

EDS Wisconsin, Inc.

Strengthening Connections!

Visit us online at www.EDSWI.org

September
2017



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!

What are Ehlers-Danlos Syndromes?

This issue of our newsletter is focused specifically on Ehlers-Danlos Syndromes (EDS). This past March, new diagnostic criteria was 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 tissues 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 of EDS, which vary from mildly loose joints to life-threatening complications.



- Joint hypermobility
- Loose/unstable joints
- Joint Pain
- Prone to dislocations and/or subluxations
- Early onset of osteoarthritis.
- Bruises easily
- Fragile skin Stretch Marks
- Soft velvet-like skin
- Skin hyper-extendibility
- Severe or unusual scarring
- Poor wound healing
- Molluscoid Pseudo Tumors
- Growing pains and early onset of musculoskeletal pain
- Chronic & various gastrointestinal issues
- Chronic Fatigue
- Cognitive issues
- Chronic headaches/migraines
- Scoliosis
- Allergies of various kinds
- Scleral fragility (white of eye)
- Poor muscle tone
- Vision issues
- POTS & other Autonomic Dysfunction issues
- Auto-Immune Issues

Main types of EDS

- Hypermobile Type
- Classical Type
- Vascular Type
- Kyphoscoliosis Type
- Arthrochalasia Type
- Dermatosparaxis Type

Pre-register for the [upcoming webinar by Dr Anne Maitland](#) about EDS comorbid condition Mast Cell Activation Disorder (MCAD) on **September 19, 2017 at 6:30 CST** at [EDSAwareness.com](#)

Upcoming & Recent Events

We had **Open Meetings on 8/22/2017 and 8/29/2017** @ 7pm at the Aspirus Medical Education Resource Center to gather input from individuals and medical professionals in Wisconsin. We were joined by a large number of people, both in person and online. It was informative and beneficial for all attendees.

On September 7 – 9th, Tammy and Steve of EDS Wisconsin, and Linda Bluestein, M.D., Volunteer Medical Consultant for EDS Wisconsin, attended the EDS Conference in Las Vegas to help support the mission!

The [Wausau Area Support group](#) will be having their first meeting on Saturday **September 16, 2017 from 1 to 2:30 pm** on the second floor of the Marathon County Public Library in Wausau. Visit our website for more details.

In October, EDS Wisconsin is supporting a **fundraising dinner in honor of the Young family in Madison**. We have been unable to confirm a date due to health problems within the family. Please keep them in your thoughts & prayers.

Looking for a support group near you....

Go to our website www.edswi.org to locate groups in your area. Please contact Tracy Joyner at tjoyner.edswi@gmail.com or 608-338-6568 with any questions or to receive information regarding support groups.

Exciting News!

We signed 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, and we can also compensate professionals with tax-deductible receipts for their time spent. Donations can be made directly on the Home page of our website at www.edswi.org

Alternatively, checks can be mailed to:
EDS Wisconsin, Inc.
P.O. Box 322
Rhineland, WI 54501

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

EDS Wisconsin Approved Resources

EDS Awareness

<http://www.chronicpainpartners.com>

EDS Wellness

<http://edswellness.org>

EDS Network CARES Foundation

<http://www.ehlersdanlosnetwork.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 Wisconsin's Board members!



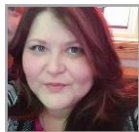
Tammy Kosbab,
President

- Diagnosed with what is formerly known as "Type 2" EDS in 2009.
- Suspected as Classical Type based on new criteria.
- Creator and Administrator for Ehlers-Danlos & Joint Hypermobility
- Graduated magna cum laude with a degree in Healthcare Management
- Elected to the Board of Directors for Ehlers-Danlos Network CARES in 2016.



Steve Swierczynski
Vice President &
Treasurer

- Successful entrepreneur: Fishing Hot Spots, Inc., Fishdy, EDS Wisconsin, and others.
- UW-Madison
- Personal and passionate connection to EDS
- Family oriented
- Served on numerous Boards and Committees in business and educational settings



Tsilos Schoener
Secretary

- Diagnosed with Undifferentiated Connective Tissue Disorder, and related conditions Sjogren's & Psoriatic Arthritis Mutilans
- Graduated with Juris Doctorate degree in 2007 from UW Madison Law School
- Family members diagnosed with EDS
- Graduated with double majors from UW Milwaukee with Honors

Hi! My name is 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.

Are you or someone you know passionate about helping individuals who have Ehlers-Danlos Syndrome 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! Inquires can be submitted to edswisconsin@live.com, or call, text or message Tammy at (715) 846-2553.

Thank you to our **AMAZING** donors & sponsors!

- **EDS Wellness** <http://edswellness.org>
- **Ring Splints** <http://www.ringsplints.com>
- **EDS Awareness** <http://www.chronicpainpartners.com>
- **Chrysalis Massage** <http://chrysalismassage4you.com>
- **Ehlers-Danlos Syndrome Network C.A.R.E.S. Foundation** www.ehlersdanlosnetwork.org
- **Aspirus Family Medicine and University of Wisconsin School of Medicine and Public Health** <http://www.aspirus.org/Main/Family-Medicine-Residency1.aspx?srcaud=Main>
- **The Caring Tree – Children’s Counseling Center** www.caringtree.us
- **Fishing Hot Spots** <http://www.fishinghotspots.com>
- **Priority Physical Therapy** <http://priorityphysicaltherapy.com/>



References

- www.edswellness.com
- www.edswellness.org



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and Community Health
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SCHOOL OF MEDICINE AND PUBLIC HEALTH



ASPIRUS[™]
Passion for excellence. Compassion for people.

Visit our website for more information, support and resources. You can find **FREE** online CME education, information about our Volunteers, and more.

In our next issue: What our Research Team is working on for you, About the EDS Conference in Las Vegas, and more! Subscribe to our newsletter on our website here.