THE MARFAN FOUNDATION'S
39 CONFERENCE Chicago
The Marfan Foundation
Loeys-Dietz Syndrome Foundation
The VEDS Movement
JULY 13-16, 2023

HEALTH FAIR APPLICATION 2023

IN ASSOCIATION WITH

Ann & Robert H. Lurie Children's Hospital of Chicago

Northwestern Medicine

INSTRUCTIONS

The Health Fair Application consists of two parts: 1) this application, including the signed Participant Consent (on page 11); and 2) your pertinent medical records. Applications will be accepted on a rolling basis; pertinent medical records must be received by June 1. Applicants who submit by April 14 will be notified about the status of a Health Fair appointment by May 15. Priority will be given to first-time attendees to the Health Fair as well as other criteria. Submitting the application does not guarantee an appointment. If you have any questions, please contact Lauren May (see below).

1. **The Application Form**
If you are submitting an application for more than one family member, please complete separate forms for each person. Completed applications must be uploaded to Marfan.org/conference/hfapp/.

2. **Medical Records**
Contact your healthcare providers to obtain recent pertinent medical records (see page 10). Records must be sent to Lauren May by June 1 using the contact information below. Records in the form of CDs (e.g., echos, MRIs, x-rays, etc.) must be mailed to the address below by the same deadline.

Lauren May
The Marfan Foundation
22 Manhasset Avenue
Port Washington, NY 11050
Attn: Marfan Conference

Email: lmay@marfan.org
Fax: 516-883-8040

You must be registered for the Conference to attend the Health Fair. However, if you are applying for a scholarship, please do **NOT** register for the conference until you have received your scholarship determination. You may submit a Health Fair application prior to registering for the Conference.

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Name of person to be evaluated:

I. CONTACT INFORMATION

Relationship to person to be evaluated: ☐ Self ☐ Parent/Guardian ☐ Other _____

Last Name:

First Name:

Street Address:

City: State: Zip: Country:

Home Phone:

Work Phone:

Cell Phone:

Email:

Emergency Contact Name:

Relationship: Phone:

If you are completing this form for someone other than yourself to be evaluated, please complete the rest of this form on their behalf (i.e., "you" = the person to be evaluated).

II. GENERAL INFORMATION

Date of Birth (mm/dd/yy): _____ Age: _____ Pronouns: _____

Gender Identity: _____ Sex Assigned at Birth: ☐ Male ☐ Female

Height: _____ feet _____ inches

Weight: _____

Have you been seen at a previous Marfan Foundation conference? ☐ Yes ☐ No

If YES, when? _____

Do you have health insurance? ☐ Yes ☐ No

Do you smoke? ☐ Yes ☐ No If YES, number of years: _____

Do you drink alcohol? ☐ Yes ☐ No If YES, number of years: _____ drinks/day: _____

Do you use other substances? ☐ Yes ☐ No If YES, please describe: _____

Do you have any allergies? ☐ Yes ☐ No If YES, please list: _____

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Name:

GENERAL INFORMATION CONTINUED

Do you have a primary medical doctor? (Check one) ☐ Yes ☐ No If YES, please provide:

Physician Name:

Street Address:

City: State: Zip:

Phone: Fax:

Do you have a physician with expertise in treating Marfan/LDS/VEDS? (Check one) ☐Yes ☐No

If YES, please provide:

Physician Name:

Street Address:

City: State: Zip:

Phone: Fax:

Please list the top 3–5 questions you would like answered at the Health Fair:

1.

2.

3.

4.

5.

Current Medications:

Medication	Dosage	x per day	Years	Months

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III. DIAGNOSIS INFORMATION

Have you received a formal diagnosis? ☐ Yes ☐ No If YES, with which condition?

- ☐ Marfan syndrome
- ☐ Familial aortic aneurysm
- ☐ VEDS
- ☐ Sphrintzen-Goldberg syndrome
- ☐ EDS - Other
- ☐ Beals syndrome
- ☐ Loeys-Dietz syndrome
- ☐ Other:

If YES, please provide:

When (mm/dd/yy): Age at diagnosis:

Physician:

Institution/Hospital:

Do you question the diagnosis received from your physician? ☐ Yes ☐ No

Please indicate which of the following your diagnosis was based on (check all that apply):

- ☐ Aortic dilation
- ☐ Arterial dissection
- ☐ Skeletal features
- ☐ Organ rupture
- ☐ Lens dislocation
- ☐ Arteriovenous carotid sinus fistula
- ☐ Family history
- ☐ Easy bruising
- ☐ Genetic mutation
- ☐ Arteries that twist
- ☐ Wide or split uvula
- ☐ Wide spaced eyes

Please indicate which of the following physical features you have (check all that apply):

- ☐ Hypermobile joints (double joints)
- ☐ Stretch marks
- ☐ Contractures – toes (hammer toes)
- ☐ Hernias
- ☐ Contractures – fingers
- ☐ Migraine headaches
- ☐ Spontaneous pneumothorax (collapsed lung)
- ☐ Thin translucent skin

Please list any genetic variants identified (pathogenic or VUS) on your genetic testing report(s), including the gene, specific gene variant, and the classification, if known. You may also submit test results, if you have them.

If genetic testing was negative (normal), please list the genes tested:

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IV. CARDIAC HISTORY

Have you experienced or been told you have any of the following?

- ☐ Aneurysm
- ☐ Aortic stenosis
- ☐ Bicuspid aortic valve
- ☐ Aortic root/ascending aortic dissection
- ☐ Descending aortic dissection
- ☐ Aortic root replacement surgery
  - ☐ Valve-sparing procedure
  - ☐ Valve replacement procedure
- ☐ Endocarditis (heart valve infection)
- ☐ Mitral valve prolapse
- ☐ Mitral valve regurgitation
- ☐ Tricuspid valve disease
- ☐ High cholesterol
- ☐ History of chest pain
- ☐ Hypertension
- ☐ Irregular heart beats
- ☐ Palpitations

Do you currently have any symptoms? ☐ Yes ☐ No If YES, please describe:

Have you had heart, vascular, or aortic surgery before? ☐ Yes ☐ No

If YES, please describe:

When: Where:

What type of surgery:

Have you had an echocardiogram? ☐ Yes ☐ No If YES, please provide:

Date of Last Test (mm/yy): Result:

Have you had a CT scan? ☐ Yes ☐ No If YES, please provide:

Date of Last Test (mm/yy): Result:

Have you had an MRI? ☐ Yes ☐ No If YES, please provide:

Date of Last Test (mm/yy): Result:

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V. ORTHOPEDIC HISTORY

Have you experienced or been told you have any of the following?

- ☐ Dural ectasia
- ☐ Foot pain
- ☐ Harrington rods
- ☐ Joint replacement
- ☐ Spondylolithesis (vertebral slipping)
- ☐ Other joint dislocations
- ☐ Pectus surgery
- ☐ Flat feet
- ☐ Kyphosis
- ☐ Hip deformity
- ☐ Scoliosis
- ☐ Other joint surgery
- ☐ Pectus deformity

VI. LOEYS-DIETZ SYNDROME

If you have been given a diagnosis of Loeys-Dietz syndrome or if it is suspected, please complete this section. If not, please skip to the next section.

Have you experienced any of the following?

- ☐ Aneurysm/dissection other than the aorta
- ☐ Aortic root aneurysm
- ☐ Arterial tortuosity
- ☐ Bicuspid aortic valve
- ☐ Cervical spine problems
- ☐ Cleft palate
- ☐ Club foot
- ☐ Congenital heart defect
- ☐ Craniosynostosis
- ☐ Food allergies
- ☐ Gastrointestinal problems
- ☐ Hollow organ rupture (uterus, spleen)
- ☐ Skin problems (easy bruising, wide scars, etc.)
- ☐ Osteoporosis
- ☐ Wide or split uvula

VII. DENTAL HISTORY

Would you be interested in a dental evaluation? ☐ Yes ☐ No
If YES, please describe your dental issues:

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VIII. EYE HISTORY

Are you interested in an eye evaluation? ☐ Yes ☐ No

Are you: ☐ Near-sighted (can't see distance) ☐ Far-sighted (can't see close)

Do you wear: ☐ Eyeglasses ☐ Contact lenses

Date of your last slit lamp exam: _____

Have you experienced a lens dislocation/retinal detachment? ☐ Yes ☐ No

Do you have: ☐ Cataracts ☐ Glaucoma

If YES, how long have you had cataracts or glaucoma? _____

When was your last eye glasses or contact lens prescription change? _____

Did you ever need eye patching? ☐ Yes ☐ No

Have you ever had eye surgery? ☐ Yes ☐ No

If YES, please indicate below which surgery and when it was done:

SURGERY	YEAR DONE
☐ Eye muscles surgery	_____
☐ Lens removal	_____
☐ Cataract surgery	_____
☐ Laser surgery	_____
☐ Retinal detachment surgery	_____

Have you experienced any of the following?

☐ Double vision

☐ Shadows

☐ Spots or flashing lights

☐ Visual field deficits

☐ Other: _____

Are you aware of, or seeing a doctor for, any other eye problems? ☐ Yes ☐ No
If YES, please describe:

_____

_____

_____

_____

What questions do you wish to discuss or do you have specific concerns?

_____

_____

_____

_____

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IX. PULMONARY HISTORY

Have you experienced any of the following?

Shortness of Breath ☐ Yes ☐ No
If YES, ☐ with activity ☐ at rest

Pneumothorax (collapsed lung) ☐ Yes ☐ No
If YES, number of pneumothoraces: ☐ 1 ☐ 2-5 ☐ >5
☐ One side ☐ Both sides

Asthma ☐ Yes ☐ No
If YES, do you use ☐ steroid inhalers ☐ bronchodilators
(albuterol, atrovent, combivent, respimat, Spiriva, etc.)

Pulmonary Function Tests ☐ Yes ☐ No
If YES, please provide date of last test: _____
Results: _____

Sleep Apnea ☐ Yes ☐ No

Chest Pain ☐ Yes ☐ No

X. PAIN MANAGEMENT

Please describe current pain issues:

Pain Level—circle the number which best describes your pain on a scale of 1-10, with 1 being lowest and 10 being highest.

lowest highest

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Frequency ☐ Always ☐ Often ☐ Sometimes ☐ Rarely ☐ Never

Location(s) _____

Triggers _____

Duration _____

Limits to daily living ☐ Yes ☐ No

Describe any treatment you receive for pain:

Prescription Medication _____

Over-the-Counter Medication _____

Physical Therapy _____

Exercise Programs _____

Mindfulness _____

What has been successful in treating your pain?

_____

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Name:

XI. FAMILY INFORMATION

Please list your family members along with their ages and heights below.

CHILDREN

First Name	Age	Height	Sex Assigned at Birth
		' "	
		' "	
		' "	
		' "	
		' "	

SIBLINGS

		' "	
		' "	
		' "	
		' "	
		' "	

HALF-SIBLINGS

		' "		☐ Paternal ☐ Maternal
		' "		☐ Paternal ☐ Maternal
		' "		☐ Paternal ☐ Maternal
		' "		☐ Paternal ☐ Maternal

PARENTS

				If deceased, cause:
		' "		
		' "		

PARENTS' SIBLINGS

		' "		☐ Paternal ☐ Maternal
		' "		☐ Paternal ☐ Maternal
		' "		☐ Paternal ☐ Maternal
		' "		☐ Paternal ☐ Maternal

GRANDPARENTS

				If deceased, cause:
		' "		
		' "		
		' "		
		' "		

Have any of your family members, and which ones, been diagnosed with the following?

☐ Marfan syndrome — Family member: _____
☐ Loeys-Dietz syndrome — Family member: _____
☐ Vascular Ehlers-Danlos syndrome — Family member: _____
☐ Another connective tissue condition — Family member: _____
☐ Aortic disease (dissections/aneurysms) — Family member: _____
☐ Bicuspid aortic valve — Family member: _____
☐ Aortic and/or heart valve surgeries — Family member: _____
☐ Sudden death — Family member: _____
Was an autopsy performed? ☐ Yes ☐ No

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Name:

XII. OTHER

Please list any other operations or hospitalizations you have had:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

XIII. RECORDS

Your medical records are needed in order for a thorough review of your application. Below is a checklist of records that you should provide, if applicable. Latest imaging (within one year) is recommended.

☐ Ophthalmology (eye care) records or dilated slit lamp eye examinations

☐ Echocardiogram (CDs ONLY) with DICOM viewer ON THE CD and the written report

☐ CT, MRA or X-ray images and reports

☐ Genetic test results

☐ Operative reports

☐ Other pertinent medical records

☐ Family member information: autopsy reports and/or photographs if pertinent to evaluation

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PARTICIPANT CONSENT

The Marfan Foundation Health Fair and Conference will be held on July 13-16, 2022, in Chicago, IL. The purpose of the Health Fair is to educate individuals about the risks of Marfan syndrome and related conditions and encourage screening for these conditions. This Health Fair is entirely voluntary and anyone may participate. I understand and agree with the following information about the Health Fair:

- This Health Fair will be run by members of The Marfan Foundation Professional Advisory Board and physicians from Ann and Robert H. Lurie Children's Hospital of Chicago and affiliated physician groups, and/or other Marfan-affiliated specialists. Also participating will be registered nurses, echocardiogram technicians, genetic counselors, and other clinicians affiliated with Ann and Robert H. Lurie Children's Hospital of Chicago (referred to herein along with the physicians and specialists as "Medical Professionals").
- The Medical Professionals involved with this Health Fair are not my personal healthcare providers. The Medical Professionals, Ann and Robert H. Lurie Children's Hospital of Chicago, and The Marfan Foundation are offering this Health Fair solely as a voluntary educational program. This means that I do not have a provider-patient relationship with the Medical Professionals or with The Marfan Foundation or Ann and Robert H. Lurie Children's Hospital of Chicago, and I should contact my personal healthcare provider(s) if I have questions after this Health Fair.
- I understand that my participation in this Health Fair is as a participant and not as a patient. The Medical Professionals may perform a screening on me using an echocardiogram and/or eye exam. The echocardiogram will show the structure of my heart and the eye exam will be a standard eye assessment. If anything causing one or more Medical Professionals concern is identified, the Medical Professional(s) will discuss with me what follow-up is recommended for consideration by my personal healthcare provider(s).
- The screening provided by the Medical Professionals at the Health Fair is not a professional screening, does not constitute professional medical advice or treatment, and is not a substitute for medical advice or treatment. The tests are provided for elective screening purposes only and the results are preliminary and not conclusive. I understand that it is my personal responsibility to follow up on the screening tests and their results and to contact a healthcare provider of my choice for a better understanding of the results of the screen tests and for obtaining medical advice and treatment.
- The Medical Professionals, Ann and Robert H. Lurie Children's Hospital of Chicago, and The Marfan Foundation will respect the confidentiality of my data, including my identity. If I agree to participate in this Health Fair and receive a free medical screening, I understand that neither Ann and Robert H. Lurie Children's Hospital of Chicago, The Marfan Foundation nor the Medical Professional(s) will keep any of the information that I provide or any test results. All information generated at this Health Fair, including without limitation test results, will be given to me so that I can show it to my personal healthcare provider(s). After this Health Fair, I will be solely responsible for such information.
- I understand that no guarantees have been made with respect to the screening services, and in no event will, Ann and Robert H. Lurie Children's Hospital of Chicago, The Marfan Foundation, or the Medical Professionals be liable for any decision made or action taken in reliance upon any screening test provided. I (on behalf of myself, my heirs, representatives and assigns) release and agree to hold harmless Ann and Robert H. Lurie Children's Hospital of Chicago, The Marfan Foundation, and the Medical Professionals, along with their respective affiliates, officers, trustees, employees, representatives, agents, and medical staff, from any and all claims, liabilities and damages (direct or indirect) arising from or relating to my participation in this Health Fair.
- In order to attend the Health Fair, I understand I must follow the COVID-19 policies at Ann and Robert H. Lurie Children's Hospital of Chicago. See https://www.luriechildrens.org/en/patients-visitors/visiting-lurie-childrens/visiting-hours-guidelines/ for more information. Policy is subject to change.

I have read this document. I understand that I may ask questions before signing this document. My signature below indicates that I freely consent to participate in this Health Fair.

Participant Electronic Signature
Please type your First and Last Name

Parent/Legal Guardian[1] Electronic Signature
Please type your First and Last Name

Date

Parent/Legal Guardian[1] Relationship to Participant
(e.g. mother, father, legal guardian)

[1] Parents or legal guardians of participants under age 18, or legal guardians of participants who are unable to act on their own behalf must execute this document.