by "Alveolar Capillary Dysplasia," (example: Jane Doe/Alveolar Capillary Dysplasia). If the name of the baby is written first, the accounting department at NORD will immediately know that this is a restricted research donation in memory of your baby.

Special Information for Families Living Outside of the United States:

NORD recommends that families living outside of the United State use a credit card to make a donation since it costs less to convert international currency when using a credit card. The person to notify with the authorization amount, type of credit card (Master card, Visa), name on the card and the expiration date on the card is Cindy Thayer cthayer@rarediseases.org. Also, please be sure to indicate the donation is restricted for ACD research, the person's complete name it is given in memory of, and the name and address of whom NORD should send an acknowledgment to. Your own name and complete address should also be included in order to process the paperwork.

Contact Information

ACD Association
Steve and Donna Hanson
5902 Marcie Court
Garland, TX 75044-4958 USA
(972) 414-7722
Email – sdesj@verizon.net
<http://acd-association.com/>