

iPain Hero of Hope Finalists 2018

Patient Advocacy

Teresa Wright-Johnson



Easton, Pennsylvania

www.teresawrightjohnson.com

Teresa Wright-Johnson is an advocate for Multiple Sclerosis and Heart Disease. She actively engages her community by distributing pertinent information, sharing her story and spreading her message of hope. Teresa truly believes that where there is life, there is hope. She recognizes the devastation that chronic illness and chronic pain has on a person's life and she is committed to emboldening others to speak their truth, live a full life and to hope for the best. Teresa serves on multiple local executive boards such as the American Heart Association and the NAACP in addition to several committees, such as iConquerMS. A writer, speaker, columnist and poet, Teresa knows that every voice matters and that there is glory in every story. You can read Teresa's work on her website and her column for MS News Today titled Patiently Awakened. Teresa is currently working on publishing her poetry, memoir and children's book. She enjoys reading, writing and spending time with her husband and family. I served the pain community in the last year by raising awareness and advocating for those battling chronic pain. I personally share my story of how I manage chronic pain and the difficulty it entails. I offer encouragement and support to all who need it, both privately and professionally. I speak at health fairs, churches, banquets and conferences.

Tenah Callison



Louisville, KY

www.facebook.com/tenah.callison

I have been with iPain since 2013 I have served as a delegate, board member, and currently Director of The Suicide Prevention Program for International Pain Foundation. I have RSD, a clotting disorder, kidney problem, stress depression, anxiety, PTSD, and I lost my 21 yro in 2015 in a horrible car crash. These are things I deal with on a daily basis but feel they have made me a better advocate. It has also has made me want to be the best I can for iPain's causes! It is truly an honor to be nominated for this award. The Hero of Hope Award is so special, again so honored someone nominated me to be considered as a candidate for this Award! In the past year, I have written an article for iPain Living Magazine about my problems with Migraines, and the effects of what I went through since I had my first one at 13yrs old. International Pain Foundation started a group for my Suicide Prevention Project on Facebook

which I manage. We are growing fast and I'm very excited to run the page and get the word out for people to get help when in a crisis. In October I finally got a booth at a huge Southwest Festival that is very popular on this end of Louisville. I have trying for years to get in. Very excited. In November Louisville hosts a Walk Out of The Darkness Run, I've contacted the board, and hope to hear back soon from then! I want run an iPain booth at this event! I'm also working on getting photograph taken for the iPain Suicide Prevention Poster to mail to Pain Management Doctors' offices. We know many people are scared to get meds taken said way so this is a way for them to get! Very excited for all that has already happened in 2018, can't wait to see how the finished project will look. Again, thank you it's a true honor to just be nominated!!

Shane Schulz



Troy, NY

www.facebook.com/shane.schulz.speakingtotheheart

Shane Schulz is a Public Speaker, Mental Health Advocate and CEO and Founder of the Speaking to the Heart Podcast Network. He is also the Executive Producer for the Zubia Live Channel, a live video streaming community that focuses on health and wellness topics. And a board member of his affiliate for the National Alliance for Mental Illness, where he works to bring awareness and empowerment for those challenged by mental illness. Shane has gained a loyal following as the Host of the Arisen Strength Motivational Podcast and his weekday morning show Motivated Strength LIVE sharing what he calls the "optimal frame of mind" to have a higher level of thinking leading you to a higher level of living! No matter the platform Shane Schulz's message will speak to your heart and empower you to take charge of your physical and mental health! He is providing both audio and video content to help others realize they are more than the challenges they face through a number of different venues such as Speaking to the Heart Radio Network, Arisen Strength Motivational Podcast, Motivated Strength LIVE Morning Show, Zubia Live Health and Wellness platform.

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Ross McCreery



Regina, Saskatchewan, Canada

www.twitter.com/Rossc006

Ross McCreery is a patient/advocate fighting to raise awareness and create change for those living with chronic pain. In 2006 I was diagnosed with a rare disease called CRPS (Complex Regional Pain Syndrome) that has no cure and very few treatments for the debilitating chronic pain. Ross is the founder of CRPS Awareness Day in Saskatchewan, an initiative designed to educate and raise awareness for the disease. I also sit on the board of directors for the Sask Pain Foundation. My efforts however stretch much further than that and I am involved with advocacy groups within Canada and the U.S. I have served the chronic pain community in a number of ways this year. I have not only had the Province of Saskatchewan proclaim a day of awareness for CRPS but this year I have succeeded in having the curriculum for second year medical students changed so that they are teaching students about the disease. I sit on the Sask Pain Board of directors as a patient/advocate and our goal there is to better educate and raise awareness in chronic pain. This year through the Rare Disease Foundation I have also launched the first Adult Peer2Peer Group within Canada.

This will establish a support group for those suffering from chronic pain and rare disease. Along with these avenues I have been involved in various patient communities through social media to not only serve as support but to get involved in trying to create change and bring about awareness and educate others about chronic pain. Finally, I have also most recently been involved with a campaign called Outrun Rare to try and raise awareness for rare disease.

Lacy Fowler



Ava, Missouri

www.facebook.com/ArachnoidChronicles

Lacy is a healthcare patient activist, chronic pain educator, patient liaison and advocate. She lives with Arachnoiditis, paresthesia, cauda equina syndrome and reflex sympathetic dystrophy.

Investigative reporting with multiple agencies, organizations and foundations covering the other side of #OurPain, spreading rare disease and chronic pain education, awareness and prevention with legislators and healthcare professional.

Judith (Judy) Flanagan



Australia

<https://www.instagram.com/unitedadvocacyaustralia>

Judy is a 38-year-old Australian Savvy pioneer member for the Savvy cooperative. Judy is a writer in Real Life Diaries-Living with Rheumatic Diseases and she volunteers with multiple orgs and supports all communities. Judy is Savvy about Migraines (lived with them since the age of 7), Savvy about Rheumatoid Arthritis (2012), Fibromyalgia (2013), Hypertension (late teens early 20's), General and Social Anxiety Disorders (since 13yrs old), Scoliosis, Mild Spinal Stenosis, Chronic Pain, Fatigue and Brain Fog. She lives with Polymyalgia Rheumatica as well. Judy decided to get in to Advocating and volunteering with orgs such as the International Pain Foundation (as they cover multiple conditions) and the International Foundation for Autoimmune and Auto Inflammatory Arthritis. Judy loves photography, Dolphins and animals in general, getting creative by creating her own graphics, writing and supporting others Arthritis Awareness Month in May I completed a fundraiser with Arthritis NSW in Australia and they shared my story for the Move it in May campaign. I have participated and helped

support the #Dazzle4Rare Rare Diseases community because Rare disease needs a lot of awareness and I support cross community awareness to share about what people live with. The Dazzle4Rare Awareness event is held in August. In June each year I always participate in #MHAM(Migraine and Headache Awareness Month) by creating graphics, sharing my story and participating in Shades for migraine as well which highlights the light sensitivity associated with living with migraines. I was one of the writers in Real Life Diaries living with Rheumatic Diseases can be found on Amazon dot com. I am a contributor in iPain Living Magazine for the International Pain Foundation.

Hannah Blum



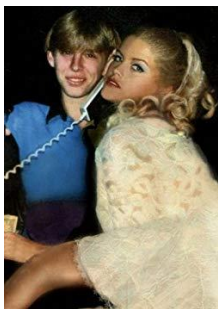
Raleigh, North Carolina

www.twitter.com/halfway2hannah

My name is Hannah Blum. I am a mental health blogger and content creator on mediated platforms. I am diagnosed with bipolar 2 disorder. I am also the author of the blog, "Im Bipolar Too" on HealthyPlace.com, and vlogger for their YouTube channel. My blog is Halfway2hannah.com, a platform discussing every aspect of mental health. I continue to create videos discussing mental health, and contribute to my blog, as well as social media platforms on a daily basis.

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Donnie Hogan



Wheat Ridge Colorado

www.twitter.com/realDonnieHogan

Hoping to help raise awareness for those who endure chronic pain and don't know why. We need to change how people are diagnosed. I am a service dog advocate and fight to help others understand ND a law many are exploiting making it harder for legit service dogs. My sister Anna Nicole shared a similar path as me. Projects I have worked on include; If only I knew then what I knew know, walkASone Ankylosing Spondylitis awareness project, don't punish pain rally media relations, Chalk where you walk awareness project, reach out program, Service Dog awareness through meds and online, Fighting for chronic pain patients who are losing pain meds daily, and All lives matter No more suicides.

Daniel Garza



Laguna Beach, CA

www.twitter.com/LilMesican

Chronically underweight and sickly, he initially blamed his hard-partying lifestyle. A caring boss and friend in the restaurant at which he worked sat him down and essentially fired him. He would take him back, but only after he sought help. Daniel wound up in hospital with 108 T cells and weighing 110 pounds. The news he had avoided for years was now there in black and white. He had the frighteningly real diagnosis of AIDS. "Oddly enough, as a kid, I never saw me going past thirty years old. I always thought I would die at thirty." In one way, it was a call to action, launching his long career as an activist and educator. In another way, it gave him the excuse to continue to use. His parents and family, who had just begun to come around to his being gay, were ill-prepared for an AIDS diagnosis. Daniel found himself lacking the adequate knowledge and tools to allay their fears. He got involved with HIV advocacy and outreach, learning as he went along. He ended up volunteering at an agency where he himself had gone to learn about his disease. He stayed in Houston for twelve years. He worked for Southern Texas organizations such as The Valley AIDS Council, The Thomas Street Clinic in Houston, The Houston Ryan White Planning Council, and Child Protective Services of Houston. He was now an activist, an HIV Outreach Ambassador, he was an educator for youth and families. Ironically, he went back to college and studied to be a drug and alcohol counselor while still using himself. Eventually, he sobered up and in

2009 moved to Laguna Beach, California, where he still resides and is busier than ever making a difference. He shares his story with students, from junior high all the way to those doing graduate work in medicine, on their way to becoming the next generation of physicians. They are not sugar-coated, the stories he shares. He dispels the current myth many have about managing living with HIV, that one simply pops some pills and everything is better. "I let them know all the complications that come with it, all the side effects. All the extra surprises you get every year." He is a witness and advocate for the those of us who've been living with HIV long-term. His story has changed over the years. Daniel says, "The way that I teach is different [now]. I have to come from, I hate to say a fear tactic, but there is a little bit of fear I put into kids."

Amanda Greene



Los Angeles, CA

www.twitter.com/lalupuslady

I became an engaged healthcare activist after living with Lupus (and other autoimmune conditions) for decades. My struggles and patient experience led me to become an advocate for myself. Now, I advocate for the entire chronic pain and lupus communities. (More details on LALupusLady.net) This year, I have actively shared my patient experience at HIMSS (the world's largest gathering of Health IT professionals) in a session about the impact of Health Technology on my healthcare. In March, I joined with the Lupus Foundation of America for the advocacy day and taught young patients how to effectively share their story. Amanda was on the patient panel at the Virtual Medicine conference sharing her perspective on how VR (virtual reality) can help people living with chronic pain held at Cedars-Sinai Medical Center. I was honored to be selected and attended the HealthEVoices conference for patient advocates in Chicago. As a woman living with chronic pain, I am proud to be the current International Pain Foundation's "Face of Osteoarthritis" and previously I was iPain's "Face of Lupus" raising chronic pain awareness for the organization on behalf of patients with a variety of pain conditions. As I like to say, "connecting and collaborating are the keys to transforming healthcare"