

VOLUNTEER HANDBOOK

Thank you for volunteering with **The Ehlers-Danlos Society**





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WELCOME TO THE EHLERS-DANLOS SOCIETY

Thank you for your interest in supporting The Ehlers-Danlos Society as a volunteer. Our efforts to serve people affected by the Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD) depend on people like you who are willing to offer their time and skills to help our community.

We sincerely value your contribution.

This handbook includes everything you need to know to make the most of your volunteer experience.

Volunteers are a valued and vital part of our organization. The Ehlers-Danlos Society is grateful to be able to recruit and support volunteers with numerous skills and abilities, such as yourself. Volunteering is incredibly rewarding, and we look forward to being part of your volunteer journey.

Please take the time to read this handbook carefully. At the end of this handbook, please sign the acknowledgement that you have read, understood, and agree to the contents. This handbook replaces any previously issued handbooks or policy statements dealing with the subjects discussed. The Ehlers-Danlos Society reserves the right to interpret, modify, or supplement the provisions of this handbook at any time. Please understand that no volunteer handbook can address every situation.

Please contact Accessibility Coordinator Sarah Hamilton, sarah.hamilton@ehlers-danlos.com, for any queries regarding your volunteer handbook or the onboarding process.

Thank you for your commitment and support to The Ehlers-Danlos Society. Please join us in our dazzle!

Sincerely,

The Ehlers-Danlos Society Team

OUR TEAM



Please find the details of our staff team:



Please find the details of our board:



ENVIRONMENT, SOCIAL AND GOVERNANCE

We aim to reduce our environmental impact, support our community, and uphold the highest standards of governance, advancing our mission with dedication and integrity. To read more about the steps we take and the goals we are working towards, please see our ESG webpage.

VOLUNTEER MISSION

STATEMENT!



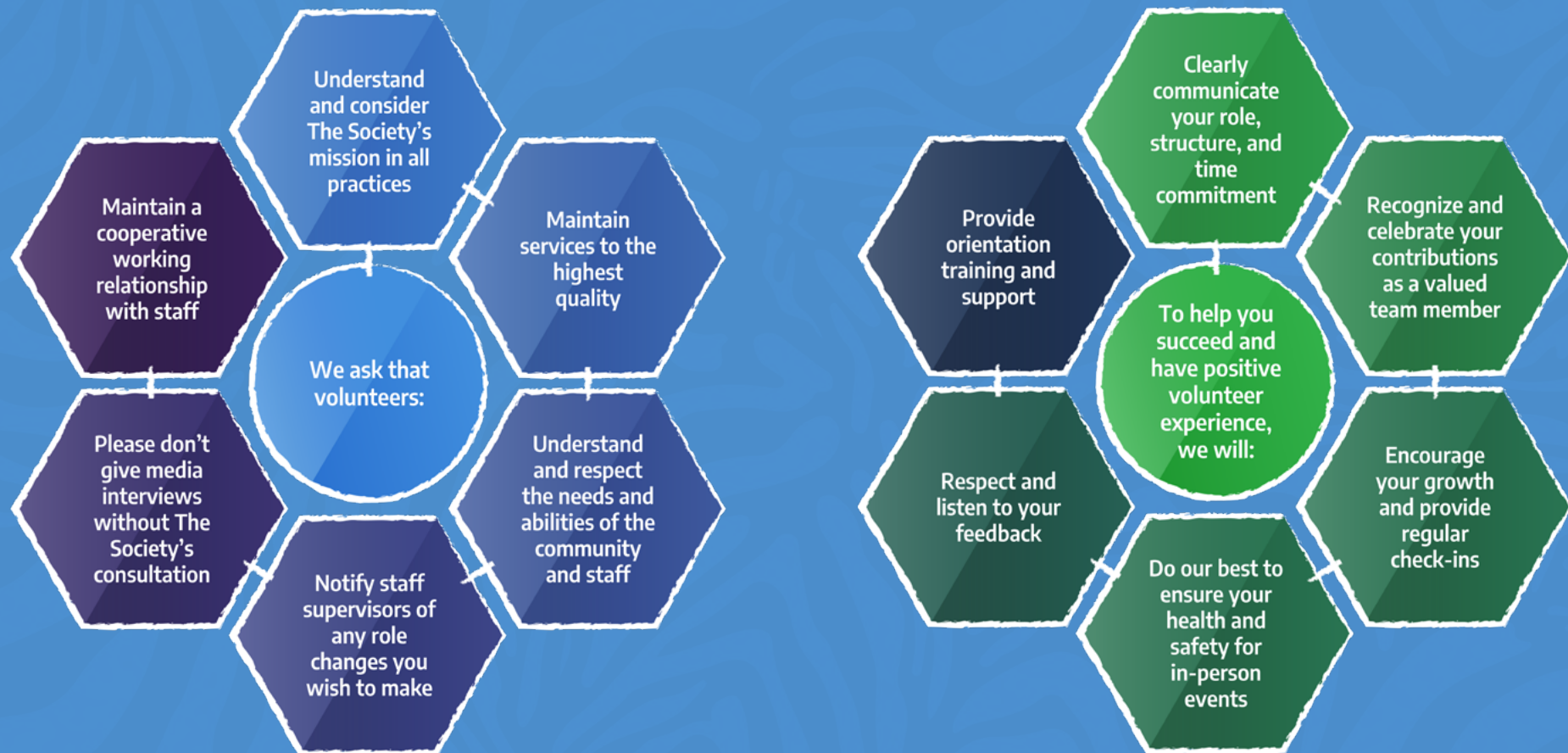
The Ehlers-Danlos Society is a global organization dedicated to advancing and accelerating research and education in EDS and HSD. We support the creation of effective and fair treatments for EDS and HSD and work together to improve the lives of those affected. Our vision is to create a world where every person living with EDS and HSD has the right treatment and care, at the right time, for their specific needs.

At The Ehlers-Danlos Society, we CARE and are committed to improving the lives of those with HSD and EDS.

It is the commitment of each volunteer to uphold the vision and mission of The Ehlers-Danlos Society. Volunteers will dedicate themselves to providing outstanding support, assistance, and empathy to the community, staff, and board members. No matter their role, volunteers pledge to show professionalism and kindness, reflecting The Ehlers-Danlos Society's strong dedication to CARE.

VOLUNTEER PROGRAM SERVICE PHILOSOPHY

The Ehlers-Danlos Society aims to bring in and retain a diverse team of trained, caring volunteers to assist our work with the EDS and HSD community. Volunteers will receive support, training, and guidance, empowering them to make a positive difference. We value our volunteers as an important part of our team, and we expect them to act professionally and be accountable to their assigned staff member and the Accessibility Coordinator.



VOLUNTEER ROLE

I want to be a volunteer

Apply through
the site

Email:

sarah.hamilton@ehlers-danlos.com

Role available

No role available -
data kept for future
contact

Interview 1
and 2

Reference checked
and role assigned if
appropriate

The Ehlers-Danlos Society defines a volunteer as an individual who contributes their time and skills to help the Society achieve its mission, driven by passion and commitment and without expectation of payment.

The Ehlers-Danlos Society's commitment to diversity and inclusion is driven by the four pillars of its mission: C.A.R.E — providing care, access, research, and education in all that we do. We are a global, multicultural organization, as such we seek to increase opportunities for individuals from diversified backgrounds and are committed to building an inclusive culture that celebrates the diverse voices in our team and community.

The Ehlers-Danlos Society, actively recruits, employs, trains, compensates, and promotes opportunities regardless of race, nationality, ethnicity, gender, marital or civil partner status, caring responsibilities, disability, gender identity, age, social class, sexual orientation, religion, and other protected status as required by applicable law.

Volunteers are chosen for their skills, abilities, and suitability for the role, as well as in line with The Ehlers-Danlos Society's needs.

The Ehlers-Danlos Society will make reasonable adjustments to ensure volunteering is accessible and inclusive for everyone.

Volunteers are expected to work cooperatively with the staff.

Volunteers under 18 must have written consent from a parent or legal guardian. Not all volunteer roles are available to minors. The Society follows child labor laws. We can only accept volunteers under 18 in the UK and the USA.

YOU'VE MADE IT TO THE INTERVIEW STAGE

WHAT NEXT ?

INTERVIEW PROCESS: Suitable volunteers will have two interviews: one with the Accessibility Coordinator and another with the relevant department. This is a chance for both you and the team to ask questions and ensure a good match.

ROLE SUITABILITY: If you are not suitable for the role you applied for there may be other roles available. If not, we reserve the right to decline the position.

REFERENCE: We require one character reference check, this can be an employer, former employer or friend. We cannot except a reference from a member of your immediate or extended family.

BACKGROUND CHECKS: Required for in-person volunteers or those involved with our junior zebra program.

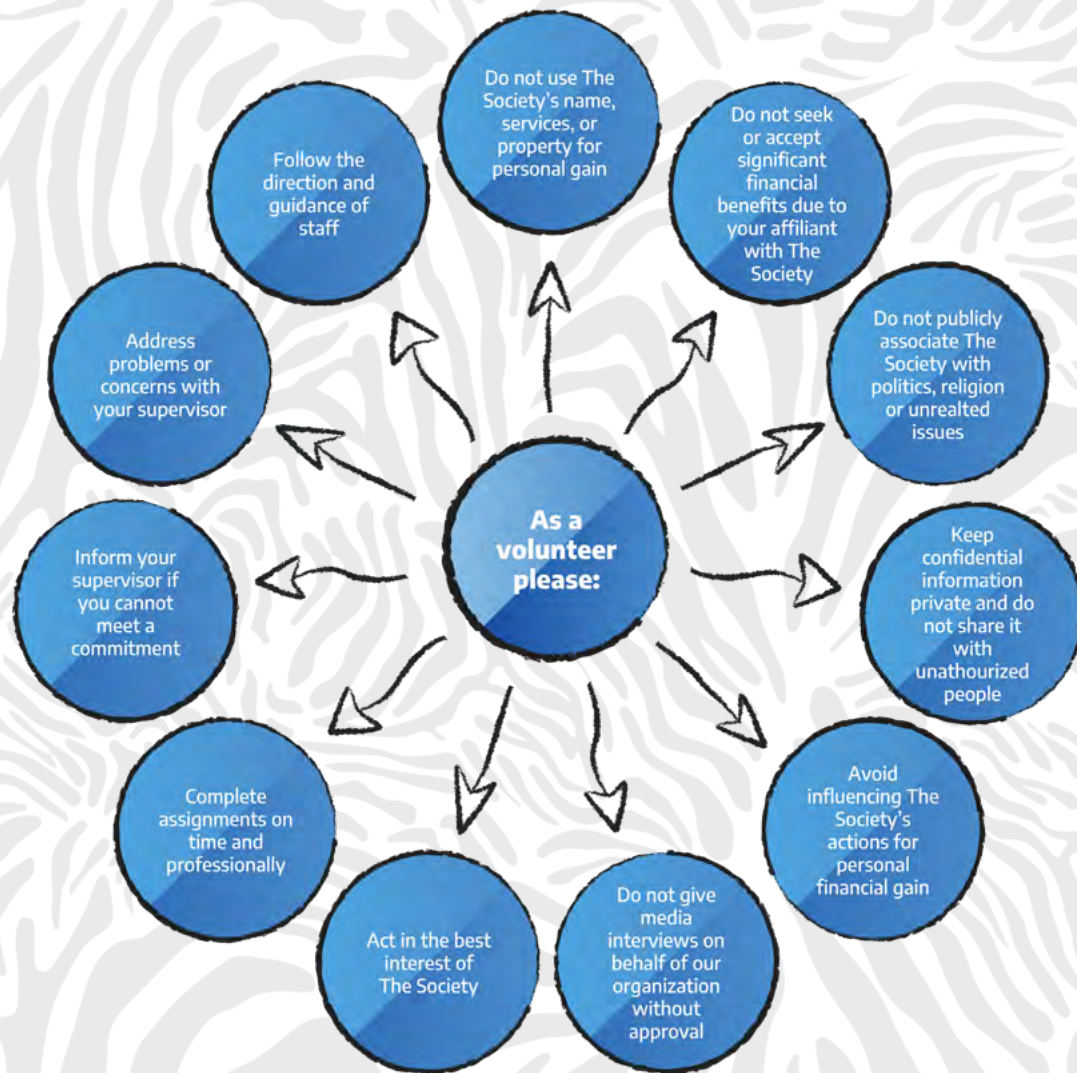
TRAINING: Volunteers may need to complete HIPAA and GDPR training dependent on their role, for example if dealing with confidential information when hosting support groups. They may also need to complete departmental training. If your role requires expense submissions, RAMP training, The Ehlers-Danlos Society's expense management software, will be provided. Expenses can include travel or supplies needed to carry out the volunteer role. Please click [here](#) for the reimbursement policy.

AGREEMENTS: All volunteers must sign the NDA, volunteer handbook, volunteer agreement, and any relevant policies and procedures. The privacy policy must also be read.

ACCESSIBILITY: For any reasonable adjustments or to access information, please contact Sarah Hamilton, Accessibility Coordinator, sarah.hamilton@ehlers-danlos.com

YOU'VE BEEN APPROVED

WHAT NEXT?



First, congratulations and welcome to the team, we're delighted to have you on board!

Your position will be confirmed by the Accessibility Coordinator, and you'll now receive an official welcome notification, sign all relevant documentation and complete onboarding steps (relevant to role).

Volunteers cannot start their role until they are officially accepted and completed all required training and screening.

You will be allocated and introduced to your supervisor.

Your time volunteered will be tracked manually by yourself and your supervisor through monday.com.

Code of conduct

SOCIAL MEDIA NETWORKING POLICIES

When posting on social media platforms like Facebook, X, Instagram, LinkedIn, personal blogs, or any other social forums, volunteers must protect the privacy and brand of The Ehlers-Danlos Society.

- ▶ You can mention The Ehlers-Danlos Society and share your volunteer experiences. Use the correct hashtags (insert hashtags here)
- ▶ For personal posts, make it clear you are speaking for yourself. Use a disclaimer like “The views expressed are my own and don’t necessarily represent The Ehlers-Danlos Society’s positions, policies, or opinions”
- ▶ If you have or want to start a blog or website and mention your volunteer work with The Ehlers-Danlos Society, discuss any potential conflicts with the Marketing Director.
- ▶ If you are well-known in your field, be careful with your personal views as they might be mistaken for The Ehlers-Danlos Society’s views.
- ▶ Be aware of your association with The Ehlers-Danlos Society and ensure your social media profiles and content reflect positively on yourself and The Ehlers-Danlos Society.
- ▶ Do not approach high-profile individuals from your personal accounts to support The Ehlers-Danlos Society. Contact the Marketing Director with any relevant connections.
- ▶ If the press contacts you about your social media posts related to The Ehlers-Danlos Society, inform the Marketing Director immediately, do not respond directly.
- ▶ Do not use The Ehlers-Danlos Society’s logos or trademarks without approval from the Marketing Director.
- ▶ Be careful with your privacy online. Consider the long-term impact of what you publish.
- ▶ Respect others and their opinions. Do not use your social media to air disputes or to be rude, racist, discriminatory, or abusive towards The Ehlers-Danlos Society or anyone associated with it.
- ▶ We encourage you to share The Ehlers-Danlos Society’s posts and tweets. When commenting on or supporting The Ehlers-Danlos Society online, follow the above guidelines to maintain a positive image.
- ▶ Remember that as a representative of The Ehlers-Danlos Society, your personal opinions can have a significant impact if shared on social media. Social media does not separate your personal, volunteer, and professional lives, and it is crucial to avoid damaging The Ehlers-Danlos Society’s reputation.

For any questions or concerns, please contact Sarah Hamilton, the Accessibility Coordinator. Failure to comply with these guidelines may result in dismissal.

MONEY HANDLING

If your role requires it, when handling money, fees, or donations, a volunteer and a staff member must be present to ensure all funds are properly accounted for. You will receive training from the Finance Director on money handling procedures.

ISSUE RESOLUTION

If you have a concern, report it to your supervisor right away. The supervisor will investigate and take appropriate action. If you're not comfortable talking to your supervisor, you can report to the Accessibility Coordinator, Sarah Hamilton. Any supervisor who learns of a harassment policy violation must inform The Ehlers-Danlos Society's Executive Team immediately.



CONFLICTS OF INTEREST

Volunteers must immediately inform their supervisor of any actual or potential conflicts of interest with The Ehlers-Danlos Society and any other organization they are affiliated with. If you are unsure whether a conflict exists, consult your supervisor. All volunteers will sign read and sign the conflict-of-interests policy.

NON-SOLICITATION

To maintain a professional environment and avoid work disruptions, volunteers are not allowed to:

- ▷ Distribute literature of printed and/or digital materials not Society approved.
- ▷ Sell non-Society merchandise.
- ▷ Solicit financial contributions.
- ▷ Solicit for any other cause during volunteering hours.
- ▷ This includes solicitations via The Ehlers-Danlos Society's communication channels.

CELEBRATING

VOLUNTEERS

We are incredibly grateful for our volunteers and love to celebrate their skills, commitment, and dedication. To show our appreciation, we offer:

- ▷ Pin badges for 6 months (or 25 hours), certificates for 1 year (or 50 hours), and 2 years (or 75 hours) of service.
- ▷ One free admission to a virtual event of your choice per year.
- ▷ One 20% discount for an in-person event of your choice per year.
- ▷ Unlimited 20% off discount for additional virtual events you wish to attend per year.
- ▷ We also celebrate Volunteer Week in the US and UK to highlight the amazing work our volunteers do. Thank you for being a valuable part of our team.



VOLUNTEER REVIEW

INPUT AND TERMINATION

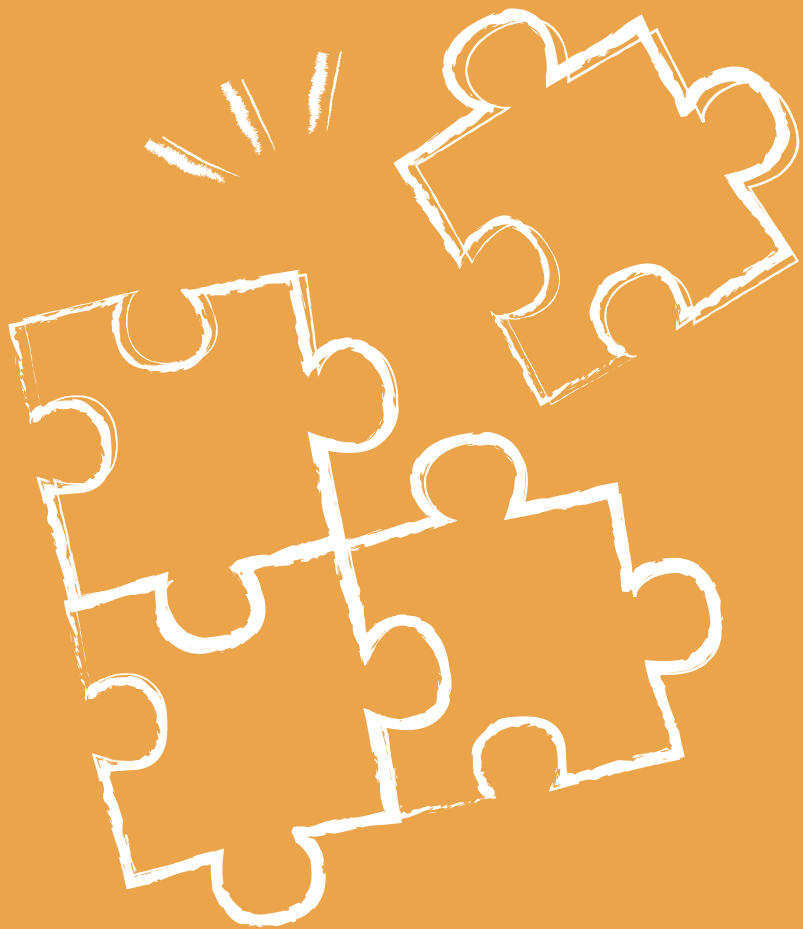
We believe in fair and consistent treatment for all volunteers. Here's how we handle reviews, feedback and termination:

Regular check-ins: Weekly for the first month then every three months moving forward.

Immediate reviews: If a problem arises, we will review it within two business days.

Improvement opportunities: Volunteers will have a chance to improve or correct issues.

Supervisor conversations: Supervisors will discuss the issue with the volunteer and explain the seriousness.



GRIEVANCES

Please read this grievance policy.

POSSIBLE REASONS FOR ACTION

Neglect of duties or poor performance.

Violation of policies, ethics, or standards.

STEPS FOR CORRECTION ISSUES

Verbal discussion/warning: Supervisor talks to the volunteer about the problem. A record of this talk will be kept.

1st written warning: Performance Improvement Plan (PIP)

Final written warning.

Termination: If issues continue, the volunteer may be suspended until the issue is resolved or terminated.

RESIGNATION

OR TERMINATION

We appreciate all the time you dedicate to us. If you need to stop volunteering, please inform your supervisor and the Accessibility Coordinator. If you wish to return, contact the Accessibility Coordinator.

REASONS FOR TERMINATION INCLUDE:

- ▷ Abuse or harassment.
- ▷ Gross misconduct or non-compliance.
- ▷ Being under the influence of alcohol or drugs during volunteer hours (please speak to the Accessibility Coordinator about any medical cannabis prescriptions you may need to use, and this will be accommodated for).
- ▷ Theft or misuse of property.
- ▷ Failure to follow policies and procedures.
- ▷ Violating the volunteer agreement.
Unauthorized data changes.
- ▷ Breaking laws or safety regulations.
- ▷ Sharing confidential information.
- ▷ Poor attitude or performance.
- ▷ Inappropriate behaviour.
- ▷ Malicious behaviour or actions that harm others.

REPRESENTING

THE EHLERS-DANLOS SOCIETY

Thank you for volunteering with The Ehlers-Danlos Society. We want you to enjoy your experience. As you learn your role, we encourage you to ask questions and are here to support you. Remember, you are representing The Ehlers-Danlos Society and must follow the terms in this handbook.



FREQUENTLY ASKED QUESTIONS

HOW MANY HOURS DO I NEED TO VOUNTEER?

Some roles have specific hours, while others are flexible (such as translations). We will work with you to find hours that fit your schedule and health. Every bit of time you donate is appreciated.

CAN YOU PROVIDE ME WITH A REFERENCE?

Yes, we can provide references for your volunteering hours and role.

WHAT IF I AM UNABLE TO FUFIL MY VOLUNTEER

RESPONSIBILITIES DUE TO ILLNESS?

If you are sick, let your supervisor know as soon as possible. If you can't do it yourself, a friend or family member can inform us.

I CAN COMMIT TO A REGULAR SCHEDULE

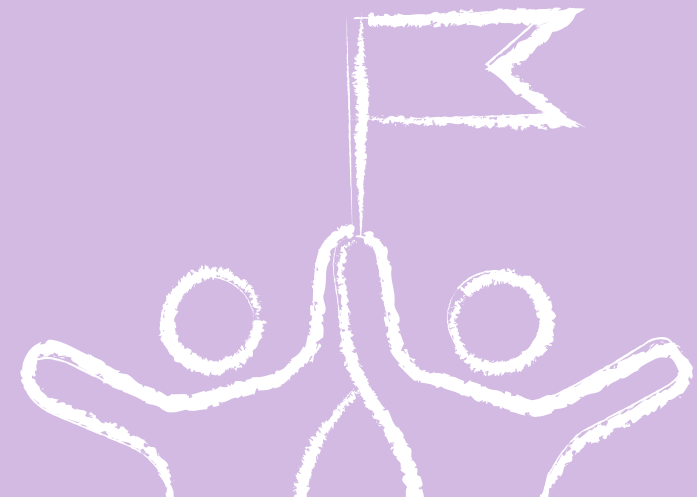
CAN I STILL VOLUNTEER?

This depends on the role. We offer various roles to fit different schedules so please apply for something you feel would be the best fit with your needs.

CAN MY VOLUNTEER ROLE LEAD TO BEING

EMPLOYED AS A MEMBER OF STAFF?

Your role is agreed on a volunteer basis only. If you are interested in job opportunities, we encourage you to check our careers page and apply if there is an opening that suits you.



VOLUNTEER POLICY:

ROLE OF VOLUNTEERS:

Volunteers are essential to The Ehlers-Danlos Society's success and daily operations.

Volunteers must follow The Ehlers-Danlos Society's policies.

Staff will provide orientation, supervision and feedback to volunteers

VOLUNTEER DEFINITION:

The Ehlers-Danlos Society defines a volunteer as an individual who contributes their time and skills to help us achieve our mission, driving by passion and commitment rather than expectation of payment.

EQUAL OPPORTUNITY POLICY:



The Ehlers-Danlos Society's commitment to diversity and inclusion is driven by the four pillars of our mission: C.A.R.E — providing care, access, research and education in all that we do. We are a global, multicultural organization, as such we seek to increase opportunities for individuals from diversified backgrounds and are committed to building an inclusive culture that celebrates the diverse voices in our team and community.

The Ehlers-Danlos Society, actively recruits, employs, trains, compensates, and promotes opportunities regardless of race, nationality, ethnicity, gender, marital or civil partner status, caring responsibilities, disability, gender identity, age, social class, sexual orientation, religion, and other protected status as required by applicable law.

Volunteers are selected based on their ability to perform the tasks defined in the role.

STANDARDS AND ETHICS:

Volunteers must cooperate, be reliable, accurate, and responsible.

Honesty, integrity, and fairness are expected.

Discrimination of any kind will result in termination.

RECRUITMENT:

Apply on our website.

Applications are screened, reference-checked, and include an interview.

Volunteers must complete training and sign necessary agreements before starting.

PLACEMENT:

We try to match volunteers with suitable roles.

Volunteers can request reassignment if needed.

OPEN DOOR POLICY:

Contact your supervisor with any concerns.

If unresolved, contact Sarah Hamilton, the Accessibility Coordinator.

HEALTH AND SAFETY:

We provide a safe and healthy environment free from harassment.

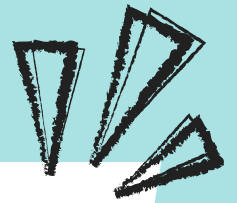
Alcohol should not be consumed during volunteer hours.

Smoking is allowed only in designated areas.

No tolerance for illegal drugs (please let us know if you have a cannabis prescription as this will be an exception to the rule).

Weapons are prohibited.

Hostility in any form is strictly prohibited.



SAFEGUARDING STATEMENT:

The Ehlers-Danlos Society is committed to protecting everyone involved.

We prevent, harm, exploitation, and abuse where we can.

Safeguarding is everyone's responsibility.

We do not tolerate harm or abuse and will act if needed.

We support staff and volunteers to manage challenging work environments.

POLICY REVIEW AND AMENDMENTS:

This policy is reviewed annually to meet the needs of The Ehlers-Danlos Society and its community.

CONFIDENTIALITY:

All information is kept confidential and shared only as required by law.

If while undertaking activities for The Ehlers-Danlos Society, you think a child or vulnerable person is at risk you should contact your supervisor.

BACKGROUND CHECKS AND TRAINING:



Background checks are carried out if the role requires it, such as volunteer face to face or supporting minors. These are conducted in accordance with local laws.

We will provide detailed training if the role requires it (HIPAA and GDPR) and we have a safeguarding statement.

NON-DISCLOSURE AND CONFLICTS

OF INTERESTS AGREEMENT:

All volunteers will be asked to sign an NDA and declare any conflicts of interest.

Acknowledgement and receipt of handbook

Please sign below to confirm you have received and reviewed this handbook, including the volunteer policy. This must be signed and returned before you begin volunteering.

I have read The Ehlers-Danlos Society's volunteer handbook and policy, which outlines the goals, policies, and expectations for my role as a volunteer.

By signing below, I acknowledge that I understand and agree to follow the information in the handbook. I realize this handbook is a general guide and does not cover every possible situation during my volunteer time.

I understand that the volunteer handbook is not a contract for employment. I agree to be considered a volunteer.

Signature