

<http://acdassociation.org>

SUMMER 2015

Issue
53

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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We have a new look! We are pleased to announce the following changes being launched today:

1. **Logo** – The ACDA has an official new logo (see it at the top of this page!)
2. **Website** – The ACDA website has a brand new look with lots of new features! Check it out today at <http://acdassociation.org>
3. **Newsletter** – The newsletter has been redesigned and streamlined!
4. **Store** – A new store with the ACDA logo on your favorite products with a designated portion of the proceeds benefiting the ACDA! Check it out from our new website!

Today marks the official unveiling of all the efforts by the ACDA over the past year to implement design changes and present the most current information available to our registered families and the public. The ACDA began in 1996 and we are so excited to enter our 20th anniversary year in 2016 with our new look. Please read more detailed information about the changes on the following pages. I hope you will spend some time exploring and sharing our redesign!

Regards, Eliza Rista (Secretary)

New Website!

The ACDA website has been *completely* overhauled to reflect our new look and provide the most up to date content. **Most importantly, please note the change to our website address, which will be our permanent home going forward. Please update your bookmarks accordingly: <http://acdassociation.org>**

The website has been carefully crafted to be a one stop portal for anything and everything related to ACDMPV. We not only wanted to provide current genetic and research information but also grief resources and community resources. Essentially anything related to ACDMPV has been consolidated into one location with easy to navigate menus. We hope you will visit the new website and share it far and wide with your friends and family.

Below is a brief summary of the website redesign:

- **New design** – Fresh new look optimized for both desktop and mobile platforms.
- **Information** – All content is now the most up to date information available, including genetics, research, FAQs, etc. We also added numerous new pages, such as a summary of NORD grants, maps, history of the ACDA, links for medical professionals, etc.
- **Donate** – The donation page is easier to navigate and includes instructions on how to donate directly to either the ACDA or the NORD Research Fund (ACD).
- **Social Media** – Our Twitter and Facebook feeds are now linked directly to our website, along with the ability

for visitors to share our content through social media services.

- **Grief resources** – Recommended support groups, book lists, song lists and links to personal blogs written directly by ACDMPV parents.
- **Community resources** – Links to every newspaper, magazine or blog article written about families affected by ACDMPV.
- **Fundraisers** – Summaries of current and completed fundraisers organized by ACDA families. Please contact us at secretary@acdassociation.org if you would like us to add a description of your fundraiser benefiting ACDMPV research.
- **Store** – An easy to use store with the ACDA logo on your favorite products with a designated portion of the proceeds going to the ACDA. Ships internationally to many countries!

Logo

Our beautiful new logo was designed and created by Ali Christensen. Ali is a friend of Bob and Kristen Rilling, ACDA parents to Fallon (October 10, 2013 - October 21, 2013). We are so incredibly grateful to Ali for contributing her time and professional talents to our organization.

We also want to express our thanks to everyone who submitted a design for consideration. We are so thankful for the participation of our community.

Items with our new logo are available for purchase in our new store!



October is Pregnancy and Infant Loss Awareness Month

In October 1988, President Ronald Reagan of the United States proclaimed October as National Pregnancy and Infant Loss Awareness Month. “When a child loses his parent, they are called an orphan. When a spouse loses her or his partner, they are called a widow or widower. When parents lose their child, there isn’t a word to describe them. This month recognizes the loss so many parents experience across the United States and around the world.”

October 15, 2015 – Pregnancy and Infant Loss Remembrance Day

The October 15th Pregnancy and Infant Loss Remembrance Day campaign began in 2002 and is a day of remembrance for pregnancy loss and infant death. The day is observed with ceremonies and candle-lighting vigils, concluding with the International Wave of Light, a worldwide lighting of candles. The International Wave of Light invites participants from around the world to light a candle at 7:00 p.m. on October 15 in their respective time zones, and to leave the candle burning for at least an hour. The result is a continuous chain of light spanning the globe for a 24 hour period in honor and remembrance of our babies we have lost.

RESEARCH NEWS

ACDMPV was part of the poster session for the 19th "[International Conference on Prenatal Diagnosis and Therapy](#)" in Washington, DC, USA on July 12-15, 2015. A poster session is a room with posters on display for attendees to view and ask questions. Vanderbilt University Medical Center prepared the poster based on an experience with a prenatal diagnosis of ACDMPV. A mother had a CVS due to concerns viewed on an ultrasound in the first trimester (cystic hygroma and echogenic bowel) and microarray analysis was done, which detected a deletion in the FOXF1 region. The family received counseling on ACDMPV and the baby was delivered at 39 weeks and unfortunately did not survive past the second day. This work is significant because according to the abstract, “This is the first reported prenatal diagnosis of ACDMPV devoid of a family history.” [Reference](#) (scroll down to Section P3-22)

AWARENESS NEWS

Diana Locke, a Registered Nurse and ACDA mom to Christopher (November 7, 2006 - December 17, 2006) gave her annual presentation to 135 first year medical students at the University of Florida College of Medicine on August 19, 2015. The presentation focused on ACDMPV, Christopher’s case and other ACDMPV babies. With this program, future doctors now know about ACDMPV. Perhaps best summed up in their own words as written in their thank you note to Diana, “Not only was it incredibly brave, but you have forever left an impact on us.” –UFCOM Class of 2019



FUNDRAISING NEWS

Donations:

To make a secure tax deductible donation to the ACDA or the NORD Research Fund (ACD), please visit our website for full instructions.

<http://acdassociation.org/donate/>

The ACDA is a 501(c)(3) non-profit, tax-exempt organization as designated by the Internal Revenue Code of the United States.

Update from NORD:

The NORD balance of the Research Fund (ACD) as of September 18, 2015 is **\$4,194.29**. The deadline is March 1, 2016 to make a donation to help us reach our goal of \$33,500 for another grant in 2016.

Update from AmazonSmile:

The ACDA was issued a **\$58.74** donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between April 1, 2015 and June 30, 2015. To designate the ACDA as your charity, please follow the link below so that all of your eligible shopping will benefit the ACDA: <http://smile.amazon.com/ch/46-2915711>

Other Fundraising Updates:

Our Café Press Account has been closed. Please purchase items from our new store linked on our website.

If anyone knows of a printer that would donate the printing of our new letterhead and brochures, please contact us.



Donations Received:

Thank you to the following families and friends that have made donations to the ACDA since the last ACDA Notes:

Donor	In Memory Of
[REDACTED]	[REDACTED]
[REDACTED]	*
[REDACTED]	*
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]

**We are sorry we do not know the child for whom the memorial contribution was made. Please contact us to let us know.*

NEW ACDA BOARD:

During the ACDA quarterly meeting on August 6, 2015, the following individuals were appointed to the Board of Directors of the ACDA for the 2015-2016 term:

- President – Steve Hanson
- Secretary – Eliza Rista
- Treasurer – John Rista

Our thanks are extended to Kim Anderson Bush and Donna Hanson for their service as Secretary and Treasurer, respectively, for the prior year.

Please check our website for a full listing of Board and Committee members and let us know if you would like to get involved!

<http://acdassociation.org/board-members>

REPORT FROM THE DAVID ASHWELL FOUNDATION:

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](http://DavidAshwellFoundation)
2. Fundraise while you online 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](http://DavidAshwellFoundation)

Please raise awareness of our small charity via social media including twitter and facebook.

Our balance at 28th August 2015 was £9,203 (\$14,197).

Since March 2011 we have raised **£151,485 (\$233,703)** for ACD Research. The David Ashwell Foundation has contributed to all five of the recent grants for ACD research issued by NORD; £33,118 (\$52,053) was transferred in February 2012, over £95,011 (\$157,072) was transferred to the NORD ACD account in March 2014 and in March 2015 £9,278 was transferred to NORD.

All the money raised is from ACD families and friends in UK and Europe.

Fundraisers in memory of ACD babies continue to happen via our Virgin Money Giving Website. This includes fundraising by the Davey Family (Hope's parents) as well as fundraising by Seb Blenkinsop's family and friends. Sarah (Seb's mum) has not only been busy fundraising but also awareness raising in the UK at a national level – and to a level never done by any UK family. A huge thank you to Sarah for her braveness and facing the media with her story of love for Seb.

Other fundraisers have included 7 year old Anna Morrison (her mum is one of Amelia's close friends) choosing not to receive birthday presents but instead to donate to The David Ashwell Foundation. Anna raised £303 (\$467). At the

other end of the age spectrum, another Ashwell Family friend decided not to receive 40th birthday gifts and donated £420 (\$647) to our charity.

Another friend of Amelia's (from her PhD days), Emma Northover and Adele Phelan decided to walk 50Km on the Thames Path Challenge on 13th September. They have almost raised £1,000 (\$1,542) and are still fundraising!

There are more fundraisers in the pipeline - Sarah (Seb's mum) has an event in October and one of Seb's family friends Jonathan is doing a sponsored bungee jump on 20th September.

If anyone in UK would like to support us, or join the team please get in touch.

UK families, please don't forget to use The Giving Machine when you online shop! Using this has raised £791 (\$1,220) 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.

For additional information, please contact Simon and Amelia.

Website: [http://David Ashwell Foundation](http://DavidAshwellFoundation)

Email: davidashwellfoundation@yahoo.co.uk

Twitter: [@TDavidAshwellF](#)

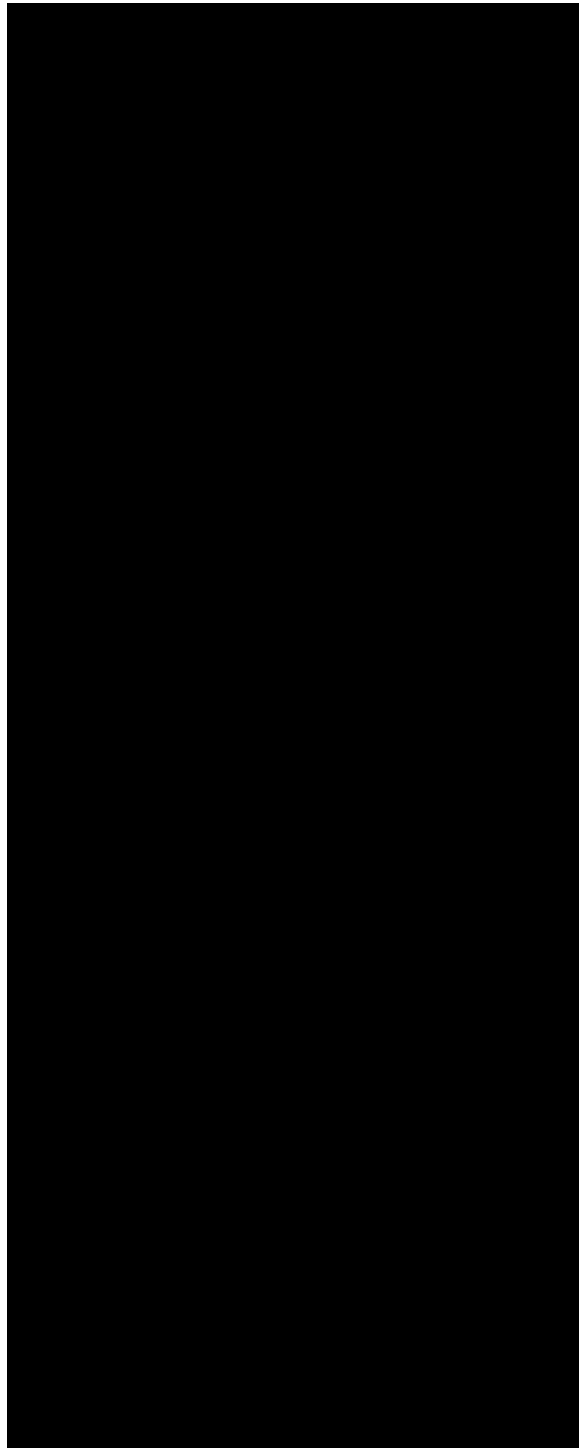
Mobile (Amelia): 07855473686

We are more than happy to hear from other families who would like to use the charity to raise money for ACD Research. Simon and Amelia run The David Ashwell Foundation on a voluntary basis. **All** money raised will be transferred to NORD to fundraise ACD Research.

Amelia and Simon are expecting baby Ashwell no. 3 in mid to late October – but we will still be contactable and hoping for news of new fundraising ideas!



Remembering Our Babies



Welcome to New Families

A sad but warm welcome to the following newly registered families:

- [Redacted family name]
- [Redacted family name]
- [Redacted family name]
- [Redacted family name]
- [Redacted family name]
- [Redacted family name]
- [Redacted family name]

We hope everyone enjoyed the new design and layout of our newsletter, ACDA Notes. Our heartfelt thanks and gratitude to Michaela Oltmans, ACDA mom to Harper (May 11, 2012 - May 24, 2012), for providing the ACDA with the beautiful new template. Please contact us with any story ideas you would like to contribute to future issues of ACDA Notes.



Safe Arrivals!

Congratulations on the birth of the following little siblings in our ACDA registered families:

- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]

CONNECT WITH US

Facebook:

- [Official ACDA Public Page](#)
- [Parent Group](#) (private)
- [Family Group](#) (private)

Read about the private groups on our website with information on how to join:

<http://acdassociation.org/support-groups/>

Twitter:

- Follow us [@acdassociation](#)

Website:

<http://acdassociation.org>

Email:

President@acdassociation.org (Steve Hanson)

Secretary@acdassociation.org (Eliza Rista)

Treasurer@acdassociation.org (John Rista)

**Please note the changes to our email addresses.*

A note from the Secretary: We absolutely want to hear from you as to how we can best meet your needs with respect to information about ACDMPV and also grief support. We are here to help in any way we can. Please know we always want to hear your ideas and we love community involvement on any level. Please never hesitate to contact me at Secretary@acdassociation.org.

Regards, Eliza Rista, mom to Johnny
(February 20, 2013 – March 4, 2013)

