

Facebook Posts for Ehlers-Danlos Society

I am in no way affiliated with the EDS Society. This was a project assigned to me in my Social Media in the Workplace class. It was meant to be a relatively small project, but I went above and beyond because of my love and respect for the organization. I was diagnosed with HEDS when I was sixteen years old and I continue to struggle with its complications to this day, but the EDS society gives us hope that one day we may find a treatment plan that works. This is the piece I am most proud of in my portfolio and every mock-post is handled, created and edited with love and care. Thank you to the EDS Society for its amazing work and I hope these posts gives you a glimpse into how great social media can be when someone is passionate about a project.

Living with HEDS webinar (December 5th, 2018)

Living with any chronic illness can be exhausting and frightening. Join us for weekly EDS webinars designed specifically to help inform you of the disorder. On March 6, we have a webinar talking about some of the most common gynecological complications involved with Ehlers-Danlos Hypermobility Syndrome with Natalie Blagowidow, MD. For more information visit our [website](#).

EDS Zebra Helpline (December 7th, 2018)

Let's be real, having EDS can be extremely painful, and if that wasn't bad enough, it could cause numerous complications both physical and mental. We here at the Ehlers-Danlos Society know this disorder can cause us to feel hopeless, lost, depressed and aggravated. Remember these feelings are always valid whether related to specific events or chronic complications. We never want you to feel alone! Zebras deserve a safe place for them to voice their feelings with people who understand.



The EDS Zebra Helpline was designed for Zebras by Zebras (Even the writer of these posts has it!) to help you continue to fight every day like you always have. Discussions can include, diagnosis frustration, complex chronic pain/exhaustion, past or present health complications,

fear, work (whether that be school, college or your occupation) and relationships. EDS hurts but at least there is a place where you don't have to hurt alone. Visit our [website](#) to start talking to someone just like you.

Donate/Volunteer (December 11th, 2019)

Please help us raise awareness for EDS by donating our volunteering. Any donations help us fund everything from our research teams to our charity events Any little bit helps and if you cannot donate money, donate some time by reposting this to your board or volunteering at some of our amazing charity events.



Research! (December 14th, 2019)

The Ehlers-Danlos Society is the leading coordinator and supporter for EDS research organizations and teams. Some of our greatest research teams are working together to help pave the road towards a cure! Some research teams are working on finding gene malformations related to HEDS, nutritional guides, and better pain management options. We could not have done this without the amazing help from people like yourself. We have much appreciation for Jamie Goldenberg for her donation of \$5,000 and to all others who donated. New EDS findings are happening every day, so please visit our [website](#) for the newest information on the disorder as we push towards better prevention, treatment and possibly even a future cure.

Video of the Day (December 17th, 2018)

Ever wonder why EDS patients are called Zebras? Watch the video below to find out why. This video is posted on our Youtube Channel. You can reach the channel by clicking [here!](#)



WHY THE ZEBRA?

Great Quote of the Week (December 21st, 2018)

"I know you're sad, so I won't tell you 'have a good day'. Instead, I advise you to simply 'have a day'. Stay alive, feed yourself well, wear comfortable clothes, and don't give up on yourself just yet. It'll be better soon. Until then, **have a day.**"
-Unknown

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For more helpful quotes and information visit our [website!](#)

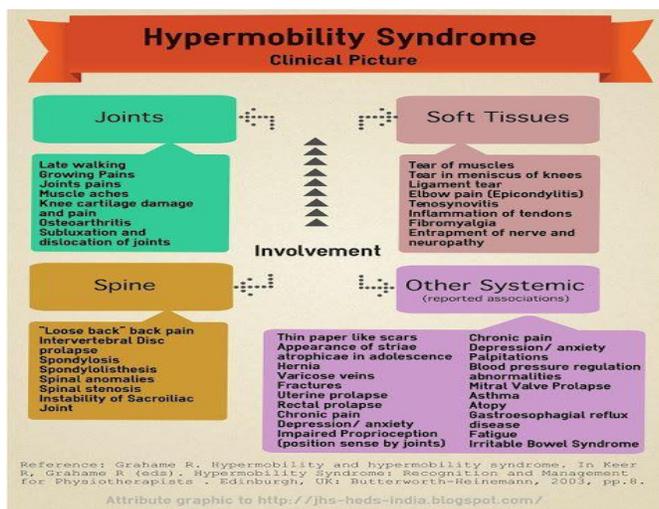
Ehlers-Danlos Hypermobility Awareness Month (Jan 1, 2019)

HEDS (Ehlers-Danlos Hypermobility Syndrome) is the most common form of EDS in the world and is strangely the most misunderstood. Did you know that most people with HEDS don't have stretchy skin? Its true and many doctors still don't realize this! Join us for a full month of HEDS information, tips and emotional support as we push towards better treatment plans!

What is HEDS? (January 8th , 2019)

Ehlers-Danlos Syndrome is an extremely complex syndrome with various types. HEDS stands for one of these types, known as Hypermobility - Ehlers-Danlos Syndrome.

This is actually one of the most common genetic connective tissue disorder in the world and is characterized by joint flexibility and pain, autonomic disorders (Like POTS), immunological disorders (like MCAS), gastro-disorders (like Gastroparesis, leaky gut and IBS) and much more. Below is a quick diagram to show you some of the other complications.



Because the disorder spans many different kinds of medical fields like neurological, immunological, gastroenterological, and rheumatological specialty areas, many doctors specialize specifically in HEDS and have knowledge of all the different kinds of systems that co-exist with the syndrome. Finally, more doctors are starting to specialize specifically in HEDS. For example, Dr. Saperstein at Complex Neurology in Scottsdale, Arizona, specializes in HEDS, POTS (cardiovascular) and MCAS (immunology) even though he is considered a neurologist.

Please visit our [website](#) for more information about HEDS. If you already have HEDS, we at the Ehlers-Danlos Society suggest meeting with a HEDS specialist in your area. There are limited options right now but just wait a few years, and we are certain the numbers will at least double. Until then, keep fighting Zebra warriors!

HEDS exercises (January 15th , 2019)

As we have said many times on prior posts, HEDS hurts a lot. The chronic pain can make it almost impossible for anyone to exercise or at least what your not-chronically-sick friends tell you is exercise. But we at the Ehlers-Danlos Society have grouped together some great workout techniques to help you guys get the necessary exercise you need without ruining those joints that cause you so much grief. For more techniques, please visit our Instagram or Pinterest page for more visuals and guides.

Zebra Exercise Tips

Do

- Exercise muscles to protect joints
- Practice cardio for heart health
- Protect joints during exercise
- Closed circuit exercises
- Exercises at the appropriate level
- Protect your neck
- Stay hydrated
- Workout 4-5x/week
- Eat clean, healthy foods
- Add to your challenge as you grow

Avoid

- Stretching before exercising
- Participating in high impact activities such as jumping, running, boxing
- Performing open circuit exercise
- Overextending joints
- Overdoing it and becoming fatigued or sore
- Taking more than one day off at a time

The Zebra Pit <http://zebrapit.com>

[Link to This Exercise](#)

Core Exercises

The Zebra Pit <http://zebrapit.com>

Pelvic Tilts

Pelvic Lifts

Benefits:

- Strengthens abdominals, pelvis, buttocks, hips & lower back
- Relieves Pain from disc deterioration & spinal stenosis
- Aids posture
- Improves balance & stability

[Link to This Exercise](#)

POTS (January 22nd , 2019)

POTS (Posterior Orthostatic Tachycardia Syndrome) is the number one most common co-existing complication alongside HEDS. As a matter of fact, many EDS specialists use a POTS diagnosis to help diagnose EDS. The two almost always coexist together in some fashion, so it is important we at the EDS Society make sure you are informed.

POTS is a condition that is caused by stress and dysfunction in the nervous system. It causes the body's blood pressure homeostasis to be disturbed, and symptoms can vary depending on changes in weather, position, temperature and emotional or physical wellbeing. Usually, the system is just temporarily disturbed (seconds to minutes); however, some conditions like Vasculitis and MCAS can create long-lasting or permanent blood pressure difficulties.

Symptoms can range from patient to patient. However, common symptoms are Tachycardia (fast heartbeat), low/high blood pressure and dizziness while standing, Syncope (passing out),

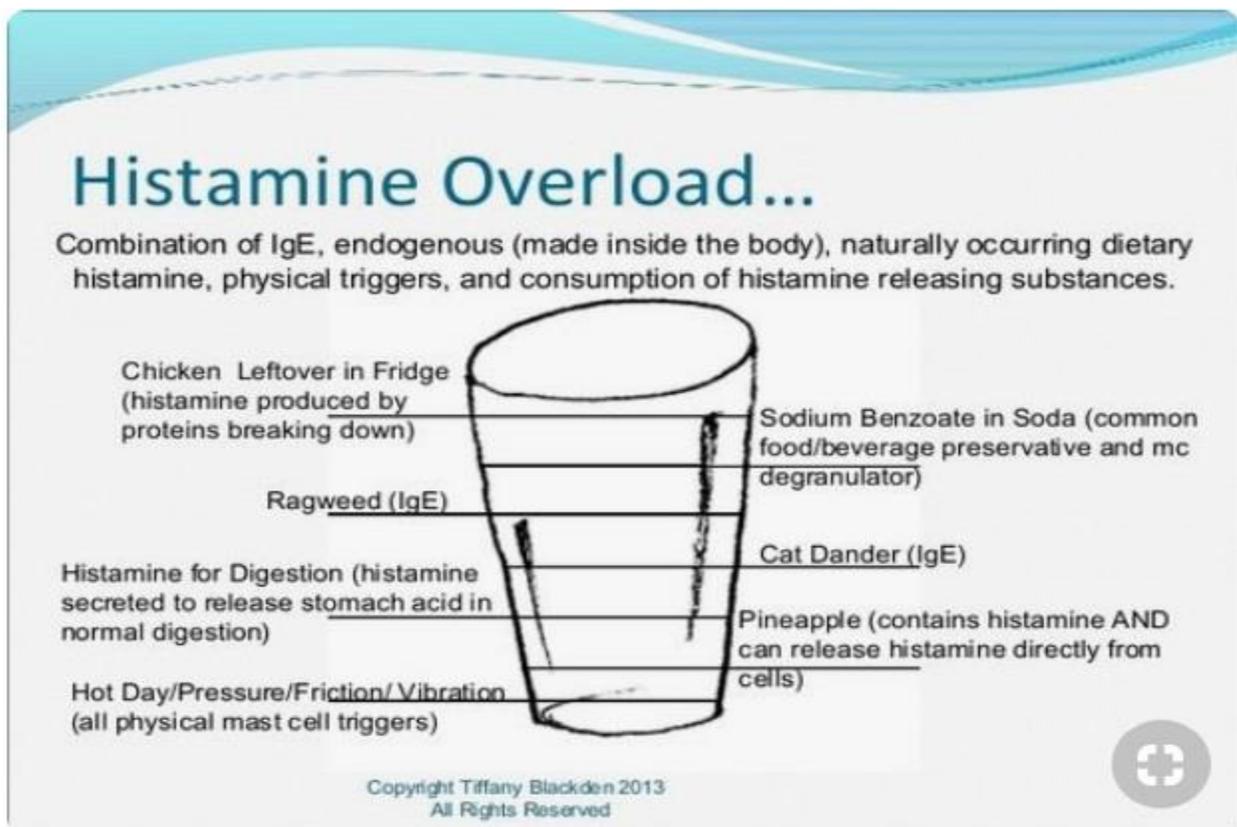
low or high blood pressure (dependent on what type), sweating, fatigue, temperature intolerance and much more.

For more information about POTS including doctors, diagnosis and treatment, visit our [website!](#)

MCAS (Mast Cell Activation Syndrome) (January 15th, 2019)

Histamine is our body's first natural defense towards pretty much anything, and even stress can cause histamine flares! Us at the EDS Society believe that everyone (EDS or not) should be informed on this swiftly increasing disorder especially for those recently diagnosed with HEDS since they co-exist very frequently.

Mast Cell Activation Syndrome is caused by rogue Mast Cells overreacting and producing way too much histamine. They can overact to pretty much anything you come into contact with, and can sometimes even be triggered by different culprits day to day. Common triggers are listed below.



Symptoms can include, itchiness, rashes, sneezing, coughing, acid reflux, bone/muscle pain, anxiety, depression, redness/swelling, and even anaphylaxis. This disorder can range from unnoticeable (mistaken for common everyday allergies) to extremely dangerous! This is why it is so important to watch out for the signs and be proactive. For more information click [here!](#)

Pain Management Tips (January 29th, 2010)

HEDS (Ehlers-Danlos Hypermobility type) can be incredibly frustrating! Not only does it create a bucket-load of complications but can also cause chronic pain both mentally and physically. The Ehlers-Danlos Society was created to help zebras live their best lives possible and thus we have listed a couple of pain techniques we know will help you. Please visit our website for other tips!

Tip: Give yourself adequate downtime to recover if possible. If not possible, try to make it possible in the future or as soon as you can. Your body needs a lot more time to recover from basic daily activities because pain is exhausting. It takes a lot of energy to overcome chronic pain and doing things like chores, work, and school work. Even things like getting up, taking a shower, and brushing your teeth can be stressful. So, listen to yourself and rest when you can.

We are a Dazzle of Zebras! So keep on going! There is always tomorrow.

Citations

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Social Media Content Paper

The Ehlers-Danlos Society is an organization designed to help inform, comfort and prepare Ehlers-Danlos patients and their families, as well as help, inform the medical community. They have a website that

receives adequate attraction across Facebook but does not have a specific Facebook group. I feel with the success of the website and the attraction it receives; they could benefit from promoting their website via Facebook by either creating their own individual group/organization or even creating promotional posts.

Post timing can range immensely in theory but is limited by a couple of factors including budget, staff, and content. This is completely dependent on statistics that are not easily found like the number of employees on any given day and how much time they need to spend on each post. However, following traditional post timing for other illness societies, I designed post updates to be released around one to two times a week depending on the events at the time and the amount of time each post takes to outline, draft, edit and finalize.

In terms of consistency, topics are all based on the most common questions surrounding the disease (What is __, Exercise techniques), emotional support (Quotes of the day, Pain Management Techniques), and information on the EDS society itself (Donations, Webinars, Research). All posts fall into one of these categories and the overlying goal of the EDS society's Facebook Page, to promote the website but doing so without coming off as forced. With this being said, some of the posts may have similar phrases like "click here" or "visit the website" but I tried to vary the word choice, so they don't come off as repetitive.

Posts range from brief to lengthy based on the amount of content necessary to explain the topic. I thoroughly examined post length and found that there are more lengthy posts than shorter ones. I think this is appropriate for the EDS Society's goal of informing the public on the disorder. Posts with informational topics are bound to be longer just based on structure alone, and they need to be able to explain the topic and promote the website which can take several paragraphs on its own. Likewise, emotional support texts do not have to be explained in as much detail, so they can be much shorter. I do believe I organized the length in such a way that the structure doesn't come off as tedious or wordy.

I attempted to variate visual elements as much as necessary. These all fall into the picture, chart or video category but all are unique in some fashion. They do not have similar color patterns, designs or word usage but all seem to fit into the organization's overall style guide, mainly in the language department. Some are even straight from the society's other social media platforms like Youtube and Pinterest. This makes each element unique but familiar to the user, making them more likely to continually read post updates which align up with the overall goal of the organization nicely. In terms of why some posts have visual elements, and some don't is based on need. Some posts are so lengthy that they need pictures or images to break up paragraphs, so the post doesn't overwhelm the reader. It is proven that big walls of text make readers uncomfortable which can lead them to move onto another post. However, I did not want to put in unnecessary images in posts that can stand alone without coming off as unfinished.

The overall goal of the EDS Societies Facebook Page is to promote the website and their other social media platforms like Pinterest and Youtube. This means that posts are designed to give just enough

information to peak interest in readers but not so much that they feel satisfied to stay on the Facebook page only. This is a challenging goal to quantify or strategize but its usually best to give the most relatable information first. This may come off as slightly “clickbaity” as they call it, but I tried my best to make it not cringe-worthy or apparent.

Finally, Facebook promotional posts are usually longer than a paragraph, unlike Twitter or Instagram which stick to a few sentences. This allows a lot more flexibility when it comes to creating posts for the platform. Facebook does not have any word count, time limits or anything else that could limit a post. However, each post is designed to convey information as quickly and accurately as possible since a reader’s attention span is generally limited especially on a platform with as much content as Facebook.