

Ehlers-Danlos Society Strategic Plan

2020/21 STRATEGIC PLAN

MISSION

The Ehlers-Danlos Society is a global community of patients, caregivers, healthcare professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes and related disorders.

PILLARS

1. Education

2. Research

3. Awareness

4. Advocacy & Support

INITIATIVES

- EDS Echo
- Events/Conferences
- Webinars
- Website
- International Consortium on EDS and HSD
- Comorbidity Coalition

- Research Grants
- Global Registry and Repository
- Hedge Study
- Surveys
- Center of Excellence
- Natural History Study
- hEDS and HSD Criteria Review

- Breaking Down Barriers
- Community engagement
- Affiliates Program
- Fund raising
- Translations

- Inspire
- Helpline
- EDS ECHO - Advocacy
- Professionals Directory
- Volunteers Program
- Virtual Support Groups

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VISION

World-wide awareness—and a better quality of life for all who suffer from these conditions. education and Research are at the center of what we do.

FOUNDATIONS

Governance

Administration

OBJECTIVES

- Strengthen and enlarge Board of Trustees with missing skills needed
- Establish Trustee committees – Finance, Trusteeship, Audit
- Strengthen and maintain Financial Governance
- Standard Operational Policies and Contingency Planning for all we do
- Strengthen and maintain Staff and Contractor governance structures
- Ensure workforce training in GDPR, HIPAA, and Equality and Diversity.
- Project Planning for development of new work and full review of existing work
- Defined outcomes, informed learning and development
- Sustainable growth
- Environmentally conscious in all we do

- Develop and maintain efficient systems and processes, regularly reviewed and adapted
- Utilise latest technologies / platforms, operating within best practice, notably more so in an increasing virtual environment
- Maintain internal and public facing policies
- Assessment, monitoring and evaluation of programs and projects
- HR management and guidance for staff, contractor, and volunteers
- Full implementation of Salesforce and Data Migration
- New website launch
- State Registration

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EDUCATION

EDS ECHO

EVENTS & CONFERENCES

- Grow EDS ECHO portfolio, ensuring resource and financial accountability
- Publish abstracts at international meetings, and commence analysis of research project.
- Provide CME / Nurse Credentialing to healthcare professionals

- Send representatives to other, non-Society led conferences
- Build a virtual community for support groups, health care professionals, charities and individuals

- Sustain and grow the EDS ECHO portfolio
- Introduce an ECHO conference series; subject-based events throughout the year.
- Explore the development of Massive Open Online Courses (MOOCs) in collaboration with Academic Institutions (Penn State, USA and UCLH, UK)

- Build upon our existing library of free webinars
- Where financially possible translate all our events into 4 languages
- Continue to be recognized as the global leader for information and advocacy of Ehlers-Danlos syndromes and Hypermobility Spectrum Disorders.
- 10 year plan (changes to our strategic mission)

INTERNATIONAL CONSORTIUM

COMORBIDITY COALITION

- Communicate the global expertise of the Society
- Maintain a database of all published research on the website
- Continue the Common Data Element process
- Utilise the Working Group expertise in developing educational materials and advice for the website

- Links to global organizations
- Continue developing practical information / resources

- Maintain the developments of 2020
- Support publication of updated and new reviews of related literature.
- Complete the CDE process

- Sustain and grow collaborative programs with other EDS and related communities and organizations
- Provide a focus group that supports ongoing research and publications managed by The Society

2020

2021

2020

2021

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RESEARCH

RESEARCH GRANTS

- Bring the research community together to fund important initiatives towards the understanding, treatment and cure of Ehlers-Danlos syndromes.
- Deliver Major grant rounds and Micro grant rounds throughout 2020

- Improve registry function, for utilisation by researchers
- Securing further funding for Society administered grants
- Fund and establish centers/clinics of excellence – care or research
- Fund research on co-morbidities and management

GLOBAL REGISTRY

- Continue to promote/ grow the Global Registry
- Increase representation on there from different countries and different types of EDS
- Enable enrollment onto HEDGE study

- Successful transition from PEER to LUNA DNA
- Move day to day management and maintenance from Woody to new Research Coordinator based at IU
- Enable external researchers to be able to survey community
- Translate the registry so that we can increase global representation

HEDGE STUDY

- Work towards target of enrolling 1000 people into study
- Work with external researchers who have previously done WGS to get them included into the study
- Select WGS Provider
- Select Analysis Team
- Recruit new Project Manager based at IU

- Complete enrollment
- Begin sequencing
- Begin analysis
- SOPs created and completed for all processes of the study
- Weekly reports generated for donors and PI's.

hEDS & HSD CRITERIA REVIEW

- Complete methodology and proposed new criteria structure.
- Gain IRB approval to assess proposed criteria
- Commence study

- Complete data capture of study, undertake analysis
- Discussions with stakeholders on findings
- Prepare comms work for announcements and determine
- Publish manuscript.

2020

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2020

2021

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AWARENESS		
	SOCIAL MEDIA AND EMAIL MARKETING	AFFILIATES PROGRAM
2020	<ul style="list-style-type: none"> • Increase activated members of our social media communities - involvement in campaigns and fundraising increased • International involvement and representation - more countries reached moving outside of US and UK 	<ul style="list-style-type: none"> • Grow and maintain formalised affiliates program • Work with comms to maintain quarterly newsletter • Continue to run quarterly meetings
2021	<ul style="list-style-type: none"> • New website layout to increase usable data for targeting effectively on paid advertising and email mailshots - health pros, subtypes of EDS, topic-specific • Type specific pages and comprehensive management and QOL resources • 20% growth on social media audience communities 	<ul style="list-style-type: none"> • Sustain and grow formal connections with patient groups globally • Work with support groups to educate at regional levels. • Share events and spotlight affiliates and their work on our social media and website • Continue quarterly newsletter & meetings
	TRANSLATIONS	FUNDRAISING
2020	<ul style="list-style-type: none"> • Introduce virtual translations and make available for post viewing • At least 4 languages for each event we do translate 	<ul style="list-style-type: none"> • Successful May Awareness Campaign - growth on 2019 • Increase community giving • Introduce Build a Bridge theme to the End of year Campaign
2021	<ul style="list-style-type: none"> • Live translations for every in person or virtual event we do into at least 4 different languages • Include Arabic and Hindi and Chinese where possible 	<ul style="list-style-type: none"> • Introduce Research For Our Futures Campaign • Growth on Build a bridge End of Year Campaign • Complete data migration and assist with the move to Salesforce • Complete audits so able to broadly solicit funds • Growth on May Campaign on 2020 • Develop year round campaign for individual fundraisers • Begin development of major gifts pipeline

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ADVOCACY & CARE

DIVERSITY AND INCLUSION

COMMUNITY SUPPORT

- Hire Diversity and Inclusion Coordinator that will project manage this project
- Develop Coalition of external experts & Contributors
- Create dedicated website page for showing our efforts
- Increasing patient stories to be diverse & inclusive

- Continue to provide information and support for patients and families
- Expand resources for COVID19
- Cont

- Expansion into new communities, development / extension of existing relationships
- Connecting with more diverse global groups: South America, Africa, Southeast Asia, China
- Freely share resources for translation into at least 4 languages
- Sustain and grow BDB Campaign

- Continue to provide information and support for patients and families
- Grow Helpline staffing - improve 24-hr cover, and
- Increase capacity to work in languages other than English, utilising volunteers.
- Grow Inspire members by 20%
- Grow & Sustain Let's Chat support groups
- Grow & Sustain Loose Connections

VOLUNTEER PROGRAM

PROFESSIONALS DIRECTORY

- Project Plan the introduction of a formal volunteer structure and program, including resources needed to support volunteers, single database, new volunteer booklet, and training and support for the variety of roles.

- Expand the professionals directory

- Introduce the volunteer program in to all aspects of Society activities and functions.

- Expand the professionals directory, alongside development of a Professionals Membership.

2020

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2020

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