ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Dear Friends and Family,

Please join us in congratulating the [redacted] and [redacted] families, both of New York, for their very successful fundraisers in memory of their sons. Their fundraisers are very duplicatable and they are willing to help you get started in your hometown.

As we mentioned in the recent e-mail, we are requesting that everyone direct their ACD donations to the National Organization for Rare Disorders to the ACD account that has been active since 2002. We think this change is in the best interest of our members, their fundraising efforts and research.

Happy Holidays to you and your families. We hope that you will find many meaningful ways to remember your baby during your holiday.

Fondly,

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

INSIDE

Fundraising Successes

Two ACDA families have been very successful at raising money recently for ACD research. We wanted to share their successes and know that you will join us in applauding their efforts.

The [redacted] Family of New York - For the last three years, the [redacted] family has held an annual golf tournament in memory of their son, [redacted]. This year their foundation, The [redacted] [redacted] Memorial Foundation, held a bowling fundraiser at the Strike Bowling Alley in New Hyde Park, New York. Their 4th annual event included 50 bowlers and raised an amazing $3,000 which was donated to the NORD account for ACD research. Their bowling event included a raffle of many prizes including four tickets to a Yankees baseball game. The [redacted]'s would love to expand this annual fundraiser to other ACDA members. If you are interested in having a

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Baylor Research Update

We recently spoke with Dr. Partha Sen about the status of research at Baylor and he provided this update:

- The immunihistological study funded by NORD has been completed and an announcement will soon be made about a journal publication by the Baylor researchers.
- Baylor is studying other genes of interest in addition to the FoxF1 gene.
- Dr. Clare Langston, the foremost expert pathologist on ACD, has come out of retirement to continue her work on ACD.

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bowling fundraiser in your hometown, contact [redacted] [redacted] at [redacted] for hints on how she and her family put together such a successful event. Thank you to the [redacted] family and their friends and family that supported this special fundraiser!

[redacted] [redacted] of New York- [redacted], mom to [redacted], was thrilled to immerse herself into a fundraiser in memory of her son. It was so successful that she hopes to do it every year to honor [redacted]! In the beginning, her goal was to be able to make a donation of $1,000 by hosting a Celebrate Home party. She chose five people from different avenues of her life - her mom, mother in law, close friend, friend, and acquaintance and asked each one to make a list of 10-15 people to come to the fundraiser. She was able to get the facility donated, offered some snacks to her guests and decorated in a Fall theme. She had the banner below specially made for the event. Thanks to her friends and family, [redacted] was thrilled to make a donation to NORD for ACD research in the amount of $2,000 – double her initial goal!!! [redacted] would be glad to help others with a similar event in your hometown. Contact her at [redacted]. Many thanks to [redacted] for her energy in producing this wonderful tribute to her son.

Safe Arrivals

Please Welcome

[redacted] [redacted]

Born [redacted] [redacted], 2009

Parents [redacted] and [redacted]

Sister of [redacted] [redacted], [redacted] and [redacted]

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.

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.
- The current balance of the Restricted Research Account at NORD is $857.
- All donations should be directed to the National Organization for Rare Disorders.
- We have ACDA brochures and letterhead if you need some for an event or fundraiser.

The ACDA - The First Decade

It has been a little more than a decade since the ACD Association was founded and we thought it was important to summarize the history of the ACDA. There are many of you that have been with us for 10 or more years and have witnessed the history, but others that are new may not know about the key milestones. We wanted to share a look back on the progress that our organization has made:

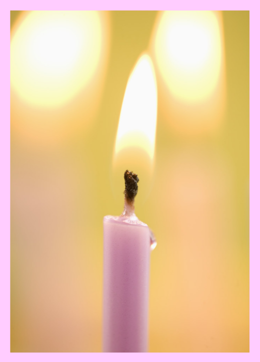
- 1996 – ACDA founded by Madonna & Jeff Myers of Tennessee
- 1998 – First ACDA website established by Madonna Myers on Yahoo
- 1999 – First newsletter, ACDA Notes, published by Madonna Myers
- 1999 – Initial work started on ACD study at Baylor College of Medicine in Houston, Texas
- 2001 – Launched http://acd-association.com with the help of [redacted] ACD father
- 2002 - Worked with Robin Steinhorn, MD to create a medical definition for ACD to gain recognition as a rare disease at the National Organization for Rare Disorders (NORD)
- 2002 - Established a research fund at NORD to raise money for research
- 2002 – Steve and Donna Hanson became Executive Directors of the Association
- 2004 – Baylor researchers publish article "Expanding The Phenotype Of Alveolar
- Capillary Dysplasia (ACD)" in the *Journal of Pediatrics*
- 2005 – membership, friends and family raised $35,000 for a NORD research grant awarded to Baylor for an Immunohistological Study.
- May 2007 – [redacted], ACDA members, design the ACDA logo
- 2007 – ACDA website completely updated
- 2007 – [redacted] and her family donated ACDA brochures and letterhead
- 2008 – Membership, friends and family finished raising another $35,000 for a NORD grant that was awarded in November 2008 to extend the previous Baylor immunohistochemical studies to investigate of other VEGF isoforms. Publication in a journal article is anticipated in 2010.
- March 2008 – Steve and Donna Hanson became Board members of the 3 Angels Memorial Fund for ACD Research
- 2008 - Began directing donations to the 3 Angels for non-profit contributions
- October 2008 – 3 Angels awarded $250,000 from CDC for developing ACD awareness materials
- February 2009 - Partnered with NORD for International Rare Disease Day which was observed February 28, 2009 to raise awareness of rare diseases.
- March 2009 – Attended meeting with Children's Interstitial Lung Disease Research Network (ChILD) in Denver to explore collaborative efforts. Baylor researchers presented initial findings on Deletions of the FOX Gene Cluster and Mutations of FOXF1 as a cause of some cases of ACD.
- June 2009 - Paper published by Baylor et al in the *American Journal of Human Genetics* detailing the Deletions of the FOX Gene Cluster and Mutations of FOXF1 as a cause of some cases of ACD.
- Currently –
  - Aware of 165 cases through ACDA and medical journals
  - Have 93 members around the world (US, Canada, UK, Spain, Australia, Italy, New Zealand, Belgium, France, Netherlands, Portugal)
  - Are aware of eight cases of familial ACD
  - Most families find the ACDA via our website; average six new family contacts per year
- As a support group the ACDA:
  - maintains the ACDA website
  - publishes a quarterly newsletter for both families and researchers
  - maintains an ACDA membership directory
  - houses a repository of medical articles on ACD cases
  - has been instrumental in creating the largest collection of ACD DNA samples which resides at Baylor College of Medicine in Houston, Texas

Remembering Our Babies

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

[redacted]

[redacted]



welcome.....

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

[redacted]

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