GOODHOPE EHLERS-DANLOS SYNDROME (EDS) PROGRAM

REFERRAL PACKAGE

In order to request assessment for adults at the GoodHope EDS Program at Toronto General Hospital, please complete the form below and append the requested documentation.

Fax complete referral package to **416-340-3792**. Due to a very high volume of referrals, only patients for whom a complete referral package is received will be triaged to determine if they are suitable to be seen in the EDS Program. We encourage you to work with your patient to complete the referral package.

Please make special note of the **items marked with an ****, which are **required accompanying documentation**. Incomplete referral packages will not be triaged.

Referring physician information:

Name	
Specialty	
Billing number	
Are you the active primary care provider?	☐ YES ☐ NO Please note we only accept patients with an active primary care provider (see last page)
Mailing address	
Telephone	
Fax	
Email	

Patient information:

Name	
Date of birth (month/day/year)	
OHIP number	
Mailing address	
Telephone	

Name / DOB	

Reason for referral

Suspected diagnosis of EDS

Please indicate what makes you and your patient suspicious of the diagnosis:

If your patient has a Known diagnosis of EDS:

We require clinical documentation, specialist reports and genetic testing if available

What type of EDS has your patient been diagnosed with? _____

What is the year of diagnosis? _____

What is the goal of this referral?

All referrals require a 2D echocardiogram report in order to triage

Referrals without 2D echo are considered incomplete and will be sent back to you

Echo should be within last 3 years

Please also send if available:

- Consultation reports from any pertinent specialists
- For patients with a previous diagnosis: Detailed diagnostics notes +/- genetic testing results
- Recent imaging (i.e. MRI) or other pertinent investigations (i.e. EMG)

Name / DOB	

All patients referred to the GoodHope EDS Clinic are required to provide Beighton score measurements using the following Health Canada approved hypermobility screening tool: **Hypermobility Assessment Tool (University Health Network)**

The **Hypermobility Assessment Tool** is a smart phone-based app available for Apple or Android that your patient must download from the Google Play Store or Apple Store. This tool is used to assess the patient's current level of hypermobility. This screening can be completed from the patient's own home or physician's office if they require assistance.

Please have your patient complete the hypermobility assessment using the **Hypermobility Assessment Tool** and **include the pdf copy of results as part of the referral package. Referral packages without the Hypermobility Assessment Tool results will not be accepted.**

Apple

Android

The Hypermobility Assessment Tool (HAT) is a screening tool used to support triage and does not confirm a diagnosis of G-HSD or EDS. HAT results may overestimate hypermobility; the Beighton score will be reassessed in-person by a clinician using a goniometer to confirm findings.

Name / DOB	

Clinical checklist for genetically identifiable EDS subtypes:

Mark if present		**Documentation required
	Developmental dysplasia of hip	**Treatment?
	Aneurysm or dissection of any vessel?	**Which vessel(s)?
	Family history of genetically identifiable Ehlers-Danlos Syndrome? (NOT hypermobile EDS)	Relationship to patient? Type of EDS diagnosed?
	Intestinal rupture in the absence of known diverticular disease or other bowl issues	**Specify:
	Uterine rupture during the third trimester of pregnancy	**Specify:
	A sudden engorgement and redness of the eye (called arteriovenous carotid cavernous sinus fistula) in the absence of trauma	**Specify
	Skin hyperextensibility/abnormally stretchy skin ***See here for how to accurately assess skin hyperextension*** See https://www.edsgoodhope.ca/skin-hyperextensibility	**Pinch and lift the cutaneous skin layers at:** Volar surface of forearm _____ cm Dorsum of hand _____ cm
	Atrophic scarring (not stretchmarks) *** See here for examples of atrophic scarring* See https://www.edsgoodhope.ca/atrophic-scarring	Specify sites:
	**Congenital malformation (i.e. club foot)	Specify:

Name/ DOB	

GoodHope EDS Exclusion criteria:

If your patient has any of the following, they will require a more comprehensive connective tissue assessment outside of the GoodHope EDS clinic.

Please refer your patients to your local medical genetics clinic for assessment of CONNECTIVE TISSUE DISORDER (NON-EDS) if they have any of the following:

1. A first-degree relative with another genetically confirmed connective tissue disorder (eg. Marfan or Loeys-Dietz syndrome)
2. An abnormal echocardiogram (e.g. dilatation of aorta, congenital heart defects)
3. Unexplained aneurysm(s) of thoracic aorta, or brain OR first degree relative with aneurysm under age 60 at diagnosis
4. History of any arterial dissection
5. Severe scoliosis (requiring intervention)
6. Unexplained spontaneous pneumothorax
7. Distinctive facial features including hypertelorism (measure interpupillary distance and include with referral) and/or bifid uvula and/or cleft palate
8. Tendon ruptures without trauma (not sports-related)
9. Congenital heart defects or congenital anomalies
10. Craniosynostosis

Name/ DOB	

Required: Primary care provider who will provide ongoing care

*Patient **MUST** have an active primary care practitioner in order to be assessed at the GoodHope EDS program. We are unable to see patients without an active primary care provider. Referrals without active primary care provider will be declined.

** All patients will have diagnosis assessed and confirmed/ruled out by the GoodHope EDS program. Only patients who diagnoses can be confirmed/verified by the GoodHope EDS program will be eligible to receive services within the program.

Referring clinician
By signing this referral, you confirm that you are actively following this patient and agree to work with the patient and the GoodHope EDS team to consider the recommendations for care provided by the GoodHope EDS program

Referring Clinician:

☐ Primary care provider

☐ Specialist

_____
Signature

_____
Print Name

_____
Fax number

_____
Date (mm/dd/yy)

Primary Care Practitioner information (if not referring clinician)

_____
Print Name

_____
Fax number

☐ Patient does not have an active primary care provider