The purpose of this database is to provide suggestions for patients with hEDS/HSD and in some cases other forms of EDS, about general and specialized physicians who will see patients with your spectrum of conditions. Furthermore, as it is developed, time and attention have been given to having these physicians and alternative care providers vetted by fellow patients and EDS knowledgeable physicians and providers. Please do not hesitate to contact the editor at rachel@rachelleepac.com if serious issues arise with any of these physicians that other patients and doctors should be aware of. Please read the disclaimer in the footer.

## Intro to the NC/SC Provider Database

Welcome! This database has been compiled with love and the experience of many patients around the Carolinas. Its purpose is not to be exhaustive but rather, to direct patients in urgent need to providers they can trust. It also provides the EDS and HSD community with a baseline of care, keeping track of providers who remain open and continue to learn, and those who sadly refuse to see EDS patients.

Each section has no particular order at present since the data is so fluid. If you need a specialty, use ctrl-f to type the name of the specialty and it will navigate you to the appropriate page.

At the end of this database is a select set of high-quality resources for your medical journey and to assist you in educating new providers who show an interest in continuing your care. From one patient to another, our efforts to help educate physicians about EDS and HSD conditions are what pave the way for future generations. Our advocacy is what creates the waves for better research, clinical studies, and more equitable care for our community. As a patient and professional advocate, your voice is important. Please send feedback about the providers you see from this list if you have any negative experiences.

## A quick note about Primary Care Providers!

These men and women see a LOT of conditions and have to maintain a HUGE mental database of issues. EDS is often overwhelming, and patients are sent away NOT because the doctor doesn't want to see them, but because the internist sees how much we need from specialists. WE can help them feel less overwhelmed and encourage them in how much they CAN support us and our needs, but not if we flood them with unreasonable demands. Here are a few quick tips for having a great relationship with your primary.

Disclaimer: This database is not infallible or meant to replace the advice of your current doctors and specialists. Its editor assumes that patients take responsibility to research each provider themselves using tools beyond online information. Many offices will take time to speak to a potential patient and answer inquiries about tests, procedures, and conditions treated. However, most will not offer a telephone triage with a nurse prior to making an appointment, if at all, so please plan your questions specifically ahead of time focusing on what is mentioned above, NOT on all your symptoms. In the event that your questions are not taken, give the contact info to a current physician who understands your condition(s) and ask them to call the physician on your behalf with questions.

1. Primary care means first, not ALL. If you haven't learned this already, no doctor has the time to consistently coordinate all of your care, find you new physicians when one doesn't work out, or juggle communication with you and your 10+ specialists. If you push them to do this for you, they often stop seeing EDS patients entirely, removing a potentially incredible provider and advocate for the rest of us.

If you need help with this, patient advocates are trained to do this job, among many other services that can save you time, stress and money. If you need help doing it yourself, my patient advocacy consulting practice can help teach you how in only a few appointments. www.rachelleepac.com

2. If you have a primary care doctor who doesn't know much about EDS/HSD but wants to learn, that is a HUGE win!! Don't leave him/her! Use the resources on my website, this database, and the Ehlers-Danlos Society to patiently and gradually give information to your GP. They can't read 600 pages the day after seeing you. Take a new article to each visit and pay them the kindness of printing it off or having an easy link to a video sent through your online medical portal.

3. In keeping with 1 and 2, don't expect your primary to be an EDS expert. The internal and family med doctors who truly become experts in EDS have spent several decades learning to treat patients like you. And they will STILL have to send you to specialists because they can't stop practicing and go back to school for degrees in all 48 specialties you need (humorous hyperbole intended).

#### YOUR help makes a difference.

Your body will help teach new doctors who just might become part of the army of EDS Experts we want and need, in another 10 years. If you give up, they won't be able to learn.

4. A good Primary should never dismiss you, ignore you, minimize you, or suggest that you have a psychogenic disorder instead of a hypermobility spectrum disorder.

Even with a good primary, you are your own best advocate. They might suggest a great EDS doc that you don't get along with. That's ok. Use this list and the amazing support groups online to interview and find one you CAN work with. Then give the name to your GP so they have options for other patients.

Together, we can change the face of treatment for hypermobile spectrum disorders and Ehlers-Danlos Syndromes.

NCAP – if you see this acronym it means that the provider is not currently seeing new patients. They are still on this list because these providers know EDS and HSD's, rotate their intake, may begin seeing new patients at any time.

#### **Primary Care**

NCAP - Dr. Shannon Roche, DO

Arboretum Family and Sports Medicine, Novant Health, South Charlotte

Dr. Roche, like most osteopathically trained physicians, is caring, attentive, and active in treating patients no matter how complex and global their conditions. She is certified in osteopathic manipulation therapy (she does NOT snap crackle pop), which uses the bodies natural movement to realign joints and encourage muscles to fire properly. She has been studying EDS extensively and increasing her field of effectiveness in caring for a growing number of hypermobile patients.

**NCAP -** Dr. Mintzer, GP Generations Family Practice

Cary, NC

If Mintzer is not taking patients, her fellow physicians are also familiar with EDS due to her influence and the large number of EDS families in the clinic.

NCAP - Dr. Glodowski

**Generations Family Practice** 

Cary, NC

EDS aware and able to assist in general care for many cases. Sends complex cases to Dr. Mitzner.

Laura Cone Gay, MD, MPH

**UNC Family Medicine at Southpoint** 

7011 Fayetteville Road

Renaissance Center

Suite 200

Durham, NC 27713

(919) 361-2644

Special interests: Women's health including prenatal care, gynecology, pediatrics, dermatology and skin procedures

Dr. Jill Hopkins, MD

ADAPT Hypermobility Clinic

A department of Levine Children's Specialty Center by Atrium Health

704-801-3097

Atrium Health Levine Children's South Lake Pediatrics

9625 Northcross Center Court

Suite 201

Huntersville, NC 28078

Dr. Jill is the new primary care physician handling all evaluations for intake into the ADAPT clinic, which

aims to provide children with EDS and hypermobility spectrum disorders with the physicians and quality of care they need to adapt WELL. More patient reviews of the clinic are requested.

Chapel Hill, NC 27514 (984) 974-0210

Highly recommended by multiple EDS and HSD patients. Caring, listens. Will not dismiss complex cases.

Dr. Cassandra Hornbuckle, DO Granville Primary Care & OB/GYN 110 Professional Park Drive

Oxford, NC 27565

Phone: 919.693.6541

Like so many osteopathic trained physicians, Cassandra is open, creative, and skilled. She has a number of EDS patients in her care and is able to manage cycle difficulties, pelvic organ prolapse, and is reported to have ordered genetic testing in order to provide an EDS diagnosis for a patient.

Dr. Warren Johnson, DO Cape Fear Hospital, Hoke Primary Care

Dr. Johnson is learning about EDS and hypermobility syndromes. He is open to natural approaches to a variety of treatment.

Dr. Silvia Shoffner Cary Medical Group, internist

Not an EDS expert but listens, accepts it for what it is and is active in working with patients to coordinate care and treat the manifestations.

Dr. Royce K. Bailey Advent Health Hendersonville, NC

Highly recommended internist by a number of current patients, many with more complicated components of this spectrum of disorders.

Richard Moore, II, MD

The UNC Family Medicine Center at Chapel Hill

590 Manning Drive

#### **Gastroenterologists**

Dr. Rory Kelly

Head of ADAPT, the new Hypermobility Clinic of Atrium Health's Levine Children's Specialty Center

Charlotte, NC

**Pediatrics** 

#### Dr. Baharak Moshiree

Atrium Health Gastroenterology and Hepatology - Morehead Medical Plaza

1025 Morehead Medical Drive Charlotte, NC 28204

Phone: 704-355-4593

PA: Mackenzie Jarvis

Known for working closely with patients to fit treatment plans to individual needs and lifestyle. Aware of how EDS impacts our lives and how unique each of us can present in our symptoms. Good for obvious GI diagnoses.

### Dr. Kenneth Kohagen

**UNC** Gastroenterology

Recommended by two patients with moderate GI issues. They were overall positive. More information will be added if it comes up in future.

#### Dr. Eli Penn

Beaufort Memorial Lowcountry Medical Group Specialty Care

300 Midtown Drive Beaufort, SC 29906

843-770-4588

Dr. Penn has EDS himself. Recently recruited to support the development of a new EDS clinic in South Carolina, in conjunction with Dr. Sunil Patel and the MUSC Genetics Research Center Norris Labs. Dr.

Penn is creative, multidisciplinary, and passionate about helping patients save money and time sussing out their GI symptoms. Dr. Penn advocates for mast cell control and low-histamine diet's in his treatment of patient GI issues.

#### **Urologists**

Dr. Robert Evans

Wake Forest Baptist Health with offices in Winston Salem and Greensboro. (patient note: appointments take time, and one might wait in the office longer than usual since he is in such demand that appointments with others tend to go longer. He will take as much time with you as he feels is needed, even an hour or more).

#### **Cardiologists**

Dr. Prosnitz, pediatric cardiology Sanger Heart and Vascular, pediatric Atrium Health, Charlotte Chief cardiologist of ADAPT

This physician KNOWS dysautonomia and EDS and will be thorough with evaluations. However, patients recommend that they go to appointments prepared with specific symptoms DIRECTLY related to cardiology rather than EDS as a whole. Symptom tracking with notes. The book Disjointed is very helpful in preparing for this type of doctor.

Dr. Sameh Mobarek UNC Cardiology

At present, Dr. Mobarek is the most experienced and knowledgable cardiologist for EDS patients in the state of North Carolina. Dr. M is an electrophysio cardiology specialist, multidisciplinary in understanding and approach to treating EDS patients, and has access to the tools for accurate diagnoses in most cases.

Cardio potentials awaiting further feedback from patients but are reported by at least 1 for diagnosis and treat in the EDS community.

Dr. Abdallah, Children's Heart Institute

**Dr. Ambati, Peak Cardiology** (ask to ONLY see Dr. Ambati, not a PA).

**Dr. Henry,** Baillard and Henry Pediatric Cardiology

Sanger Heart and Vascular, Atrium Health (Establishing new physicians who are expanding a department which include Ehlers-Danlos Syndromes. Search for Sanger Heart and Vascular, Aneurysm and Aortic Disease).

Carolina Functional Neurology Center 10235 Hickorywood Hill Ave Suite B, Huntersville, NC 28078

Very EDS and Dysautonomia aware and helped me a ton with Dysautonomia and working on anxiety/OCD as well.

## Psychology, Psychiatry and Behavioral Health

Dr. Allison Mikel, MD p: 919-378-9761 | f: 919-234-0494 admin@carypsychiatrycenter.com 1616 Evans Rd | Ste 105 | Cary, NC 27513

Knowledgable, caring, and invested in wholistically approaching mental health. Her practice offers psychiatry and neuropsychiatry and she is known for NOT turning away complex patients.

Dr. Katherine Peppers

Doctor of Nursing Practice

Pediatric Nurse Practitioner

Pediatric Mental Health Specialist

Behavioral and Developmental

Pediatrics

8358 Six Forks Road, Suite 203-204 Raleigh, NC 27615, 919-720-4000

Dr. Peppers comes highly recommended for pediatric EDS care. The mother recommending her said Dr. P was the first to suggest hEDS and an evaluation for POTS. She also provided an autism diagnosis for the young girl rather than minimizing symptoms and misdiagnosing in a way that traumatizes so many young women. Her practice has many essential services including nutritional disorders.

Jennifer Sutton Chronic Hope Counseling, PLLC 180 Mine Lake Court Suite b100 Raleigh, NC 27616 (984) 205-9321

From her website: If you are feeling overwhelmed or anxious about your pain, isolated, lonely or simply want to learn how to live your best life with your pain Chronic Hope Counseling is the place to be. We offer counseling services for those with chronic pain and illness. We help people learn to live beyond by getting them in their best place mentally. Jennifer Sutton struggles with chronic pain and has Ehlers Danlos Syndrome, this allows her to have a unique and empathetic approach to her counseling. We can help with anxiety, depression and everything that goes along with struggling with long term pain, we just look at it from a pain perspective.

Dr. Graham Hunter, PhD And Staff at QC Psychology 447 S. Sharon Amity Rd, Suite 140 Charlotte, NC 28211

qcpsych447@gmail.com

Office: 704-900-9143

Fax: 704-364-6267

QC offers testing and counseling for a myriad of conditions and

developmental disorders, including autism for both adults and children age 6+, male and female. Dr. Hunter is a neuropsychologist and father of children on the spectrum. His clinical staff also frequently have personal experience with challenges like ADHD and autism, and they are thorough, compassionate, and do their best to provide full services in timely manner. They also accept Medicaid for both testing and counseling services.

#### **Neurologists**

Dr. Charles Matthews, MD, PA
North Carolina Comprehensive
Headache Clinic – headache specialist
919-781-7423

(patient notes: Dr. Matthews is very familiar with EDS patients and patients post surgery for various conditions. He keeps himself educated about the multisystem manifestations in our condition, and understands what types of headache medications will be the most effective considering both dysautonomia and MCAS/MCAD. For patients concerned about CCI, cord tethering and small fiber neuropathy he will be insightful and able to direct to other specialists). Matthews does not accept insurance in order to provide more wholistic treatments for his EDS patients. It is very reasonably priced and highly effective treatment.

Appointments available within the month.

Dr. Sunil Patel
MUSC Charleston

Neurosurgeon/Spine Specialist

This specialist is the referral suggested by Dr. Spanos and many others brain and spine manifestations in EDS including: tethered cord, Chiari malformation, CSF leaks, intercranial hypo or hypertension and cranio-cervical instability, and more serious spine surgery needs. His office uses dynamic MRI imaging in Greenville, SC (Imaging Express) due to reliability of images. Dr. Patel has also authored and coauthored leading literature on the treatment of these conditions in the EDS population and trained with Dr. Henderson.

PA: Jared (Jared has great experience working with Patel, a non-black and white thinker. Intuitive, personal, and knowledgable. Does not care to have to repeat himself or answer questions that a patient could easily have found out about themselves through online sources. Jared has taken on a considerable amount of work in order to support the patient load of Dr. Patel. Please be kind to any nurse or assistant who works as hard as he does!).

LJ Neurology

Dr. Laura

Dr. Laura

#### **Pain Management**

Dr. Skye Margolies, PhD

UNC Hospitals Pain Management Center (Chapel Hill)

410 Market St. Southern Village Suite 362 Chapel Hill, NC 27516 (984) 974-6688

Assistant professor of anesthesiology. Specializes in pain management and holds a PhD in clinical psychology. Her approach to pain management is as a counselor, not just a prescriber. Dr. Skye works with her patients to help make lifestyle changes and adjust to the loses of activity and movement that come with chronic illness. She invests personally in each unique patient.

#### Rheumatology

Dr. Sheetal S. Vora

Levine Children's Specialty Center in South Park

ADAPT Hypermobility Clinic 4501 Cameron Valley Pkwy #300 Charlotte, NC 28211 Phone (984) 974-0499 Dr. Vora has been highly recommended by several mothers as a go-to guide for navigating EDS in their children. She is a part of the care team for the new hypermobility clinic at Atrium Health, and a physical therapist attends all new patient visits to help assess movement in children with EDS and potential autoimmune complications.

#### Arthritis and Osteoporosis Consultants of the Carolinas

This multifaceted clinic employs an incredible and diversely experienced staff. Multiple physicians have experience with mast cell involvement in autoimmune disorders, small fiber neuropathy, and the protective treatment of Ehlers-Danlos patients. In short EDS patients will not be turned away because they have EDS.

This clinic requires referral with clinical notes describing the need for rheumatological care. Dr. Heather Gladue has led the clinic in experience with hEDS and is thorough and comprehensive in her testing and care. Patients have same day access to xray and ultrasound, as well as comprehensive blood work.

1918 Randolph Rd Ste 600, Charlotte, NC 28207, Ballantyne location available as well.

Aocc.md

(704) 342-0252

#### Allergy and Immunology

NCAP – a new physician may be coming on soon to help with the patient load. Call to inquire

Dr. Iweala & Dr. Kwan

**UNC** Allergy and Immunology

Raleigh/Durham

(Both physicians work as a team to treat patients with MCAS/MCAD issues, an appointment with either is worth waiting for. They often see patients with hEDS/HSD and will treat symptoms. They are also familiar with Dr. Mobarek who has sent many potential EDS patients to them for care). Dr. Iweala is friendly and thorough. Dr. Kwan is detail oriented and direct. Visits with both will be improved if the patient has thought ahead of time, in detail, about MCAD/MCAS symptoms they experience. Patients will also have a chance to share how the other parts of EDS, rheumatological, neurological.

Dr. Frank Lichtenberger

Piedmont HealthCare

Allergy & Immunology

1525 Davie Ave.

Statesville, NC 2867

Phone: 704-873-5055

No detailed patient referral data at this time. Dr. L is reported to diagnose and treat MCAS and MCAD conditions in the hypermobility spectrum population.

Dr. Maeve O'Conner

Allergy Asthma & Immunology Relief of Charlotte

AAIR has three locations in and around the Charlotte area. Dr. O'Conner and her team focus on an integrative medicine approach to mast cell disorders and welcome hypermobility spectrum patients of all kinds. In addition to traditional allergy care, AIRR offers acupuncture, nutrition coaching and sublingual immunotherapy.

Read about Dr. O'Conner: <a href="https://www.aairofcharlotte.com/our-founder/">https://www.aairofcharlotte.com/our-founder/</a>

#### **Gynecology and Urogynecology**

Dr. Elizabeth Geller

UNC Urogynecology and Reconstructive Pelvic Surgery at REX

4325 Lake Boone Trail

Suite 315

Raleigh, NC 27607

(984) 974-0496

Phone: (984) 974-0499

Dr. Claire S. Bowles

Bradford Clinic, Charlotte NC

Thorough, and completely invested in her patients. Above and beyond to advocate and help patients receive specialty care and specific therapy referrals for female issues.

Dr. Cassandra Hornbuckle, DO
Granville Primary Care & OB/GYN
110 Professional Park Drive

Oxford, NC 27565

Phone: 919.693.6541

Like so many osteopathic trained physicians, Cassandra is open, creative, and skilled. She has a number of EDS patients in her care and is able to manage cycle difficulties, pelvic organ prolapse, and is reported to have ordered genetic testing in order to provide an EDS diagnosis for a patient.

Dr. Peter Sami Halib Novant Health Southeast OB/GYN (704) 321-1077

Report from complex patient: Knows about MTHFR gene mutants specifically 2 copies of C677T and how it relates to risk in family planning and working with PCP and cardio specialist for homocystine and cardiovascular health. He's in the know for basics of EDS in women's health and is searching more about it. Chiari he sees commonly and every case is different.

Dr. Lipscomb Novant Health Triad Ob/Gyn 2909 Maplewood Ave, Winston-Salem, NC 27103 Dr. Lipscomb is knowledgeable in MTHFR and other issues. He is learning about EDS and he is a great listener. "After years of being told all my symptoms were in my head he made me (and continues to make me) feel validated!" – EDS Patient

This practice also keeps a certified nurse midwife on staff and is dedicated to wholistic pro-life, profamily approach to women's care.

Dr. Scott Anderson Raleigh, NC

https://www.dukehealth.org/find-doctors-physicians/scott-gary-anderson-md

#### Multiple locations available

Dr. Scott is personally familiar with EDS. His wife is diagnosed Classical EDS. He is familiar with the complete picture of EDS and its co-conditions and prefers to take a whole picture of each patient, including POTS, MCAS/MCAD, and other skeletal, muscular, and neurological challenges the patient might be facing. Dr. Scott has relationships with multiple other providers for EDS patients needing specific referrals and supports proactive treatment for hypermobility symptoms regardless of official genetic confirmation which is nearly impossible for hypermobile EDSers to obtain.

## **Physical Therapists and Musculoskeletal Rehabilitation**

Susan Novak

Carolinas Rehabilitation - Union West 6048 Hwy 74 West Indian Trail, NC 28079 980-993-5540

Susan is a wonderful resource for hypermobility due her clinical interests in TMJ and vestibular rehabilitation. She has worked with EDS patients with spinal cord injuries and other manifestations. She is in the Atrium health network.

#### Joel Cabrera

Myo Durham Fitness and Physical Therapy

105 Hood St #4, Durham, NC 27701 919-695-3133

EDS knowledgeable, recommended by Dr. Spanos, Dr. Matthews and Dr. Patel in our region, as well as numerous patients. Custom treatment plans with modified Muldowny technique, osteopathic manipulation technique, dry needling and more. Emphasis on stability, decreased inflammation, increased functionality and independence. Joel can do an evaluation of hypermobility with Beighton Score, etc. Is knowledgable about the impact of MCAS/MCAD and POTS in EDS patients, whom he

has been treating and supporting for many years.

Cheri Courtright, PT

Head of the physical therapy department for

**Integrative Therapies** 

7E Oak Branch Drive

Greensboro, NC 27407

(336) 294-0910

Patient review: Cheri is EDS, POTS, Chiari, and CCI literate! She's also incredibly kind. They take BCBS and also do therapeutic massage, dry needling, craniosacral manipulation (not if you have Chiari!) and biofeedback.

Grace Tang, PT

Strive Physical Therapy & Fitness 5103 Grace Park Dr, Morrisville, NC 27560

#### (919) 467-4558

From another PT who treats EDS: She is a craniofacial certified PT and sees many patients with EDS. Always treats 1-on-1, 30 min appointments. She is a great choice for headache, neck and facial issues. dry needles, taping. Mostly manual with very little strengthening. Josh Olinick

Steps for Recovery

Cary, NC

Dysautonomia knowledgeable. Emphasizes posture and breathing technique, aware of EDS and vision issues among other neurological aggravations to the body.

Susan Chalela, MPT

Physical Therapy for EDS and hyper mobility, ergonomics, neuro, ortho, Pilates, posture, osteoporosis

Fyzical Therapy and Balance Center Charleston

125 River Landing Dr.

Suite 103

Daniel Island, SC 29492

http://www.fyzical.com/charleston 843-377-8210

schalela@fyzical.com

Chalela is the primary go-to PT for Dr. Sunil Patel's patients prior to his decisions to perform surgery.

Pediatric Boulevard, LLC

2814 Gray Fox Rd, Indian Trail, NC 28079

(704) 821-0568

The ladies at PB are warm, caring, and very experienced in children with special needs. Patients in the EDS community found therapists in occupation, physical and speech to be open, educable, and very helpful in

observing early symptoms and providing documentation for other physicians.

#### **Genticists**

Dr. Laurie Demmer

Levine Children's Specialty Center -Medical Genetics 1001 Blythe Blvd. Charlotte, NC 28203

Phone: 704-381-6810

Dr. Edwin Ferren

Levine Children's Specialty Center - Medical Genetics 1001 Blythe Blvd. Charlotte, NC 28203

**Phone:** 704-381-6810

Dr. Ferren is highly intelligent, focused, and able to retain a large quantity of information about his patients. He is very good at relating to children during examinations, and not afraid of questions from parents no matter how complicated, simple, or seemingly off topic. He understands the role of genetics in the human body and will be thorough in his approach to a child's condition. He does not like to diagnose EDS until children are approaching puberty due to the likelihood of other genetic conditions manifesting around that time and not wishing EDS to become a Go-To diagnosis among the child's other physicians as the cause of their problems.

#### **INVITAE**

https://www.invitae.com/en/individual
s/

A California based service offering general testing and specific testing such as the EDS diagnostic panel which can confirm or rule out vascular EDS. A kit is sent to your house. Professional genetic testing provided before, and after if needed. System is new to the public. INVITAE has been processing genetic testing from the University of North Carolina and other medical facilities for a number of years.

#### Ophthalmology and Vision Dysfunction

Dr. Steven Haleo, OD Vision Therapy Center of Charlotte

(Dr. Haleo is both a doctor of optometry and highly specialized in the diagnoses and treatment of binocular vision disorders which effect 90-95% of people on the autism spectrum, and over 20% of the general population in a manner which warrants therapy. hEDS is frequently associated with binocular vision disorders and therapy has been known to positively impact visual performance, eye pain, headaches, migraines, photo sensitivity and internal visual processing skills in our population).

3685 Center Circle Fort Mill, SC 29715 US 888-262-2020 704-973-0664

Nancy Mackowsky

http://www.drmackowsky.com/

Raleigh Location: 919-787-7600

Email Us:

jill.warren@drmackowsky.com

Neuro-developmental optometrist, broad spectrum care, EDS aware, vision therapy and complex visual disorders. Understands the neuroscience of how dysautonomia affects our brains and provides a variety of therapeutic options to reduce resulting anxiety, stress and even pain these conditions can cause.

Can be difficult to get a call back but keep trying. They are kind, just busy with many patients.

# Alternative Care; Acupuncture, chiropractic, functional medicine and more.

Dr. Vickie Jordan

Family First Chiropractic and Acupuncture

6303 Carmel Rd., Suite 101 Charlotte, NC 28226, US

704-541-4747

https://familyfirstchiropractor.com/

Dr. Jordan has extensive experience with treating patients with unique needs. She is certified in manual chiropractic techniques as well as activator (much more gentle for EDS), and acupuncture. Traditional Chinese method.

Atlas Orthogonal Chiropractic in Raleigh.

EDS safe chiropractor. Not an EDS expert but aware of it, and he only uses the activator for adjustments. Patient has worked with them for years. Very kind and professional staff.

EDS patients should always advocate for gentle treatment of the spine AND pay attention to your reactions! Uncontrolled mast cell inflammation in the spinal fluid, or conditions like Chiari and tethered cord may have strong adverse reactions to even the activator. In these cases, acupuncture and osteopathic manipulation therapy are recommended.

Melissa Dittmer,

Return to Wellness NC

Specializes in Orthopedic & Medical Massage, Trigger Point, Deep Tissue, Pre-Natal, Reiki, Chakra Clearing & Balancing, Aromatouch Technique.

Phone: (919) 999-0723

Email:

returntowellnesstm@gmail.com

Website:

www.returntowellnessnc.com

#### Dental, and Oral & Facial Surgery

Nathaniel Leedy Dentistry Specialization in Sedation Dentistry

Dr. Elizabeth Rushin is no longer practicing. It is not known whether or not her fellow providers are as good with EDS or not. Please let us know!

Provider is recommended by EDS patients with mild to moderate dental issues. Provider claims to be "a gentle and compassionate dental office."

Dr. Bobbie Stanley Stanley Dentistry Cary, North Carolina

Works with EDS patients, mild to severe issues, and claims to understand our needs in regards to daily care, anesthesia and other surgical interventions.

Dr. Erik Reitter

Carolina's Center for Oral and Facial Surgery, Billingsley Road office in Charlotte, or Lake Norman offices.

Specializes in TMJ and sees hypermobile patients regularly. Office can be difficult to deal with. Bright

lights and friendly staff but possible long waits. Dr. Reitter will evaluate and treat TMJ beginning with a mouth splint (mouth guard), and then other treatments like botox injections. Is interested in alternative methods for treating this condition. Understands anesthesia with EDS populations.

Dr. Joel J. Napenas, DDS Atrium Health Carolinas Center for Oral Health 1601 Abbey Pl, Charlotte, NC 28209 704-512-2110

Dr. Joel is EDS and Hypermobility aware. He uses a combination of traditional treatments and dry needling for TMJ, improving fascial dystonia, issues with chewing and swallowing, and overall wellness.

Dr. Tasha Hinton 2880 Slater Rd. #103 Morrisville, NC 27560 919-388-3719

Dr. Hinton has been recommended as an excellent EDS resource due to careful consideration of individual cases, and the option of sedation for treatment. Services include TMJ dentistry.

#### **Additional Valuable Resources**

The following websites have produced excellent FREE materials for the understanding and navigation of hypermobile spectrum disorders, and Ehlers-Danlos syndromes.

Dr. Alan Spanos, North Carolina

Dr. Spanos has spent more than twenty years of his medical practice focusing on complex connective tissue disorders. He does not regularly take new patients but has been invaluable in creating a network of providers in the research triangle who understand EDS and care for patients. These articles are for patients and FOR physicians who are educable.

www.alanspanosmd.com > Articles

The Mount States Regional Genetics Network serves a large portion of the west coast in the diagnosis and treatment of Ehlers-Danlos syndromes. The resources provided at this URL include a guide for beginners, and individual articles addressing all of our comorbidities.

<u>https://www.mountainstatesgenetics.</u> org/projects/eds-algorithm

#### Disjointed, ed. Diana Jovin

#### www.hiddenstripes.com

Disjointed is one of the only true patient manuals for HSD/hEDS, published in 2019. It contains over a dozen chapters by specialists who work with EDS patients on a daily basis as well as thorough charts for understanding what various specialists DO, HOW to prepare for appointments, and how to navigate disability. The specialists write on cardiology, allergy and immunology (though lacking in thorough treatments for MCAD/MCAS), extensive thoughts on pain management, spinal and cerebral complications, and more. Hard copy is \$50, ebook is around \$20.

Diana Jovin is a mother of a daughter with severe hEDS complications and wrote this book in the hopes that it would become a textbook for medical training, therapists and alternative care providers as well as a resource for patients. If you love this book and/or find that it needs MORE, please leave an honest review on Amazon. If you want to help further the mission of hEDS/HSD awareness, please take a moment to call your local library and submit a request for this book as well as email your recommendation to your current medical providers, school counselors, and local medical schools including but limited to; chiropractic,

functional medicine, occupational therapy, physical therapy, etc. Thank you. -Rachel Lee Davis

For free educational resources and connections please visit my website RachelLeePAC.com. This database is compiled by Rachel Lee Patient Advocacy Consulting, LLC. If you are a physician and wish to be recommended by us, please email your information to rachel@rachelleepac.com including a contact number where we can reach you for an interview.

Thank you! -RD