ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 16, Issue 3 http://www.acd-association.com Summer 2014

Summer Time

As we all enjoy summer time with our families and friends, please keep each other in your thoughts and prayers as we all struggle with holidays that are meant to celebrate with family and those meant to remember.

We have had a lot of rainbow babies born this year, so there is much to celebrate.

We would also like to extend our deepest condolences to Natalie Hislop & family who lost a great father, son and husband Cameron who bravely fought his battle with cancer and went home to see his baby Ruben on June 12, 2014

Diana Locke, Editor
Mom to Christopher Josef
11/7/2006-12/17/2006

INSIDE

Grants for ACD Research Posted on NORD Website

From Donna & Steve Hanson

NORD has posted its Requests for Proposals (RFPs) for 2014 funding opportunities and ACD research has two of the six grants that are available this year to researchers. These research grants were made possible because many of you raised money over the last two years or made donations to our restricted research account at NORD.

Two 2-year-grants of up to $93,500 per grant, for a scientific and/or clinical research study related to Alveolar Capillary Dysplasia with Misalignment of Pulmonary Veins (ACDMPV) will be awarded. To see the full RFP and abstract proposal template go to http://www.rarediseases.org/medical-professionals/research-grants/rfps .

The grants will be awarded in December with the following evaluation schedule:

July 10, 2014	Deadline for preliminary abstract proposal submission.
Mid-August	NORD Medical Advisory Committee invites finalists to submit detailed proposals.
October 5, 2014	Deadline for full proposals from finalists.
Mid-December	Winners selected and awards announced.

Thanks to all of you that raised money for these ACD grants. Please share this information with your family and friends that helped you in your fundraisers or who donated to NORD in memory of your baby(ies). It takes all of us to find the answers we seek.

IRS Filing Made for ACDA to Become a Non-Profit

From Donna & Steve Hanson

We are excited to announce that the paperwork for the ACDA to become a non-profit has been filed with the United States Internal Revenue Service (IRS). The IRS is the government agency that, among other things, oversees and approves the establishment of non-profit organizations in the United States. We would like to thank supervising attorney, Larry Jones, and his student attorneys at the Southern Methodist University (SMU) School of Law Small Business Clinic, for leading us in the development and submission of the required documents. The student attorneys that assisted us include Robert Gallman, Benjamin Perez, Rachel Kakures and Nicholas Shemik.

The legal documents that were drawn up include the Certificate of Formation (for the State of Texas), the organization's Bylaws, and the IRS Application for Recognition of Exemption Under Section 501(c)(3) of the Internal Revenue Code (Form 1023). The first meeting of the organization was held by "Consent of the Board of Directors in Lieu of Organizational Meeting of Alveolar Capillary Dysplasia Association." The Consent in Lieu adopted the following resolutions:

1) Adopted the ACDA's Certificate of Formation
2) Adopted the ACDA's Bylaws
3) Identified the following officers to serve a one year term:
    a. President – Steve Hanson
    b. Secretary – Kim Anderson Bush
    c. Treasurer – Donna Hanson
4) Identified the Officer's salaries to be $0
5) Established a bank account

The attorneys at SMU are telling us, based on their experience, that it might take a year for the IRS to grant approval. In the meantime, we will continue to operate as a support group. Until we receive our non-profit status, the ACDA can accept donations but they will not be recognized by the IRS as tax deductible.

Becoming a non-profit was a goal of founder, Madonna Myers, and we are thrilled that this goal is so close to being met! Thank you to those that donated to help with our IRS filing fee of $850.

Three Members Working on Update to ACDA Logo

From Donna & Steve Hanson

With the filing of our non-profit papers to the IRS, it is time to renew our efforts to revise our ACDA logo. Some time ago, we solicited ideas from ACDA families and we received one from Shannon Cone and one from Amelia Ashwell Lake's cousin. Recently, Michaela Oltmans, Roelina Jut, and a friend of the Rilling family have all agreed to draft some additional ideas.

The only guidelines for the logo are that the colors in our awareness ribbon must be used. We hope to roll out a new logo in conjunction with the receipt of non-profit approval from the IRS. If anyone else would like to create a logo for consideration, please contact us at sdesj@verizon.net.

Thanks to all! May your creative juices really get flowing!

Fallon's Tree

By Kristen and Bob Rilling

Losing Fallon was life-changing and devastating to our family. At the same time, losing Fallon hit the daycare center, Children's Choice Childcare, where our two other children attend, extremely hard as well. The director, Doreen Viola, is not only the woman in charge, she is our friend. We've grown close over the past 4+ years ~ and she was anxiously awaiting Fallon's arrival just as we were.

Immediately, Doreen felt a connection with Fallon, even though they never met. She kept the other parents up to date and she was heartbroken, along with us, when Fallon passed away. Other parents were asking what they could do. Doreen started taking donations and she knew, right away, that she wanted to do something big in memory of our daughter.

Because the fall and winter are not ideal planting seasons here on Long Island, a tree planting was planned but put off until the spring. No one wanted to plant a tree and have it not survive. This past Christmas, Doreen went out and bought a tree and put it up at the front door of the daycare center, calling it "Fallon's Giving Tree." She had charities come and drop off huge, empty boxes ~ and within a few days, all boxes were overflowing with new and unwrapped toys for underprivileged children. The kids at daycare all made their own ornaments and hung them on the tree. We picked out the most beautiful, color-changing star to put on top of her tree and it was so wonderful to look at and think about what great things Fallon was doing.

We decided to pick out a blue spruce as the tree that was to be planted on the grounds of the County-run daycare center. It'll grow into a beautiful, hearty tree that all of the kids can decorate – not only at Christmas, but any holiday. Doreen made the rest of the arrangements. We knew she had some big things planned for the day, but we had no idea how much.

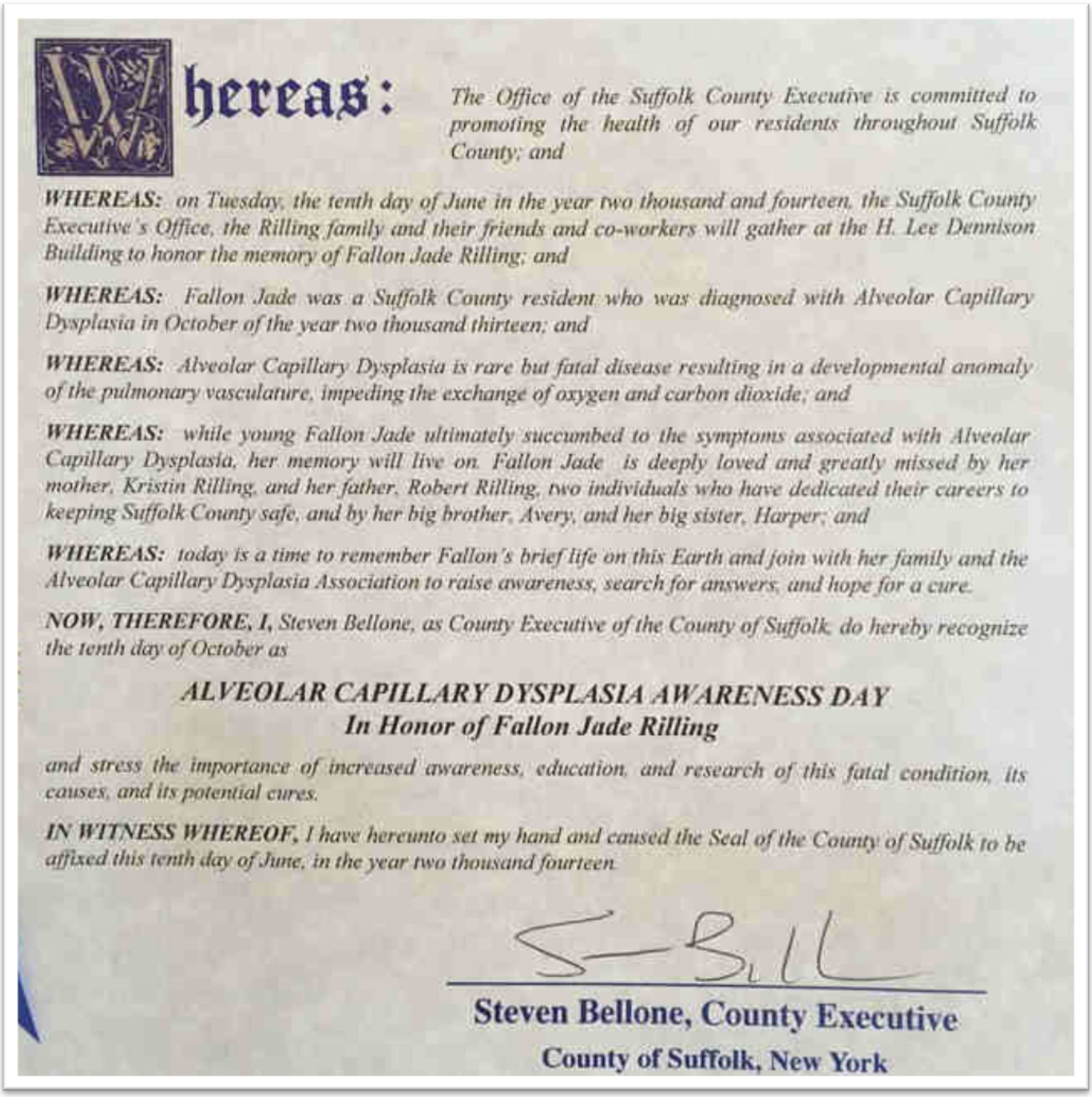
On June 10th, Fallon's 8-month birthday, the ceremony took place – at 4:44pm – in honor of Fallon's birth time (4:44am – "surrounded by angels"). Doreen had special personalized purple shirts made up for us, our extended family, and all of the daycare workers. A bagpiper played while people gathered. Doreen spoke to everyone – and then I read something that I had written up to thank everyone for coming – and to also fill them in on Fallon and her short life with us – from finding out we were pregnant up until when we had to say goodbye to her. Doreen had also arranged for 2 boxes of live butterflies to be released, which myself, Bob, Avery and Harper tearfully let go. Doreen had many shovels and we all, including Avery & Harper, helped fill the hole and plant the tree.

We wanted to "give back" – and we knew Fallon did, too, so we offered to donate some new playground equipment. Because it is a County-owned facility, we weren't allowed to donate anything large or cemented in. Doreen suggested a playhouse – and I found the most perfect one. Bob built it and I meticulously wrote "Fallon's House 444" over the doorway, with a butterfly in the center. Fallon's House now sits next to her tree and the kids all love playing in it.

One of the mothers from daycare happens to work for the County Executive and she had asked me about Fallon and about ACD. I did a write-up for her and then she asked me if I'd like the County Executive to give us a proclamation, declaring any day we choose as "Alveolar Capillary Dysplasia Awareness Day in honor of Fallon Jade Rilling." Of course we said yes (right away) and we chose October 10th as the day our County will recognize, from here on forward, as ACD Awareness Day. The County Executive, Steven Bellone, came to the ceremony, talked to Bob and myself, gave a speech to all those that were there, and handed us the proclamation. It was wonderful.

The County Executive and members of his office said they will now work with me to get this to the federal level. Hopefully, with a little help and some hard work, we can get a federal day of recognition for ACD. But for now, every October 10th, they will light up the County Executive building in ACD colors and everyone in our County will not only hear about ACD, but hopefully learn about it, as well.

A photo montage of Fallon's tree planting, dedication and ceremony held at Children's Choice Chidcare on June 10, 2014 can be found at: Fallon Jade Rilling: Tree Planting, Dedication, & Ceremony



Whereas: *The Office of the Suffolk County Executive is committed to promoting the health of our residents throughout Suffolk County; and*

WHEREAS: *on Tuesday, the tenth day of June in the year two thousand and fourteen, the Suffolk County Executive's Office, the Rilling family and their friends and co-workers will gather at the H. Lee Dennison Building to honor the memory of Fallon Jade Rilling; and*

WHEREAS: *Fallon Jade was a Suffolk County resident who was diagnosed with Alveolar Capillary Dysplasia in October of the year two thousand thirteen; and*

WHEREAS: *Alveolar Capillary Dysplasia is rare but fatal disease resulting in a developmental anomaly of the pulmonary vasculature, impeding the exchange of oxygen and carbon dioxide; and*

WHEREAS: *while young Fallon Jade ultimately succumbed to the symptoms associated with Alveolar Capillary Dysplasia, her memory will live on. Fallon Jade is deeply loved and greatly missed by her mother, Kristin Rilling, and her father, Robert Rilling, two individuals who have dedicated their careers to keeping Suffolk County safe, and by her big brother, Avery, and her big sister, Harper; and*

WHEREAS: *today is a time to remember Fallon's brief life on this Earth and join with her family and the Alveolar Capillary Dysplasia Association to raise awareness, search for answers, and hope for a cure.*

NOW, THEREFORE, I, *Steven Bellone, as County Executive of the County of Suffolk, do hereby recognize the tenth day of October as*

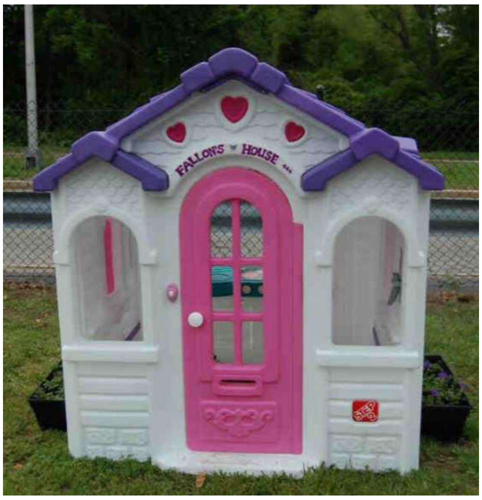
ALVEOLAR CAPILLARY DYSPLASIA AWARENESS DAY
In Honor of Fallon Jade Rilling

and stress the importance of increased awareness, education, and research of this fatal condition, its causes, and its potential cures.

IN WITNESS WHEREOF, *I have hereunto set my hand and caused the Seal of the County of Suffolk to be affixed this tenth day of June, in the year two thousand fourteen.*

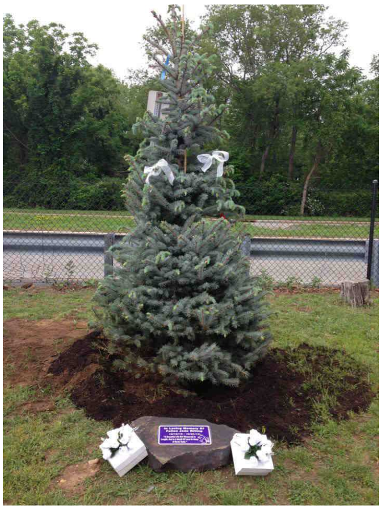
Steven Bellone, County Executive
County of Suffolk, New York

Proclamation from County Executive, Steven Bellone, declaring October 10
ACD Awareness Day in the County of Suffolk New York

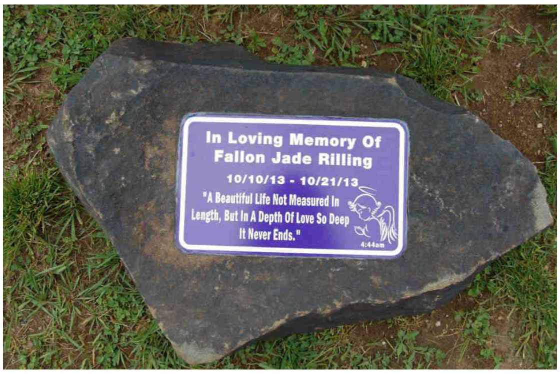


Fallon’s House built by her Dad that sits next to Fallon’s Tree at the County day-care center

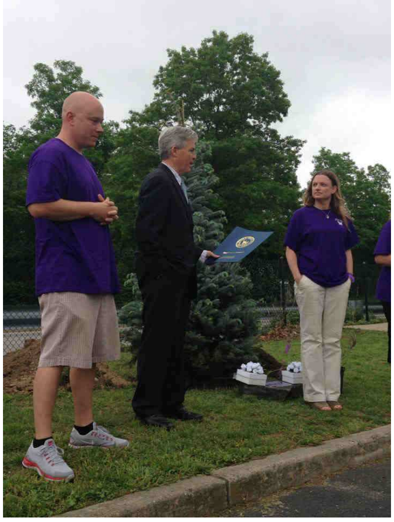
Fallon’s Brother Avery and Sister Harper helped to plant Fallon’s Tree



Fallon’s Tree



The memorial marker under Fallon’s Tree



County Executive Steve Bellone reading the proclamation at the dedication of Fallon’s Tree with Bob and Kristen Rilling

FundraiSing News

By Emily & Tim Eschweiler
ACDA Fundraising
Committee Chairpersons

Welcome to Kristen Rilling and Jennifer Bruno who will be taking on new fundraising responsibilities! We are still working out the details and will have more information on the transition in the next newsletter. Donna recently sent out a description of the responsibilities for this role. If anyone is interested in joining us, please contact us. The information that Donna provided is below.

Summer is a great time to raise funds! There has been some transition at NORD and the contact we have received fund balances from in the past is no longer there. I am working with NORD to determine the new contact, and hope to have an updated fund balance shortly after July 1st. I will post the balance to the Facebook page once received. Thank you to everyone who made the two current grants possible! It would not be possible to do without your contributions!

I have looked into the possibility of reordering car and/or fridge magnets. From the responses I have received so far, it does not appear that there is sufficient interest to reorder at this time. It takes a significant amount of time, and we need to order a large number for the price to be economical. We would need a commitment of approximately 40 car magnets (at $10 each) and 160 fridge magnets (at 4 for $10) in order to break even. We could also order just car magnets, or just fridge magnets. If you are interested, please contact me at Emily_eschweiler@comcast.net.

Reminder that the CafePress site does have product with the logo and the ribbon! The balance at CafePress is currently $48.88. The funds transfer to the ACDA in $50 increments, and we make 10% of the purchase price (less fees), so one more sale should put the balance over the threshold! http://www.cafepress.com/acdawareness

There have been a few fundraisers posted on the ACD Parent Group page. You are encouraged to also summarize your information for the newsletter; please be sure to send an update to Diana Locke!

Information from Donna re: fundraising committee:

1) Fundraising Committee- The bylaws of our non-profit (still to be approved by the IRS) allow the Board to establish committees and delegate specified authority to the committees. It is the intent of the Board to do this for fundraising. Until we have IRS approval for the ACDA, however, we would like to have a Committee that would act in a similar role. It is possible that this group could transition to a formal committee of the ACDA when we become a non-profit. Responsibilities include but are not limited to:

1. Tracks all the fundraisers
2. Researches fundraising opportunities
3. Proposes fundraising ideas and encourages members to raise money
4. Writes an article for each quarterly newsletter
5. Contacts NORD periodically to check on fund balance

Update from The David Ashwell Foundation

Since our last update in March when we transferred the money to the NORD research account there have been two fundraisers. Our current balance is £1476.00 ($2,508) – we have a long way to get our balance back up to where it was before the NORD transfer.

It is so amazing to see that we (The David Ashwell Foundation and the ACDA) have raised enough money for TWO substantial research grants on ACD. This will generate more interest in the topic and should interest more researchers, as well as sustain our current researchers.

We have had a few events since December. Dave Upton a friend of Jo Taylor has been one of our fundraisers (see Jo's report) .

Amelia's university friend Clare Pettinger ran a half marathon for David. Clare has twin boys who are 6 months younger than David would have been (3 years old). Clare raised £621.00 ($1,055) – which is a great amount!

Nearly £200 was donated by Simon's cousin. Instead of wedding favours (gifts on the table at a wedding meal) money was donated to The David Ashwell Foundation and a card was put on the table with the logo and brief explanation about the charity for every guest.

Please don't forget to use The Giving Machine to shop and in Germany the equivalent website (thanks to Karin!). If any other European Country has a Giving Machine equivalent and a UK charity can be your charity, please get in touch!

Stamp donations continue to come through! Thank you all for your contributions. Please all collect your used stamps for me – even if you are in US, Australia anywhere in the world – please collect them and we will figure out a way of getting them here!

All UK & Europe based families are welcome to use The David Ashwell Foundation as a means of fundraising for ACD Research.

If you live in the UK (and elsewhere), there are a number of options available for funding ACD research through The David Ashwell Foundation.

1. You can make a donation directly, using the Virgin Money giving website to gather donations for your fundraiser. http://David Ashwell Foundation
2. Fundraise while you shop (The Giving Machine) (a percentage of what you spend is donated)
3. Fundraise when you ebay (ebay for Charity).
4. Collect postage stamps http://David Ashwell Foundation

For additional information, please contact Simon and Amelia. http://David Ashwell Foundation
davidashwellfoundation@yahoo.co.uk
Amelia's mobile: 07855473686

We are more than happy to hear from other families who would like to use the charity to raise money for ACD Research. All money raised will be transferred to NORD.

Fundraising News con’t.

Our beloved son, Johnny, was born on February 20, 2013 and died on March 4, 2013. $20 for the 20th" was a fundraiser we held in February 2014 to collect $20 donations in honor of Johnny's first birthday on February 20th. Due to the loving generosity of more than one hundred supporters and the employee matching gift program at Bank of America, we are now in the process of making a $12,000 donation (for each of the 12 days Johnny was with us) to NORD to benefit the ACD research fund. In addition, our local newspaper, The Charlotte Observer (North Carolina, United States), published an article about our son’s story on February 25, 2014 to raise awareness about ACD and the annual observance of Rare Disease Day on February 28. Thank you so much to everyone that donated, tweeted, shared or read our story. We appreciate every single outreach and will never be able to say thank you enough for the support we received during these first anniversaries.

Sincerely,
Eliza, John, Annie (two and a half years old) & Grace (rainbow baby born May 2014)

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From Jo Taylor (mum to Alexander):

I wrote in our last newsletter about my friend Dave who was running from Richmond (in London) to Brighton (on the South Coast of England) on Saturday, 24th May, a total of 60 miles or 100km. Sadly though, the day before the Challenge, Dave collapsed at work (he is a Police officer) and was taken to hospital. The Doctors there advised him not to run due to the collapse and so Dave unfortunately had to drop out.

He was devastated, especially after training for a year and was anticipating running it in 11 hours.

On a positive note, he is now well and will definitely be running in next year’s event. Dave has also already raised over £1000 for the David Ashwell Foundation, an amazing amount.

Chris and I also designed a freestanding flag that we were going to have at the mid-way point and finishing line to cheer Dave on. The company next door to Chris' one (www.approved.co.uk) make them and were happy to help us with the final design. It was then made it up to have flying in honour of our babies and to raise awareness. We've now sent it up to Amelia so it's now a challenge to get it flying all over the North East of England!!

Please Welcome Our New ACDA Families:

[redacted]

[redacted]

Safe Arrivals

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Make a Tax-deductible Contribution for ACD Research

In the spring of 2002, the 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. In the "Additional Comments" box, type "Alveolar Capillary Dysplasia Restricted Research Account."

Special Information for Families Living Outside of the United States

NORD recommends that families living outside of the United States 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.

Contact Information

Executive Directors

Steve and Donna Hanson
5902 Marcie Court
Garland, TX 75044-4958
USA
(972) 414-7722
Email – sdesj@verizon.net

Committee Chairpersons

- *Fundraising: Emily & Tim Eschweiler*
    - *Email: Emily_Eschweiler@comcast.net*
- *Research: Diana Locke*
    - *Email: 4wheelin@earthlink.net*
- *Family Support: Kim Anderson Bush*
    - *Email: ratherbinak@gmail.com*