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**What's New at the APF**  
www.porphyrifoundation.com

**Is Your Membership and Contact Info Up to Date?** The APF is able to maintain our physician and patient education programs and many other services because of your support. Since we do not receive government funding, we need your support and donations. We also need your new contact information if you have a new address or email. Be sure to send us your email address so you can receive the ENEWS.

**Follow the APF Purple Light Blog!** It is administrated by Amy Chapman, who has been our longtime member and longstanding volunteer. This blog is dedicated to all the Porphyria patients worldwide and contains the latest news from porphyria world. You are welcome to join: <http://porphyrifoundation.blogspot.com> Also, don't forget to follow us on Twitter: [https://twitter.com/Porphyria\\_Help](https://twitter.com/Porphyria_Help)

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**CHRISTMAS GREETINGS, HAPPY HOLIDAY AND HAPPY NEW YEAR**

*The APF staff sends you greetings for this Christmas and Holiday Season. We also wish you happiness and good health in the coming New Year. It has been our joy to meet many of you and become fast friends. You are all important to us, so we hope that you will reach out to the APF office for all of your porphyria needs. We are there each day for one reason, YOU.*

**A GIFT OF HOPE** EXCITING NEWS!!! We have been given the gift of hope. We are very proud to announce



that The Porphyria Research Consortium has won a \$4.4 million grant to conduct eight research projects from the National Institutes of Health (NIH) Rare Disease Office. Considering there are over 7,000 rare diseases and only 30 rare disease grants awarded, this was an enormous feat. Drs. Robert Desnick, Karl Anderson, John Phillips, Herbert Bonkovsky, Joseph Bloomer and Montgomery Bissell deserve our heartiest thanks for their monumental effort to attain this prestigious grant. Now they need research patients to partici-

pate. Every person with every type of porphyria is needed as a research volunteer. Some projects require you to take an experimental treatment, while others require only that you send your blood and fill out a lengthy questionnaire that you will update over several years. This form is extremely important to the understanding of porphyria, including why the pain associated with the disease is so severe, and why some people have symptoms and others don't. YOU are the KEY to research and RESEARCH is the KEY to your CURE. Please take this seriously and ponder or pray or whatever you do to come to a decision about critical decisions.

**New treatments cannot be discovered without YOU.**

Some projects require that you fly to the research center and others do not involve any travel. You can stay right in your own home. All of your travel expenses will be paid. You will also receive DNA testing. If you have insurance, your insurance will be billed, but you will not have out of pocket expenses. If you do not have insurance, your DNA testing will be free to you, which is normally a very expensive process. The research parameters for acute porphyrias require that you have a definite diagnosis and frequent attacks. In one such research project, you will need to have suffered at least three attacks in a year. Requirements for EPP and PCT are that you have a definite diagnosis. To become a patient volunteer, please contact Natalia at the APF office by calling 866.APF.3635. You can be a Medical Hero. **Please volunteer for research!!! It only takes few days of your life to participate and will improve the health of you and your family now and in the future. RESEARCH IS THE KEY TO YOUR CURE!**



**A SPECIAL GIFT** One of the attendees at the recent patient meeting in Florida was young **Kylie Moczynski**, whose sister, Alicia, received a stem cell transplant for EPP. Therefore, Kylie knew firsthand the value of research. And because of that, she wanted to help fund research. We at the APF are very grateful for all the gifts we receive, but when they come from young people, they are particularly special. When Kylie attended a singing group event over the summer, the attendees were awarded with a monetary gift. Kylie received her winnings and pre-



sented her donation to support research during the patient meeting in Santa Rosa Beach, Florida. Her sister, Alicia, was extremely ill with EPP and recently received a stem cell transplant for EPP. Her care was overseen by Dr. Joseph Bloomer at the University of Alabama, who is one of the leading experts/researchers in the world. After the stem cell transplant, Alicia is now healthy and free of EPP. Research made her stem cell transplant possible. Research has brought a new treatment for EPP and research is being conducted for more treatments for all other porphyrias. Thank you, Kylie, for your gift to the APF research program.

Your gift is very special, too. Whatever you decide to donate in terms of your time or your finances is sincerely appreciated. Every person is needed, because the APF is not merely an office or an organization, rather, the APF is all of us. You are the key to everything we do at the APF. Together we can continue to make an enormous impact on physician and patient education, research and training new doctors to treat and diagnose the porphyrias.

## **CME COURSE Acute Intermittent Porphyria: A View From The Trenches.**



Continuing Medical Education (CME) courses are required for physicians to maintain their educational requirements to retain their continued licensure. Content for these programs is developed, reviewed, and delivered by faculty who are experts in their individual clinical areas. Many of these courses are now online, so the physician can take the course at home or office. Over the past five years, Medscape has maintained a number of CME courses on porphyria, all of which featured members of the APF Scientific Advisory Board. The courses are complimentary and provide required CME credit to the physician. We are pleased to announce that the newest Medscape CME course on the porphyrias was released in late September. The course, called **Acute Intermittent Porphyria: A View From the Trenches**, featuring moderator, Dr. Herbert Bonkovsky and the two presenters, Dr. Lisa Kehrberg and Dr. Brendan McGuire. Dr. Bonkovsky is an esteemed figure in the world of porphyria having been an expert and researcher in the field for thirty years. In fact, Dr. Bonkovsky was the first doctor to have ever given hemin therapy. Dr. McGuire, who is head of Liver Transplant at the University of Alabama, trained as one of the **Protect the Future** doctors with his mentor, Dr. Joseph Bloomer. As an experienced porphyria expert, Dr. McGuire expanded on the key points of diagnosis and management of AIP. In addition, he noted the little known data about the number of kidney transplants, hepatocellular carcinoma cases and other pertinent facts about AIP. Dr. Kehrberg offered a different and extraordinary perspective, because she was recently diagnosed with AIP after a long series of misdiagnosis. Since Dr. Kehrberg had suffered the pain of a porphyria attack, she was able to convey the intensity of the pain during an attack, as well as discuss the chronic pain that can follow. Dr. Kehrberg also has received Panhematin® with the twofold purpose of stopping the attack and taking a weekly dose to prevent an attack.

The goal of this course is to improve a physician's ability to recognize, diagnose, and initiate appropriate next steps for patients with Acute Intermittent Porphyria. Since the other acute porphyrias, VP and HCP have the same symptoms, they also have the same treatments. Your doctors will greatly benefit from this course.

Please advise your own physician about this free CME course granting free CME credit. If your doctor is not in the APF database, please send your doctor's name and address and email if you have it. Your doctor will then receive a doctor's packet, which includes the CME announcement card, as well as ENEWS updates and other information pertinent to physicians. Remember, the CME course is free, so your physicians will receive free CME course for CME credit. You, too, can learn more by watching the video by joining the complimentary Medscape online site:

<http://www.medscape.org/viewarticle/831382>

## **TV IS HAPPENING** Porphyria is happening on television in the near future. **NBC Dateline** is filming a program



about EPP and other photosensitive conditions. Camp Discovery, a summer camp for kids who can't tolerate sunlight, was the site of their filming this summer. They also filmed at the home of Kristen Wheeden, whose son has EPP.

Next, **PBS** will be filming a documentary about the acute porphyrias featuring Dr. Karl Anderson at the Porphyria Center at the University of Texas Medical Branch and Dr. Lisa Kehrberg, an AIP

patient. We are very excited about both videos, because television is a major means to promote public awareness about the disease.

Additionally, Dr. Kehrberg will also be featured in a new program on the **Discovery Channel** called **Diagnosis Unknown**. It was filmed recently and the broadcast date will be announced in the APF ENEWS. The focus of the program is on the long journey to diagnosis and how people cope after finally receiving appropriate medical treatment. One of the means Dr. Kehrberg uses to cope is by focusing on how to help other people with porphyria. She has volunteered her time not only to do videos, but to talk with patients who need help understanding medical information and complex research questions. She and her entire family also helped promote the recent Facebook Pie Challenge. Lisa and her family also will be hosting the **Shadow Ride** on her mother and father's Oklahoma ranch.

The APF will announce the broadcast dates of all the programs on the APF internet update ENEWS. If you do not receive the ENEWS, please contact the APF office at 1.866.APF.3635 or [porphyrus@aol.com](mailto:porphyrus@aol.com) and give them your email address. If you have not joined the APF and want to be a member, please ask for an educational packet.



Don't forget the APF BLOG, Facebook, Twitter, Newsletter and E-NEWS. Also, register for all the social media on the APF website: [www.porphyrifoundation.org](http://www.porphyrifoundation.org). Please note that we need your stories for the Members Stories section of the website. People enjoy reading the experiences of others. If you are willing, we would like to have your porphyria experience and will publish it in the website and/or Newsletter.

## **ROCCO FALCHETTO EPP** A portion of his story follows: *Sometimes the pain takes hold of the psyche and*



*then takes over your life completely. At such moments, I have often wished that my illness could somehow be more apparent to others. Sometimes when I am treated with condescension because the pain - which feels like boiling oil on my skin - is not visible, I think about people who are blind or paralyzed. Nobody doubts a person's disability when they see them with a white stick or a wheelchair. Thoughts like this are irrational - of course I am thankful that I don't suffer from the additional problem of a visible disability. Despite this, the disease has a significant effect on my*

*quality of life and it is hard to get away from the negative mindset - especially when doctors downplay the symptoms because they don't know what they are talking about or as a result of their lack of specialist knowledge about the illness. I always get angry when I hear similar stories from other sufferers. While I would like to experience more understanding and sympathy for my condition, I can't stand pity at all. I have the disease, but Rocco Falchetto is not the disease - he is much more than that. While my illness has partly shaped who I am today, I still lead a fulfilling life and have achieved things that I can be proud of. This is another reason why it is so difficult for me to talk about it. People should get to know me first without knowing anything about the illness. However, I now know just how important it is to tell my story.*

Read about Rocco's childhood, his long path to acceptance, and hope for a normal life. Also read introduction to the new experimental treatment that became Scenesse® and the great success and then the difficulties surrounding the drug's approval. Rocco says, "It is high time that society takes the needs of sufferers of rare illnesses and diseases into account and the difficulties we face in finding treatments." Read Rocco's entire story on the APF website or at: <http://www.novartis.com/newsroom/feature-stories/2014/09/no-longer-living-in-fear.shtml>

**DIAGNOSINGAIP.COM** If you would like to view a great site in addition to the APF website, check out [www.diagnosingaip.com](http://www.diagnosingaip.com) It explains AIP, the signs and symptoms, the tests, the experts recommendations, and much, much more. The site includes a number of videos, including two CME courses: **Acute Porphyrias Recognition Through Follow Up and The Management of Acute Porphyrias Through Follow Up**, as well as a webcast entitled, **AIP, An Educational Webcast for Emergency Care Providers**.

You can also download the following articles of great interest: **An Approach to Identifying and Managing Attacks of AIP, Physician Information on Diagnosing AIP** and **Frequently Asked Questions about AIP**.

Please also let your doctors know about this website. It simplifies testing for AIP and basic testing for all acute porphyrias. It is very important for us to lead doctors to the best educational materials available. Although they are not happy for us to hand them a stack of articles from the website, we can give them links to see or ask that such articles be added to our medical record.

**GIVING MADE SIMPLE TEXT YOUR DONATIONS** Our new Donations System makes it easier to donate to the APF. You can now make a donation via text or online giving.



### **Text Donations using your Smart Phone:**

Simply text the amount you wish to donate to 281-730-8161.

Example: \$5 or 5= \$5.00, \$10 or 10 = \$10.00, \$100 or 100= \$100.00, \$1000 or 1000 = \$1,000.00.

Choose any \$ amount you wish to donate. You will then be sent a link for a one time registration for text donations. Once you've registered, your future donations are completed by simply texting the chosen gift amount to 281-730-8161. You will receive a text confirmation that your donation were received.

### **On-Line Giving:**

Our new on-line giving is very convenient and allows you to choose where you would like to apply your gift.

Example: In Memory or In Honor of a loved one, or to the Protect the Future (PTF), or physician education, etc.

Just enter the amount you would like to donate on the donate section of the APF website and click the go button.

You then have the option of donating as a guest or register and make it easier for future donations.

You should receive an email confirmation that your donation has been received.

**NEW MEMBERS STORIES** Read the newest member stories from our Members Section on the APF website: <http://www.porphyrifoundation.com/about-the-apf/member-stories>. Rocco Falchetto, Michelle MacMeekheen, Sandra Ihrig, Ryan Taal, Joe Cochran, Ruth Bruno, Evelyn Jacobucci, Amanda Boston, Nathan Carr, Alicia Moczynski, Pernilla Mannson, Oscar Mannson, Megan Davenport, Vickie Gehn, Amy Burke, Shawn Willis and Elyse Adam.

**APF PARTNERSHIP Association of American Medical Colleges** The Academic Medicine is the official, peer-reviewed journal of the Association of American Colleges. Recently, the editor asked Desiree Lyon Howe, APF Director, to write an article about the relationship between the APF and the Porphyria Research Consortium because the synergistic relationship between the two is widely recognized and admired. Desiree was thrilled to be able to share how the cooperative efforts of the APF and the Consortium enhanced the research and educational projects of both. Her article, **Porphyria Research Consortium: A Partnership Between the American Porphyria Foundation and Physician Researchers** was published in their website: <http://academicmedicineblog.org/the-porphyrria-research-consortium-a-partnership-between-the-american-porphyrria-foundation-and-physician-researchers>

**GREAT NEWS** Congratulations!! Australia's Clinuvel Pharmaceuticals Ltd recently announced that its drug SCENESSE® (afamelanotide) has received its first approval from the European Medicines Agency (EMA) to treat EPP. The EMA's Committee for Medicinal Products for Human Use (CHMP) voted in favor of marketing authorization for SCENESSE® under exceptional circumstances for EPP. The first of five trials of SCENESSE® for EPP started in 2006, with Clinuvel pioneering the development of a new formulation of the drug, and designing and executing an entirely novel clinical program for EPP. SCENESSE® is the first drug developed by an Australian company and taken from novel molecule to marketing authorization.

"Today's EMA outcome is a landmark achievement by Clinuvel and all those who worked with this program for nearly a decade," Clinuvel's Acting Chief Scientific Officer, Dr Dennis Wright said. "My first thoughts go out to the EPP patients and families who have been asking us for the release of the drug for many years. The life of a patient with EPP is one of social deprivation, punctuated by periods of second degree burns and unspeakable pain following exposure to daylight or bright indoor lighting. For a decade now my team remained motivated by the unique opportunity to provide a product that could be life altering for these patients."

We sincerely thank the almost two hundred patients, who traveled as far away as Alaska to participate in the research project at seven Porphyria Centers and research sites. We extend our gratitude to the researchers who devoted their time and energy far above the usual requirement for such a project. Please accept our heartfelt thanks. Lastly, we thank all of you who helped the APF in this monumental effort to gain approval for Scenesse® and provide a normal life for those with EPP. HOOORAY and Congratulations to all of you. Now that the drug is approved in Europe, it is time for the FDA to approve the drug here in the USA. So many of you have contributed letters and testimonies of your experience on the drug and your poignant letters of why EPP people need Scenesse®. Desiree will take your letters again to the FDA and will again bring a group of EPP people with her. Patients can soon toss off their hats, gloves, long sleeve and coverings and step out in the sunshine pain free. WE will PREVAIL!

**DR. CYNTHIA LEVY** We welcome Dr. Cynthia Levy to our **Protect the Future (PTF)** program to train the next generation of experts. It is one of the most important programs of the APF. As our porphyria experts begin to retire, they must be replaced with young doctors who have gained expertise by training with the foremost experts in the country. The APF **Protect the Future** program addresses the shortage of physicians and scientists and lack of knowledge about porphyrias among physicians, patients and the general public. Dr. Cynthia Levy is our newest PTF physician. She has been practicing medicine for 19 years. She graduated from the University Fed De, Rio De Janeiro, Brazil and practices medicine now in Miami, FL at the University Of Miami Hospital and Jackson Memorial Hospital, specializing in Hepatology. Dr. Levy is board certified in Gastroenterology, Internal Medicine and Transplant Hepatologist and is an Associate Professor of Medicine at the University of Miami Hospital.

**These young doctors are the ONLY experts that will be left in the country. YOUR future health depends on their continued training. This cannot be accomplished without funding. Please consider a special donation to the APF to train an expert. Aside from their general training, they will be attending a training week at the University of Texas Medical Branch with all the Porphyria Research Consortium and other young PTF doctors. Please help us bring all of these PTF doctors to the training week.**

**DOCTOR'S PACKET** One of the most important projects of the APF is physician education. You can do your own awareness and education project by asking the APF to send your doctor a very comprehensive packet. The packets are complimentary and are written by porphyria experts. It also includes information on the CME courses and the *Annals of Internal Medicine* article on treating porphyria. Order yours NOW.

**PATIENT MEETINGS** In a few short months, the APF hosted three patient education meetings with more to come next year. After the Baltimore and West Palm Beach meetings, we decided to increase the number of patient meetings we would host each year. In September, we held a meeting at Desiree's home in Santa Rosa Beach, Florida. Families gathered to exchange stories and learn about upcoming research and the many programs of the APF. One of the participants, Alicia Moczynski, shared her story of discovery of her diagnosis of X-linked EPP and her subsequent bone marrow transplant. After the successful implant, she decided to go into medical education at the University of Alabama where she received the implant. Dr. Joseph Bloomer was her doctor and she could not have had enough good things to say about him. Her entire family attended the meeting. Attendee, Joe Harbour, had an unusual story about Hereditary Coproporphyrria (HCP). He was one of nine children and the only one with HCP. Rita and her husband told the group of her many misdiagnoses and the unfortunate times when doctors would not believe the severity of her symptoms. It was a sad tale that unfortunately was similar to so many others. Dr. Lisa Kehrberg, Rose Jeans and Warren Hudson also attended the meeting, as did Alexandra Dice, her mother, Melissa and her daughter, Alise. More meetings will occur in San Francisco and Boston (*next newsletter*).



**A GOD INCIDENCE** When a coincidence is extraordinarily unusual, I call it a God Incidence. Here is one that happened at the patient meeting at my home. When the patients identified themselves and shared their experience, they were all enthralling but one involved me as follows:



About twenty five years ago, while I was still living in Montgomery, Alabama, I received word that a young soldier, Robert Dice, was in critical condition with Acute Intermittent Porphyria (AIP) at the VA hospital in Tuskegee. His mother called and told me that her son's condition was worsening. I had already begun trying to get him help, including Panhematin® (then hemin therapy), which would have saved his life but sadly, he died prior to treatment. Even now I still think about the young man. Now for the rest of the story. The last group to tell their story at the meeting was Alexandra Dice and her mother, Melissa. She shared that her father had died of porphyria when she was a baby. Oddly, I asked Melissa to tell me more about her husband. When she began to relay the story, I suddenly realized she was the wife of the same young man that I had tried so desperately to help save many years ago. The more she talked, the more I knew she was the wife of the young man and Alexandra was his daughter and her little Alise, his granddaughter. I couldn't believe that twenty five years later I met his daughter and shared the story of trying to save her father. It was such an emotional moment. I went to bed that night thinking of all the people I had met over the years and all the good and sad stories we have shared.

**WARREN HUDSON** Serves on the APF Board of Directors and also serves as the Director of the Caretakers Forum, which is a forum the APF established to help those who are suffering from porphyria. They are our physical and emotional support. Being a Caretaker is not easy. Caring for people when they are sick can be a thankless job, because patients often don't know how difficult their care can be. They don't know what it is like for the caretaker to deal with nurses and doctors and all the hospital health professionals. Caretakers deserve our highest praise and thanks. You might also join the Caretaker Forum and find others in your same situation. You, too, might need a helping hand or might share your own story to help another Caretaker. To join, contact Warren Hudson, at the Caretaker Section on the homepage of the APF website. <http://www.porphyrriafoundation.com/Caretakers-Support-Forum>.



**MEDICAL CONVENTIONS** The APF maintained an exhibit booth at two major conventions, the American Society of Hematology (ASH) and American Association for the Study of Liver Disease (AASLD). Over 8,000 doctors from around the world attend these conventions, so it essential for the APF to maintain an exhibit booth to promote porphyria education. We thank the APF members who manned the booths and distributed information to doctors. This is a terrific opportunity for you, our members, to educate physicians and tell them your story. Many of the doctors have had no experience treating porphyria and ask questions about treatments, like Panhematin®. They are keen to hear patients who have received treatment. Volunteering at conventions gives you the chance to answer doctors directly. Thanks to all of you who volunteered, Jill and Joyce Gould, Meredith McGinley, Karen Ashe, Leetha and Zeena Wilson, Amanda Rich, Robin Curley, Mira Geffner, Molly Buffington, Gunja Garharia, Monica Firchow, Dr, Joseph Heflin, Natalia Sturza, Yvette Strange and Desiree Lyon Howe.

**EXPRESSIONS** APF members express their suffering in many different ways. We have published their poetry in the newsletter many times with these two poems. You are not alone as you can see below:

**Megan Parrish** has AIP and writes:



*Uninvited tears  
Tired of all pain  
Lonely and afraid*

Thank you, Megan. We look forward to more of your poetry about life with acute porphyria.

**Rob Saupe** has EPP and cannot tolerate the sun and sources of visible light. We thank Rob for sharing his poetry about living with EPP:



*Living within the shadows I feel so far away. I'm present in the moment, but yet so far away.*

*As I sit in the shadows away from the gathering, I see the fun and the enjoyment you all have while in the*

*sun where you play.*

*From within the shadows I'm dreaming of the day, when I receive news from the FDA, the medication has been approved, and I will no longer have to be so far away. Dreaming of the day I can shed my extra protective wear, let down my guard and run from the shadows, hoping to never return!*

*Until then, within the shadows I shall have to be dreaming of the day, when I'll no longer be so far away.*

**James Rawnsley** A baby was born back in the



*70's, these were the days when it took 3 or 4 days to get an appointment to see your GP. The parents of this baby noticed that every time they took him out in the sun he would scream. Not just a*

*normal baby cry but an obviously pained cry. The mother booked an appointment with the GP, but by the time she got to see the doctor all symptoms had gone and she was just a "neurotic new mum". This happened time and again with the same outcome.*

*Eventually the mother had enough of this and one day when it happened again, she took the baby back to the doctor, didn't make an appointment, went straight past the receptionist, burst into the doctor's office whilst he was in the middle of a consultation, put the baby down on the doctor's desk and said, "Now is that my imagination?" Credit goes to the doctor, who got the baby in to see a dermatologist, who was able to diagnose EPP. That baby was my brother. Thanks to my mother's determination, we were both diagnosed at an early age. You have to be persistent, you have to be a down right pain in the bum and maybe even break the rules. Eventually someone will listen.*

**OH JOY** Little Addison shows us that sometimes



words are not necessary. Most of us think of the joy of a sunrise, but Addison is rejoicing at the sunset because she has EPP and can't play until sundown. Sunrise or sunset, you can see the pure **JOY** in her expression

**In Memory** We are saddened to hear of the passing of dear family members and friends. Some of you have chosen to honor a life by making a gift to the APF to help others with porphyria. Please join us in thanking:

Desiree Lyon Howe for **Robert Steele Roth**, Lisa F Neal for **Augustus P Neal**; Susan Miller for **Mark Spencer**; Darrell R Large for **Jeffery Blake Large**; Florida League of Cities, Debra and Gregory Humphries for **Rose Mary Warfield**; Francis J Burke, Rita M Nelson, Claudia Malenczak and Family, Fernando Suarez, Madeline Safray, Pete and Jeanne La Rosa, Kristen Rounsley, Sara Pesserillo, Kristen Latof, Lauren Nash, Christopher Maloney, Jay and Leslie Sokol, Marie Zidzik, Sandy Grierson, Nadine Gannos, Tom Mayette, John and Maureen Beers and Family, Suzanne and Jay Benjamin, Stephanie Adler, Frank and Kathleen Burke, Charles and Rita Nelson, Ben and Rhonda Sosna, Karen Zobro, Gladys Nieto for **Melinda M Marcalo**; Melissa Wade for **John Byrd**.

**In Honor** We also thank those who donated to the APF in honor of a friend or family members. Jonathan Turell for **Desiree Lyon Howe**; Michelle Hubler, Ronda Thomas, Gretchen Kehrberg, Mary Hull, Melissa Wade for **Dr. Lisa Kehrberg**; Lana Malone for **Candace Johnson**; Drs. Carl L Tishler and Bonnie L Katz for **Dr. Peter V Tishler**; Michael Godsted for **Tracy Godsted Yelen**; Christine Troyer for **Terri Witter**.

**SURGICAL LIGHTS IN EPP** Read about lights and filters used for surgery with EPP patients in an interesting article in the **Liver Transplantation** medical journal article, **Protection from phototoxic injury during surgery and endoscopy in erythropoietic**



**protoporphyrin**. The article written by porphyria researchers, Drs. Staffan Wahlin, Nirthiga Srikanthan, Børge Hamre, Pauline Harper and Atle Brun can be found in Volume 14, issue 9, pages 1340-1346, Sept 2008 or on the website:

<http://onlinelibrary.wiley.com/doi/10.1002/lt.21527/full>  
Note-One such light film is Medico TA 81.



## Porphyria Awareness and Fundraising Events

### SARAH LEE #PorphyriaPieChallenge

Alexandra Dice proposed we do a challenge. The APF Facebook groups decided to initiate a Porphyria Pie Challenge to raise funds for research, physician education, and to enhance awareness. The challenge accomplished both and was fun to boot. In fact, \$3,000 was donated and many thousands saw the pies go flying and the information about porphyria came with them. It was great, too, to see devoted friends of the people with porphyria become involved and tell others about the disease. Many of the members said they liked seeing their Facebook friends and watch as their personalities shined through the during the pie challenge. AIP person, **Sarah Lee**, suggested *The Pie in The Face* challenge and designed the wonderful banner. We had a lot of participants from family and friends. Over 1,600 people watched as **Pierre Mouldoux** received his pie in the face. Desiree's sister, April Heflin, was unable to have a direct pie hit as she was on bone marrow transplant, but she plopped a roasted marshmallow on her nose instead. The effect was just as much fun.



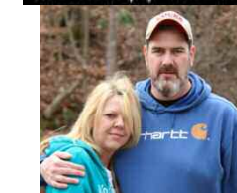
We sincerely appreciate all the patients, family and friends who participated in the pie challenge and spread porphyria awareness. Many thousands of people viewed the videos and heard about porphyria. We also thank all those who donated to porphyria research and physician education. Take a look at all the fun at the pie challenge on YouTube and our many Facebook groups. We had over 180 people participate in the Pie challenge with more on the way. A few of the pie in the face participants are: Sarah Lee, Michelle Cuninghame, Jessica Goodwin, Tara Cantley, Edrin Williams, Natalia Sturza, Yvette Strange, Joe Cochrane, Patrick Petersen, April Heflin, Deborah Fedele, Lisa



Kehrberg, Rose Jeans, Warren Hudson, Desiree Lyon, Georgina Ashley and Cory Brown, John Hull, Monica Hull, Mary Hull, Pierre Mouldoux, Rob Suape, Scott MacMeeken, Michele MacMeeken, Victor Mejias, Amanda Boston, Phelps Family, Evelyn Jacobucci, Nikki Zimmardo, Alexandra Dice, Joanna Floyd, Megan Davenport, Emily Cunningham, Terri Witter and many more.

## THE SHADOW RIDE, A Cowboy Love Story

What better story than a cowboy love story? We have a wonderful one for you. Cowboy, **Scott MacMeeken** fell in love and married his beautiful bride, **Michelle**. All was great except Michelle has EPP. Since Scott couldn't help her, he conceived of the **Shadow Ride**, a horseback adventure to spread the word about porphyria across the small and big cities of America and to ask all of you to join them along the way. The Shadow Ride is a



horseback ride that will eventually track across the American Discovery Trail starting in 2016, but the **2015 Kick Off** ride will be held in Oklahoma near Tulsa, on the prominent Hull and Drummond ranches and will be followed by a national patient meeting in



Oklahoma City in April, 2015. Soon thereafter, we will host a patient education meeting in Oklahoma City with renowned porphyria expert, **Dr. Sylvia Bottomley**. She will be making a

presentation about porphyria and answering your questions at the Patient Meeting. Dr. Bottomley has been a major force in the porphyrias for decades. In fact, she wrote the most recent porphyria chapter in the prestigious *Winthrop Medical Textbook*. Dr. Bottomley can be seen, too, in the *Porphyria Live* DVD, that can be purchased on the APF website or received free with each donation. Attending a Patient Education Meeting is a great way to learn from and teach others with porphyria. You will receive a notice with all the details of the ride and the National Patient Meeting. With a \$30 donation to the APF, you can purchase a **Shadow Ride T-Shirt** with above logo. See at: [www.theshadowride.com](http://www.theshadowride.com)

Contact the APF to order your T-Shirts with a \$30.00 donation. Your donations will support the physician education. Drag out your cowboy hats and boots and join the Partner Round Up. If you are willing to help with the Oklahoma City meeting or the Kick Off ride, please contact the APF.

**Gary Eyster** upon his passing donated his entire



works of art to the APF i.e.: paintings, prints and sculpture. Your purchase of any of his original work benefits the APF. See his fantastic art seen in museums and galleries: [www.garyeyster.com](http://www.garyeyster.com)