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.

Primary Care

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.

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.

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.

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

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.

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.

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. 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. 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. 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.

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. Very aware of how EDS impacts our lives and how unique each of us can present in our symptoms

(patient note: "She and her PA have been godsends."

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.

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 – the new hypermobility clinic arm of Levine Children's Specialty Center

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.

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

Dr. Joel Bumgarner, REX

Dr. Kronenburg, Wakefield

Dr. Abdallah, Children's Heart Institute

Dr. Frazier-Mills, Duke

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

Dr. Henry, Baillard and Henry Cardiology

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

Neurologists

Dr. Russ Bodner

Neurosciences Institute - Neurology Huntersville 9625 Northcross Center Court Huntersville, NC 28078 Phone: 704-403-1911

Dr. Bodner is a thorough and open neurologist who is familiar with autonomic disfunction, small fiber neuropathies, and neurological symptoms from MCAS/MCAD. He will say that he does NOT treat EDS (under current official definitions, EDS is a connective tissue disorder, not a neurological one). Bodner WILL take your entire history into consideration and test thoroughly suspected causes that other neurologists would avoid.

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 others for suspected tethered cord, Chiari malformation, CSF leaks, intercranial hypo or hypertension and craniocervical instability. 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!).

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.

Dr. Kinga Veruzchkey UNC general gen

Reportedly understands EDS and mast cell diseases and disorders.

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.

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

Dr. Doug Johnston, DO Carolina's Asthma and Allergy Charlotte, NC adult and pediatric

Johnston has a lifelong personal vested interest in complex immunological disorders. Both he and his daughter have been impacted by them, and he says it has shaped his career. He is attentive, reasonable, listens to his patients and is willing to learn. He is also an osteopathic doctor and views the bodies systems a whole.

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. Mauve 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: https://www.aairofcharlotte.com/ourfounder/

Eye, Ear, Nose and Throat

Dr. Heavner

Charlotte Eye, Ear, Nose and Throat Charlotte, NC Steele Creek office

Throat specialist who sub specializes in vocalists and patients who use their voices often for speaking in their careers. He is very familiar with EDS/HSD/hEDS and it's impact on the throat, both vocally and with motility. He will take time to look and test, and set you up with specialized vocal therapists if needed.

Dr. Matthew Ellison

Duke Otolaryngology, ENT

Dr. Ellison has been recommended by three patients with glowing reviews. They report that he is kind, knowledgable about dysautonomia, actively pursues alternatives to surgeries and is an excellent surgeon.

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.

Physical Therapists and Musculoskeletal Rehabilitation

Laurel Mogensen

Carolinas Rehabilitation Pediatric Therapy - Wendover 427 Wendover Road Charlotte, NC 28211

Phone: <u>704-304-0620</u>

Dr. Sonya Rissmiller, MD

704-863-4878

Atrium Health Musculoskeletal Institute Sports Medicine Randolph

3030 Randolph Road

Suite 105-B

Charlotte, NC 28211

Dr. Sonya comes recommended by EDS patients with spinal injuries and complications related to hypermobility. She has a special interest in Ehlers-Danlos and hypermobility syndromes and is aware of the many comorbidities that complicate movement. She works with acupuncture and myofascial release among other techniques.

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 and 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.

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, does graston, taping. Mostly manual with very little strengthening. So a good option for pain relief but not for long term 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.

South Carolina

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.

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: <u>704-381-6810</u>

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.

Orthopedic Surgeons

Dr. Hillsgrove, knees OrthoCarolina

OrthoCarolina Hip and Knee Center Charlotte (Former employee recommends Dr. Walter Beaver, Dr. Mason or Dr. Springer).

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.

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.

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 comorbitities.

https://www.mountainstatesgenetics. org/projects/eds-algorithm

Disjointed, ed. Diana Jovin www.hiddenstripes.com

Disjointed is one of the only true <u>patient</u> 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. Kindle version has arrived! https://hiddenstripes.com/

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