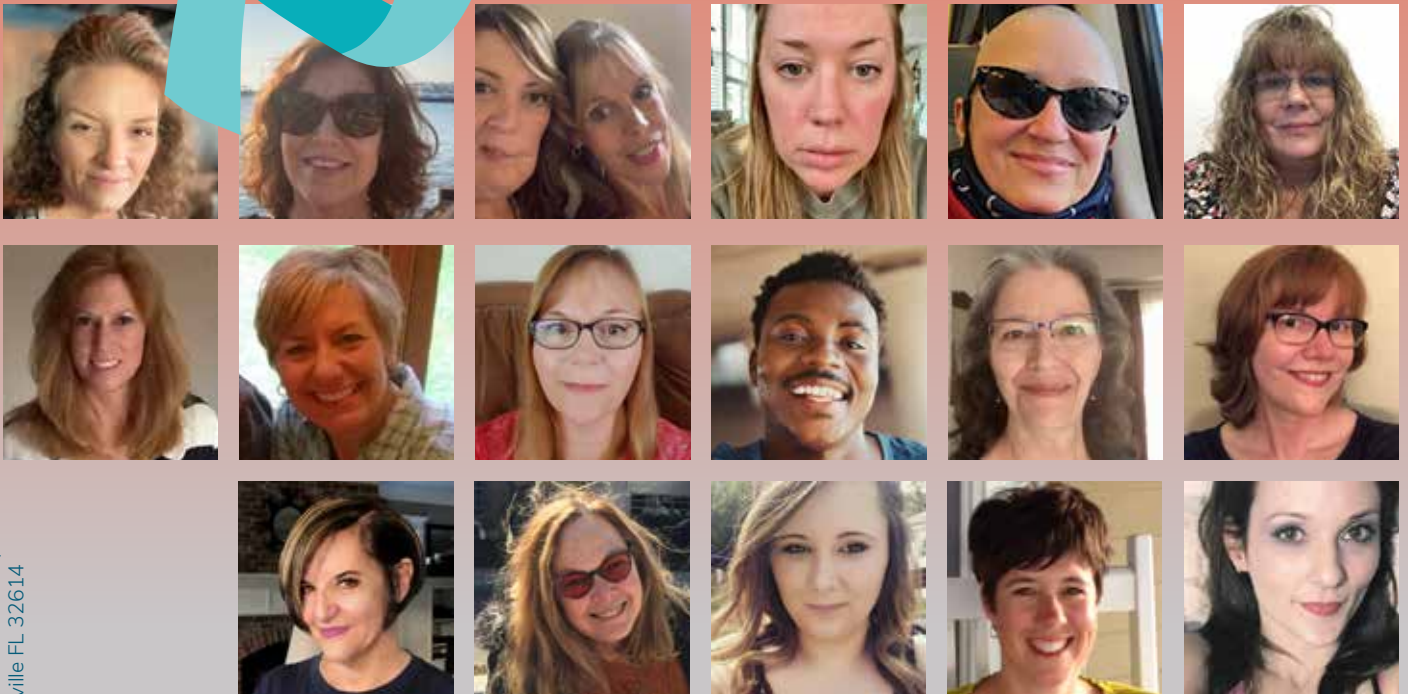
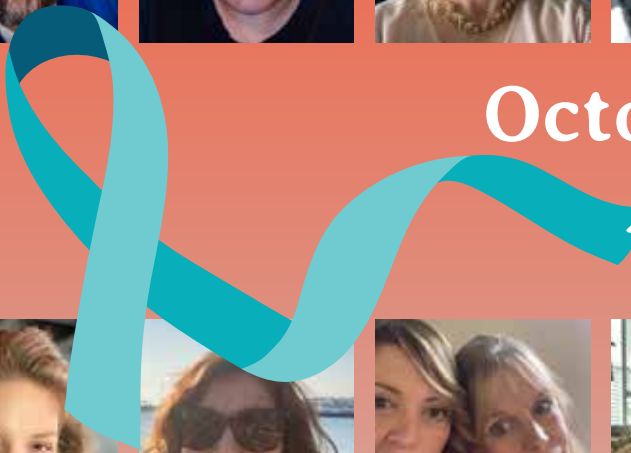


Quarterly



October is Facial Pain Awareness Month



EVERYONE'S
FACIAL PAIN IS UNIQUE.
SO SHOULD THE
TREATMENT.



The Valley Hospital Gamma Knife Center

Paramus, New Jersey

201-634-5677

If you are searching for relief from the facial pain of trigeminal neuralgia, now is the time to learn about gamma knife.

TELEHEALTH APPOINTMENTS are available, saving you time and travel.



The road to successfully treating trigeminal neuralgia can be a long one, especially if you've relied on medications for years with only modest success. It's time to take a unique road: outpatient, nonsurgical treatment at The Valley Hospital's Gamma Knife Center in Paramus, New Jersey.

And to help you down that road are Valley's highly experienced nurse navigators who literally meet every patient at the door, taking them through each step of their treatment journey.

We are one of very few gamma knife centers in the **New York / New Jersey / Connecticut** area, and we have been effectively treating trigeminal neuralgia for many years.

Care is delivered in a beautiful and calming outpatient setting, off-premises from The Valley Hospital. Access is easy and direct from all main highways.

Learn more at ValleyGammaKnife.com/FacialPain

Care Like No Other™





From the Chairman of the Board

You probably already know that the FPA's mission entails providing information, support, and advocacy for you. Truth be told, most of the organization's focus in the past has been on providing information so you and your healthcare partners can make the best decisions, and support to help everyone make it through this difficult time in your life. With our limited resources, these focus areas were rightfully given priority.

This year, the FPA will be expanding its efforts to include much more advocacy, specifically in two vital areas. First, the FPA will significantly expand its efforts to help organizations that are developing new procedures, imaging technology, and medications that can help those of us with neuropathic facial pain. These major medical centers and pharmaceutical companies have embarked on providing more treatment options for us, and we are going to help them be successful by providing information, guidance, and participants for their research. To be clear, we are not going to duplicate the Facial Pain Research Foundation's (FPRF) efforts of raising money and directly funding research. We are going to help those who already have the funds and programs in place to be successful. Between the work that was started last year and what we hope to accomplish this year, we are striving to assist ~ 25 research efforts. In short, we are working to put more treatment options in your healthcare providers' hands so they can better serve you. And you can help. This year the FPA will be launching a patient registry so we can become the "go-to-research-partner"

for those working to help our community. Please consider joining the registry when it goes live.

The second vital advocacy area that the FPA will be focused on this year is to make dentists aware of neuropathic facial pain to help prevent unnecessary dental procedures that so many of us had to endure because of dentists' ignorance of our condition and to hasten a proper diagnosis so members of our community can get the care they need sooner. The FPA has worked on this in the past by going through the American Dental Association and other dental organizations, and we were not successful. We are taking a much broader approach this time to help ensure success. If you have expertise in marketing / communicating directly to dentists, please let our CEO, Allison Feldman, know.

We are able to embark on these vitally important efforts because last year the FPA was the recipient of four bequests (money left to us in a person's will), and we now have the resources to do this. My wife and I were so inspired by the generosity of these wonderful people that we recently amended our will to include a bequest to the FPA. (You can read an inspiring story about one of these bequests on page 22.) Please consider including the FPA in your will and join my wife and I in FPA's Legacy Society.



David Meyers, Chairman of the Board
The Facial Pain Association



A Message From the CEO



Allison Feldman,
Facial Pain Association CEO



FacialPain
Association

New Year, New Objectives

With the start of a new fiscal year, FPA completed an update of our Strategic Plan. During this process, we reviewed feedback we received via the FPA Organizational Survey, 2020 Virtual Conference, and from all of you over the past year. We analyzed the successes and challenges of our program provision, and researched what new opportunities are available to organizations such as ours. The newest iteration of the FPA Strategic Plan contains several new initiatives, which we are excited to share in upcoming Quarterly journals.

This year, FPA will be embarking on a new initiative to promote and provide support to research that is relevant to the neuropathic facial pain community. This is something we have been doing unofficially in the past year to more than a dozen researchers- connecting them to patient volunteers, sharing surveys, assisting in garnering research participants, providing insights on study structure, and more. As it became obvious to the FPA board of directors that our organization was able to make a real impact on research being conducted for the betterment of the lives of people with facial pain, we decided to make these efforts one of our main objectives of this fiscal year, and beyond.

You may know that FPA previously included the Facial Pain Research Foundation (FPRF)- an arm of the organization that funded research- that officially separated from FPA in 2016. It is important to note that FPA will not be providing funding for research as the FPRF does; rather, FPA will be able to promote studies that are funded by FPRF.

You can learn more about medical research and studies, volunteer with FPA, read updates on past studies, and more at FacePain.org/Research. If you are a researcher, I encourage you to contact me to discuss ways FPA can help your efforts.

Allison Feldman
Chief Executive Officer

2022 FPA Conference
January 29-30

Save the Date!

You told us you want another virtual conference- and we listened!

Don't miss the next FPA Conference.

Sat., Jan. 29 &
Sun., Jan. 30, 2022

Dialogue with the most informed medical experts in the world.

Registration opens November 2021



Paving A New Path

Charity Harris

My name is Charity Harris, and I live with multiple life-changing diseases. I was born in Tulsa, Oklahoma, and moved to Los Angeles when I was seven years old. Shortly after moving, I was diagnosed with Charcot Marie-Tooth Disease, and I have type 3, known as Dejerine-Sottas. At that time, doctors were amazed I was still able to walk and told my parents to prepare for me to use a wheelchair soon. Little did the doctors know, that was not happening...

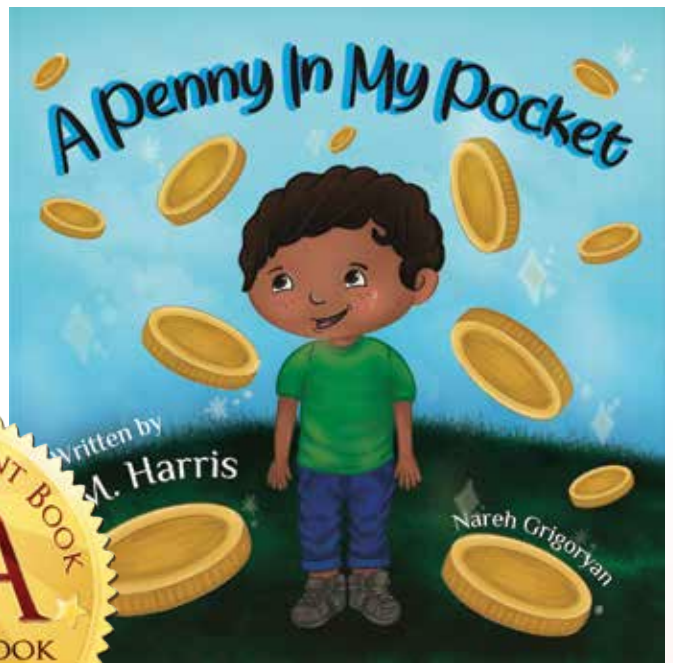
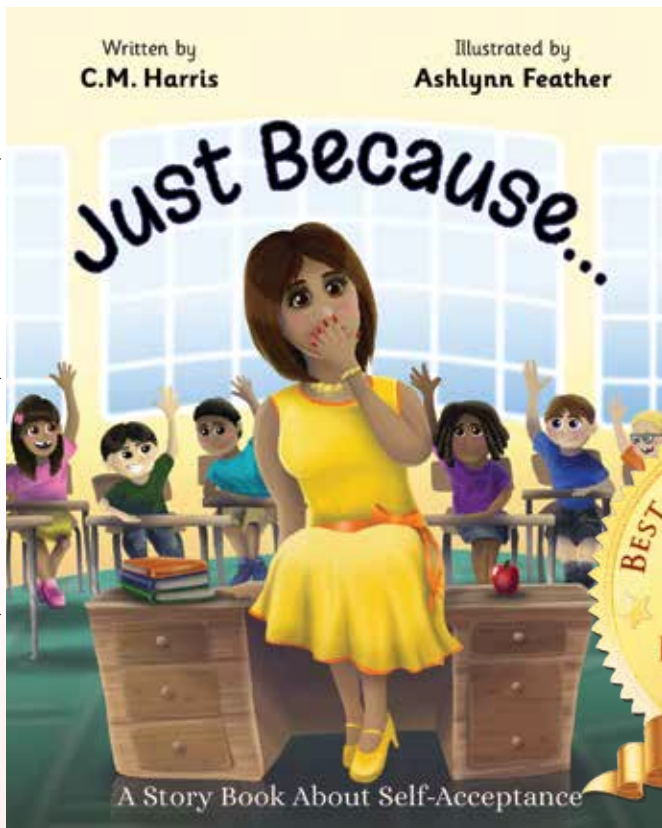
I grew up like any other child; rode my bike, went swimming with friends, Disneyland with the family, walked the dog, and any other normal activities any child would do. When I entered high school, I also did what any teen did, looked for my first job. I applied to multiple local places around my neighborhood; some pet stores, quite a few clothing stores, and office supply stores, but each one was a no.

I was young and think I assumed I didn't get the jobs because I had no prior work experience. It wasn't until after I graduated from the university and started looking for jobs again that I discovered the real reason. I attended California Polytechnic University, Pomona, and earned my Bachelor of Fine Arts Degree in Graphic Design and a minor in Marketing Management. Unfortunately, at the end of my first

semester at Cal Poly, I experienced my first shock of trigeminal neuralgia. It was debilitating and quite a nuisance for a college student, but during my last semester at the university, I had finally received a diagnosis and chose to undergo surgery and had a



"Paving A New Path" continued on page 14



“Paving A New Path” continued from page 13

Microvascular Decompression performed on the right side of my brain. I have bilateral TN, but it has been a blessing that my left side has been in remission for many years, and I currently live pain-free from TN.

Two weeks after I had surgery, I started a marketing internship that I finally landed and had two days to celebrate before quickly scheduling the surgery. Nothing was going to stop me from the opportunity to work. I was ready to work! I never told the company that I just had surgery for fear that they would change their minds. I loved the four months I spent as an intern, and I was surprised when I received an exceptional letter of recommendation that I couldn't wait to use. I was ecstatic when I graduated, thinking this was it, I was finally going to get a job, I just had surgery, I just completed an awesome internship, and I was ready for my career to start. Until it didn't.

For two years, I applied to over 100 jobs, went on over 30 interviews. Some interviews were by phone, but many were in person. I never indicated that I was in a wheelchair. By this time, I had become fully reliant on needing a wheelchair after graduating high school. Many

“... I'm going to face many battles as someone born with a life-changing disability, but I never allowed it to prevent me from doing what I wanted.”

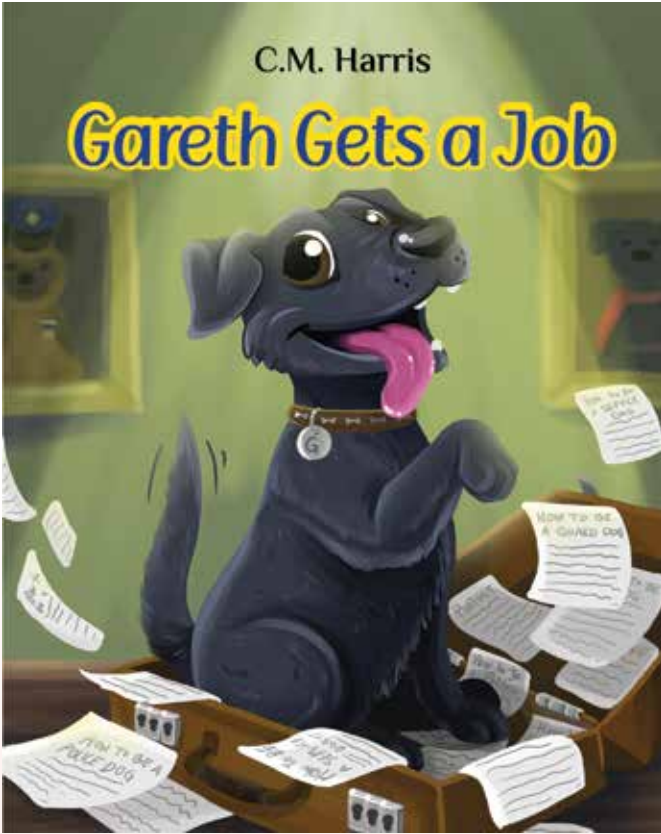
employers were impressed by my resume, so I thought for sure when I show them my portfolio in person, they'll have to hire me. I went all out on my portfolio, had it custom-made

acrylic, and printed high quality with my designs. But there was the same surprised look on their faces when they saw me.

I received great remarks about my work and how qualifies I was and whatnot, but I was never officially offered a contract to sign and join a company, and I believe it was due to using a wheelchair. There is an unspoken and unfair bias towards individuals who are disabled, and although there are laws to protect against discrimination, it still happens. It's not fair, and something absolutely needs to be done to change the bias.

In 2018 I received my certification as an ADA (Americans with Disabilities Act) Coordinator and decided I wanted to bring a change in some way to how employers hire fully trained and qualified individuals. Just because someone may have mobility limitations, it doesn't mean they will not be able to accurately get the job done when they have the qualifications and the desire to work. Everyone should be given the same and fair opportunities when employers hire. I have been to many places, and never have I seen a wheelchair user employed in a store, a theater, a

By C. M. Harris, Illustrator: Ashlynn Feather, Publisher: Purple Diamond Press



restaurant, or anywhere else, and that should change, a change I hope to focus on shortly. After many years of unsuccessful networking and interviews, I decided to create my own job and started my own business.

In 2019, I started Purple Diamond Press, LLC, and published my first children’s book. I wrote, “What If We Were All the Same!”, a children’s book about

diversity and inclusion. I wanted to write a fun story that embraces equality. Growing up, I learned I’m going to face many battles as someone born with a life-changing disability, but I never allowed it to prevent me from doing what I wanted. I’ve faced many people who doubted me and told me I could not do something, but I live my life not to prove to anyone they were wrong about me, but I live my life to prove to myself how strong I know I can be.

When I had my first sting of trigeminal neuralgia, I did not see a light on my dark days, but thankfully I was mentally prepared to keep moving forward. To date, I’ve written eight children’s books, and I focus on embracing differences and acceptance. I write for children and hope my collection of C.M. Harris Books encourages readers to treat people who rely on mobility aides the same as anyone else. Our differences are good, and everyone is different in one way or another, and we should all be accepted. My latest story is in memoriam to my service dog of ten years, Gareth. Gareth was with me and encouraged me as I battled through my job hunt. “Gareth Gets a Job” will be available on December 21st. Today, I am very grateful for the job I have but I hope to help others who have faced similar employment experiences. ■

Author site : <https://cmharrisbooks.com>

Publishing site: <https://purplediamondpress.com>

Amazon: www.amazon.com/author/harriscm

By C. M. Harris, Illustrator: Ashlynn Feather, Publisher: Purple Diamond Press

