



EDS Wisconsin, Inc

Strengthening Connections!

Spring 2018

IN THIS ISSUE

About EDS Wisconsin

EDS Wisconsin, Inc. was organized in April 2017 and is Fiscally Sponsored by Chronic Pain Partners aka EDS Awareness.

The Mission of EDS Wisconsin, Inc is to provide support and resources to Wisconsin patients and medical professionals about Ehlers-Danlos Syndromes and related conditions via education and research.

Our Vision is a better Wisconsin where EDS and related conditions are fully understood, treated, and supported.

EDS Wisconsin is here to help. Don't give up, reach out to us. There is hope!

EDS Wisconsin was a dream of Tammy's because she had watched her mother suffer in pain her entire life. In 2004 her mother passed away when she was only 50 years old without ever knowing the cause of her ailments.

In May 2017, EDS Wisconsin, in conjunction with EDS Wellness a 503(c) organization, had their first event "5 Ways to Reduce Persistent Pain," presented by Linda S. Bluestein M.D. Since then, EDS Wisconsin obtained a long-term fiscal sponsorship agreement with Chronic Pain Partners, aka EDS Awareness.

In 2017 with the help of Volunteers and the support of many people and organizations, EDS Wisconsin developed TWO regional Support Groups, and one Kids & Teens Support Group. We also formed a team of researchers who are working on creating

much-needed resources for the Wisconsin EDS community. In addition, we helped distribute information to the medical community about FREE CME education which recently became available through their fiscal sponsor EDS Awareness. On a more personal level, several members of the organization and their sponsor organization EDS Awareness traveled to help an individual from Wisconsin who was hospitalized out of state to help get her home.

The organization also sponsored several individuals and families for Christmas 2017, consisting of approximately 9 children and 9 adults. It has also developed other resources (on their YouTube page and their website) with the help of Linda S. Bluestein, M.D., EDS Wellness, and EDS Awareness.

Most recently, EDS Wisconsin has been working on developing an agreement with a genetics testing lab to create greater accessibility to genetic testing for EDS. Currently, it is not uncommon for patients to have to wait 2 to 3 years to see a geneticist in Wisconsin for this testing. Watch for updates on our FaceBook Page or website!

In addition, EDS Wisconsin is also currently developing THREE more regional Support Group Meetings throughout the state, one of which will be held online for those who cannot attend in person.

In March 2018, EDS Wisconsin is hosting quarterly educational events. See page 3 for

more info. In the future, EDS Wisconsin hopes to use their organizational structure develop support and resources within additional states beyond Wisconsin.



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By Stephanie Goettl

I still remember my first hospital stay after my first surgery. I was 15 and afraid. I woke up from surgery, though, and everything seemed totally fine. All I wanted was Taco Bell...

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What are Ehlers-Danlos Syndromes?

In March 2017, new diagnostic criteria were released and a new group was defined called Hypermobility Spectrum Disorders (HSD). Please see our website to view the new diagnostic criteria and to learn more about EDS, HSD, and related conditions.

EDS is a group of heritable connective tissue disorders that are caused by various genetic defects in the collagen protein used to make our connective tissue. These defects can affect the connective tissues that support the skin, bones, blood vessels, and many other organs and tissues. Defects in connective tissues cause the signs and symptoms, which vary from mildly loose joints to life-threatening complications.

Common Signs and Symptoms

- Joint hypermobility
- Loose, unstable, lax joints
- Pain in multiple joints
- Multiple Allergies
- Chronic Fatigue

- Chronic and various GI issues, IBS
- Cognitive Problems – “Brain Fog”
- Chronic headaches/migraines
- Bruise easily
- Dysautonomia, commonly POTS
- Poor wound healing
- Early onset of musculoskeletal pain
- Scoliosis
- Vision issues, astigmatism common
- Severe or unusual scarring
- Scleral fragility (white of eye)
- Poor muscle tone
- Auto-Immune Issues
- Early onset of osteoarthritis
- Fragile skin
- Stretch Marks
- Soft velvet-like Skin (with some types)
- Varying degrees of Skin hyper-extensibility
- ...and more!

For more information:

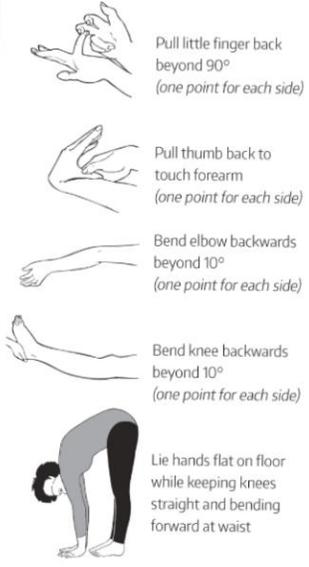
Find the link to print the one-page “Diagnostic Criteria for Hypermobile Ehlers-Danlos Syndrome (hEDS)” on our website. This diagnostic checklist is for doctors across all disciplines to be able to diagnose EDS.

www.EDSWi.org

THE BEIGHTON SCORE

How to Assess Joint Hypermobility

A numerical mobility score of 0 to 9, one point allocated for the ability to perform each of the following tests:



1. Pull little finger back beyond 90° (one point for each side)

2. Pull thumb back to touch forearm (one point for each side)

3. Bend elbow backwards beyond 10° (one point for each side)

4. Bend knee backwards beyond 10° (one point for each side)

5. Lie hands flat on floor while keeping knees straight and bending forward at waist

A positive Beighton score for adults is 5 out of the 9 possible points; for children, a positive score is at least 6 out of 9 points.

As joint mobility is known to decrease by age for adults, include historical information by asking, “Can you now or have you previously been able to...”



Find the link to register for the FREE online education on our website at www.EDSWi.org

FREE Ehlers-Danlos Syndromes Physician CME Education

At the September 2017 EDS Learning Conference, EDS Awareness announced the exciting launch of the first ever FREE, online CME program on EDS and related disorders. This highly successful program was created and managed by EDS Awareness aka Chronic Pain Partners and is accredited through the Medical College of Wisconsin. Thanks to the combined and ongoing efforts of these organizations, this critical education is available to physicians in a manner that is easily accessible and convenient.

Please share the program information to improve care for all those affected by these frequently missed disorders.

"Overview | Ehlers-Danlos Syndromes Physician CME Education

The Ehlers-Danlos Syndrome CME Physician Education Program is the first online EDS course providing CME credits and covering the fundamental principles for the diagnosis, classification, and treatment of Ehlers-Danlos Syndromes and related disorders as well as associated conditions. The focus of this program is on a basic understanding of these complex disorders that often present with a diversity of symptoms which make diagnosis challenging."

Information taken from <https://ehlers-danlos-cme.org/>

EVENTS



Quarterly Events in 2018

In 2018, EDS Wisconsin in conjunction with its dedicated volunteers and supporters will be bringing events to Wisconsin each quarter. In the second quarter watch for a presentation about a condition that commonly occurs with EDS called Mast Cell Activation Disorder; an EDS 'clinic' in the third quarter; and for the fourth quarter we are accepting suggestions (although we have many ideas, we want to do what our State needs!). We would love to hear your ideas and feedback! Send us an email at edswisconsin@live.com, Like us on Facebook and watch for event listings there and on our website



Our Next Event

Conquering Appointment Anxiety for Medically Complex Patients Education and Support for Patients and Medical Professionals

When: March 24, 2018, 1–3 PM

Where: Aspirus Medical Education Resource Center, 425 Wind Ridge Dr, Wausau, WI 54401

PATIENTS, have you ever gone to a medical appointment and wondered, "Where do I even start? What IS important and what's NOT important? I hope they believe me."

MEDICAL PROFESSIONALS, do you have patients who have complex symptoms and wonder, "Where do I start? How do I best help this patient? I don't have enough time."

At this first educational event in a series of four for 2018 hosted by EDS Wisconsin, patients and medical professionals will be given tools and tips to help get through these appointments with confidence and ease.

Join Linda Stapleford Bluestein, M.D., and Tammy Kosbab, President and Founder of EDS Wisconsin, Inc for this empowering event! You don't want to miss this! What do you have to lose, besides the anxiety?

FOR MORE INFORMATION



Like us on Facebook and watch for event listings at www.facebook.com/EDSWisconsin/



A Love Letter to My Nurses, From Your Lifelong Patient

by **Stephanie Goettl**

I still remember my first hospital stay after my first surgery. I was 15 and afraid. I woke up from surgery, though, and everything seemed totally fine. All I wanted was Taco Bell. I would have traded anything for Taco Bell. I begged my mother to go get me Taco Bell—and she did, because I was her child, I had just been through a challenging endeavor, and it was a simple request. As far as we both knew I was fine. As soon as she left, my pain levels rose, I began violently throwing up all over my bed and myself, the swelling inside my cast on my leg became too much—and I pushed that call button next to my hospital through terror and tears.

I'll never forget the nurse who came through the door and moved the curtain around my bed. I was embarrassed. I was "grown up" and I didn't want to need my mom or help, but I was covered in my own vomit and I couldn't move at all because it hurt too much. She didn't even think a thing of it. She didn't just do her job, though, she held my hand with her other one, which made cleaning me up much more difficult. She stayed by the side of my bed and held that hand, releasing only once so I could remove my arm from my hospital gown. She let me cry about things I was too embarrassed to say before she held my hand—I told her that I had a catheter in and I had my menstrual period and I felt dirty. I told her I was so nauseous I didn't know what to do. After she finished cleaning me up, she stayed by my bedside until my mother got back, holding that ugly pink tote while I continued to throw up all the red Jell-O I thought I needed after surgery. I know I threw up on her that day. I still remember her pretty pink scrubs and her

name being Jennifer. I remember she was pregnant and there is no way the smell of my vomit didn't bother her. But she stayed there while I threw up and she stayed there and let me cry—and she made me feel comfortable enough to tell her how mortified I was.

I should have seen that as the start of a lifetime full of nurses being the warriors on the battlefield that is my chronic illness. I don't know that I often have a chance to acknowledge all of the work all of the nurses have done for me in all of my years seeking treatment. It was another ten years of seeing doctors after that first surgery before I got my EDS diagnosis and there were nurses at every doctor's office and dozens of visits trying to understand what was happening, all of whom played a role in me finally figuring out my life and my body. They were just as much a key component of my diagnosis as any doctor, because I'm not sure without them I would have been strong enough to keep seeing doctors.

Too often, when things are just too bad and I need help, it is an amazing nurse who has to take my phone call. I have tremendous doctors, but that means they see a lot of patients. My nurses have taken many phone calls from me crying that I need help with something (cont.)



(continued) Those same nurses have hunted down my very busy doctors to get prescriptions filled, appointments squeezed into calendars and referrals made for me—none of which would have happened without their loud, booming voices speaking for the patients they represent.

Part of what I've sought to do through my work in real life and in the words on this blog is to advocate and speak for the patients who face a lifetime of incurable, chronic illness; what I'm telling you right now is that nurses do this one hundred times better than I do every single day—and often while being vomited on, yelled at, and not getting enough sleep.

This morning, I had my first round of an infusion therapy we are experimenting with for my pain. It is administered entirely by nurses. The first nurse attempted to get the IV in twice. I have wonderful veins for IV placement, but my EDS skin makes it so challenging. After she didn't get it the second time, I was crying and she apologized so quickly, wanting to find a second nurse. She asked me if I was in pain from the needle pokes. As I choked back the tears and told her it wasn't her and it wasn't the needle pokes, but just that I'm so scared and I'm so

tired of trying everything and nothing working so this just felt like another failed attempt already, she got another nurse to do the IV, but only so she could hold my other hand while she did it and tell me it was going to be okay. She sat there next to me and let me know that she was going to be there every second I was there making sure I was okay. She is a highly trained medical professional and she still fetched me a soda for comfort, carried my purse because it's hard on my crutches, and asked me questions about the work I do in the city I live in. She couldn't cure what's wrong with me, but she did distract me for moment. When she held my hand as the other nurse inserted the IV into my other arm, I flashed back to being 15 and covered in my own vomit as a nurse took twice as long cleaning me up with one arm so she could make sure I felt safe and secure while she did it.

The nurse today kept her word. Katie checked on me several times throughout the process. She brought me extra pillows and dimmed the lights when it made me tired. She took notes on my side effects and fetched the emergency nausea prescription I have to carry in my purse when the side effects got to be too much. She made sure to

offer to slow down my drip when I was uncomfortable.

Katie was a wonderful nurse. I hope she gets the recognition she deserves—but what strikes me is that she isn't even all that unique. I have encountered dozens, maybe hundreds, of nurses with this level of dedication to their patients. If doctors are the generals on our battlefields, they are our foot soldiers—and I will salute them every single time. What do you want me to write about next? Thoughts?

Follow Stephanie's blog at www.EDSWi.org

EDS RESOURCES

EDS Wisconsin, inc.
<http://www.EDSWi.org>

EDS Awareness
<http://www.chronicpainpartners.com>

EDS Wellness <http://edswellness.org>

EDS Society <https://www.ehlers-danlos.com>

EDS Society Helpline <https://www.ehlers-danlos.com/eds-helpline/>

EDS Society Resource Guides
<https://www.ehlers-danlos.com/brochures/>

EDS Network CARES Foundation
<http://www.ehlersdanlosnetwork.org>



Introducing... Wisconsin Integrative Pain Specialists

Did you know that there is a clinic in Wausau that specializing in treating people with Ehlers-Danlos Syndromes (EDS) and related disorders? In December, Dr. Linda S. Bluestein opened Wisconsin Integrative Pain Specialists, S.C. (WIPS). Dr. Bluestein treats a full range of issues that cause chronic pain and connective tissue disorders like EDS. She is able to order genetic testing for EDS as well as for metabolic and drug metabolism variants. In addition, other co-occurring symptoms are also addressed, and treatment plans are comprehensive. Nutritional, environmental, physical and psychologic factors are significant confounding variables usually not addressed in traditional clinic settings but are closely evaluated at WIPS. A personalized strategy will be developed that considers your unique circumstances and appropriate interventions from an array of

scientific disciplines will be utilized to help you regain your optimum health. Dr. Bluestein also continues to dedicate much of her time as a Volunteer Medical Consultant for non-profit organizations such as EDS Wisconsin, Inc., and EDS Awareness/Chronic Pain Partners as well as serve on the Medical Advisory Board of EDS Wellness. In her role as part of the Clinical Faculty at the Medical College of Wisconsin, Central Wisconsin (MCW-CW), Dr. Bluestein works to raise awareness about EDS and related disorders. She is also actively involved in programs at MCW-CW that bring patients and medical professionals together so that they may better understand each other.



Dr. Bluestein is very passionate about educating other physicians about EDS and related disorders as well as co-morbid conditions. She works very closely with each person's entire healthcare team. To learn more about WIPS or Dr.

Bluestein, visit LindaBluestein.com or call 715-600-1722.

Linda Stapleford Bluestein, M.D.

www.LindaBluesteinMD.com

Email: WisconsinIntegrative@gmail.com

President, Wisconsin Integrative Pain Specialists

Course Director, Healer's Art Program - Medical College of Wisconsin - Central Wisconsin

Member, Medical Advisory Committee, EDS Wellness, a 501c3 non-profit

Volunteer Medical Consultant, Chronic Pain Partners, a 501c3 non-profit

Volunteer Medical Consultant, EDS Wisconsin, Inc., non-profit

Volunteer Medical Consultant, Woodson YMCA Active Older Adults Program

Professional Member – Hypermobility Syndromes Association (HMSA)

Tel: 715-600-1722
601 S 32nd Ave, Wausau, WI 54401

Meet Physician Dr. Kris Ferguson



Dr. Kris Ferguson is an established and highly skilled physician with over 12 years of experience in pain management. He has a special interest in helping to treat and manage patients with Ehlers-Danlos Syndromes (EDS), Hypermobility Spectrum Disorders (HSD), and related conditions.

Dr. Ferguson is Board Certified in Anesthesiology and Pain Management. He takes great pride in the care provided by the Aspirus Langlade Hospital Pain clinic by providing not only interventional pain management but also coordinating care between physical therapy and pain psychologists.

Dr. Ferguson's passion is driven by the bonds he builds with his patients over the course of their lives and the enjoyment he holds in keeping them healthy and well.

Call 715-623-9432 to schedule an appointment with Dr. Ferguson!

Location:

Aspirus Langlade Hospital Pain Clinic
112 East 5th Avenue
Antigo, WI 54410



Meet Therapist

Kc Graveen

LPC-IT, MSAT

I am knowledgeable in Ehlers-Danlos Syndromes (EDS), Hypermobility Spectrum Disorders (HSD), and related conditions. I have completed 3 of the 4 currently available EDS Physician CME Education Program Curriculum Modules. I am interested in the healing power of art for individuals with various medical illnesses and chronic pain.

In May 2016 I received my Masters of Science degree in Art Therapy with an emphasis in Counseling from Mount Mary University in Milwaukee Wisconsin. I also completed my Bachelor of art degree in Art Therapy at Mount Mary University in May 2014.

I strongly believe in the healing and therapeutic benefits of alternative approaches to therapy. As an art therapist I strive to adapt to the specific needs of my clients. I work from a person-centered approach, meeting each individual where they are physically, mentally, emotionally and spiritually. I work alongside each individual and aid them in reaching their therapeutic goals. Being an artist and an art therapist, I view each encounter with a client as our own collaborative art piece, working together until the piece is complete.

I specialize in working with individuals experiencing chronic pain, depression, anxiety, suicidal ideation, self-harm, ADHD, mood disorders, oppositional defiant disorder, conduct disorder, PTSD, trauma and substance abuse.

I utilize art making to develop interpersonal skills, positive

relationships and coping strategies that promote overall physical, mental, emotional and spiritual well-being. Using a creative approach to therapy, I can better provide my clients with the materials they need to succeed.

Kc provides services at The Caring Tree Children's Counseling Center in Wausau, Wisconsin where she will be having group sessions for Children and Teens with EDS. Kc can also see children and teens for Individual Therapy sessions. If you would like your child to see a knowledgeable Therapist to help him or her deal with having chronic illness and/or related conditions, schedule an appointment with Kc by calling 715-301-0667. Kc can also be contacted directly at 715-659-0387 or kccaringtree@gmail.com



501
Division St.
Wausau, WI 54403
715-301-0667

If you are a medical professional who is knowledgeable about EDS, HSD & related disorders and would like to be involved with EDS Wisconsin, please contact Tammy at edswisconsin@live.com or go to www.EDSWi.org to express your interest. We are also looking for partners, sponsors, donors and volunteers!

36 Things We Have Tried When We Are in Pain

Compiled from ideas shared by members of the Facebook Group Ehlers Danlos & Joint Hypermobility Wisconsin



www.CaringTree.us

****Always check with your doctor. This list is not intended to replace medical advice and is solely a compilation of opinions of different things that others have tried****

1. "Epsom salt bath (2 cups Epsom salt, 1 cup baking soda for 45 minutes). Since magnesium is best absorbed through the skin, this helps achy muscles. If you cannot take a bath, soaking your feet in a foot bath with Epsom Salt will also work."
2. "Heat and/or ice. One or the other, or alternating."
3. "I'm always distracting myself from my pain since I'm no longer taking pain meds."
4. **Self-hypnosis** – Find more information on Alicia Cramer's Facebook Page.
5. "Compile a list of books you want to read. The social website Goodreads you can find your friends and family and find out what they like." A different member adds "I keep a list of books I want to read on my phone, so when I go to the library, I can be in and out, always have a book to read!"
6. "YouTube video for Dr. Weil's 4-7-8 Breathing exercise to help counteract the body's fight or flight response."
7. **Prayer**
8. C.H. says "benadryl can curb panic attacks and [help to] relax (can also put you to sleep).
9. "I also keep lavender spray near my bed, and a sleep Febreze air thingy too."
10. "Nice smelling hand cream by my bed."
11. **"My TENS unit** has been a godsend sometimes for all types of pain. I only wish it weren't dangerous to use on certain body parts (head / chest) otherwise I'd use it everywhere."
12. "Natural anti-inflammatories like Arnica -- Arnica Montana."
13. **"Biofeedback** -- hand warming has been amazing both for reducing stress and decreasing pain. Used to be that one could get a cheap indoor / outdoor thermometer and just use the outdoor probe in the fingers to track it. Sadly I haven't been able to find one in the stores for several years, but they still sell biofeedback thermometers for this."
14. B.W. says "Ucla also has great (FREE) MP3 downloads of **mindfulness tracks**, they have a whole university program on it"
15. "Tennis balls for myofascial back pain -- a cheaper alternative for back knots for people who are single like me, or for those whose partners either suck at backrubs or work too much or for whatever reason aren't able to help out. 2 tennis balls properly placed lying on a soft surface like a bed or very plush carpet can really do great for trigger points." To get the back, put the tennis ball in a pillowcase and lean against a wall.
16. "Taking magnesium can also be helpful, potassium -- sometimes we drink a lot water, and don't have the electrolytes or other things we need to absorb it. Making sure that we have more than just water in the system." Another member adds, "Coconut water and Gatorade have electrolytes. Be careful with Coconut water if you have high potassium though."
17. **"Breathing.** Deep breathing can do a lot, and as we get stressed we tend to take shorter breaths and deplete our oxygen.... 10 deep breaths can help counteract this."
18. "The word "nothing" repeated to **clear my mind.**"
19. T.M. says "I've been listening to some subliminal message on YouTube about 'healing' and it helps me relax and eventually fall asleep. Now I don't know if this will help me when I'm in the worst of my pain but it's helped some. The messages are about believing your body is healthy, feeling good, etc. Here is another one.
20. "Power posing! If you don't do this already, just 2 minutes can change your cortisol (and testosterone) which can both change your stress and pain."
21. "Although easier said than done -- **not isolating.** I always do this when my pain gets bad, and I know it makes things worse. It can be scary because people can lack understanding and can be rejecting when we most need empathy (or they can be condescending with sympathy, rather than empathy). I think that groups like this might be able to help, though, because there might be people who have been there. I think reaching out to someone, anyone, can be helpful.
22. "Of course we all probably know that there is pain and there are times where it feels like (or there literally is) nothing that's going to fix it or work enough. And that sucks. But I think hope - **having hope is the most important thing.**"
23. "For me getting diagnosed with EDS was really important and having validation. So...hope. Music (for me), love, and letting ourselves live on those days when we feel well enough to do so."
24. "Making sure we don't lose sight of those things that make us us."
25. **"Remembering we are more than just a diagnosis."**
26. S.R. says "What I find interesting is that when my pain tries to take me over from head to toe...oddly enough, my ph balance is off. Prylosac (sp) is good. Weird but works, or h2o2 therapy. Just a spray for under your tongue."
27. D.K. says "The nerves that perceive pain also feel tickles, joy, sadness. You can, only hold one emotion at a time. Choose JOY!"
28. B.W. says, "Distraction. Find a movie that makes you laugh till it hurts or scares the heck out of you, you'll forget about lots of the pain."
29. T.K. says: Watch Why **Breathwork Matters** by Andrew Weil. Breathwork is a free and easy practice that can significantly benefit your health. Dr. Weil discusses..Vitamins! Vitamin C helps synthesize collagen, Vitamin D helps with body aches and depression especially in the winter, Magnesium and potassium help muscles aches and spasms."
30. B.T. says **"permission to rest.** One thing that sometimes helps me, often helps me, is to lie down and listen to myself breathe. Focusing on my breath as it goes in and out can redirect your thinking away from the pain. It does take a little practice, but it cannot hurt."

CONTINUED ON PG. 9

Meet Diane Durante MEPD, OTR, LMT, CST I I am a conscientious, integrative, and compassionate therapist who believes in the practice of comforting through empathetic presence and healing touch embedded into the physical modalities that I employ. I am an avid reader and researcher continuously learning new relevant approaches to patient care and I am passionate about sharing my knowledge with others. My years of learning have allowed me to obtain over 40 credits in post graduate coursework relating to **childhood behavioral disorders, sensory processing disorders, health/wellness promotion, and complimentary and alternative medicine practices**. I've utilized my Master's in Education from UW LaCrosse to be an anatomy and physiology instructor through Health Touch Spa School of Massage and have provided countless hours of individual patient education and public speaking. Since 2000 I have been actively practicing as an Occupational Therapist in the following settings: schools skilled nursing, orthopedics, and home health. Since my licensing in 2011 as a Massage Therapist I have built a **specialized medical massage therapy practice** out of my home which also includes hospice massage.

I balance my roles to provide holistic approaches to care, with an emphasis on patient centered goals. As an Occupational Therapist, I have **experience in psychosocial rehabilitation (psychological well-being) and pain management** (including manual techniques, home exercise programs, teaching relaxation techniques for pain management / anxiety, splinting and daily living aids). My therapy practices frequently incorporate use of manual techniques such as CranioSacral Therapy, Trigger Point, and Myofascial Techniques which are highly effective modalities to address chronic and acute pain.

My medical massage practice provides non-invasive therapy intended to improve, correct, maintain previous therapy results or serve as an adjunct to existing therapies associated with diagnosed medical, orthopedic or mental health related condition; including palliative care. **Unlike traditional massage therapy, the goal of a medical massage is generally not relaxation or tension release; rather, a medical massage seeks to stimulate or restore the integumentary, musculoskeletal, immune, nervous, and circulatory systems through non-invasive and gentle forms of therapy.** For example, a doctor may send a patient for a medical massage to help stimulate their nervous system when battling depression...

CONTINUED ON PG 10

SPOTLIGHT ON VOLUNTEERS



Sheilah Kring, Director of Education & Research

It was incredibly serendipitous that prior to the onset of my disability that I had spent years working in complex health care needs, disability, advocacy, had two master's degrees and was working on a Ph.D. researching health care. I even had great health care and knew some incredible doctors. Still, even with all of those resources it took many years and many doctors to finally get diagnosed with EDS and several other related disorders, and I had far too many 'close calls' before I got a comprehensive health team and access to the treatments I needed to stabilize things. I became keenly aware that the difficulty in my journey, even with all of the resources at my disposal and the medical providers who went an extra mile to keep me here, speaks volumes for the countless others who lack those same resources. Since my diagnosis, I spend much of my free time keeping up with EDS-related research and sharing whatever I can with other patients and providers, as well as administrators, whenever possible. I simply

want the current generation to be the last generation that struggles with diagnoses and treatment options for EDS, and I firmly believe we can work together to make that happen.



Christine Quackenboss, Milwaukee Area Support Group Leader

Hello! I live in Eden, WI with my husband (Chuck) and our dog (Remy). We have three grown children and 3.33 grandchildren (who are the light of our lives!).

My career is Manager-Distribution Network Planning & Operations - K&BA, which really means that my awesome team creates the strategy, alignment, and execution of finished goods to customers in the most efficient way possible. I also teach part-time at Lakeland University

(Supply Chain, of course!), lead/participate in a book club for professional/personal growth, past president for WIMI (Women in Management)-Sheboygan chapter, and now....very excited to be the Support Group Leader for EDS, WI - Milwaukee!

I was formally diagnosed 12-21-2017 (we all have that date in our hearts! The confirmed "not crazy" date!). Still waiting for DNA tests between Classical or Hypermobility. My

motivation for volunteering was first, to meet others that run out of spoons on a daily/weekly basis, and then quickly came to realize, there is so much more to this. There is strength in numbers, there are so many Zebras to be found and it is great to know that we are not alone....we are a group...we are a ZEAL of Zebras! I want to connect, bounce ideas, and make new friendships that I hope last a very long time!



Stephanie Goettl, Blogger and Advocate

Stephanie is a 27-year old EDS patient living in southern Wisconsin and while she considers that having EDS makes her a qualified blogger for the site, she thinks her strength and love of advocacy are more important parts of why she's qualified to write here. Stephanie is a dedicated advocate for EDS patients, after more than a decade of waiting to understand what was happening with her own body. Her empathy for patients gives her a unique perspective in her writing, particularly for young adults or parents looking for insight into how to handle their children's needs as EDS patients.

Outside of her own medical needs and working with EDS Wisconsin to blog, Stephanie manages a student rental company and has served on the Common

VOLUNTEERS CONTINUED

Council for her city since she was 20 years old, part of her advocacy streak. Stephanie is absolutely obsessed with her 1-year old Papillon puppy, Essex and is currently planning a summer wedding to her long-time boyfriend, Nathan.

Stephanie looks forward to sharing with you and would love any and all insight you have for her blog!



Sally Jolles,
Associate
Researcher

Sally's postgraduate studies include doctoral training in medical anthropology and Masters Degrees in both Cultural Anthropology and International Affairs. Currently, she is an Associate Researcher in the Wisconsin Surgical Outcomes Research Program (WiSOR) in the Department of Surgery at the University of Wisconsin School of Medicine and Public Health. As a trained cultural anthropologist, Sally has expertise in field research, which includes ethnography, observation, participant-observation, and in-depth interviews.

Sally is interested in the intersection of health, public policy, and minority rights. To that end, she has conducted fieldwork in China, Germany, and the United States. Sally conducts health services research focused on surgical education, patient-provider decision-making, and health disparities research. She has completed work as a project manager on Project ADOPT, a novel surgical training program that used simulation, hands-on practice, and surgical coaching to teach practicing surgeons a new procedure. Sally has held a dual (WOC) appointment at the William S. Middleton Veteran Affairs Hospital since 2014 where she has worked on a five-year grant that seeks to identify and address barriers to bariatric surgery within VA. Sally's skills include project management, regulatory compliance, clinical database design and development, formative assessment, development of logic models, chart review, design and development of interview guides and surveys, conducting

semi-structured interviews & focus groups, inductive and deductive coding, qualitative data analysis, writing and editing grants and manuscripts, and conducting in-depth literature reviews. Sally has experience using Atlas.ti, NVivo, REDCap, and Qualtrics.

Sally was diagnosed with EDS in 2015 after a failed surgery and many years of seemingly "unrelated" health problems. After her diagnosis, she was fortunate enough to find this community. She has never been more thrilled to join such a positive, supportive, and welcoming group of people. Sally is an original consultant with EDS Wisconsin.



Tracy Diehl,
Social Media

Hi, My name is Tracy Diehl. I am originally from

Wisconsin, but now live in Georgia.

I was diagnosed with Ehlers-Danlos hypermobility type in 2007. Since then, I am always in search of the best strategies to care for my EDS body--understanding that it is important to be your own best advocate. Searching the internet, I have found some informative resources. I enjoy researching and finding different types of ideas. Through EDS Wisconsin, I have been given an opportunity to share some of my research with you and I am looking forward to expanding my knowledge and research even further. I thank the organization for allowing me this opportunity!



Mariah Liisa Holterman,
Graphic Designer

Current city: Madison

Profession: Designer and Retail Manager
Education: Attended the Milwaukee Institute of Art and Design, earning a BFA in Illustration. Check out her website at www.MariahLiisa.com

If you're interested in Volunteering, go to www.edswi.org for information about how to apply!

Thanks to all of our generous and caring Volunteers who are helping to make a difference in Wisconsin:

- Angela Braun, Wausau Area Support Group Leader
- Beth Wroblewski, Kids & Teens Support Group Leader
- Andee Dunn, Office Support & Advocate
- Tammy and Michael Price, Online Support Group Meeting Leaders
- Judith Newton, Event Coordinator
- Amy Adams, Volunteer Paralegal
- Tracy Joyner, Graphic Design
- Joe Windeknecht, Graphic Design
- Damon Webber, Research Assistant and Administrative Support
- Dawn Dembosky, Milwaukee Area Support Group Co Leader
- Deb Klecker, Volunteer Psych Advisor and Milwaukee Area Support Group Co Leader
- Lisa Klatkiewicz, Awareness and Research
- Kailee Knudsen, Administrative Assistant
- Cody Knudsen, Tech Support
- Hunter Stark, Event Assistance
- CJ Dunn, Office Assistant
- Andrea Robinson, Sales and Marketing

CONTINUED FROM PG 6

31. H.A. says "when I'm in pain I focus on the idea that pain isn't the worst thing in the world. It's a thing, and it's distracting, but I've been through worse. This can lead me to overdo it, so be careful, but I suppose you would call it "meditating on the pain" and I believe that has been shown to be effective. It involves deep breathing, and that's helpful as well. It also distracts me from blaming myself, which is very helpful. Eating right/ electrolytes and water are helpful but if I mess it up I'm very hard on myself, so that's not a go-to when I'm already beat up."

32. D.K. says "app on my phone with binaural beats. Very relaxing. Anything that can help you focus on something other than 'tactile' sense can help relieve pain."

33. "I put on **music** of my pre-teens and teens yesterday... A time when I definitely felt better. It was energizing as it woke up that part of my brain when I was singing and dancing and having fun in my less painful years. I haven't put my list together but you are all doing a great job with the variety of ideas."

34. Essential oils

35. "I play multiple games of Words With Friends, and several other games to **keep my brain busy** and occupied."

36. "Drink hot tea and honey to relax

Recommended Reading

Managing Pain Before It Manages You	Margaret Caudill, MD***
The Pain Survival Guide	Dennis Turk, PhD***
Healing Yourself	Martin Rossman, MD***
The Relaxation Response	Herbert Benson, MD***
Timeless Healing	Herbert Benson, MD
Prescriptions for Living	Bernie Siegel, MD
Finding Balance	Monica Aggarwal, MD, Jyothi Rao, MD
The Mayo Clinic Guide to Stress Free Living	Amit Sood, MD
Stressaholic	Heidi Hanna
The Gifts of Imperfection	Brené Brown, PhD
The Miracle Mornings - Art of Affirmations	Hal Elrod, Brianna Greenspan
Simple Catastrophic Living	Jon Kabat-Zinn PhD
Wherever You Go, There You Are	Jon Kabat-Zinn PhD

SUPPORT GROUPS

Wausau Area Support Group, and Kids & Teens Support Group Meetings

The Wausau Area Support Group and the Kids & Teens Support Group will both have their next meetings on Sat. February 24, 2018 from 1 - 2:30 pm at the Marathon County Public Library in Wausau. Sign up on our website www.edswi.org or contact Tammy at edswisconsin@live.com.

Milwaukee Area Support Group Meeting

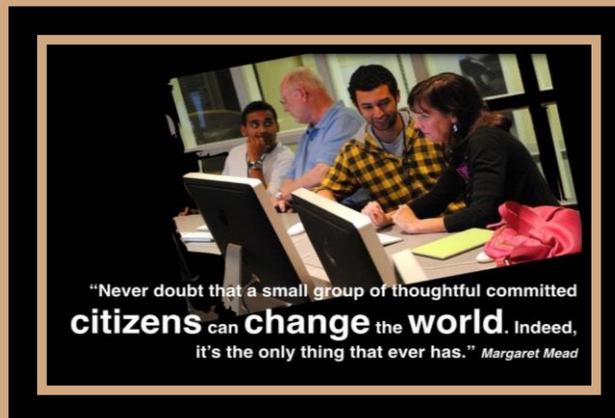
The Milwaukee Area Support Group's next meeting will be held on March 8, 2018 at the Menomonee Falls Public Library from 6 - 7:30pm. Sign up on our website or contact Christine at Christine.Quackenboss@kohler.com.

Looking for a support group near you.... We are developing Support Groups in Madison, Eau Claire, Green Bay/Appleton, and to have Online Meetings. Go to www.edswi.org to sign up or contact Tammy at edswisconsin@live.com with questions or inquiries.

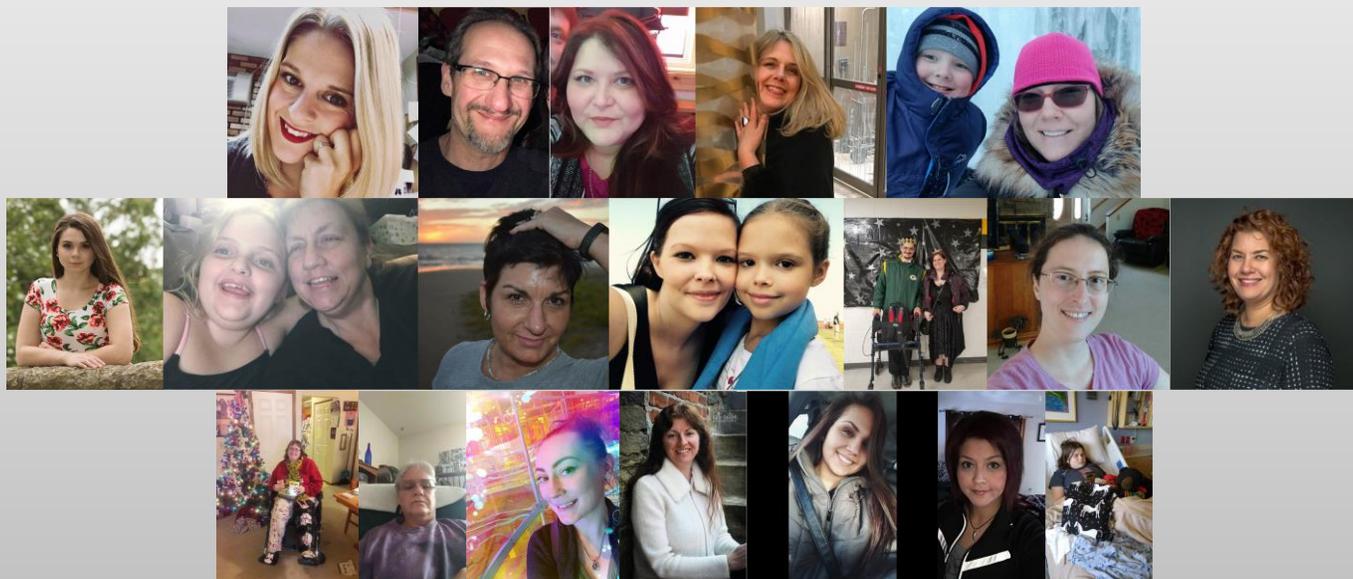
Help Needed!

Are you or someone you know passionate about helping individuals who have Ehlers-Danlos Syndromes or related conditions? EDS Wisconsin, Inc. is looking for motivated individuals with various skills to help with nonprofit business, grant writing, legal, accounting, support groups, a support hotline, event planning and more.

Please tell your family and friends about these opportunities! Fill out the Volunteer application on our website at www.edswi.org. Other inquiries can be submitted to edswisconsin@live.com, or call, text or message Tammy at (715) 846-2553.



FACES OF WISCONSIN EDS



CONTINUED FROM PG 7 DIANE DURANTE

A doctor may also order a medical massage in the case of a patient suffering from chronic headaches. While another doctor may refer a patient to aid in body – mind integration for a patient who has experienced trauma. In each scenario, there is a very specific ailment that the medical massage is seeking to address. Medical Massage is often “prescribed” by a Primary Care Doctor, Psychiatrist, Psychologist, Orthopedic Doctor, Physical / Occupational Therapist, or Licensed Counselor.

I have a personal investment in helping others who have chronic pain conditions, EDS, POTS, Mast Cell Activation Disorders, ADHD and Autism. These disorders have affected myself and/or family members and I have spent countless hours researching, reading, and attending conferences to educate myself and others about the unique treatment needs of these individuals. I think you will find my

professional skills and personal experiences to be invaluable to your healing needs.

At Chrysalis Massage Therapy you will be offered professional medical massage or occupational therapy services by a Nationally Board Certified Occupational Therapist who is also a Licensed Massage Therapist. The specialized Medical Massage services offered in my practice include: Emotional Freedom Technique, Tapping, Breath work, Progressive Muscle Relaxation, Autogenics, Craniosacral Therapy, Muscle Mobilization Technique, Myofascial Release, Palliative Massage, Trigger Point Therapy, Lymphatic Drainage and specialized services for children who have conditions such as chronic pain ADHD, Anxiety or Autism. In addition to orthopedic body work, other conditions I specialize in include: POTS, EDS, Thoracic Outlet Syndrome, chronic migraine, digestive disorders, trauma, post mastectomy or pre-surgical body preparation.

I will be happy to answer questions related to Medical Massage to see if it might be of benefit to you. Some individuals may require an order from a doctor to ensure that its practice is safe and appropriate.

Visit my website or call me at:

715-432-9399

www.chrysalismassage4you.com

Break Free and Come to Life!

In health and well-being,
Diane M. Durante; MEPD, OTR,
LMT, CST I



ABOUT THE BOARD



Tammy Kosbab, President & Founder

Tammy is passionate about helping those with EDS and related disorders since watching her mother suffer and then pass away in 2004 without ever knowing the cause of

her ailments. In 2009, Tammy was diagnosed with what is formerly called "Type 2" or Mild Classical Type of EDS. She has attended 2011 and 2012 EDNF Conferences, the 2016 Ehlers Danlos Society Global Learning Conference, and EDS Wellness' "Wellpalooza" Integrative Health and Wellness Conference in 2017. She is the creator and administrator for Ehlers-Danlos & Joint Hypermobility on Facebook, which currently has over 600 members. Tammy went to school for Healthcare Management so she could help others with EDS. She graduated magna cum laude in 2016, and soon after she was elected to the Board of Directors for Ehlers-Danlos Network CARES. In the past, she had been a successful Entrepreneur and salon owner for over 9 years.

Steve Swierczynski, Vice President and Co- Founder

Steve is a successful entrepreneur: Fishing Hot Spots, Inc., Fishidy, EDS Wisconsin, and others. He has served on numerous Boards and Committees in business

and educational settings. He is a family oriented person who has a personal and passionate connection to EDS.

Tsilos "Jewels" Schoener, Secretary

Tsilos graduated with a Juris Doctorate degree in 2007 from UW Madison Law School. She also graduated with double majors from UW Milwaukee with Honors. Tsilos has family members who have been diagnosed with EDS. She has been

diagnosed with Undifferentiated Connective Tissue Disorder, and related conditions Sjogren's & Psoriatic Arthritis Mutilans.

SPONSORSHIP

In 2017 we obtained a Fiscal Sponsorship Agreement with EDS Awareness. YAY! This is exciting news because it means we can accept tax- deductible monetary and in-kind donations!

Our organization relies on generous donations from caring individuals like you! Donations can be made directly on the Home page of our website at www.EDSWi.org

Checks can be mailed to: EDS Wisconsin, Inc., P.O. Box 322 Rhinelander, WI 54501

Checks **must** be made out to: Chronic Pain Partners FBO EDS Wisconsin or EDS Wisconsin must be in the memo line.



Thank you to our GENEROUS donors & sponsors!

EDS Awareness www.chronicpainpartners.com/

Fishing Hot Spots www.fishinghotspots.com

Wisconsin Integrative Pain Specialists & Linda Bluestein, M.D. www.lindabluesteinmd.com

The Caring Tree – Children's Counseling Center www.caringtree.us

EDS Wellness www.edswellness.org

Soleil Beads www.soleilbeads.com

Ring Splints www.ringsplints.com

Chrysalis Massage <http://chrysalismassage4you.com>

Aspirus Family Medicine and University of Wisconsin School of Medicine and Public Health
www.aspirus.org/Main/Family-Medicine-Residency1.aspx?srcaud=Main

Priority Physical Therapy <http://priorityphysicaltherapy.com>

Ehlers-Danlos Syndrome Network C.A.R.E.S. Foundation www.ehlersdanlosnetwork.org



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EDS Wisconsin, Inc Strengthening Connections!

PO Box 322
Rhineland, WI 54501

Message from the President & Founder Tammy Kosbab

Thank you for your interest in EDS Wisconsin! The Mission and Vision of EDS Wisconsin has been a dream of mine since before I even knew about EDS. I saw the devastation that this genetic disorder could cause, and I made the conscious decision to never stop believing that there are better answers and solutions; and that if we persevere, that we CAN and we WILL find the answers that we need!! I won't and I can't give up hope because I know there are individuals suffering at home, in pain, feeling helpless and hopeless, as well as the medical professionals who suffer because they want to help them but are unable due to the lack of support, resources, research and education.

Currently, the combined efforts of individuals and organizations around the world has significantly helped to progress the diagnosis, management and treatment options surrounding EDS and related conditions! Even so, there is much more to be done!

*Starting now and moving forward, every single one of us must fully support the efforts of individuals and organizations so that progress can be made! We MUST find better ways to manage and treat the symptoms, and this must be done the best and fastest way! We must combine our efforts and work together, in unity, to be the most effective and efficient so we can help more people sooner! I look forward to working with you and **Strengthening Connections!***