ACDA NOTES

From The Alveolar Capillary Dysplasia Association

http://www.acd-association.com Fall 2014

Dear Families and Friends,

In this transitional time for the ACDA, the Board of Directors is extremely busy implementing new programs and updating the website. The Board held its first meeting last month, and you will find many articles in this edition of *ACDA Notes* that discuss the results of that meeting.

Now that the ACDA is a recognized non-profit in the United States, the Board is establishing some on-line fundraisers so you, friends, and family members can make tax-deductible donations to the ACDA – in some cases, just by shopping on the internet. We will, however, continue to use NORD and their Medical Advisory Board to issue grants for ACD research when we have raised sufficient funds.

We hope that you will share this information with family and friends, especially as we enter into the holiday giving season. Page 2 of this newsletter discusses ebay Giving Works and Amazon Smile and how you can easily participate to raise money for ACD research. I hope you will join me in selling some items on ebay Giving Works and buying on Amazon.

May the upcoming holidays be joyful and a meaningful time to do something special in memory of your baby.

Fondly,

Steve Hanson, President

INSIDE

ACDA Holds Its First Board Meeting

The ACDA Board of Directors held its first meeting as a non-profit on September 5, 2014. The discussions resulted in numerous actions that the Board will be undertaking including the establishment of committees, update of the website and formation of on-line fundraisers. Some of these actions are discussed in other articles in this newsletter. Below is a summary of the Board's decisions:

- The Board of Directors one year service began in August and will end July 31, 2015.
- The creation of two committees was approved - Fundraising and Communications.
- The ACDA website will transition to a .org domain in 2015 to reflect its non-profit status.
- A PayPal "Donate" button will be added to the current ACDA website to allow for on-line donations.
- Two on-line fundraisers will be initiated – ebay Giving Works and Amazon Smiles.
- Dr. Partha Sen (now at Northwestern) is working with Baylor on an agreement to share data and samples in a complementary manner and is developing an IRB. Once complete, the Board will vote to add Dr. Sen as another point of contact on the ACDA website.

While the Board of Directors is the governing body for the ACDA, we are always open to ideas, suggestions and comments. Please feel free to participate!

Committees Being Formed

If you are interested in finding out more about how you can help on the new ACDA committees, contact Kim or Donna.

Communications Committee – contact Kim Anderson Bush at secretary@acd-association.com

Fundraising Committee – contact Donna Hanson at treasurer@acd-association.com

Even if you only have a limited amount of time, there is something you could help with. Thanks for considering!

ACDA Announces Two On-Line Fundraisers

ebay Giving Works

How You Can Participate

For those of you that have a PayPal account or sell and shop on ebay, the ACDA has set up three ways for families and friends to help raise money for the ACD research through ebay Giving Works. Everyone can donate directly to the ACDA, donations can be made every time you buy on ebay or sellers can donate a portion of their sale to the ACDA on our ebay Giving Works page. Please follow the instructions below to ensure your donations make it to the ACDA:

Option 1 – Donate Directly to the ACDA on our Ebay Giving Works Page

With a PayPal account, you can make direct donations through the ACDA's "About Me" page at:

http://givingworks.ebay.com/charity-auctions/charity/alveolar-capillary-dysplasia-association/69889/

Option 2 – You can add a donation to the ACDA every time you shop

- When buying on ebay, ensure that the ACDA will display in checkout by adding the ACDA as a favorite either in your Donation Account or through the ACDA's ebay Giving Works page; Go to: http://givingworks.ebay.com/charity-auctions/charity/alveolar-capillary-dysplasia-association/69889/
  Then click on the red heart "Add to My Charities" Button.

- As a Buyer, you have the choice to add a donation to each transaction to benefit the ACDA.

Option 3 – Sellers Donate a Portion of Their Proceeds When Selling

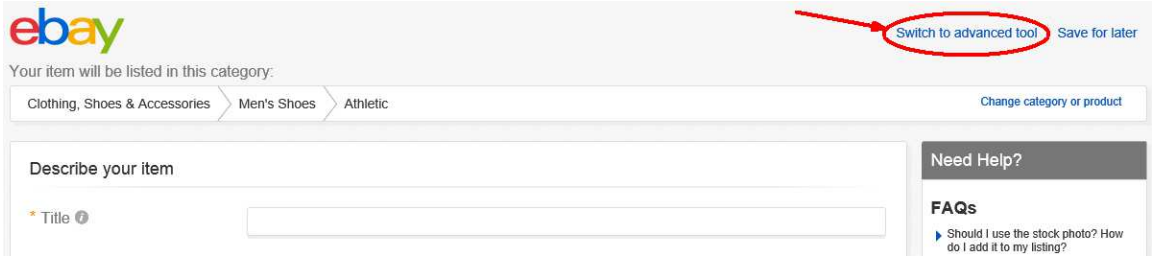
Step 1 - Choose the ACDA as Your Charity

- Go to http://givingworks.ebay.com/charity-auctions/charity/alveolar-capillary-dysplasia-association/69889/
- Click on the red heart "Add to my charities"

- You will then be asked to log into your ebay account

Step 2 – When you are ready to sell on eBay:

- NOTE: If you use the Quick Listing Tool, you will need to switch to the Advanced Tool.



- Under the "Choose a format and price" section of the listing, there is a section for ebay Giving Works. Click on "Or select another nonprofit you love" and then search for Alveolar Capillary Dysplasia Association. Then click on the blue "Select" button. That sets the ACDA as the beneficiary and then you set the donation percentage you want for the listing.
- Your item will stand out to buyers with a blue and yellow ribbon logo displayed right next to the item's title. Charity listings on ebay have up to 30% higher sell rates then non-charity items and they sell for between 2-6% higher prices.
- After the sale ends, sellers pay their donation to PayPal Giving Fund (PPGF) through their ebay Donation Account. You can actively pay the donations or wait four weeks for PPGF to collect the donations automatically.
- Once you sell your charity items, you'll receive listing fee credits for the same percentage amount you donated.
- PayPal Giving Fund processes the donation, distributes tax receipts and pays the donation to the ACDA in a monthly donation payout.

For more information for sellers, go to http://givingworks.ebay.com/charity-auctions/charity-sellers/

Amazon Smile
How You Can Participate

In addition to ebay Giving Works, the ACDA is also participating in Amazon's on-line fundraising program called Amazon Smile:

What is Amazon Smile?

- a simple and automatic way for you to support the ACDA every time you shop, at no cost to you.
- at smile.amazon.com, you have the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to ACDA.
- The Amazon Smile Foundation will donate 0.5% of the purchase price from eligible Amazon Smile purchases, excluding shipping & handling,
- Donations are made to the ACDA by the Amazon Smile Foundation and are not tax deductible by the purchaser.

To Set up Your Amazon Account with the ACDA as the Beneficiary:

- Go to https://smile.amazon.com/
- Log in with your Amazon password or create an account
- Go to "Your Account"
- Select "Alveolar Capillary Dysplasia Association" as your charitable organization
- Shop!

As the holiday season approaches, be sure to remember these easy ways for you to contribute. Please share this information with your families and friends – think of the difference we can all make!

ACDA Now On GuideStar

The GuideStar Exchange is an initiative designed to connect nonprofits with current and potential supporters. With millions of people coming to GuideStar to learn more about nonprofit organizations, the GuideStar Exchange allows nonprofits to share a wealth of up-to-date information with GuideStar's many audiences. The GuideStar Exchange level logos are symbols of transparency in the nonprofit sector.

The ACDA has received the GuideStar Exchange Bronze level logo, a symbol of transparency and accountability provided by GuideStar USA, Inc., the premier source of nonprofit information. The logo demonstrates the ACDA's commitment to nonprofit transparency and accountability.

Find us at: http://www.guidestar.org/SearchResults.aspx and search on Alveolar Capillary Dysplasia Association.

Raising Awareness of ACDA

Thanks to one of our ACD moms, future doctors studying at the University of Florida continue to be schooled in ACD. Diana Locke (mom to Christopher), along with Paul Locke (big brother of Christopher), made their yearly presentation on August 13, 2014 to 130 first year medical students. The presentation focused on ACD, Christopher's case and some of our other ACD babies. According to Diana, the students had a lot of good questions this year, and of course they enjoyed the Krispy Kreme donuts once again. A special thanks goes out to Professor Brian Harfe of the University of Florida for hosting Diana and her son once again and for keeping this mission alive by inviting them back every year. With this program, our future doctors now know about ACD and know the names of some of our ACD babies.

For another story about raising awareness about ACD, check out this link for NORD's article on baby Johnny Rista http://blog.rarediseases.org/taking-action-for-acd/. Thanks John and Eliza!

Proceeds of Children's Book to be Donated to ACD Research

Hello. My name is Susan Anderson, Kim Anderson's mom. I have written a children's book, "The Miracle of the Shared Lily Pad." It is a story about Freddie the Frog who learns the blessing of sharing. 75% of all profits from this book will be donated to research for ACD. Dr. Partha Sen has written a paragraph explaining the disease that will be included in the book.

I am extending an invitation to all parents who have lost a child to this disease to have their name included in the book. If you would like your child's name on a lily pad, please send their first name and year of birth to me so the illustrator can include it.

Susan Anderson
GmaSeedSower@comcast.net

Report from The David Ashwell Foundation

From Amelia Ashwell Lake, mother to David

Our balance at 1st September 2014 was £2349 ($3,816). Since March 2011, we have raised **£130,586 ($212,143)** for ACD Research. The David Ashwell Foundation has contributed to two recent grants for ACD research issued by NORD; £33,118.00 ($52,053) was transferred in February 2012 and over £95,011 ($157,072) was transferred to the NORD ACD account in March 2014. To have raised over £130,586 ($212143) in memory of David and so many precious babies is simply incredible! We are not many in number and it's a great effort! Thank you to all the ACD families, their relatives and their friends who have contributed.

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 jumped on the ice bucket challenge which was a social media craze which hit our screens in August (just as the weather got chilly). It involved a person being nominated to pour a bucket of ice water over their head, donating money to charity and nominating further individuals. Our ice bucket was called #FreezeOutACD and using our online virgin money giving page we raised £930.00 ($1,510). Friends of ACD families, parents, relatives of ACD babies around Europe contributed to this craze! There were 51 donations in and this amount was raised in just over a week! Thank you to all who contributed and to all those who got wet in the process! If you'd like to see video proof of a number of us (including Jo Taylor, Chris Coe, Alison Hardisty, Amelia and Simon Ashwell) getting wet for ACD, find the links on Facebook!

As ever, if anyone has any fundraising ideas – please get in touch. In November, I (Amelia) will have an Usbourne book party at home with a percentage of all sales going to The David Ashwell Foundation.

Please don't forget to use The Giving Machine when you shop! Using this has raised £566 ($919) since 2011 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

Status of Two ACD Research Grants to be Awarded by NORD

To promote the current ACD grants, NORD posted a Request for Proposal (RFP) for ACD on their website, promoted the RFP in multiple email blasts, and reached out directly to 39 previously published individual researchers. They also reached out to several organizations who were well positioned to promote the opportunity further including American Lung Association, Ann & Robert H. Lurie Children's Hospital of Chicago, Children's Hospital Colorado- Research, Children's Hospital of Philadelphia, Cincinnati Children's Hospital Research, NIH/National Heart, Lung, and Blood Association, Pulmonary Hypertension Association, Pulmonary Hypertension Program at Boston Children's Hospital, and University of Michigan- ECMO.

As a result, NORD received five abstracts in response to the RFP. The NORD Medical Advisory Committee invited all five researchers to submit proposals as the abstracts all received comparably high scores from the committee members.

We know that current ACDA researchers Dr. Partha Sen, Dr. Pawel Stankewicz and Przemyslaw Szafranski, PhD will be submitting proposals in October. Two $93,500 grants will be awarded by NORD in December 2014. These grants were made possible by many of you that made donations or held fundraisers. Thank you!

ACD Research in the News

The research being conducted by Baylor College of Medicine has been in the news! Specifically, the work being done on the parental testing approach to exclude low-level somatic mosaicism that they have been using in their ACD research has received a lot of attention and press. Their recent *American Journal of Human Genetics* article, *"Parental Somatic Mosaicism Is Underrecognized and Influences Recurrence Risk of Genomic Disorders"* had comments in the *New York Times* and *Science* magazine (pg. 7). Simon Ashwell, father of David, has summarized this new research below:

This research, performed by Professor Pawel Stankiewicz's group at Baylor, investigated the issue of somatic mosaicism in the transmission of genetic diseases. Somatic mosaicism describes the situation where an individual has more than one type of genetic material in their body (eg both normal and abnormal copies of a gene). This arises due to mutations as our cells divide. Conventional genetic tests often fail to find somatic mosaicism as it is often low-level (sometimes <1% of DNA) and thus cannot be detected. This has resulted in children with genetic diseases from parents with apparently normal DNA being labelled incorrectly as having a new 'de novo' genetic abnormality.

The researchers identified 100 parental couples who had had infants with apparently de novo mutations leading to a variety of genetic conditions. Families with ACD were not included in the study but its results have some relevance to the ACD community. All families had been investigated with conventional genetic testing and neither parent had been found not the carry the genetic abnormality affecting their child. The researchers then developed novel detailed techniques to look more closely in the parents' blood DNA in the specific area of genetic abnormality that were found in their child. Using these techniques 4 parents (4%), 2 mothers and 2 fathers, were found to have somatic mosaicism that was responsible for their child inheriting the condition. The parents' amount of mosaicism (abnormal DNA) varied from less than 1% to 9% of total DNA.

The researchers developed a computer model to explore issues around recurrence risk. They calculated that, by virtue of having had a child with an apparently de novo genetic disorder, the risk of a couple having a second affected child is approximately 0.1% (one in a thousand). The risk was much higher in parents who were found to have mosaicism detected in blood DNA than those that did not. Parents of affected infants without detectable somatic mosaicism are likely to have mosaicism limited to eggs or sperm, but testing to confirm this is currently not possible. Mothers with mosaicism (as is always the route of transmission to an infant with ACD) have a higher risk of recurrence than fathers as they tend to carry a higher proportion of affected eggs vs. sperm.

The take-home message for the ACD community is that the risk for a couple of having a subsequent infant with ACD might be able to be predicted by testing them for somatic mosaicism. Its absence would suggest a low chance of subsequent pregnancies being affected by ACD. This might help in making decisions about pre-natal testing. Importantly this requires first the identification of a FOXF1 deletion in the affected infant. The lab is unable to test for somatic mosaicism in the parents of infants with ACD who have a FOXF1 mutation due to unreliability of this test at such levels.

Professor Stankiewicz tells me that the Baylor lab routinely tests for low-level somatic mosaicism in parents of infants with ACD who have FOXF1 deletions. So far. none of 22 tested families have demonstrated mosaicism.

From *The New York Times*
August 5, 2014

After the Fact

Parents Can Pass Genes That May Surprise Them

THE FAMILY SEEMED to defy the rules of genetics.

After Meriel M. McEntagart, a geneticist at St. George's University of London, met the family in 2012, she discovered that three of the children had a rare genetic disorder called Smith-Magenis syndrome. They were all missing an identical chunk of a gene known as RAI1.

One of the children had a different father from the other two, so the mother could be the only source of their altered gene. But the test results were not so straightforward: The woman had a normal version of RAI1.

Perhaps the mother was a genetic mosaic.

We tend to think of ourselves as having just one set of genetic material that exists in identical form in every one of our cells. But sometimes people have two or more significantly different genomes. As our cells divide, some may go through a major mutation. So some individuals end up with groups of cells that have very different DNA from the rest of them.

Dr. McEntagart said she suspected that the mother had a normal version of RAI1 in some cells but an altered version in others, including her eggs.

Researchers at Baylor College of Medicine in Houston were developing new methods for pinpointing mosaics, and they confirmed that some of the mother's cells carried the Smith-Magenis syndrome mutation.

Though scientists have known about mosaicism for decades, they've studied it mostly case by case, so it has been hard to tell if the kind of mosaicism Dr. McEntagart encountered was a fluke or common enough to be medically important.

In a new study in The American Journal of Human Genetics, the Baylor team and colleagues describe the biggest search for cases in which mosaic parents passed down disease-causing mutations to their children.

It turns out to be far from a fluke.

The scientists studied 100 families. "We thought going into this study we'd find maybe one or two if we were lucky," said Ian M. Campbell, the lead author. "And then we found four." And the scientists suspect the true number was even higher.

The results suggest that people can have serious genetic diseases without any symptoms because they have the defective version of a gene in only some cells. But such people are at risk of having children with full-blown diseases if the mutation appears in their reproductive cells. CARL ZIMMER, *author of the Matter column. The full column is at nytimes.com/science.*

From *Science* September 5, 2014

HUMAN GENETICS

When genetic diversity hurts the kids

Although we think of the genome as fixed, errors in DNA replication and recombination can cause changes. As the organism develops, individual nucleotides may mutate, or genetic material may duplicate or be deleted. Such "somatic mosaicism" means that different cells and tissues in the body may have different genomes. To determine whether this affects human disease, Campbell *et al.* took blood samples from 100 families with children who have genetic disorders. They found that approximately 4% of the parents (who were all healthy) exhibited somatic mosaicism, which suggests that the affected children inherited the mutation from a mosaic parent. These results suggest that somatic mosaicism is probably more common than previously thought and affects human health. — LMZ

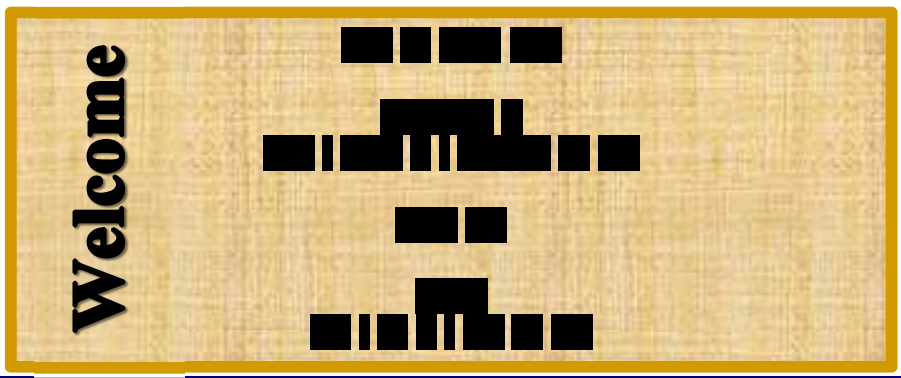
Am. J. of Hum. Genet. 10.1016/j.ajhg.2014.07.003 (2014).

DID YOU KNOW….

That there are many companies that offer "volunteer grants." This means if you volunteer a certain number of hours with the ACDA, these companies will make a donation to the ACDA. While program specifics vary by company, here are some employers that provide volunteer grants:

Aetna
Allstate
Amgen
Bank of America
Campbell Soup
Chevron
Cointstar/Redbox
ConocoPhillips
ExxonMobil
HCA
Kimberly-Clark
Levi Strauss
Microsoft
Pfizer
PNC Financial
PPG Industries
RealNetworks
Thomson Reuters
Time Warner
Traveler's Company
Verizon

So, be sure to check with your company to see if they have a volunteer program for you to participate in! Next time, we'll share a story of an ACDA dad who is participating in his company's program!



Genetic Testing Information Now on the ACDA Website

Thanks to Dr. Pawel Stankiewicz at Baylor College of Medicine and Simon Ashwell, father to David, the following information is now on the ACDA website. This information is provided to help new parents navigate the options they have for obtaining more information about their baby's case.

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There is an on-going research study for Alveolar Capillary Dysplasia with Misaligned Pulmonary Veins (ACDMPV) being conducted at Baylor College of Medicine in Houston, Texas in the United States. The following information is made available so that parents can obtain additional information about their infant's case, help further ACDMPV research by participating in the study and/or obtain genetic testing.

What is the purpose of genetic testing?
Many infants with ACDMPV have a detectable genetic abnormality in or around the FOXF1 gene. Testing for this in the infant and parents can help to determine whether the parents carry the genetic abnormality. This would have important consequences for any future pregnancies. However, even without a detectable genetic abnormality in the parents' blood, it's possible that future infants could be affected by ACDMPV (see ACDA information on the genetics of ACDMPV) and knowing the genetic abnormality in one child allows prenatal testing to be performed in future pregnancies, if desired.

Do I need to sign a consent form to participate in study?
Yes.

Where can I get this form?
Baylor College of Medicine (see contact details below).

How exactly do I participate? Tissue samples, blood samples, autopsy results, etc.
Postmortem genetic testing of the *FOXF1* gene in the infant's and parents' blood samples will be performed on a research basis after the initial ACDMPV diagnosis is verified by an experienced pathologist at Texas Children's Hospital in Texas Medical Center in Houston.
First it's important to speak to your pathologist or physician so that your infant's samples can be sent to Texas. Your medical team should be able to co-ordinate this for you. The samples and information required are:

1. A lung biopsy or autopsy sample of lung tissue. These can be sent as slides (stained or unstained) and/or formalin fixed paraffin embedded (FFPE) lung tissue block;
2. The local pathology report of the lung biopsy or autopsy, if available;
3. Your infant's blood (if stored in +4C fridge) or isolated blood DNA (blood sample containing only genetic material) in EDTA tubes (purple top) if available. If a blood sample is not available, frozen lung tissue can also be used to obtain DNA and RNA.
4. Completed and signed consent forms.

What genetic tests will be performed?
Analysis of the FOXF1 gene for point mutations will be performed first. If this is negative, Array Comparative Genomic Hybridization (CGH) studies of chromosome 16 in the FOXF1 region will be performed to look for deletions of genetic material around the FOXF1 gene. If both of these tests are negative whole exome sequencing using next generation sequencing can be considered. This studies peripheral blood nucleated cell DNA.

Who do I contact/where should it be sent?
Pawel Stankiewicz, M.D., Ph.D.
Associate Professor

Dept of Molecular & Human Genetics
Baylor College of Medicine
One Baylor Plaza, Rm ABBR-R809
Houston TX, 77030
USA
Email: pawels@bcm.edu
Tel: (+1) 713 798-5370

Do I have to pay for this?
No, the study will be performed in Dr. Stankiewicz's laboratory free-of-charge.

What is the process for sending family member blood samples? Together with the infant's sample, you can include the blood samples from the parents as fresh whole blood or isolated DNA samples in EDTA tubes (purple top). Alternatively, you can send them later on. Parental testing on a research basis is also **free-of-charge**. If a gene deletion is detected in the infant's DNA sample, Dr. Stankiewicz's laboratory will attempt to exclude low-level somatic mosaicism in the parental DNA samples (this is where a person carries more than one variation of genetic material in their body) for more accurate information on the risk of having another infant with ACDMPV.

Can these tests be performed anywhere else?
In the UK, Exeter Molecular Genetics can perform FOXF1 mutation analysis. Many centers can perform array CGH.

Exeter Molecular Genetics
Royal Devon and Exeter Hospital
RILD Level 3
Barrack Road
Exeter
EX2 6DW
UK

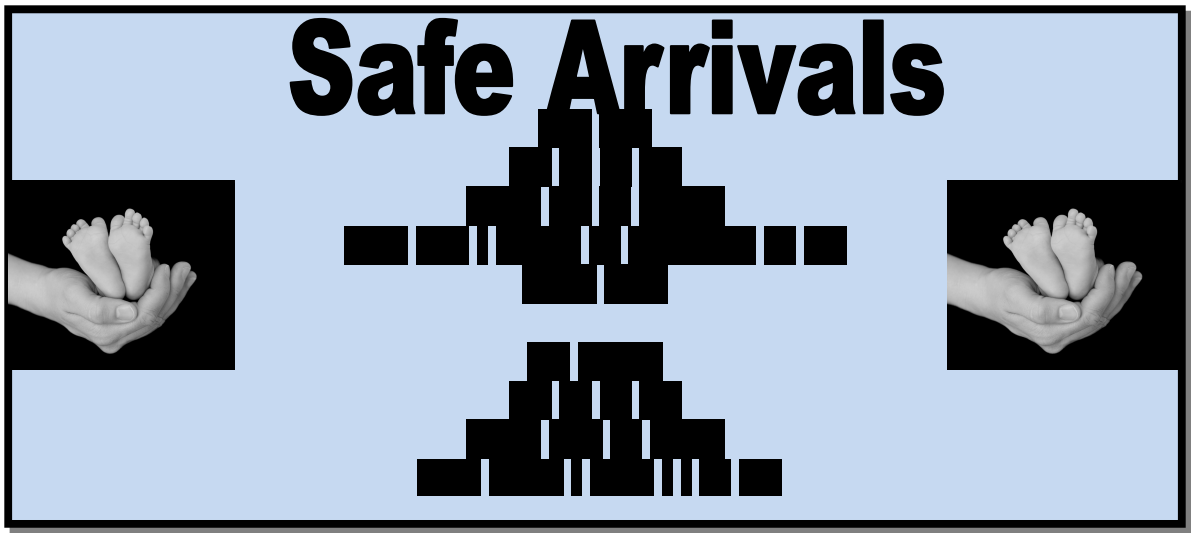
What if my baby is alive?
Clinical genetic testing is available in the CLIA-certified Medical Genetic Laboratories (MGL) also in the Department of Molecular and Human Genetics at Baylor College of Medicine (BCM) in Houston, Texas. Please contact: https://www.bcm.edu/research/medical-genetics-labs/ This study is performed on a fee-for service basis.

What about prenatal testing? Is it available?
MGL at BCM also offers prenatal testing of *FOXF1* mutations and genomic deletions on a fee-for service basis.

Contact name for prenatal testing
Pawel Stankiewicz, M.D., Ph.D.

Contact's title and institution for prenatal testing
Associate Professor

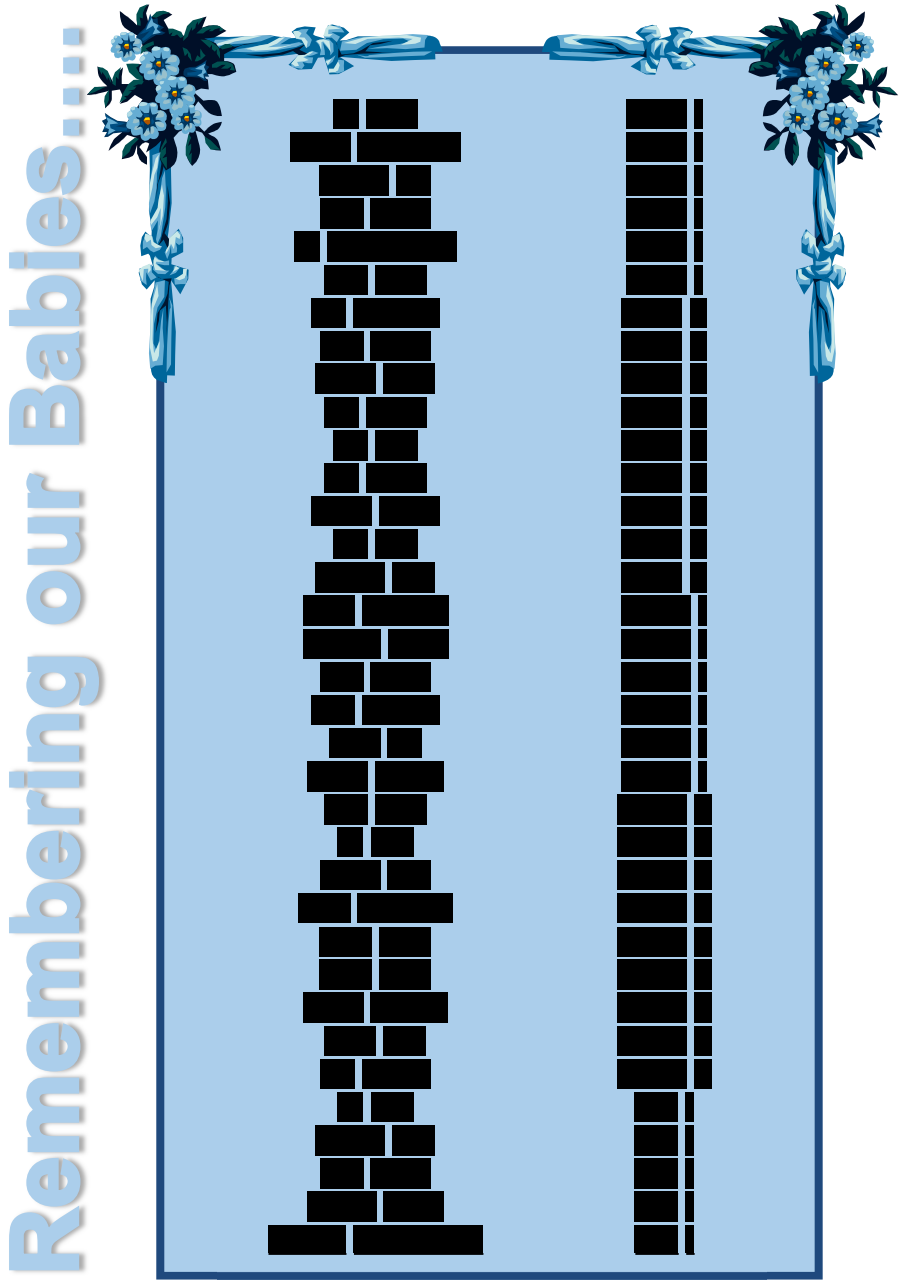
Reminder: Our **CafePress** site has products your can purchase (t-shirts, mugs, etc.) with the current ACDA logo and the ribbon! We receive 10% of the purchase price (less fees), so encourage your friends and family to support this fundraiser for the ACDA. Check out our site at http://www.cafepress.com/acdawareness.



…To Kevin and Jill McMaster, uncle and aunt to Meghan Kinane, for their donation to the ACDA – the <u>first</u> since IRS approval! Thank you also to Noelle Sproul for her donation in memory of Johnny Rista and to Emily and Tim Eschweiler for their contribution in memory of their son, Joey.

…To Simon Ashwell, father to David, who continues to provide "translation" services for medical journal articles and other technical issues. The ACDA is grateful for his layman's explanations of very complex information.

…To Roelina Jut, Michaela Oltmans and a friend of Kristen Rillings who are all working on new logo ideas for the ACDA. We can't wait to see their ideas!



Facebook

For those of you on Facebook, we encourage you to “like” the ACDA’s public page, which promotes ACD awareness and encourages families to contact the ACDA, (https://www.facebook.com/ACD.Association) and to encourage your friends and family to do the same. We’re also happy to “like” the NICUs where your babies stayed in order to help promote the word about ACD.

We also encourage ACD parents to join the “ACD Parent Group” (https://www.facebook.com/ACD.Association#!/groups/168480916544514/). The ACD Parent Group is a closed group that provides support, information, and a place for families to share pictures and stories of their babies. Contact Emily Eschweiler for more information at Emily_Eschweiler@comcast.net (or search for Emily John Eschweiler on Facebook).

MAKING DONATIONS FOR ACD RESEARCH

Now that the ACDA is a non-profit, your donations are tax deductible. There are several ways for you to make a secure donation:

- If you have a PayPal account, the preferred way (to eliminate all transaction fees) is to use PayPal through ebay Giving Works. Go to: http://givingworks.ebay.com/charity-auctions/charity/alveolar-capillary-dysplasia-association/69889/?favorite=siteadd&favnpid=69889 Once on the ACDA Giving Works page, select your donation amount on the right side and click DONATE NOW.
- If you don't have a PayPal account, you can use a Credit Card to make a donation. Just follow the 'DONATE' link on our "Donations" page - http://www.acd-association.com/donations.php Then, on the lower left section on the PayPal donation page that follows, click the 'Continue' link under "**Don't have a PayPal account?**".
- Check to see if your company has a Matching Gifts Program. If so, they may match any donation that you make to the ACDA.
- If you prefer, tax deductible contributions can also be mailed to:

The Alveolar Capillary Dysplasia Association
c/o Donna Hanson, Treasurer
5902 Marcie Court
Garland, TX 75044-4958
United States

Checks should be made payable to: The Alveolar Capillary Dysplasia Association

We will continue to support and contribute to our ACD Restricted Research Fund at NORD. Until the ACDA can assemble its own Medical Advisory Board, we will have NORD continue to issue research RFPs and grants on behalf of the ACDA.

Please remember that when you make a donation to NORD, earmark the donation to our restricted research fund by writing on your check (or enclosed note) that your donation is for our account. Otherwise, the funds will go to NORD's general fund. See page 13 for how to make a donation to NORD.

The balance of our restricted account at NORD as of August 31, 2014 is $206,674. Two grants will be awarded later this year that total $187,000.

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.

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