

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Winter 2008

Dear Friends and Family,

The last four months have been very busy for the ACDA - a visit to Baylor College of Medicine, achieving the funding threshold for another research grant at NORD, being contacted by eight new families (more than in most years) and investigating a new direction for the ACDA. With the best interests of the group under consideration, we have begun evaluating the organization of the ACDA with an aim of strengthening advocacy for ACD (see the details on page 2). While change is difficult for all of us, we firmly believe that the changes that the ACDA will be undergoing will benefit all of us, including our healthy children. Like all of you, we want to have an answer to the questions that we've been asking since our son, Eric, died 11 years ago – what is the cause of ACD, do our two “healthy” children carry this disorder and how can we prevent others from losing a baby to ACD? Craig Snyder and NiCole Robinson of the *3 Angels Memorial Fund for ACD Research* are extremely dedicated and focused on helping all of us find answers to these questions. We encourage you to join us in our efforts to support their fundraising, be inspired by their media awareness campaign and most of all, thank them for devoting their enormous energy, time and personal resources to unlocking the mysteries of this horrific disorder.

It is because of your fundraisers, donations from family members and friends and personal donations over the years that we were able to begin supporting ACD research. As a small group of families (only 76), we have made a difference in our babies' memory. We are grateful to all of you and we hope that you will continue to support the objectives of the organization. We need everyone to be involved to be a strong organization and as Madonna Myers, our founder, once said, “as our numbers grow, our voice in the medical community gets louder.”

As we enter into a new era for the ACDA, please feel free to contact us with your questions or concerns. We have dedicated ourselves to maintaining an advocacy group for ACD and we take very seriously the responsibility of representing you. We will continue to keep you posted on organizational changes.

Steve and Donna Hanson
Executive Directors, ACDA

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Changes Underway for the ACDA

The ACDA has been working closely with the *3 Angels Memorial Fund for ACD Research* on research initiatives since October 2007. Craig Snyder and NiCole Robinson founded the *3 Angels Fund* as a non-profit organization after they lost their son, Lincoln. In an effort to provide a unified organization with a single voice on ACD, the ACDA and the *3 Angels Fund* have begun working toward consolidating into one organization. Consolidation is logical because the organizations have complementary strengths and share common goals.

The National Organization for Rare Diseases (NORD) has been very helpful and responsive to the ACDA over the years. However, the near term ACD research opportunities are anticipated to be very dynamic which could be hampered by NORD's somewhat lengthy process for Request for Proposal, proposal evaluation and award. In addition, it is not possible to control what research efforts NORD chooses to fund. They could fund meaningful ACD research, but it might not be the most strategically important or expeditious path to finding the cause of ACD.

As mentioned in an article on page 4, the NORD grant threshold has been achieved and all donations to NORD made through February (\$37,330) will be included in a grant to be awarded in October 2008. The research grant will be for \$32,330 (after \$5,000 NORD administrative fee). This will effectively leave a zero balance in the Restricted ACD Research Fund. Therefore, this is the ideal time to change the method by which ACD research funds are accrued.

As part of the initial steps of the consolidation, the ACDA Executive Directors have become members of the Board of Directors of the *3 Angels Fund*. The *3 Angels Fund* Board provides direct control of what research is funded, makes more efficient use of donations and is more responsive to changing research needs. Therefore, from this time forward, the ACDA asks you to make tax deductible contributions for ACD research to the *3 Angels Fund* (instead of NORD as you have done in the past). The ACDA website section on Donations has been updated with this information.

Therefore, to make a tax-deductible contribution for ACD research, please visit <http://www.3angelsfund.org/contribute.html>. You can use either a credit card or PayPal for your donations. For other donation options, please contact the *3 Angels Fund* at <http://www.3angelsfund.org/contact.html>.

We will keep you apprised of further developments in the evolution of this consolidation.

3 Angels Fundraiser in New York City

NiCole Robinson and Craig Snyder of the *3 Angels Memorial Fund for ACD Research* have been feverously working to hold a fundraiser for ACD research in New York City. NiCole, who is an actress, asked her friend, Kristin Chenoweth, to sing a private concert to benefit the *3 Angels Fund*. You may recognize Kristin as the multi-talented star of Broadway (originated the role of Galinda in *Wicked*), television (*The West Wing*, and currently *Pushing Daisies*) and movies (www.imdb.com/name/nm0155693/). Considering Kristin sells out Carnegie Hall and The Disney Hall, they are expecting a great turnout. This private performance will be held on April 12 at the Helen Mills Theater in New York City from 8:00-11 p.m. The tickets for this show are sold out. However, a preview show has been added at 7:00 p.m. for \$150 per ticket. Check out the Playbill at <http://www.playbill.com:80/news/article/115659.html>.

Prior to the concert there will be a brief cocktail reception with light hors d'oeuvres including a short live auction of four items:

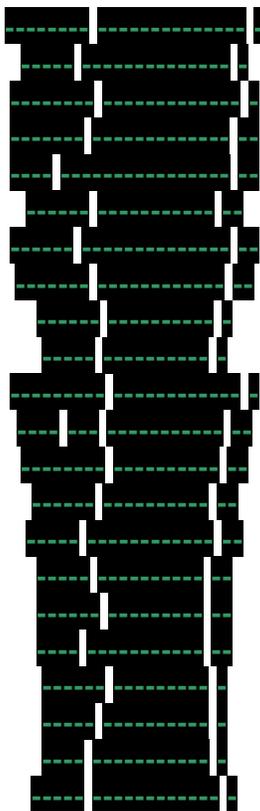
- A VIP visit to the *Desperate Housewives* set including a private tour by a cast member, signed script and stay at an executive condominium located on the corner of Sunset and Vine.
- Jen Rade (personal stylist to Angelina, Brad, Pink, etc... Style Channel host and E! correspondent) will "rade" your closet and tell you what to keep and what to throw away. Jen will tell you what you are missing and then escort you in a chauffer driven SUV to Barneys New York for an afternoon of shopping.
- *All My Children* make up artist Vanessa Elese will come to your house and show you how to do your make up for day, evening and no make up looks. She will compile the perfect make up artists kit personalized for you. Vanessa will then take you to Barneys in a chauffer driven SUV to pick up any make up or skin care essentials you may need.
- A four day, four night stay in a chi-chi ultra modern Miami Beach condo with full views of the port of Miami. Watch the sunset from the balcony as the yachts and cruise ships set sail then go out and enjoy the undisputed best nightlife in the world. This stay also includes a brand new, Limited Edition, Mini Cooper Convertible to cruise South Beach in style. And, if that's not enough, it's dinner on Danny, DeVito that is. He has a new restaurant, it's the hippest in town, and he's treating you and a guest to dinner.

If you would like to attend, please contact NiCole at hollywoodnicole@yahoo.com or buy your tickets on the *3 Angels* website at http://www.3angelsfund.org/news/chenoweth_concert.html. Even if you cannot attend, you can still make a donation to support the event at the same web site address.

Thank you to NiCole and Craig for coordinating this exciting and entertaining evening to benefit ACD research. They have been working tirelessly to plan and promote this event. In the Spring ACDA Notes, we will provide coverage of the fundraising event as well as some photographs.

Memorial Garden

Please pause to remember these babies that have been taken from us by this rare disease. We hope that parents find a way to honor their babies on this special day of their birth. Please let us know if we have inadvertently omitted your baby's name or if you do not wish to have your baby's name included in this section. You can email us at sdesj@verizon.net.



NORD to Issue RFP for ACD Research

We are excited to announce that the ACD research account at NORD has exceeded \$35,000 which allows NORD to issue a Request for Proposal (RFP) for ACD research. The RFP is posted on the NORD website at <http://www.rarediseases.org/research/requests> with an expected award date of October 2008. Many thanks to all of you that have completed fundraisers, encouraged your friends to donate and made personal donations. We are aware of a few families that have recently made major contributions and would like to acknowledge them:

- - \$3,700 for annual golf fundraiser in memory of their son, ----
- - \$2,910 from Albany Funding Fundraiser in memory of their daughter, -----
- - fundraiser in memory of their son, -----
- Steve Lake – personal donation in memory of his nephew, Eric Hanson
- - personal donation in memory of their son, -----
- Steve and Donna Hanson – personal donation in memory of their son, Eric

We know there are many other people that have made donations over the last few years. We are grateful to all of you and would love to hear about your contributions, fundraising plans and fundraising events.

Research News

There is exciting ACD research news to report for the last quarter. There are updates to on-going efforts and well as interesting new research.

UPDATES

- We reported in the last *ACDA Notes* that through the efforts of Craig Snyder, the Congress of the United States appropriated \$250,000 for fiscal year 2008 for ACD related activities, to be managed by the Centers for Disease Control (CDC). These funds are intended to develop information for neonatologists and to establish a biobank for ACD. The CDC is currently developing a program plan to submit to the United States Senate.
- Partha Sen, PHD of Baylor submitted his final report to NORD on the Immunohistochemical study on lung tissue of ACD patients. Seven proteins were studied that are associated with various aspects of lung development. The final data is being analyzed to prepare a manuscript for submission to the medical journal "Pediatric Pathology."

NEW RESEARCH NEWS

- The *3 Angels Memorial Fund for ACD Research* has been working with Dr. Hakon Hakonarson at Children's Hospital of Philadelphia (CHOP) to analyze genetic samples from Craig Snyder's family. Dr. Hakonarson is the director at the CHOP Center for Applied Genomics. In his initial study of Craig's family DNA, he has identified several regions in the genome that are common among the affected individuals and not present in the unaffected individuals. This is an exciting development and warrants further investigation. The next step is to analyze additional family samples to validate the initial findings. Therefore, Partha Sen at Baylor College of Medicine and Dr. Hakonarson are currently working on the details of a collaborative effort to perform additional genetic tests.
- An article was published in the American Journal of Human Genetics in March 2007 entitled *Mutations in STRA6 cause a broad spectrum of malformations including anophthalmia, congenital heart defects, diaphragmatic hernia, alveolar capillary dysplasia, lung hypoplasia, and mental retardation*. This Germany study indicated a link between mutations of STRA6 (a receptor protein on chromosome 15) and the occurrence of ACD. Independent testing by Baylor College of Medicine on ACD samples did not show STRA6 mutations. One key difference is that all the Baylor samples were of ACD with Misaligned Pulmonary Veins and the German study samples did not display the pulmonary misalignment. Baylor's findings have not been published.

ANNOUNCEMENTS

- [REDACTED] [REDACTED], mother to [REDACTED], is the ACDA point of contact for families in the UK. [REDACTED] has been instrumental in reaching out to families in England the last several years. You can reach her at [REDACTED] [REDACTED] [REDACTED] [REDACTED]
- *ACD in the News* – Marie McCullough, a medical staff writer for *The Philadelphia Inquirer*, wrote an article on Craig and NiCole's family in the February 17 edition of the paper. Go to <http://www.philly.com/philly/news/breaking/15700892.html> to read the story titled *Unspeakable loss, genetic puzzle*. Raising awareness of this rare disease is crucial to securing funding and support for research. This article is the beginning of an effort by the Snyders to stimulate involvement and action on ACD. As Craig wrote, "this should meaningfully aid our efforts to fight this disease."
- Family participation is crucial to the success of ACD research. If you have not already donated blood, tissue samples, or cord blood, please consider doing so. For more information, contact us at sdesj@verizon.net.

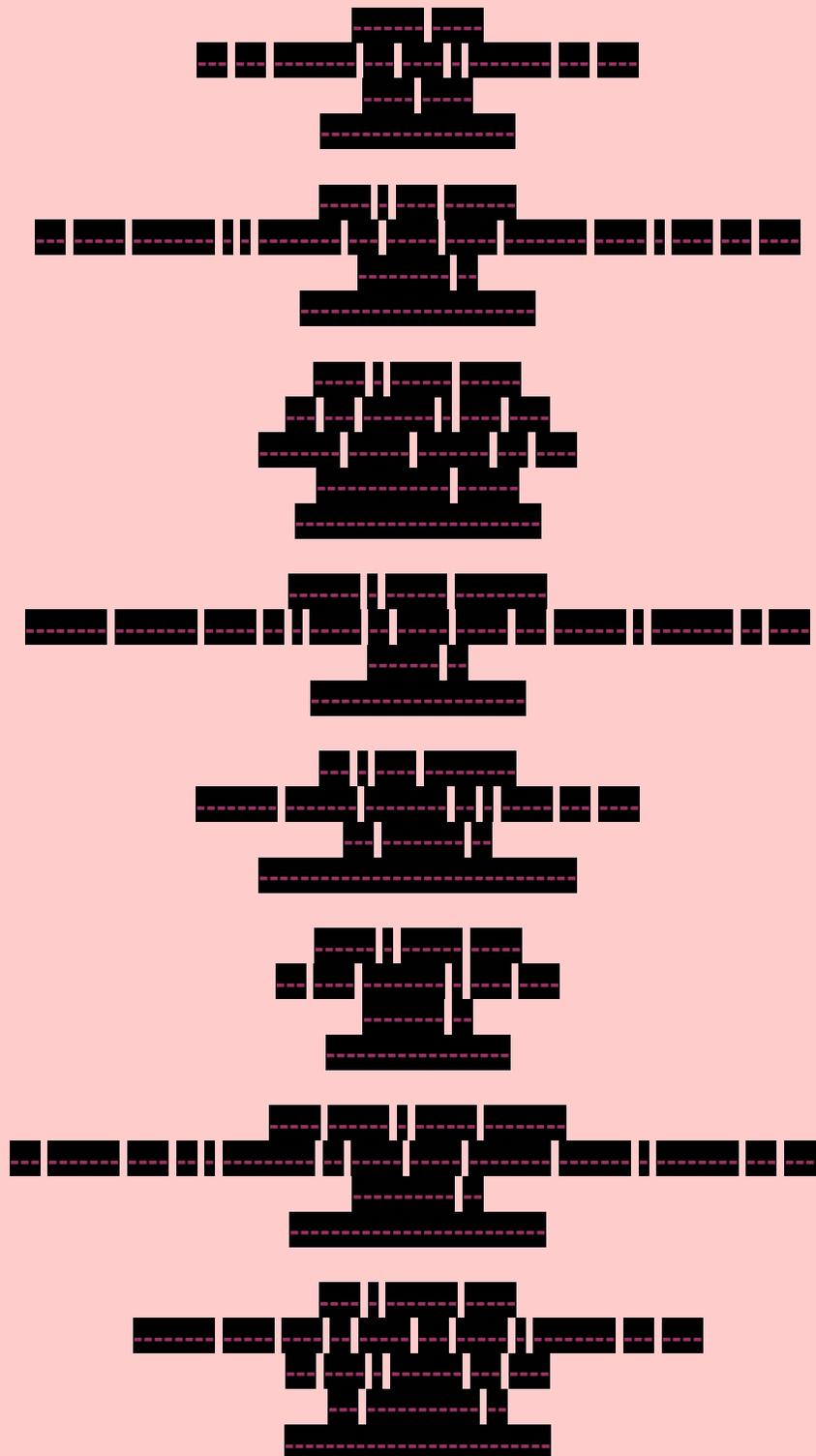
Fundraising Highlights

- [REDACTED] [REDACTED] [REDACTED] of England have been busy raising money for ACD research in memory of their daughter, [REDACTED]. [REDACTED] completed The Benfleet 15 mile run carrying 45 lbs. of weight with him. What is even more amazing than carrying that much weight such a long distance is that just a few weeks prior to this race, [REDACTED] cracked his hip! Despite the injury, [REDACTED] raised \$600. [REDACTED]'s friend, [REDACTED], also ran this 15 mile race and raised additional money for ACD research. The [REDACTED]'s were also involved in a Football match in [REDACTED]'s honor in which the footie boys raised \$200. [REDACTED]'s colleagues at Greenwoods Solicitors raised another \$120 in return for free mail stamps for their personal letters and Christmas cards.
- Albany Funding, owned by ACDA mother [REDACTED] [REDACTED], is so grateful for more than 11 years of success and the loyalty of its customers, that it donated a portion of its commissions on each file originated in October, November and December to the ACD account at NORD. For this last quarter in 2007, Lisa donated \$2,910 for ACD research.

Thank you to the [REDACTED] and the [REDACTED] and their generous friends, colleagues and employers that have supported them in their fundraising efforts in memory of their babies.

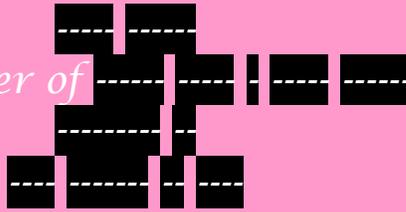
WELCOME TO OUR NEW FAMILIES

We have been contacted by so many new families in the last few months. It is heartbreaking to hear of all the babies that have been lost to ACD. The silver lining in all the sad news is that the medical community is becoming more aware of this devastating disease. We hope you will reach out to these families in their time of overwhelming grief.



SAFE ARRIVALS

Daughter of



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