

Central New Jersey EDS Support Group

2014

Developed and Presented by
EDSers United
www.EDSers.org

The Benefits of an EDS Support Group

“None of us, including me, ever do great things. But we can all do small things, with great love, and together we can do something wonderful.”

- Mother Teresa



DEFINITION OF SUPPORT That which upholds, sustains, or keeps from falling, as a prop, a pillar, or a foundation of any kind.

- Creates an arena to discuss feelings and increase personal empowerment
- Provides education
- Enhances networking and identification of resources
- Reinforces health, safety, and prevention message
- Creates an atmosphere of camaraderie and redirects focus from self to others
- Gives group facilitator a venue to reach a group of people and to follow-up with group members for a common cause.

According to David Spiegel, an author who has conducted landmark research on support groups.

- 1) *Support groups can improve quality of life – reduce anxiety and depression, increase coping skills, and help symptom management*
- 2) *A thorough understanding of illness affects physical and psychosocial factors that affect response to treatment and resistance to disease progression*
- 3) *The most effective techniques involve facing the illness directly*
- 4) *There is no evidence that these techniques will cure an illness, but there is evidence that these may prolong life with cancer, heart disease, and other chronic diseases**

(*Excerpt from *Living Beyond Limits* by David Spiegel)

Mission Statement:

The mission of the EDSers United: Central New Jersey EDS Support Group is to offer education and support to those who have been diagnosed and/or suspect diagnosis of Ehlers-Danlos Syndrome and other related conditions. The purpose of the group is to provide a safe, open, and non-judgmental environment to discuss Ehlers-Danlos Syndrome, related conditions and co-morbidities, and its impact on our lives.

Ground Rules:

- Confidentiality is of the utmost importance, so what is shared in this group, stays in this group.
- Please put cell phones on silent or vibrate
- Please respect everyone's moment to share and wait until they are finished sharing in order to begin speaking. Please avoid interruptions and side conversations.
- This group is composed primarily of people with or suspected to have EDS as well as their family and friends so we ask all attendees to strive to be non-judgmental and accepting of others
- Try to arrive on time, stay entire time, and end on time. We understand life happens and that our bodies don't always cooperate so we appreciate the attempt to arrive on time, but we don't hold you to it.

Type of Group:

Hybrid of Social and personal support and networking with emotional support and education.

Who Does The Group Serve?

The local community of individuals affected by Ehlers-Danlos Syndrome and similar conditions. Those affected include those who have been diagnosed, those who have yet to be diagnosed, and the friends, family, and support systems of those born with this condition.

Basic Format of Meeting:

1. Sign-in when you arrive
2. Welcome and optional quick self-introductions (~15 minutes)
3. Support session: share more detail about personal updates, stories, issues, etc. (~1hr)
4. Refreshment Break (30-45 minutes)
5. Main topic or speaker presentation (30-45 minutes)
6. Closing Feedback and announcements (10-15 minutes)

A Great Resource to read up on forming, managing, and maintaining friendships is <http://www.psychologytoday.com/basics/friends>

Friendships: Enrich your life and improve your health

By Mayo Clinic Staff

Friendships can have a major impact on your health and well-being, but it's not always easy to build or maintain friendships. Understand the importance of friendships in your life and what you can do to develop and nurture friendships.

What are the benefits of friendships?

Good friends are good for your health. Friends can help you celebrate good times and provide support during bad times. Friends prevent loneliness and give you a chance to offer needed companionship, too. Friends can also:

1. Increase your sense of belonging and purpose
2. Boost your happiness and reduce your stress
3. Improve your self-confidence and self-worth
4. Help you cope with traumas, such as divorce, serious illness, job loss or the death of a loved one
5. Encourage you to change or avoid unhealthy lifestyle habits, such as excessive drinking or lack of exercise

Why is it sometimes hard to make friends or maintain friendships?

Many adults find it hard to develop new friendships or keep up existing friendships. Friendships may take a back seat to other priorities, such as work or caring for children or aging parents. You and your friends may have grown apart due to changes in your lives or interests. Or maybe you've moved to a new community and haven't yet found a way to meet people.

Developing and maintaining good friendships takes effort. The enjoyment and comfort friendship can provide, however, makes the investment worthwhile.

What's a healthy number of friends?

Quality counts more than quantity. While it's good to cultivate a diverse network of friends and acquaintances, you also want to nurture a few truly close friends who will be there for you through thick and thin.

NJ EDS SUPPORT GROUP DOCTOR LIST

Specialty	Name	Address	Phone Number
Allergy/Asthma	Dr. Eric W. Bantz	103 Old Marlton Pike. Suite 211, Medford, NJ 08055	(609) 953-9085
Bracing/Prosthetics	Lawall and Sons Prosthetics	86 Franklin Corner Rd. Lawrenceville, NJ 08648	(609) 895-1141
Cardiology	Dr. Nicholas Tullo	741 North Ridgefield Ave. Suite 205, West Orange, NJ 07052	(973) 467-1544
Gastroenterology	Dr. Li Thomas	2231 Lemoine Ave. Fort Lee, NJ 07024	(201) 944-1008
Gastroenterology	Dr. Aditi Chhada	130 Kinderkamack Rd. Suite 301 River Edge, NJ 07661	(201) 489-7772
Genetics	Dr. Punita Gupta	703 Main Street Paterson, NJ 07503	(973) 754-2727
Genetics	Dr. Susan Brook	89 French Street, 2 nd Floor New Brunswick, NJ 08901	(732) 235-6230
Nephrology	Dr. Prasad G. Acharya	1025 Briggs Road Suite 148, Mount Laurel, NJ 08054	(856) 222-1975
Nephrology	Ocean Renal Associates	1146 Beacon Ave. Manahawken,	(609) 978-9740

		NJ 08050	
Nephrology	Dr. Daniel Brouder	308 Lakehurst Rd. Suite 34, Toms River, NJ 08753	(732) 341-4600
Nephrology	Dr. Syed Raza	20 Prospect Ave. Suite 709 Hackensack, NJ 07601	(201) 678-0300
Physical Therapy	Frank Previte	1130 US 202 Raritan NJ 08869	(908) 725-9595
Podiatry	Dr. Dana Webb	720 Highway US 202/206 Bridgewater, NJ 08807	(908) 704-8778
Rheumatology	Dr. Kimel	1415 Queen Anne Rd. Teaneck, NJ 07666	(201) 837-7788
Sports medicine	Dr. Jeffrey Rosenberg	1 Diamond Hill Rd. Berkley Heights, NJ 07922	(973) 429-6577

Out of State Recommended Doctors

Specialty/State	Name	Address	Phone Number
Hip Surgeon/NY	Dr. Bryan Kelly	541 East 71 st St. New York, NY 10021	(212) 606-1159
Hip Surgeon/NY	Dr. Ernest Sink	541 East 71 st St. New York, NY 10021	(212) 606-1268
Reconstructive Surgery/NY	Dr. Lloyd Gayle	50 East 69 th St. New York, NY 10021	(212) 452-5121
Pediatrics/OH (has several families with EDS in his practice)	Dr. Phillip Simon	110 Polaris Pkwy., Westerville, OH 43082	(614) 865-4800
Geneticist	Dr. Howard Levy	10753 Falls Rd. Suite 325 Lutherville, MD 21093	(410) 583-2774