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James Young of STYX, Co-Founder of APF

The American Porphyria Foundation was founded 40 years ago. But many don't realize that Desiree Lyon's co-founder was none other than James Young ("JY"), the lead guitarist of the famous rock band Styx. He's been a quiet leader, supporter and advocate for porphyria. Now, the former APF Board President is breaking his silence. Here is JY's story.



James "JY" Young with his beloved wife Susie. Susie lived with AIP. A huge supporter of her husband's career, she used to tour with Styx to be together.

It's been my honor to be co-founder and Board President of the APF for 40 years. My interest in porphyria began when Susie, my beloved deceased wife of 50 years, became ill with an undiagnosed disease. After a circuitous journey, we received a diagnosis of acute intermittent porphyria (AIP) and found a

porphyria expert, Dr. Karl Anderson. He led us to Dr. Claus Pierach in Minnesota, who treated Susie and helped her regain her health.

Susie started on hemanin, which was experimental. It saved Susie's life. I later discovered it saved the lives of many patients, which makes me proud to be involved in its FDA approval as the first Orphan Drug.

Because Susie's diagnostic journey had been so complex and difficult, I felt other people with porphyria were enduring the same dreadful problems and needed a foundation. When I related my idea to Dr. Pierach, he told me about Desiree Lyon, who suffered from AIP and also wanted to create an association. He facilitated our meeting each other.

It was evident at our first face-to-face meeting that the two of us were compatible and had similar ideas about patient needs. Our friendship would endure 40 years, and together, we would create the APF, which has become the world's leading and largest patient organization for porphyria.

In the beginning, Desiree and I were the only two members. I provided the financial undergirding and oversight while Desiree undertook

the administrative duties and awareness programs. From a meager beginning, we have grown to over 17,500 members strong in 100 countries and helped patient organizations around the globe create their own foundations.

Throughout these 40-plus years, we have maintained our Patients First mission and our focus on the integrity of the APF. We have educated tens of thousands of patients worldwide and thousands of doctors. Our research programs helped secure two FDA-approved treatments for AIP, HCP, VP, and ADP and one FDA-approved treatment for EPP, with two more in the pipeline. We were pioneers in the approval of the Orphan Drug Act and all major rare disease legislation for the last four decades. These and many other programs have facilitated a great change in patient care for the porphyrias. We recognize, however, that the need for enhanced knowledge continues.

The APF is one of the most respected rare disease groups in the world and has an esteemed Scientific Advisory Board and Board of Trustees, of which I am a member. You, too, can become an APF member!

— James Young

New Executive Director: Nicole Castellano

Nicole Castellano's porphyria journey has inspired thousands, showcasing the resilience and determination she displayed in fighting the immense challenges most porphyria patients face. From her impressive academic and athletic achievements to her entrepreneurial success, Nicole's accomplishments before and since her illness demonstrate her remarkable abilities and drive. However, her battle with porphyria tested her strength to the core.



Nicole Castellano is the APF's new Executive Director and will lead the organization into the future.

Before porphyria, she was a [world-class pairs figure skating champion](#), placing in the top three from 1989-1991 in the US National Championships, Olympic Festivals, Pan-American games, and her proudest moments, the World Championships. She graduated from Northwestern University with honors and a double major.

After college, Nicole got her pilot's license, started a successful business, and was loving life. People describe her as a "firecracker," but porphyria almost snuffed out her light. It took over twelve years for her to get diagnosed. During that time, she had to close her business, almost died three times and spent two years in a wheelchair. She had nine abdominal surgeries, including a devastatingly unnecessary hysterectomy. She endured excruciating pain, weakness and mental changes, countless doctor visits, and spent considerable time in hospitals and the ER, all while

searching for answers and relief with little to no progress. The fear of watching herself slip away and not knowing the cause was the worst part of her journey.

Receiving a proper diagnosis was a turning point for Nicole. With the guidance of her healthcare team, she embarked on a journey of recovery and management.

To learn more about the disease, she read Desiree Lyon's book [Porphyria: A Lyon's Share of Trouble](#). After so many years in darkness, Nicole found an instant connection with Desiree's story and saw a future where she could be healthy again. After reading Desiree's story and knowing how much it helped her, Nicole vowed to share her own story when she got better. The APF became a beacon in her life, where she found important resources and, more importantly for her, a connection to a wonderful community that started her on a healing journey that continues today.

Desiree Lyon Retirement

It has been my great pleasure to serve as Executive Director of the APF for most of its 40-year history. For the past year, I've mentored Nicole Castellano to take my place. My greatest joy as director has been communicating with over 25,000 people who needed help. Hearing their stories and being a part of the team to lead them toward diagnosis and treatment has been a heartwarming, gratifying experience. When patients and their families contact the APF for help, I feel honored they would share their

lives with me and our staff. As an AIP patient myself, I understand how desperate we can be to speak with a knowledgeable person and to find a

shoulder to lean on and a hand of friendship from people who are suffering my same pain and misery.



DESIREE LYON,
retiring APF Director

I thank every patient, every family member, every caretaker, every doctor, every industry partner, and every supporter with whom I crossed paths these past 40 years. I thank God for the wonderful people I've met along the way and for the treasured friends I've made. May the APF be blessed and bless others for the next 40 years!

ANNOUNCEMENTS

It took years of ups and downs, but she finally got to a place with her health where she could dream again. Nicole wanted to try for an impossible goal; she decided to run the 40th Anniversary Chicago Marathon to spread awareness for porphyria and raised almost \$5,000 for the APF. She posted her progress on social media to bring awareness. Her own videos discussing porphyria on social media have almost two million views. She has also been featured on [Suncoast News Network](#) for Porphyria Awareness Week 2023, [The Balancing Act](#) on Lifetime TV and the podcast [Gastro Girl](#).

"I tell my story so doctors, healthcare professionals, and caregivers continue going the extra mile to figure out those hard cases that just don't make sense," said Nicole. "I was fortunate to have my parents and a few doctors stay the course—listening to me, believing in me, and knowing I didn't want to be sick. I am here because they kept fighting even when I couldn't, and I owe them everything. I tell my story to give a voice to those

still in the thick of the fight for their lives—don't give up, and don't take no for an answer."

Like our members, Nicole is a true "Porphyria Warrior." She spent the last year training and has an inspired vision for the future of the APF. "Nicole's shown great dedication, compassion, knowledge and commitment," said Desiree. "Patients can count on her fearless ability to take action and advocate. I am thrilled to have her take the reins of the APF, and I am confident she is the best person for the role. She believes wholeheartedly in the tried-and-true principles that have made the APF the oldest, largest and most celebrated porphyria organization in the world."

As a patient herself, Nicole's dedication to and compassion for patients is evident, and it is clear that she will carry the torch of our "Patients First" motto. "I am up for the challenge, and feel all my life experience has led to this," Nicole said. "I wish no one ever had to go through living with porphyria, but

I'm constantly learning by listening to all of you who call, email, and interact on social media. I am incredibly inspired by the physical and emotional fortitude and ability to keep hope alive through the pain, isolation, and uncertainty living with porphyria can bring. I'm grateful for the opportunity to learn and grow with our community. This is not just a job to me; it is my passion! I definitely have big shoes to fill with all that Desiree has done for porphyria."

"Our members ARE the APF, and I am dedicated to helping as many individuals and families affected by porphyria as I can. Don't be a stranger. My door is open, and I'm looking forward to connecting with each and every one of you. Nothing I have done in my life so far has given me the deep satisfaction of helping patients navigate this rare disease. At the APF, I feel like I'm home."

Nicole Castellano advocates locally and nationally.

[WATCH NOW!](#)

Scientific Advisory Board Member: Dr. Lim

The APF is proud to announce that our Scientific Advisory Board Member, Dr. Henry Lim, was elected president of the International League of Dermatological Societies (ILDS) at the World Congress of Dermatology in Singapore in July. He was also named by *Dermatology Times* as one of the "[Giants in Dermatology](#)."

In a recent publication, Dr. Lim referenced porphyria in referencing what's most important about being a doctor. "It was about a patient with erythropoietic protoporphyria

(EPP) whom I met when she was an infant. I assisted in establishing the diagnosis and coordinated her management, including bone marrow transplantation. The management of this patient showed the advances that have occurred in medicine: early diagnosis and state-of-the-art treatment, resulting in this young girl being able to have a relatively normal quality of life, living with a disease that in the past invariably resulted in severe disfigurement." Dr. Lim continues to treat EPP, and he and his

team are some of the doctors who can implant Scenesse®.



Dr. Henry Lim at the recent IDLS World Congress of Dermatology, the largest and most influential dermatological organization worldwide.

New SAB Member Dr. Saardi

The APF is honored to announce that Dr. Karl Saardi has joined the esteemed Scientific Advisory Board. Dr. Saardi, who lives and works in the Washington, DC area, made an outstanding presentation for a recent EPP Patient Day. Within days, patients called the APF to find ways to see Dr. Saardi as their EPP specialist. Others shared they were fortunate to have Dr. Saardi as their physician. Dr. Saardi treats EPP and XLP patients, and he is one of the physicians who provides the Scenesse® implant.

Dr. Saardi serves at George Washington University Hospital Faculty in the Department of Dermatology. He completed his undergraduate training at the Johns Hopkins University and went on to Rutgers-New Jersey Medical School for his medical degree. His publications include skin disease in dialysis patients, severe medication reactions, graft-versus-host disease, and auto-immune conditions.



Dr. Karl Saardi is a dermatologist who treats EPP and XLP. He recently joined the APF's Scientific Advisory Board.

Member Spotlight: Lorin and Chris DeMase

Chris DeMase had his first EPP flare at age 2 months. From that time, his parents brought Chris to what seemed to be an endless ordeal with doctors. They were desperate to help their son. According to his wife Lorin, "While growing up, his struggle was confusing, heart-wrenching and filled with indescribable pain, not only for Chris but also his family. This led to isolation and a way of life that was not normal in any way. For many years, he was poked and prodded with endless vials of blood being taken, only to come up with nothing to help." At age 12, he had been prodded so much that he announced to his parents, "I've had enough. NO more."

At age 15, Chris and his parents heard about a brilliant EPP doctor, Dr. Maureen Poh-Fitzpatrick, who was renowned in the field of porphyria. She knew immediately he had EPP. Finally, 15 years after his first episode, Dr. Poh-Fitzpatrick gave Chris the answer to his horrible, burning skin.

EPP kept him inside, which, in turn, gave him the time to devote to developing a successful trucking and warehouse business. Because of his severe photosensitivity, Chris couldn't drive the trucks, but he could handle administrative tasks and did it very well. His office became his pain free, safe place. Lorin provided a light-protected home, ensuring he had a safe world inside and outside.

Lorin learned all she could about the disease. She was not only his life partner but also his EPP partner, handling the many administrative issues for treatment. Lorin said, "Decades went by, then in 2017, at the age of 47, we were put in contact with the APF, and that is when things started to change. They helped Chris get to the correct doctors, educated us both on new studies and have been the greatest support system."

With the exception of photoprotective clothing, there was nothing new for Chris until a 2018 *Dateline* featured



Chris DeMase, who lives with EPP, and his wife Lorin both thank Scenesse® for changing their lives.

afamelanotide/Scenesse®, a new treatment for EPP. Lorin promptly contacted the APF, who put her in touch with Dr. Minder in Zurich. In 2019, they left for Zurich for the first implant. Their lives did not just change with Scenesse®; they were revolutionized. Chris said, "Scenesse® is my armor! There is NO PAIN!" With Scenesse®, he can now enjoy a normal life.

Katie Marie Lives with CEP

Katie Marie Green is one of the 127 patients in the world with Congenital Erythropoietic Porphyria (CEP). She hails from Chestershire, England. Katie's philosophy is to live life to the fullest. Family and friends are struck by her courage and forthrightness

about her condition. She wants to encourage others to live as normally as possible under photosensitive circumstances while still taking measures to protect the skin.

Find Katie Marie Green on Facebook and share porphyria experiences.



Sian Ball Exemplifies Bravery

Sian Ball has exemplified courage her entire life despite facing numerous severe health challenges, including EPP. Sian was born with a heart condition followed by hearing loss at three.

Her EPP symptoms came after a day at Six Flags when she began screaming in pain. Her family headed home immediately, and Sian screamed the entire five-hour drive. They sought medical attention. She was enduring the searing pain of EPP, but no one knew it. One nurse even said she was making it up. Imagine how Sian's mother, Kimberly Merrill, felt when hearing such an accusation about her four-year-old.

Kimberly began searching the Internet for answers, and after reading a blog by a mother in Europe, knew immediately she'd found it! As an adult, Sian participated in trials and will be receiving treatment soon.

Her next diagnosis was erythema nodosum, a painful disorder characterized by tender bumps under the skin and severe bruising. Later, she was diagnosed with Addison's disease. If these were not enough to deal with, Sian recently discovered a breast tumor. At present, it is being tested. Despite health challenges, Sian maintains a brave, hopeful, positive attitude and is majoring in Psychology.



APF Member Sian Ball manages EPP and other chronic conditions.

Sian has a particularly wonderful friend, Ariana, who understands her illnesses. Life with EPP and other porphyrias can be extremely isolating. Thank God for friends like Ariana!

If you would like to meet patients like Sian, consider joining the Porphyria Partners Program. Call 866-APF-3635.

Megan Parrish and "Queen Charlotte"

APF Member Megan Parrish (pictured, right) was recently featured on local news in Little Rock, Arkansas. She has acute porphyria and is faring better than in years past. Her porphyria journey was filled with misdiagnosis, surgeries, endless doctor visits to many different types of doctors, non-stop wrong treatments, and seemingly endless attacks until she found the APF.

Media in porphyria has heightened due to the popularity of Netflix's *Queen Charlotte*. The show features King George III, who was thought to have acute porphyria.

WATCH NOW!

You, too, have a great story to tell! Contact your local news about the King George connection and you.



Pharma Friends: Dr. Linda Teng with Clinuvel

In the last 16 years, Dr. Linda Teng has focused much of her life on EPP, first on studying it and, more recently, on facilitating access to the only FDA-approved treatment for EPP patients. She started out in clinical operations for Clinuvel and now oversees the U.S. operations as Director of North American Operations, part of the global company's executive team.

Linda's involvement in EPP began in the early days of clinical trials when she built long-standing relationships with patients. Her responsibility now ranges from engaging with physicians and insurers to facilitating treatment. Now, she helps Clinuvel reach the next level of care.

Her deep understanding of the unique challenges faced by EPP patients drives her and her team to engage doctors and patients through their unique circumstances. Since 2020, her team's built a network of specialty EPP centers, greatly increasing awareness of the disorder and enabling patients to get care closer to home. "The goal is to have 120 centers across the US, with no patient having to drive more than three hours from a center," said Linda.

When Linda's not working, she loves spending time with her family in nature. She traveled to visit the deer park in Japan, and her children experienced the wonders of nature.



Dr. Linda Teng took a break from her work at Clinuvel to take her daughter to visit the deer park in Japan.

Linda understands the importance of family and wants to help others get their lives back so that they, too, can enjoy nature.

Meet Imani Thomas

The APF is excited to introduce our newest staff member, Administrative Assistant Imani Thomas! Imani works in our new Bradenton, Florida office. Born in New York, she lives in Florida and is an undergraduate medical student focusing on Psychiatry and Forensic Psychology. With over five years of experience in customer service, her most recent position was as an executive assistant and office supervisor.

"I am extremely proud to be a part of the APF. The underlying motivator for all my ambitions is to help improve people's lives, and I feel I have an opportunity to do that," Imani said. "I have already learned so much from Nicole. She even invited me to her porphyria doctor's

appointment and her Panhematin infusion to understand what some acute porphyria patients go through to receive care. It was very interesting to me."

Imani wants to learn as much as she can about porphyria. She looks forward to working with, learning from, and getting to know everyone. Welcome, Imani!



Imani Thomas is the APF's newest staff member at the Bradenton office.

A VP Poem

Eryn Sallee had a very difficult time with VP, including finding the right diagnosis, treatment and doctor. She decided to express her experiences in a poem.



Eryn Sallee's powerful poem about VP is online.

[LISTEN NOW!](#)

New T-shirts in the APF Store

PORPHYRIA, IT'S IN MY BLOOD

Our new T-shirt, "Porphyria It's In My Blood," was designed by Andrew McManamon, who's on the Member Advisory Board. It's become a fast favorite, so get yours soon!



THERE'S NO FEAR IN PORPHYRIA

This shirt is "porphyria armor!" It reminds us of the strength and the fearlessness it takes to battle porphyria every day, no matter the pain and exhaustion.



Both shirts in all types and colors are available in the online APF store, where you can find more porphyria-themed apparel and gifts.

[SHOP NOW!](#)

APF Reaches Spanish Speakers

Dr. Ronny Kershenovich recently led a Spanish-speaking Zoom presentation, and nearly 100 people impacted by porphyria tuned in.

The event was made possible by a collaboration between the APF and Fide Mirón with the Spanish Porphyria Society, Kika Shabot with the Mexican Porphyria Society, Beatriz Agudelo with the Colombia Porphyria Foundation, and Eileen Hudson with the Chilean Porphyria Association. Participants tuned in from the U.S.A., Mexico, Venezuela, Costa Rica, Brazil, Colombia, Guatemala, Honduras, Peru, Chile, Ecuador, and Paraguay.

Dr. Kershenovich spoke on all the porphyrias and answered questions. Clearly, people around the world are eager to learn about their disease and make connections with others. Thanks to all who made this event possible!



Dr. Ronny Kershenovich is the Deputy Chief of Medical Research at the National Institute of Genomic Medicine in Mexico City.

APF FRIENDS OFTEN GIVE DONATIONS IN MEMORY OR HONOR OF THEIR DEAR LOVED ONES. WE ARE GRATEFUL FOR EACH OF THEM.

— In Memory

Paul Petersen
in Memory of his sister,
Christine Alexandria Petersen

Robert Overall
in Memory of William C. Lambert III

Desiree Lyon
in Memory of Russell McCraw

George Rusnak, Jr.
in Memory of Carol Rusnak

Ken and Bev Broadhead
in Memory of Cathy Bass

Dee Dee and Terry Livingston, Fay Ray
and Family, Davis Nolan, Rose Palermo
and Denty Cheatham and Office
in Memory of Hilary Edward Hailey II

— In Honor —

Trudy Eaton with ITA Group
in Honor of Claire Richmond

Ralph Gray
in Honor of his father, Fred L. Gray

Nicole Castellano
in Honor of her sweet pups, Mila & Laszlo

Joe and Bekah Gray
in Honor of Ralph Gray

Rita Dodd in Honor of Anne Jacobs

Desiree Lyon
in Honor of her doctor, Monica Loghin

Millie Jackson, Julia Carleton, Christopher
DiNapoli and Blair Cumming Falivene
in Honor of Pax Cumming

Judson Wallace in Honor of Butch Dean

COMING SOON:

PORPHYRIA
CENTERS OF
EXCELLENCE!



What's New?

Check out www.PorphyrriaFoundation.org

The information contained on the APF website or newsletter is provided for general information only. The APF does not give medical advice or engage in the practice of medicine. The APF under no circumstances recommends particular treatments for specific individuals, and in all cases, recommends that one consult with a personal physician or local treatment center before pursuing any course of treatment.

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Donate on our website 24 hours a day,
7 days a week. Thank you!



DONATE NOW!



The APF does not receive government funding. Your contributions help educate physicians and patients with life-saving information about the porphyrias. Donations are tax-deductible. Become an APF member today!

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