

Submissions to ACIMH Congress 2018 Baltimore

Approaches to Integrative Health & Mind-Body Strategies for Persons with Hypermobility-related Disorders, such as Ehlers-Danlos syndromes (EDS), Hypermobility Spectrum Disorders (HSD), and comorbid conditions: A Movement and Mindfulness-Based Health Education Program

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Overview:

Kendra Neilsen Myles, C.H.E.S., RYT 200, founder of EDS Wellness, Inc. a Maryland-based 501(c)(3) nonprofit, joined forces with Dr. Clair Francomano, Director of The Harvey Institute for Human Genetics at Greater Baltimore Medical Center (GMBC), to establish evidence-based patient and health education resources on integrative health therapies, and to develop and implement a mindfulness and movement-focused program for Individuals with Hypermobility-related disorders, such as Ehlers-Danlos syndromes (EDS), Hypermobility Spectrum Disorders (HSD) and comorbid conditions. Combined with educational materials on integrative health strategies, the ability to attend weekly gentle yoga classes with a knowledgeable instructor, and the support of a monthly mind-body-centered group meeting, EDS/HSD patients are provided the opportunity to learn about and engage in diverse self-care and mind-body-focused activities to help manage chronic pain and other common symptoms associated with hypermobility-related disorders. These activities include: learning how to practice yoga safely with hypermobility, engaging in several types of yoga practices, exploring various breathing and mindfulness exercises, cultivating the principles of natural movement and restorative exercise into daily life, and experiencing various types of meditation.

Rationale:

Through a collaborative agreement with Deborah Norris, Ph.D., founder of The Mindfulness Center in Bethesda, Maryland (also a Maryland-based 501(c)(3) nonprofit), and led by a Certified Health Education Specialist (C.H.E.S), who is also a 200 hr Certified Yoga Instructor, patients living with chronic pain and multisystemic conditions such as EDS and HSD, explore their fears, discover their strengths, and face their weaknesses – all with a collective goal of increasing physical strength and stamina, regaining function, finding self-empowerment over the medical condition(s) they live with and improving their general health status. This program culminates in a mind-body-focused exploration in discovering evidence-based integrative strategies for living well.

Clinical significance:

Ehlers-Danlos syndromes (EDS) are a collection of connective tissue disorders that affect the structure or function of collagen, the most abundant protein in the body. Since collagen is in nearly every type of connective tissue in our bodies, including our bones and blood, EDS often impacts each system in the body in some way. EDS is believed by some researchers and specialists to be the ‘most neglected disorder(s) in modern medicine.’ Previously believed to be “rare,” [geneticists](#) and providers who specialize in the diagnosis and management of patients with hypermobility-related disorders, such as EDS, believe that in reality, EDS is “rarely diagnosed.” In the persistent quest to validate and understand the numerous chronic and multisystemic issues EDS patients face, EDS researchers and specialists collaborated on a major classification update to all types of Ehlers-Danlos syndromes and introduced the newly-described Hypermobility Spectrum Disorders (HSD) – both groups of conditions fall under the broader hypermobility-related disorders umbrella. The newly updated EDS and HSD classification was published in *The American Journal of Medical Genetics* on March 15th, 2017 and includes management and care guidelines that providers of all specialties can follow. However, despite the recent classification update or the increased awareness in some groups, most of the mainstream medical community still lacks understanding and knowledge on EDS, HSD or other hypermobility-related disorders. Additionally, other multisystemic conditions that often found comorbidly with hypermobility syndromes, such as Mast Cell Activation Syndrome (MCAS) and Dysautonomia/POTS, are also poorly understood and overlooked. Patients are left lonely, often feeling hopeless and scared of either mistreatment or injury in the hands of uneducated providers. They scramble, often alone, trying to put the pieces of their medical puzzle together and search for ways to stop their bodies from becoming unglued – literally. *The result?* All of us, patients, healthcare providers, and caregivers, are left with the reality that we are facing a true public health crisis -- an epidemic of misdiagnosis after misdiagnosis, preventable medical mistakes, and life-threatening disability – even death.

Patients need treatment options and hope. Most will never live to see a cure, and waiting for researchers to discover the gene responsible for Hypermobile Ehlers-Danlos syndrome (hEDS), will not help us find ways to live well now. Hence, the rationale behind EDS Wellness’ mission and vision to help patients learn ways to regain function and live as well as possible now, through research and the development of programs focused on integrative health. The same rationale applies to the development of this program and the submission of this abstract. We are facing a public health crisis and the “EDS Spiral” can be halted through proper professional & medical education, the development and implementation of health education programs and research initiatives focusing on integrative health strategies – we need to help patients help themselves.

Objectives:

Based on Jon Kabat-Zinn’s *‘Mindfulness-Based Stress Reduction Program,’* patients employ the use of gentle movement and meditation as self-directed strategies for managing chronic pain and other symptoms often associated EDS, HSD and other multisystemic conditions. Movement

and mindfulness-based activities are used to help guide patients to uncover long-standing insecurities surrounding their health, and explore their physical, mental and emotional weaknesses in safe, supportive environment. Patients are challenged to hone life-long lifestyle and behavior changes needed to regain confidence, a sense of personal control over their healthcare and stability in their overall well-being.

Methods:

EDS Wellness' Mind-Body Strategies for Hypermobility with Chronic Pain program focuses on three principle components – weekly 1hr-long gentle yoga classes, developing a consistent self-directed gentle movement and meditation practice at home, and monthly group meetings (aprox 45mins-1hr). Over the past year, approximately 20 individuals have developed lifestyle and mind-body strategies for living well with EDS, HSD and related chronic conditions, evolved through slow and deliberate behavior changes, and learned through participation our program. Post-implementation program evaluation includes: interactive group participation, weekly or monthly program and attendance and completion of the post-program evaluation and feedback survey. Individual gains are evident through increased physical strength and endurance, improved mental and emotional health, regular journaling, and a commitment to a consistent, self-directed movement and mindfulness-based at-home program

Outline:

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Materials To Be Distributed:

The program flyer will provide content outlines for 4 classes or workshops and the presenters will have additional program resources, videos and health education materials on integrative therapies available for participants to review. The program implementation plan will provide specific instructions for incorporating evidence-based mind-body strategies and integrative therapies at their home institution. Research and virtual program participation options are currently being explored.