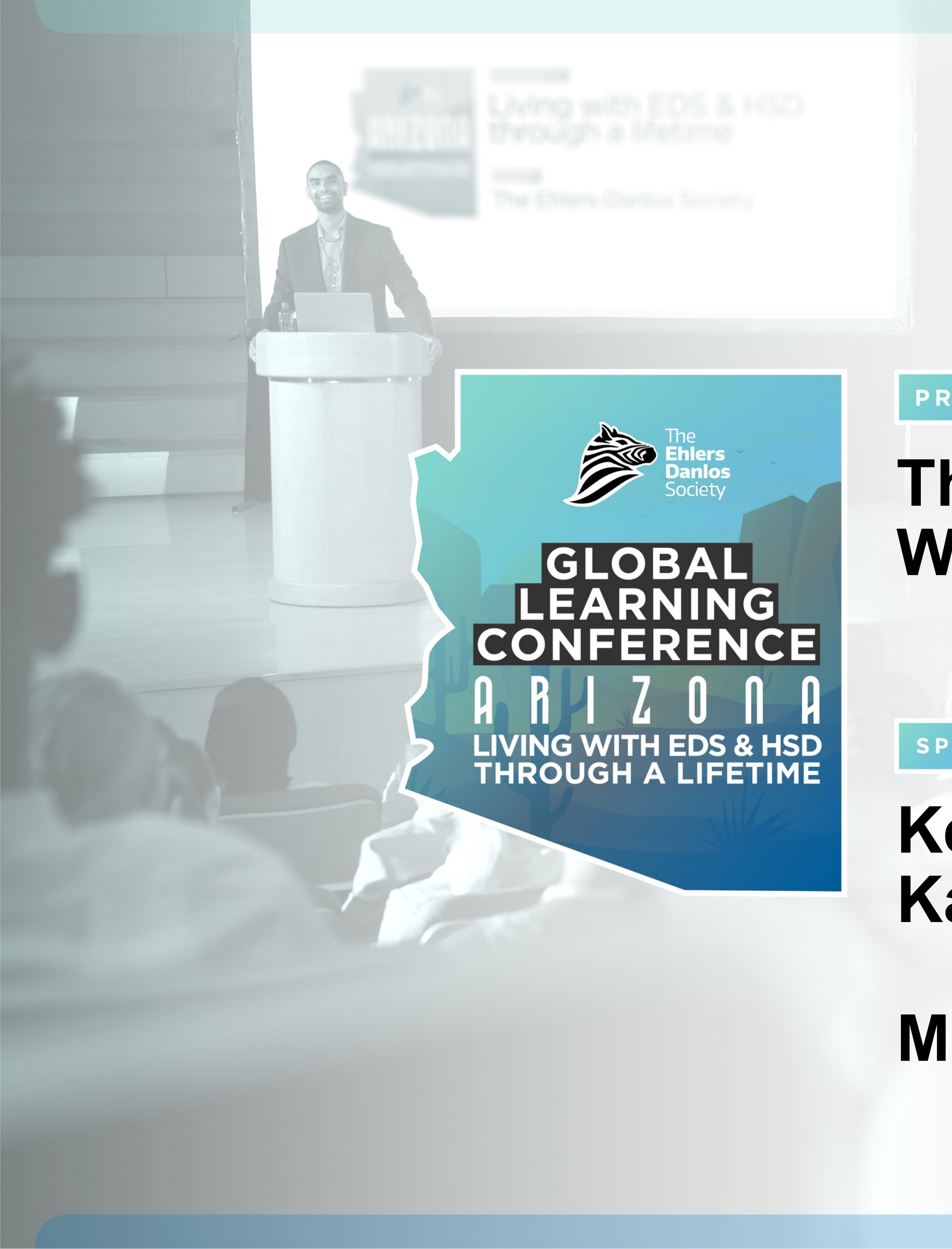


The Ehlers Danlos Society

GLOBAL
LEARNING
CONFERENCE
ARIZONA
LIVING WITH EDS & HSD
THROUGH A LIFETIME

PRESENTATION

The Muldowney Protocol: How It Works And Roadblocks To Progress.

SPEAKER

Kevin Muldowney, MSPT
Kathleen Muldowney, MSPT

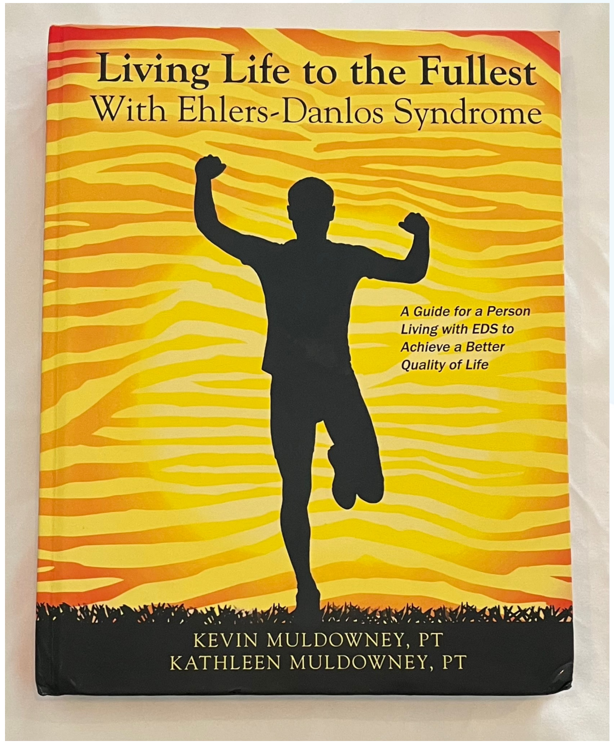
Muldowney Physical Therapy, Inc.

KEVIN MULDOWNEY, MSPT
KATHLEEN MULDOWNEY, MSPT

- We have been treating EDS since 2007

- Our practice sees over 125 EDS patients per week, both in person and virtually from all over the world. Primarily Hypermobile or Classical Type.

- We published our book in 2015, *“Living Life To The Fullest With Ehlers-Danlos Syndrome,”* which outlines our unique PT protocol.



HOW DID WE DEVELOP OUR PROTOCOL?

- In 2007, there were no standardized protocols for people with EDS.
- We looked at hundreds of EDS patients to determine if there were common dysfunctions among them. There were!
- What are the biomechanical reasons for these dysfunctions?
- What muscles do we need to strengthen to help these dysfunctions?
- Make the exercises easy for both the patients and their PT to understand. Give helpful hints to them if the exercise hurts. What are your options? (for the physical therapist)
- DO NO HARM!!
- How to split the body into sections in order to strengthen efficiently. (T7 above and T8 below)

WHERE IS MY PAIN COMING FROM?

- Our protocol helps pain from joint instability due to muscle weakness and biomechanical dysfunction.
- Other sources of dysfunction and pain that may slow down progress with our protocol and should be referred to a specialist:
- Neurological: CCI, AAI, Tethered Cord, bulging disc, spondylolthesis, etc.
- Systemic: POTS, Mast Cell, GI, food allergies, etc.
- Injury: labral tear, meniscus tear, failed surgery

WHERE DO I BEGIN STRENGTHENING WHEN EVERYTHING HURTS?

- Begin at the SIJ because this is the joint where weight from the HAT is transferred to the legs and vice versa. (GRF)
- First goal of strengthening any joint is to decrease inflammation in that joint. Our protocol uses muscle activation to pump inflammation out of the joint so it will be safer to strengthen. Chapter 2: Level 1 Mat, Level 1 Ball, Chapter 3 Level 2 UE, Chapter 4 level 1 LE.
- Increase muscle tone, not strength= do most exercises for time not reps.
- Strengthen primarily stabilizing muscles.
- Maintain muscle balance within a section of the body.
- Chapter 2: SIJ, low level hip, lumbar spine to T8.
- Chapter 3: midback T7 above, neck, shoulders, elbows, wrist, hands, TMJ
- Chapter4: high level hip, knee, ankle, feet

WHY USE A STANDARDIZED PROTOCOL INSTEAD OF INDIVIDUALIZED TREATMENTS?

- Consistency among therapists.
- Easier to figure out problems as they arise. Both with exercises and other issues missed.
- Easier for patients to follow exercises in a book and can see progressions.
- Know if you are not doing exercises. Every 2 weeks should be going up a level unless PT changes progression.

HOW DO WE USE THE MULDOWNEY PROTOCOL IN OUR CLINIC?

- Chapter 2: mat exercises intended to stabilize the pelvis and ball exercises intended to stabilize the sacrum and facet joints.

- We have A and B exercises that are modifications that can be made for patients with unstable hips.

- We do a reverse ball mat protocol for patients with discogenic issues and spondylolisthesis.

- PT performs MET to SIJ and L5-T8 and ribs. MFR to all tight muscles that are prohibiting the patient from performing their exercises. Tape low back and SIJ or have patient get an SIJ belt (Don Joy). Teach family to fix SIJ at home.

- PT fix hip and tape hip so patient can get through protocol.

- PT performs SIJ decompression to help with disc.

HOW DO WE USE THE MULDOWNEY PROTOCOL IN OUR CLINIC?

- Chapter 3: Intended to strengthen neck, mid back, ribs, shoulders, elbows, hands, TMJ and cranial bones.
- If patient has unstable shoulders, do not add TYI exercises until level 4 of this chapter.
- Use posture against wall exercise to help with increased forward head posture.
- Patients with CCI, AAI and Chiari can perform all exercises in supine and/or with Aspen collar.

- PT performs manual therapy to T8-C1 and ribs, shoulders, elbow, wrist, hand, TMJ, CST. (prn)
- PT tapes shoulders and instructs family member how to tape shoulders at home.
- PT performs MFR to psoas, pecs, and SCM. (prn)
- PT has to decide if manual therapy and exercises are helping or does the patient need a surgical consult.

HOW DO WE USE THE MULDOWNEY PROTOCOL IN OUR CLINIC?

- Chapter 4: Intended to strengthen hips, knees, feet, and help with balance.
- If patient has pronated/supinated feet, they may need custom orthotics to help with gait.
- If patient has unstable patella, tibia, fibular do not begin squats/lunges until level 3 of this chapter.

- If side stepping with tubing hurts patients SIJ or hips, discontinue this exercise and continue with progression Add side stepping in with tubing in phase 2 exercises in chapter 5
- PT performs manual therapy to tibia/ fibula and tarsal bones. Tape tibia/fibula and if it helps, teach family member to fix and tape these areas.
- PT determine if custom orthotics are appropriate for patient.

HOW DO WE USE THE MULDOWNEY PROTOCOL IN OUR CLINIC?

- Chapter 5, phase II: Intended to begin functional training.
- Once completed, patient can perform our protocol 3X per week and then do Pilates or workout in gym with specific instructions.

- DANGEROUS EXERCISES:
- Elliptical: subluxes SIJ
- Running: 10X GRF
- Swimming: shoulders dislocate (can use snorkel and kick board
- Recumbent bike is best cardio for EDS patients.

BRACES TO HELP WITH PROTOCOL

- Aspen collar: neck
- Don Joy SIJ belt: LBP
- Ossur hip stabilizing brace
- Custom orthotic: feet and knees
- Futuro sports wrap: wrist
- Selbite posture corrector: ribs OK
- Ring splints or arthritis gloves: hands

- Fightech shoulder brace or Sully brace
- Milk of magnesia for taping
- Opsite tape before leuko tape
- Medicline pillow for side sleeper
- Hommitt cordless shower scrubber

FINAL THOUGHTS

- Manual therapy alone does not help people with EDS in the long run and maybe harmful to them.
- Exercise alone may help a little, but will take time with those more limited by their symptoms of EDS.
- Combination of manual therapy to help with subluxations and associated muscle spasm and exercise of the specific area where the manual therapy is being performed will yield the best results, in our experience.

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REVIEW PLAN OF CARE WITH PATIENT

- What team members do they need to see?
- What areas are we beginning to treat first?
- How can family members help at home? Our goal is to have patients be able to help themselves as much as possible outside of PT.
- What is their lifestyle (work, kids, etc.) and what plan is realistic for them to carry out and be successful with? If treating a kid, also ask the parent what is realistic and appropriate for them.
- What can interfere with progress? Screening for common co-morbidities.

WHAT AFFECTS PROGRESS WITH PT WHEN UNTREATED?

- Mast Cell (MCAS) (observed in approx. 50% of my patients with EDS)
  - Excessive fatigue
  - ↑ pain due to joint inflammation
  - ↑ subluxations and ↓ muscle strength due to inflammation
  - GI distress (↓ energy due to poor nutrition, nausea, abdominal cramping, difficult to exercise due to pain)
- Tethered Cord (observed in approx. 35-50% of my patients with EDS)
  - Leg weakness/numbness/fatigue
  - Excessive back pain (↓ tolerance to strengthening)
  - Hip subluxations make it difficult to walk
  - Constipation/gastroparesis (difficult to exercise)

WHAT AFFECTS PROGRESS WITH PT WHEN UNTREATED?

- CCI and Chiari (observed in approx. 25% of my patients with EDS)
  - Chronic, severe HA's, trouble concentrating/thinking clearly
  - UE weakness and numbness
  - Visual disturbances, tinnitus, hearing problems
  - Difficulty swallowing (can lead to poor nutrition, low energy)
  - ↓ balance, difficulty walking, fainting

- Dysautonomia/POTS (observed in approx. 75% of my patients with EDS)
  - SOB, irregular HR, fatigue, ↓stamina with exercise
  - Easily dehydrated
  - Lightheaded/ fainting
  - Blood pooling, difficulty walking

- Endometriosis (observed in approx. 20% of my patients with EDS)
  - excessive back pain (↓ tolerance to strengthening)
  - ↑ ligament laxity due to hormones, leading to ↑subluxations
  - Severe abdominal pain (some patients are bed ridden for 1-2 days)

WHAT AFFECTS PROGRESS WITH PT WHEN UNTREATED?

- Food Allergies, Medication Allergies/Intolerance (observed in approx. 50-75% of my patients with EDS)
  - Could cause MCAS flare
  - Fatigue, GI distress
  - ↑ pain if meds not working effectively, leading to ↓ tolerance to exercise

- Gastroparesis (observed in approx. 20% of my patients with EDS)
  - Severe abdominal pain
  - ↓ nutrition→ fatigue and ↓ tolerance to exercise

- Ironically, it is often the patients who come in with little hope because they have so many problems and complaints who are the ones we can help the most. They usually have at least 1 (and often more) co-morbid conditions of EDS that have not been diagnosed or treated. Once we refer them to the appropriate specialists, many of their symptoms and their overall function improves dramatically.

PERFORM SCREENING FOR CO-MORBID CONDITIONS

- We developed specific questionnaires and some physical tests to screen for common conditions often seen in patients who have EDS.

- Neurological Issues
  - Tethered cord, CCI, Chiari

- Systemic Issues
  - Mast cell (MCAS), Dysautonomia, POTS, Allergies

- Other
  - Gastroparesis, Endometriosis

- I have been fortunate to have treated numerous people with EDS over the past several years, spending an average of 1-2 hours per week, every week with each patient.
- I ask LOTS of questions and **LISTEN** to the problems my patients are having.
- This has allowed me to recognize patterns and similarities among patients and identify when people might have common co-morbid conditions of EDS.
- This can truly be life changing for many patients.

A SUCCESS STORY OF KATE *“LIVING LIFE TO THE FULLEST”*

- This is Kate 5 Months Post-op Tethered Cord surgery

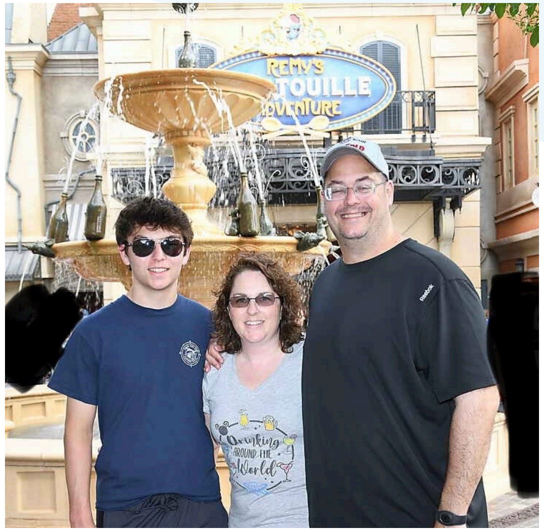
- This was the first time in several years that Kate was able to feel like a “normal teenager.” She went to a carnival with friends and was able to join in the fun going down a slide.

- Prior to surgery, she had difficulty trying to: attend college, keep up with her classes and hang out with friends. She struggled significantly with: studying for long periods and even simple things like typing, brushing her teeth, doing her hair. She had been dealing with chronic pain since she was 14.

- Now she is just over 1 year post-op and she is: living on her own on at college, maintaining an impressive GPA, going out with friends and finally starting to live a “normal life.”

- She was a patient in whom I promptly identified tethered cord and mast cell and referred her for proper evaluation with specialists. She has told me that her journey at Muldowney PT has been life changing.

“IT’S KIND OF FUN TO DO THE IMPOSSIBLE”
-WALT DISNEY-



- We are passionate about treating people with EDS, hypermobility and chronic pain and have dedicated our practice to helping this population (Over 80% of our patients have EDS).

- We treat people who have very complex issues and have often failed traditional PT in the past.

- We do the impossible every day, helping people with EDS and chronic pain *“Live Life To The Fullest,”* achieving their goals and dreams and enjoying life like MY family does.

- We hope that we can help you or someone you know who has EDS *“Live Life To The Fullest.”*

- Thank you for your time today.

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Thank you for listening