ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
acdassociation.org
SPRING 2019
Issue 67

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

What's INSIDE

Rare Disease Day 2019 was a tremendous success for the ACDA. Together with The David Ashwell Foundation, we raised over $5,850! Our sincerest thanks to the families, friends, colleagues and classmates of the ACDA and The David Ashwell Foundation. Please read all the details on page 4!

Regards, Eliza Rista, President

RESEARCH NEWS

2019 NORD Grant:

It is the great pleasure of the ACDA and The David Ashwell Foundation to announce a **$50,000 grant will be issued in 2019 for ACDMPV research.** NORD announced the Request for Proposals (RFPs) on April 30, 2019 (see the box to the right for additional RFP information).

As background, over $600,000 has been issued for ACDMPV research through NORD with a **total of eleven grants since 2005**. Thank you for keeping the momentum going with **annual ACDMPV research grants through NORD the last six years in a row**.

Every single dollar matters in rare disease research. The smaller seed grants issued in recent years through money raised by ACDMPV affected families and friends has helped collect data for use in larger multi-year government grants, including the $1,900,000+ grant awarded to Baylor from the NIH in 2017 for a four-year study. The seed grants also sustain ACDMPV research during the very difficult NIH application process. It can take research institutions a few years (and rejections) to finally have enough research material for NIH approval. **These larger governmental grants would simply not be accessible without the ongoing seed grants raised by families and friends affected by ACDMPV.** So please keep up those birthday fundraisers, off-roading events, softball tournaments, marathon pledges and all the other amazing ways you raise money for ACDMPV research! Progress is being made each year and we are thankful for every donation. Please visit our website HERE to read a full history of NORD grants for ACDMPV research.

None of this would be possible without the hard work, contributions and fundraising efforts of families and friends affected by ACDMPV. We are deeply grateful for the support as we continue to work towards ending this disease.

NORD Request for Proposals ("RFP") – 2019 Research Grant:

NORD, with funding from the Alveolar Capillary Dysplasia Association (ACDA) and The David Ashwell Foundation, **is accepting applications for a total of $50,000** for scientific research studies and/or clinical research studies related to Alveolar Capillary Dysplasia/misalignment of the pulmonary veins (ACDMPV). NORD encourages all U.S. and international researchers interested in studying ACDMPV to consider applying for 2019 funding. **The Abstract Submission Deadline is June 18, 2019. See the full RFP and abstract template HERE**.

Genetic Testing (updates):

Baylor College of Medicine

Since 2001, the ACDA has supported ACDMPV research at Baylor College of Medicine in Houston, Texas, USA. The ACDA encourages all newly registered members to donate DNA and tissue samples to the ACDMPV research team at Baylor in order to keep all known samples in one central location and database. As such, **Baylor has accumulated the largest collection of DNA and tissue samples related to ACDMPV in the world.**

In 2014, 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 (e.g. 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 very difficult to detect. In theory, this could result in children with genetic diseases from parents with apparently normal DNA being labelled incorrectly as having a new '*de novo*' genetic abnormality.

Baylor routinely tests with PCR sensitivity for low-level somatic mosaicism in parents of ACDMPV infants with FOXF1 related **deletions**.

As an update to Issue #65 of ACDA Notes, the lab had previously been unable to test for somatic mosaicism in the parents of ACDMPV infants with a FOXF1 **mutation** due to unreliability of this test at such levels. However, Baylor has recently tested multiple parental samples in families with children with point mutations with the more sensitive method for mutation testing (approaching PCR sensitivity) and found a couple instances of very low-level somatic mosaicism. Baylor is in the process of writing a manuscript about their recent findings.

Journal Article (Clinical Epigenetics):

Baylor College of Medicine in Houston, Texas, USA recently published a manuscript entitled "*Novel parent-of-origin-specific differentially methylated loci on chromosome 16*" in Clinical Epigenetics, which can be found HERE. Researchers from Cincinnati Children's Hospital Medical Center, Northwestern University Feinberg School of Medicine and Washington University School of Medicine also contributed to the research.

The research team performed high-resolution bisulfite sequencing of chromosome 16 on lung tissue from patients with ACDMPV-causative 16q24.1 deletions. The high-resolution bisulfite sequencing approach allowed the researchers to closely evaluate DNA methylation across chromosome 16 and found evidence for novel candidate imprinted loci on chromosome 16 that would not be evident in array-based assays and could contribute to the birth defects observed in patients with ACDMPV.

RareDiseaseFacts™

What is a RARE DISEASE ?

Any disease, disorder, illness or condition affecting **fewer than 200,000** people in the United States is considered RARE.

NORD®
National Organization for Rare Disorders

AWARENESS NEWS

Update on Rare Disease Day (February 28, 2019):

We are pleased to announce $5,045 was raised by the ACDA and an additional £630.36 was raised by our sister UK registered charity, The David Ashwell Foundation, for a **grand total of $5,850 in connection with Rare Disease Day on February 28, 2019**!! Our sincerest thanks to the families, friends, colleagues and classmates of the ACDA and The David Ashwell Foundation for raising such an incredible amount for ACDMPV research!

Please click HERE to check out our ACDA families and friends wearing the ACDA logo and #JeansforGenes on Rare Disease Day!

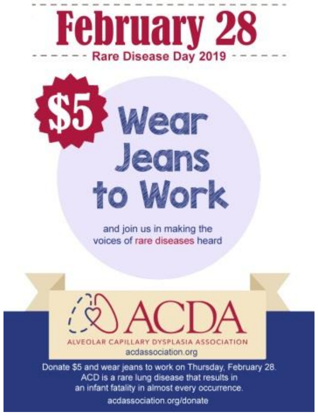
We would like to thank all of our individual donors and everyone who wore #JeansForGenes or sent pictures wearing the ACDA logo! Thank you for your outstanding support of our ACDA families.

The silicone wristband campaign was incredibly successful! Available *ONLY* on Rare Disease Day 2019, all $20 minimum donations made on February 28, 2019 received two ACDA silicone wristbands per address as a THANK YOU! Each wristband was blue with white debossed lettering featuring the ACDA logo, website address and motto, "*Searching for answers…hoping for a cure*." The wristband incentive reached **many new first-time donors** and the number of honoree families nearly doubled from eighteen children on Rare Disease Day 2018 to **thirty-five children on Rare Disease Day 2019**!

One Day Exclusive! Rare Disease Day 2019


Every $20 minimum donation on February 28, 2019 received two ACDA wristbands per address as a THANK YOU!!

The ACDA created flyers for use at workplaces and schools encouraging colleagues and classmates to donate $5 / £5 / €5 to wear jeans to work or school on February 28 for Rare Disease Day. The flyers can be modified for a **Jeans Day at any time of year, contact the ACDA for help!**



Donate $5 and wear jeans to work on Thursday, February 28. ACD is a rare lung disease that results in an infant fatality in almost every occurrence.
acdassociation.org/donate

Donate £5 and wear jeans to work on Thursday, February 28. ACD is a rare lung disease that results in an infant fatality in almost every occurrence.
acdassociation.org/donate

Donate €5 and wear jeans to work on Thursday, February 28. ACD is a rare lung disease that results in an infant fatality in almost every occurrence.
acdassociation.org/donate

Below please find a "Thank You" badge for donations made on Rare Disease Day 2019 in your child's honor:

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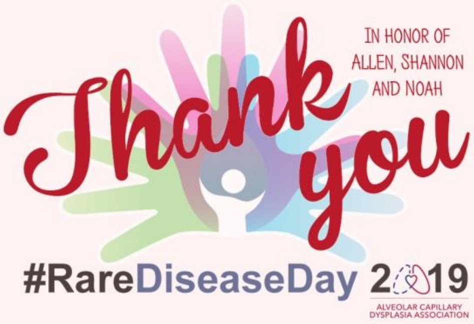

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In the UK, we would like to give our very special thanks to:

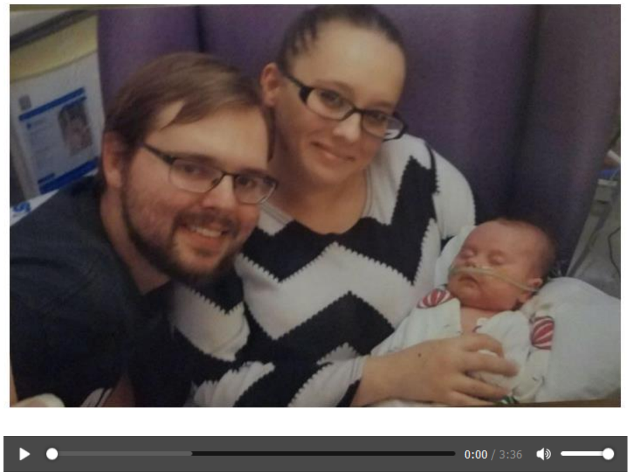
- **Teesside University**
- **Human Nutrition Research Centre, Newcastle University**
- **Co-op Springfield**
- **Appleton Wiske School**
- **Kirby Great Broughton school**
- **Westons Pharmacy Brighton**
- **Moulscoomb primary school**
- **Hertford infants school**

In the U.S., we would like to give our very special thanks to:

- **East Quogue Teachers Association** (East Quogue, NY)
- **East Quogue Elementary School** (East Quogue, NY)
- **The Suffolk County District Attorney, Financial Investigations & Money Laundering Bureau** (Hauppauge, NY)
- **Suffolk County Department of Law & Suffolk County Office of Risk Management** (Hauppauge, NY)
- **Suffolk County Budget Office & Management Office** (Hauppauge, NY)
- **Suffolk County Department of Audit & Control** (Hauppauge, NY)

Families in the News (Dean Grant):

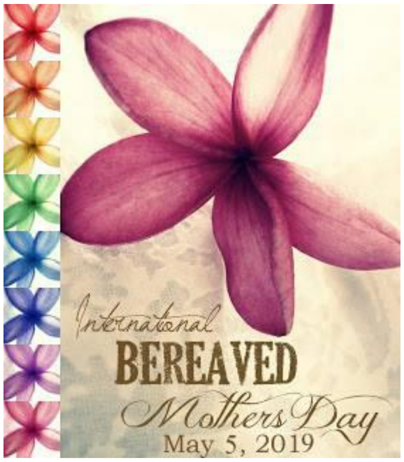
Derek Grant, ACDA father to Dean (September 13, 2016 - July 27, 2017), recently asked his wife, Ashley Grant, about a special song to their family in an interview called "*Lyrics Carry Special Meaning for a Special Family*," which was published by Media Milwaukee in April 2019. Please click HERE to listen to the touching audio (see also Issues #60 and #66 of ACDA Notes).



Dean and Ashley Grant share an audio story about their son, Dean, and a special song

International Bereaved Mother's Day (May 5, 2019):

Love and light to our bereaved ACDA mothers this past International Bereaved Mother's Day.



ACDA Tattoo (Aurora Splawn):

In March 2019, Tiffany Hensley, ACDA mom to Aurora (July 23, 2016 - August 6, 2016), and Tiffany's mother recently both got tattoos of the ACDA logo! In Tiffany's own words, "So proud to represent our ACD angel and her whole ACD family for the rest of my life…I love bringing awareness of ACD to my community. This right here fills my heart. This was my mom's first tattoo at 53 years old. I'm so proud that I experienced this with my momma." The ACDA is now aware of a total of **eight tattoos featuring the ACDA logo!**

Rare Disease Rally (Johnny Rista):

Eliza and John Rista, ACDA parents to Johnny (February 20, 2013 – March 4, 2013), attended and displayed ACDA awareness materials at the World Rare Disease Day Rally hosted by the Rare and Undiagnosed Network of

Charlotte, North Carolina on February 23, 2019. The event featured special speakers and guests, a symbolic walk and other fun activities such as a live band, face-painting and crafts.

LUNG TRANSPLANT UPDATES

Lung Transplant Update (Luca Palmisano):

Luca, age 2.5, a lung transplant recipient #VacationModeActivated

We wrote about Luca Palmisano in Issues #57, #58, #59, #61 and #66 of ACDA Notes and had to share this special vacation photo of Luca from April 2019, as captioned by his ACDA parents Ashley and Thomas!

In November 2016, Luca received a lung transplant at 4.5 months old at Children's Hospital of Philadelphia in the USA. You can follow Luca's Lung Transplant Story HERE. #teamluca

Lung Transplant Update (Tom Schnierle):

Tom, age 2.5, a lung transplant recipient and hospitalized from birth for 2+ years until transplant, explores the outdoors

In December 2018, Tom received a lung transplant at 2.5 years old in Germany, which was complicated by limited organ availability and the fact that lung transplants were not performed on small children in Germany. Prior to his lung transplant, Tom had been in the intensive care unit **since birth** (See Issues #64 and #66 of ACDA Notes). #acdwarriors

ACDA COMMITTEE POSITIONS

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

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.

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 minimum amount required for the issuance of a 2020 NORD grant is $35,000.

Balance of ACDA account:

The balance of the ACDA bank accounts as of May 15, 2019 is **$[redacted].**

Update from AmazonSmile:

The ACDA was issued a **$**[redacted] donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between October 1 and December 31, 2018. 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

Update from Spreadshirt:

The accrued commission payment from Spreadshirt between February 1, 2019 and May 14, 2019 is **$**[redacted]. Items with the ACDA logo are available for purchase in our Spreadshirt store HERE. Don't forget the ACDA earns a commission equal to **20% of every product sold**! **Look for FREE SHIPPING from June 1-4, 2019!** Ship, ship, hooray! (Use code: SHIPIT19)

Donations Received:

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

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

Birthday Fundraiser (James Perrella):

[redacted]

In honor of Baby James. Please help find a cure 💙

[redacted] Birthday Fundraiser in honor of Baby James

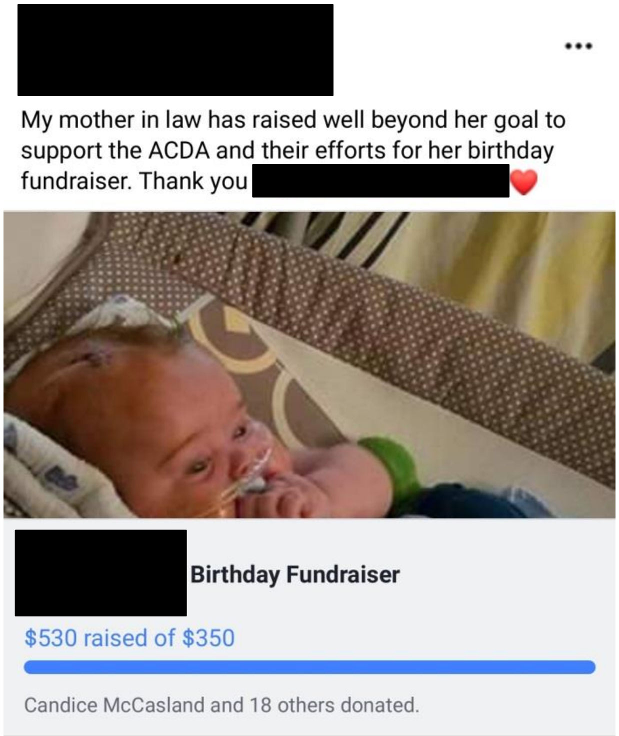
$10,533 raised of $10,000

Maria exceeded her $10,000 goal by raising $10,533 through a Facebook birthday fundraiser in honor of her son, James Perrella. Outstanding!!

In March 2019, Maria Catalano, ACDA mom to James Perrella (January 23, 2019 - February 15, 2019), organized a birthday fundraiser for **ACDMPV research in honor of James**. In Maria's own words, "For my birthday this year, I asked for donations to the Alveolar Capillary Dysplasia Association…We would like to sincerely thank everyone for their love and support in reaching our goal! We couldn't be more blessed having friends and family like all of you. We hope this donation helps the association work towards finding more information on causes and treatment of ACDMPV in the future. Thank you for helping honor and remember Baby James."

Our heartfelt thanks to the families of James Perrella and Dean Grant for organizing such fantastic Facebook fundraisers for ACDMPV research!

Birthday Fundraiser (Dean Grant):



[redacted]

My mother in law has raised well beyond her goal to support the ACDA and their efforts for her birthday fundraiser. Thank you [redacted] ❤️

[redacted] Birthday Fundraiser

$530 raised of $350

Candice McCasland and 18 others donated.

Joyce exceeded her $350 goal by raising $530 through a Facebook birthday fundraiser in honor of her grandson, Dean Grant. Thank you Joyce!!

In April 2019, Ashley and Derek Grant, ACDA parents to Dean (September 13, 2016 - July 27, 2017), supported a birthday fundraiser organized by Dean's grandmother **for ACDMPV research in honor of Dean**. In Joyce's own words, "To honor my grandson, Dean, I'm asking for donations to the Alveolar Capillary Dysplasia Association for my birthday. I've chosen this nonprofit because their mission is very personal for me, and I hope you'll consider contributing as a way to celebrate with me. Every little bit will help me reach my goal. I've included information about Alveolar Capillary Dysplasia Association below. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder. Thank you. 🐢💙"

REPORT FROM STICHTING ACD (NETHERLANDS):

Mathijs Lourens, ACDA father to Myla (November 20, 2015 - December 17, 2015), continues his amazing work in support of his Dutch ACDMPV foundation, "**Stichting ACD**." Mathijs plans to continue running marathons for ACDMPV awareness in Europe and then worldwide! He previously completed the Rotterdam Marathon (April 2017, April 2018 and April 2019), the Amsterdam Marathon (October 2016 (*half*), October 2017 and October 2018 (*Kids Run*)), and various other running events. **Please contact Mathijs if you are interested in participating or cheering on his upcoming plans to raise ACDMPV awareness in the Netherlands, Germany or beyond!** For additional information about the upcoming runs highlighted below, please visit Run4ACD on Stichting ACD's website, Dam tot Damloop and BMW Berlin Marathon.

Radboudumc (February 16, 2019):

On February 16, 2019, Mathijs gave a lecture to a group of young medical students at Radboud University Medical Center in Nijmegen to teach the next generation of medical professionals about ACDMPV. In Mathijs' own words, "One of the things I am also doing for our Dutch foundation Stichting ACD is teaching, motivating and inspiring our doctors of the future. Creating awareness so hopefully one day we will find a cure for ACDMPV. Good things are currently going on regarding research in the Netherlands. It remains a process that will take years, but we can't and we won't give up. We will get there step by step. **It doesn't bring our precious babies back, but we can make a difference for the future.**"

Groet uit Schoorl Run (February 10, 2019):

On February 10, 2019, Mathijs and team Stichting ACD ran the 30 km **Groet uit Schoorl Run in North Holland**. The Groet uit Schoorl Run attracts 9,000 runners to this North Holland resort and has been held every year on the second Sunday of February since 1979.

LenteMarathon 2019 (March 24, 2019):

On March 24, 2019, Mathijs cheered on team Stichting ACD during **the AmstelveenZ Lentemarathon 2019** to raise ACDMPV awareness!

Zandvoort Circuit Run (March 31, 2019):

On March 29, 2019, Mathijs and team Stichting ACD ran the 12 km **Zandvoort Circuit Run** for ACDMPV awareness!

NN Marathon Rotterdam (April 7, 2019):

On April 7, 2019, Mathijs and team Stichting ACD ran the **Rotterdam marathon for the third year in a row**! In Mathijs' own words, "Today was another amazing day running my fourth in total marathon with Myla. It was hot and it was tough, but my little girl always gets me through difficult moments. I know she is waiting for me around 41 kilometer. That's my finish! Quite a few runners ran the streets of Rotterdam today again with the Myla shirt on. And not to forget our amazing fans! Thousands of people have seen us and are aware a bit more about ACDMPV. Also got some unexpected publicity again on local TV and social media. It keeps me motivated but the best thing is to show Myla to the world and cross the finish line together."

Dam tot Damloop (September 22, 2019):

Upcoming Event: Dam tot Damloop (Dam to Dam Run in English) is an annual road running competition held in North Holland in the Netherlands. It is a ten mile race from Amsterdam to Zaandam. Mathijs plans to participate in the **Dam tot Damloop on September 22, 2019!**

BMW Berlin Marathon (September 29, 2019):

Upcoming Event: Chasing the dream to cross the world with Myla! Mathijs trained hard with focus and determination for many months in order to expand his marathon adventure across the border in October 2018 (see Issues #65 and #66 of ACDA Notes). For his first foreign marathon, he planned to run the marathon in Cologne, Germany on October 7, 2018 to raise ACDMPV awareness in Germany. Despite his best efforts and tremendous optimism, a significant cold mandated that Mathijs sit out his first foreign marathon attempt. But Mathijs never gives up and is already planning his next marathon adventure in Germany! Mathijs plans to participate in the **BMW Berlin Marathon in Berlin, Germany on September 29, 2019!**

Angel Gallery:

You are invited to view the "Angel Gallery" on Stichting ACD's website for a touching image display featuring many of our ACDA babies.

REPORT FROM THE DAVID ASHWELL FOUNDATION (UK):

We moved house in March 2019 and life has been rather hectic before, during and after this move. Post house move, I am now hoping for even more fundraisers in 2019/20! Get in touch with any ideas please – I need help!

Thank you to those who had Rare Disease Day fundraisers at their schools and workplaces. In Yorkshire we had two Schools who fundraised – my son's and a friend's school. In the South of England, Imogen's incredible mum Hayley Bolton had two fundraisers at her children's school and through a personal fundraising page. In total we raised £630.36. But…there is more to come from my local supermarket who had collection buckets and two cafes who are local to me and who are incredibly supportive of all our fundraisers

In April 2019, we **transferred £5,529.27 ($7,221.78)** to the ACDMPV research fund at NORD. Since March 2011, **£207,197 ($270,023)** has been raised for ACDMPV research by families in the UK and Europe. This has contributed to the funding raised internationally to the ACDA. We are always very enthusiastic to raise more money for ACDMPV research and would appreciate any help! **Thank you to those families who have set up direct debits for the charity and whose families fundraise at work for us.**

At the moment not many people are using The Giving Machine. Please, UK families can you use The Giving Machine (GO HERE) to generate income from online shopping. Everyone in the UK can do this – it is **so easy to register and is a way of earning easy and free money**. Please also encourage your friends and family too! Watch HERE how it works! I have the giving machine app on my phone and it makes giving as I shop so easy. It's very quick and easy to sign up!

Please use **The David Ashwell Foundation Virgin Money Giving pages**. On our Virgin Money Giving pages, **set up a page in for your precious baby/child and encourage people to donate there**.

We are here to help UK families fundraise for ACDMPV research so that we can help to find answers to the condition that has become such a major part of our lives.

Simon and I run this as well as working and bringing up our children, Auden and Faye. We are very, very grateful to anyone who uses this charity in memory of their precious babies. Thank you especially to those who have a standing order and put money into The David Ashwell Foundation charity bank account each month (ACDMPV and non ACDMPV families).

UK families you can set up direct debits to The David Ashwell Bank Account (we have a number of people who do this).

Additionally we have a Virgin Money Giving account where you can set up a page in memory of your child or for special occasions (such as birthdays or Christmas).

If you live in the UK (and elsewhere), there are a number of options available for funding ACDMPV 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.
2. Fundraise while you online shop (The Giving Machine) (a percentage of what you spend is donated)
3. Collect postage stamps

All UK & Europe based families are welcome to use The David Ashwell Foundation as a means of fundraising for ACDMPV Research. Please raise awareness of our small charity via social media including Twitter and Facebook. We are more than happy to hear from other families who would like to use the charity to raise money for ACDMPV Research. Simon and Amelia run The David Ashwell Foundation on a voluntary basis. **All** money raised will be transferred to NORD to fund ACDMPV research. Thank you to all who have used The David Ashwell Foundation to fundraise in memory of their precious child. For additional information, please contact Simon and Amelia.

Website: http://David Ashwell Foundation
Email: davidashwellfoundation@yahoo.co.uk
Twitter: @TDavidAshwellF
Mobile (Amelia): 07855473686

REMEMBERING OUR BABIES

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WELCOME TO NEW FAMILIES

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

[redacted]

- [redacted]
- [redacted]

(continued on following page)

- [redacted]
- [redacted]
- [redacted]
- [redacted]

SAFE ARRIVALS!

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

[redacted]

[redacted]

CONNECT WITH US

Facebook:

- Official ACDA Public Page
- Parent Group (private)
- Family Group (private)

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

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

Twitter:

- Follow us @acdassociation

Website:

- acdassociation.org

Email:

President@acdassociation.org (Eliza Rista)
Secretary@acdassociation.org (Renee Murray)
Treasurer@acdassociation.org (John Rista)

A note from the President: 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 President@acdassociation.org.

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