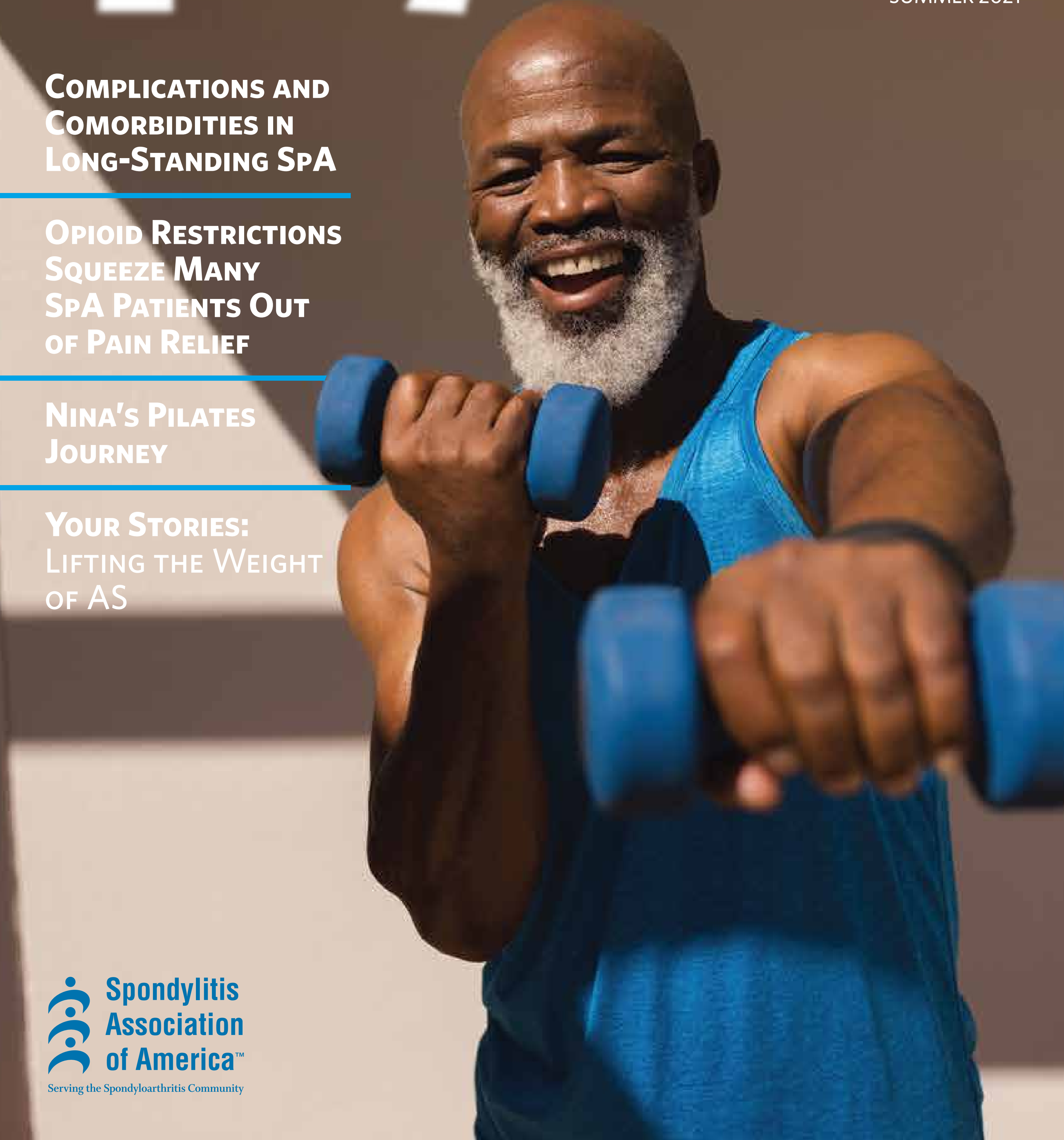
SpondylitisPLUS

SUMMER 2021



COMPLICATIONS AND COMORBIDITIES IN LONG-STANDING SPA

OPIOID RESTRICTIONS SQUEEZE MANY SPA PATIENTS OUT OF PAIN RELIEF

NINA'S PILATES JOURNEY

YOUR STORIES: LIFTING THE WEIGHT OF AS

Spondylitis Association of America™
Serving the Spondyloarthritis Community

SPONDYLITIS ASSOCIATION OF AMERICA
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To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest.

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HOW CAN WE HELP?
SAA's staff and board of directors are sending our wishes for health and safety to you and your loved ones. Is there anything we can do to help? What are your needs? Reach out to us at **info@spondylitis.org**. Now, and always, you're on our minds and we are here for you.

SAA Spotlight:

Serving the Spondyloarthritis Community

The past 15 months have brought changes that few of us could ever have imagined. Collectively and individually, we have adjusted the ways in which we approach work, home life, social interactions, relationships, education, and just about everything that we'd come to know.

Now that the veil is being cautiously lifted, many things will go back to "normal," or at least something more familiar and comfortable. I think we're all looking forward to resuming some of the things that gave us joy with more direct interactions.

But I also think that there are aspects of the pandemic changes that may, and should, continue into the post-COVID world. I recently came across a popular post on social media that said, *"If the pandemic has taught us anything, it's that 50% of the workforce can work efficiently from home and the other 50% are under-valued."* An oversimplification, perhaps, but I'm grateful that many of us have a new appreciation for the "frontline workers" that typically don't get much glory – the grocery clerks, emergency medical workers, delivery drivers, and so many more who helped get us through this difficult time.

On March 15th of last year, when the "go home" word was received, SAA staff did just that. And on March 16th, we were 100% open for business.

As luck would have it, we'd already been working with a tech company on setting up a more efficient remote-work situation for when staff was traveling, or when someone needed a work-from-home day, and were also in the process of renewing our expiring lease on our modest office space. As a result of the former, we were far ahead of the game in the transition to remote work. As a result of the latter, we were able to easily downsize to a much smaller "hub" with one onsite team member to handle the things that need to be done in person. The rest of the crew were set up to work efficiently offsite, and have remained there thus far, which means that more of your donated dollars are going directly to serving the mission.

Despite being spread out, we've kicked things into overdrive. We've been working hard on a multi-year program called "Rheum to Diagnose" that's geared to promote earlier SpA diagnosis, as well as another program aimed at educating PCPs and chiropractors to the same end. Both will be rolling out in the coming months. And of course, we're still hard at work with all of the other programs and services we offer and have plans to expand many of them.

And we couldn't do any of it without the unwavering support of members like you. Thank you for sticking with us through these challenging months. Here's to a joyful summer for us all!

Cassie Shafer
Chief Executive Officer

LETTERS TO THE EDITOR:

"I want to thank you and SAA for the recent article with Dr. Reveille re: Women and AS. *It was 27 years late for me. However, it was an excellent overview and covered most of what I learned from decades of researching as well as eventually finding two rheumatologists who were open-minded to treat me as an individual based on my experience. I persevered, but the despair and humiliation I felt after repeatedly being dismissed because "AS is a man's disease!" took a high toll on me when I was very unwell and had two young children to parent.*

My way of coping forced me to take a very active role in managing my condition — a positive overall; but even that was at times rudely dismissed as an attempt to create a false narrative of my symptoms. Science has proven me right...over time. I've been encouraged to write about my experience, and I may do that again. Years ago I wrote about pain in an article printed in The Northwest Observer, *the Arthritis Foundation's Pacific NW newsletter. I also communicated regularly with one of your predecessors who published weekly research summaries, and that dialogue contributed to SAA's reassessment of women and AS issues (still bearing fruit after 20 years).*

Again, thank you for your excellent engagement on behalf of SpA patients.

~ Patricia B.

Editor's Note: Below we are sharing some participant comments from our two recent programs, our SpA Patient Educational Seminar in April , and our Global SpA Summit in May.

"The recent SAA Patient Seminar was life changing for me. I am newly diagnosed and have been confused about what I can and cannot do. I had attributed so much of my pain to overusing muscles, getting older, etc. I am still doing the "Back In Action, Again" exercises almost daily, and have found new confidence in my ability to help myself get better. My doctor has been great, but he hasn't been enough, since his main focus has been (as it should be) on finding medications that work.

Thank you!"

~ Mary C.

"A huge congratulations on a fantastic Global SpA Summit. I enjoyed it and learned a lot. Warm wishes."

"This was an incredible 3-day event. Many thanks to your entire team for developing a well-balanced SpA Summit. It was informative, engaging, and entertaining. Thank you to all!

"Thank you very much for making the Summit a really successful one. I greatly appreciate the presentations. Good job. From Kenya."

"The entertainment (magic show and jazz) was fantastic! It was so neat to have those as a part of the daily events of the Summit. Hope they continue to have things like that in future programs. Awesome job, seriously."

CONTENTS:

LETTERS TO THE EDITOR:

We want to hear from you! Send your thoughts, questions, opinions, and rebuttals.

Please send letters to:

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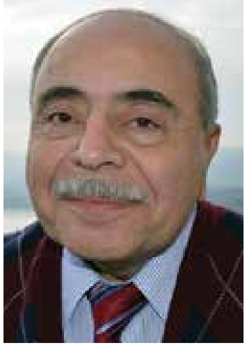
Please note that we reserve the right to edit for space and clarity.

COMPLICATIONS AND COMORBIDITIES IN LONG-STANDING SPONDYLOARTHRITIS



An interview with rheumatologist, researcher, AS patient, and long-time member of SAA's Medical and Scientific Advisory Board, **Muhammad Asim Khan, MD**

We begin this conversation around possible impacts of long-standing spondyloarthritis with none other than Dr. Khan — a noted and beloved rheumatologist, who himself has long-standing ankylosing spondylitis. Our thanks to Dr. Khan for helping us kick off this topic!

Spondylitis Plus: What cardiac related risks and potential complications should those with long-standing spondyloarthritis be aware of? What screenings are recommended for these issues? And are there any preventative measures people can take to reduce cardiac risks?"

Dr. Khan: Some patients with longstanding spondyloarthritis (SpA) may develop a slowly progressive inflammation and resultant scarring (fibrosis) at the root of the aorta where it comes off from the heart. This inflammation can extend to the adjacent initial few centimeters of the wall of the aorta and can be much better visualized by PET/CT scan. It can also involve the aortic valve (causing leaky valve – *aortic valve insufficiency*) and even the heart's electric conduction system (causing *electric conduction disturbances*, leading to slowing of the heartbeat that may be serious enough to require a pacemaker). The worsening aortic valve insufficiency, which can easily be detected by echocardiography, can cause symptoms of heart failure, including leg or ankle swelling (edema) and shortness of breath during exercise or exertion. This requires monitoring and, in some cases, aortic valve replacement.

The risk for aortic insufficiency and electric conduction disturbances increases with the age of the patient, the duration of SpA, and is more common among those who are HLA-B27 positive, as well as among those with hip, shoulder, or peripheral (limb) joint involvement. Cardiac electric conduction disturbances occur in up to 3% of those with disease of 15 years' duration, and in up to 9% of those with disease duration of 30 years or more. I may add that I underwent cardiac pacemaker implantation in April of this year, a week after my 77th birthday. I have suffered from ankylosing spondylitis since age 12, have had bilateral hip joint replacements, possess HLA-B27, and have named my website **HLAB27.com**.

Some patients have impaired relaxation of their heart muscle but with normal ability to contract to pump blood out. This however can lead to impaired cardiac function after many years. Lastly, it is worth stating that, as among the general population, high blood pressure, high cholesterol, smoking, and sedentary lifestyle all increase the risk of coronary (heart) artery disease and stroke. Controlling and minimizing these are some of the preventable measures that can reduce cardiac risks.

Spondylitis Plus: We know that some with long-standing SpA experience lung restriction / chest expansion issues and pain in the rib cage. Can we discuss this, and any other lung-related impacts of SpA?

Dr. Khan: People with axial spondyloarthritis (axSpA) can complain of pain in their rib cage that is worsened by coughing or sneezing because of inflammation of the joints where the ribs attach to the backbone. They may also complain of soreness (tenderness) of the anterior chest wall. It is commonly called costochondritis because the tenderness is most prominent over the cartilaginous parts of the ribs where they attach to the breast bones (sternum and manubrium).

People with axSpA have no symptoms of lung disease; nevertheless, they may have functional lung impairment — documented by lung function testing - because of restricted chest expansion resulting from progressive fusion of the ribs with the spine. However, this does not usually result in breathing insufficiency because of compensatory increased use of diaphragm muscles (that separate the lungs from the abdomen) used in normal breathing.

Some patients may take longer to recover from severe influenza, bronchitis, or pneumonia. COVID-19 infection can also potentially result in longer recovery times. Patients should discuss with their doctor the need for vaccines against viral infections and bacterial pneumonia.

Very rarely, there can be some changes (fibrosis) in the lung tissues, especially at the uppermost part of the lung. This may or may not cause breathing problems or other complications.

Patients may also be more prone to obstructive sleep apnea (especially if they also have forward stooping and immobile neck, and/or are markedly overweight) that may result in poor sleep and require use of breathing assistance machines (CPAP or BIPAP). Smoking tobacco cigarettes, including electronic cigarettes (vaping) should be completely avoided by everyone with SpA.

Spondylitis Plus: Can long-standing SpA, or medication used for SpA, lead to kidney involvement?

Dr. Khan: Kidney disease in SpA can occur for various reasons and present with protein leakage in the urine (sometimes associated with presence of red cells detected on routine urinalysis) with or without impairment of kidney function. NSAIDs can cause fluid retention, mostly manifested by swelling of the ankles.

Their long-term use can impair the normal functioning of the kidneys and can also cause hypertension (increased blood pressure) or blunt the effect of drugs used to treat it, such as diuretics (water pills), ACE-inhibitors (such as lisinopril [Zestril]), and ACE-receptor blockers (such as losartan [Cozaar]). This makes their use risky for patients who already have kidney disease, and for the elderly population. NSAIDs can also cause acute inflammation in the kidneys, called acute interstitial nephritis, after a few days of use. This side effect seems to be under recognized.

Adverse effects on kidney function can also result from other drugs used to treat SpA. Deposition in the kidneys of a protein called amyloid (amyloidosis) has now become very rare in the U.S. and most of the other developed countries due to very effective disease management and is now mainly seen in patients with poorly controlled disease.

Spondylitis Plus: Can there be neurologic involvement in long-standing SpA? And is there any relationship between peripheral neuropathy and biologic medications, such as TNF inhibitors?

Dr. Khan: Neurologic involvement may occur in axSpA patients due to fracture of the spine and resultant spinal instability. Although TNF inhibitors are generally well-tolerated, there have been rare but well-documented reports of associated peripheral neuropathies, including Guillain-Barre syndrome. There is also an extremely rare and very slowly progressive complication in patients with very long-standing, severe AS. It is called cauda equina (meaning horsetail) syndrome because of the involvement of lowermost spinal nerves that slope downward as a bunch before leaving the spinal column. It is caused by fibrous entrapment and scarring of the lowermost nerve roots and can result in "saddle anesthesia" (so called because of loss of skin sensation over the parts we sit on), urinary retention and incontinence, and fecal incontinence due to decreased urinary sphincter and rectal tone. Men may develop erectile dysfunction or impotence. It may also cause some pain and weakness in the legs. Its characteristic feature is presence of enlarged sacs containing spinal fluid and erosions of the spinal canal, best seen on CT or MRI.

Citations:

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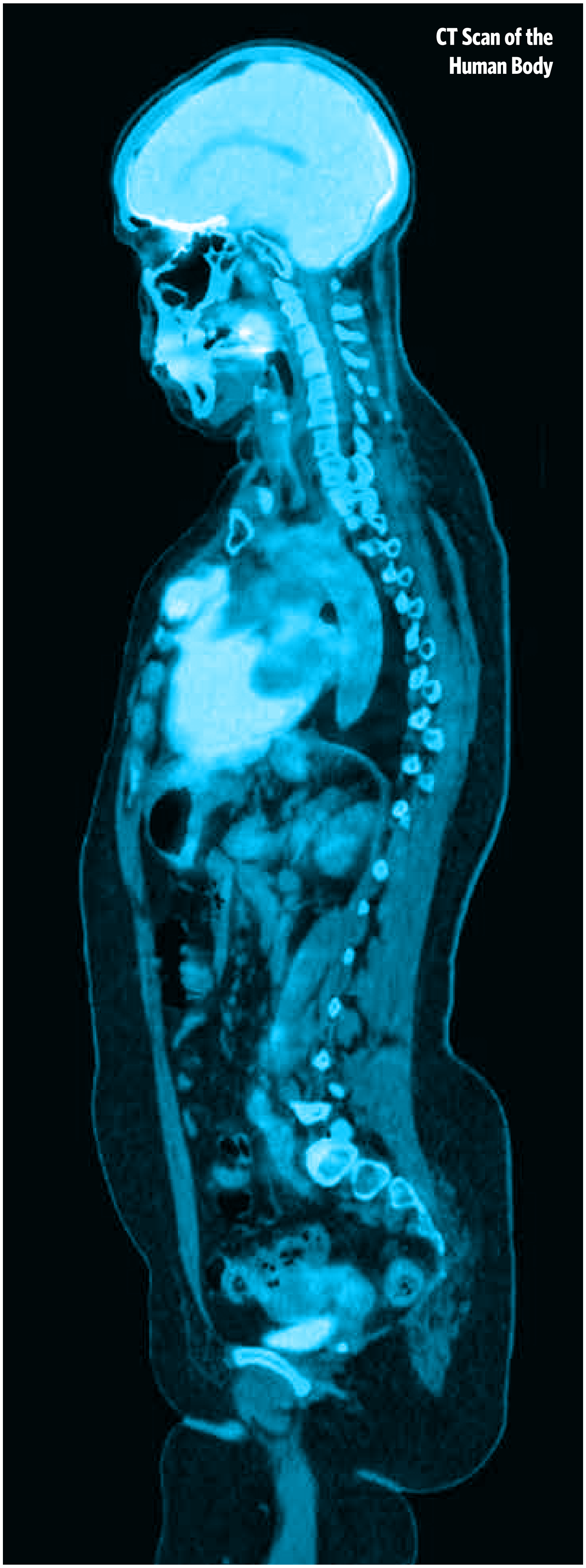
Editor's Note: We will highlight additional complications and issues associated with long-standing SpA in our fall 2021 issue of *Spondylitis Plus*. Keep an eye out for part two of this important topic, and if you'd like to suggest questions around long-standing SpA complications please send them to the editor at **Elin@spondylitis.org**.


CT Scan of the Human Body

EMERGENCY PREPAREDNESS: WALLET CARDS ARE HERE!

Be Prepared for Emergency Situations with SAA's First Responder Information Card

In an emergency, time and accuracy are of the essence. Though that is true for everyone, those with axial spondyloarthritis have an especially pressing need for emergency preparedness. That's because fusion in the spine, combined with an increased risk of osteoporosis, puts many with spondyloarthritis at 11 times greater risk of spinal fracture. This means that even minor falls, accidents, or small jolts may cause unexpected fractures in the spine. What's more, standard treatment and handling protocols used by first responders in emergency situations can also cause severe injury in those with spinal changes due to axial spondyloarthritis.

That is why SAA developed our First Responder Accredited Training program, originally distributed via DVD starting in 2009, and recently updated and transitioned to an online, interactive and accredited learning module. "EMS Pitfalls: Ankylosing Spondylitis," is our free, online learning course, offering continuing education hours to first responders and nurses!

But educating first responders and emergency personnel is just one piece of the puzzle. We also want to ensure that our SpA community is as prepared as possible in the event of a medical emergency. To that end, we offer the following resources and information to help you stay prepared.

Please find attached an enclosed card, meant to be kept in the wallet, to assist first responders in safely caring for anyone with axial spondyloarthritis.

We hope you will never need it!

Keep in mind and consider these tips and recommendations:

- Carry the enclosed EMS wallet card, along with a general medical information card listing your vital personal information, such as any conditions and medications you take. (Carry the card in your wallet next to your driver's license and health insurance card. Be sure that it is legible to the average reader.)
- Consider wearing medical identification jewelry/tags since emergency medical personnel are trained to look for these items. "Brittle Spine Disease" and "Ankylosing Spondylitis" (or "Spondyloarthritis with spinal fusion") should be inscribed on the tag to alert first responders to your special situation.
- Consider including an ICE (In Case of Emergency) contact in your mobile phone. Emergency personnel are trained to recognize the acronym "ICE." Be sure that your ICE contact is aware of your medical needs.
- For smart phone users who lock their phones – you can set your Emergency Medical ID to make it accessible from your locked screen, without needing your passcode.

Need more EMS wallet cards, or want to download a printable PDF? Reach out to us at **info@spondylitis.org** or visit **Spondylitis.org/medical-emergencies** to print and fold your own! You will find additional emergency preparedness resources at the link above.

To safety and health for all of our members and friends.

Our thanks to Novartis for their financial support of this EMS wallet card through an educational grant.

NOVARTIS

COVID-19's IMPACT ON SUBSTANCE ABUSE AND OVERDOSE RATES:

THE UNTOLD STORY OF THE OTHER PANDEMIC

by Marina Dykhne, PharmD, BCACP, APh, CDCES

The COVID-19 pandemic has interrupted our daily routines and caused many people to feel uncertain, stressed, and isolated. While this was a difficult time for many, it could be especially challenging for those with underlying substance use disorder. When the world slowed down and tried to cope with the novel virus, millions of people continued to deal with the struggles of substance addiction.[1-3]

In addition to the ongoing challenges presented by the COVID-19 global pandemic, the nation's opioid misuse epidemic has grown into a much more complicated and deadly drug overdose epidemic. Overdose deaths increased in almost every state; 24 states and the District of Columbia had an estimated increase of at least 30%, and the overall U.S. total increased by 33%.

A reporting system called Overdose Detection Application Program (ODMAP) shows that the early months of the pandemic brought an 18% increase nationwide in overdoses compared with those same months in 2019. The trend has continued throughout 2020, according to the American Medical Association (AMA), which reported in December that more than 40 U.S. states have seen increases in opioid-related deaths along with ongoing concerns for those with substance use disorders.

According to the Centers for Disease Control and Prevention (CDC), as of June 2020, 13% of Americans reported starting or increasing substance use as a way of coping with stress or emotions related to COVID-19. Overdose related deaths spiked to record levels in March 2020 after the pandemic hit. Monthly deaths grew by about 50% between February and May to more than 9,000. Prior to 2020, U.S. monthly overdose deaths had never risen above 6,300.

So, what are some of the reasons for such a spike?

Most experts agree that this spike is multifactorial. Researchers suggest that sudden disruptions in the supply of street drugs when the pandemic began were associated with an increase in overdose deaths and other harms. Though it may seem counterintuitive at first, the fact is that some people who use substances were very likely to seek and start new, unfamiliar drugs when their usual substances became more difficult to access. One such example is the increased use of fentanyl or fentanyl analogs (a potent synthetic opioid that's increasingly produced illicitly) potentially due to a shift in the drug supply availability. Although, that data is limited at this time.[5]

According to a survey published in the *International Journal of Drug Policy*, individuals who regularly use psychoactive substances reported experiencing various negative impacts during the COVID-19 pandemic, including increased usage and fear of relapse or overdose. Forty-seven percent of respondents indicated that their substance use had increased during COVID-19, and 38% said they believed they were at higher risk of overdose due to supply disruptions that made drugs more expensive, harder to get, and of unknown origin. Among those using syringes or other paraphernalia, forty-seven percent responded that they started re-using or sharing for the first time after the beginning of the pandemic, when COVID-19-related restrictions decreased access to harm reduction or needle exchange programs. Seven percent of survey respondents indicated they had relapsed during the COVID-19 pandemic.

While social distancing and isolation were necessary measures to stop the transmission of the coronavirus, these strategies and the pandemic itself, have been associated with negative emotions, such as stress, irritability, anxiety, fear, sadness, anger, and boredom.[3] These conditions are known to trigger relapse, even in those long-term abstainers, or intensify drug use.[5]

Dealing with stress:

Each person develops their own coping mechanisms for managing stressful situations. For some people, coping mechanisms can include exercise, food, mediation, or prayer. Research into cravings has shown that stress produces stronger and more frequent cravings. When a person has used substances such as alcohol or drugs in the past to manage stress, they are more likely to fall back on those behaviors when faced with stress again.

Examples of positive coping strategies:

- Establish a new at-home routine to have structure and purpose.
- Exercise to reduce stress.
- Spend time outdoors.
- Seek activities that improve mood and limit cravings.
- Regularly connect with friends and family.
- Practice mindfulness exercises, such as deep breathing, focused attention on thoughts and feelings, imagery or writing in a journal.
- Join a local support group. Many are now available virtually and have strong attendance with familiar peers.

Editor's Note: Many of SAA's Spondylitis Educational Support Groups are meeting online (and some are starting up in-person again). Visit **spondylitis.org/groups**

Feeling isolated:

Many states implemented stay-at-home orders during the pandemic. While extended isolation is unhealthy for most people, people with substance use disorders can struggle even more in isolation than others, as substance use disorder is more difficult to manage when someone feels isolated. When a person is in early recovery, they often need the support of a recovery community to maintain their recovery. Withdrawal symptoms triggered during stay-at-home orders jeopardized recovery for many. Additionally, medical assistance geared for these symptoms was severely limited, since medical efforts were largely focused on the COVID-19 pandemic.

Loss of routine:

Routines are comforting for many people and provide a rhythm or anchor to the day. They lower stress levels and encourage healthy habits. Structure and routines are incredibly helpful for people in recovery, especially early in the recovery process. Changes in routine, such as those experienced as a result of the COVID-19 pandemic, put people at higher risk for cravings because the coping strategies they previously relied on were not available.

The pandemic has substantially increased risks of substance and health-related harms, including overdoses, while decreasing our ability to mitigate risky behaviors. We need increased accessibility of safe supply programs, naloxone, trained providers, and support strategies to mitigate these risks.

To successfully address the opioid crisis, our public health approach must include expanding funding and resources, reforming the criminal justice system, increasing insurance coverage, and widening access to medication-assisted treatment (MAT) and mental health care.

If you are a friend or loved one of someone with a substance use disorder, use the following tips to aid them during this time:

- Reach out and ask about recovery often.
- Express support.
- Encourage behaviors that are healthy for recovery.
- Ask about activities and feelings other than the person's recovery journey.
- Engage in safe activities together.
- Help set measurable and achievable goals.
- Celebrate small victories.

Editor's Note: If you are in crisis or suspect you may be approaching it, please reach out now. You will find a listing of professional associations, crisis hotlines, and other helpful resources at **spondylitis.org/crisis**.

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Dr. Marina Dykhne is a Clinical Assistant Professor at West Coast University School of Pharmacy. She is a Board Certified Ambulatory Care Pharmacist, Advanced Practice Pharmacist and Certified Diabetes Care Education Specialist. Her clinical and research interests include chronic disease management and disease prevention in the areas of cardiovascular health, dyslipidemia, hypertension, and diabetes. She practices as a clinical pharmacist in primary care at a federally qualified health center and is involved in community education task force for opioid addiction management, and overdose prevention through pharmacists provided naloxone distribution.

Dr. Dykhne is a patient and student advocate and encourages student pharmacists to get involved with the professional organizations and be the voice for the profession and the patient. Her passions specifically lie in the areas of chronic disease prevention and increasing access in primary care for communities that are generally underserved.

OPIOID RESTRICTIONS SQUEEZE MANY SPA PATIENTS OUT OF PAIN RELIEF

by Rachel Zaimont

For Dawn Gibson, pain is a constant, everyday component of life. It's always there, "gnawing away" at her in the background, she says, but during a flare it can spike without warning. That's what she calls breakthrough pain. "This pain is bright, sharp, and stabbing," says Gibson, who has lived with ankylosing spondylitis (AS) since 2001. "Both types of pain divert energy and ability from my life."

Opioid medications helped Gibson reduce her pain to a tolerable level, so that she could work full-time, exercise, garden, and live her life with a sense of normalcy – sitting through long plane trips, for example, or doing youth work at her church. "They didn't make me high or anything like that," says Gibson. "It was just a way to turn down the volume."

But Gibson, like millions of chronic pain patients across the U.S., now finds it nearly impossible to get a prescription for opioid medications when she needs them. Efforts to restrict opioid usage in the wake of a surging addiction and overdose crisis – which (as discussed on page seven of this issue) has only intensified during the COVID-19 pandemic – have left many who live with severe pain cut off from access to treatment.

According to SAA's 2017 Life Impact Survey, some 13.8% of spondyloarthritis (SpA) patients interviewed had taken opioid medications, usually either hydrocodone or oxycodone. Pain is one of the foremost complications of SpA – and the SpA community is not alone. Fifty million people in the U.S. live with chronic pain every day or nearly every day, while about twenty million people have chronic pain so great that it interferes with basic life activities, according to the nonprofit National Pain Advocacy Center (NPAC). Pain is the number one cause of long-term disability, globally.

And yet, pain is not well understood by researchers or clinicians, and is often diminished or dismissed. "Pain is just not taken seriously. It has been under-researched, under-addressed in education, and subject to stigma," says NPAC president and founder Kate Nicholson, JD.

Opioid medications, which can provide effective pain management for many, have become entangled in controversy due to misuse and abuse – and people living with chronic pain end up suffering.

How did we get here? In the 1990s, healthcare providers began prescribing opioids more broadly – especially once OxyContin hit the market in 1995. The number of opioid prescriptions filled

at U.S. pharmacies nearly tripled from 76 million in 1991 to 219 million in 2011. During that time, addictions rose and overdose deaths spiked, making media headlines. Between 1999 and 2019, nearly 500,000 people died from an overdose involving an opioid, including prescription and illicit opioids, according to the CDC.

Yet the story is more complicated. Only about 1 to 8% of people taking opioids for pain become addicted to them, Nicholson says. And most people who misuse prescription opioids don't get them directly from doctors, instead borrowing or stealing pills from family or friends, or buying them on the street. Tainted street drugs and illicit fentanyl have caused the death toll to soar, sounding a national alarm.

To stem the crisis, the CDC in 2016 released its Guideline for Prescribing Opioids for Chronic Pain, which urged providers to use caution when prescribing and to try other, less risky treatments first. But as policymakers rushed to apply the guidance, many states passed draconian laws that severely curbed the dose and duration of opioid prescriptions in situations the CDC never intended to regulate, Nicholson says. A new web of state and federal oversight – including from the Drug Enforcement Agency (DEA) – led to a chilling effect in the medical community; doctors who drew scrutiny for their prescribing practices could receive a penalty, or even lose their license.

The effect on those who relied on opioids for managing chronic pain has been devastating. Patients were suddenly told they had to rapidly taper their medications, or that they couldn't get more than a month's or a week's supply at a time. Some clinicians refused to continue prescribing opioids at all. And in the worst cases, pain patients have been turned away from medical practices, or completely dropped from care.

Forcing abrupt tapering of opioid medications has dangerous side-effects, studies show. Patients can become destabilized, leading to hospitalization, suicidal thoughts or actions, or seek relief in other, more harmful substances. "Peoples' lives can fall apart if they suddenly have no access to medications," Nicholson says.

In 2019, the FDA released a safety warning about the detriments of forced discontinuation and abrupt tapering, and the CDC issued a statement saying its guidance had been applied too strictly. But these reversals and warnings largely have not trickled down to patients. More than 50% of doctors still won't see new patients who take opioids for pain, according to a University of Michigan study – which represents illegal discrimination under the Americans with Disabilities Act (ADA), Nicholson notes.

"We've seen a huge increase in discrimination against people who require these medications," Nicholson says. "It's partly fear of oversight, and partly hearing in the media for years that they [doctors] were responsible for killing people, and feeling shamed and blamed. It's much easier not to deal with these patients."

But leaving millions of people with unmanaged pain inflicts its own cost. Pain causes financial, physical, and psychological damage. Without proper treatment, those living with chronic pain may lose the ability to work, take part in their families, or perform the functions of daily life.

Nicholson knows this first-hand. She was working as a civil rights attorney for the Justice Department when nerve damage from a surgery left her bedridden and in disabling pain for 20 years. "If you cannot go to work, shower, cook a meal – the most basic life activities – that's impeding your ability to live."

Managing her pain with opioids, Nicholson was able to continue working as a federal prosecutor, sometimes arguing cases while reclining in a lawn chair. But in 2014 she moved cross-country and couldn't find a new doctor willing to prescribe her medication. She had to fly back to her former city to get proper care. "That helped me see what was coming for other people in the community," she recalls.

After Gibson could no longer obtain opioids, she was encouraged to exercise, lose weight, and use NSAIDs. But long-term NSAID use led to anemia and vitamin deficiencies that ravaged her health.

"Patients aren't met with comprehensive approaches to their pain," says Gibson, who is the head of NPAC's Community Leadership Council and founder of the Twitter group Spoonie Chat. "This is unsurprising, given the poor understanding of chronic pain and cultural antipathy for people in pain. Most healthy people don't want to believe that an 'innocent' person could start hurting one day and never stop. They want to believe that patients must be to blame."

Chronic pain disproportionately affects certain demographic groups. Up to 70% of chronic pain patients are women – but women are also more likely than men to have their pain dismissed, Nicholson says. People of color face even greater barriers to care; clinicians tend to rate the pain of Black and Hispanic patients lower. People of color are also more likely to be perceived as drug-seekers and denied pain medication.

"It's isolating and painful to be seen as lazy, drug-seeking, or a bad person for being in pain," Gibson says. "Every patient deserves respectful and dignified care." In the meantime, she relies on over-the-counter pain treatments, nutrition, and self-care to maintain her quality of life. "It's not enough because I need medical care that's not available to me right now."

Under the spotlight of the opioid addiction crisis, chronic pain patients must navigate the twin stigmas of pain and addiction. Nicholson herself says she felt self-conscious taking a medication that is considered addictive. An anonymous member of the SpA community wrote to SAA, saying, "When you take narcotics for pain relief, you are branded a criminal. You are made to justify and prove your innocence to everyone who knows – even yourself at times."

These issues together form the crux of the problem NPAC is working to solve. Created as a policy-focused advocacy group, NPAC's mission is to advance the health and human rights of those living with pain and address inequalities in pain treatment. "We want to shift the narrative to help people understand pain as a distinct disease process," Nicholson says. "Unless people really understand its consequences, there's never going to be a social will to change."

At least 40 states, along with many major insurers and retail pharmacies, have laws or strict policies limiting opioid prescriptions. NPAC – comprised of clinicians, civil rights advocates, scientists, and members of the chronic pain community including SAA volunteers Jed Finley and Charis Hill – advocates against arbitrary limits on medication, and pushes for better pain education and access to treatments.

In April of this year, NPAC successfully fought a provision in a federal bill that would have imposed rigid three-day limits on opioid prescriptions nationwide. They have also submitted comments opposing one-size-fits-all medication limits in multiple states, including an Oregon health board's recommendation not to cover opioids for Medicaid patients with 170 conditions of the back, neck, and spine.

NPAC board members including Nicholson were part of meetings that led to the CDC's 2019 correction in *The New England Journal of Medicine* recognizing "inflexible applications" of its 2016 guidelines by policymakers that endanger patients' health and safety.

Now, Nicholson and others are part of a workgroup advising the CDC on a full update of those guidelines. "If the new guidelines come out and do what we hope they will do, I have hope that they will trickle down," she says.

In the meantime, there are steps those living with chronic pain can take if they experience forced tapering or are denied care. They can file a complaint with their state medical board, the Department of Justice, or the Department of Health and Human Services. They can report their stories to NPAC, or the American Medical Association, which has an opioid taskforce. And they can advocate for themselves with their healthcare providers – although the burden to patients may be great.

"It's a really difficult situation on an individual level – going into their doctors and saying, 'What you're doing is not right. The CDC says you shouldn't be doing this,'" Nicholson says. "When people are already in pain, having to advocate for themselves is challenging."

But NPAC and other organizations are working to turn the tide on three levels: policy, societal understanding, and personal acceptance. "You shouldn't feel stigmatized," Nicholson believes. "If these medications work for you and allow your life to continue, understand that for you they are appropriate."

Editor's Note: Is access to pain medications an issue for you? Please share your experience with us. Write us at **programs@spondylitis.org**.

NINA'S PILATES JOURNEY

by Nina Narejko

My journey with ankylosing spondylitis (AS) started in 2015, with an injury that would not heal. I was doing a quick workout at home with some resistance bands. As I landed from a jump, I felt my knee roll in. The next morning my knee was very swollen, with a dull pain. I knew something was wrong, so I went to see a doctor and got an MRI. The MRI did not reveal any damage. I was put into physical therapy and received a cortisone shot, but nothing was helping.

After months of unchanging swelling and pain in my knee, I knew I had to find another doctor to help figure this out. I figured the swelling probably meant inflammation, so I went to see a rheumatologist. It was then that we discovered, after many appointments and tests, that I had AS.

My journey with Pilates had started in my early 20s. I'd been working as a receptionist at a Pilates studio since I was a teen. At first I had no interest in doing Pilates, but over the years, as I saw clients with chronic pain and conditions get better through Pilates, my interest in Pilates grew. Eventually I started doing Pilates myself, and in 2013, after many years of practice, I became a certified Pilates instructor.

Little did I know when I started my Pilates journey just how beneficial and instrumental Pilates would be to my own personal health. Since getting diagnosed with AS six years ago, I have noticed a decrease in my spinal mobility, more stiffness in my back, and less ability to turn and twist my spine. X-rays and images do show disc degeneration in my lumbar spine, damage and inflammation in my SI joints, and the start of a few curves in my thoracic and lumbar spine.

My doctor and I truly believe that even though there is some damage to my spine and SI joints, my Pilates practice is helping me stay a few steps ahead of AS and minimize my pain and stiffness.

Slowing the damage my body is doing to itself is becoming increasingly harder, but I am willing to do all that I can to keep myself moving and strong. A big part of that, for me, is my Pilates practice.

The goal of Pilates is to keep our spines mobile, supple, and strong. All Pilates exercises and routines focus on creating a balance of optimal spinal mobility and core strength to support our postures. The aim is to find the best posture we can for our bodies, as well as the strength to maintain it.

Pilates also focuses a great deal on strengthening and mobilizing the rib cage in order to provide optimal breathing patterns for our bodies, as oxygen is critical to the body's healing process. Finally, Pilates teaches us to move and work our bodies more efficiently. From our toes to the tops of our heads, when everything is in alignment and working efficiently, activities and tasks can be performed with greater ease and less strain.

It can be challenging (and uncomfortable) to mobilize a body that is trying so hard to make itself less mobile, but it is worth it. It is especially important for those of us with spondyloarthritis to regularly do range of motion exercises, safely working the spine and other joints to preserve function. I especially recommend upper back and core strengthening exercises, and stretches that round the spine forward, arch the spine back, bend the spine side to side, and twist the spine left and right.

I'd love to share some of my favorite exercises for keeping my spine strong and mobile. But first, here are a few important things to keep in mind when doing Pilates exercises:

1. If it is uncomfortable to lay down flat, place a pillow under your head. A small to medium pillow will ease strain on the neck and lower back.
2. If it strains your spine to keep your legs straight, bend the knees slightly. This will allow the spine to move more freely.
3. Always go only as far as is comfortable in an exercise or stretch on any given day. Pilates is not about how many repetitions we can do, or how great a range of motion we can accomplish. It is about quality of movement. Maintaining correct posture, engaging the abs, and proper alignment will largely determine the number of repetitions and the range of motion accomplished.
4. Finally, as with any exercise program, please consult your physician or physical therapist before starting a new exercise routine. And listen to your body. If something doesn't feel right or safe to you, please don't do it.

Here are some of my favorite Pilates exercises. Many of these movements are demonstrated in recorded videos, and available on my various social media channels noted below.

THE HUNDRED: Start by lying flat, or with a pillow under the head if desired. Stretch the arms forward. Bend the knees and bring the legs in toward the chest. Lift the head up, looking down toward the belly button. Start pumping the arms up and down. Inhale for a count of 5, exhale for a count of 5. Slowly work up to doing this 10 times. Keep the inhale and exhale through the nose only.

For a more challenging exercise, try to straighten the legs up toward the ceiling while maintaining the spine on the mat. (Maintaining the spine on the mat is most important, so keep knees bent if need be.) Next, start lowering the legs down towards the floor, again ensuring the spine stays connected to the mat. If the lower spine lifts off of the floor, then raise the legs up or bend the knees.

ROLL BACK: Sit up tall. Place the hands under or on the side of the thighs. Start to roll the upper body back towards the mat. Do not let the shoulders lead, roll back by pulling the abs in and up, forcing the movement to come only from the lower abs. Roll back as far as you can while maintaining control of the movement and not causing tension in the legs or shoulders. As soon as you feel tension in the shoulders, roll back up to a sitting position.

SINGLE LEG STRETCH: Lie flat on the mat with the entire spine touching the mat. Bend both legs in towards your chest. Lift the head and shoulders off the mat, looking toward the belly button. If it is too straining to keep the head lifted, place a pillow under the head and neck. Keeping the abs pulled in and up, and the spine and lower back connected to the mat, place both hands on one leg. Pull the leg in toward your shoulder as much as possible while extending the other leg straight out in front of you. If it is too straining on the lower back to extend the leg straight out then lift the leg up higher toward the ceiling.

DOUBLE STRAIGHT LEG STRETCH: Start lying flat on the mat. Place both hands behind the head (place one hand over the other, do not interlock the fingers). Lift both legs straight up to the ceiling. Lift the head up and look toward the belly button. Focus on pulling the lower abs in and up to support the legs while pulling the upper abs in and up to support the head and neck. While keeping the entire spine flat on the mat, start to lower the legs down. As soon as you feel the lower back lift off of the mat, pull the lower abs in and up and lift the legs back up to their starting position. If it is too straining to lift the head and neck, place a pillow under the head and neck.

SPINE STRETCH FORWARD: Sit up straight with the legs straight out in front of you and open as wide as you can (more than shoulder width apart). If it is too challenging to keep the spine straight then sit on a small step stool or cushion that is one foot or less off of the ground. Keep the foot flexed from the ankle; do not flex the toes towards you, keep the toes relaxed. Keep the shoulders anchored and down; do not let the shoulders lift up toward the ears. Pull the lower abs in and up and start to round the spine forward. Again, do not let the shoulders lift towards the ears when rounding forward. Imagine the head lowering down toward the mat. The most important thing is not how far forward you can reach, but how far down you can sink your head toward the mat. Repeat 3-5 times. Each time, try to get the spine to stretch deeper.

SAW: Sit straight up with legs as wide apart as possible. If it is too challenging to sit straight up with the legs straight, bend the knees until you are able to sit with the spine perfectly straight up, or sit on a small prop that is about a foot off the ground. Reach the arms out to either side, making sure you maintain the lifted spine and keep the shoulders down and relaxed. Twist the spine to the right and as you exhale bend forward and reach the left hand past the right foot if possible, or toward the foot. The other arm reaches out long and back behind you. Focus on keeping the hips even and not shifting the weight from one hip to the other. You want to feel like the twist is coming from the lower abs that support the lower back.

SPINE TWIST: Sit up tall with legs straight out in front of you. Keep the legs together and feet flexed towards you. If it is too challenging to keep the spine lifted and the legs straight, sit on a small prop about a foot off the ground or bend the knees until you are able to sit with the spine straight up. Pull the abs in and up to feel like you are lifting and stretching the lower spine up. Stretch the arms out to either side with thumbs up to the ceiling. Keeping the hips even and feet together, twist to the right and then to the left. Repeat 3-5 times, trying to deepen the twist each time. When twisting be mindful to not lean back but instead focus on feeling like you are lifting the upper body up and forward as you twist.

SPINE LIFT: Sit up tall with legs straight out in front of you, hip width apart. Flex the feet toward you. Flex from the ankle; do not flex the toes towards you. If it is challenging to keep the spine lifted and straight with the legs straight, bend the legs until you can sit with the spine straight up. Place both hands behind the head, one hand over the other, without interlocking the fingers. Slightly press the back of the head into your hands while pulling the abs in and up to feel like you are stretching and lifting the spine up. Continue to lift the spine up slightly. Bend the head and upper back and push the chest and sternum forward and up toward the ceiling.

SIDE KICKS: Lie on your side, both legs straight out in front of you at a 45-degree angle. Support the head with one hand and place the other hand on the mat in front of you. Keep the abs pulled in and up; do not let the side that you are laying on sink into the mat. Keep the shoulders relaxed. The foot that is on the mat is flexed and stretched out long. Lift the top leg to hip height. While maintaining relaxed shoulders and keeping the abs pulled in, kick the top leg forward and back. Do not let the shoulders, back, or hips rock back and forth as you kick; keep the kicks small to keep the upper body still. Next, kick the top leg up toward the ceiling and imagine it stretching forward as you lower it back down. Then do 5 small circles in both directions. Keep the circles small to ensure the upper body stays still.

KNEELING SIDE STRETCH: If it is too challenging on the knees to kneel, you can do this exercise seated with legs straight out or crossed in front of you. Stretch the left leg out to the side as far as you can. Lift the right arm up, bring the arm as close to your ear as you can and keep it there throughout the stretch. Let the left arm hang relaxed in front of your hip. Lift the abs up and in and stretch to the left. As you stretch imagine reaching up and out. The focus of this exercise is not how much you can bend to the side, but how much you can bend AND lift to the side. Imagine reaching up and out toward where the seam of the ceiling and wall meet. Keep the shoulders aligned; do not let the right shoulder roll forward, keep that shoulder up and back. Repeat on the other side. Do this 3-5 times, each time trying to deepen the lift and reach.

Nina Narejko lives in Rancho Cucamonga, CA where she has a boutique Pilates studio, focusing on private sessions. She also offers virtual private and group sessions for clients from all over the U.S. and internationally. Nina received her Pilates certification in 2011 and is a third-generation instructor with a training lineage stemming directly from the founder of Pilates, Joseph Pilates.

You will find Nina on Instagram at **@body_redefined_pilates**; on Facebook at **@BodyRedefined**; as well as on YouTube at **Body Redefined**, where she shares exercise videos and tips. To learn more about her studio, visit **body-redefined.com**.

YOUR STORIES:
LIFTING THE WEIGHT OF AS

by LaRiena Ferguson

My name is LaRiena Ferguson. I was born in 1978. Unbeknownst to me, I was born with spina bifida. I remember as a small child that my back always hurt, but I thought it was normal and that everyone felt that way. When I was older, I decided to go into the U.S. Airforce, as I was from a military family and that's just what we did. (From my grandparents to my son, we have served in every branch of the military.) I enlisted and started my journey.

When I started my enlistment process and began boot camp, I was 19 years old, 5'8", and only 125 lbs. My back began to hurt a lot, but I continued to just blow it off. Still, the grueling relentlessness of boot camp put such a strain on me that I could no longer hide the pain. As my agony grew, it became unbearable and I was sent to the medics. Day after day and test after test finally revealed the source of my discomfort — ankylosing spondylitis (AS) and spina bifida - two diagnoses at once that changed my life permanently.

I was told I could have surgery and there would be a 50/50 chance I would be able to walk again. In other words, surgery might help, might not help, or might even leave me paralyzed. I was given a medical discharge, which crushed me. I was on medical hold for six weeks before they sent me home. The doctors told me I would be in a wheelchair by the time I was 40. Yea, me! To be given this prognosis at 19 was terrifying and incredibly disheartening.

Life suddenly took on a somewhat grim look, but I pushed on. Fighting depression and bad relationships, I gave birth to two beautiful kids (neither of whom have AS or spina bifida, thank goodness) and moved on with life as a single mom.

I met my husband John when my daughter, Kiara, was two and my son, Keith, was three. A year after we met, we became a family. A real team. John had been a competitive powerlifter for most of his life and has been a USAPL and USAW certified coach for over 30 years. He got the kids into lifting in their early teens. They both have numerous state and national titles and both hold world record lifts. It was amazing to watch this man take my/our kids and do what he did.

In the back of my mind, I wanted it to be me, too. However, the doctor said no. He told me I had to lose weight, but not how to do it, which I didn't find helpful.

Over the years, the weight piled on and I became more and more unhealthy and obese. You gain weight, get depressed, and then gain more weight. With more weight comes more pain. It's a terrible cycle.

My husband was getting worried. As a coach, he knew what he was seeing and it was bad. He finally sat me down one evening and told me we need to fix this. I was fed up and wanted change, too. We talked about what the doctors had said. My husband looked me square in the eyes and said, "I don't give a shit what they said. They don't have to watch you die. I do, and I don't want to see that."

That's where the next chapter of my journey begins. Last year I was 41 years old and over 260 lbs. We started with getting my diet in order. Portion control was the key for me. Fad diets work short-term, but are not permanent. I wanted the change to stay. I started at 262 lbs. and I dropped down to 214 lbs. After eight months of portion control, I lost 50 lbs. I felt great! My metabolism had been reset. The change felt permanent.

Next, I wanted to do something with my newfound boost in health and energy. So I started weight training. We started with strengthening my back, and my body was up to the task. My mind felt great, too. I was truly happy.

John coached me and watched me like a hawk. He taught me to "listen to my machine." Push but be cautious. He taught me how to do certain exercises and why we do them – what they strengthen and how they affect the body. I always make sure to listen to my body, too. When something feels painful, I stop immediately. I can't do certain types of deadlifts, for example. But squatting is my passion. My record is 355 lbs.

Slowly but surely, we put me back together. I now feel better than I can ever remember. My back is strong and my head is clear.

I'm now a competitive powerlifter. In my first competition this past February, I reset all four state records for Florida – and that's competing against people without AS or spina bifida. My wonderful husband/coach had a custom weight belt made for me with my motto: "Tell me I can't, I dare you." What does this mean to me? I'm not taking "no" for an answer anymore. The doctors said I couldn't do it – now, they can stand back and watch. I also sport the awareness ribbons of my two conditions. I am in full support of "my people."

I used to be a very angry person because I hurt all the time. Now, it takes a lot to even make me agitated. I'm so proud that I've done this. By the way, I'm now 42 – two years past when the doctors originally told me I'd be confined to a wheelchair. How do you like that?

We need to be able to look inside ourselves and see how strong we can truly be. We may face stumbling blocks, but we can prevail and overcome them in creative ways. It's not easy, and it may take time, patience and grit. We all have it inside of us. Sometimes we just need to look within and find it again. So keep your head up! Keep your head in the game! You may not become a powerlifter like me, but you don't have to give up. Be a winner in your own way.

LaRiena and John Ferguson

Axially, I Do Have Spondyloarthritis!

"I thought of this phrase in the middle of a presentation about spondyloarthritis at a medical conference and almost began laughing out loud in a room of 500 people who were quietly listening to the speaker. I hope this phrase offers many opportunities for the community to raise awareness about spondyloarthritis in a fun, witty way." - Charis Hill

Charis is a professionally disabled writer, speaker and model living with ankylosing spondylitis (AS), major depressive disorder, anxiety, and post-traumatic stress disorder. Charis created and was selling a t-shirt with "Axially, I Do Have Spondyloarthritis" displayed proudly on the front. They (Charis identifies as non-binary) thought it would be a great fundraising and awareness builder for SAA. We could not agree more! SAA is so grateful to Charis for sharing their "Axially, I Do Have Spondyloarthritis" t-shirt idea to raise funds and awareness of spondyloarthritis. We are proud to have this shirt in our SAA online store.

The humble SAA online store may simply appear as a place to purchase a mug or a t-shirt. However, it is a powerful and important part of SAA's disease awareness program and fundraising plan. Every item that you find in the store has been carefully vetted, designed and curated to help our community. We ensure that the shirts are comfortable, and the tote bags are easy to carry. Our staff finds the best quality products, always in our signature blue tone!

All funds raised from the sale of products in the SAA store support our mission to be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live their lives to the fullest.

In celebration of summer, SAA is offering the "Axially, I Do Have Spondyloarthritis" t-shirt at a discounted rate through July 31st ($14.00 members/$17.00 non-members).

We are always looking for new products for the SAA online store. If you have a witty quote and creative product idea, we would love to hear from you! Email your ideas to Sean Ewert at **sean.ewert@spondylitis.org**.

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