

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 13, Issue 2

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

Spring 2011

Dear Friends and Family,

Since we announced the creation of the ACDA Chairpersons in the Winter 2011 *ACDA Notes*, we have quickly realized what a critical and pivotal decision that was! Having the Durands, Eschweilers and Diana Locke on board to help in the activities of the Association has been a blessing from which all of us will benefit. You will see from this newsletter that they have been very busy spreading the word about ACD, reaching out to families and devising ways to raise money for research.

We have five new ACDA members this quarter. It is bittersweet to hear from so many new families that have lost a baby to ACD, but we hope that they will find comfort in becoming part of our support group. Please take a minute to contact them and share your story with them.

Lastly, be sure to share this newsletter with your family members, friends and co-workers. You will read that Jeff Myers has been doing just that for 15 years.

Fondly,

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

A Note from Donna

I recently had the opportunity to meet Jeff Myers, father of Shelby, when he was in the Dallas area on business. Unfortunately, Steve was out of town, but Stephanie, Jennifer and I had dinner with him. We have known Jeff and Madonna, founders of the ACDA, for 14 years but had only talked to them on the phone or corresponded via email. It was wonderful to finally meet Jeff and share our stories after so many years.

Jeff shared the story about the day that he and Madonna started the ACDA all those years ago. It was Mother's Day 1997, almost a year after Jeff and Madonna lost their precious Shelby to ACD. On that Mother's Day, Madonna told Jeff she had to learn more about ACD. That very day they went to the store and bought a computer, printer, and scanner to start contacting doctors and gathering information on ACD. That decision by Madonna was a lifesaver for Steve and I as we searched for some answers after we lost our son, Eric, a year later. I am so grateful for that pivotal decision that Madonna and Jeff made 14 years ago to learn more about this rare disease.

Jeff also shared with me how proud he is to be Shelby's dad, and he demonstrates that by telling everyone he knows or meets about her. He also prints out each ACDA newsletter and posts it on the employee bulletin board at his office. His colleagues know all about Shelby and ACD. I know that even though Shelby has been gone for 15 years, she is still a big part of the Myers' daily thoughts and life.

Jeff - Thanks for reaching out and giving me an opportunity to give you a hug and say thank you in person. I hope that all of you will stop by if you are ever in the Dallas/Fort Worth area for business or pleasure – Steve and I would love to hear more about your precious loved ones.

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Research News *From Diana Locke*

On May 24, once again, a group of future doctors were educated on ACD. Since my son Christopher died, it has been my mission to teach our medical community about ACD. How many times after Christopher died did I ask various doctors and nurses if they knew what ACD was only to be told "no, never heard of it." Well, that is all changing now. Every year, my family goes to the University of Florida in Gainesville, Florida to present Christopher's case to 100 first year medical students during their genetics class. For three years, ACD has been included in their curriculum for medical school and included in their final exam for that class. It's a big step in ACD awareness!

This year's presentation went well, with lots of questions asked by the students. We even had guests (Jesse & Brett Reagin, parents of Wade). If anyone would like a copy of the genetics class PowerPoint, just email me at 4wheelin@earthlink.net.



Diana Locke giving presentation
at the University of Florida

I have been invited to present our son's case in a Level 3 NICU here in Jacksonville for nurses, residents and neonatologists. I have also approached other medical schools about presenting and I am awaiting responses from them. If you would like more information on how to get started in your area, please email me at 4wheelin@earthlink.net!

On the research front, Dr. Partha Sen from the Baylor College of Medicine, stated that they "are now preparing a new manuscript where we describe ten new and unique mutations in unrelated patients." We will let you know when the article is published.

There have been a lot of questions raised about prenatal testing and if it is available for ACD. I am still waiting on the experts' response about that. What I know so far is that testing can be done by amniocentesis prenatally to look for the specific FOX F1

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deletion. But as we all know so well, some babies with ACD do not show this deletion, so it may not be conclusive.

More cases are being reported and that is because of parents like you who have increased awareness of this terrible disorder in the communities! It is heartbreaking that we are having a spike in cases, but hopefully it will lead to more concrete research and hopefully even a cure!

Recently, there are two ACD cases of babies awaiting lung transplant for treatment. My thoughts and prayers are with these families and babies as they wait.

New ACD Article

On March 11, 2011, Dr. Naomi Bishop, Dr. Pawel Stankiewicz, and Dr. Robin Steinhorn published an article on ACD in the *The American Journal of Respiratory and Critical Care Medicine Articles In Press* entitled "Alveolar Capillary Dysplasia." "Successfully discussed are what is known about the epidemiology, pathogenesis, pathophysiology, diagnostic indicators and approaches, genetic testing, treatment, and cases of delayed onset. The review concludes with suggestions for future directions to answer the many unknowns about this disorder."

You can view the abstract at <http://ajrcm.atsjournals.org/cgi/gca?gca=201010-1697Clv1&sendit=Get+All+Checked+Abstract%28s%29>. If you would like to view a copy of the entire article, please contact us at sdesj@verizon.net.

Parent Questionnaire Being Developed

We have all been there...learning the worst possible news about our gorgeous child and then trying to find out as much as we can about the diagnosis, only to be frustrated by the lack of current knowledge. Following this experience in March this year, my husband (a physician) and I (an academic researcher) hope to be able to make a small contribution to the knowledge that is available on ACD. Along with the ACDA chairpersons and in collaboration with the academics working on ACD, we are putting together an online parent questionnaire. This questionnaire is an opportunity for you, the parents of a child/children who has been diagnosed with ACD to add to the knowledge base for the benefit of both parents and medical staff. We hope that this can help to answer some of the currently unanswered questions about ACD that many of us have. The questionnaire will be coming soon to the ACD website, and we hope very much that all parents will feel able to contribute to this small piece of research.

You will be hearing from us again soon!

Amelia & Simon Ashwell
Parents of David Ashwell

Fundraising News *From Lisa & Harry Durand*

I am Lisa Durand and my husband Harry and I lost our daughter Olivia Leona Durand on May 23, 2002. We are fortunate that we live in a time of technology and were able to connect with Steve and Donna and the ACD Association. Once we learned that ACD was such a small community of victims we tried to create ways to raise awareness and money to find a cure for this disease.

When she first passed, we had people donate money in lieu of flowers. We had a commercial building with a vacancy and we decided to do something with the space to raise money and awareness and opened up a Women's Fitness Center. My husband and I thought that if we had this business it would give us the opportunity to explain the name (Olivia's Circle) and we also donated a portion of every membership fee to NORD. This created such a great feeling among our customers and the community that we were able to raise thousands of dollars and let everyone know what ACD was and who Olivia was. We also had the membership contribute to a collaborative cookbook with their favorite recipes which was a very easy and lucrative fundraiser. We actually still have some cookbooks left at \$8 with the proceeds going to ACD if you are interested in some good recipes or good ideas. The mortgage company I worked for chose ACD as a recipient of a fundraiser they were doing one year along with a local Nursery School who heard our story. Our most recent attempt to raise money was the Paracord Survival Bracelet, which is being made by Alex (Olivia's Brother) and sold with some of the profits going to ACD.

These are just a few ideas that we have explored and were successful with and hope that this may encourage you to think of ways to raise money and most importantly awareness of the disease. Feel free to share your ideas and successes with us. Email: casper119@aol.com

Running for David

By Amelia and Simon Ashwell

Our son, David, was born on 4th March 2011 and we had the privilege of knowing him for 15 days. David's memorial was held in Stokesley, North Yorkshire, where we live. During and subsequent to this, we received donations from friends and family that we agreed to divide between The PICU at the Freeman Hospital, Newcastle upon Tyne where David was treated and the research account at the ACDA. We have currently raised £2900 (approximately \$4,800). Additionally, our close friend, Sarah Lemon, ran the London marathon in David's name in April 2011 and raised £1379.00 (approximately \$2,237) for the PICU. Sarah (#362 in the photo below), a dedicated runner, completed the 26.2 mile run in 3 hours and 10 minutes – a personal best for her! Further fund raising continues with events including the Great North Run (a half marathon in Newcastle, UK), a half marathon in Perth Australia and a coast to coast cycle.



David Ashwell
taken on March 4 - just a few hours old



Sarah Lemon running the London marathon

NORD Updates Website for Donations

We are thrilled that the National Organization of Rare Disorders (NORD) recently updated its website to permit on-line donations earmarked for our restricted research account. You can specify the research account in a pull-down menu and note that the donation was made in memory of your child and include information on who else should be notified of the donation.

Use this link to go directly to the page on the NORD website:

<https://www.rarediseases.org/about/support/research-donations>

Please pass this along to your friends and family.

Family Support News *From Emily & Tim Eschweiler*

Greeting Parents,

I hope everyone is enjoying spring, which has finally arrived – even in Minnesota! Welcome to the new families who have joined us since the last newsletter. I am glad you have found us, but am so sorry for the circumstances that have brought you to the organization.

It has been a busy quarter. There are exciting things happening in ACD research, which will hopefully bring the answers we are seeking. But with new answers also come a lot of questions and the need to rely on one another. I encourage you all to become involved with the organization. Donna and Steve are wonderful resources and the families that I have met through the ACDA have been so helpful to me this past year.

Transplantation:

One of exciting things happening in the world of ACD is that there are two babies that are on lung transplant lists. I encourage you to read their stories and to offer their families your support.

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<http://www.carepages.com/carepages/Ronanbushmunsonnicu>

<http://www.faysfriends.com/transplant-community/>

http://www.stlouischildrens.org/content/Features.htm?page_id=2588&inCtx12news_id=294&inCtx12view=10&inCtx12pg=0&inCtx12news=9&site_id=1&minor=1&major=2

■■■■■ ■■■■■■:

http://blogs.laweekly.com/informer/2011/06/baby_girl_lung_donation_organ.php#more
<http://www.nbclosangeles.com/news/local/Infant-With-Rare-Lung-Disease-Needs-Transplant-123140543.html#comments>

Facebook:

If you are on Facebook, we have two new places that you can join us. The first is the ACDA fan page at <https://www.facebook.com/ACD.Association>. This is a public page, viewable by all. The purpose of this page is promote ACD awareness, announce fundraising opportunities, and to provide another avenue for families with ACD to find us. Remember when you “like” this page, you are not liking alveolar capillary dysplasia, but are instead indicating that you like the ACD Association.

The second page is open only to ACD Parents and is a closed group, meaning that you need to be a member to see the information on the wall. This is a place where we can post pictures of our children, tell our stories, and seek support. It’s also an excellent place to brainstorm new fundraising ideas and seek guidance from others.

All parents are encouraged to join:

https://www.facebook.com/home.php?sk=group_168480916544514&ap=1

Magnets:

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I do still have ACD Awareness Magnets available. If you are interested, I would encourage you to contact me about the number that you wish to order. Car magnets are approximately 5 x 7 inches and are \$10.00 each; refrigerator magnets are 2 x 4 and are \$3 each (or 4 fridge magnets for \$10.00). I will cover the shipping costs while the rest of the magnet supplies last, so 100% of your purchase price will go to NORD. Contact me for more details.

Book Recommendation:

■■■■■, mom to ■■■■■ ■■■■■ ■■■■■ ■■■■■ sent a recommendation for the book "Heaven is for Real" by Todd Burpo. It is the story of a little boy, who during a near death surgical ordeal, experienced heaven first hand. After reading the book, she wrote, "it gives me hope and a sign that our angels are alive and well." After reading the book, I agree completely with her recommendation.

Question of the Quarter:

Part of being the parent coordinator is assisting everyone in sharing ideas. To that end, I thought that it would be fun to ask a question each quarter, and to share the responses in the next newsletter. Please let me know in your response if you would like to be anonymous (and would like to share only your response), or if I can share your name as well.

The question for this quarter is, "What is something that you do to keep your angel close to you?"

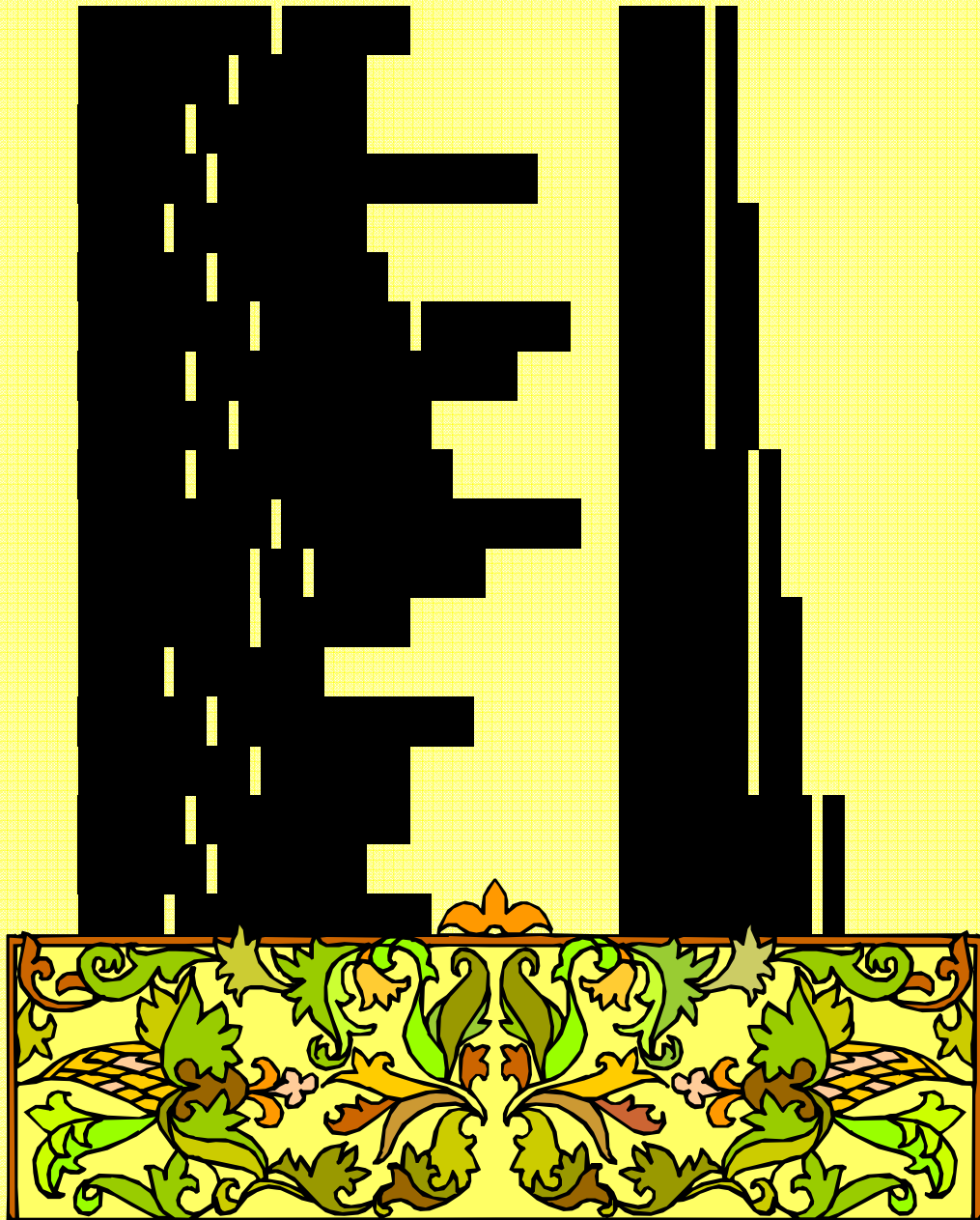
Please send your responses to emily_eschweiler@comcast.net. Please feel free to let me know if you have a recommendation for other parents or if this is a resource that would be helpful to provide to you as well.

ANNOUNCEMENTS

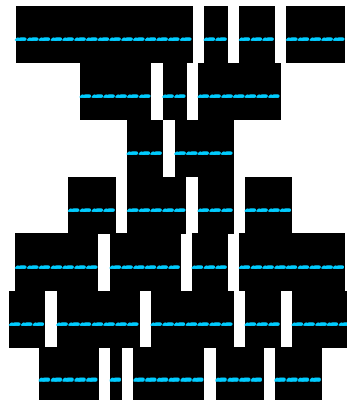
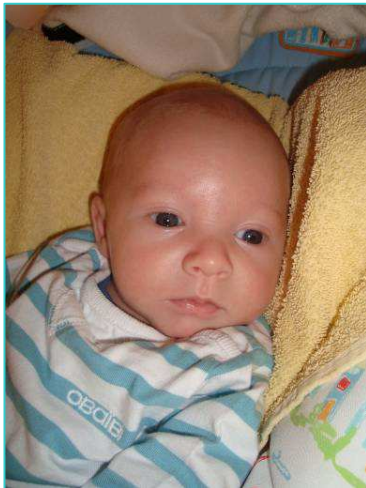
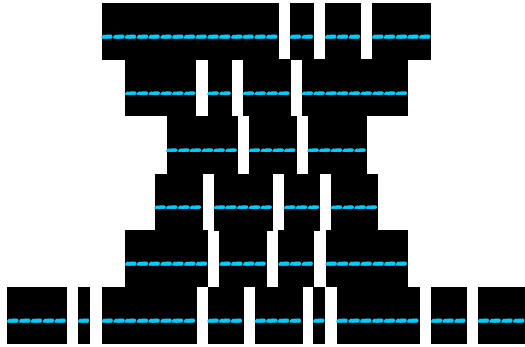
- The ACD Research Fund at NORD reached \$26,535.00 as of May 17, 2011. Our goal - \$33,500.
- Cami McGraw, aunt to Bella, announced that Stretch Productions sent its second quarterly gift to NORD. The donation is an on-going contribution based on CD sales and downloads for "The Answer" CD that she and her husband produced. The CD can be purchased at the following places:
Stretch Productions Website: <http://stretchproductions.com/theanswer.html>
CD Baby: <http://www.cdbaby.com/cd/stretchproductions>
I-Tunes: <http://itunes.apple.com/us/album/the-answer/id396571667?i=396571689&ign-mpt=uo%3D4>
Amazon.com: <http://www.amazon.com/>

Remembering Our Babies

Please join us in celebrating the
precious life of these babies.



Safe Arrivals



A poster with a dotted border. On the left, the word "welcome..." is written vertically in pink. On the right, there are five rows of black and white pixelated patterns, each with a horizontal pink dashed line through its center. The patterns are symmetrical and resemble stylized, pixelated versions of the letters 'W', 'E', 'L', 'C', and 'O' from top to bottom.

Make a Tax-deductible Contribution for ACD Research

In the spring of 2002, ACDA established an ACD Research Account at NORD. This means that your contribution to NORD can be earmarked specifically for ACD research. As stated below in *NORD's Rare Disease Clinical Research Program Policy*, NORD requires that a research account reach \$33,500 before it will initiate the grant process to award research money to the medical community. Therefore, the goal of the ACDA is to raise more than \$33,500 for research.

To make a tax-deductible contribution to NORD for ACD research either by mail or on the NORD website, please use one of the instructions:

*** Make a Donation by Mailing a Check ***

- 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 with promptly 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.

*** Make a Donation on the NORD Website ***

Go to <https://www.rarediseases.org/about/support/research-donations>. Select "Alveolar Capillary Dysplasia" in the research fund pull-down menu and complete the rest of the form.

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. Use the NORD website at <https://www.rarediseases.org/about/support/research-donations>.

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