

Propionic Acidemia Foundation

VOLUME 1, ISSUE 21

FALL 2016

DEERFIELD HIGH SCHOOL FUNDRAISER: SCHOOL CHEST 2016

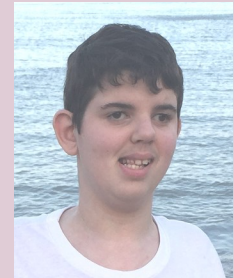
When my son Jordan passed away on June 26th, I was distraught and immobilized, but Jordan's cousin, Shayna Rosenson stepped up to help make PAF the recipient for the 2016 DHS School Chest Fundraiser!

It was the end of July when I received the phone call that PAF was chosen to be one of five organizations remaining, from over 100 applications, with the hopes of becoming chosen for School Chest, Deerfield High School's annual fundraiser. We had only 2½ weeks to prepare. Shayna knew that I was still trying to grasp the fact that Jordan wasn't here anymore. She immediately took charge! Instead of working on her college essays, Shayna began working on the 25 minute presentation and three minute video that we needed to advance. She was determined to do everything to get information on Propionic Acidemia out there. We wanted the support of others at the presentation to share their stories about Jordan, the importance of our organization, and some of the challenges that come with the disorder. Shayna and I were very lucky to have Brittany and Talli Smith (PAF Board Member and her daughter, who has PA), Zach Dolnick (DHS Junior and Warrior Buddy to Jordan), Ben Serck (DHS alumni and Past Warrior Buddy in Jordan's classroom), and Amy Rosenson (my sister and Jordan's aunt) alongside us, as we spoke in front of the group of over 100 student council members and teachers. The presentation was difficult and it was hard for each of us to get through while we were thinking and talking about Jordan, but it was a success and earned us a spot in the final two. Next, came the 3 minute video. It could only have two speakers and Shayna quickly took charge again. In addition, to being in the video, she helped create the script, photo montage, and edits. She did an amazing job!

On September 9th, all DHS students and teachers were shown two videos, ours and the other finalist group, and were given the opportunity to vote. We were on pins and needles waiting for the results. That afternoon, we received the phone call that PAF was chosen as the recipient of this year's fundraiser at DHS. Having the support of School Chest means so much! Not only will we be able to look forward to three weeks of fun events including a 5K run/walk, benefit dinner, bake sales, and even DHS Idol, but it is a time when the entire community will get involved to raise funds, awareness, and hope for our PAF families.

None of this would have been possible without Shayna's dedication and take charge attitude. She has truly honored Jordan's memory with her work on behalf of the PAF. -Jill Franks

In Memory of Jordan Franks



January 28, 2000-
June 26, 2016

(Page 6)

INSIDE

KRAUS STUDY UPDATE	2
GENETICS ARTICLE (PART 2)	3
LUCY'S STORY	4
CADY'S STORY	5
FUNDRAISING UPDATE	6
IN MEMORY OF JORDAN FRANKS	6
PAF ANNUAL REPORT	7

MISSION: The Propionic Acidemia Foundation is dedicated to finding improved treatments and a cure for Propionic Acidemia by funding research and providing information and support to families and medical professionals.

VISION: To create a future where Propionic Acidemia can be prevented and any affected individual can be cured and live a productive life.

STUDY UPDATE: ENZYME REPLACEMENT THERAPY

Progress report on PAF grant for “Enzyme replacement therapy for propionic acidemia”.

Jan P. Kraus, Ph.D.

Propionyl-CoA carboxylase (PCC) deficiency causes propionic acidemia (PA). PCC is a complex mitochondrial matrix protein composed of pairs of nonidentical subunits. Human PCCAB is an $\alpha_6\beta_6$ heterododecamer of ~800 kDa. The subunits are translated in the cytoplasm as larger precursors, imported into mitochondria, the N-terminal leader sequences are proteolytically removed and the mature enzyme is assembled. We have been expressing the human PCC subunits in E.coli, the bacteria adds covalently the PCC cofactor biotin to the α subunits, and a fully functional mature enzyme is produced. The bacterial expression occurs in the presence of a second plasmid encoding the molecular chaperone GroES/EL. PCC is purified to homogeneity in a 2-step procedure.

Currently, there is no cure for PA and treatment provides only partial alleviation of the symptoms. Enzyme replacement therapy is a therapeutic approach in which the deficient enzyme is replaced by recombinant active protein. However, the ability to specifically deliver PCC to the mitochondria presents a challenge. One strategy for delivering proteins into cells is to fuse them with protein transduction domains such as the human immunodeficiency virus activator of transcription (TAT) peptide. Our recent unpublished findings are that we can posttranslationally modify

covalently a cysteine residue(s) on the purified enzyme with a commercial preparation of the TAT peptide or a mitochondrial penetrating peptide (MPP), and the modified PCC is then added to the tissue culture medium of control or PA patient fibroblasts. Following the incubation, the cells are washed with PBS, lysed and enzyme activity is measured. Exposure of the PCC deficient fibroblasts to TAT-PCCAB leads to a large increase of PCC activity from less than 1% to ~ 400% of control.

Staining the patient’s cells with fluorescent anti-PCC antibodies, following the PCC import, showed positive staining of the cells including mitochondria. Measurement of metabolite levels in mutant cell extracts showed normalization of the propionyl- to acetyl-carnitine ratios.

In addition, we have carried out import of MPP2 modified PCCAB into isolated mutant mouse mitochondria, followed by trypsin treatment of the mitochondria with trypsin and shown that we have imported active PCC into the mitochondria where the enzyme was protected from trypsin. The PCC activity in the mitochondrial extract far exceeded the original residual mutant activity and was even higher than an activity of an extract prepared from wt mitochondria.

Import of the MPP2 modified PCC into patient cells followed by staining of the cells with PCC antibodies and with mitotracker, a mitochondria specific stain, revealed that the two stains overlap thus documenting proper targeting of the enzyme to mitochondria.

PA MIX-UP

nmoiaam	-----	apydmcyoihtora	-----
estkoen	-----	lmfuaro	-----
eenmyz	-----	ecitnrain	-----
vreeeicss	-----	ptaonyiho	-----
neeg	-----	caid	-----

Answers (out of order) : enzyme, gene, ketones, ammonia, hypotonia, acid, cardiomyopathy, formula, recessive, carnitine

The Propionic Acidemia Foundation Newsletter is designed for educational purposes only and is not intended to serve as medical advice. The information provided should not be used for diagnosing or treating a health problem or disease. It is not a substitute for professional care. If you suspect you or your children may have Propionic Acidemia you should consult your health care provider.

The Propionic Acidemia Foundation does not recommend nor endorse any particular products, companies, or manufacturers.

PA GENETICS, PART 2

Prenatal diagnosis is a way for your doctor to determine if your baby has a certain condition, such as Propionic Acidemia, before the baby is born. In order to detect Propionic Acidemia in a baby, the laboratory needs to know the specific genetic mutations causing Propionic Acidemia in a family member. It can also test for more common genetic disorders, such as Down syndrome, which can occur in any pregnancy. Lastly, prenatal diagnosis can tell you the gender of the baby if that is information you want during your pregnancy. There are two traditional ways to undergo prenatal diagnosis.

The first method involves analyzing the DNA in cells from the placenta. The cells are gathered from a procedure called **chorionic villus sampling or CVS**. A CVS can be done two ways, one involves inserting a catheter through the cervix and the other is performed by inserting a thin needle through the abdomen. Both methods obtain a small sample of the placenta to perform the genetic test. A CVS can be performed from 10-13 weeks into the pregnancy. Results take approximately 7-10 days depending on the laboratory. There is a small risk of miscarriage associated with the procedure which varies from center to center, but generally <1% (<1/100).

The second method is called **amniocentesis** and analyzes the baby's DNA from cells present in the amniotic fluid (normal fluid that surrounds the baby in the womb). The procedure is performed by inserting a thin needle through the abdomen to obtain a sample of the amniotic fluid. An amniocentesis can be performed after 15 weeks into a pregnancy. Results take approximately 10-14 days to come back depending on the laboratory. There is a small risk of miscarriage associated with the procedure which varies from center to center but generally <0.5% (<1/200).

Both CVS and amniocentesis have the same degree of accuracy for genetic testing. The main difference between the two procedures is timing of when testing takes place during pregnancy and the difference in miscarriage risk, with risk associated with amniocentesis less than the risk associated with CVS.

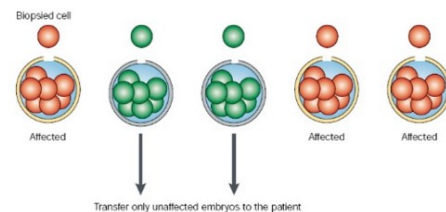
There is a newer technology used for prenatal diagnosis called **pre-implantation genetic diagnosis (PGD)**. Instead of testing an ongoing pregnancy, PGD works by testing DNA from embryos before they are implanted into the uterus. The embryos are created through standard **in vitro fertilization (IVF)**, the process where an egg is fertilized by a sperm in a laboratory instead of in the woman's uterus. At an early embryo state, 1 – 2 cells are safely taken from the embryo and used to analyze the DNA for the genetic disorder. The embryos without the genetic disorder are then implanted into the mother's uterus.

If you are interested in learning more about traditional prenatal diagnosis or preimplantation genetic diagnosis, we recommend that you meet with a genetic counselor to discuss these methods in greater detail.

Robyn Hyland
Genetic Counseling Student
Northwestern University
Graduate Program in Genetic Counseling

Preimplantation Genetic Diagnosis

- **Definition:** "A process which allows parents to have the option of detecting potential defects in an embryo within days after conception."



Publication Note: The PAF Newsletter is published twice a year. Readers may subscribe by writing to PAF, registering online or calling 877-720-2192. Letters and article submissions are welcome for consideration and may be sent to paf@pafoundation.com or mailed to Propionic Acidemia Foundation 1963 McCraren, Highland Park, IL 60035. If you would like to be removed from our mailing list or receive the newsletter via email, please contact us.

LUCY'S STORY



My name is Lucy And I have PA. I am 18 years old and graduated High School in May. I also have: Autism, Aspergers, Prolong QT Syndrome, and some intellectual disability. All of these things make some parts of my life difficult for me to handle. Sometimes when I have to go through certain things like my health problems it can get a little stressful for me. However I am so happy that even though I am the only person in my family who has special needs

whatsoever, my family and all my cousins love me a lot anyways and they love having me around. Now I want to tell you a little bit about my family. Besides my parents I have: two siblings, a dog and two cats.

Out of everything I do for physical activity my favorite would definitely have to be Ballet Dancing. I started doing Ballet at the age of 3. I am now in a Special Needs dance class.

In July 2015 my mom and I traveled with my cheer team to Los Angeles for the Special Olympics world games. We cheered for athletes at lots of the sports events and we got to perform our routines. We became celebrities, we were on the news, people stopped us everywhere for pictures and autographs. It felt really cool to be famous. I also did Rhythmic Gymnastics for a couple years for Special Olympics as well, and I won lots of gold metals. I also do a Special Needs beauty pageant every year in April. In 2014 I won the whole pageant and I got crowned as: Young Ms. Fabulous. I got to ride on a float in the Christmas parade downtown that year in December. I was freezing!!!! However I thought that was really super cool!, because I had never done anything like that before.



I have a collection of 24 American girl dolls. I still play with them constantly when I am not at school, and it's my favorite hobby. When I play with them it relieves a lot of my stress. In middle school people made fun of me for playing with them at my age, but now I just overlook those people, because it's what makes me happy. My favorite thing to do with them is brush out and style their hair. Especially with braids

As far as school goes I am really good at math. I have taken high school Algebra and Geometry. I was definitely better at algebra. I was in a resource Special Ed English class, because I can't comprehend that well when I read. I can read very well, but I can still often comprehend at about a 3rd or 4th grade level, so I choose to often read those books so that I can actually enjoy the story.

When I was a Junior I went to my school prom for the first time. I took my friend Niki to the prom with me because I didn't want to go with a guy. When I went to prom it was not like I had imagined it being, but I thought it was so cool and I was overly excited to be

going!!!! I danced that whole night constantly. But by 11:00 pm I was ready to drop and I fell fast asleep on the way home.

Some children & teenagers who have a disability don't have very many friends or any at all. I consider myself lucky because I have a whole lot of friends. And they have all been also very supportive of me having a disability and this health condition.

My Summary: The older I have gotten the more I have been able to do with taking care of myself and my diet. I can now make my own formula with supervision and I can do all of my own tube feedings. I only use my tube for my formula. The more we have learned about my daily values, the more choices I have to eat regular food at school during lunch and when I am out with my friends. Some of the things that I eat are: apples, bananas, grapes, blueberries, raw tomatoes, carrots, broccoli, asparagus, green beans cooked mushrooms and onions, fried pickles, pickles, sweet potato soft pretzels, salad, macaroni and cheese, popcorn, crackers, pretzels, goldfish, fruit chews. Candy: mint chocolate, Sour Patch, Jolly Ranchers, suckers. My favorite food is Spaghetti. I am also able to keep track of all of my daily values using an app on my phone Myfitness. I get more independent all the time.

I graduated in May from high school. For my career I want to take care of as many children as I possibly can with all kinds of different special needs and disabilities. I want to help them learn and grow just like other normal children. To make this happen, I will be working with Vocational Rehab to explore future job possibilities and the further education I will need to do these jobs.

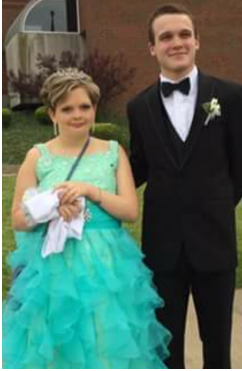
To sum it all up I have to face a lot of challenges in my life especially with learning because of my cognitive delays and learning disability. I always try to put forth all the effort I've got in everything I do.

And in general I am a very caring and compassionate person. Everyone in my family and at school tells me all the time you are an extremely good friend. I think they are right about that. Having a disability makes it so that unfortunately I am a little less mature in some ways than other people my age. But sometimes I feel like that is what makes me who I am and also what makes me special. A lot of people have told me throughout my life in high school that I am a really strong girl. I really do try to be strong even when I don't feel that way, but sometimes I have no other choice. I am a very smart and determined teenager.

I am always determined to do whatever makes me most happy in life. The motto I have for myself is: "You can do anything you want to as long as you stay strong and put your mind to it. With faith all things that you want to happen in life are possible you just have to believe in yourself." I plan to use this quote for the rest of my life.



CADY'S STORY



I'm not sure where to start with this update, it seems that Cady has been around forever, that this life has been going on since the beginning of time, and yet I can't believe I'm 43 and Cady has hit 20 years old. Back in 1996 when she was born, I was told that she wouldn't see two months, let alone 20 years. Those times, vivid as they are, seem so far away. And yet, how could two decades have passed?

For those of you new to the PAF (at least since our last update) I'll just recap from

the beginning. Cadence was born on June 15, 1996 in a small hospital here in northern WV. Everything seemed fine the first two weeks, until one day Cady would not wake up for me. I rushed her into the local ER and things only became more grave from there. She was sent out to WVU Children's Hospital, but with a pretty clear warning that she wouldn't make the hour and half journey. Well, she made it, but things continued to be pretty bad for a while. That summer we spent 32 days at Children's, much of that time being on a tightrope of whether she'd make it to see another day. Hers was the first case of its kind they'd seen at WVU, and the medical staff there had pulled out all the stops to keep her alive. After 32 days, we knew what ballpark we were in, if not which disease we were dealing with, and she was stable enough to come home. During her time those 32 days, fibroblasts were grown and sent away for assay. The result came back after Cady was home about two weeks.. She had Propionic Acidemia. She was the first child ever born in WV to survive to diagnosis. To this day, 20 years later, she is still the only survivor born here.

Things were kinda woogy for the first two years, but she stabilized out and we led a pretty uneventful life until she was 12 years old. Then in the summer of 2008, she became ill and the rules seemed to change. We had no idea why she kept decompensating. It took what seemed to be forever figuring out how to treat these decompensations. During the winter of 2009, she spiraled so badly that it really looked like we'd lose her. She made it through that episode, but lost most of her hearing to the wild electrolyte swings and crazy blood chemistry. Finally, her GI specialist got her started on a flagyl regimen and that seemed to help. It didn't stop the decompensations, but it did seem to fight them back a little.

In 2012, Cady became the Children's Miracle Network Champion Child representing the state of West Virginia. It was a busy year, with many ups and downs. That was the year she turned 16, and also the time her doctors decided to look at her growth. They did a bone age study and at 16 years old, Cady's bones were aged at 144 months (exactly 12 years). Her plates hadn't closed yet, and there was some discussion about putting her on growth hormone to get more growth out of her before they fused. We tried it, and she absolutely flourished. The reaction was immediate and dramatic.



Her appetite increased, she had more energy, better muscle tone.. it seemed growth hormone was a wonder drug for her. But she took to it a little too well and it swelled her brain in a condition called pseudo-tumor cerebrii. The pressure in her skull was crushing her optic nerve, threatening to blind her. I couldn't stand the idea of that... this disease was picking my baby apart, first her hearing, now her sight. We stopped the growth hormone and put her in the ICU. She had to be started on Diamox, which is a cerebral diuretic. The problem with Diamox is that it causes hyperammonemia and bicarb wasting at the level of the kidneys (you all know what that means... high ammonia and low pH. Yay, just what we need!) It was a dance with the devil, balancing the need to quickly get the swelling down in her brain against causing a metabolic crisis. Fortunately, it was a dance that we won. No more growth hormone for Cady. Ever. But she kept her sight intact and didn't suffer much more than a metabolic hiccup.

That same autumn, she won Homecoming Princess, voted by her sophomore class. Her classmates had grown up with her since the time they were all four years old. They are very fond and very protective of Cady. She won by unanimous decision.

The last few years, up until this past late Spring, Cady continued to be unstable. I tried different things with her diet, and that would work for a while, but we'd always end up back at square one. We began alternating flagyl therapy with augmentin, which also seemed to help. I was never a fan of giving her flagyl all the time, due to it's black box warning and the fact that I'd like to figure out WHY she's decompensating and stop it instead of just trying to treat it all the time. It appears I've finally hit on the right combination, for Cady, at least. Cady had been orally fed for years, but in light of the fact that she was on the pump with her decompensations about as much as she was off, I decided to put her on the pump exclusively and give her system a rest. I also could find nothing but unproven theories regarding what was going on in her gut, causing these cascades so frequently, but what I did find was that her symptoms seemed to be more consistent with imbalance of gut flora versus over growth. I changed the supplement regimen that she'd been on for years and began using ID Life, which uses a specialized, individualized health assessment to generate a personalized recommendation. There were probiotics in her recommendation, something that her doctors had not wanted her on in the past. These supplements are also pharmaceutical grade, unlike the unregulated, unverified supplements on store shelves everywhere. So, I took the plunge and started her on the new supplementation. All I can say is, WOW. She is stable again, happy, growing like a weed and the healthiest she's been in a decade.

She also attended prom this year, her Senior year. She was once again the darling of her classmates' eye, as they voted her Prom Queen. A couple of weeks later, and in defiance of every odd levied against her when she was two weeks old, she graduated high school... with honors.

I cannot convey how very proud I am of her, of how blessed I feel to have walked this journey with her, nor how humbled I am that I was chosen to be this very special child's mother. She makes me proud every single day. -Leslie Pierce, Mom to Cadence, 20, Propionic Acidemia, and DJ, 17, Autism

PAF EVENT & FUNDRAISING SPOTLIGHT

PAST EVENTS & CAMPAIGNS:

- Matz Family Garage Sale
- Ohio Families 11th Annual Tailgate Party & Corn Hole Tournament— Raised \$7,500 (and counting!)

UPCOMING/ONGOING EVENTS

- PAF Annual Giving Campaign
- Deerfield HS School Chest, Illinois
- Fundraiser Crop, October 22, Ohio

CORPORATE MATCHING GIFTS AND VOLUNTEER HOURS DONATIONS:

- **Corporate Matching Gifts** may enable you to double your donation. Check with your HR department to see if they match. It makes a big difference.
- **Volunteer Hours:** Some companies have a volunteers program and will donate based on your volunteer hours. PAF is always looking for volunteers. Please check with Human Resources to see if they have a program.

ONLINE TOTALS RAISED TO DATE:

- Igive: \$4,516.47 (FY 2015-2016, \$301.71)
- Goodsearch: \$1410.98
- AmazonSmile: \$146

DEDICATED GIFTS FROM INDIVIDUALS:

Among the many contributions received, the following is a list of some that were dedicated to those who have inspired the giver.

- **In Honor Of:** Administrative Professionals Day (Ann Marie Young), Gwen Mouat, Allison Ellis, Zach Matz
- **In Memory Of:** Connor McKillop, Sean Patrick Callahan, Courtney Leigh Callahan, Jordan Franks, Kerrie Fessler, Wesley Jones, Bobby Joe Utley, Vincent Franze

If you have anyone you would like to have us add to our campaign, please e-mail paf@pafoundation.com

IN MEMORY OF JORDAN FRANKS 1/28/2000– 6/26/2016

Jordan was surrounded by people that loved and cared for him including family, friends, medical providers, teachers, and therapists and he loved them back. Jordan touched so many people and has made our world a better place. Jordan was smart - he decided within minutes of meeting you what song he would like you to sing: "ants go marching, down on Barney's farm, wheels on the bus, head-shoulder-knees-and-toes" to name a few.

Jordan was a happy teenager. He would often say "I am happy" over and over on his talker as if to let us know he was okay. When we hid that button, he chose to start repeating "I am excited" as opposed to the other options of "ok", "mad", "sad", or "frustrated".

Jordan was an athlete. He had his father's athletic ability and loved participating in boxing, soccer, baseball and a variety of buddy sports. He particularly loved the ladies. He usually had a harem around him and would "collect" the girls (blondes, brunettes and redheads). Jordan had an interesting way of playing catch, and he had crazy ball skills and could consistently throw or kick the ball just beyond your reach, have you retrieve the ball, throw it back to him and the same process would repeat again. He had uncanny hand-eye and foot-eye coordination. He also loved bowling and basketball. Jordan's home is full of balls on every level and Jordan loved playing soccer and bowling in the basement and basketball in his bedroom. There is a rather long hallway in our house and Jordan would love to kick the ball to family and have it kicked back throughout the day.

Like his brother, Jordan was a scientist and taught himself by experimenting with gravity while throwing things over the 2nd floor balcony: computers, 27 inch monitors, ipads, ipods, socks and



underwear. Jordan like most teenagers could multitask with the best of them. He could be watching TV, playing Tiger Woods Golf on one iPad, listening to his favorite videos on another iPad, listening to his other favorite songs on an iPod while playing music on his CD player at the same time. No matter where we would hide his devices he somehow would find them and then, hide them from us and then we would all work together to try and locate them together. Most recently, I thought I could leave my laptop out and open without fear of Jordan closing out my work or our browsers by simply removing the mouse. Not to my surprise Jordan taught himself how to use the laptop touchpad to find his favorite videos (usually Barney) on YouTube.

Jordan had the opportunity to attend Prom. Jordan loved his friends from high school and had the opportunity to spend time with his cousins at school. We have received letters from his friends talking about how Jordan taught them about unconditional love, patience, and being a friend. Jordan truly impacted the lives of many.

Our family would spend time at the Botanic Gardens, Six Flags Great America, going on vacations, and even several cruises with extended family. Jordan's favorite activity was "Barney Live" at Universal Studios. We would watch the show over and over and over and over. Jordan enjoyed spending time at the beach. He would love throwing rocks and sand in the water, walking into the water, sitting near the shoreline and letting the waves splash him.

We would like to thank all of our amazing family and friends that have been making this very unbearable situation a little less unbearable due to their love and support. -Love, Jill, Steve and Ryan

PAF FY 2015-2016 ANNUAL REPORT

FINANCIAL REPORT

Revenue:

Contributions:	\$95,753
Royalty Income	\$6,400
Grant Reimbursement	\$443
Interest Income:	\$151
In Kind Donations:	\$1,372
Total Revenue:	\$104,119

Expenses:

Programs:	\$15,860
Printing (in-kind):	\$1,372
Fundraising:	\$542
Management & General Expenses:	\$1,948
Total Expenses:	\$19,722

Cash Assets 8/1/2015: \$142,353

Cash Assets 7/31/2016: \$226,749

Note: Off \$1 due to rounding

PROGRAM ACCOMPLISHMENTS

- Distributed fall and spring newsletters to affected families, clinicians, and donors
- Participated in PROP Nutrition Guidelines Nominal Group Meeting
- Attended and exhibited at 2016 SIMD Meeting
- New Website

BOARD OF DIRECTORS/OFFICERS

Jill Chertow Franks, President
 Brittany Smith, Treasurer
 Angela Waits, Secretary
 Maria L. Cotrina
 Ann Marie Young

Board Disclosure: Donations from Board Members totaled \$380

The PAF is pleased to share that through the research efforts that we have funded, a company is attempting to develop a product. As a part of the agreement with our researchers when the PAF funded their research grant, the PAF has a right to share in any proceeds the University of Colorado receives from its licensee as the licensee works to develop a product based on the research. As a result of this, the PAF has received a royalty payment from the University of Colorado as this company works to develop a new treatment for PA. This royalty payment is noted in our annual report for FY 2015-2016. Just as the initial research projects took time, product development does as well. A product may or may not come to market, but in the meantime the PAF will use the royalties to operate the foundation and pay for additional research and outreach activities.



Thank you for all donations and the kind notes we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration. PAF couldn't do what we do without your incredible support.

We want to hear from you! Have a PA story to tell, event to promote or news? Fall newsletter submissions due by February 28, 2017!

Help Us Find the Cure!

Name _____ Address _____ City, State, Zip _____ Phone _____ E-mail _____	Please send an acknowledgement to: Name _____ Address _____ City, State, Zip _____
--	---

Enclosed is my contribution of \$ _____ in honor of/in memory of _____

If you work for a company that has a matching program, please include the matching form.

Please mail your check made payable to: Propionic Acidemia Foundation 1963 McCraren, Highland Park, IL 60035

Thank you for making a difference.

SEARCHING FOR A CURE
HOPE FOR OUR CHILDREN

Propionic Acidemia Foundation
1963 McCraren Rd.
Highland Park, IL. 60035



Phone: 1-877-720-2192 toll free
Fax: 1-877-720-2192
E-mail: paf@pafoundation.com
Website: www.pafoundation.com

PROPIONIC ACIDEMIA FOUNDATION

Board of Directors

Jill Chertow Franks, President
Brittany Smith, Treasurer
Angela Waits, Secretary
Maria L. Cotrina
Ann Marie Young

Newsletter Gold Sponsor

Nutricia North America

Medical Advisory Board

Gerard T. Berry, M.D.
Barbra Burton, M.D.
William Nyhan, M.D., PhD
Mendel Tuchman, M.D.

Newsletter Committee

Julie Howard
Toni McKinley
Dave McKinley
Jennifer Mouat

Fundraising Committee

Amy Rosenson
Shayna Rosenson

**PAF volunteers and
board members
are needed!**

paf@pafoundation.com



Join and follow
Propionic Acidemia
Foundation on Facebook

Please email
paf@pafoundation.com to join a
committee.