

REAL PEOPLE. REAL PHOTOS. REAL HOPE.

INVISIBLE PROJECT

IN

VISIBLE  
PROJECT

# OSTEOARTHRITIS AND CHRONIC LOW BACK PAIN

## Many Faces, One Goal:

— living despite pain —



11

INSPIRING PERSONAL  
STORIES FROM REAL PEOPLE  
WITH OSTEOARTHRITIS  
AND CHRONIC  
LOW BACK PAIN

DIVERSABILITY

OSTEOARTHRITIS AND CHRONIC LOW BACK PAIN

PATIENT STORIES + ADVICE ON ADVOCACY, TREATMENTS, AND MORE

# THE PROGRAMS OF U.S. PAIN FOUNDATION

As an organization serving tens of thousands of people with pain, U.S. Pain Foundation strives to offer a wide array of programs designed to help people wherever they are on their pain journey.

## **AWARENESS & ADVOCACY PROGRAMS**

INvisible Project  
Pain Ambassador Network  
Pain Awareness Month  
Pain Warrior Bracelet  
Advocacy Network  
People With Pain Matter  
Medical Cannabis Program

## **EDUCATION PROGRAMS**

Take Control of Your Pain  
Learn About Your Pain  
Pain Medicine 411  
National Coalition of Chronic Pain Providers and Professionals

## **SUPPORT PROGRAMS**

Pain Connection  
Pediatric Pain Warriors  
Veterans In Pain

## **FUNDRAISING PROGRAMS**

Real Hope, Real Heroes Gala  
Triumph Over Pain  
Points for Pain



**LEARN MORE AT: [USPAINFOUNDATION.ORG](https://uspainfoundation.org)**

# IN VISIBLE PROJECT



THE INVISIBLE PROJECT WOULD LIKE TO THANK ELI LILLY AND PFIZER FOR THEIR HUGE SUPPORT OF THIS CAMPAIGN. WE THANK THEM FOR WORKING HARD ON INNOVATION, WHICH IN TURN, GIVES HOPE TO PEOPLE WITH PAIN.



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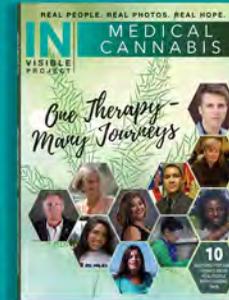
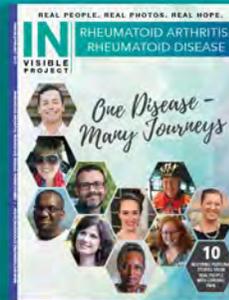
### NICOLE HEMMENWAY

Nicole Hemmenway is an author, motivational speaker, and patient advocate. Her book, *No, It Is NOT in My Head: The Journey of a Chronic Pain Survivor from Wheelchair to Marathon*, details her struggles and triumphs in dealing with a debilitating neurological and pain disorder. Nicole, who believes that all patients have a story to tell, currently serves as Chairman of the Board and interim CEO of U.S. Pain Foundation. She founded Heroes of Healing, a support group network, and directs the INvisible Project, a magazine and gala that highlight the courageous stories of people living with pain and other invisible conditions. In September 2015, Nicole was featured in the centerfold of *USA Today* as part of a chronic pain campaign, and in 2017, she received the Unsung Hero Award for her work in the pain community.



### JENNI GROVER

Jenni Grover is editorial advisor for the INvisible Project and a Pain Ambassador in the State of Illinois. She's also the founder of ChronicBabe.com, where she draws on her experience with fibromyalgia and other conditions to teach people to craft incredible lives despite illness. Since 2005, Jenni has taught thousands of people to take charge of their lives through her website, videos, and speeches around the world. Her book, *ChronicBabe 101: How to Craft an Incredible Life Beyond Illness*, was published in 2017.



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# IN VISIBLE PROJECT

The **INvisible Project** depends on support from our readers—people living with chronic pain, their caregivers, and those who want to help empower them, educate and raise awareness for people whose lives are touched by chronic pain.

If you would like to support our cause, you can do so in the following ways:

Go to our web site and donate online at [invisibleproject.org](http://invisibleproject.org)

**OR** Fill out the card and use a credit card or send a check. Mail the card in an envelope to: **INvisible Project**  
c/o U.S. Pain Foundation  
670 Newfield Street, Suite B  
Middletown, CT 06457  
Please do not send cash.

Your support makes the **INvisible Project** possible.

**YES**, I'd like to support the national campaign that is creating awareness, educating the public, and inspiring and empowering others.

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SIGNATURE: \_\_\_\_\_

# THE DETERMINATION AND STRENGTH OF PEOPLE IN PAIN WILL TURN THE TIDE

BY BEN MARSHALL, D.O., FAAPMR



## ABOUT DR. MARSHALL

Dr. Ben Marshall is an assistant professor at the University of Colorado, School of Medicine and a board-certified physician in physical medicine, and rehabilitation and pain management. He specializes in the non-operative management of musculoskeletal, spinal, and peripheral nerve injuries including interventional spine procedures and electrodiagnostic testing.

Nearly 84% of adults have experienced at least one episode of low back pain, which is the single leading cause of disability worldwide. Chronic low back pain and osteoarthritis are the primary constituents of an epidemic of chronic musculoskeletal pain, the treatment of which is estimated at \$240 billion, not including the associated lost wages, productivity, and quality of life.

Given the prevalence of this debilitating problem, one may assume that there is sufficient understanding—along with a matched sense of urgency—to address it. However, while some progress has been made in recent years, we are undoubtedly losing ground to a rising tide of chronic musculoskeletal pain across our society, which has doubled since the early 1990s. Increased health care utilization (e.g. physician visits, physical therapy, opioid medications, injections, and surgery) have been implemented in an attempt to better manage these maladies, without significant improvement.

The reason for this disconnect is not entirely apparent but can, in part, be attributed to deficits

in our current framework for understanding these complex conditions. For example, more than 95% of low back pain is classified as “mechanical low back pain”—a diagnosis meant to reflect a lack of a specific dangerous or progressive entity such as cancer or infection, but one that offers little specificity or differentiation between the cause and treatment of pain experienced by an 80-year-old car mechanic or a 21-year-old competitive athlete.

Despite these trends, I am optimistic that the tide will turn. With the rise in awareness of the opioid epidemic and the gradual shift in health care practices that emphasize patient outcomes, financial incentives and societal will has begun to turn towards making meaningful progress in the fight against chronic musculoskeletal pain.

But mostly I see the determination and strength of my patients and others, like those who have been brave enough to share their personal journeys with you through this project. Please read through their stories and understand that you are not alone. There is a silent majority who suffer with these ailments, yet still find joy and achievement despite them.

# IN

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PROJECT

## KEY MEMBERS OF THE U.S. PAIN FOUNDATION TEAM:

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U.S. PAIN FOUNDATION:  
**USPAINFOUNDATION.ORG**

INVISIBLE PROJECT:  
**INVISIBLEPROJECT.ORG**

**MISSION STATEMENT:**

The mission of U.S. Pain Foundation is to educate, connect, inform, and empower those living with pain while also advocating on behalf of the entire pain community. As a 501(c)3 non-profit organization dedicated to serving those who live with pain conditions and their care providers, U.S. Pain Foundation helps individuals find resources and inspiration.



# NATIONAL PAIN

## REPORT

*What you don't know can hurt you.*

The latest in PAIN NEWS

- Daily articles
- Reader stories

The screenshot displays the National Pain Report website interface. At the top, the logo reads "NATIONAL PAIN REPORT" with the tagline "What You Don't Know Can Hurt You". A navigation bar includes links for "N/P", "ABOUT US", "BLOG", "CONTACT", "ADVERTISE", "PRIVACY POLICY", and "TERMS OF USE".

The main content area features a featured article titled "Figures Lie and Liars Figure – Why the Demographics of the So-Called 'Prescription Opioid Crisis' Don't Work" by Richard A. Lawhern, Ph.D. The article includes a video thumbnail of a man speaking and a red "ADDICTIVE" stamp. Below the article are navigation arrows and a "BUILD & PRICE" button.

To the right, there is a "SUBSCRIBE TO OUR NEWSLETTER" section with input fields for "Email Address", "First Name", and "Last Name", a "Subscribe" button, and a search bar.

Below the main article, there are two more article teasers: "BACK PAIN" with an image of a hand on a back, and "FIBROMYALGIA" with a red "FIBROMYALGIA" stamp and the word "Fibromyalgia" in a stylized font. The fibromyalgia article is titled "Why Conventional Medical Doctors Fail Fibromyalgia Patients (and what to do instead)" by Donna Gregory Burch.

At the bottom right, there is a "Recent" comments section with two entries: "Researchers Develop New Painkillers, Reduce Overdose Risk" and "A Call to Arms for the Chronic Pain Community".

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# THE PREVALENCE—AND COST—OF OSTEOARTHRITIS

BY ALLISON NAPIER, B.S., CHES - PROGRAM ASSISTANT, OA ACTION ALLIANCE



## ABOUT ALLISON

Allison is a public health professional with knowledge and expertise in health behavior, program management, and health communications. She has a B.S. in Health Promotion and is a Certified Health Education Specialist (CHES).

Allison began her career serving in AmeriCorps as a Campus Compact. She was later competitively selected to join the Public Health Associate Program at the Centers for Disease Control and Prevention (CDC).

Allison currently works as a program assistant at the Osteoarthritis Action Alliance and is pursuing a Masters degree in Public Health Leadership.

Currently, more than 32.5 million adults of all ages, races, and ethnicities in the U.S. have osteoarthritis (OA). This means that 1 in 7 adults has OA.

The high prevalence of OA manifests in enormous societal and personal costs. Direct medical costs alone reach \$65.5 billion annually, with an average per person cost of \$2,018. The overall economic burden associated with OA is \$136.8 billion annually. This stunning figure has more than doubled over the last decade. For perspective, the annual economic cost of arthritis surpasses that of tobacco-related health effects, cancer, and diabetes.

Osteoarthritis, the most common form of arthritis, affects the cartilage in the knee, hip, hand, foot, and spine joints, with the knee being the most common site of pain. Previously, OA was known as a wear-and-tear disease; however, current thinking is that it is caused by excessive joint load and/or inflammation in the joint.

## WHO GETS OSTEOARTHRITIS?

Osteoarthritis is influenced by age but also by race, gender, occupation, nutrition, genetics, obesity, joint injury, joint shape, and malalignment.

Women bear a disproportionate burden of OA, with nearly 8 out of 10 adult women having the disease. Although older adults (ages 65 and older) make up only 20% of the country's population,

they make up almost half (40%) of those with OA. Additionally, women hospitalized due to OA outnumber men two to one.

The number of adults with OA will continue to increase with the aging population, leading to an estimated 78 million adults with arthritis (all forms) by 2040.

## THE IMPACT OF ARTHRITIS

In the U.S., 24 million adults are limited by arthritis in their everyday activities, such as holding a cup, lifting a grocery bag, or walking to a car.

Almost half of adults with osteoarthritis, 16.7 million, are working age (18 to 64 years). Disability among working-aged adults leads to an estimated annual \$71.3 billion in lost work earnings. With osteoarthritis being the leading cause of disability for U.S. adults, this leads to a great economic effect at the individual, community, and national levels.

Economic impacts are increased with co-morbidities such as heart disease, diabetes, and obesity; half of all adults with diabetes and heart disease and one-third of adults with obesity also have arthritis.

## PREVENTING AND MANAGING OSTEOARTHRITIS

However, OA is not an inevitable symptom of aging. There are strategies that can help to prevent and manage it.

Coalitions like the Osteoarthritis Action Alliance (OAAA) are committed to elevating OA

as a national health priority and promoting prevention policies and strategies that can help to curb this rising epidemic.

These strategies include physical activity, weight management, injury prevention, and self-management to prevent and/or manage OA.

You can learn more about these strategies and other resources to help you advocate for your care in the OAAA online resource library ([oaaction.unc.edu/resource-library](http://oaaction.unc.edu/resource-library)).

You can also attend events like Walk With a Doc in your local community to connect with your health care provider while being physically active. Promoting these cost-effective strategies, as well as increasing funding for research and better coordination between clinicians and patients, will help us address the burden of OA.

## RESOURCES

**Osteoarthritis Action Alliance:**  
[oaaction.unc.edu](http://oaaction.unc.edu)

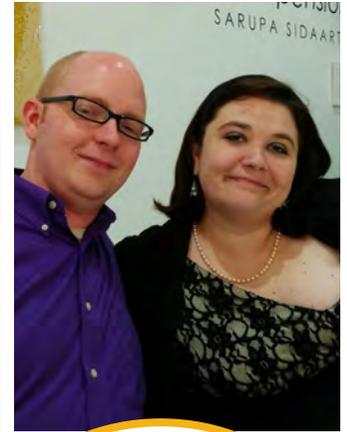
**Walk with a Doc:**  
[walkwithadoc.org](http://walkwithadoc.org)

One way we can all work to lessen the impacts of OA and other forms of arthritis in our communities is through education.

The U.S. Bone and Joint Initiative (USBJI) offers a public/patient education program called "Experts in Arthritis" at [ControlArthritis.org](http://ControlArthritis.org), including instructional videos in English and Spanish. USBJI encourages everyone to share these videos with anyone who may need more information.

# INSPIRE

STORIES THAT SHOW THE REALITY OF PAIN, AND BRING INSPIRATION AND HOPE



As you read the patient profiles in this edition of the INvisible Project, you will see that OA and chronic low back pain impact a broad range of people—and that they're able to utilize a wide variety of approaches to achieve relief and thrive. We hope you feel inspired by their stories!

## ➤ WHAT IS THE INVISIBLE PROJECT?

We strive to make visible the internal, often hidden challenges faced by those with chronic pain. We want to show what it's like to live with pain—and to thrive in spite of it. This project includes profiles of 11 people (and their families) living with osteoarthritis and chronic low back pain, with photos of them on their best days... and in their darkest moments. Our goal: to show the reality of life with pain, and why people living with it need and deserve more help, treatment options, and research while offering hope and inspiration. >>>



# IN PAIN, YOU'RE NOT ALONE

The INvisible Project and the U.S. Pain Foundation: A natural fit.



In 2010, Nicole Hemmenway was relatively new to activism. She had just written a book describing her journey living with chronic pain and was searching for more ways to become involved with the pain community. Nicole felt certain others would also benefit if they had an avenue to share their stories too.

However, she recognized that the pain journey was oftentimes difficult to describe in words. And she knew she wasn't alone in feeling this way! Many others could sometimes barely find the strength to explain how they were feeling. One look at their faces, though, and the pain was obvious.

## MAKING THE INVISIBLE VISIBLE

It was while attending a pain summit that Nicole connected with a small organization that would later evolve to the U.S. Pain Foundation. Putting their heads together, Nicole partnered with a fellow person with pain who was a professional photographer to create a project that would bring public visibility to the invisible, internal struggles of people living with chronic pain. That first year, nine people were featured in a magazine-style publication, with profiles by Nicole and professional photos, taken on a day in the life of each person.

But Nicole wasn't satisfied. "We realized that explaining a day in the life of a person with pain



Nicole Hemmenway, Vice President of U.S. Pain Foundation and Director of the INvisible Project

through images would necessitate more than a beautiful headshot—more than the edited perspective of a professional photographer’s lens,” says Nicole. “We needed to show the rough spots, the hospital visits and sleepless nights, to really put a face to what a person with chronic pain experiences daily.”

### SOMETHING THEY CAN HOLD

Thus was born the current version of the *INvisible Project* magazine, with tens of thousands of copies distributed to patients, caregivers, and health care providers. This publication highlights stories and photos from real people about their day-to-day lives.

“A magazine is an easy way to make sure people can access the project, return to it frequently for information and inspiration, and share it with others,” says Nicole. “When people have something they can hold, it feels more real, more reliable, and it can be a strong source of hope.”

### BARING THE TRUTH

During the past few years, individuals featured in the project have shared their stories—the good, the bad, and the ugly. People like Kelly O’Neill Young, who lives with rheumatoid disease and has spent years advocating for patients like herself at meetings around the U.S. “My daughter Kathrynne is now earning her Ph.D. in immunology because of the passion she developed attending scientific meetings with me,” says Kelly. “We hope to work together one day to advance understanding of rheumatic disease in a way that leads to new treatments.”

Stories like Kelly’s serve to inspire others with pain to share their stories, and that’s why the *INvisible Project* is an essential component of our programming. (For a copy of the rheumatoid arthritis/rheumatoid disease

edition that includes Kelly’s story, head to [INvisibleProject.org](http://INvisibleProject.org).)

### INVISIBLE ON THE ROAD

The U.S. Pain Foundation also offers traveling displays in a few different sizes for those who wish to hold awareness events. The photo displays are lightweight and easy to install, and they provide excellent visual impact at pain awareness events, disability expos, health fairs, medical conferences, and other public events.

Several Pain Ambassadors for the U.S. Pain Foundation have taken the displays to state legislatures, using the opportunity to educate lawmakers as they consider legislation that affects access to health care and veteran issues.

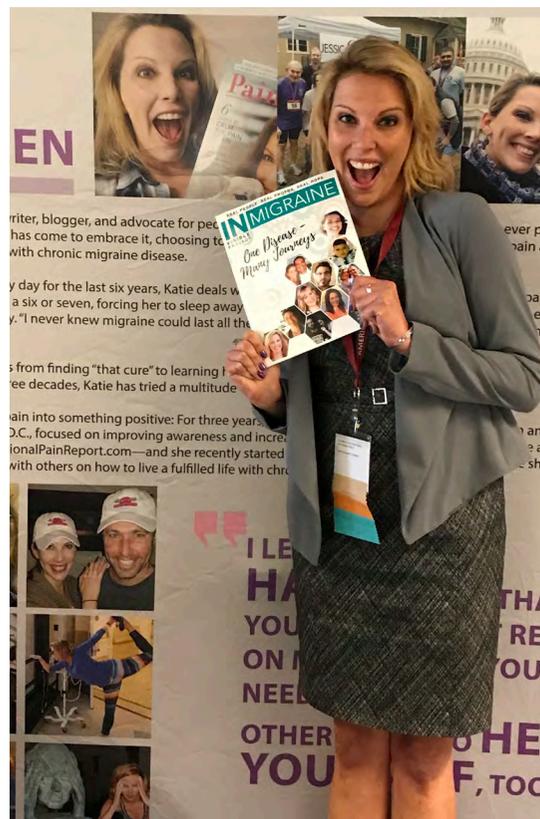
### WANT TO PARTICIPATE?

Do you want to share your story, to educate and inspire others? To put a face to the otherwise invisible challenges you face as a chronic pain patient? We welcome your ideas, and we’re looking for candidates for the next edition of the *INvisible Project* magazine.

➤ [Learn more and introduce yourself at INvisibleProject.org.](http://INvisibleProject.org)



Want to borrow some traveling displays for an awareness event? Contact the U.S. Pain Foundation. We make it easy for you to have access to powerful materials.



**Above:** Migraine expert Katie Golden standing in front of her *INvisible Project* display at the 59th American Headache Society Annual Meeting.

*“I just want to be happy every day. To do that, I created rules to live by: It is OK to fail as long as you learn. Know that asking for help makes you stronger. Try until you figure it out; just don’t give up. Keep moving forward—always. Do what makes you happy and have fun every day. You’ve got one life, make it a good one.”*

**BRYAN ANDERSON**  
INVISIBLE PROJECT: VETERANS

## U.S. PAIN FOUNDATION PROGRAMS

AS AN ORGANIZATION SERVING TENS OF THOUSANDS OF PEOPLE WITH PAIN, WE STRIVE TO OFFER A WIDE ARRAY OF PROGRAMS THAT HELP PEOPLE WHEREVER THEY ARE ON THEIR PAIN JOURNEY.

### AWARENESS & ADVOCACY PROGRAMS



#### PAIN AMBASSADOR NETWORK:

Volunteer Pain Ambassadors represent the organization in their communities across the country. They help individuals in need, organize educational events, connect with lawmakers to advocate for better health care laws, and more. Pain Ambassadors are the face of the U.S. Pain Foundation. To participate, go to:

[uspainfoundation.org/get-involved](http://uspainfoundation.org/get-involved).

**ADVOCACY NETWORK:** The U.S. Pain Foundation is dedicated to making sure people with pain are heard by policymakers at both the state and national level. We strive to improve policy and legislation in the areas of: high-quality treatment; patient safety; fair, accessible insurance coverage; innovation and research; and quality of life. Working each day to make sure people have access to necessary treatment options, we are raising awareness in hopes of ending the stigma associated with pain. To learn more, go to:

[uspainfoundation.org/advocacy](http://uspainfoundation.org/advocacy).

#### MEDICAL CANNABIS:

U.S. Pain offers a designated medical cannabis program led by two expert advocates. The program seeks to increase safe,

fair access to medical cannabis for people with chronic pain and provide education and training on medical cannabis as a treatment option.

For more information, visit [uspainmedicalcannabis.org](http://uspainmedicalcannabis.org).

#### PAIN AWARENESS MONTH:

During September, Pain Awareness Month, U.S. Pain hosts a number of activities, events, and campaigns to both empower and educate pain warriors and to increase awareness and empathy in the general public. Efforts include obtaining state proclamations; lighting up local landmarks and decorating local buildings in blue; op-ed drives; and more.

To learn more, visit: [uspainawarenessmonth.com](http://uspainawarenessmonth.com).



#### PAIN WARRIOR BRACELETS:

Our rainbow of colors represents all the many different conditions that cause pain. The bracelet itself is a constant reminder that we are strong, that we are warriors in the fight against pain. We rise above the idea of “suffering” and instead strive in spite of pain—and our bracelets help educate those around us.

Get your bracelet: [uspainfoundation.org](http://uspainfoundation.org).

#### PEOPLE WITH PAIN MATTER:

People with Pain Matter is a

national program designed to raise public awareness of the impact of chronic pain on the lives of nearly 100 million Americans. The goal is to encourage policymakers, members of the media, and other stakeholders to recognize the needs of people with chronic pain and to enact public policy that better supports the pain community. Get involved today: [peoplewithpainmatter.org](http://peoplewithpainmatter.org).

### EDUCATION PROGRAMS

#### LEARN ABOUT YOUR PAIN:

This website is designed for the newly diagnosed who are looking for concrete, credible information. Browse the directory of pain conditions to learn more and gather resources. Start learning today: [learnaboutyourpain.com](http://learnaboutyourpain.com).

#### PAIN MEDICINE 411:

This website shares credible information regarding medications. Discussing the risks and benefits involved with prescription drugs, Pain Medicine 411 empowers patients to make informed decisions about their personal treatment program. Learn more: [painmedicine411.org](http://painmedicine411.org).

#### TAKE CONTROL OF YOUR PAIN:

These daylong seminars for patients offer the chance to share their perspectives with others who have had similar experiences. We also invite health care providers to discuss the latest advances in pain management and complementary therapies. Find out about the next event: [uspainfoundation.org/tcoyp](http://uspainfoundation.org/tcoyp).

**NATIONAL COALITION OF CHRONIC PAIN PROVIDERS AND PROFESSIONALS (NCCPPP):** This network of

health providers, professionals, and organizations has come together in a coalition to more efficiently and effectively serve the chronic pain community. To become involved: [nccppp.org](http://nccppp.org).

### SUPPORT PROGRAMS

#### PAIN CONNECTION:

Pain Connection helps individuals with chronic pain by empowering them to connect with other pain warriors and develop strategies for coping. It offers in-person support groups, live conference calls, military outreach, and support group leader trainings, so people with chronic pain and their families gain the support they need. For more information: [painconnection.org](http://painconnection.org).

#### PEDIATRIC PAIN WARRIORS:

The Pediatric Pain Warriors program assists children and their families in finding a network of support and community. This program offers scholarships to a special camp, dedicated resources, and works to advance research for pediatric patients. To find help, visit: [pediatricpainwarrior.org](http://pediatricpainwarrior.org).

#### VETERANS IN PAIN:

U.S. Pain Foundation is proud of our American heroes. It is of the utmost importance that our veterans receive the proper care, benefits, and support they deserve and need. We partner with Wings for Warriors ([wingsforwarriors.org](http://wingsforwarriors.org)) to support combat-wounded military service members. Additionally, our Veterans in Pain program offers emotional support and help to veterans and military members. To get started: [uspainfoundation.org/veterans](http://uspainfoundation.org/veterans).

# ANKLE ARTHRITIS: A CASE STUDY

A doctor explains joint arthritis, and shares how she treated one of her patients.

BY CASEY JO HUMBYRD, M.D.



**M**y patient came into the office, limping and using a cane. She was 31 years old and in constant pain. Before getting her an X-ray, I asked what brought her into the office.

She had an ankle fracture treated with surgery 10 years ago, she said, and since then the ankle hadn't been the same. In recent years, her pain went from intermittent—only noticeable with bad weather—to a constant, dull ache requiring the cane. I obtained a weight-bearing X-ray, which confirmed my fears: at 31 years of age, my patient had end-stage ankle joint arthritis.

## PREVALENCE OF ANKLE ARTHRITIS

More than 50 million Americans have arthritis, including 4 million Hispanic adults and 6 million non-Hispanic black adults. Arthritis can impact any joint, but it is most common in the hips, knees, and shoulders. Most of the arthritis is caused by “wear and tear” and is called osteoarthritis or primary osteoarthritis. In contrast, ankle arthritis most often occurs in patients who have had a traumatic injury, commonly an ankle fracture, a severe sprain, or

a sports injury.

The worse the injury, the higher likelihood of future arthritis. Approximately 80% of ankle arthritis is due to a prior injury.

## DISPARITIES IN TREATMENT

Based on limited studies, it doesn't seem that ankle arthritis is more common in communities of color, though hip and knee arthritis is more common within this population. Unfortunately,

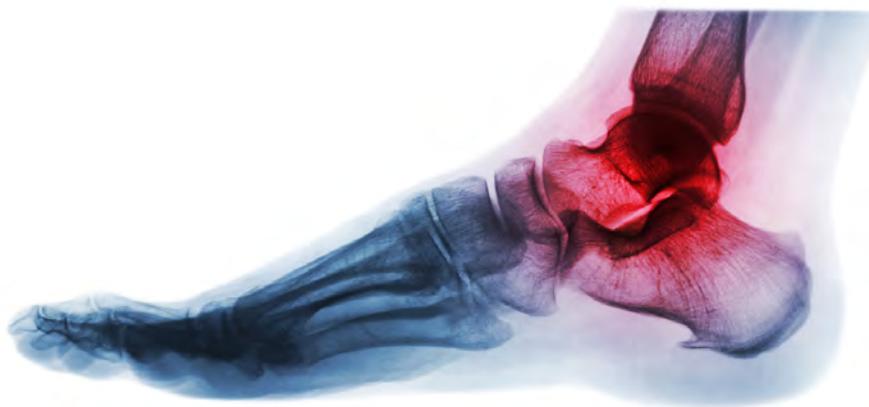
while black patients are more likely to have arthritis, they are also less likely to be treated for their arthritis.

This is true for all joints, including hip, knee, and ankle. White patients receive four times as many ankle replacements as black patients, which is even worse than the discrepancy seen in hip and knee replacements. While we have known about these differences in total joint replacement for many years, we don't yet know why they occur or how to best fix them.

## TREATING A SEVERE CASE

I told my patient her diagnosis. I explained that arthritis is when a joint loses its cartilage. Cartilage is the smooth tissue at the intersection where bones meet to form a joint. It allows sliding and gliding, which is why we can bend our elbows, knees, and ankles, and swivel our hips and shoulders. I explained that without the cartilage, her bones were now rubbing against each other, creating inflammation and pain—and that there is no cure for arthritis.

Initial treatment of arthritis begins without surgery. Modifying athletic activities helps; lower impact activities like biking and swimming are easier on the joints. Bracing can be very helpful to support the painful joint. Sometimes we can modify a shoe to a rocker bottom, which can unload the ankle joint. Anti-inflammatories such as naproxen or ibuprofen also help. Steroid injections into the joint can help with the symptoms, though it doesn't offer a long-term cure and will not change the arthritis.



## INSPIRE

In my patient's case, I also discussed another treatment option: weight loss. My patient weighed 215 pounds and was 5'1", making her "obese" by body mass index calculation. While discussing weight loss is always challenging, I advise patients about the benefits for their joints.

While weight loss will not cure her arthritis, it will decrease the force on her joints, likely improving her pain.

### SURGICAL OPTIONS

When non-surgical treatments are no longer providing adequate pain relief, I begin to discuss surgery. There are two surgical treatment options: ankle fusion (also called arthrodesis) or ankle replacement (also called arthroplasty).

In a fusion, the two major bones that make up the ankle joint are fused together using metal hardware. The two bones then become a single bone. This surgery is incredibly suc-

cessful for pain relief, though it is not without potential complications.

Ankle replacement is a newer procedure. Similar to hip and knee replacement, the bones around the ankle joint are replaced with metal and plastic. This allows preservation of motion in the ankle, unlike in a fusion. The downside of a replacement is that the durability isn't as certain as the ankle fusion, and high-impact activity (for example, running and jumping) is generally discouraged.

In my patient, I helped her get a brace and she tried aqua therapy to improve her cardiovascular health. She did a weight loss program as well as steroid injections. All of this improved her symptoms but didn't remove the pain, which gradually progressed over the next year. Ultimately, my patient decided to undergo an ankle fusion, and for the first time in 10 years, she was able to run and play with her children.



### ABOUT DR. HUMBYRD, M.D.

Casey Jo Humbyrd, M.D., is an Assistant Professor of Orthopaedic Surgery in the School of Medicine at Johns Hopkins University. She is an Associate Faculty Member of the Berman Institute of Bioethics. Dr. Humbyrd's research interest focuses on ethical concerns related to surgery in general and orthopedic surgery in particular. Nationally, she is involved in advocacy work as an alternate delegate to the American Medical Association and Chair of the Health Policy Committee of the American Orthopaedic Foot and Ankle Society.

## NICOLE HEMMENWAY

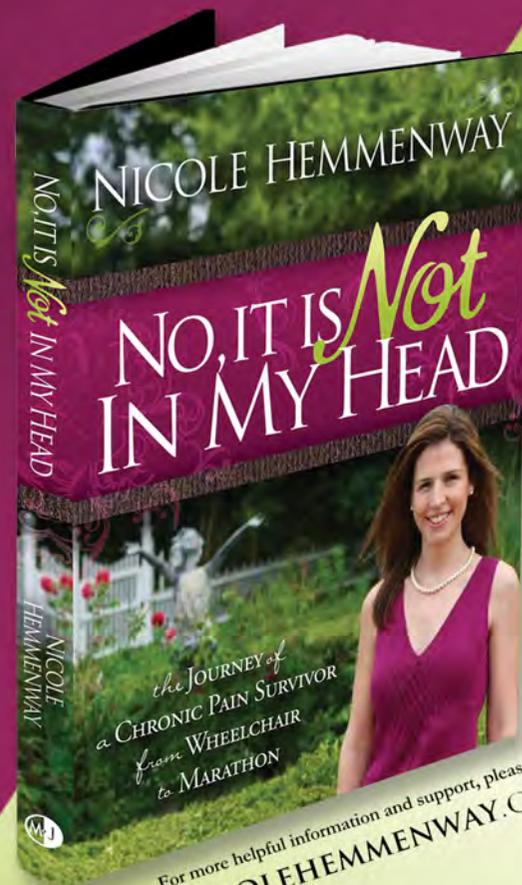
*Author, Speaker &  
Chronic Pain Advocate*

*"You still control how you cope with the pain. Becoming empowered and involved is key to taking control of your pain and living a proactive, fulfilling life again."*

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# CURRENT AND FUTURE THERAPIES FOR OSTEOARTHRITIS

BY COREY GREENBLATT - GRADUATE FELLOW, GLOBAL HEALTHY LIVING FOUNDATION

Often referred to as “wear and tear” arthritis, osteoarthritis (OA) is the most common form of arthritis in the U.S., affecting over 30 million Americans. For those living with OA, joint pain and damage (often in the ankles, hands, hips, and knees) develops slowly, and progressively gets worse. While OA affects men and women over the age of 55 in very similar rates, factors such as obesity, trauma, and a history of athletic activity also can lead to a diagnosis of OA at a younger age.



## ABOUT COREY

Corey Greenblatt is a current Graduate Fellow for Legislative Affairs with the Global Healthy Living Foundation, a non-profit patient advocacy organization that supports increased access to treatment and advocates on behalf of patients with autoimmune disease and chronic pain management.

## COMMON OA TREATMENTS

OA can be diagnosed by rheumatologists, orthopedists, or primary care physicians who may recommend a nonpharmacological treatment approach before moving on to medication. Weight loss (for knee OA), exercise, and physical therapy are all shown to have a positive impact in managing OA pain and improving function. For patients trying to avoid medical or surgical interventions, working with physical therapists to exercise and strengthen the muscles around the damaged joint has proven to be an effective initial treatment option.

Should pain not diminish, patients can work with their physician to develop a multi-faceted treatment approach. As noted in the recently published “Raising the Voice of Patients: Living with Osteoarthritis” (developed by CreakyJoints, a GHLF community), OA cannot be cured; however, it can be managed. The table on the next page describes some of the most commonly available medication treatments.

Regarding the most common therapies, Dr. Vinicius Domingues, a practicing rheumatologist in Daytona, Fla. and medical advisor to CreakyJoints, says “Despite a good variety of OA medication options, our tool kit and approach in treating OA has not changed substantially

in 20 years. We can treat pain and try to slow progression, but some patients will inevitably get to the point where joint replacement surgery is a serious consideration. People with OA need to feel empowered to ask probing questions about joint replacement surgery options.”

A research team at CreakyJoints recently completed a two-year project called BeTTER SAID (Bringing STakeholders Together for Engagement in Research for the Selection of Arthroplasty Implant Devices) which identified the decisions that are most important to patients about joint replacement. Deciding on the timing of surgery (i.e., when is OA bad enough to have hip or knee replacement?) was the most important decision, followed by choice of surgeon and clinic.

*“The investigation of OA medications that offer long-term pain relief while addressing actual healing via cell and cartilage regeneration is the most exciting development in OA treatment in the last 25 years.”*

— DR. VINICIUS DOMINGUES

## TREATMENT BREAKTHROUGHS

Many patients report benefits from incorporating complementary and alternative medicine (CAM) therapies into their management strategy. Some common CAM therapies include acupuncture, nutrition/dietary supplements, hydrotherapy, and massage therapy, among others. As always, before actively engaging in integrative medicine or complementary therapies, consult with your doctor.



From a medication perspective, emerging regenerative therapies, called DMOADS (Disease Modifying Osteoarthritis Drug for OA), are of interest to the scientific community as they have shown potential to go beyond temporary symptom relief alone by promoting cartilage repair and regeneration within a joint.

Several different drugs and biologics are in development in the U.S. and have not yet been approved by the FDA. But Dr. Domingues says, “The investigation of OA medications that offer long-term pain relief while addressing actual healing via cell and cartilage regeneration is the most exciting development in OA treatment in the last 25 years.”

### ARTHRITISPOWER

OA is incredibly common. People with OA and their physicians need to work collaboratively to develop a treatment plan that meets the individual patient’s functional goals.

ArthritisPower, the first ever patient-led, patient-centered research registry for joint, bone, and inflammatory skin conditions created by CreakyJoints, can be used to track symptoms and a person’s response to treatment. If, before an appointment, the patient emails their data to their doctor, it facilitates a data-driven conversation during appointments. If each individual visit to a doctor’s office shows a photograph of the patient’s life, ArthritisPower allows doctors to view the full film and make more informed decisions.

Simultaneously, because ArthritisPower is a research registry, when patients enter data, it is collected and used in research that improves understanding of arthritis. For more patient-friendly information on osteoarthritis symptoms, treatments, advice, and more, visit [CreakyJoints.org](http://CreakyJoints.org) and download the Osteoarthritis Patient Guidelines.

Medication Class	How it Works	Considerations
<b>Analgesics (oral)</b>	<ul style="list-style-type: none"> <li>Includes medicines like: oxycodone, morphine, codeine</li> <li>Available both over the counter (OTC) (low dose) and by prescription (high dose)</li> <li>Commonly used in pill form or as a topical cream</li> </ul>	<ul style="list-style-type: none"> <li>Stronger analgesics, such as opioids, can lead to dependence</li> <li>Common side effects may include: constipation, nausea, vomiting</li> <li>Potentially more expensive, but often covered by insurance (check your individual plan)</li> </ul>
<b>NSAIDs (oral)</b>	<ul style="list-style-type: none"> <li>Includes medicines like: aspirin, ibuprofen, naproxen</li> <li>Available OTC but higher doses can be recommended by health care providers</li> <li>Long history of use for headaches, joint/muscle pain, menstrual cramps</li> </ul>	<ul style="list-style-type: none"> <li>Overuse can be a problem because OTC medicine is so readily available</li> <li>Side effects may include: decreased appetite, rash, ulcers, and gastrointestinal upset</li> <li>Potentially less expensive than prescribed treatments, but they may not be covered by insurance</li> </ul>
<b>Hyaluronic acid injections</b>	<ul style="list-style-type: none"> <li>A natural, gel-like, lubricating substance that acts as a shock absorber in your body</li> <li>Injected directly into the knee joint for targeted and stronger pain relief</li> <li>Only approved for use in the knee</li> </ul>	<ul style="list-style-type: none"> <li>A series of three to five injections is required for the pain to subside, and on average it takes five weeks to experience full benefits</li> <li>About 40% of patients do not respond to injections</li> <li>Limited evidence to prove the long-term efficacy of these injections</li> </ul>
<b>Glucosamine Chondroitin</b>	<ul style="list-style-type: none"> <li>A natural lubricant taken orally, usually as a tablet</li> </ul>	<ul style="list-style-type: none"> <li>Some studies show it is effective and some show no efficacy. It can be taken individually or in a glucosamine chondroitin combination</li> </ul>
<b>Anti-inflammatory supplements</b>	<ul style="list-style-type: none"> <li>Includes specialized pro-resolving mediators, usually as gels, which some believe have ultra-inflammatory reducing properties</li> </ul>	<ul style="list-style-type: none"> <li>They can be expensive, and while considered to be without side effects, there are no clinical trials that prove efficacy</li> </ul>
<b>Natural pain supplements</b>	<ul style="list-style-type: none"> <li>Includes turmeric, devil’s claw root, capsaicin/capsaicin (from chili peppers), and others</li> </ul>	<ul style="list-style-type: none"> <li>Some patients say these are not strong enough to effectively reduce pain.</li> </ul>

(For more comprehensive information, visit [CreakyJoints.org/patientguidelines](http://CreakyJoints.org/patientguidelines) to download “Raising the Voice of Patients” for free.)



# THERAPEUTIC OPTIONS FOR CHRONIC LOW BACK PAIN

BY **JULIE PILITSIS, M.D., PH.D.** - ALBANY MEDICAL COLLEGE, DEPT OF NEUROSURGERY;  
AND **CHARLES ARGOFF, M.D.** - ALBANY MEDICAL COLLEGE, DEPT OF NEUROLOGY



We all know somebody who has suffered with low back pain. Maybe it was one of our parents, whose back went out—and who asked our other parent to walk on their back. Or maybe we watched the President on the TV show *Scandal* hurt his back by performing some overly aggressive yoga.

For most people, these acute back pain episodes are short-lived. Though excruciatingly painful, they will often resolve with the use of over-the-counter anti-inflammatory medications, chiropractic manipulation, stretching, heat, massage, or warm showers.

Unfortunately, in some cases pain does not resolve and people seek medical care. Even in these cases, back pain and sciatica (leg pain that extends down from the lower back) often resolve with conservative (non-surgical) therapy.

## CONSERVATIVE THERAPIES— MOST PATIENTS START HERE

Conservative therapy can refer to the techniques discussed above, as well as additional anti-nerve pain medications, muscle relaxants, acupuncture, physical therapy, and other modalities.

In less-common cases where pain is not self-limited (ending in a period of time without treatment), a physician will then order an MRI of the area and if there is anything amenable to surgery, a surgical consultation is sought.

Very few medical communities are the same; the method of referring a patient for surgical treatment will vary from place to place. Sometimes the surgeon orders further conservative care, like additional physical therapy or a directed exercise program, core strengthening, weight loss, or maybe a referral to pain management for injections. Typically, for pain radiating into the leg, these are epidural steroid injections; for back pain, these are facet injections.

Newer techniques, such as radio-frequency lesioning, may also be considered by a pain management physician. Although the vast majority of people with an episode of low back pain improve, approximately 10% of patients will go on to have surgery. Not all surgeries are successful, and some people will go on to experience chronic pain. If doctors find a back issue that could be

amenable to surgery, at this point, it may be the patient's best option.

## SURGICAL THERAPY—GET A SECOND OPINION

Surgery is only an option in people who develop pain despite these therapies—pain that interferes with quality of life. Surgeries can be highly variable based on the type of pathology in the spine.

If a patient suffering with back pain is offered a surgical option, we recommend that they get another opinion—and make sure that the opinion is not just for surgery, but about what type of surgery should be done. Some patients receive relief quickly from surgery.

It should be noted that in cases where you have any weakness in the legs, or any problems with your bowel or bladder, a complete return to normal function in a short period of time is not normal.

In cases where surgery is not an option, and after medical management has failed, neuromodulation techniques such as spinal cord stimulation and intrathecal pumps should be considered.

## SPINAL CORD STIMULATORS—A PERMANENT APPROACH

When surgery is not indicated, spinal cord stimulation may be an option.

In spinal cord stimulation, a device is implanted (or placed) near the

spine. It's designed to "trick" the nervous system into not feeling pain. Basically, the signals that administer pain are blocked in some fashion, often by causing a signal that leads to a vibration or tingling sense. This can be an extremely effective treatment in many people.

Spinal cord stimulation device technology has improved greatly over time, leading to even better therapeutic options. This is a permanently implantable device, so it is important to make sure that you and your doctor have decided on a device that you are most comfortable living with.

## INTRATHECAL PUMPS—FOR THOSE WITH ONGOING DEGENERATION

In cases where chronic low back pain is due to something that is ever-changing, such as in a person with osteoporosis and multiple levels of spine fracture, the patient will likely continue having fractures and be ineligible for surgery. Another option could be an intrathecal pump.

The pumps give a patient the option of delivering medication directly to the affected area, instead of waiting for oral medications to absorb. Traditionally, intrathecal pumps have provided opioid medications for patients, but today, some non-opioid options also exist—and should be considered.



### About Dr. Pilitsis

Julie G. Pilitsis M.D., Ph.D. is a Professor of Neurosurgery and of Neuroscience at Albany Medical College and Chair for the Department of Neuroscience and Experimental Therapeutics. Dr. Pilitsis is an active member on several National and International Neurosurgery and Neuromodulation Committees. She began the NANS Women in Neuromodulation Section, where she

was the first chair and currently serves as senior advisor. Dr. Pilitsis maintains an NIH-sponsored research program focused on device optimization for neuromodulation and has published over 100 journal articles, four books, and numerous chapters. She serves as section editor of functional neurosurgery in *Operative Neurosurgery*, is on the editorial board of *Neuromodulation*, and sits on multiple NIH study sections.



### About Dr. Argoff

Charles E. Argoff, M.D. is Professor of Neurology at Albany Medical College and Director of the Pain Management Fellowship at Albany Medical Center. Dr. Argoff is a member of the American Academy of Neurology, the IASP, the AAPM, the APS, and Neuropathic Pain Section Co-Editor for Pain Medicine.



# COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) FOR OSTEOARTHRITIS AND CHRONIC LOW BACK PAIN

*Four providers explain how their techniques help.*

## KATE CAMPOS

**LICENSED ACUPUNCTURIST  
AND HERBALIST**

*invigorateacupuncture.com*

Acupuncture releases muscular trigger points, interrupts pain signals, and starts an immune response, which promotes healing and lessens pain.

Acupuncture reduces inflammation, which can diminish aching and swelling in the joints. Some herbal formulas reduce pain and inflammation without the harsh side effects of NSAIDs like ibuprofen.

Acupuncture has been proven in clinical trials to be effective in treating lumbar disc herniations, lower back muscle spasms and sprains, and chronic low back pain. Cupping can also provide relief for built-up muscle tension often found in those with chronic low back pain.

A big misconception is that acupuncture is painful. Acupuncture needles are very fine (about the size of a hair) and although you may have some initial mild discomfort, once they are in place, there should be no discomfort and most people relax and even sleep.

Another misconception is that it is strictly energy-based and that you have to believe in things like “qi” for it to work. The insertion of a needle sends a signal to the brain to start pushing blood to certain areas. Lack of proper blood circulation means that the tissue isn’t receiving the oxygen and nutrients to repair and regenerate. Chronic pain often means that the body has given up trying to send new blood to the area in order to preserve the rest of the body; acupuncture works to re-establish the connection and improve blood flow.

## JOHN WHITE

**PILATES PRACTITIONER**

*johnwhitemovement.com*

I teach physical conditioning to improve strength, flexibility, balance, control, posture, and breathing. I draw from Pilates, Gyrotonic®, Gyrokinesis®, yoga, and dance.



For osteoarthritis my motto is: “If it hurts, do a little.” If you do nothing, you lose ability—and if you do too much, you risk injury and setback. I work to maintain or improve range of motion and to develop good body mechanics for daily tasks and chores.

My approach with low back pain is to identify the movements that alleviate and the movements that exacerbate and build a workout around them. Strengthening “the core” is always essential. Also essential is stretching tight leg and hip muscles. Movement education is needed to learn how to do all the things you want to do in life without further hurting your back.

It seems everyone has heard of “so-and-so who hurt their back doing yoga or Pilates.” I can assure you that many more have used these methods to ease pain, improve health—even avoid surgery.

Our bodies have an innate wisdom based on a lifetime of experience. That is why the relationship between patient and therapist should be collaborative. I make an effort to remain open and receptive to the intuitive knowledge my students share with me, and to let that inspire my teaching.

## GWENN HERMAN, LCSW, DCSW

**LICENSED CLINICAL  
SOCIAL WORKER**

*gwennherman.com*

I employ a variety of approaches and techniques, including cognitive therapy, reality therapy, communication skills, problem solving, assertiveness training, role playing, sculpturing, gestalt therapy, guided imagery, meditation, hypnotherapy, art therapy, and 12-step programs.

Because I have been living with chronic pain for 23 years, I share my journey with my clients—so they can see what is possible.

I teach clients with OA and/or chronic low back pain how to: deal with personality changes; normalize their pain; change their messages to the brain; navigate the grief process; reorganize their daily schedule; learn to pace themselves; develop realistic expectations; help communicate their pain to medical providers and family; use guided imagery; incorporate breathing techniques and meditation; re-create themselves; and develop an individualized treatment plan.



**DAVID YRIGOYEN****MEDICAL CANNABIS EXPERT***naturalhealingcarecenter.com*

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Herbs (including cannabis) and alternative medicine have been used to treat numerous conditions for thousands of years. When using alternative medicine, it is best to be patient and consistent for the first few months. The body can do wonderful things, but it needs time to adjust and get acclimated to herbs or treatment.

Our most popular service is the Arizona Medical Marijuana Card Certification. For arthritis and back pain, cannabis can be applied topically for instant, non-psychoactive relief on a targeted area, or ingested for long-lasting and preventative relief.

**WHY TUCSON?**

There are CAM practitioners all over the U.S., but Tucson has a particular draw. “Tucson is located in the basin of five beautiful mountain ranges, and nature permeates into everyone’s daily lives,” explains David. “We believe this connection to nature allows Tucson residents to open their minds to natural medicine.”

“We are lucky to have the Arizona Center for Integrative Wellness, Dr. Andrew Weil’s program that introduces doctors to how CAM therapies can be useful to their patients,” says Kate. “Couple this with an open-minded population and these therapies become ‘normal’ to the public.”

**> Learn more:**

National Coalition of Chronic Pain Providers & Professionals: [nccppp.org](http://nccppp.org)

National Association of Complementary and Alternative Medicine: [nacams.org](http://nacams.org)

National Center for Complementary and Integrative Health: [nccih.nih.gov](http://nccih.nih.gov)

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# THERE'S LIFE AFTER A HERNIATED DISC

BY DR. PETER ABACI



**W**hat do you do when your doctor diagnoses you with a herniated disc in your lower back? Well, first off: don't panic! How you approach this new piece of information has a lot to do with your particular clinical situation. For starters, think closely about where you feel your pain. Is it mostly in your lower back, or do you feel the most intense symptoms going down one leg?

Experiencing pain primarily in the lower back is a common problem that will afflict two-thirds of the population at some time. The causes of low back pain are often nondescript and difficult to define. In other words, it can be difficult

to accurately pinpoint factors contributing to the ache in your back, and evidence dictates that ordering an MRI for back pain is not really cost-effective when it comes to adding value to the treatment process.

But if your doctor went ahead and got the MRI for you anyway, don't assume that just because the radiologist found a herniated disc that this finding is clinically relevant. In fact, past studies have shown that a large proportion of asymptomatic volunteers do have herniated discs in their lower spines even though they don't have symptoms. When it comes to choosing management strategies for your back ache, it may

not be all that helpful to approach it as a herniated disc problem.

On the other hand, if most of your pain is shooting down one leg or the other, a symptom often referred to as sciatica, then an MRI finding of a herniated disc may be much more relevant. Herniation means that disc material, including the outer cartilage annulus and inner gelatinous annular elements, has pushed out beyond the normal margins of the disc space. When this happens, nerve roots can get irritated by the mechanical pressure exerted on them as well as by chemical inflammation created by the herniation.

The pain associated with a nerve

root irritated by a herniated disc can be acutely intense, and it is often described as shooting, electrical, sharp, or like pins and needles. A pinched nerve root can also lead to annoying numbness down the leg, as well as muscle weakness when the motor nerves that communicate with specific muscles in the leg are affected. In some cases, foot drop can occur, characterized by difficulty pointing the foot up, or conversely, weakness pointing the foot down to lift the heel off the ground. The end result of all of this is that sciatica from a herniated disc can, in some cases, become quite debilitating.

The good news is that the body is well-equipped to recover and heal from a herniated disc, meaning the odds are in your favor to get better over time! Consider these facts:

- **Research shows that in most cases (up to 87%) the pain subsides after an average of three months.**
- **Sciatica pain usually improves without surgery.**
- **Muscle weakness usually improves over time (81% recovery rate in the first year).**
- **Leg and foot numbness may be more persistent but will resolve in the first year 50% of the time.**
- **Herniated discs shrink over time, with an estimated 76% resolved after one year.**

So what do you do when faced with what appears to be a symptomatic herniated disc? Given that the odds are good for a meaningful recovery in the three- to 12-month range after the problem starts, I usually recommend taking a conservative approach whenever possible while trying to give the body its best chance to heal.



Unfortunately, finding relief can be hard to come by while waiting out the healing process. Studies have not found opioids to be more effective than nonsteroidal anti-inflammatory drugs (NSAIDs) like ibuprofen or naproxen in treating back pain or sciatica. We also know that bed rest is not helpful, and excessive avoidance of activity can lead to delays in recovery. Moving the body when it is feeling intense pain can be tricky, though. (Here are some tips: [bit.ly/exercisewithbackpain](https://bit.ly/exercisewithbackpain).)

Alternative approaches that may help include acupuncture and chiropractic treatment, and if symptoms persist beyond the first month, epidural cortisone injections have been found to provide mostly short-term relief. While more immediate relief can be found after surgery, studies have not found any benefit to surgery over conservative care after the first year, although surgery may be considered when bad neurologic deficits are present.

The good news is that for most of us, there is a good chance the effects of a herniated disc will subside over time if we can hang in there and work through it.

*Dr. Abaci usually recommends conservative treatment in the first year after diagnosis. This may include complementary and alternative medicine (CAM) techniques like acupuncture.*



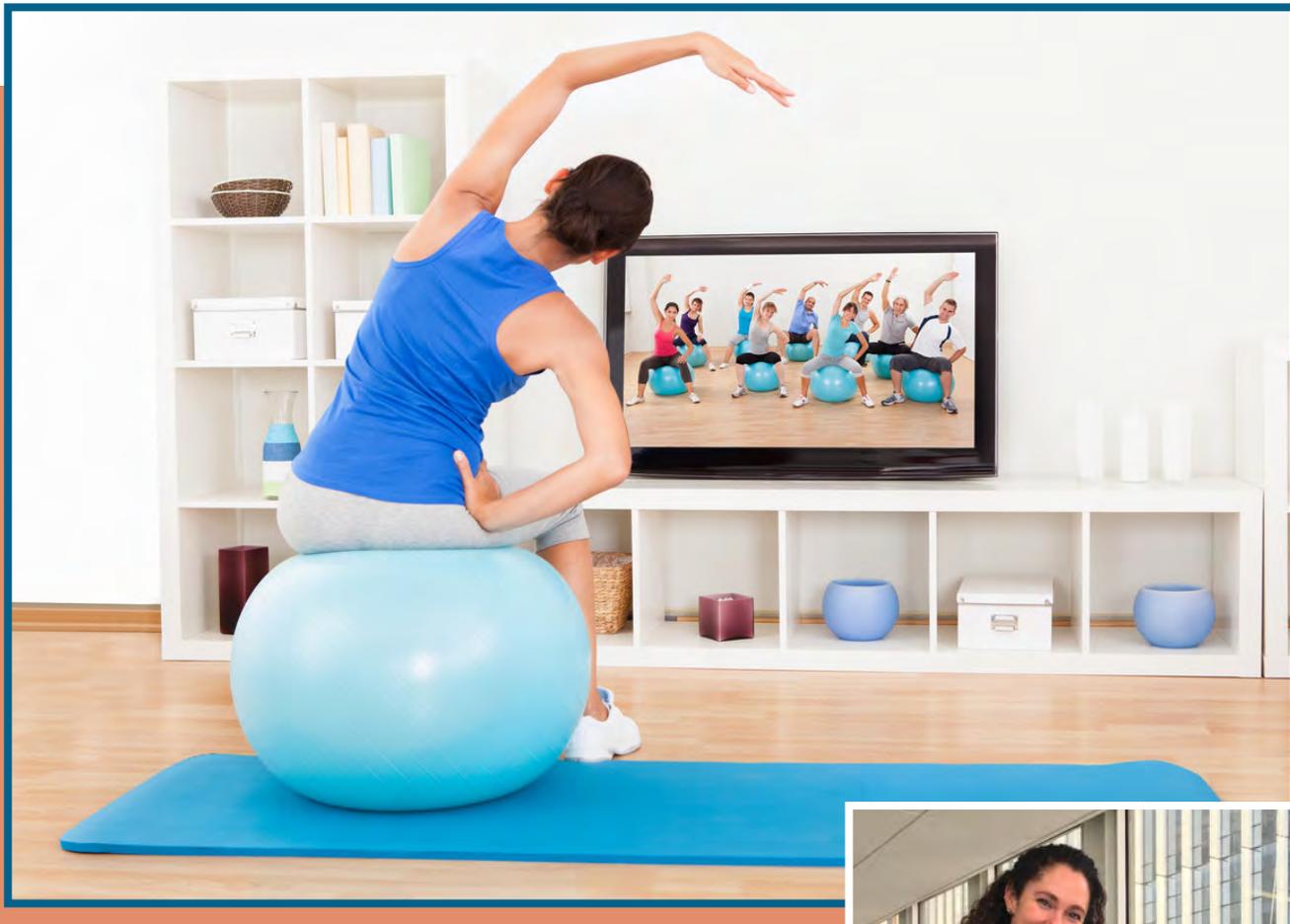
#### About Dr. Abaci

Peter Abaci, M.D., is certified in anesthesia and pain management by the American Board of Anesthesiology. He serves as the Medical Director of the nationally recognized Bay Area Pain and Wellness Center, located in Los Gatos, California, which he cofounded with Dr. John Massey. A widely respected expert on chronic pain management and a highly successful chronic pain sufferer, he is the author of two books, including *Take Charge of Your Chronic Pain: The Latest Research, Cutting-Edge Tools, and Alternative Treatments for Feeling Better*.

# PHYSICAL AND OCCUPATIONAL THERAPY: AN ACTIVE APPROACH

A CONVERSATION WITH **ELIZABETH GAFFRON**, MOTR/L, LMT, AND **HANNAH NILLES**, PT, DPT, CERT. MDT

BY **JENNI GROVER**, FOUNDER OF CHRONICBABE AND U.S. PAIN AMBASSADOR—ILLINOIS



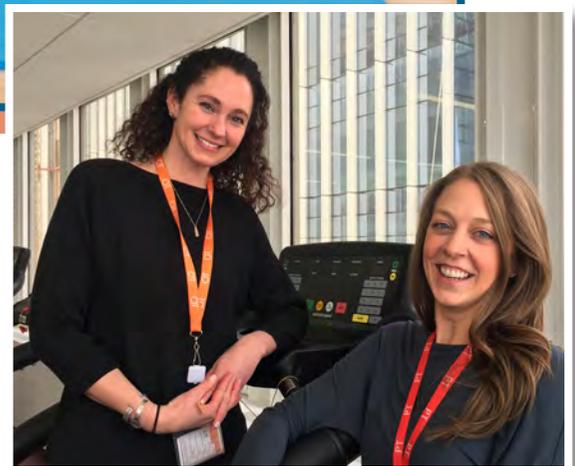
The Pain Management Center at Shirley Ryan AbilityLab in Chicago is one of the world's leading interdisciplinary pain clinics. I caught up with occupational therapist Elizabeth Gaffron and physical therapist Hannah Nilles to talk about how they work with patients with chronic low back pain. Together, they have more than 15 years of experience at Shirley Ryan AbilityLab—and share a passion for empowering patients.

**Hannah:** Patients with chronic low back pain tend to be passive pain management users, commonly relying on ice and heat

packs, staying in a recliner, having weekly chiropractic or massage appointments. More than any other population, they tend to use passive approaches to managing their pain, for many years.

**Jenni:** Why is that?

**Elizabeth:** It's culturally ingrained that at some point, you're going to have back pain if you're in certain fields; we've accepted it as a culture that this is normal. Many of our workplace demands are in static positions. And people in more labor-intensive



*Elizabeth Gaffron, Occupational Therapist, and Hannah Nilles, Physical Therapist, work at the world-renowned Shirley Ryan AbilityLab Pain Management Center in Chicago.*

positions feel like good posture and mechanics are never an option because the emphasis is always on working their fastest.

**Hannah:** Our physical environment, work culture, and societal expectations cultivate a myth that pain management is done outside of the functional environment instead of integrating it into your life. Plus, our media is filled with buzzwords like “herniated disc” or “bulging disc” that scare people into seeing a doctor and getting a “fix” without being aware of all the other options that are non-pharmacological or non-invasive. People gravitate to “quick” fixes that don’t provide long-lasting relief.

**Elizabeth:** Patients rarely ask: What is my responsibility for my own body? They seek health care providers to “fix” them—there’s that passivity—as opposed to thinking, ‘I’m seeking health care solutions to help myself.’

**Jenni:** If our culture is focused on passive approaches, how can we empower patients to take a more active approach?

**Hannah:** We need to treat pain as not just a musculoskeletal issue. So many factors contribute to the pain...

**Elizabeth:** ...And focus on sustainable, long-term solutions, so patients invest in themselves instead of handing over the power to someone else.

**Hannah:** We encourage patients looking for health care providers to search for those who offer active pain management approaches, multi- or inter-disciplinary approaches, functional restoration, and self-management techniques.

**Elizabeth:** We need to be exercising and treating the brain as much as the body. In patients with chronic pain, their whole being is involved. Pain is biopsychosocial—it involves more than biology. We can’t ignore the psychological and social aspects. We have to stop treating patients from the neck down.

**Hannah:** In PT, we encourage patients to cultivate a desire to learn more strategies: I want to walk away with tools to do this

on my own. Also, there’s a myth that you need to see a PT for three times a week for six months—so many clinics push that style, unfortunately. In reality, you should see the therapist for a handful of appointments and get the tools to use on your own.

**Elizabeth:** There’s a myth that OTs just treat upper extremities, or even just hands. But “occupation” is anything that occupies your time. We ask patients: How has pain changed your ability to participate in your desired roles, habits, and routines? We look at ergonomics and environmental adaptation, and we explore the connection to mental health. We become attuned to the mental and emotional barriers (or supports) that could impact each patient’s ability to manage pain. We love to work in tandem with physical therapists.

**Jenni:** How does that work?

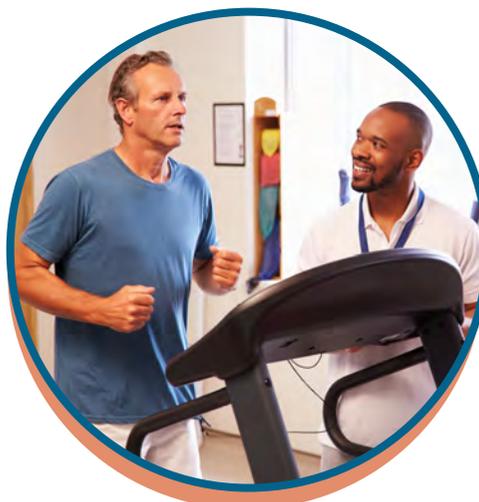
**Hannah:** It’s awesome to co-treat patients, using each other’s eyes and expertise.

**Elizabeth:** For example, if Hannah and I are working with someone who has limited tolerance for standing and sitting, she might be working on strengthening and endurance...

**Hannah:** ...while Elizabeth is teaching them the continuum of postures.

**Elizabeth:** We help patients implement an HEP (home exercise program) and learn to identify what kind of personal and environmental changes are possible so they can stick with it and create lasting change.

**Jenni:** I live with chronic low back pain myself, and I’m lucky to work with an



interdisciplinary team—it makes an enormous difference. How can we help patients advocate for that kind of care?

**Elizabeth:** There is a systemic issue with access; doctors don’t default to sending patients our way. We have a responsibility to educate patients about their options, and educate physicians that they should send people for OT or PT.

**Hannah:** Patients need to seek a better understanding of what’s happening in their body. Not from the internet, commercials, or their second cousin—but from professionals. Once you have that information and understanding, you become your own expert and accountable for your own body. That’s really powerful.

**Elizabeth:** If you find a place that just offers medication management, injections, and manual body work, you need to expand your search.

**Hannah:** And it’s OK to get a second opinion or try somebody different if the therapy isn’t effective.

**Elizabeth:** That’s not to say stop taking medication and do this instead, but you can have many tools in your toolkit. Meds don’t have to be the only thing. But meaningful movement is a chemical intervention.

**Hannah:** Right, think of a runner’s high—it doesn’t just happen at marathons. If you exercise your body, you get a rush of endorphins—naturally occurring happy hormones—and they can be more powerful in pain reduction than strong opioid medications.

**Elizabeth:** Joy and passion are chemical interventions.

*MAKING AN IMPACT BY BREAKING DOWN BARRIERS TO CARE AND ADVOCATING FOR POSITIVE CHANGE FOR THE PAIN COMMUNITY, U.S. PAIN FOUNDATION HELPS INDIVIDUALS FIND RESOURCES, SUPPORT, AND INSPIRATION.*



# U.S. PAIN FOUNDATION

## **WHO WE ARE**

Established in 2011, the U.S. Pain Foundation is a 501(c)(3) organization created by people with pain for people with pain. The organization's mission is to educate, connect, inform, and empower individuals who live with chronic conditions that cause pain while also advocating at the state and federal levels.

## **WHAT WE DO**

The organization offers dozens of direct-service resources, programs, campaigns, and events to help people with pain find the support and information they need.

[uspainfoundation.org](http://uspainfoundation.org)

# PROFILES

REAL STORIES. REAL PEOPLE. REAL HOPE.

David Nonemacher has not let joint replacement and repairs keep him from achieving great things. Head to page 26 to read his story.



## ➤ EMPOWERMENT THROUGH WORDS AND PICTURES.

For eight years, the INvisible Project has brought to light the often-hidden challenges faced by those with chronic pain. Through inspiring patient stories and excellent visuals from personal photographs, the campaign shows what it's like to live with pain—and to thrive in spite of it. >>>





*David*

Despite many chronic health issues and pain, David stays active and shows others that it's possible to do so.

ATHLETE

# *Nonemacher*

From hip replacement to professional athlete, he thrives.

To look at David Nonemacher’s Instagram account, you would never guess that he has lived with severe pain for more than a decade... or that he had a hip replacement at the age of 28... or that anyone would not want him as an employee. Athletic and creative, he has achieved the difficult balance of pursuing an active life and crafting an arts-based business.

But look beyond the pictures, and you’ll see the image of a complex person who is facing obstacles every day. You’ll see a 36-year-old man who has lived with degenerative hip dysplasia, severe osteoarthritis, avascular necrosis, and scoliosis.

An athlete who has had to dramatically change the focus of his fitness regimen. A man who has battled addiction to stay sober for seven years.

David is proof that chronic pain doesn’t have to stop you—that it’s possible to adapt and craft a fulfilling life, even in the face of daily pain. “Pain has changed my life completely,” he says. “Every decision is based on whether or not it’s smart for my daily health.”

### ADAPTING WITH EXERCISE

David was always an active person, and although he had some pain when younger,

it was not severe. He lives in Oceanside, Calif., and played tournament beach volleyball in his early 20s. The events were always sponsored by alcohol companies, so he would be drinking all day, running and jumping on the sand, feeding off the adrenaline from competing in front of a crowd. He thought the pain he felt at night was normal—“this is just from a day of torturing my body”—and didn’t suspect anything was medically wrong.

But when he got sober, he learned that the drugs and alcohol he was abusing were a form of self-medication. “It was another way of coping with the constant

pain and discomfort my whole body was in,” he says. “When I started to get completely detoxed, I started ‘feeling’ things again, both inside and out.”

The pain was severe, and David says he quickly realized he would have to become “addicted to health and addicted to taking care of myself.” He found himself with a lot more free time, so fitness and wellness took a front seat. He switched to low-impact athletics, with less jumping and running, and more gymnastics and strength training.

*“Pain has changed my life completely ... every decision is based on whether or not it’s smart for my daily health.”*

**HIP REPLACEMENT AT 28**

Soon after getting sober, David knew he had to get serious about the pain in his right hip. His health care team put off the hip replacement surgery as long as they could, but because of David’s hip dysplasia, the angle of his hips is wrong. With each step or jump, there’s pressure on the tops of his femurs, and on the right side it was cutting off blood supply, causing avascular necrosis of the femoral head. “I had a bunch of cysts in there, and it was bone on bone... the bone was dying.” He had a right hip replacement and partial femur replacement in 2013.

For years, he had been unable to get health insurance. Before the Affordable Care Act, David found himself taking jobs partly because they offered health insurance. But when he took time off from his last full-time job to get the hip replacement, the company let him go. He had to reconcile being released from a job he liked, just for taking care of his health.

**GETTING INTO ADVOCACY**

In the weeks following his hip replacement, David was antsy—he wanted to get active

again. Five weeks after surgery, his doctor cleared him to ride a stationary bike. David, who is nothing if not stubborn and passionate about fitness, signed up for a Century Ride... a 100-mile bike race.

“It gave me something to look forward to,” says David. “I completed it in seven hours, which was not a fast time, but it felt great to finish.” After the race, he was

walking through the expo area, checking out the exhibitors, “and using my bike like a cane, because I was having trouble walking.” He says he never really knew there were other young people with health issues like his, but that day, he encountered the National Arthritis Research Foundation (NARF)—and discovered an entire organization with a focus on keeping people



David’s older brother, Michael, ran with him for part of the Escape from Alcatraz race. (He jumped in wearing street clothes to offer support!)

Below: David lives in Oceandale, Calif., a great environment for an outdoor athlete.



active and healthy despite arthritis.

NARF was sponsoring a team for the upcoming Escape from Alcatraz Triathlon in San Francisco and recruited David to join the team. He was excited, but three months before the race, tragedy struck: he dislocated his new hip and was injured in a hit-and-run accident, which split his femur. Determined as ever, David kept finding ways to train for the race. He ended up participating, and his older brother Michael ran with him just to make sure David could make it to the finish line.

**PROFESSIONAL ATHLETICS, PROFESSIONAL ARTS**

Today, David is sponsored to participate in all kinds of athletic events, as a competitor and celebrity athlete. “Part of my allure is that I’m a guy in my upper 30s who has all these ailments, and has battled addiction, but I’m still doing this—and I show other people they can do it too,” he says. “You don’t have to have perfect DNA or perfect training. You can be athletic within your own abilities, even with things stacked against you.”

He knows professional athletic work isn’t sustainable for a long time, but he’s happy to be involved as long as he can be. His wellness routine includes lots of water-based exercise, which suits his Pisces personality and gives his joints some relief. He eats a vegan diet and doesn’t use any pharmaceutical medications.

David balances his athletic work and passion for fitness with a small metal-working shop, where he creates sculptures and furniture. “I like how small and simple my business is,” he says. He rarely advertises his services, preferring instead to work on large commissioned art pieces whenever possible.

**SCARY TIMES IN SURGERY**

David has had numerous surgeries. Both wrists have been extensively repaired with bone grafts, titanium replacements, pins, screws, and fusions. And he knows he has a lifetime of surgeries ahead, including a left hip replacement in his near future.

That’s why it’s extra-scary that David

is allergic to propofol, a drug regularly used in anesthesia. Before his health care team determined he had a propofol allergy, they thought it was a morphine reaction, so he had a wrist surgery without morphine—but had a severe allergic reaction anyway and almost died in surgery.

Propofol allergies are so rare that the anesthesiologist was “a little bit too excited about it,” says David. (““Wow, I’ve only read about this in books!” is what he said after surgery.”) “You gave us quite a scare,” a nurse said to David when he woke up from that procedure. He can’t take that risk again, so his team is researching alternatives.

**LOOKING AHEAD**

David and his girlfriend, Laura, help each other stay as well as possible, honoring each other’s wellness goals. She’s a personal trainer, and they’re looking for a house to buy together. Laura’s sister is an anesthesiologist, so she’s on the hunt for an alternative medication so David can safely get the surgeries he needs.

David rarely talks about his pain, and says many people are surprised when they learn his background. “They all assume I was in a motorcycle accident or something dramatic, not that I have arthritis everywhere,” he explains. But by working with NARF—and sharing his story here—he hopes he can show more people that it’s possible to live an active life in spite of pain.

**RESOURCES**

Instagram: @davidnonnynonemacher

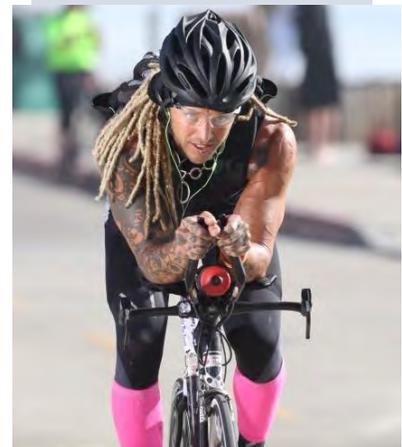
National Arthritis Research Foundation: curearthritis.org



Strength training is a big part of David’s routine.



David’s girlfriend Laura is a trainer, and the two love staying active together.



No- and low-impact athletics like cycling are a big part of David’s self-care.

Shirley inspires all those around her to be strong. Here, she celebrates with fellow advocates at the Health Union Conference for Patient Advocacy in 2018.



# Shirley REBEL Norris

## Laughing through the pain.

The first thing you’ll notice upon meeting Shirley Norris is her infectious laughter—it is the best medicine. She’s not afraid to share the nitty gritty details of her daily life, making jokes along the way to put everyone at ease. She’s accepted the changes her body forced upon her and she’s not ashamed to share. In the last three years, her body has rebelled against her in drastic ways... some visible, others manifesting under the surface.

### WITHOUT WARNING

Shirley used to be a successful senior manager overseeing departments of finance and customer service, responsi-

ble for 150 employees. It has been three years since she has been able to return to work. Shirley developed osteoarthritis very quickly after turning 50, requiring more than eight surgeries. Three more are planned to address this degenerative joint disease.

For some people, osteoarthritis is focused in one area of the body and can be managed through medication, exercise, and weight management. However, the cartilage between Shirley’s joints that causes pain, stiffness, and swelling is felt in her hands, elbow, knees, and throughout her spine.

Shirley’s right thumb joint was fused together via a surgery that “welds” the two bones that are causing pain, eliminating the joint. Typically, a bone fusion in

any part of the body stops any mobility, as the joint has been removed and two bones have essentially become one. Due to a connective tissue disorder, Shirley is able to use her fused thumb without much trouble.

On a recent trip to Philadelphia, she dislocated her left thumb but didn’t seek treatment. Knowing it typically pops back into place, she chose to bear the pain for days instead of seeing a doctor while on vacation. That is one surgery she needs to have in the near future.

Due to widespread osteoarthritis, Shirley had a ligament transfer in her left elbow, which required a second surgery to replace the ligament with a synthetic one. Bone cysts caused her immense pain, so another surgery, which entailed a bone graft, was needed to remove the growths. Shirley needs a knee replacement in her left knee and has a large meniscus tear on the right one.

### REALITY OF CHRONIC PAIN

“My pain is almost constant,” says Shirley.



“That toothache-type pain if you’re having a good day! The severe throbbing that almost takes my breath away on a bad day.”

Pain restricts her daily function, forcing her to “think about what realistically I can commit to.” Full-day shopping trips, standing in long lines, bending over, walking, and hiking are everyday activities that cause Shirley to make choices about what she can handle. She has adjusted, picking her battles. “I do my food shopping online and get it delivered to my kitchen. Clothes shopping is mainly done online. No dancing at family gatherings, either.”

**LIFE WITH WINNIE**

Osteoarthritis, connective tissue disorder, bone cysts, and fibroid tumors so large she required a hysterectomy—it’s quite the list of medical conditions for one person to manage.

Shirley began experiencing constant urinary tract infections and had an alarming amount of blood in her urine. Her urologist kept treating her with antibiotics and catheterization. She knew something was seriously wrong but kept getting dismissed by her specialist. “I was brought up in a generation where you didn’t question doctors,” she says. Finally, she listened to her body and got a second opinion, which revealed she had bladder cancer.

Her cancer was very aggressive and within four months, she had a cystectomy, a procedure which completely removed her bladder. Surgery created a stoma (a small opening in the surface of the abdomen) that redirected the flow of urine into an ostomy bag.

Shirley is cancer-free more than a year after having her bladder removed. True to her humorous nature, Shirley named her stoma “Winnie.” Friends will ask how Winnie is doing or if the ostomy bag leaks, Shirley blames Winnie—her way of redirecting any feelings of discomfort, embarrassment, or guilt.

“Winnie has surely been a blessing and not a curse,” says Shirley. “She has saved my life and is my new best friend.” She copes with the effects of her surgery by



Shirley always inspires others to laugh with her, despite the pain she lives with, as evidenced in part by the images below.



**Spine:**  
 There is sacralisation of L5 vertebral body.  
 Vertebrae show evidence of osteopenia. Anterior osteophytes are seen from lower dorsal vertebral end plates.  
 Desiccation of lower lumbar intervertebral discs is seen.  
 Bilateral facet arthrosis is noted at C4-C5.  
 At C5-C6, there is posterior disc bulge with early uncovertebral arthrosis mildly indenting both ventral traversing nerve roots.  
 At C6-C7, there is posterior disc bulge, indenting both ventral traversing nerve roots.  
 There are small left paracentral disc herniations noted at D2-D3, D3-D4 and D4-D5 levels, causing no significant nerve root compression.  
 At D6-D7 and D7-D8 there are left paracentral disc herniations mildly indenting left traversing nerve roots.

helping others, or else “what would be the purpose?” she says. Shirley boldly tells her tales and adventures with Winnie at BladderCancer.net.

**CONTINUED BACK PAIN**

Before her cancer diagnosis, Shirley had undergone many surgeries to deal with her osteoarthritis. When her lower back began hurting, doctors assumed it was from the recurring UTIs, and then from her inflamed bladder. But after the cystectomy, the back pain persisted. Shirley self-funded a 4D full-body scan, wanting to know what else was lurking in her body.

The diagnostic report listed eight significant areas causing concern. Osteoarthritis had found a new home in her spine. Multiple bulging discs, hernias, nerve root compression, and disc desiccation (hardening of the discs between the vertebrae) were among her diagnoses.

Shirley will face additional surgeries and continues to find ways to cope with the rebellion inside her body, invisible to the outside world.

**MISCONCEPTIONS AND ADVICE**

Shirley wants the public to understand

that with osteoarthritis and low back pain, “just because you can’t see my pain, doesn’t mean it doesn’t exist. Arthritis of the spine is real—too many people shrug off the condition.” She has seen many people use the label of having a “bad back” as an excuse to get out of work, which is unacceptable to her. “Take my condition seriously, as it’s very serious for me,” she says. “This condition rules my life and stops me from doing lots of the things I used to take so much for granted.”

To those living with chronic pain, she says, “don’t beat yourself up, don’t overdo it, and don’t apologize.” Shirley makes time to rest, keeps good comedies on hand to entertain her on bad days, and makes meals to freeze for the future on good days. Keeping her mind busy helps her manage her pain, so she saves housework for when she needs a distraction.

*“Take my condition seriously, as it’s very serious for me,” says Shirley*

**LIVING LIFE ON HER TERMS**

With all that Shirley has been through in three years’ time, her outlook on life is amazingly positive. She and her husband are seizing the day, knowing every moment is precious. He retired early to focus on living with Shirley in the here and now. Even with an ostomy bag, multiple surgeries, and chronic pain, Shirley and her husband find ways to make life work for them, instead of being controlled by her health. They are planning to live in India during the winter, returning to England in the warmer months.

“I now appreciate all those little things in life, like beautiful flowers and sunsets, the company of good friends and family... things that I all but ignored or just took so much for granted previously.”

**➤ RESOURCES**

**BladderCancer.net:** [bladdercancer.net](http://bladdercancer.net)

Shirley has a great smile and sense of humor, but even she has tough days, as evidenced in the photo to the right. She and her husband, below, split their time between India and England.



Shirley has learned to savor the sunshine, outdoor time, and laughs with friends, no matter how much pain she is in.



WARRIOR

# Ryan Lamb

## Overcoming obstacles to find a new normal.

“Pao won’t let me get out of bed yet, or Pao is really being mean this morning,” says Ryan Lamb. Pao isn’t a person or one of his beloved dogs. Pao is the word Ryan uses to refer to his pain. In fact, it stands for “Pain All Over.” Giving his pain a name allows a separation from his condition and recognizing that his pain isn’t his identity. “It’s just a way for me to accept it, and it gives those that are close to me an easy way to relate to me with regard to what I’m currently experiencing from a pain perspective,” he explains.

### THE CRACK OF THE BAT

Ryan was playing softball with his company’s team when he heard a loud pop in his back. He tried to ignore the searing pain. Days later, Ryan’s knees buckled, sending him to the ground. He knew it was time to see a doctor. That loud pop was the sound of his L5 vertebra breaking.

Ryan received a spinal fusion in April of 2012. During the healing process, he re-broke the bones that had been fused together, which meant another surgery. While the second surgery may have been successful from a surgeon’s point of view, Ryan’s life was forever changed.

### BECOMING CHRONIC

Because of the surgeries, Ryan developed post-laminectomy syndrome, also known as “failed back surgery syndrome,” creating chronic low back



pain. He categorizes his symptoms as mini-flares (which last less than 12 hours) and flares (which last four to five days without relief). Mini-flares occur approximately every one to two days, while flares happen once or twice a month. “I have some sort of pain every day,” says Ryan.

In 2014, Ryan had a spinal cord stimulator implanted. It was surgically placed under his skin and has a wire that runs up the spinal cord. When activated, it sends electrical pulses that disrupt the nerves that are firing pain signals. The stimulator is controlled by a remote that Ryan can turn on and off.

While the stimulator provided some relief, Ryan also relied on extremely high doses of prescription opioids just to survive each day. But eventually, state

legislation surrounding opioid prescriptions significantly impacted Ryan’s ability to obtain the drug. In 2015, over a six-week time frame, he decided to detox from opioids by himself—a practice not recommended, and potentially dangerous without a doctor’s supervision.

Ryan was still experiencing significant pain that radiated down his legs two years after the neurostimulator was implanted and a year after he had detoxed. He compares the sensation to a feeling of numbness and tingling in his legs—similar to when a limb “falls asleep,” except instead of lasting minutes, it happens for hours at a time. He was finally also diagnosed with complex regional pain syndrome (CRPS).

CRPS is a disorder of the nervous system that heightens the nerves’ responses to

certain stimuli. A person usually develops this condition after an accident or even something as simple as spraining a wrist or fracturing a bone. Those with severe CRPS find that the slightest touch creates an incredible amount of pain, with the affected area swelling, turning red, and feeling like the bone is on fire or is cold as steel. Even air passing over the skin can cause a CRPS flare-up.

**SEARCHING FOR BETTER PAIN MANAGEMENT**

In 2016, Ryan’s doctor suggested high-frequency neuromodulation. Using his existing stimulator, Ryan turns up the frequency of his stimulator for longer periods of time. He’s noticed an improvement in the severity of discomfort he has on a daily basis. The constant numbness and tingling has diminished, but it’s still not a cure for CRPS or post-laminectomy syndrome.

Ryan’s most recent surgery was to install an intrathecal pain drug pump, which was implanted in July 2017. The pump is placed between the muscle and skin of the abdomen. A catheter carries pain medication to the spinal cord and nerves, slowly releasing medication over a period of time.

**FINDING A NEW NORMAL**

“Pain has changed my life 180 degrees,” says Ryan. “I used to have a very good job, made great money, was in a relationship, enjoyed myself physically and socially—that is all gone now,” he says. Friends have slowly stopped asking Ryan to attend social activities. He had to move in with his mom, and was unable to return to work. He was recently approved for Social Security Disability benefits, a process that required many appeals and a hearing before a judge.

Ryan is only 32 years old but has been dealing with chronic pain for over a decade. Because he is so young, he finds that others can’t believe how he experiences such intense pain and has had so many surgeries. “I have a pretty high tolerance and keep a lot of it to myself,” he says. Sometimes he feels he has to prove his pain by lifting his shirt to show

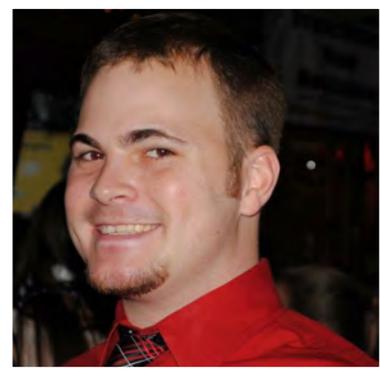


Above: Ryan with his stepmother, Angie, brother Carl Paul, sister-in-law Aimee, sister Laura, and mother, Kathleen, at Laura’s engagement party in 2017. Family is important to Ryan. He considers his dogs, Kona and Kayla, family too.



people the huge bulge in his abdomen from his pain pump. “That seems to catch people off guard and then it’s like a flipping light bulb goes off in their minds and they all of a sudden believe me,” Ryan says, dumbfounded that it has to come to that.

Ryan’s life revolves around his two dogs, Kona and Kayla. They give him a reason to get up every morning, even when Pao begins to scream within his



body. He tries to be active in the morning. Ryan is proud of a new goal he has set for this year. He wants to do “at least one physical activity per day, even if it’s just walking around the block once or twice. Also, I’ve started guided meditation with the help of a friend who is a nutritionist.”

Ryan has been through a lot at a young age, which has given him wisdom beyond his years. “I wish the general public understood that they need to be more supportive of folks with chronic pain, regardless of their age,” he says. For those who are newly diagnosed, he offers this advice: Take your time. Learn your pain and learn to accept it. Pain can make you grumpy, “and no one wants to spend time around a grump, right?” jokes Ryan.

During dark moments he suggests finding a way to look at yourself from an outside perspective. “Decide if you like the person that you see,” he says. Remain positive or at least optimistic. “This was very hard for me because no one wants to accept that they have a chronic pain condition,” Ryan explains.

**APPRECIATING SUPPORT**

Ryan’s life would be drastically different if he didn’t have the help, love, and support of his mother, who has been right by his side for the last two years. She helps with the puppies, picks up his medication, does the laundry—anything and everything that his pain condition has made it difficult to do. Ryan’s mom managed the cumbersome Social Security Disability application and appeals process for him. The recent victory of finally being awarded benefits is a win that he attributes to her hard work. He believes it will alleviate some of the burden she has taken on as a caretaker, at least from a financial standpoint. It will give him the ability to stand on two feet on his own for the first time in a long time.

➤ **RESOURCES**

- Boys and Girls Club of America: [bgca.org](http://bgca.org)
- Collegiate Charities: [collegiatecharities.org](http://collegiatecharities.org)



Ryan has a big family; this is his father’s side of the family during his father’s 61st birthday in 2017.



Above: Kona and Kayla are Ryan’s constant companions.

Right: Ryan with his sister Barbie, and best friend Haris on New Year’s Eve 2017.





Paula has endured many challenges, but she keeps a sunny attitude and a focus on service; she's starting a chronic pain support group in Detroit.

# Paula Perry

CHAMPION

Despite trauma and abuse, she remains a fighter—for herself and others.

Paula Perry was 17 when it happened: a fall that sent her to the E.R. with extreme back pain. They gave her a shot for the pain and sent her home with muscle relaxants, but she felt no relief. Paula's doctor sent her for an MRI (the first of many) and they discovered she had several slipped discs.

Physical therapy didn't help, and Paula was frustrated. "I was constantly going to the E.R. for pain relief," says Paula. "This was before the current opioid epidemic.

I'm not proud of it, but I would go to the hospital where I knew they had all my test results and records, and they would give me something, like morphine, and send me home." It was the only way she could get some relief from the pain.

Eventually, Paula found her way to a pain specialist, who prescribed injections—including one that burned the nerves that deliver pain signals to the brain. The procedure provided a couple years of relief,

but Paula developed neck pain and had another MRI, which revealed multiple slipped discs in her neck.

## CONNECTING THE DOTS

"You're so young to have this—were you in a car accident?" asked Paula's pain specialist. No, she wasn't. Another round of physical therapy helped a little, and kinetic tape, gabapentin, and cognitive behavioral therapy all helped a little more.

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**CONNECTING THE DOTS**

“You’re so young to have this—were you in a car accident?” asked Paula’s pain specialist. No, she hadn’t. Another round of physical therapy helped a little, and kinetic tape, gabapentin, and cognitive behavioral therapy all helped a little more. Paula thought she finally had her pain under control.

But in 2016, once again, Paula began experiencing severe back pain. Another MRI showed multiple slipped discs in places not previously diagnosed, with the discs bulging severely. Why would she have such injuries?

It was around this time that Paula’s mind opened up, and she connected the dots. As a child, she was raised in a family with an abusive parent. She began to recall a long history of abuse, including being pushed down the stairs multiple times and falling on concrete basement steps. Perhaps this was the source of her injuries and pain. She found another pain specialist to work with, one with more experience with patients with post-traumatic stress disorder (PTSD).

“I have herniated and bulging discs in



Above: At a recent Pain Connection training, Paula met other advocates, like Illinois Pain Ambassador Jenni Grover, who all plan to create support groups. It’s through work like this that Paula hopes to create meaning from her own pain.

the thoracic spine, and my physical therapist says that’s incredibly rare,” Paula says. “It’s uncommon to find people under 65 with thoracic slips. With my pain team, I’ve determined that my injuries and resulting pain are 100% the result of childhood trauma.” She sees a therapist to continue her work on reconciling her past and her present.

**FINDING THE RIGHT TREATMENT**

Today, Paula says she’s happy with her pain specialist and the course of treatment. “My doctor determined that even though I’m 29 now and live with severe pain, there IS hope,” she says. “The tricky thing is that for me, opioid medicines are the only thing that keep me functioning, and many of us on these medications are being vilified.”

She’s tried physical therapy, cognitive behavioral therapy, kinetic tape, anti-depressants, non-narcotic pain medicines, sleep medicines, ice packs, muscle relaxants, TENS units, meditation, lidocaine patches, injections, creams—everything her pain care team has suggested. But the thing that brings her the most relief is opioid medication. And she’s afraid for her future.

“I’m very happy with my pain specialist because it’s so difficult right now to find a doctor who will consistently prescribe

opioid pain medications,” says Paula. “The Centers for Disease Control have stopped recommending opioids as a first-line treatment. And many people are dying from overdoses, so it makes sense that doctors are being careful. But I’m one of the people for whom this is the only thing that keeps me functioning, working, and living.”

Because she can access the medication her doctor prescribes, Paula’s able to work a full-time job as a receptionist for a tax firm and is in the process of finishing her college degree. It’s taking her longer than she wanted, but she’s determined. She’s fluent in three languages besides English: Arabic, French, and Danish.

Paula says she gets frustrated when she sees people attacking pain patients who take opioids. “Just because I need pain medication doesn’t mean I’m a drug addict,” she says. “I’ve been taking these medications

for 12 years, and I'm not an addict. When my pain is worse, I contact my doctor so she can modulate my dose—I don't make that decision alone. I'm responsible, and my doctor trusts me."

**FIGHTING FOR HER RIGHTS**

"Right now, you can walk into an E.R. or a doctor's office and see signs posted that say, 'We don't prescribe narcotic pain medicines,' and that's appalling," says Paula. "Why are we punishing all pain patients for the actions of a fraction of those who use these meds? Why aren't doctors better trained in how to prescribe them? Why aren't we researching addiction to figure out why some patients have issues, and some don't? There are so many unanswered questions."

Paula says she's excited to begin doing advocacy work, and recently attended a U.S. Pain Foundation Pain Connection support group training so she can begin to teach others how to live well with pain—and how to advocate for their rights.

"I was so happy to be able to introduce myself at the chronic pain support group training and explain that I have PTSD, which makes treating and living with pain more difficult," says Paula. "Whatever I can do to help people, I want to do, including telling my story. There are so many ways people's backgrounds impact their pain stories, so I hope I can run a support group that helps people with a wide variety of experiences." Paula lives in Detroit, and plans for her group to meet at the Detroit Public Library.

**AN UNUSUAL TWIST**

Paula's background has an unexpected twist, one with a lifetime of ramifications she's currently working to understand. She recently was finishing one of her college French courses when the professor held her after class to reveal something powerful: the professor was Paula's birth mother.

Paula had never known she was adopted, let alone who her birth parents were, and was skeptical at first, but the professor, Samar, produced Paula's birth certificate. Samar had become pregnant while living in her home country of Lebanon, and because

Paula's father is black, Samar had moved to the U.S. to give birth because she feared Paula would experience racism in Lebanon.

When Paula was born, her skin was a light color... but in time, her skin tone became significantly darker. (Paula has a skin pigmentation issue and is working with a dermatologist to determine the genetic source of her dramatic skin tone change.) Still fearing Paula would experience discrimination in Samar's Middle Eastern community in Michigan, she gave up custody of Paula. Then, in a bizarre coincidence, she became Paula's professor decades later.

Today, Paula is slowly developing a relationship with her birth mother. She has not converted to Judaism but honors her birth family's practices by sometimes wearing a kippah, a small yarmulke, that Samar crocheted for her. (Paula's birth grandparents were Holocaust survivors.) She is slowly coming to understand more about her background.

**PUTTING THE PIECES TOGETHER**

Paula knows she still has a lot of work to do to reconcile all of her experiences. She lives with pain caused by physical and emotional abuse. She endured years of trauma and still she is a multilingual professional with a passion for helping others. She has an entire family to get to know, and she's being thoughtful and measured in that effort. She cares deeply for her community in Detroit, and is working to help others.

"People in pain should not be ashamed to seek help," she says. "Chronic pain is a lifelong problem, and we must teach each other how to live as well as possible despite being in pain." Resilient, feisty, and strong, Paula is determined to do her part.



Top: Paula as a baby. Above: Paula's birth mother, Samar. Below: Paula maintains hope for less pain and even more meaning in her life.



# Katy Brennan

WRITER



**Young but mighty: creating a stir through journalism and activism.**

Sixteen-year-old Katy Brennan lives with a host of chronic illnesses. She has Ehlers-Danlos syndrome (EDS), celiac disease, postural orthostatic tachycardia syndrome (POTS), chronic fatigue syndrome, hemiplegic migraine, and severe low back pain from kyphosis and mild scoliosis. All of these conditions limit Katy’s ability to be a “typical teenager.” Many in her position would be angry at the world, but not Katy. She is finding a way to make a positive societal impact through her experiences.

Growing up, Katy seemed to have constant problems with her joints and spine. She was diagnosed at 12 with mild scoliosis (a 16- to 20-degree curvature) in her spine. In eighth grade, she needed surgery to repair a dislocated left shoulder. As she recovered, she managed to dislocate her right shoulder carrying her backpack. Six months later, she underwent another surgery to repair the right shoulder.

This didn’t seem normal to Katy, but those treating her kept saying she was fine. They brushed aside her complaints as growing pains or normal joint hypermobility for children.

It wasn’t until her freshman year of high school when her knee gave out causing her to fall down the stairs at school that her orthopedic surgeon questioned Katy’s loose joints. She was referred to a geneticist to look into a

At 16, Katy Brennan lives with more pain than most adults, but she hasn’t let it steal her smile. She’s pursuing advocacy work and finding meaning.

probable EDS diagnosis; following a nine-month wait, that geneticist confirmed her surgeon’s suspicions, diagnosing Katy with hypermobile EDS.

“I ultimately was lucky,” says Katy. “Fourteen is considered relatively young to receive an EDS diagnosis.”

Unfortunately, she cannot say the same thing about her lower back pain. She believes this is due to her having multiple diagnoses. “I would say that my back hurt really bad and get the response, ‘Well, what’s new? All your joints hurt,’” she shares. Because of this reasoning, it took Katy over three years to receive a kyphosis diagnosis.

“That’s the difficult thing about having widespread chronic pain; when you complain of a new pain, it is treated as normal, and it is difficult to obtain treatment.”

## MANAGING THE DAY TO DAY

Katy’s pain is constant, but the intensity can vary daily. Her back pain can be so excruciating that the only way to cope is through tears. These hour-long meltdowns happen a few times a month. During these periods of intense pain, she uses heat and music to get through the pain.

Additionally, her episodes of hemiplegic migraine (a rare and serious type of headache causing muscle weakness mimicking a stroke) are torturous. Without fast treatment, they can last a long time; one lasted six weeks for her. Thankfully, her episodes are becoming further apart (every three months or so) and Katy is learning to catch the symptoms early to minimize the longevity of the attack.

She also has widespread joint pain in every major joint including her lower back. “A few years ago I thought of it [pain] as a leech,” shares Katy. “It

was literally draining the life from me.” After adapting to it, getting some treatment, and turning it into a positive influence in her life, she now describes it as static: sometimes it’s louder and sometimes it’s quiet.

After much trial and error, Katy relies on specific therapies for relief. An anti-inflammatory medication reduces swelling. Progestin-only birth control balances her hormone levels, which has helped to significantly improve Katy’s POTS, joint dislocation, and hemiplegic migraine. Heat helps her back, and she tries to get as much sleep as possible while using a weighted blanket.

The most important part of her wellness routine is physical therapy. “PT is critical for maintaining joint stability,” she says. “It also improves my back by strengthening my spine and working on keeping it in alignment. That lowers my pain.”

### **NOT FINDING THE SUPPORT SHE NEEDED**

What has been disheartening are the obstacles Katy has encountered in order to receive necessary care. On multiple occasions, Katy’s voice was discounted by those treating her.

A therapist once told her that being a type-A perfectionist was the root of her intense pain. Then there were doctors who only wanted to treat with medications like opioids; they also refused to listen to Katy when she said they were not touching or helping the pain. After a year of being unheard, Katy stopped the medications on her own with no withdrawal or increase in pain.

Wanting real answers, she kept insisting on a drug-gene test. But her pleas were ignored by those treating her. It took Katy’s POTS specialist recommending this test (for a separate matter) for her to get the information she had been requesting. And just like she had been telling her doctors for years, her body is unable to process most medications.

Another huge hurdle for Katy was getting people to take her back pain seriously. It was her physical therapist who referred her to a spine specialist after a particularly rough session where Katy

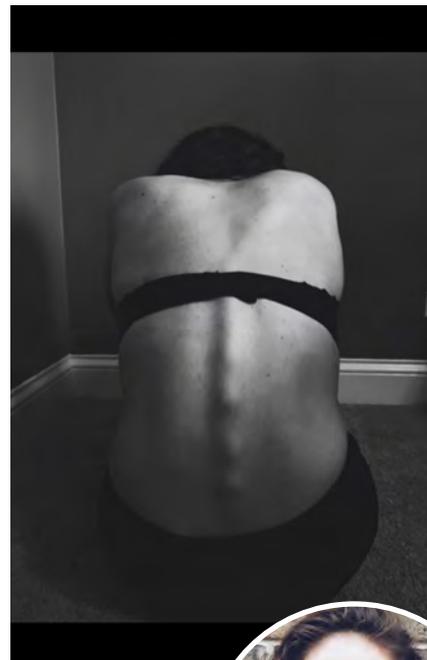
broke down from the pain and lack of acknowledgment from the medical system. On her first visit, she was diagnosed with kyphosis. While there aren’t any treatments to help the excessive outward curvature of her low spine, Katy says having a name to describe the pain is validation.

While these challenges impeding her care are frustrating, she refuses to let them break her spirit or psyche. In fact, she is still hopeful for advancements in pain medication (which her body can process) and medical cannabis legislation. (She is unable to obtain a medical card for cannabis in Illinois due to her conditions not being covered under current law.)

In the meantime, Katy has become more outspoken. She is using her experiences to educate, support, and empower others in similar circumstances.

### **THE POWER OF HER WORDS**

When Katy came to the realization that attending law or medical school would not be feasible because of pain and her limitations, she was upset. Being a lawyer or doctor is all she had wanted to be and pain had taken



**Kyphosis means Katy has constant low back pain. It took her fierce determination to get her diagnosis.**



that dream from her. But a new focus quickly entered her life, one she now believes is for the better.

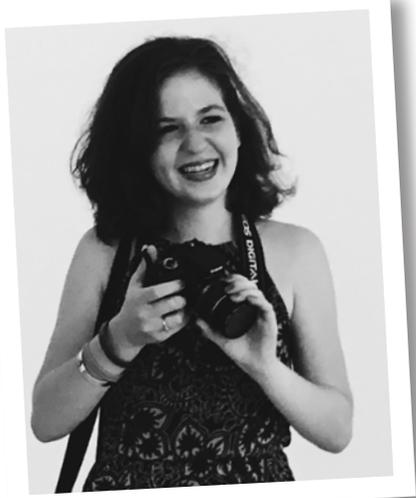
“Between my freshman and sophomore year, someone shared a story from ‘The Mighty’ with me,” explains Katy. “I have always liked writing. Learning ‘The Mighty’ was an online hub to connect people facing health challenges, I decided to submit a piece.” It was accepted and published.

“That was my defining moment. Having my work out there showed me that people cared about my voice and wanted to hear my story. In return, I became an advocate for myself.”

Since then, she has contributed over 30 articles that encompass her honest, raw feelings about who she is, her pain, and the need for societal compassion and change. “It has led me to find a more positive connection with my pain. Rather than looking at it angrily as something that ruins my life, I began to see it as a motivator and a driving force in everything I do; even if it kicks my ass (pardon my language) pretty often,” laughs Katy.

With this newfound change of direction in her life, Katy plans to pursue a double major in college in journalism and political science. Interested in connecting the personal advocacy story to the political side, she wants to better understand the political game to make health care changes.

To intermesh these worlds, Katy



interns with political campaigns. Right now, she interns for Illinois Governor Bruce Rauner. She is highly aware that many judge her for aligning with a conservative politician. But she won't let assumptions deter her. “I work with people I feel are most honest,” shares Katy. “I think many would be surprised how they lean socially liberal in this arena; they just might not make that comment publicly often.”

**FINDING PEACE, JOY, AND SUPPORT IN TODAY**

Despite living with low back pain and myriad other chronic illnesses, Katy has managed to find positives in her life. She might not be as physically active or able to cheer anymore, but she has a purpose. She has new life goals and objectives that bring her meaning.

Katy is fortunate to have her parents, especially her mom, by her side since day one. Due to her dad's work travels, he hasn't been around as much to see the day-in and day-out pain like her mom. Katy's mom is her rock—she helps her find the right doctors and does tons of research to better understand Katy's conditions and also the therapies available to her.

She also found some incredible resources. The online sites *Suffering the Silence*, *Diversability*, *Sick Chicks*, and *Yoocon* provide community support, informative materials, and strength. (Katy now interns with *Suffering the Silence* and is the digital content manager at *Diversability*.) She also turns to *Invisible Disability Project*, *Blanket Sea*, and *Deaf Poets Society* for inspiration. She explains how helpful it is to connect with other people with pain: “Through their stories, you see your own and you feel less isolated and alone.”

Katy Brennan is a passionate individual with wisdom greater than her 16 years. As a writer, she is motivating others to tell their stories in hopes of finding acceptance and support. She will not let pain override her story; instead, she is using her experiences to make a difference.

“I wish the general public understood



Above: Katy in the office of Jesse White, Secretary of State of Illinois. Below: Katy and her family, who have been very supportive.



that every individual pain matters. Just because I live in widespread chronic pain does not mean that a flare-up in my lower back is less significant. If you want to be helpful, don't pity me but also don't say, ‘Oh well, you're always in pain.’ Every pain is different, and every pain matters.”

➤ **RESOURCES**

- The Mighty:** [themighty.com](http://themighty.com)
- Suffering the Silence:** [sufferingthesilence.com](http://sufferingthesilence.com)
- Diversability:** [mydiversability.com](http://mydiversability.com)
- Sick Chicks:** [thesickchicks.com](http://thesickchicks.com)
- Invisible Disability Project:** [invisibledisabilityproject.org](http://invisibledisabilityproject.org)
- Blanket Sea Magazine:** [blanketsea.com](http://blanketsea.com)
- Deaf Poets Society:** [deafpoetsociety.com](http://deafpoetsociety.com)
- Yoocon:** [yooconfind.com](http://yooconfind.com)

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—Vijay B. Vad, MD, sports medicine specialist at the Hospital for Special Surgery and author of *Back Rx*

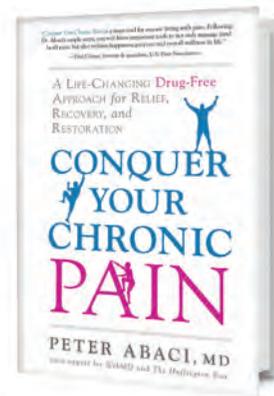


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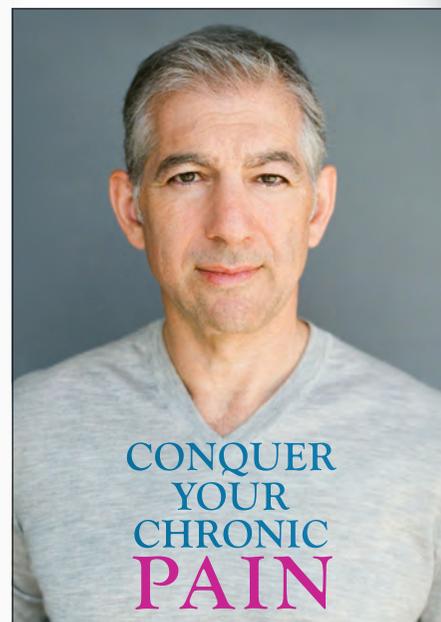
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**Pain Expert & Regular  
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**Peter Abaci, M.D.**

Peter Abaci, M.D., is one of the world’s leading experts on pain. He is the author of *Take Charge of Your Chronic Pain*, host of *Health Revolution Radio*, and a regular contributor to *WebMD*, the *Huffington Post*, and *PainReliefRevolution.com*. As the medical director and cofounder of the Bay Area Pain & Wellness Center, his innovative strategies for integrative pain treatment have helped restore the lives of thousands struggling with pain. He resides with his family in Los Gatos, CA. Visit [peterabaci.com](http://peterabaci.com) for more information.



# Lynn Julian

SURVIVOR

Lynn Julian, her husband, Doug, and her dog Lil' Stinker. Lynn was felled by a traumatic brain injury during the Boston Marathon bombing in 2013; she has been a fierce pain advocate ever since.

## Boston strong, she's become a fierce advocate.

On Patriot's Day, April 15, 2013, Lynn Julian walked a few blocks from her apartment to join the thousands of people lining the streets to cheer on the Boston Marathon runners, as she had done for years. She sat on a metal bench, basking in the camaraderie that overtakes the city.

Lynn was sitting less than 50 feet away when the first bomb blast occurred. Miraculously, she had no outward signs of injury. The damage lied within, invisible

to those around her.

Knowing the hospitals would be overflowing, Lynn waited until the next day to go to the emergency room. Shortly after the blast, she had severe head pain, vomiting, confusion, and back pain. Her hearing felt like she was underwater. She explained to the doctor that her entire body ached from the impact of her body bouncing out of the metal chair and slamming back down.

Many of Lynn's symptoms pointed to traumatic brain injury and potential damage to her spine. Yet, she was brushed off by the emergency room doctor because of "pre-existing conditions." Lynn was sent



home without a diagnosis, medication, treatment plan, or even a referral for a follow-up.

**PRE-EXISTING CONDITIONS**

In 2006, Lynn was a professional singer and actor in the Boston area. During a performance, a cord that ran across the stage floor had been neglected to be taped down, a violation of standard safety practice. Lynn’s foot rolled over the cord; she fell backwards and was knocked unconscious.

The accident left her bed bound... for years. She had constant vertigo and vomiting, chronic neck and back pain, and developed chronic migraine. Prior to the accident, Lynn dealt with fibromyalgia and Ehlers-Danlos Syndrome (a connective tissue disorder, or CTD). This combination of medical challenges left her body too weak to walk, and she rarely left the house.

Lynn was determined to take control of her pain, even though she faced many challenges. After much hard work and finding the right doctors, she began to venture out of her bedroom, using a wheelchair. Five years after the accident, she was able to rely less on her wheelchair and transitioned to using a cane. The following year, she was walking on her own, had established herself as a “Boston Actress” in over a dozen short films, and was accepted to college to complete her B.A. in theatre arts.

**CHRONIC LOW BACK PAIN AND SCIATICA**

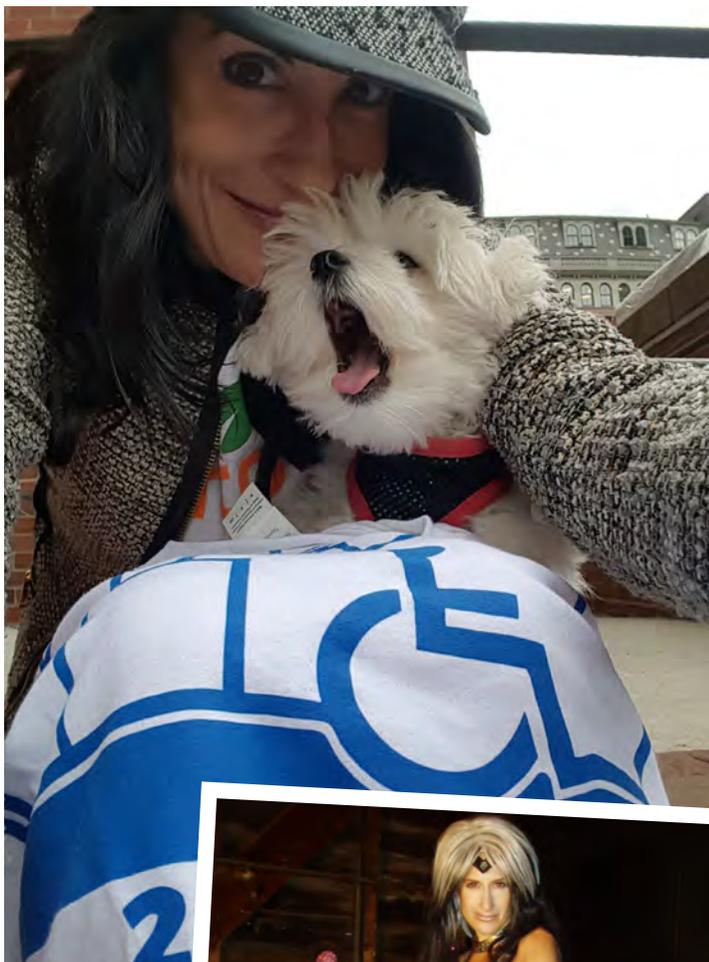
Soon after Lynn began walking unassisted, she realized there was one area of her body she had been ignoring—her lower back. The other symptoms had dominated her life, yelling at her and demanding her attention. Only after they had quieted down was she able to focus on the damage in her spine. After seeing a specialist, her doctor determined Lynn had a bulging disc at the L5 vertebra.

For the first time, Lynn experienced a bout of sciatica—a painful medical condition that occurs when the sciatic nerve becomes impinged through contact with the surrounding discs. Painful flare-ups are usually triggered by a routine movement such as lifting a heavy object or even stepping off of a curb. Sciatica pain can radiate from the low back all the way down one or both legs. It can be burning or tingling, and creates feelings of weakness, numbness, and difficulty moving, sitting, or standing.

**THE AFTERMATH**

Lynn had been walking on her own for less than a year when the bombing occurred.

When she entered the emergency room the day after the attack, the doctor saw her history of a previous traumatic brain injury, chronic migraine, and vertigo,



Top: Lynn’s first service dog, Lil’ Stinker, was like a best friend. When Lil’ Stinker passed away in 2018, Lynn was devastated. Now, she’s training a new service dog to help with managing her PTSD, migraines, and pain. Above: Lynn loves being in costume and performing.

along with an MRI taken two months prior showing a bulging disc. Lynn explained the bulging disc caused her low back pain, which had previously resolved. Her new pain radiated all the way down her right leg and foot. Still, many attributed her new symptoms to her prior accident. Lynn knew that was wrong.

In the days and weeks that followed, Lynn's existing conditions of vertigo, chronic migraine, and low back pain intensified. Hearing loss, tinnitus, cognitive impairment, and post-traumatic stress disorder (PTSD) were new conditions that developed after the bombing. Clearly these were not related to her "pre-existing conditions." Just as she had advocated for herself after the stage accident, Lynn set out to find answers. However, answers are not easy when it comes to invisible illnesses.

*“Being a patient advocate has given my life a greater sense of purpose by giving me a way to pay it forward.”*

**ROADBLOCKS**

Doctors were dismissive, blamed her pain on depression, insinuated to others that she was "attention-seeking," told her to "learn to live with it," and even labeled her as a "non-compliant patient" in her medical records. Lynn didn't give up even when others had.

After a year, she finally received the correct diagnosis of traumatic brain injury (TBI). This diagnosis is typically associated with a forceful, direct blow to the head. Lynn was not hit during the explosion, but the shockwaves from an explosion can impact the brain just as severely (also called blast force trauma).

Due to a year gap between the bombing and diagnosis, Lynn laments, "my brain was further traumatized by not following 'concussion protocol' for the first two months after my TBI. Also, since my treatments were delayed, this minimized



At the finish line of the 2014 Boston Marathon, Lynn showed her strength and advocated for survivors and other people in pain.

their benefit." To treat her entire body, she required speech therapy, occupational and physical therapy, cognitive behavioral therapy, vestibular therapy, and ocular therapy. Because of her injuries, Lynn was forced to drop out of college and put her new acting career on indefinite hold.

She has tried over 100 prescription medications, eventually finding out that her body is incapable of metabolizing certain medications, creating a toxic build-up and leading to side effects. She has found medical cannabis to be quite effective in managing her illness. It helps her back pain and relaxes her muscles, reducing the frequency of sciatica episodes.

"I think of my pain as separate from myself... like a twin that lives within me," she says. "My pain also breaks down into various parts of my body. I refer to each of these as my 'children,' and some can act like a two-year-old throwing a tantrum at times. Some days, the 'kids' are fighting for attention. Others, we're one big, happy family."

**THE LIFE-CHANGING EFFECTS OF CHRONIC PAIN**

Lynn feels that she is often misunderstood, a sentiment shared by many who have invisible illness. "I wish the general public understood that no two types of pain are alike. With that in mind, no two people with pain are alike either. For many people, no two days in pain are even alike."

The road to acceptance of living life with chronic pain and being comfortable in your new "normal" is different for everyone. "As crazy as it might sound, you need to learn to love your pain... or, more specifically, love yourself—a person living with pain."

**PURPOSE IN PAIN**

Lynn thrives despite her pain. Over time, she has been able to put her pain into perspective and focus on living around the pain instead of being stuck in it. Her advice is to "invest in whatever you discover helps you lead a life with purpose."

Lynn has found that belonging to support groups helped to validate her pain and realize she is part of something larger than herself. Beyond the personal benefit she receives, she finds it incredibly rewarding when she can help someone else in the group. She says that's the reason why she became an Ambassador for the U.S. Pain Foundation.

"Being a patient advocate has given my life a greater sense of purpose by giving me a way to pay it forward."

**RESOURCES**

- U.S. Pain Foundation:** [uspainfoundation.org](http://uspainfoundation.org)
- Strength to Strength:** [StoSglobal.org](http://StoSglobal.org)
- Inspire.com:** [Inspire.com](http://Inspire.com)
- Ehlers-Danlos, Marfan and Related CTDs New England/MA Support Group:** [bit.ly/edsctdgroup](http://bit.ly/edsctdgroup)

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**PainPathways** MAGAZINE  
[pinterest.com/painpathways](https://pinterest.com/painpathways)

Ryan Rankin loves hiking, and has been able to find ways to continue his outdoor adventures despite pain.



# Ryan Rankin

FIGHTER

Not sitting still, he finds new challenges to conquer.

The National Institutes of Health (NIH) reports that the average age of someone diagnosed with osteoarthritis is 47. That number increases to age 58 when narrowed down to those who specifically have osteoarthritis in the ankle.

Ryan Rankin was only 28 when he was diagnosed, more than half the average age. “I still try and be as active as I can be,” he says. “It’s not easy, but I can’t let my ankle arthritis get the best of me. Not at this age.”

Growing up in Wisconsin, sports were the center of Ryan’s world. He excelled at basketball and played in college. He sustained multiple injuries along the way, especially to his ankle. “From tricking the trainers into thinking I was OK, to telling

my coach that if I sat out the next few practices I would be ready for the game, all I cared about was getting out there doing what I loved, which was to play basketball,” says Ryan. His injuries never fully healed.

Sports-related injuries are one of the most common reasons why people develop osteoarthritis. Over time, the cartilage in Ryan’s ankle began wearing away, causing pain, inflammation, and swelling—and leaving him sidelined.

## TREATMENT

Osteoarthritis is a chronic disease. There is no cure. Analgesics, non-steroidal anti-inflammatories (NSAIDs), and corticosteroids are the first line of defense

in treating osteoarthritis. Weight management and regular physical activity are two effective methods to combat further deterioration and manage pain. These are all a regular part of Ryan’s approach to dealing with his osteoarthritis. He also uses a transcutaneous electrical nerve stimulation (TENS) machine, continues exercises he learned through years of physical therapy, monitors his diet, and has found taking cannabidiol (CBD) pills help to alleviate daily pain.

Acupuncture and dry-needling provided short-term relief, but Ryan wonders if he had continued either practice more regularly, they would have proved to be more beneficial. “I’m always searching for and trying something new that might be able to help my situation,” he says.

## BEYOND LIMITATIONS

“Do not let what you cannot do interfere with what you can” is a quote by John Wooden that Ryan lives by. This quote

is also the first thing your eye is drawn to when you open Ryan’s blog, My Life With Osteoarthritis. Through this, he has found purpose in sharing his story, focusing on how he can inspire people living with the same condition.

Ryan’s an avid fisherman and enjoyed planning and taking backpacking trips. In 2014, he had planned an ambitious 20-day, 211-mile hike of the John Muir Trail in Yosemite Park... solo. Considered one of the most beautiful and challenging hikes, the John Muir Trail includes hiking Half Dome, El Capitan, and Glacier Point, and ends near Mt. Whitney, the highest peak in the contiguous United States at 14,505 feet tall.

Ryan researched the best ways to complete the trail, bought the right equipment, and trained so his ankle could sustain the ambitious solo hike.

However, two weeks before he planned to embark on his dream backpacking trip, Ryan required a second major surgery on his ankle. The Brostrom procedure was needed to reconstruct damaged lateral ankle ligaments by reattaching the affected ligaments. And a calcaneal osteotomy, which is a controlled break of the heel bone, was performed to correct deformity in the ankle joint and surrounding areas.

Ryan’s extreme goal of hiking the John Muir Trail began to slip away. In his blog Ryan writes, “It’s hard as hell accepting new limitations when you’re still young and active. I want to keep moving and exploring. But when someone, or something like OA, tells you ‘No, you need to stop now,’ it’s almost second nature to figure out a way to break through that barrier and go the extra mile.”

The ankle surgery did not provide much long-term relief and the next step was an ankle fusion.

**SURGERY**

Prior to the second surgery, the pain in his ankle became so severe that his doctor felt an ankle fusion surgery, also called ankle arthrodesis, was the best treatment option. This entails directly connecting the bones that make up the ankle joint: the tibia (shinbone), fibula, and talus bones in the foot. The goal is to reduce pain caused by



Ryan writes about his determination at his blog, [mylifewithosteoarthritis.com](http://mylifewithosteoarthritis.com). Below: Ryan atop Mt. Whitney, a goal he worked for years to achieve.

joint movement that is already limited due to degenerating cartilage in the ankle.

The ankle joint allows the foot to move in all directions. An ankle fusion severely impacts the ability to move the foot; in many cases, the foot is no longer able to move independently of the lower leg. The surgery changes the way a person moves. Physical therapy, stretching, and orthotics can help someone learn to walk comfortably and potentially avoid a noticeable limp as they walk.

Still in his 30s, Ryan did not expect to be facing a surgery that could potentially limit his mobility. He was determined to not let it define him.

Before the possibility of an ankle fusion became reality, Ryan was determined to complete his dream hike. Ryan is stubborn, a trait that many who live with chronic conditions face in learning to accept what our bodies can handle while still living our best life. Ryan researched alternatives to hiking the John Muir Trail that offered a better chance of success. He would hike the High Sierra Trail, a 75-mile hike that would take eight days. The big payoff at the end still included conquering Mt. Whitney.



*“After all, learning to live with and properly manage osteoarthritis is a marathon, not a sprint...”*



**A DREAM REALIZED**

In 2016, the feeling of reaching the top of Mt. Whitney at the end of his excursion was triumphant, emotional and empowering. Here’s how Ryan described it on his blog:

“While I was battling my osteoarthritis, other people had their reasons for hiking: the loss of a loved one, a father and son rekindling a long-lost relationship, people just wanting to escape society for a few days. Hearing why they wanted to make the journey was very inspiring. We all had our own reason for taking the hike and our own vision of what would make it a success. But while we were on the same trail, we were having unique journeys and being inspired from other hikers’ motivation was a wonderful feeling.”

Two months after his successful and challenging hike, Ryan realized his ankle actually felt better than he expected. He

immediately began to think of new and different challenges to face. However, he checked himself, having learned important lessons about life with osteoarthritis. “After all, learning to live with and properly manage osteoarthritis is a marathon, not a sprint,” Ryan admits.

**MOVING FORWARD**

Ryan’s daily life includes constant soreness and stiffness in his ankle. He believes osteoarthritis in his hip and knee isn’t far behind. He wakes up each day not knowing how severe the pain will be. He says, “It’s always around, letting you know it’s still there.”

For someone so active his entire life, Ryan’s biggest challenge has been learning to transition from high-impact activities to ones that are slower-paced. He’s learned to listen to his body, sometimes begrudgingly realizing he has to make

adjustments. His beloved basketball is no longer an option.

**IMPARTING WISDOM**

Ryan wants people to realize that osteoarthritis doesn’t only affect those over age 60. “There are a lot of individuals in their 20s and 30s suffering from the condition and trying to figure out the best way to manage the condition—and they also need support and guidance.”

**➤ RESOURCES**

**CreakyJoints:** [creakyjoints.org](http://creakyjoints.org)

**Osteoarthritis & Sports/Exercise FB group:** [bit.ly/oasportsFB](http://bit.ly/oasportsFB)

**My Life With Osteoarthritis:** [mylifewithosteoarthritis.com](http://mylifewithosteoarthritis.com)

# Karen Scifo

TROOPER

## Accepting her limitations to find a new way to live.

In 2008, Karen Scifo was an active 38-year-old mother, wife, friend, and colleague. She had been through some rough times in her life and was finally at a place of peace—raising three sons, working a job she loved, and having married a man who adored her. But everything changed one afternoon in late November.

Her middle son wanted to decorate the house for Christmas. Obliging, Karen went up in the attic to bring down the holiday decor. As she bent down to move one final empty box in the attic, she found herself unable to move, paralyzed with intense, burning pain. Her husband, George, had to carry her down the stairs.

Karen's primary care doctor ordered an MRI. A radiology transcriptionist by profession, Karen knew it was herniation from seeing the images and scheduled an appointment with a back doctor that same afternoon. The specialist confirmed her speculation: she had an L4-5 herniation. Surgery was needed.

### UNSUCCESSFUL TREATMENTS AND MORE UNWANTED DIAGNOSES

The invasive L4-5 hemilaminectomy failed. With discs now resting bone on bone, Karen has herniations throughout her lumbar spine—and pain that has never gone away. She also has pinched nerves and a herniation in her neck that radiates pain down her shoulders and



Karen with her cousin, Helen, and her mother at a cancer survivor's breakfast. Karen says having the support of her family has been critical to her success.

arms. "I live in chronic lower back pain that shoots down both of my legs to my toes," she says. "While the herniation in my neck comes and goes every couple of weeks, this back pain never ceases."

With surgery unsuccessful and a fusion not in her best interest, she sought a second opinion, who referred her to a physical therapist and pain management specialist. Karen tried a neurostimulator, which brought on further pain. She had over a dozen lumbar punctures before calling it quits (most exacerbated her symptoms).

For nearly a decade, Karen has been an active participant in her health journey. She knows how to advocate for herself, when to seek out other opinions, and whom to trust. She stores and takes her medications (including an opioid) safely and as prescribed, refusing to take any over-the-counter medications



Karen on one of her extra-bad days.



without a doctor consult. She attends physical therapy as needed.

Despite being a stellar patient, Karen's health woes have magnified. She was diagnosed with fibromyalgia, and experiences excruciating tailbone and low abdominal pain. The worst medical issue to arise since Karen's herniation is rectal prolapse.

No one can definitively say why Karen developed prolapse, but most of her doctors agree that her back issues, medications, and subsequent constipation triggered the condition. "There was a time that I could go 40 days without a bowel movement," explains Karen. "Sometimes I couldn't even strain or push hard enough to remove the stool, and had to visit the hospital to have it removed."

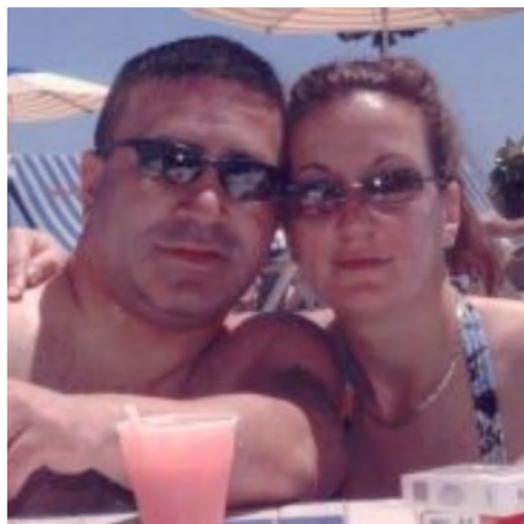
She underwent surgery to correct her prolapse in November 2013; the surgeon also removed nearly four feet of her colon that had gone septic. But the surgery as a whole failed. "I now have rectocele, a herniation between the rectum and vaginal walls," she shares. With her rectal muscles no longer functioning, Karen must go to extraordinary circumstances to have a bowel movement.

**MINUTE BY MINUTE**

Karen no longer can work and lives on disability. She goes through periods where she is able to do more, and times when she is in bed a lot.

When she can, she likes to walk and has a membership to Silver Sneakers (a gym for the disabled and seniors), where she uses the pool. She also tries to stay healthy by eating well.

Spontaneity has left Karen's life. Instead, she lives by routines that allow her to function. "I have to live minute by minute," she shares. "The times of planning outings days or weeks in advance no longer exist for me." She explains that sometimes, taking a shower is like climbing Mt. Everest. Going to the store with her husband requires her to bring her wheelchair since she may start walking, but three minutes in, need to be pushed. "It's frustrating never knowing



Karen says her husband, George (that's them on the left on their honeymoon), has been ultra-supportive throughout her ordeal. Above: She hates this photo of herself, but says she wants to show what she looks like when in enormous pain.

what I will be capable of doing each moment. But I keep trying and just do the best that I can."

**FACING CHALLENGES HEAD ON**

Karen's challenges far exceed the limitations of pain and disability. Karen has had to deal with unnecessary stress stemming from long waits for her health insurance to approve medications, therapies, and tests. She even recently had to change her medication due to insurance practices surrounding the new pain guidelines.

"I am constantly scrutinized because of the fact that I take narcotics for pain," states Karen. "Every time I see a doctor



*“All I wanted was to feel normal ... But the pain just wasn’t going to go away despite the treatments. I was running a race I could not win.”*

for an issue, especially in the emergency room setting, I face speculation of being a drug seeker. It is demoralizing and infuriating, as a legitimate pain patient who responsibly follows her treatment plan, to be accused and treated poorly because of my medicine.”

But Karen is a fighter and takes the pushback in stride while advocating for the care she deserves.

**A NEW PERSPECTIVE ON LIFE**

The first seven years Karen had pain, she attempted to live life as normally as possible. She didn’t want to let anyone down or acknowledge she couldn’t do some things. Wanting to be seen and treated the same—but also wanting empathy and help—caused an internal tug-of-war.

“All I wanted was to feel normal,” explains Karen. “But the pain just wasn’t going to go away despite the treatments. I was running a race I could not win.”

Then came her “aha moment.” She remembers being outside grieving the loss of her dad when an overwhelming feeling came over her. “I realized I will always live in pain, and whether I liked it or not, life would forever be different,” Karen shared. “It was like someone was telling me, ‘You are not normal. Accept your limitations, and everyone else will do the same.’”

Not needing to pretend she was fine as her body progressively worsened, Karen found her own normal.

“I finally accepted that this is who I am, and I have to take each day as they

come.” It was liberating. “I was finally able to say ‘I can’t do that today.’” Now, on the days she isn’t able to cook, George will order pizza and it’s OK.

**COMING TO TERMS**

Karen has had to acknowledge how her pain impacts others. It took her a long time to see she is not the only one involved—her husband and family are affected, too. This realization has eased some of the tension of feeling unheard or misunderstood.

She has been married to George (the stepfather to her three sons) for 14 years, and is thankful for his support. She says they have an unspoken language: “He can just sense my pain by looking at me.” While this connection reassures her, it is George’s actions and support that truly show Karen his love for her.

Pain is hard for those not experiencing it to fully understand. Her extended family tries to be understanding and helpful, but they, too, get frustrated sometimes and lose sight of her daily struggle.

Karen has come to learn that it’s just who they are, and it is OK that they don’t grasp what she endures. “I now see that it’s not necessary to have their validation,” she says. “I can’t keep trying to live up to others’ unattainable expectations of me.”

**ADVICE LEARNED**

Now 47, Karen Scifo is proof you can have a life while living with pain. Being able to accept her new life and limitations has been vital to her happiness today. She also gathers strength knowing she is not alone. “Reach out for help; it exists. That’s how I found U.S. Pain Foundation—it was 3 a.m., the pain was unbearable, and I was searching the internet for information and help. I am so glad to have an outlet that is here to help us all along on our journeys.”

**RESOURCES**

**Silver Sneakers:** silversneakers.com

**U.S. Pain Foundation:** uspainfoundation.org



Above, Karen and her mom on a trip to Las Vegas. Below, Karen joins her son, Zach, at a concert. While Karen can’t be as active as she once was, she tries to get out and do things when she’s able.





Tammy relies on family for support. Here, she joins husband Mark, mother-in-law Karen, and her granddaughter, Erica, at her kindergarten graduation.

# Tammy Price-Hummel

ADVOCATE

Supporting the community so no one has to suffer needlessly.

At 52 years old, Tammy Price-Hummel has been living with pain for nearly four decades. Sadly, she was also forced to deal with the pain mainly alone for nearly three of those decades. Not wanting anyone else to have to suffer needlessly without proper care is why she has become a passionate advocate. Tammy is on a mission to use her experiences to help others.

Tammy was just 15 when she fell off a swing and could not move. Her hips had locked, and terrifyingly, she had to wait until they relaxed before seeking help. She saw her doctor who informed her that she not only had bursitis in both hips but also

in her shoulders.

The news was devastating. “I never thought little things kids do like bouncing down the stairs was harmful,” she explains. “How was I supposed to know at that age that childish antics could hurt my body and cause bursitis?”

### JUST THE BEGINNING

Her health continued to decline. Tammy quickly experienced daily pain—typically lasting a few hours at a time, but sometimes days on end. Yet no one seemed to listen to her. “My doctors did nothing for me at 15,” Tammy laments. “In fact, I didn’t get proper treatment until 43 when

my primary care doctor realized vicodin was not helping or working.” At her husband Mark’s, insistence, she was finally referred to a rheumatologist.

“From the moment I saw the rheumatologist, I felt vindicated and validated,” gushes Tammy. She was diagnosed with scoliosis, sjogren’s syndrome, osteoarthritis, fibromyalgia, psoriatic arthritis, and rheumatoid arthritis. The care she received was like night and day: “I had answers, a supportive doctor, and a treatment plan that gave me hope again.”

Tammy has tried a multitude of therapies since that first visit. She has been on over-the-counter medications, opioids,

and pharmaceutical medications. She has had lumbar punctures and nerve blocks (when they missed the position and her buttocks went numb instead, she never did them again). Physical therapy was a love-hate relationship for her.

“The therapist was sweet, which I loved,” chuckles Tammy. “But I hated the therapy. PT seemed to irritate my osteoarthritis and then I found myself at war with my body for lengthy bouts of time.”

Tammy tried a diabetic and a low-sodium diet as well, but didn’t see any improvements. And she doesn’t exercise much. For her, exercise consists of walking to the mailbox and back; but even that requires her to stop a few times due to the pain.

She describes the pain as episodic, meaning the intensity and sensations constantly change. There are times when she feels irritation that could be described as a bee sting; then there are the more extreme sensations like being stabbed by a knife or natural childbirth. Tammy also suffers from upset stomach and gastrointestinal issues, memory loss, and severe fatigue.

When flared, no medication or therapy can stop or even decrease the pain. In the beginning, she would have warnings that a flare was coming. But without adequate treatment for so many decades and an acceleration in her health deterioration, these flares come and go with no warning now. What used to last a few horrific



Above: Tammy, right, joins her husband, Mark; Mark’s son Logan; and Logan’s mom, Lisa, for Logan’s graduation ceremony. Right: One of the many selfies Tammy posts in her Facebook ministry group.



minutes has also progressed to days without reprieve.

Currently, Tammy is battling for use of her legs and has horrendous pain in her spine near L2-L5. Doctors explain she has bad arthritis in the area as well as discs breaking down.

*“I never want another soul to experience the pain, isolation, and deep despair that I endured for decades.”*

**FINDING RELIEF IN NATUROPATHIC THERAPIES**

Tammy has done away with most of her medications (including opioids) to focus on natural healing. She explains that being very religious (she is an ordained minister), she would rather deal with a more holistic, God-given approach to medicine than taking pharmaceuticals.

“Please don’t misunderstand me,” Tammy says. “I do not shy away from western medicine. Doctors are needed and so are medications that I have used in the past or currently take. But

I would much rather use herbs and natural medicine to treat myself.”

From the bible, she understands that God gave us many different oils, spices and natural medicine (like cannabis—which she has not tried, but wishes there was more research on it) to use to heal.

Tammy uses doTerra essential oils and has seen drastic improvements to not only her physical pain, but also to her mental and emotional well-being. Her pain is now tolerable; at night, she is able to relax and sleeps soundly. “It has been an amazing transformation,” she shares enthusiastically. “God sent me an angel when Tito entered my life and told me about doTerra. I can’t even explain the difference in my body from using oils. They are working wonders.”

**DETERMINED TO DO THINGS RIGHT**

While Tammy will never know how her life might have been different had she received proper care early on, she does know there is a purpose for her. Realizing she is stronger than the pain and



Tammy, Mark, and their grandson, Austin.

can beat it, she blogs, participates in a secret online support group led by Deborah Allen and Carla Moessner (a group that has been there for her during the darkest of times), and started an in-person support group. She started the Open Door Ministry because she knew people in her community had chronic pain and no place to go to talk about their journeys. “It is a small, but mighty group of three,” she explains. “We meet every Thursday at the local McDonald’s since they have a free conference room we can use.”

Regardless of how Tammy is feeling, if it is Thursday, she will push through any flare and show up. “You never know what day someone may be having, or who may come in desperate need of help,” she states, “so I have to be there.”

As a pain warrior, she wants to do things right for the pain community. The work is personal and important to her. “I am here to help someone catch that pain before they have to go through what I have been through my entire life. I never want another soul to experience the pain, isolation, and deep despair that I endured for decades.”

**LESSONS LEARNED**

Witnessing a lot, Tammy has come to learn some important truths:

- Just because you can’t see it, doesn’t mean the pain isn’t real, or that we are lazy and faking it. These unfair judgments and false assessments hurt us mentally when we are already physically hurting so much.
- Help does exist but you have to learn how to ask and where to find it. (Two online resources beneficial to Tammy are U.S. Pain Foundation and MyChronicPainTeam.com.)
- Do your own research. If you are getting the care you need, seek another practitioner; if you don’t feel a certain treatment course is right, trust your instinct.
- Try natural remedies.



Tammy sometimes loses her hair because of her medications; this time, Mark shaved his head in solidarity. Above: Tammy is surrounded by cousins Marsha, Bridget, and Susan at a family get-together.

**STRENGTH FROM LOVE**

Tammy has been lucky when it comes to support. With grown children (Amanda and Tyler, and their spouses Chad and Tasha), stepchildren (Courtney, Ashley, Logan, and Jordan), their spouses, and grandchildren, they all have played an important role in her journey. Her kids were her main support during those early years when she did not have medical support she needed and deserved. Her stepkids have been right by her side since entering her life, especially Ashley. “Each step along the road, they have had their hand in helping me through some part of this journey,” she notes.

Then there is Mark: her rock. Her husband gets the good and the bad. Mark advocates for her when she is unable to do so for herself. As long as Tammy sees his ‘big ole grin,’ she knows things will be alright.

Pain has been a limiting factor Tammy’s whole life. It kept her homebound and

isolated. She had to learn the hard way that life doesn’t stop because of suffering. Because of these experiences, Tammy is dedicated to helping others avoid that same fate. With kindness and compassion, she is doing her part to make an impact in the lives of others with pain.

“With my faith and amazing support system, pain has not slowed me down. I keep moving forward while doing my best to ensure others don’t have to go down my path: that they find the medical care they need immediately and a community of outreach and support. Pain should never cripple a life to such an extent.”

**► RESOURCES**

**MyChronicPainTeam:**  
mychronicpainteam.com

**Open Door Ministry:**  
facebook.com/opendoorministry2014

Kate says her husband, Ben, has been an amazing source of support. They keep each other laughing despite the pain.



# Kate Schultz

HOPEFUL

Learning self-compassion in the face of disabling pain.

“I’ve always had some kind of lower back pain,” says Kate Schultz, 35. She was diagnosed with Ehlers-Danlos syndrome (EDS) at the age of seven, and the condition causes both chronic and acute joint pain and other complications. Kate can’t really remember a time when she didn’t have chronic pain—but the past few years have been the worst.

“I have flat feet, so I don’t walk correctly, making my knees, hips, and lower back hurt,” Kate explains. “I’ve had 14 surgeries in the past five years—mostly on my knees, but also on my feet, plus a kidney stone removal—and I use crutches, all of which aggravate my lower back pain. Plus, I have hypermobile hips, and sometimes my sacroiliac (SI) joints get out of whack, probably from walking unevenly.”

All of these issues contribute to something Kate refers to as chronic-acute pain:

the experience of having a chronically occurring series of acute injuries. “The pain is chronic, in that I have it all the time with no relief or specific injury or damage,” she explains. “But every so often, my SI joints flare up, causing acute pain that needs different treatment from what I do for the chronic pain.”

In addition to low back pain, Kate lives with depression and anxiety, temporomandibular joint dysfunction (TMJ), neck and shoulder pain, elbow pain (including osteoarthritis on one side), carpal tunnel syndrome, hypermobile joints, and a handful of other chronic conditions.

“I have an awesome physical therapist, who did his research on EDS and he’s been able to help a lot with my low back pain,” says Kate. He gives her exercises to do to alleviate some pain and helps loosen tight muscles so she can relax. Kate also

uses heating pads, changes position frequently, and uses the hot tub at her gym to release muscle tension. Aquatic therapy has helped increase her mobility, and she gets a monthly massage.

## ACCESS ISSUES

In addition to all these things, Kate uses opioid medications to manage her pain. But lately, she’s had increasing obstacles to getting her medications; she’s required to visit her doctor once every month or two to get her prescription refilled, which is tough on high-pain days. Her insurance company could cancel her prescription at any time without explanation if the laws and regulations change, something she fears. More health care organizations are removing all (or almost all) patients from opioids, and she’s afraid that anytime she sees one of her doctors, they might want

## PROFILE

to take her off opioids without totally understanding her pain.

“I had my meds stolen, and I had to go through police reports, appointments, and phone calls to get the replacement medication I depend on to live my life,” says Kate. “I was made to feel it was my fault that the meds were stolen.” Kate says that with all the rules and regulations doctors have to follow, they can seem suspicious of all patients. “While I freely admit that opioid addiction and death are a serious problem, so often people forget about those of us who rely on these medications to function.”

Kate says a frequent challenge she’s faced is denial of medication post-surgery. Her pain can be quite extreme, but she doesn’t often show that pain on her face or in her body language, so at times, it’s been impossible to get health care providers to believe the high level of her pain. “Medicine is so stuck in protocols and what the ‘typical’ patient needs that when a patient comes around that doesn’t fit in their boxes, health care providers can get stuck in the protocol, to the detriment of the patient,” says Kate.

She says she’s hoping for the development of effective non-opioid pain medications. “A non-opioid medication that works for me would help with issues of access to medication, and eliminate the stigma associated with taking opioids—that would be a relief,” says Kate.

“I’d also love for more insurance companies to cover alternative sources of pain management,” she adds. “Obviously there needs to be some kind of indication that they’re effective, but I don’t think people are going to acupuncture just for funsies.” She finds it frustrating—and rather telling—that her insurance would rather cover a month’s worth of opioids (about \$50) than massage (which can cost between \$70 and \$150 per visit).

She says she’ll keep doing both, because it’s important to her to take the best care of herself that she can. She also sees a



**Determined to feel beautiful on her wedding day, Kate decorated her crutches to give them visual appeal, and even had them photographed to commemorate the day. Her strong spirit endures. Photos by Ora Photography and TeStrake Photography.**

health psychologist and another counselor a few times a month; journals to process her feelings and frustrations; practices self-care every day, like taking care of her personal hygiene so she feels “put together”; and tracks her pain levels to spot trends.

### EXPERIENCING DISABILITY

Kate says her pain and reduced mobility caused her to lose her job in 2017, and four months later she was approved for disability benefits. “For most of my life, EDS wasn’t an active issue—I was able to do so much, I planned my days from 8 a.m. to 10 p.m. and had a very full life,” she says. “The last couple years, my disability and pain took over my life. It took me a while to understand how limited I had become.”

Losing her work life was a huge blow to her sense of self-worth. “I had won a lot



of awards, was one of the people on my team with the longest tenure and a lot of experience, and loved my work—that was really hard to lose.” Kate says she misses all the daily interactions she enjoyed with co-workers and friends.

“I feel at loose ends a lot of the time now because I don’t have a lot of the activities that used to take up my time, and even though I have more time now, I’ve been severely limited in what I can do,” says Kate. “My pain is unpredictable, so I’ve had to cancel on plans at the last minute and miss important events. I always have to make sure people understand that plans are tentative, and continually have to weigh activities against the pain they’ll cause and what I can do to treat that pain—is it worth having the pain in order to do the thing?”

### EXPLORING SELF-COMPASSION

“You have to respect the pain and accept where it’s taking you—and respect your body’s needs,” says Kate. “Having to learn to be compassionate for myself has been essential. I’ve always been an over-achiever, always volunteered for things, so it’s difficult to slow down and say no. But I’m learning to appreciate other things about myself and my life. I try not to look at my disability as ruining my life and think instead that it is changing my life.”

One thing that Kate says has helped

her practice this kind of self-compassion and acceptance is membership in the ChronicBabe Secret Club, a low-cost monthly subscription program designed by U.S. Pain ambassador Jenni Grover to teach people how to live as well as possible in spite of chronic illness. “I love how Jenni has so many different ways to interact with members: emails, a Facebook group, live calls, music playlists,” says Kate. “It is a place to find solutions, support each other, and lift each other up. I have gotten so much from the group and I’m able to offer support to others, too.”

**FEELING THE LOVE**

Kate is also thankful for her husband, Ben, who has stayed by her side through the toughest moments. They met in 2012, and after only six weeks of dating, she ruptured a tendon and needed help with even basic household activities during recovery—and Ben said he would stay with her and care for her. As the relationship

progressed, “I told Ben, ‘I understand that this is something you did not sign up for,’ but he called me crazy, and said he would take care of me for the rest of his life,” says Kate. He has supported and advocated for her ever since.

Kate hopes the lessons she’s learned can help others: “Honor your feelings and limitations, positive and negative. Be kind to yourself; it will be difficult because limitations suck. It’s going to be a part of your life, and not letting it take over can be hard. Advocate for yourself and the assistance you need—among friends and family, at work, and with doctors. You only have one body, and it deserves to be cared for.”

➤ **RESOURCES**

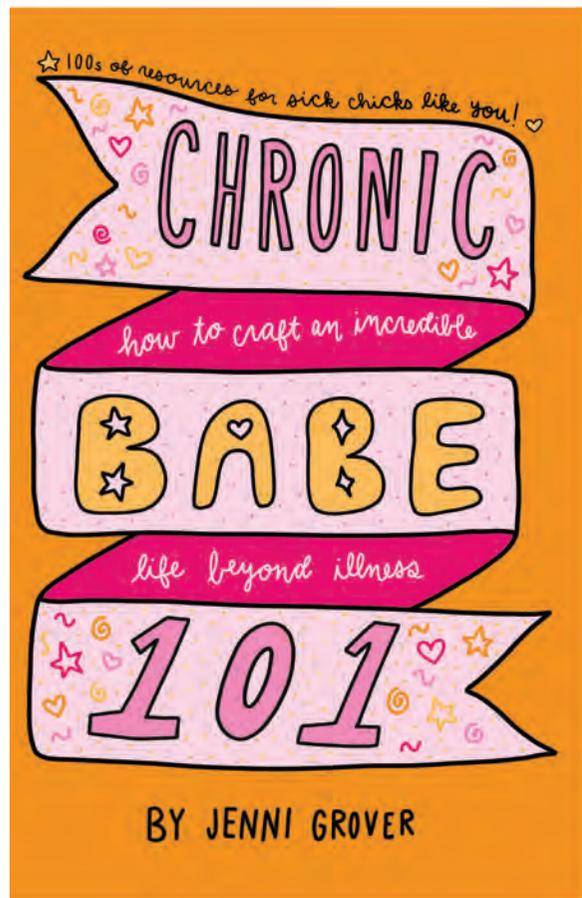
**Ehlers-Danlos Society:** ehlers-danlos.com

**ChronicBabe Secret Club Membership:** chronicbabe.com/secretclub

**American Chronic Pain Association:** theacpa.org



Kate has two adorable cats, Simon and James, to help keep her company at home. She has a microwavable stuffed animal named Gerald, filled with flax seed and lavender, to help ease her pain and stress.



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# Richard Kreis

CAREGIVER

Focusing on caregiving and humor keeps his spirit strong.

Twenty-five years ago, Richard Kreis was excelling in his career and pursuing a degree in psychology when an accident changed his life. While driving toward his Sacramento home from Fresno, Calif., Richard had to stop on the highway for construction, and his car was rear-ended at an angle by a drunk driver going approximately 75 to 80 miles per hour. Richard’s car was moved 18 feet, pushing the vehicle in front of him into a delivery truck.

“I couldn’t have asked for better luck, though,” says Richard, “because in the cars behind me were an off-duty fireman and an insurance claims adjuster who saw the whole thing.” He’s lucky he had immediate help and witnesses to back up his story. The other driver should never have been on the road in the first place; it was his fourth DUI accident. And that kind of appreciation for the good, even in the worst situation, is one of Richard’s most powerful qualities.

### LIFELONG RAMIFICATIONS

Richard was severely injured. He has four bulging and three leaking discs that were sealed, collapsing discs at L3-L5, and rotational tears in all of the L1-L5 lumbar and sacral vertebrae. He has severe nerve damage in more than half of the L1-L5 vertebrae, and because of these injuries, he also has sciatic nerve pain in his right leg. Restricted blood flow and blood pressure in his lower extremities

can't be repaired, so he has experienced venous ulcers, each of which took more than a year to heal, the most current one requiring two skin graft surgeries.

Richard, now 53, lives in constant, severe pain. He can only sit or stand for 15 to 20 minutes at a time before he has to change positions or stretch to ease the pain. He wakes every night for about 60 to 70 minutes to work out knots in his muscles and sleeps fitfully the rest of the night because of pain.

### FIGHTING THE MIDDLE MAN

Richard's story exemplifies some of the worst problems plaguing our health care system. Because he was working when injured, workers' compensation insurance controls the health care he receives now.

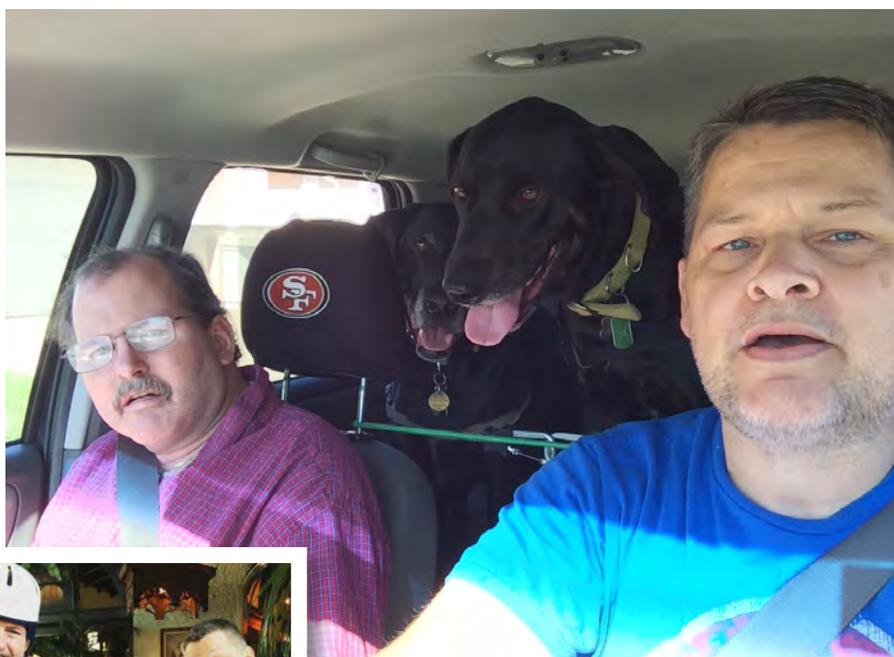
"Since this all started in 1993, I have experienced nothing but roadblocks," he says. A rotating handful of companies has handled his care and paid (or denied) his claims, including a few "middle man" companies who operate as go-betweens from Richard to his insurance. Keeping track of who's in charge of what is a challenge, and the constant changes make it even harder to get things approved. Often, the treatments his doctors order are flat-out denied.

He's been to court numerous times: "One time, the hearing was about a treatment plan my doctors ordered that insurance tried to deny. I waited three and a half hours to meet with a judge, then opposing counsel spent two and a half hours deciding who would pay for a \$1.95 postage fee." For someone who now has very few hours during the day when he can function, that kind of time is an enormous waste.

Sometimes it would take him four or five months to meet with doctors to update his treatment plans, and in the meantime, his medications would run out—so he would experience detox symptoms.

### LEARNING TO ADAPT

Unfortunately, Richard was not a candi-



Above, Richard takes a drive with his brother-in-law, Robert, and two of his dogs, Oz and Taz. Left, Richard and Robert enjoy a fun night out for dinner. Being a caregiver gives Richard a great feeling of worth.

date for surgery, but in 25 years of living with pain, he has tried numerous treatments. Most pharmaceutical medications don't help, and even though medical cannabis is legal in California, Richard's pain team won't treat him if he uses it. Nerve blocks helped for many years, but his insurance's in-house medical advisor recently denied them. Physical therapy, chiropractic manipulation, acupuncture, and massage help, but again, Richard's insurance deems them "unnecessary."

Richard has taken steps to do what he can to control his pain, including cleaning up his eating habits and losing a significant amount of weight. He works hard on his attitude, choosing to embrace humor whenever possible—including things like seeking out wacky compression socks instead of plain black and beige options, and cracking jokes everywhere he goes. "Pain

without humor is just painful," he says.

One treatment that helps Richard a great deal is an intrathecal pain pump, which places fentanyl directly into his spine and helps deaden the nerves, relieving about 40-60% of his pain. He's thankful for the pump, but he had a scare a few years ago during a routine refill of his pump medication. Usually, the medication is injected into a fill port in the patient's abdomen. That time, he experienced a "pocket fill"—the medication missed the port and went straight into his abdomen. He was in intensive care for a week and nearly died.

Today, Richard still goes every five to six weeks to get a refill, dealing each time with symptoms of post-traumatic stress disorder in order to get his medication. "It's scary to live with, but it's the best device on the market," says Richard.



“Until I can find something that matches the pump’s pain-fighting capabilities, I just have to deal with it.”

Richard says it’s important to remember that he’s not alone in living with the impacts of pain. “Anybody and everybody who’s involved in my life is impacted by my pain,” he says.

**FOREVER A CAREGIVER**

Richard’s wife of 21 years, Trish, is one of those people. “My wife has only known me since I’ve had pain—she’s put up with so much from me,” he says. “I definitely found the right person. She’s my rock.”

Richard and Trish met when they were both “ballet parents” to three-year-old girls. They worked on making backdrops and sets for shows, and their girls bonded, joking that they were twins. Birthday parties and sleepovers meant Richard and Trish spent more time together, and eventually fell in love.

Trish wrote a book about caring for her parents, *Forever a Caregiver*, and soon Richard was bitten by the writing bug, too. In recent years, the two have co-authored (with three other caregivers) three more books, two of which are available in Spanish, under the *365 Caregiving Tips* umbrella: *Practical Tips From Everyday Caregivers: Hospitals, Care Facilities and Hospice: Practical Tips From Everyday Caregivers*; and *Travel and Respite: Practical Tips From Everyday Caregivers*. Richard also authored *A Journal of Care*, which allows people to collect all the needed information for future appointments (like insurance information, contacts, medications, appointments, notes, and calendar). The books are available on Lulu.com and Amazon.com.

For their books, the team draws on their experiences of being the primary caregivers for their loved ones. Carol, Richard’s mom, lives with them part-time; she had a stroke and lives with chronic heart failure and chronic obstructive pulmonary disease (COPD). Robert, Trish’s brother, has severe epilepsy and lives with them full-time.

Richard says he feels a sense of personal worth from being a caregiver, especially since he has not been able to work for many years. “Trish and I believe that being a caregiver



is an essential skill, but not something we’re usually taught, which is why we’re so passionate about getting our books into as many hands as possible,” he says. Richard also runs a blog that shares resources for people in pain, and recently trained through U.S. Pain Foundation’s Pain Connection program to create a new support group. Richard is also a Certified Caregiving Consultant.

“Pain doesn’t have to stop your life,” says Richard. “You may have to give up some things, but try to look at it differently—you may have to try a different approach or get help, but you can still have a life that has love and humor. Never give up on that.” He says the best way to think of it is: “Adjust, adapt, and admire yourself.”

Richard likes to joke that he’s a grump, but he’s equal parts comedy and compassion. The family’s dogs, Oz, Charlie, and Taz are affectionately known as “an exploded Oreo cookie.” Richard loves his mom, Carol.

**➤ RESOURCES**

**U.S. Pain Foundation:** [uspainfoundation.org](http://uspainfoundation.org)

**Richard and Trish’s books:** [365caregivingtips.com](http://365caregivingtips.com)

**Richard’s blog:** [pickyourpain.org](http://pickyourpain.org)

**Empowered Patient:** [intake.me](http://intake.me)

**Real Warriors Campaign:** [realwarriors.net](http://realwarriors.net)

**Crazy Compression Socks:** [crazycompression.com](http://crazycompression.com)



# WE ARE IN THIS TOGETHER

By Trish Hughes Kreis and Richard Kreis

Chronic pain hasn't just affected Richard. Of course, he is the one waking up several times a night in pain, trying various medications (sometimes with disastrous results), and saying goodbye to a career he loved—but the whole family has been affected too.

Dealing with chronic pain has been a learning experience for all of us and it has not been an easy road. What got us through all of it is our shared commitment to raising our family, and to each other. We now have added something more: a passion and commitment to help other caregivers.

Richard calls himself a “trifecta” caregiver. He cares for his mom, helps care for his brother-in-law, and also cares for himself. Trish cared for her mom, helps with Richard's mom, and cares for her brother, who lives with us. We joined forces with three other caregivers as co-authors of *365 Caregiving Tips: Practical Tips From Everyday Caregivers*. Two more books followed and the first two have even been translated into Spanish!

Richard knew tips for chronic pain patients and their caregivers should be included in these caregiving books.

In the *365 Caregiving Tips: Travel and Respite* book, Tip 140 comes straight from our experience traveling with the kids: “When traveling with a loved one suffering from chronic pain, allow extra time to stop to take rest breaks.” The kids grew up thinking the beach was five hours away and were delighted to find out it was half that when they were of driving age!

One of Trish's favorite tips for caregivers of those with chronic pain is Tip 142: “As caregivers, we need to bite our tongue when our loved one is in extra pain or extra tired because they pushed themselves too much! We can't even say ‘I told you so’? Well, maybe in our head.”

(After 21 years of marriage, Trish has that “I told you so” in her head down pat!)

As caregivers, we also know how important it is to rejuvenate ourselves. A vacation is not always possible, so we are huge fans of “Self-Care Quick Refreshers.” A chapter on this topic from *365 Caregiving Tips: Travel*

and *Respite* includes many ways to take quick breaks to clear your head.

Sharing this passion to help other caregivers has strengthened our bond, which makes it so much easier to get through the tough caregiving and chronic pain days. (And there are plenty of those!)

Laughter also helps, so we will leave you with this final tip from the travel book: “Laugh. Laugh as much as you can. Laugh until you cry and your stomach hurts. Laugh!”



Richard and Trish are determined to keep being terrific caregivers for others, and to keep taking care of themselves. They travel together, laugh together, and make the most of every day.

## ABOUT THE 365 CAREGIVING TIPS BOOKS

Trish and Richard, as well as the other authors of the *365 Caregiving Tips* books, joined forces to help other caregivers by sharing practical caregiving tips. The authors are or have been caregivers and come by these tips through research, common sense, and trial and error. Their goal is to save other caregivers the trial and error part.

The books are available in print, PDF, and eBook formats, and the first two books have also been translated into Spanish. They're available through Lulu.com or Amazon.com.



# SPOTLIGHT

ADVOCATE. RESEARCH. FUNDRAISE. SUPPORT.



➤ **MANY ORGANIZATIONS REPRESENT PATIENTS ACROSS THE UNITED STATES.**

A select few do a significant amount of work to make sure the voices of those impacted by osteoarthritis and chronic low back pain are heard. In the Spotlight section, we give space to some of the top organizations in the U.S. >>>

# THE GLOBAL HEALTHY LIVING FOUNDATION



**The Global Healthy Living Foundation** was co-founded in 1999 by arthritis patient and advocate Seth Ginsberg (diagnosed with Spondyloarthritis at age 13), and social entrepreneur Louis Tharp. GHLF includes disease-specific communities, the most visible being CreakyJoints, a network of nearly 100,000 arthritis patients and caregivers in all 50 states, Western Europe, South America, and Australia. Other disease areas of focus include psoriasis, chronic pain, cancer, and diabetes.

GHLF is a leader in social and conventional media health care engagement, leveraging new technology to address old paradigm health care problems such as ongoing observational or interventional research. In 2014, GHLF was awarded a contract from the Patient Centered Outcomes Research Institute to build ArthritisPower, a robust arthritis patient registry with a capacity for increased data linkage, which

allows patients to track symptoms and treatments so their doctor can make the most informed treatment decisions.

Additionally, GHLF advocates for improved access to care at the community level, amplifying education and awareness efforts within its social media framework. Central to this advocacy is the 50-State Network, a grassroots advocacy organization comprised of patients around the country. Through it, GHLF is working to share the patient perspective with legislators, which is crucial in the state and federal health policy and regulatory arenas. Patients need a voice in all conversations that relate to their access to treatment, safety, or the quality of care.

Our community is made up of patients living with diverse chronic illnesses, including rheumatoid arthritis, lupus, and psoriasis, and the people who care about them. The 50-State Network is about transforming pain into purpose and empowering those who may feel victimized by disease. The organizational

focus is on repurposing the energy of frustration, despair, and helplessness into positive mobilization, action, and fair representation to benefit all of us.

#### Some of the advocacy actions we take:

- Assist advocates to prepare and present congressional testimony on health care issues such as Step Therapy, Prior Authorization Reform, and Biosimilar Substitution
- Contact legislators on behalf of patients to support or oppose health care reform legislation at the state and federal level
- Work with advocates on op-eds and letters to the editor for their local papers

#### GET INVOLVED:

[Facebook.com/creakyjoints](https://www.facebook.com/creakyjoints)  
[Twitter.com/GHLFForg](https://twitter.com/GHLFForg)  
[Twitter.com/creakyjoints](https://twitter.com/creakyjoints)



*GHLF includes disease-specific communities, the most visible being CreakyJoints, a network of nearly 100,000 arthritis patients and caregivers*

# ARTHRITIS NATIONAL RESEARCH FOUNDATION



arthritis such as rheumatoid arthritis, juvenile arthritis, ankylosing spondylitis, and lupus—where the body attacks its own tissues.

In addition to the research work we have supported, the Foundation has received third party validation from Charity Navigator, Guidestar, and an independent Scientific Review Team. Charity Navigator awarded the



The **Arthritis National Research Foundation** is the charity that funds research to cure arthritis. With one in four Americans suffering with arthritis, including 300,000 children, now more than ever is the time to find a cure.

At the Foundation, we focus solely on supporting arthritis research to find a cure, as over 90% of every donation is placed into research programs. We also focus only on funding early-career, innovative investigators. Our grant recipients have their M.D. and/or Ph.D. and are working in a great lab environment, but don't have the funding to test their idea. We provide the critical funding they need to explore their ideas and push the field of arthritis research forward.

We fund newer scientists because they

are in a position to think outside of the box. Their careers are just beginning, and they are able to remain open to all possibilities. Our Scientific Advisory Board chooses the best and brightest researchers across the country looking to make an impact in arthritis and autoimmune research.

Now, more than ever, these young investigators need our support. Research funding from national sources like the National Institutes of Health (NIH) is shrinking every year—and younger, less experienced scientists are competing with well-established investigators for the same research dollars.

The Foundation funds research into all forms of arthritis, from osteoarthritis—the wear and tear of joint tissues—to the debilitating, autoimmune forms of

Foundation its highest 4-star rating for nine consecutive years, placing us in the top 1% of all U.S. charities; Guidestar presented us with their highest platinum seal for transparency; and the Scientific Review Team gave us a perfect 5-diamond rating for research effectiveness.

Our goal at the Arthritis National Research Foundation is to cure arthritis through research and we truly believe that together we can cure arthritis.

**GET INVOLVED:**

[CureArthritis.org](http://CureArthritis.org)

[Facebook.com/curearthritis](https://Facebook.com/curearthritis)

# U.S. BONE AND JOINT INITIATIVE



restricting freedom of movement, independence, and the ability to lead life to the fullest, and can lead to an early death. These disorders are a major cause of Americans having to miss work. But for many, this storyline can be different. Simple lifestyle changes and new habits can lessen the chances of developing a bone or joint disorder. If necessary, treatments can be prescribed to reduce symptoms, or surgery can be performed to regain function.

Live sessions of **Experts in Arthritis** and **Fit to a T** can be arranged in your community, where you can learn from an expert health care professional and ask questions. Email USBJI for more information: [usbji@usbji.org](mailto:usbji@usbji.org).

For nearly one in two Americans over the age of 18, and many children, movement is restricted by a musculoskeletal disorder—arthritis, back pain, a fracture due to osteoporosis, injury or sports trauma, and other ailments that affect function and mobility.

The American musculoskeletal community has come together as the **United States Bone and Joint Initiative** (USBJI) to improve prevention of bone and joint disorders, as well as the quality of life for those affected. Their goal begins with increased awareness, solid information, and research.

While there is no cure for the many forms of arthritis, evidence-based research has led to advances in knowledge and therapies that can change lives. Experts in Arthritis is a free public education program offered by the USBJI to help people with arthritis—and people who care about them—learn how to manage the condition. The USBJI offers short animated videos on

ControlArthritis.org about how to prevent and manage arthritis featuring Theresa, her dog Ginger, and Roberta.

One in two women over the age of 50 will break a bone from a low-impact traumatic event, like tripping on a rug at home, as will one in five men over

the age of 50. Bones are living organisms. To remain strong, they need nourishment, exercise, and sometimes medications proven to improve bone density.

**Fit to a T** is a free public education program offered by the USBJI to educate Americans on fracture prevention, bone health, and osteoporosis. A short animated video featuring Sylvia and her dad learning how to avoid fractures due to frail bones is featured at [fit2t.org](http://fit2t.org).

Bone and joint disorders are disabling,

## GET INVOLVED:

[USBJI.org](http://USBJI.org)

[Twitter.com/usbji](https://twitter.com/usbji)

[Facebook.com/USBJI1](https://facebook.com/USBJI1)



# MOVEMENT IS LIFE



**Movement is Life** is a multidisciplinary coalition (surgeons, primary care physicians, nurses, physician assistants, physical therapists, community organizers, faith-based and industry leaders) founded in 2010. We seek to eliminate racial, ethnic, and gender disparities in muscle and joint health by promoting physical mobility to improve quality of life among women, African Americans, and Hispanics.

Our Mission is to raise the awareness of the impact of racial, ethnic, and gender disparities on chronic disease management and quality of life. We do this by promoting the importance of early intervention! We seek to slow musculoskeletal disease progression, reduce disability, and encourage physical activity and daily movement to improve the overall health of the nation.

Our Goal is to be a catalyst for change by energizing multidisciplinary work groups to develop measurable, short-term action plans that “move the needle” on critical factors that drive musculoskeletal disparities. We must find ways to make an impact now, while long-term solutions are being developed.

One of our signature programs is **Operation Change**. Operation Change is community intervention focused on education, exercise, and motivational interviewing to achieve sustainable behavior change. Our program is tailored to meet the needs of participants where they are! We use small groups and interactive educational programming to break down the barriers to movement.

It is not uncommon for a participant to state that “Operation Change saved my life.” While the program structure is key to its success, Operation Change may be tailored to rural and urban areas and to the needs of Spanish language participants.

Along with Operation Change, we have numerous digital and print educational materials that you can share with your community FREE of charge!

We also advocate for health care policies that eliminate health disparities at local, state, and national levels!

**Are you ready to Start Moving and Start Living?  
Join the Movement!**

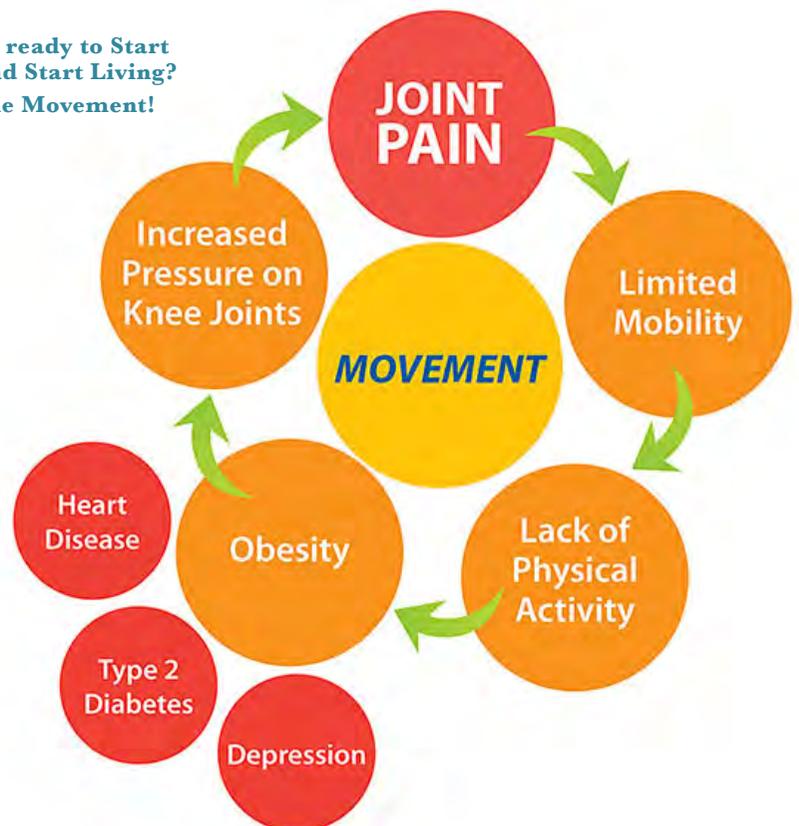


**WE MUST BE WILLING TO TAKE SELF-RESPONSIBILITY FOR OUR HEALTH WHICH IS A BLEND OF RESPONSE AND ACCOUNTABILITY.**



#### GET INVOLVED:

[startmovingstartliving.com](http://startmovingstartliving.com)  
[movementislifejourney.com](http://movementislifejourney.com)  
[Twitter.com/StartMoveLive](https://twitter.com/StartMoveLive)  
[Facebook.com/StartMoveLive](https://facebook.com/StartMoveLive)



# VERITAS HEALTH, LLC **VERITAS** health™

An online publisher for people with chronic conditions seeking trusted, comprehensive health and medical information.

Veritas Health is a leading online health publisher dedicated to painful medical conditions. Our websites have achieved top online rankings by providing unbiased, comprehensive, and in-depth health and medical information. The sites' unique content helps millions of people understand their conditions, get accurate diagnoses, and prevent and treat symptoms, including acute and chronic pain.



**GET INVOLVED:**  
Spine-health.com  
Arthritis-health.com  
Sports-health.com  
Pain-health.com  
Veritashealth.com

**Veritas Health publishes 4 websites:**

- Spine-health.com for back and neck pain
- Arthritis-health.com for degenerative and inflammatory joint pain
- Sports-health.com for sports injuries, including both acute and overuse injuries
- Pain-health.com for understanding and coping with chronic pain

All 4 sites feature articles, blogs, and videos that are 100% original. Our articles are produced through a rigorous editorial and oversight process that includes physician authors, professional editors, and blind peer reviews—similar to articles in professional medical journals. This editorial process helps

ensure that articles are accurate, complete, balanced, and free of commercial interests.

Visitors to our sites will find content that helps guide them through the **Symptoms > Diagnosis > Treatment > Recovery cycle** for various health conditions. In addition, our sites offer:

- Community forums for people with similar conditions to communicate with each other
- Condition-specific email newsletters that feature news and expert tips for coping with a variety of health conditions
- Opportunities to learn about additional treatment options through sponsors
- Directories of medical professionals, so

people can find doctors by area and specialty

Veritas Health connects people to trusted health information, qualified physicians, and a supportive online community. We offer hope for a life with less or no pain.

**Our History**

In 1999, Stephanie Burke and Peter Ullrich, M.D., co-founded Spine-health.com to offer patient information that has the same quality and reliability as a peer-reviewed medical journal. Over time, Spine-health.com became Veritas Health LLC, which operates a series of websites and has over a quarter billion page views each year.

# RESOURCES



## RESEARCH AND ADVOCACY ORGANIZATIONS

**American College of Rheumatology:** [rheumatology.org](http://rheumatology.org)

**Arthritis Care:** [arthritiscare.org.uk](http://arthritiscare.org.uk)

**Arthritis Foundation:** [arthritis.org](http://arthritis.org)

**Arthritis National Research Foundation:** [curearthritis.org](http://curearthritis.org)

**Arthritis Research UK:** [arthritisresearchuk.org](http://arthritisresearchuk.org)

**Global Alliance for Musculoskeletal Health:** [bjdonline.org](http://bjdonline.org)

**National Association of Complementary and Alternative Medicine:** [nacams.org](http://nacams.org)

**National Center for Complementary and Integrative Health:** [nccih.nih.gov](http://nccih.nih.gov)

**National Scoliosis Foundation:** [scoliosis.org](http://scoliosis.org)

**North American Spine Society:** [spine.org](http://spine.org)

**Osteoarthritis Action Alliance:** [oaction.unc.edu](http://oaction.unc.edu)

**Osteoarthritis Research Society International:** [oarsi.org](http://oarsi.org)

**Scoliosis Research Society:** [srs.org](http://srs.org)

**United Spinal Association:** [unitedspinal.org](http://unitedspinal.org)

**United States Bone and Joint Initiative:** [usbj.org](http://usbj.org)

**World Spine Care:** [worldspinecare.org](http://worldspinecare.org)

## CHRONIC LOW BACK PAIN SUPPORT AND INFORMATION

**BackCare:** [backcare.org.uk](http://backcare.org.uk)

**Back Pain video:** [bit.ly/worldspinevideo](http://bit.ly/worldspinevideo)

**Don't Turn Your Back On It:** [dontturnyourbackonit.co.uk](http://dontturnyourbackonit.co.uk)

**HealthCentral - Back pain:** [healthcentral.com/back-pain](http://healthcentral.com/back-pain)

**Healthline - Back pain:** [healthline.com/health/back-pain](http://healthline.com/health/back-pain)

**Setting Scoliosis Straight:** [settingscoliosisstraight.org](http://settingscoliosisstraight.org)

**Spine-health:** [spine-health.com](http://spine-health.com)

## OA SUPPORT AND INFORMATION

**Arthritis-health:** [arthritis-health.com](http://arthritis-health.com)

**CreakyJoints:** [creakyjoints.org](http://creakyjoints.org)

**HealthCentral - Osteoarthritis:** [healthcentral.com/osteoarthritis](http://healthcentral.com/osteoarthritis)

**Healthline - Osteoarthritis:** [healthline.com/health/osteoarthritis](http://healthline.com/health/osteoarthritis)

**My Life With Osteoarthritis:** [mylifewithosteoarthritis.com](http://mylifewithosteoarthritis.com)

**Movement Is Life:** [movementislifejourney.com](http://movementislifejourney.com)

**Osteoarthritis and Sport/Exercise Facebook page:** [bit.ly/oasportsFB](http://bit.ly/oasportsFB)

**OA Knee Pain:** [oakneepain.co.uk](http://oakneepain.co.uk)

**Oh My Arthritis:** [ohmyarthritis.com](http://ohmyarthritis.com)

**Start Moving Start Living:** [startmovingstartliving.com](http://startmovingstartliving.com)

## PEDIATRIC RESOURCES

**Childhood Arthritis and Rheumatology Research Alliance (CARRA):** [carragroup.org](http://carragroup.org)

**Children's Scoliosis Research Foundation:** [childrensscoliosisfoundation.org](http://childrensscoliosisfoundation.org)

**Journal of Pediatric Health Care:** [jpedhc.org](http://jpedhc.org)

**Kids Get Arthritis, Too:** [kidsgetarthritisoo.org](http://kidsgetarthritisoo.org)

**OrthoKids:** [orthokids.org](http://orthokids.org)

**Pediatric Pain Warrior:** [pediatricpainwarrior.org](http://pediatricpainwarrior.org)

**Pediatric Orthopedic Society of North America:** [posna.org](http://posna.org)

**The Coalition Against Pediatric Pain:** [tcapp.org](http://tcapp.org)

## DRUG SAFETY INFORMATION (PAIN MEDICINE INFORMATION)

**Acetaminophen Awareness Coalition:** [knowyourdose.org](http://knowyourdose.org)

**Drugwatch:** [drugwatch.com](http://drugwatch.com)

**Know Your OTCs:** [knowyourotcs.org](http://knowyourotcs.org)

**Lock Your Meds:** [lockyourmeds.org](http://lockyourmeds.org)

**Pain Medicine 411:** [painmedicine411.org](http://painmedicine411.org)



**The Medicine Abuse Project:**  
medicineabuseproject.org

**Up and Away:** upandaway.org

**National Coalition Against  
Prescription Drug Abuse (NCAPDA):**  
ncapda.org

## SUICIDE HOTLINES AND HELP

**Crisis Text Line:** crisistextline.org  
or text "HOME" to 741741

**National Suicide Prevention Lifeline:**  
suicidepreventionlifeline.org  
or call (800) 273-8255

**Project Semicolon:**  
projectsemicolon.com

**Suicide Hotlines:**  
suicide.org/suicide-hotlines.html

**To Write Love On Her Arms:**  
twloha.com

## PAIN ADVOCACY ORGANIZATIONS

**American Academy of Pain  
Medicine:** painmed.org/advocacy

**Academy of Integrative Pain  
Management:** aapainmanage.org

**American Chronic Pain Association:**  
theacpa.org

**Consumer Pain Advocacy Task  
Force:** consumerpainadvocacy.org

**For Grace:** forgrace.org

**Global Healthy Living Foundation:**  
ghlf.org

**National Coalition of Chronic Pain  
Providers & Professionals:**  
nccppp.org

**National Fibromyalgia & Chronic  
Pain Association:** fmcpcaware.org

**Reflex Sympathetic Dystrophy  
Syndrome Association:** rsds.org

**State Pain Policy Advocacy Network  
(SPPAN):** sspan.aapainmanage.org

**U.S. Pain Foundation:**  
uspainfoundation.org

## MORE INFORMATION AND SUPPORT

**365 Caregiving Tips:**  
365caregivingtips.com

**Abilities.com (formerly Abilities  
Expo):** abilities.com

**Blanket Sea Magazine:**  
blanketsea.com

**ChronicBabe:** chronicbabe.com

**Diversability:** mydiversability.com

**Engaged Patients:**  
engagedpatients.org

**Golden Graine:** goldengraine.com

**Heroes of Healing:**  
heroesofhealing.com

**Inspire.com:** Inspire.com

**Invisible Disability Project:**  
invisibledisabilityproject.org

**INvisible Project:** invisibleproject.org

**Learn About Your Pain:**  
learnaboutyourpain.com

**MyHealthTeams:** myhealthteams.com

**National Pain Report:**  
nationalpainreport.com

**Nicole Hemmenway:**  
nicolehemmenway.com

**Ouchie:** ouchie.com

**Pain Connection:** painconnection.com

**Pain-health:** pain-health.com

**Pain News Network:**  
painnewsnetwork.org

**PainPathways Magazine:**  
painpathways.org

**Pain Matters:** painmatters.com

**Pain Relief Revolution:**  
painreliefrevolution.com

**People With Pain Matter:**  
peoplewithpainmatter.org

**Peter Abaci:** peterabaci.com

**Real Warriors:** realwarriors.net

**Rooms that Rock 4 Chemo:**  
roomsthatrock4chemo.org

**Sick Chicks:** thesickchicks.com

**Silver Sneakers:** silversneakers.com

**Suffering the Silence:**  
sufferingthesilence.com

**The Empowered Patient Coalition:**  
empoweredpatientcoalition.org

**The Mighty:** themighty.com

**Tiny Buddha:** tinybuddha.com

**Walk with a Doc:** walkwithadoc.org

**Yoocan:** yoocanfind.com





# THANK YOU!

The INvisible Project would like to recognize and thank our sponsors for their support. They make it possible to share the stories told by the people in this magazine.

Our sponsors help us raise awareness about chronic pain and its impact on the lives of millions of people living in the United States.



abbvie



Academy of Integrative Pain Management



Bravelets<sup>bc</sup> brave



ALEX AND ANI



Genentech  
A Member of the Roche Group



healthline



PainPathways<sup>MAGAZINE</sup>  
Information & Inspiration for Living with Pain

