



The  
Ehlers  
Danlos  
Society

**EDS&HSD**

*Awareness*

**MONTH 2026**

# Fundraising Pack



[Click Here to Start Your Fundraiser](#)



Set up your page, share your story, and start raising funds in minutes.



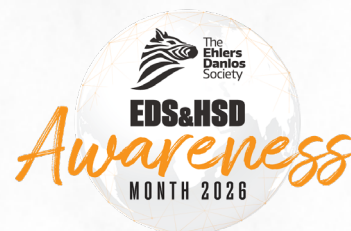
**The Ehlers-Danlos Society**

**UK:** Office 7 | 35-37 Ludgate Hill | London | EC4M 7JN **US:** 447 Broadway | 2nd FL #670 | New York | NY 10013

**Charity Number:** 1180984

**✉ Giving@ehlers-danlos.com**

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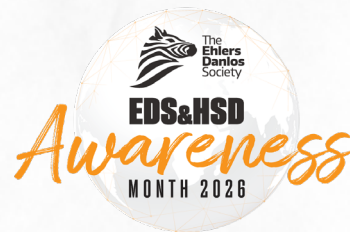
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# | Welcome



Welcome to our EDS and HSD May Awareness Month Campaign and thank you for standing alongside us. Your interest and support mean more than words can fully express—to our organization and to the individuals and families affected by Ehlers-Danlos syndromes and hypermobility spectrum disorders.

Our mission is to improve the lives of people living with Ehlers-Danlos syndrome through education, research, advocacy, and support—so that every person with EDS is recognized, believed, and able to access appropriate care. This commitment guides everything we do, and your involvement helps make it possible.

Ehlers-Danlos syndromes are a group of 13 disorders caused by genetic changes that affect connective tissues. The conditions are caused by genetic changes that affect connective tissues. Each type of EDS has its own set of features with distinct diagnostic criteria. Some features are seen across all types of EDS, including joint hypermobility, skin hyperextensibility, and tissue fragility. Because EDS is often invisible and widely misunderstood, patients frequently face delayed diagnosis and barriers to proper care.

That is why awareness, and actions, are so critical.

By supporting this campaign, you are directly advancing our mission by helping us:

- Educate medical professionals to improve early, accurate diagnosis and treatments
- Provide trusted resources for patients and caregivers
- Fund and promote research that leads to better treatments and improved outcomes
- Advocate for recognition, equity, and compassionate care for the EDS community

Every gift and act brings us closer to a world where people with EDS and HSD are no longer overlooked or dismissed but are instead supported and empowered..

We are so grateful to have you with us this May and beyond. Together we are raising awareness, advancing research, and changing lives.

With sincere appreciation,

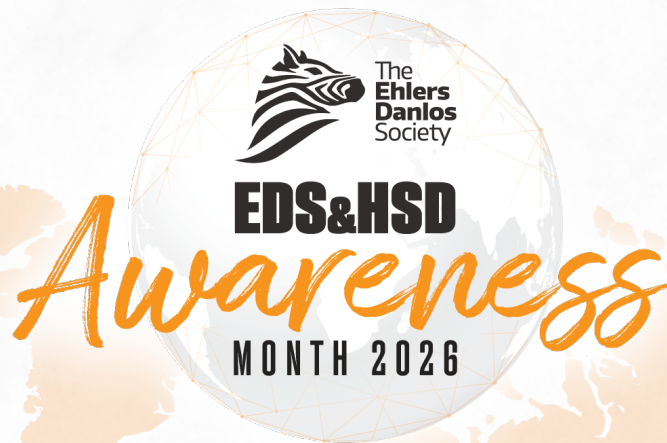
*Danielle Hohlier, Development Director*

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# | Gift Aid



**FOR EVERY £1  
DONATED WITH  
GIFTAID**

**THE EHLERS-DANLOS SOCIETY  
RECEIVES AN **EXTRA 25P**  
FROM THE UK GOVERNMENT,  
AT NO COST TO THE DONOR**

**TOGETHER WE DAZZLE!**

## Gift Aid

Gift Aid is a government scheme that allows charities to reclaim the basic tax rate you pay as a UK taxpayer. It means that with your permission **The Ehlers-Danlos Society can claim 25p of tax for every £1 you donate, at no extra cost to you the donor.**

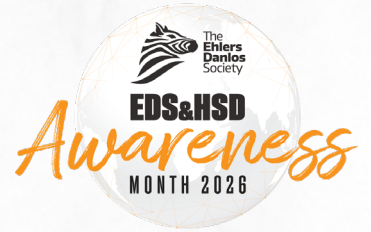
All you need to do is complete the Gift Aid declaration that is provided for all online donations through [Funraise](#) (EDS and HSD Awareness Month 2025), [Tiltify](#) and [Just Giving UK](#). If you have any questions don't hesitate to reach out to us at any time at: [giving@ehlers-danlos.com](mailto:giving@ehlers-danlos.com) and we would be happy to help you through this process

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# | Thank You!



Dear Supporter,

Thank you so much for choosing The Ehlers-Danlos Society for your fundraising event. We really do appreciate all your hard work and dedication.

You'll find in this pack some tools to help you with your fundraising event.

Please remember to tag us on social media, so we can see all the fantastic work you are doing!

Please do not hesitate to contact the development team at: [giving@ehlers-danlos.com](mailto:giving@ehlers-danlos.com) if you need anything.

Good luck!

*The Development Team*

**RAISING**  
*Awareness*  
**MAKING A**  
*Difference*



Prefer Tiltify for Streaming or Distance Tracking



Click Here to Start Your Fundraiser



Fundraising in the UK? Use JustGiving



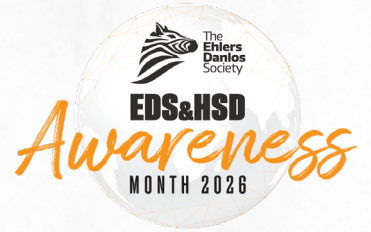
Join the Walk & Roll Challenge

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# Walk & Roll Challenge



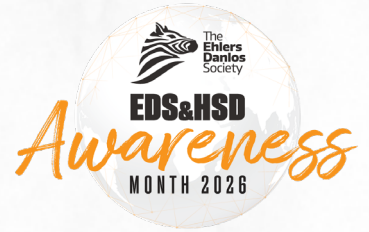
The **Ehlers-Danlos** Society

**WALK AND ROLL**

Join the herd, spread the word.



# Walk & Roll Challenge



## Join Us for the 2026 Walk and Roll Virtual Charity Event!

The Walk and Roll is a virtual charity event hosted by The Ehlers-Danlos Society, taking place from **May 1st to May 31st, 2026**. This exciting event unites individuals and teams from around the world to raise awareness and funds for Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD). Whether you walk, roll, or participate in your unique way, this event is about coming together to make a difference, support vital research, and amplify the voices of those living with these conditions.

### Incentive Tiers and Prizes

To show our appreciation for your fundraising efforts, we've created an **incentive tier system** filled with exclusive prizes! Participants who meet specific fundraising milestones will be eligible to claim rewards, such as event T-shirts, branded merchandise, or exclusive discounts on future events. Each incentive tier is designed to encourage and celebrate your contributions to the Walk and Roll's success.

Please note our **tier disclaimer**: Incentives are awarded based on the highest tier you achieve, and incentives from lower tiers are not included. For example, if you raise £360 and qualify for the third tier, you will only receive the third-tier incentive, not the items from the first or second tiers. This approach allows us to allocate resources efficiently and ensure a meaningful thank-you for your fundraising efforts.

### Claiming Your Incentives

After the event concludes, you can claim your incentives by filling out a simple form. The form will ask for your **contact information and proof of fundraising**, such as screenshots from your fundraising page or donation receipts. Once submitted, our team will verify your information and arrange for your incentives to be delivered.

**Incentive codes will be distributed no later than June 19th.** If you have earned an incentive, you will receive an email with a unique code that you can use online to claim your reward. Please note that participants are responsible for any **shipping and handling fees** associated with their incentives. To claim your incentives, please complete the [Participant Form](#).

Join the 2026 Walk and Roll and be a part of this global movement to support the EDS and HSD community. Together, we can raise awareness, fund critical research, and celebrate the resilience of individuals living with these conditions. Let's make this May unforgettable!

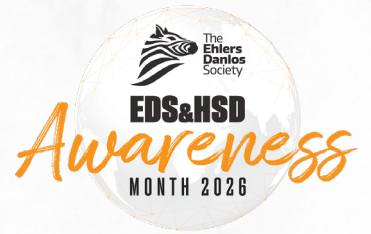


**Start Your Walk & Roll Fundraiser**

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# Walk & Roll Challenge

At the end of May - no later than June 19th, all submitted forms will be reviewed to confirm fundraising activities and other relevant details. Once verification is complete, unique incentive codes will be given to participants. These codes will be emailed to recipients, along with your certificate.



**Tier 1: Raise £50 - £100**  
May Awareness T-Shirt.



**Tier 2: Raise £101 - £200**  
Walk and Roll T-Shirt and Cap.



**Tier 3: £201 - £360**  
Walk and Roll T-Shirt, Cap and Sticker.



**Tier 4: Raise £361 - £560**  
Walk and Roll T-shirt, Cap, Tote Bag and Mug.  
Name Recognition on May Awareness webpage – listed as a key fundraiser in our virtual “Walk of Fame”.



**Tier 5: Raise £561 - £800**  
Walk and Roll T-shirt, Cap, Tote bag, Travel Mug with Handle, Lapel Pin and Sticker.  
Name Recognition on May Awareness webpage.

## Exclusive Bonus!

\* Anyone raising £1,605 or more will get a free virtual pass for any EDS ECHO Summit in 2026 or 2027

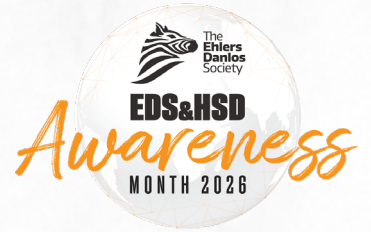


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# Earn Exclusive Incentives

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[Click Here to Start Your Fundraiser](#)

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# Earn a Limited Edition T-Shirt

Raise **£50** and earn a limited edition EDS & HSD Awareness T-Shirt!



## How to claim yours:

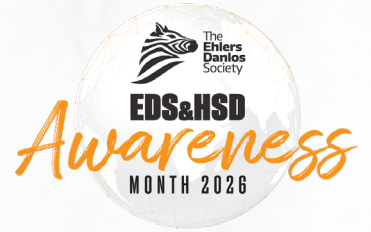
- Raise £50 and submit your Acts of Awareness Form
- The Ehlers-Danlos Society will email you a gift card
- **Follow this link** and order your May Awareness shirt (or any other May Awareness item you like!)

\*Gift cards are for the amount of the shirt only. Taxes, Shipping, and Delivery will not be covered by The Ehlers-Danlos Society and will need to be covered by the donor receiving the order. All gift cards will be emailed by June 19th.

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# Create Your Fundraising Page

**Creating a fundraiser is simple. In just a few minutes you can launch a page, share your story, and invite friends and family to support a cause that matters to you.**

**Many supporters create fundraisers that reflect their personal connection to Ehlers-Danlos syndromes (EDS) or hypermobility spectrum disorders (HSD).**

**Here are a few ways people choose to fundraise:**



## **Honor a Diagnosis Anniversary**

Turn the date that changed everything into a moment of awareness and hope.



## **Support Research That Matters to You**

Raise funds to support progress in research, education, and diagnosis.



## **Dedicate Your Fundraiser**

Create a fundraiser in honor of someone living with EDS or HSD, or in memory of someone who inspired you.



## **Celebrate a Milestone**

Turn a birthday, diagnosis milestone, or personal achievement into an opportunity to make a difference.



## **Join the Walk & Roll Challenge**

Create a page and invite friends and family to support your participation. Every fundraiser helps advance research, education, and care for the global EDS and HSD community.



**Prefer Tiltify for Streaming or Distance Tracking**



**Click Here to Start Your Fundraiser**



**Donate**



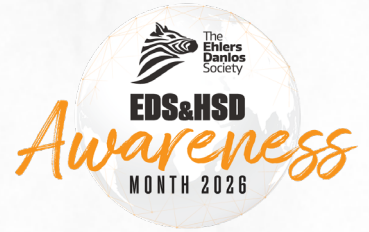
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# Create Your Fundraising Page



In minutes you can create your own fundraising page to share your personal story, fundraising photos, and keep your supporters up to date with your progress and event! Follow the steps to create a [UK/EU page](#), then share your page with friends and family, by email, and on social media using the included and easy templates.

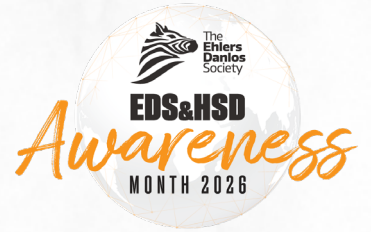
## funraise

- 1: Visit:** <https://may-awareness-fundraiser.funraise.org/>
- 2: Click "Start Fundraising":** Look for the fundraising button on the page.
- 3: Create an Account:** Sign up with your email or log in if you already have an account.
- 4: Set Up Your Campaign:**
- 5:** Enter a campaign name (e.g., "Support EDS & HSD Awareness").
- 6:** Set a fundraising goal.
- 7:** Personalise your campaign description.
- 8:** Upload a photo or video.
- 9. Launch and Share:** Publish your campaign and share it using the provided tools, such as social media links or email invites.

## TILIFY

- 1: Visit:** <https://tiltify.com/the-ehlers-danlos-society/the-2026-zebra-walk-and-roll-join-the-herd-spread-the-word>
- 2:** Select "Start fundraising."
- 3. Create Your Campaign:**
  - Give your campaign a unique name.
  - Set a fundraising target and choose a campaign end date.
  - Customise your page with a description and images.
- 4. Add Incentives or Milestones** (optional): Encourage donations by adding rewards or goals.
- 5. Start and Share:** Once your campaign is live, share your Tiltify page with friends and family via social media or email.

# Create Your Fundraising Page



## JustGiving®

- 1. Visit:** <https://www.justgiving.com/ehlersdanlossociety>
  - Click "Fundraise for us."
- 2. Select a Fundraising Activity:**
  - Choose from activities like events, challenges, or personal projects.
- 3. Create Your Fundraiser:**
  - Add a title, fundraising goal, and a compelling story explaining why you're raising funds.
  - Include a photo or video for a personal touch.
- 4. Launch and Promote:** Publish your page and share it widely with your network.

## facebook

- 1. Log In to Facebook:** Open Facebook on your browser or app.
- 2. Navigate to Fundraisers:**
  - Click on the menu (three horizontal lines) and select Fundraisers.
  - Alternatively, visit The Ehlers-Danlos Society's Facebook page and click Create Fundraiser.
- 3. Choose The Ehlers-Danlos Society:**
  - Search for The Ehlers-Danlos Society as the beneficiary.
  - Select it to tie your fundraiser to the organisation.
- 4. Customise Your Fundraiser:**
  - Set your fundraising goal and end date.
  - Write a description explaining why you're raising funds.
  - Add a cover photo to personalise your page.
- 5. Start and Invite:**
  - Launch your fundraiser and invite friends to donate.
  - Share updates and thank donors as the campaign progresses.

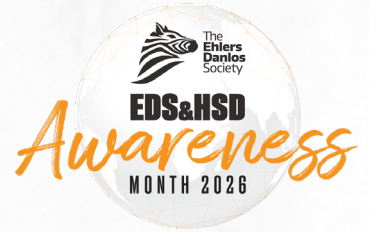
CLICK HERE TO  
**DONATE**

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# How You Can Donate Funds



**We are extremely grateful for your donations, so we like to offer multiple ways of sending your donations!**

**Take a look at the ways you can send in your donations:**



### **Online Donations:**

You can make a one-time or monthly donation via The Ehlers-Danlos Society's [website](#). Your gift directly supports The Society's mission to improve the lives of individuals with EDS and HSD.



### **Donate by Mail:**

If you prefer not to donate online, you can also donate by mail by sending a cheque to the Society's office in the UK. Below is the address our UK office:

The Ehlers-Danlos Society, Office 7, 35-37 Ludgate Hill, London, EC4M 7JN, UK



### **Honor and Memory Gifts:**

One way to honor or memorialise a loved one is by donating to The Ehlers-Danlos Society on their behalf. When you donate, you create a lasting impact for them and their families, no matter the size of your gift. We will send a letter to notify loved ones of the generous gift you've made in honor or in remembrance. Please ensure you state the name and address of the person you are dedicating the donation to.



### **Matching Gifts:**

Many employers offer matching gift programs, allowing your contribution to be doubled or even tripled. Check with your employer to see if they offer a matching gift program and submit your donation details for processing.

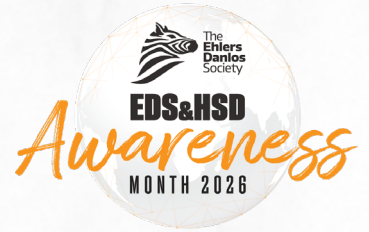
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# How You Can Donate Funds



## Workplace Giving:

Workplace giving is a simple and impactful way to show support for The Ehlers-Danlos Society. Every year, many employers are allowed to direct a portion of their pay cheque to a charity of their choice through company or organisation workplace giving. This gives you the option to donate to the cause that is most important to you. Check your employee giving platform to select The Ehlers-Danlos Society, or find us on Benevity, Cybergrants, and YourCause.



## Planned and Legacy Giving:

If you want to leave a lasting legacy, consider planned giving. This can be done through your will, IRA, or other financial avenues, ensuring your support continues well into the future. Click [here](#) to find out more.



## Donor-Advised Funds (DAF):

If you manage a Donor-Advised Fund, you can easily direct a grant to The Ehlers-Danlos Society. This is an efficient and tax-smart way to support the cause. Our partner is [Every.org.](#), Visit to find out more information.



## Stocks:

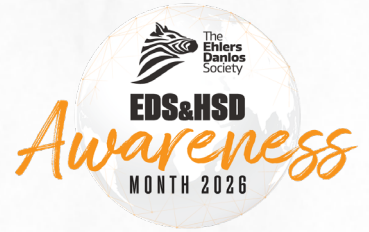
Donating stocks to The Ehlers-Danlos Society is a tax-efficient way to support, allowing you to avoid capital gains taxes and receive a charitable deduction for the full market value. This lets you contribute more without increasing out-of-pocket expenses, making stock donations a meaningful way to maximise your impact. Please contact [giving@ehlers-danlos.com](mailto:giving@ehlers-danlos.com) for further information.



## Other Ways of Giving:

The Ehlers-Danlos Society also accepts cryptocurrency including Bitcoin, and in the US only, cars and Venmo. These methods provide flexibility and maximise your impact. Please reach out to the development team for further information at: [giving@ehlers-danlos.com](mailto:giving@ehlers-danlos.com)

# Start Your Fundraiser in Minutes



**Creating your fundraiser is simple. In just a few minutes you can launch a page, share your story, and invite your friends and family to support a cause that matters to you.**



**Every fundraiser is unique.** Many supporters choose to create a fundraiser that reflects their personal connection to EDS or HSD.

**Here are a few meaningful ways to take part during May Awareness Month:**

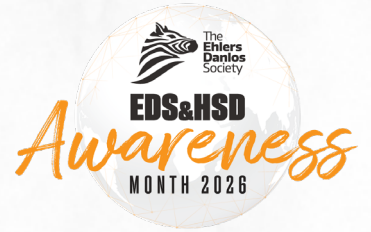
Honor a Diagnosis Anniversary, Support Research That Matters to You, Dedicate Your Fundraiser, Host a Virtual Fundraiser, Celebrate a Milestone

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# Tips For Fundraising

**It can be hard to think up great ideas for raising funds and awareness for a cause or charity close to your heart. We are so grateful that you have chosen The Ehlers-Danlos Society and want to give you some tips and advice.**

## Organise It!



### Stalls:

Check the local papers, schools, or community boards for somewhere you can set up a table. Hold a raffle, guess the number of jellybeans (or anything) in the jar, sell donated items, or just give out our flyers.



### Sponsor Events:

Sponsor sports events such as a 5K race, a bicycle tour, or a swimathon - get involved in a local sports club and coordinate through the club. Or ask people who enter events to be sponsored with the proceeds going to The Ehlers-Danlos Society. Alternatively, sponsor a film festival at a local theatre.



### Organise Activities:

Organise an informational walking tour such as an interesting historical or local site. Make it as accessible as possible too! Or perhaps ask local school children to sponsor a car wash or old clothes drive (depending on the school, students may be able to get extra credit for volunteering). Other ideas include hosting a fashion show for people or pets with an entrance fee, or a face-painting booth.

## Raise It!



### Bucket List:

Ask for donations in a bucket at your local supermarket (permits are often needed, please enquire at chosen location). Some even have a charity of the month, so get in early and apply. Of course, you must make arrangements with the management prior to your fundraising, and some managers may be able to match donations that you raise.



### Hair Salon:

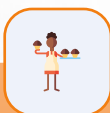
Ask your barber or hairstylist to donate a small cash amount from every haircut they complete over one weekend, or set up a tip jar for The Ehlers-Danlos Society.



### Tip/Donation Jars:

Set up buckets at local restaurants and stores with The Ehlers-Danlos Society logo. A picture is also often helpful. Check in with them weekly.

## Sell It!



### Sell It:

Hold a bake sale, garage sale, or even a fun baking contest with small entry fee. You can then raffle off the goodies afterwards for even more proceeds!



### Sponsor a Raffle:

Ask for donations of goodies and unwanted unused gifts and hold a raffle. This can be done as part of another event or even a family and friends gathering.



### Auction:

Hold a silent auction. Use your contacts to gather donated items from local businesses - vouchers for dinner, wine gifts, experience day gifts, spa discounts, etc. Ask individuals or approach local sports teams, celebrities, or local artists you may know to donate any items they can.

## Work It!



### Corporate Matching:

Many firms will match funds you raise charitably; you can find local or national companies who will do the same. Use all your contacts!



### Bad Tie Day:

Charge your colleagues a small amount to come in wearing their loudest tie/Christmas jumper/zebra print clothing or even pyjamas! Award the winner a percentage of the collected funds, or get a prize donated.



### Dress Down Day:

If your office is business formal or business casual, arrange to allow co-workers and employees to wear jeans for one day if they donate money to The Society. You can go one step further with larger companies and ask the company if they would match the amount of money collected from employees for jeans day.

## Big Night Out!



### Host an Activity Night:

Hold a fun evening event with a competitive edge. Some ideas include darts, bingo, snooker/pool tournament, a karaoke contest, or a dance tournament. Charge entry and if at a local pub or bar, negotiate with management for a donation from the extra proceeds from the bar income your event brings in.



### Movie Night:

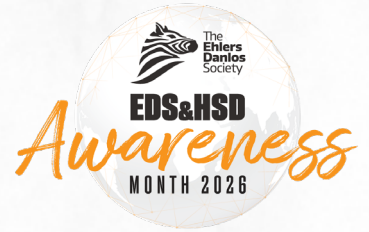
Recreate an evening of vintage cinema by showing classic films and musicals, and charge and entrance fee. For a young audience, a favourite box set marathon.



### Pampering Evening:

Host a gathering with a presentation from a Pampered Chef, Avon, Virgin, or other party company. Gather your friends and acquaintances who you think would be interested, and take a portion of the product sales as well as have a fun evening!

# Some Of Our Fantastic Fundraisers!



"My wife Hayley, lives with Ehlers-Danlos syndrome (EDS) and it's something that has taken so much from her. We see first hand how much this condition impacts on daily life. I want to do all I can give to raise funds to aid EDS research and awareness. I've decided to run the Kettering half marathon to raise money for The Ehlers-Danlos Society, a charity that means a lot to us as a family, and I'm aiming to raise £300."

**Ed**



"I'm fortunate that I have been able to access treatment to help relieve my symptoms, and have grown strong enough to complete a 5k. It's been a tough road, but I'm so proud I've made it here! I know many can't afford private healthcare. As such, I want to run (now I can run!) to raise £200 to go towards EDS and HSD awareness, programs, and research."

**Alix**

"EDS continues to affect members of my family so it's a cause that's very close to my heart. As such, I signed up for the 57 mile (91.5 km, or two-and-a-bit marathons) Glasgow to Edinburgh ultramarathon and raised £408 + Gift Aid in support of The Ehlers-Danlos Society."

**Ross**



**The Ehlers-Danlos Society**

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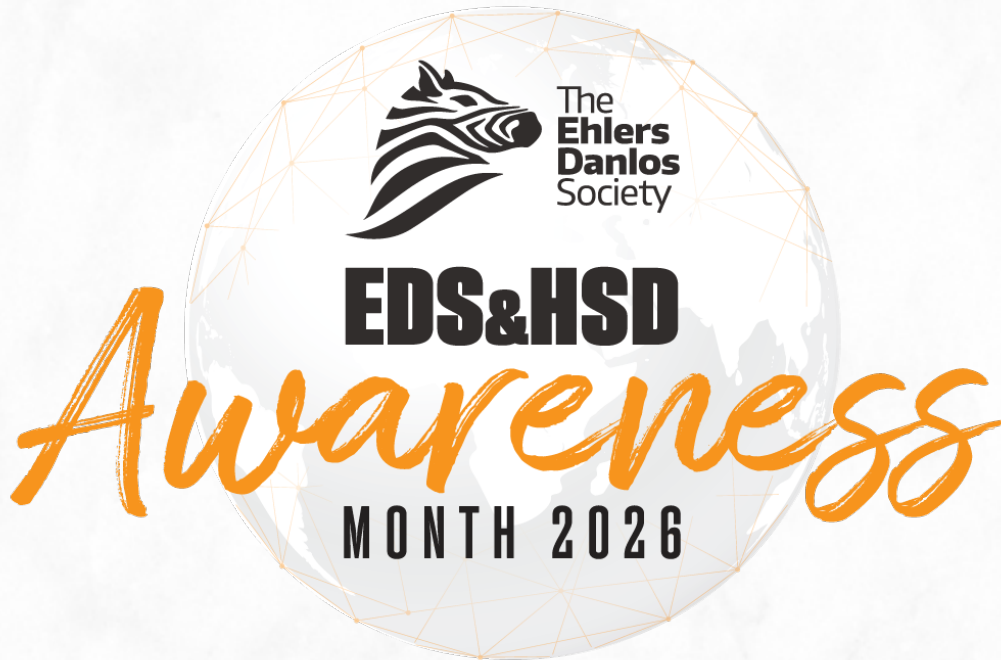
**Charity Number:** 1180984 **Giving@ehlers-danlos.com**



@ehlers.danlos



@ehlers-danlos



**Friday 1st May -  
Sunday 31st May 2026**



Don't forget to tag us on social media  
*We can't wait to see what you get up to!*



**Click Here to Start Your Fundraiser**



**Donate**



**Join the Walk & Roll Challenge**

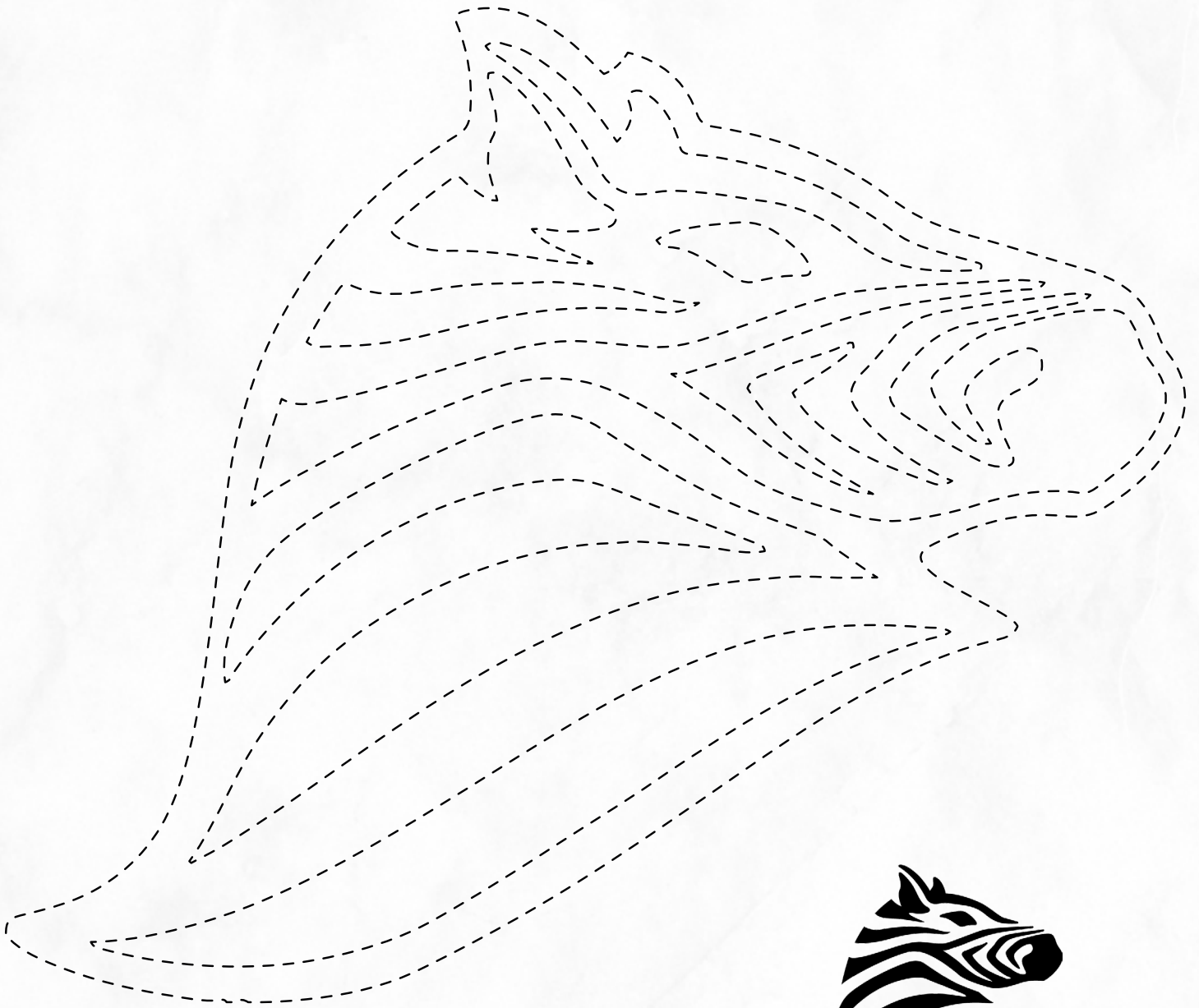
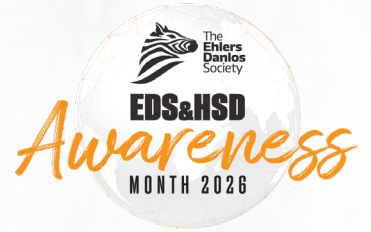
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# Make Your Zebra Dazzle!



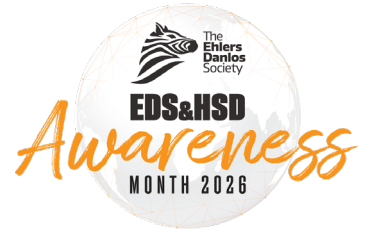
Our original logo

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# Activity Tracker



**Activity:**

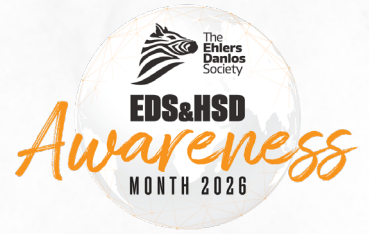
**Date:**

**Time:**

**Location:**

**To Support:**

# Bingo Card



<p><b>Social Media:</b> Share one of The Ehlers-Danlos Society's social media posts.</p> 	<p><b>Walk and Roll:</b> Walk or Roll 1 mile throughout May.</p> 	<p><b>Post a Zebra Fact:</b> Share an interesting fact about EDS or HSD on social media.</p> 	<p><b>Download the EDS &amp; HSD App:</b> Enhance your knowledge and stay connected by downloading The Ehlers-Danlos Society's app from the <a href="#">Download Our App page</a>.</p>	<p><b>Educational Read:</b> Read <a href="#">What is HSD</a></p> 
<p><b>Wear Zebra Stripes:</b> Sport zebra-patterned clothing or accessories for a day.</p> 	<p><b>Subscribe to the Newsletter:</b> Stay informed by subscribing to The Ehlers-Danlos Society's newsletter via the <a href="#">Join the Newsletter page</a>.</p>	<p><b>Zebra Themed Fundraiser:</b> Ask people to wear Zebra-themed clothing, ask for donations in return.</p> 	<p><b>Educational Read:</b> Read <a href="#">What is EDS</a></p> 	<p><b>Light it up!:</b> Request a building to be lit up for May Awareness.</p> 
<p><b>Host a Mini Fundraiser:</b> Organise a bake sale, lemonade stand, or small online auction.</p> 	<p><b>Reach Out:</b> Share an EDS or HSD awareness message with your workplace, school, or community group.</p> 		<p><b>Zebra Selfie with Friends:</b> Take a group photo wearing zebra stripes.</p> 	<p><b>Advocate for EDS &amp; HSD Awareness:</b> Write to local healthcare providers or community leaders, informing them about EDS and HSD.</p> 
<p><b>Donate Your Coffee:</b> Skip a coffee or treat and donate the cost to The Ehlers-Danlos Society.</p> 	<p><b>31 Days of EDS &amp; HSD:</b> Join our 31 Day Social Media Challenge!</p> 	<p><b>Share &amp; Pledge Challenge:</b> Share a fact about EDS or HSD with your followers and ask for small donations (e.g., £1) for each like or share.</p> 	<p><b>Write a Poem or Story:</b> Create something inspired by the resilience of people with EDS &amp; HSD.</p> 	<p><b>Watch an EDS &amp; HSD Video:</b> View and share an educational video on our <a href="#">Youtube Channel</a> about EDS &amp; HSD.</p> 
<p><b>Create a Fundraising page:</b> Create an online fundraising page and share with your friends and family.</p> 	<p><b>Write a List of Gratitudes:</b> Reflect on 3-5 things you're grateful for and share them with a friend or in a journal.</p> 	<p><b>Explore Mental Health Resources:</b> Access the <a href="#">Mental Health Resources</a> page to learn about coping strategies and support. Share a helpful resource with your community.</p>	<p><b>Stretch Safely:</b> Share your favorite gentle stretch or exercise.</p> 	<p><b>Email Campaign:</b> Send a heartfelt email to friends or family, explaining your cause and including a donation link.</p> 

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# | Bunting

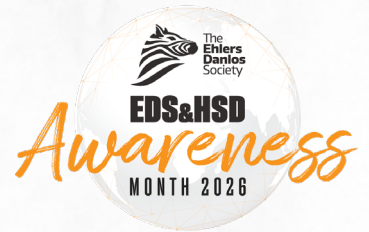


**RAISING**  
*Awareness*  
**MAKING A**  
*Difference*



**CUT ME  
OUT!**

# Merchandise For EDS & HSD



Find EDS & HSD Awareness merchandise, as well as our usual offerings, in our online store at: <http://www.ehlers-danlos.com/shop>.

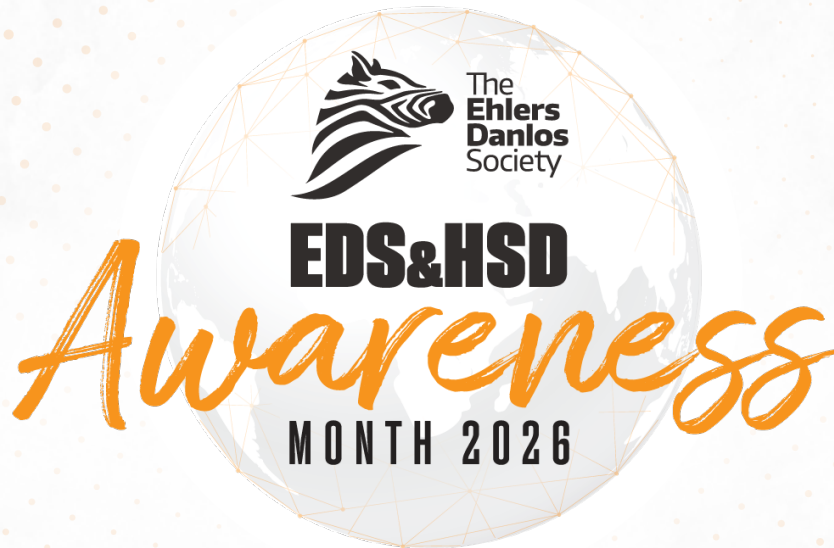
Proceeds from purchases on our site go towards supporting The Ehlers-Danlos Society, so please take a look.



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