Síndrome de Ehlers Danlos e Transtorno de Hipermobilidade Articular no Brasil e no Mundo

Dra KALINY Cristine TREVEZANI de Souza

Membro do Comitê de Hipermobilidade e Dor da Sociedade Brasileira de Estudos da Dor

Membro Revisor do Consórcio Internacional de Ehlers Danlos

EUA

childrenshospital.org/conditions/ehlers-danlos-syndrome#:~:text=Ehlers-Danlos%20syndr...

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Ehlers-Danlos Syndrome (EDS)

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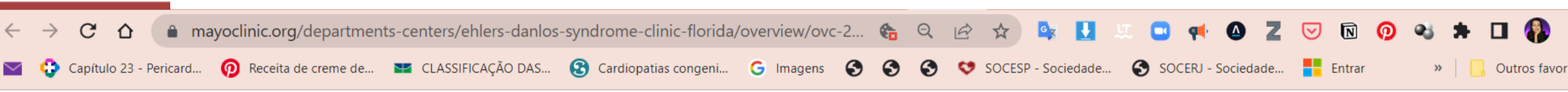

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Ehlers-Danlos Syndrome Clinic in Florida

Overview

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The Ehlers-Danlos Syndrome (EDS) Clinic on Mayo Clinic's campus in Jacksonville, Florida, offers

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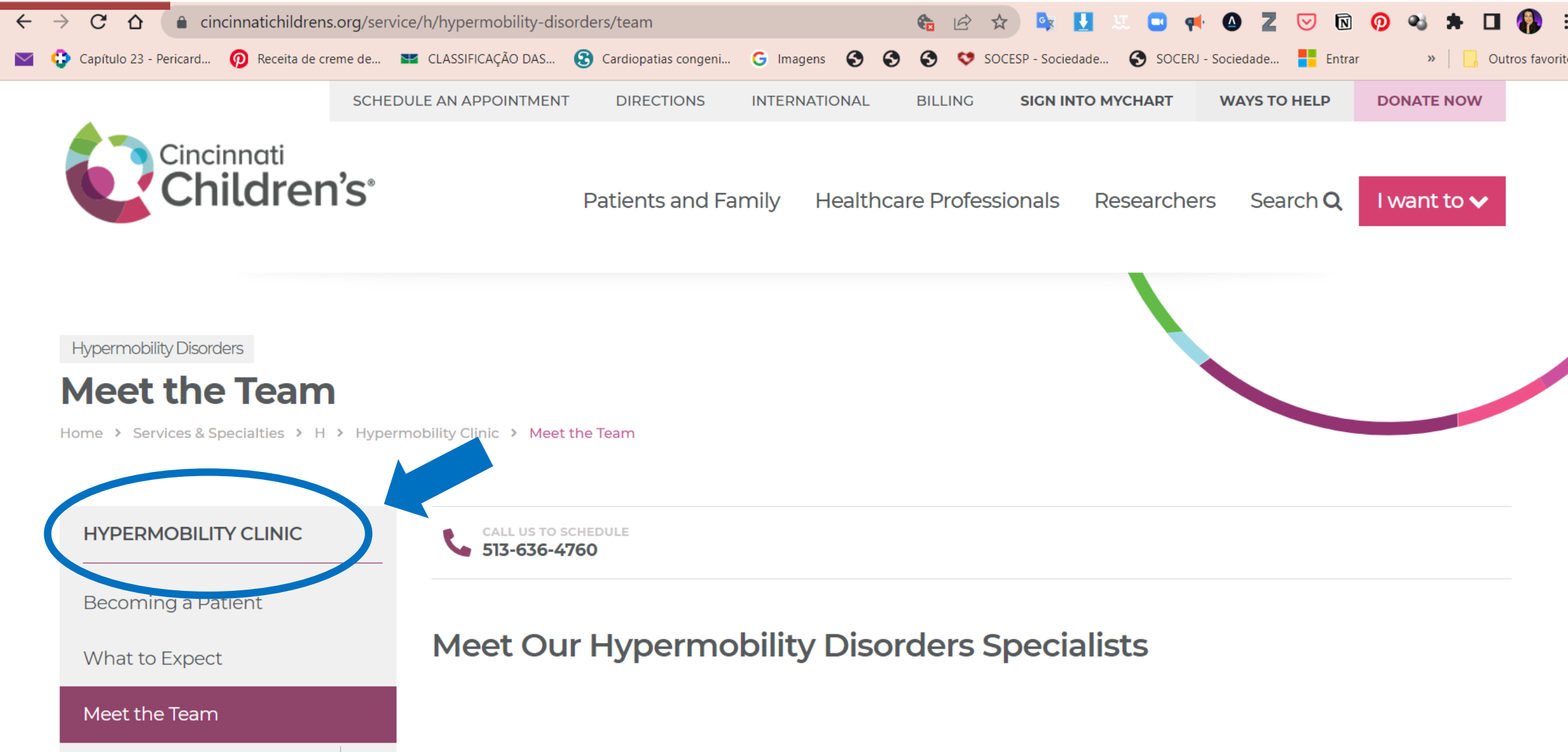
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iuhealth.org/find-medical-services/connective-tissue-disorders

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Connective Tissue Disorders

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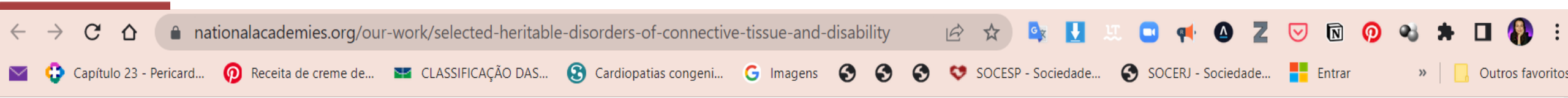

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Selected Heritable Disorders of Connective Tissue and Disability

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The U.S. Social Security Administration has requested the National Academies of Sciences, Engineering, and Medicine establish an ad hoc committee to review certain heritable conditions related to connective tissues, including but not necessarily limited to Ehlers-Danlos syndrome and Marfan syndrome. The Committee will use published evidence and professional experience to develop a report that will examine the diagnosis, treatment, and prognosis of the selected conditions, as well as levels of associated

Austrália

healthdirect.gov.au/ehlers-danlos-syndrome

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Ehlers-Danlos syndrome

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What is Ehlers-Danlos syndrome?

Symptom checker

Worried about your health?

Select a symptom, answer some questions, get advice.

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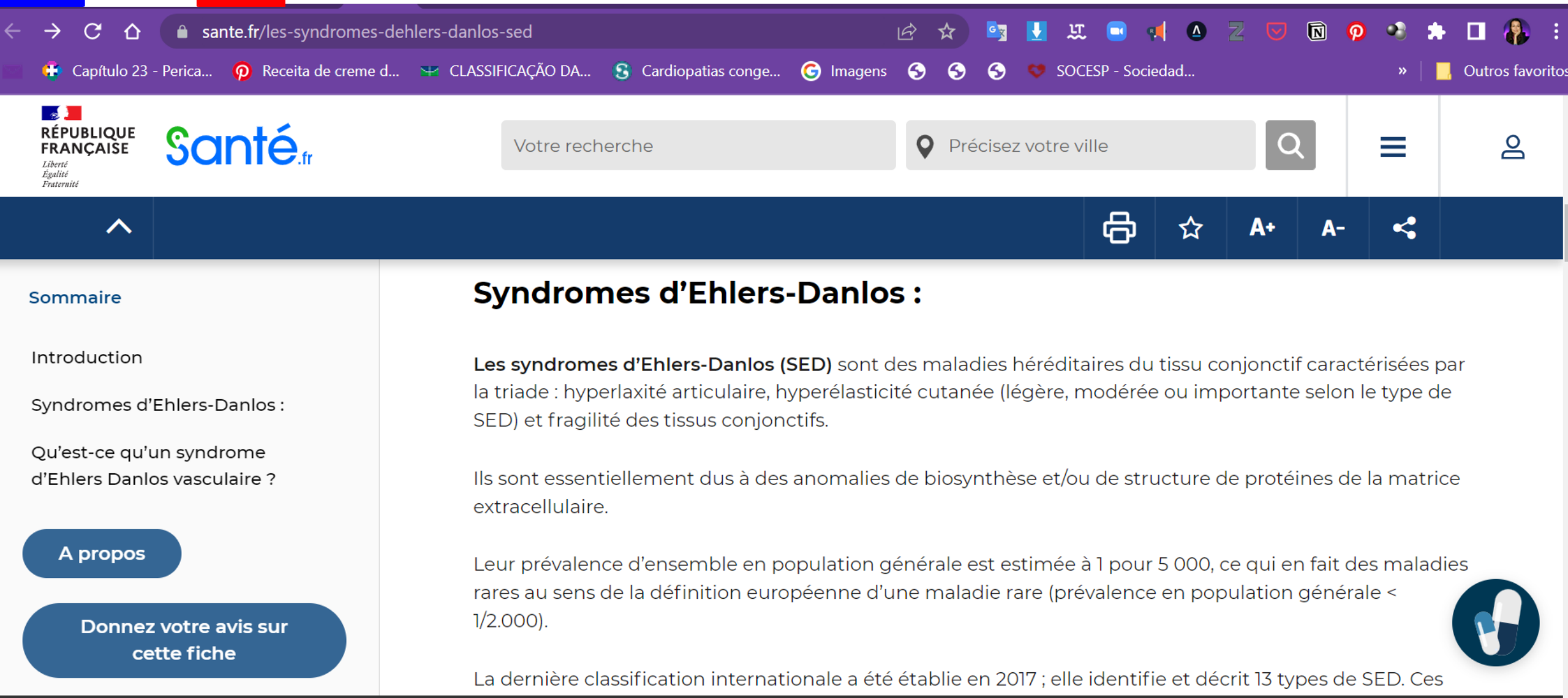
sante.fr/les-syndromes-dehlers-danlos-sed
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Sommaire
Introduction
Syndromes d'Ehlers-Danlos :
Qu'est-ce qu'un syndrome d'Ehlers Danlos vasculaire ?
A propos
Donnez votre avis sur cette fiche
Syndromes d'Ehlers-Danlos :
Les syndromes d'Ehlers-Danlos (SED) sont des maladies héréditaires du tissu conjonctif caractérisées par la triade : hyperlaxité articulaire, hyperélasticité cutanée (légère, modérée ou importante selon le type de SED) et fragilité des tissus conjonctifs.
Ils sont essentiellement dus à des anomalies de biosynthèse et/ou de structure de protéines de la matrice extracellulaire.
Leur prévalence d'ensemble en population générale est estimée à 1 pour 5 000, ce qui en fait des maladies rares au sens de la définition européenne d'une maladie rare (prévalence en population générale < 1/2.000).
La dernière classification internationale a été établie en 2017 ; elle identifie et décrit 13 types de SED. Ces

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sheffieldchildrens.nhs.uk/services/clinical-genetics/ehlers-danlos-syndrome/

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Ehlers-Danlos Syndrome Service
Department of Clinical Genetics
OPD2
Northern General Hospital
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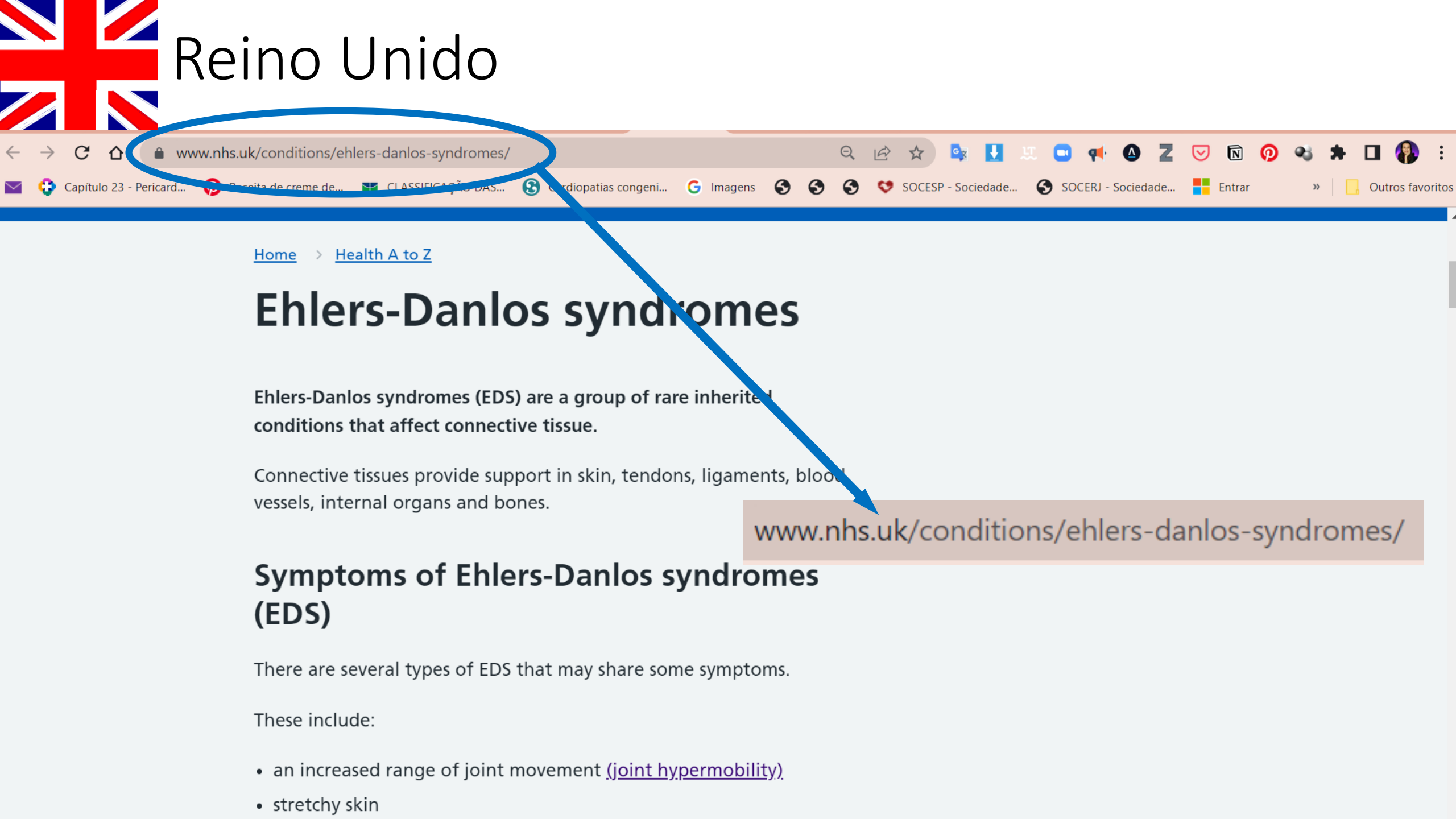
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Ehlers-Danlos syndromes
Ehlers-Danlos syndromes (EDS) are a group of rare inherited conditions that affect connective tissue.
Connective tissues provide support in skin, tendons, ligaments, blood vessels, internal organs and bones.
www.nhs.uk/conditions/ehlers-danlos-syndromes/
Symptoms of Ehlers-Danlos syndromes (EDS)
There are several types of EDS that may share some symptoms.
These include:
an increased range of joint movement (joint hypermobility)
stretchy skin

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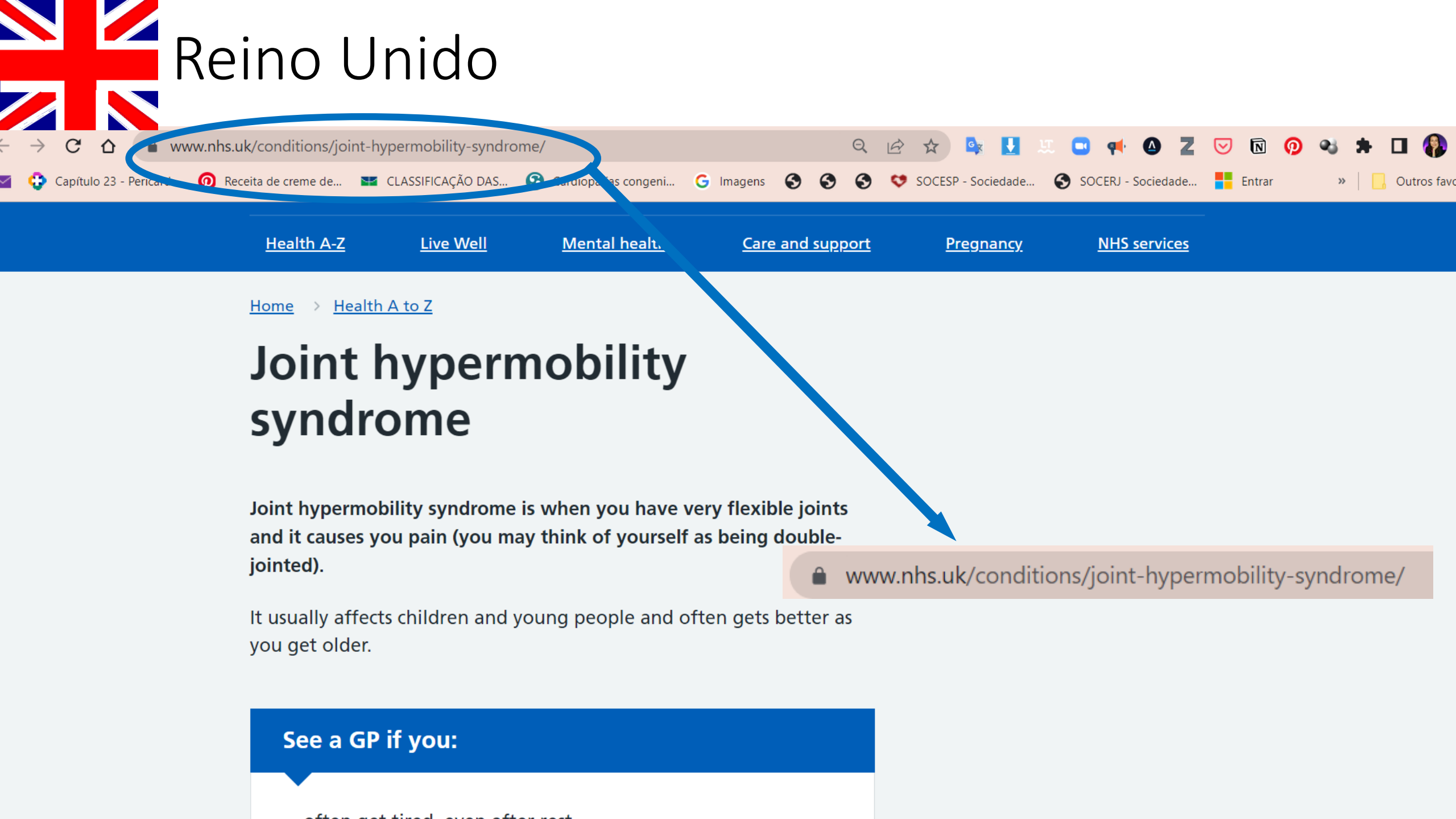
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Joint hypermobility syndrome
Joint hypermobility syndrome is when you have very flexible joints and it causes you pain (you may think of yourself as being double-jointed).
It usually affects children and young people and often gets better as you get older.
See a GP if you:
www.nhs.uk/conditions/joint-hypermobility-syndrome/

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nhsggc.org.uk/kids/resources/health-a-z-resources/advice-for-joint-hypermobility-in-children/

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Advice for Joint Hypermobility in Children

Most children are very bendy compared to older people, as children get older their joints become less bendy. Hypermobility refers to an increased range of movement in multiple joints, for their age.

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University of BRISTOL

KING'S College LONDON

North Bristol NHS Trust NHS

Royal National Hospital for Rheumatic Diseases NHS

Physiotherapy for Hypermobility Trial (PHyT)

Patient Biographical Details

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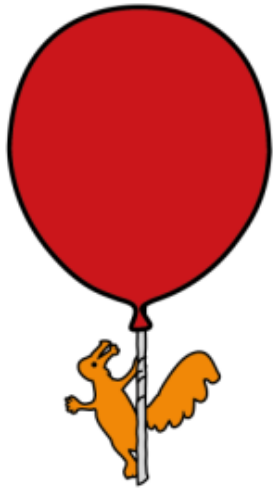

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Occupational Therapy Department

Hypermobility

Information for parents, carers and schools

Introduction

All joints have varying ranges of movement. Ligaments and muscles provide a joint with stability and allow movement. Children who are hypermobile have too much movement around their joints. The looseness of the supporting structures lead to joint instability. Excess movement may cause brief discomfort, pain and swelling. A growth spurt, lack of exercise or an accident can increase symptoms.

If there is an underlying reason for joint hypermobility, this will be investigated by the doctors. Therapy advice will remain the same, regardless of the reason for the hypermobility.

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Hypermobility information and advice

NHS
Lancashire & South Cumbria
NHS Foundation Trust

Children with **hypermobile joints** have too much movement in their joints. This can occur with just a couple of joints or all joints. A joint is the place on the body where two bones meet. Often even normal activities that put stress on loose joints will irritate them.

For some children hypermobility can cause the symptoms described below. A growth spurt, lack of exercise, illness or an accident can sometimes increase these symptoms:

Fatigue
Children may complain of a general tiredness and fatigue, because they are working very hard to maintain positions and move due to laxity in the joints. Children may also experience joint or muscle fatigue.

Pain
Children often experience joint pain, again because their joints and muscles are working harder to stabilise the joint and move throughout the day.
Repetitive activities may cause pain due to muscle fatigue and should be paced and regular rest breaks scheduled.

Difficulty with activities
Children may have difficulties with pencil grip, managing clothes fastenings or manipulating objects. They may be slower to complete activities than their peers.

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Children & Young People's Physiotherapy

NHS
Gloucestershire
Care Services
NHS Trust

Hypermobility in Children: Information for parents

What is hypermobility?

Hyper means 'more' and mobility refers to movement, so hypermobility means 'more movement'.

Ligaments hold joints steady and prevent excess joint movement. In hypermobility these ligaments are more lax and therefore allow more movement at the joints.

Hypermobility may affect just one joint or many joints. It is not an illness or disease and is a normal variation.

How common is hypermobility?

Encourage normal everyday activities such as swimming, cycling, PE and dance.

Pacing

If your child gets muscle pain following activity do not stop them from being active as this is required to build muscle strength. Instead, pace the activity so that it builds gradually to a level that is manageable.

Try not to do too much activity in one day. Instead, space it out little and often throughout the week. The pain from hypermobility is often a result of muscle fatigue. A warm bath or hot water bottle may help soothe this muscle pain.

Japão

nanbyou.or.jp/entry/4801

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エーラス・ダンロス症候群（指定難病168）

えーらすだんろすしょうこうぐん

病気の解説（一般利用者向け) | 概要・診断基準等（厚生労働省作成) | よくある質問

「厚生労働省作成の概要・診断基準等及び臨床調査個人票」（PDF版）はこちらにあります。

1.「エーラス・ダンロス症候群」とはどのような病気ですか

皮膚、関節の過伸展性、各種組織の脆弱性（もろさ）を特徴とする遺伝性疾患です。1901年にエーラス先生が、1908年にダンロス先生が報告したのが始まりです。2017年に発表された国際分類・命名法では、12の病型（古典型、類古典型、心

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50音別索引

告示番号順索引

(Ehlers-Danros Shokougun) Síndrome de Ehlers-Danlos

Explicação da doença | Esquema, critérios diagnósticos, etc. | Formulário individual de inquérito clínico 1 2 3 4 5 6 7

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[Grupo de Pesquisa] Entendendo a história natural e as complicações de toda a fase da vida da síndrome de anomalia congênita: uma lista de grupos de pesquisa de abordagem, incluindo fenotipagem reversa

Canadá

sickkids.ca/en/care-services/clinics/ehlers-danlos-syndrome-clinic-eds/

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Ehlers-Danlos Syndrome (EDS) Clinic

Location: 555 University Avenue, Black Family Wing, 7th floor

Phone: 416-813-7768

Email: eds.clinic@sickkids.ca

Fax: 416-813-6770

About the Clinic

The mission of the Ehlers-Danlos Syndrome (EDS) Clinic is to support patients and families living with EDS by providing timely diagnosis, coordination of medical care, education and expertise in the treatment and management of EDS.

Canadá

uhn.ca/Medicine/Clinics/Ehlers-Danlos_Syndrome_Clinic

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GoodHope Ehlers-Danlos Syndrome Clinic

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Location

Toronto General Hospital

Eaton Building – 5th Floor

Contact

Phone: 416 340 4800 ext. 6536

Referral Fax: 416 340 3792

Hours

Monday – Friday

8:00 am – 4:00 pm

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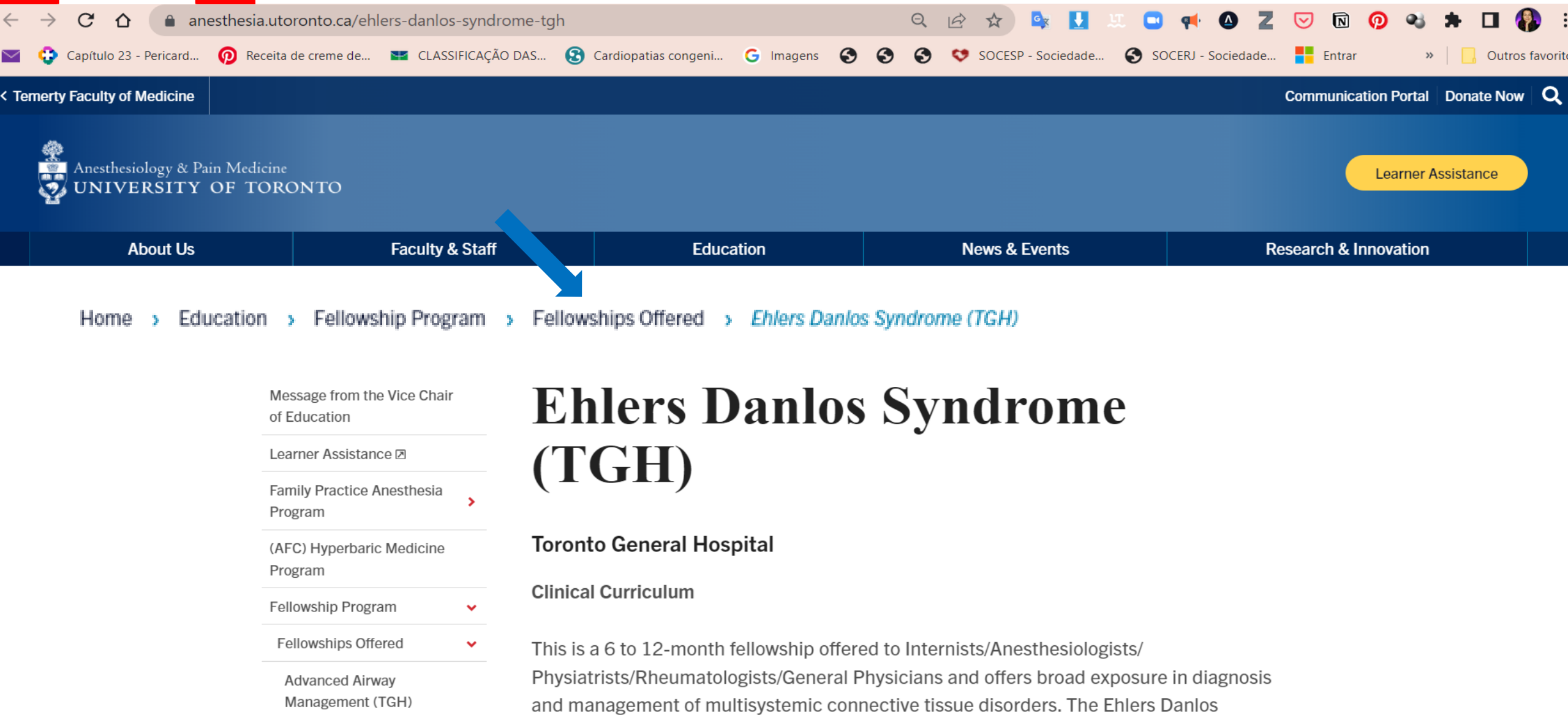
anesthesia.utoronto.ca/ehlers-danlos-syndrome-tgh
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This is a 6 to 12-month fellowship offered to Internists/Anesthesiologists/ Physiatrists/Rheumatologists/General Physicians and offers broad exposure in diagnosis and management of multisystemic connective tissue disorders. The Ehlers Danlos

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