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Our ACDA families came up with fun and creative ways to raise funds for ACDMPV research the past couple months! Examples include a Sip and Paint Fundraiser, Color Obstacle Rush and Off-Road Club Charity Run! We love to see the unique ways our ACDA families continue to raise funds for ACDMPV research while having fun doing it. Please let the ACDA know if you are having an event so that we can help promote your event on social media and share your results in the next newsletter!

This newsletter also includes a few ideas (see page 6) as to ways your employer may be able to help fund ACDMPV research and spread awareness, such as matching gifts, volunteer grants or a write-up in a corporate newsletter. Please do not forget to check with your employer’s Human Resources department to see if there are any opportunities for corporate involvement!

We are also excited to share the very special story of Imogen, an ACDMPV survivor in the UK after a lung transplant in May 2016! Please see page 3 to read all of the details and follow the link to Imogen’s Facebook page!

On behalf of the ACDA, thanks to everyone for all of the dedicated work in support of our very important mission!

Regards,
Eliza Rista, Secretary
Upcoming Date: August 19, 2016 – Day of Hope

“August 19th is about coming together as a whole community to openly speak about these children and celebrating their short lives. Each year thousands of people around the globe take part in The Day Of Hope by hanging up prayer flags in honour of their babies and children that have died. Many people also share our Prayer Flag awareness images on facebook, instagram, twitter and other social networks.” From the CarlyMarie Project.

Prayer flags created by family and friends of Candice and Brian McCasland, parents to Sadie (February 5, 2014 – February 19, 2014) for a prior August 19 “Day of Hope”.

AWARENESS NEWS

June 7, 2016 Legislative Day in Raleigh, North Carolina, USA:

The ACDA was represented with its own table display at the NC Legislative Building for the June 7, 2016 Legislative Day in Raleigh, North Carolina, USA. This event was co-sponsored by the NC Rare Disease Advisory Board and the NC Rare Disease Coalition and had over 125 medically-related companies and patient advocacy groups registered to attend. John Rista, father to Johnny Rista (February 20, 2013 - March 4, 2013), attended with a table display on behalf of the ACDA and handed out materials about ACDMPV to the public and legislators.

Check out the ACDA banner in the picture and remember you can sign-up to use the banner in the USA for your upcoming events! The ACDA has also created new informational rack cards and can share the printing details if anyone would like to print their own to distribute at their events.

Please see page 4 of this newsletter for additional details on the banner or email Eliza Rista at Secretary@acdassociation.org.
**Upcoming Date: August 16, 2016 - University of Florida presentation**

Diana Locke, a Registered Nurse and ACDA mom to Christopher (November 7, 2006 - December 17, 2006), plans to give her annual presentation to first year medical students at the University of Florida College of Medicine in Gainesville, Florida, USA on August 16, 2016 at 9:00 a.m. The presentation will focus on ACDMPV, Christopher's case and other ACDMPV babies. With this program, future doctors will learn about ACDMPV. Diana has extended an open invitation to any of our ACDA families and friends if they would like to attend the presentation! Please send an email to Secretary@acdassociation.org for Diana’s contact information and more details.

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**This is amazing - meet Imogen!**

Imogen is an ACDMPV survivor in the UK & Europe’s smallest lung transplant recipient.

Imogen was born on November 22, 2015 to parents Hayley and Jason Jarvis. Imogen did not present with the symptoms of ACDMPV immediately and had a relatively normal newborn period. However, she suffered a number of infections when she was four months old that involved her being ventilated and later put on a small amount of oxygen. At around five months old, Imogen was given a diagnosis of ACDMPV. Limited reports have begun to emerge in the medical literature of presentation of ACDMPV beyond the neonatal period. Imogen was stable enough to be considered for transplantation and, in May 2016, Imogen received a bilateral lung transplant.

In the United States, a handful of patients have previously survived with atypical or late presenting ACDMPV long enough to receive a successful lung transplant. However, the ACDA is unaware of a UK or European lung transplantation previously performed on a child as small as Imogen.

**To follow Imogen’s full and amazing story, please click HERE to read all of the details.**

Imogen’s family created the page to tell Imogen’s story but also to raise awareness, particularly with respect to organ donation.

The ACDA is incredibly thankful to have another ACDMPV survivor in our records and hopes to report on more of these cases in the future.
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](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.

Balance of ACDA account:

The balance of the ACDA bank account as of June 29, 2016 is $11,591.30. The ACDA and The David Ashwell Foundation are currently working towards collecting the minimum amount ($33,500) for the issuance of a NORD research grant in 2017.

Update from Spreadshirt:

The accrued commission payment from Spreadshirt between April 14, 2016 and June 29, 2016 is $48.22. Items with the ACDA logo are available for purchase in our Spreadshirt store [HERE](http://acdassociation.org/).  

Update from AmazonSmile:

The ACDA was issued a $67.64 donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between January 1 and March 31, 2016. 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](http://smile.amazon.com/ch/46-2915711)

Banner:

Don't forget the ACDA recently announced the addition of two new custom ACDA banners! Both banners are 2.5’ x 6’ and are made of durable, waterproof vinyl with grommets for hanging. The intended use of the banners is to allow ACDA registered families to request use of a banner for their fundraising and awareness events!

If you would like to request use of a banner in the U.S., please send an email to [secretary@acdassociation.org](mailto:secretary@acdassociation.org) to discuss sign-up for availability and shipping information. Availability will be on a first come, first serve basis and the requesting family is responsible for shipping costs to the next location on the sign-up sheet or return to the Secretary. Poster tubes for shipping can be obtained for free at U.S. Postal Offices. Shipping costs will vary but an example cost was $11 to ship a banner from North Carolina to Missouri.

Please feel free to request the use of a banner if you have an event coming up! We hope the use of a banner will help our ACDA registered families in the United States coordinate and organize their own fundraisers and awareness events for ACDMPV research!

Other Fundraising News:

If anyone knows of a printer that would donate the printing of our letterhead, rack cards or brochures, please contact us at [secretary@acdassociation.org](mailto:secretary@acdassociation.org).
In honor of Fallon Jade Rilling:

Fundraiser Date: April 30th, 2016
Location: Rausch Creek Off Road Park, Pine Grove, Pennsylvania
Amount Raised: Just over $500.00

Description: Our tiny angel, Fallon, has a huge influence over those of us that still remain here. This year, she chose to influence the 4x4 and off-road enthusiast community. I (Bob, Fallon’s dad) am a member of a large off-road club called the FJNortheasters, which predominately consists of modified Toyota trucks; specifically the Toyota FJ Cruiser. Each year, the FJNortheasters club sets out to complete a "charity run" in which the club organizers and leaders gather up sponsors to deliver tons of incredible prizes to be raffled off at the charity run. The charity run usually lasts about 3 full days of off-roading and boasts over 100 vehicles and drivers of all levels of experience. The event is closed out with the above mentioned raffle and huge dinner. Each year, the club chooses a specific charity in which to donate the proceeds from the event. This year, the charity chosen was the Make-A-Wish Foundation. But then Fallon stepped in with her influence. Not to take anything away from the primary charity, the club's president, Richard LaRusso, along with this year's event coordinator, Patti Williams, decided that they wanted a portion of the proceeds to go to Fallon and her band of angels to help aid research for ACDMPV. The raffle took in just over $5,000 this year and just over $500 was donated directly to fund ACDMPV research.

Fallon passed away in 2013 and, since then, the FJNortheasters club (and even its individual members on their own) have been extremely generous to the Rilling family and the ACDMPV family, as well. I won't get into the numbers since this is about this year's charity run, but since 2013, the FJNortheasters club, thanks to Richard LaRusso and the individual members, have donated thousands of dollars. A huge *thank you* goes out to Richard LaRusso, Patti Williams, and especially to Jean-Pierre Gagne for gathering all of the sponsors (whose donations directly fuel the funding for the club) as well as to all individual members of the FJNortheasters club.

With love from Fallon Jade Rilling (10/10/13-10/21/13) and the rest of the Rilling family.

In honor of David Ashwell:

On Saturday, June 11, 2016, Amelia Ashwell of The David Ashwell Foundation was part of a team of mummies who ran the Color Obstacle Rush 5K in Stockton-on-Tees, England, UK. The team raised nearly £700 ($1003), plus had the best morning of fun together in memory of Amelia’s son, David (March 4, 2011 - March 19, 2011). Read more from The David Ashwell Foundation on page 8!
In honor of Callie Murray:

On May 1, 2016, the Murrays held a Sip and Paint Fundraiser to honor Callie Murray (May 15, 2016 – May 23, 2016) as her 1st birthday approached.

Family and friends near and far came to celebrate and honor what an amazing little girl Callie is. The painting was chosen by the Murrays in advance with one addition, butterflies! Butterflies soon became very important to them shortly after Callie passed. It was a meaningful addition to the painting!

Renee said how therapeutic it was for her to quietly paint and think of her beautiful daughter and reflect on just how much she changed her life. A Chinese Auction was also held during the fundraiser, which was extremely successful thanks to all of the generous donors and ticket buyers.

On Callie’s birthday, May 15, the Murrays made a donation to the ACDA in the amount of $3,000.

Matching Gifts:

Don’t forget about Matching Gifts – If your employer has a Matching Gifts Program for charitable organizations, your contributions to ACDMPV research can grow! Please check with your Human Resources department. The ACDA Tax Identification Number is 46-2915711.

In May 2016, the ACDA would like to thank AMC Theaters for matching $1,000 in honor of Finley Smith and Bank of America, NA for matching $516 in honor of Johnny Rista!

Volunteer Grants:

To honor those who give their time and service to causes important to them, Bank of America, NA, through its Bank of America Charitable Foundation, awards unrestricted grants for volunteer work to any eligible nonprofit organization for which an employee has committed substantial volunteer hours within a calendar year. For 50 hours of volunteer time within a calendar year, Bank of America Charitable Foundation will give a $250 grant. For 100 hours of volunteer time within a calendar year, the grant is $500.

Thank you to Bank of America, NA for providing a $500 grant to the ACDA in honor of John Rista’s volunteer work in 2015 for the ACDA. Please follow up with your Human Resources department to see if similar volunteer grants are offered through your employer and let us know if you would like to get involved!

Corporate Newsletters:

We would like to also thank Bank of America, NA for the inclusion of an article about ACD, the ACDA and Johnny Rista in their April 2016 Newsletter Serving Employees of GIF (Global Infrastructure Finance). Corporate newsletters featuring a human interest story about an employee can be a tool to spread the word about ACDMPV to a wider audience.
**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.*

**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](http://acdassociation.org/board-members)
REPORT FROM THE DAVID ASHWELL FOUNDATION:

Thank you to all who have used The David Ashwell Foundation to fundraise in memory of their precious child.

Our current total is £8,224.29 ($11,791). Since David died in March 2011, The David Ashwell Foundation has raised £183,956.52 ($263,744.90).

Recently, we received £535 ($767) raised by the aunt of a baby Joey (whose parents haven’t yet joined the ACDA or the Facebook Parent Group). Joey’s aunt, [redacted], organized a raffle and sold cakes at [redacted].

I was approached by our local Betty’s café to apply for one of their £500 ($716) charity grants. We were unsuccessful in February 2016 but were successful in May 2016!

On Saturday, I (Amelia), was part of a team of mummies running the color obstacle rush (see pictures on page 5 of this newsletter), we have raised nearly £700 ($1003), plus had the best morning of fun together in memory of David.

Our neighbor, Barrie Spence, is riding the coast to coast on 26th June & has raised £160 ($229) so far!

Every little bit of fundraising helps to raise an amount that will enable us to fund more research into this disease.

Remember that 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. 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://DavidAshwellFoundation

Please raise awareness of our small charity via social media including Twitter and Facebook.

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 significant sums and in Germany the equivalent website has raised 260 Euros ($285 thanks to Karin Titze-Frech, see the report in the Fall 2015 newsletter!). 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 ACDMPV Research.

For additional information, please contact Simon and Amelia.

Website: http://David Ashwell Foundation
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 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.
REMEMBERING OUR BABIES

The ACDA extends its sympathies to a beloved member.

WELCOME TO NEW FAMILIES

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

- Family A
- Family B
- Family C
SAFE ARRIVALS!

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

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:
- acdassociation.org

Email:
- President@acdassociation.org (Steve Hanson)
- Secretary@acdassociation.org (Eliza Rista)
- Treasurer@acdassociation.org (John Rista)

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)