

Start an EDS Support Group + Raise EDS Awareness = Friends and Doctors Who "Get It"!

BY: SHANI WEBER, M.S.

Why have a support group?

To provide support for those with EDS or HSD and those who love us!

It's **not** about members...

- Complaining
- Whining
- Feeling powerless
- Depressed

Who needs more of that!





During a support group meeting...

Members:

- Interact with others like themselves
- Describe challenges
- Work as a group for solutions
- Learn from group members and speakers better ways to live with Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorders (HSD)

EDS and HSD Support Groups...

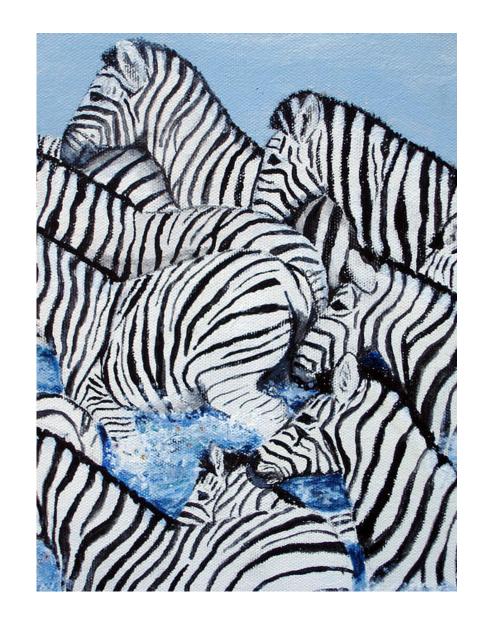
Are independent and unique

Reflect the members' interests and skills

May be small or large

Can be run how you want





An EDS Support Group

Is more like a family than a business

Is a great gift for your community

Can be easy and fun to lead

Beyond support, what else can we do?

- Mentors for the newly-diagnosed
- Public and medical profession awareness/education
- •Fundraising for the EDS and HSD community and research needs
- Political advocacy



Where can we hold support group meetings?

- Think carefully each venue has pros and cons
- Private homes of our members?
- Public settings?





Possible Public Spaces for Meetings



- Community center
- Office meeting room
- Library
- Hospital
- Church
- Business
- Restaurant

Holding Meetings in Private Homes

PROS

- Privacy for discussions
- A level of comfort
- "Always" available



CONS

- Rarely wheelchair accessible
- Parking may be inadequate
- May contain pets or cleaning products that trigger allergies or MCAS reactions

Holding Meetings in Public Spaces

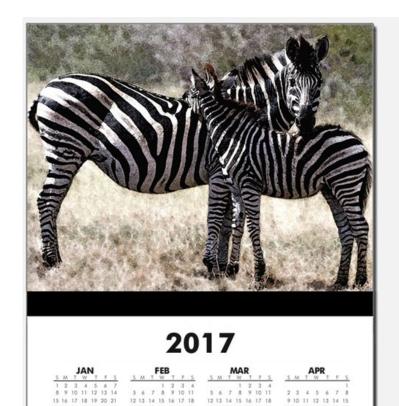
PROS

- Adequate space
- Wheelchair accessible
- Adequate parking
- Less intimidating for newcomers
- Often easier to find

CONS

- Less privacy
- Can be challenging to schedule space
- Seating may be less comfortable





How often should we meet?

- Depends on the goals and the needs of your community
- Can meet monthly, every other month or quarterly
- Consider alternating formal meetings with social get-togethers

Keep in mind your own well being!

How do we get people to join?

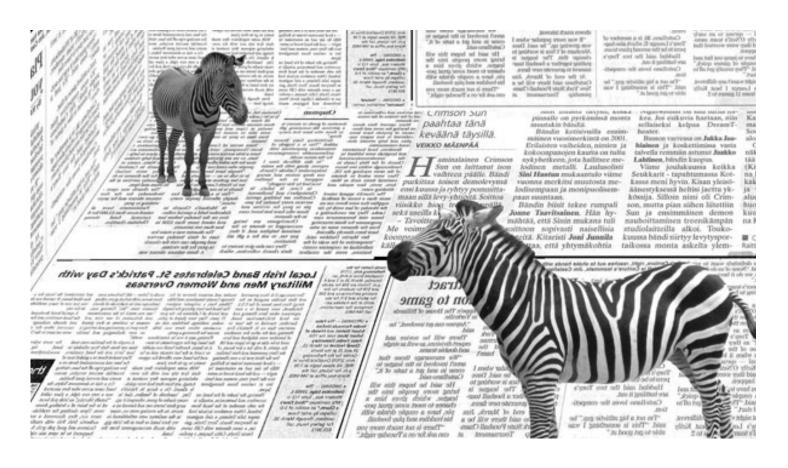
 List your group on the Ehlers-Danlos Society's website https://ehlers-danlos.com/support-groups/

•Write a post announcing your meetings on our message board

https://www.inspire.com/groups/ehlers-danlos-syndromesand-related-disorders/

Announce your meetings on our Facebook page https://www.facebook.com/ehlers.danlos/



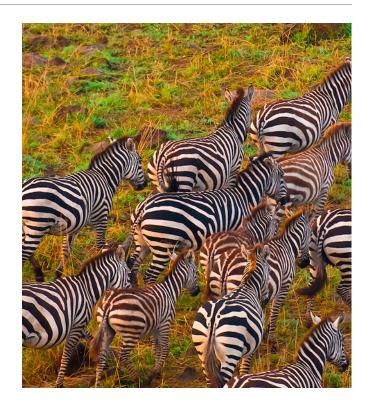


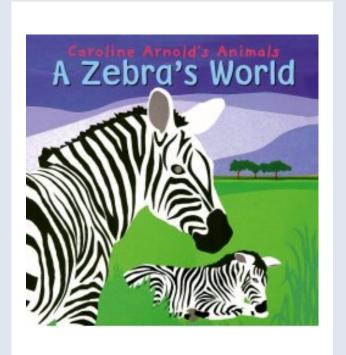
Other Places to Advertise Your Group

- Advertise in local newspapers, hospital newsletters, or health magazines
- Use on-line resources such as Craigslist and www.meetup.com
- Inform local doctors, hospitals, and therapists about your support group

What Might a Meeting Look Like?

- Introduce the leader(s)
- In small groups, introduce everyone; but in large groups, use nametags
- New announcements/information







Host a "Show & Tell"

Encourage members to bring something that helps them live better with EDS and HSD. It may be a new book, an app they found to track symptoms, a great brace, or a kitchen gadget that helps them prepare food. When seated in a circle, allow each member who brought an item to show it to the group and talk about it, including how others can find it. Be sure to take notes so that the Show & Tell items can be written up and emailed to all group members.

Share Information about Doctors and Other Resources

- Provide ways for members to discuss local doctors and therapists or to ask questions, e.g. Google or Facebook groups or email lists
- Compile an updatable, sharable Doctors List
- Provide ways members can arrange carpools to meetings
- Announce upcoming events such as Disability Expos, Rare Disease Day events, Conferences, or opportunities to advocate





Leave time for...

- Shared experiences
- Members' successes and challenges
- Breaks ~ mingling matters!
 - Form friendships
 - Ask specific questions of others
 - Exchange contact information

More ideas for great meetings

The goals of your group dictate the agenda for your meetings.

- Host speakers, e.g. doctors, therapists
- Plan social events
- Organize a fundraiser
- Discuss important topics for your members, e.g. advocating for effective pain management options



Remember to...



- Consider accessibility needs ~ wheelchairs, canes, walkers
- Have snacks and water at meetings ~ be aware of
 GI issues and food intolerances, so label ingredients
- Restrict use of perfumes, lotions, or allergy products
- Encourage members to listen to each other and have one speaker at a time



How to Sustain Your Group Have Co-leaders!

Having two leaders means:

- Less work for each person
- More fun
- A backup when one leader is busy or not well

A Support Group Provides...

- Answers ~ They are so hard to find.
- Validation ~ We're not crazy!
- Friends ~ Join people who "get" us.
- <u>Fun</u> ~ Makes life worth living!



Raise EDS and HSD Awareness

Zebra

Equus quagga



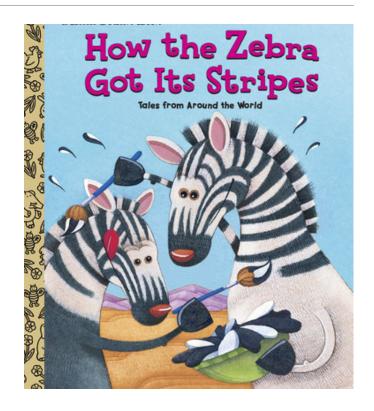
ww.exploringnature.org

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Share Your Story

Living with EDS or HSD gives you experience and expertise. Telling your story creates greater awareness and understanding.

- What is life like with EDS or HSD?
- What is it like to dislocate unpredictably?
- What is it like living with both chronic and acute pain?





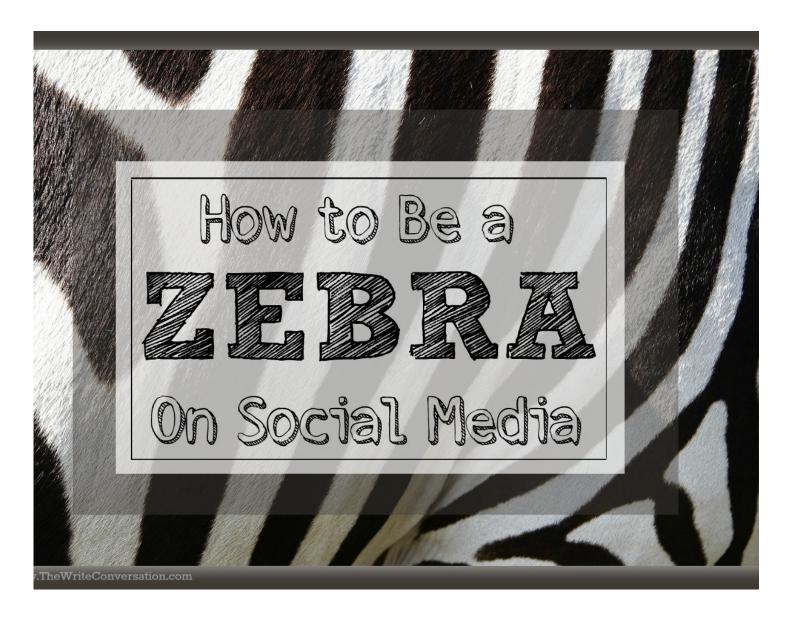
Places to share your story

- Volunteer to be a practice patient at a teaching hospital
- Attend a conference on medical issues and talk with speakers and attendees
- Ask your doctor how to reach out to colleagues

There are many ways to raise EDS and HSD Awareness ~ Organize Educational Events



- a meet-and-greet at your local hospital
- a presentation at your local schools
- a workshop with area physical therapists
- an information table at a local health fair or disability expo



Use Social Media

Share EDS Information on:

- Facebook
- Twitter
- Instagram
- Snapchat
- Pinterest
- Blogs

Leave EDS and HSD Brochures at:

Doctors' Offices

Physical Therapy Practices

Hospital Waiting Rooms

Medical Schools

Public Schools

https://ehlers-danlos.com/wp-content/uploads/WhatAreEDS2017-USletter.pdf

https://ehlers-danlos.com/wp-content/uploads/WhatAreHSD2017-USletter.pdf



Plan a Fundraiser

- Host an Art Exhibit of EDS and HSD-related projects your support group makes to sell or auction
- Plan a 5k Walk with participants getting sponsors
- Sell T-shirts, car magnets, cups or other items with "Ehlers-Danlos Syndrome" and "Hypermobility Spectrum Disorders" on them (raises awareness and money)
- Arrange a Comedy Night or other event ~ attendees' fees are donated

Some support groups donate to The Ehlers-Danlos Society for our mission, Circle of Hope, or Center for Research and Clinical Care.

Others fundraise to send a member or local doctor to the annual EDS Conference





Have a Video Contest

Ask for short video submissions about EDS and HSD

Use a committee to choose the winners

Have EDS support group members, their family members, and friends share the winning EDS and HSD Awareness videos through their social media

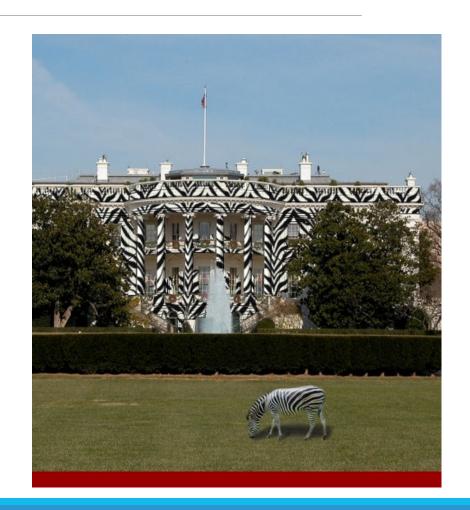
Raise Awareness with Our Government

Write letters and emails to elected and government officials about how their decisions affect our EDS and HSD community

Attend Lobby Days and explain to your Representatives how they can help our community

Speak at Public Hearings for or against proposed legislation affecting our community

With each of these, explain simply what Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders are and refer them to www.Ehlers-Danlos.com for more information.





Teachable Moments to Raise Awareness

- Person glaring as you park in a handicap space
- Interactions with your doctors
- Get-togethers with family and friends
- Serendipitous moments in public
- Commenting in online articles and forums
- Speaking or writing opportunities in larger venues



Our Time Is Now

Any moment can bring an opportunity to raise EDS and HSD awareness and increase education...let's be ready!

Thank You!

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