JOHNS HOPKINS
MEDICINE

New Patient Appointment Questionnaire
Institute of Genetic Medicine, Johns Hopkins University
Cardiovascular Connective Tissue Clinic

Dear Patient/Parent,

Thank you for your interest in having a clinic appointment in the Institute of Genetic Medicine at Johns Hopkins. Because of the expanding field of genetics and growing interest/knowledge of medical professionals and the general public, we have an increasing demand for appointments.

> IMPORTANT: If you are pregnant, OR, have an urgent vascular problem
> please DO NOT complete this packet and call 410-955-0316 (Gretchen MacCarrick)

In order for us to continue to provide excellent care for our patients, we ask that you fill out the attached questionnaire regarding the patient who you are making this appointment for. Once completed, please return the questionnaire back with any additional records by:

Fax: 410-614-9246
Phone: 410-955-3071
Email: CTDinfo@jhmi.edu

Mail: Genetic Counselors--CTD
Institute of Genetic Medicine
Johns Hopkins University
600 N. Wolfe St, Blalock 1008
Baltimore, MD 21287

For appointments in 2018, We have two options for appointments:

1) Genetic counseling appointment for discussion and coordination of genetic testing for aneurysm syndromes, psychosocial counseling, resource identification, for those people with:
   a. known aneurysm/dissection personal histories where no genetic testing has been performed
   b. familial genetic testing when gene mutation is known in the family.
   c. pneumothoraces
   d. arterial aneurysms/dissections
   e. bowel rupture

Generalized management and surveillance is also discussed with appropriate referrals facilitated. *These appointments can typically be scheduled within 1-2 months*

2) Medical evaluation with physical exam, review of specific imaging, and medication management (prescriptions) performed *>>typically schedule within 5-7 months unless urgent concerns*

You can schedule both types of appointments or arrange management follow-up if a genetic diagnosis is made after genetic counseling/testing. Genetic counseling and testing benefits will be checked prior to scheduling. Once we receive your questionnaire and medical records, a genetic counselor will review your information and determine the appropriate physician to see the patient and determine if there are any needed ancillary appointments to be scheduled before or on the day of the appointment. We will do our best to have the patient scheduled as soon as possible, however please be patient as we have a high volume of appointment requests.

Revised: July 2017

Cardiovascular Connective Tissue Clinic Information:

Connective tissue provides support and strength for our joints and organs. Some individuals can have longer bodies, skeletal findings such as long arms, flat feet, scoliosis and flexibility that ultimately are not associated with medical problems or a diagnosable connective tissue disorder. ***We think that around 15% of the population have connective tissue features***. However, some individuals can have more severe involvement of the cardiovascular systems necessitating specialized cardiac and other medical management.

Marfan syndrome: Many individuals are referred to our clinic for consideration of the diagnosis of Marfan syndrome. This disorder has specific findings in the skeletal, cardiovascular and ocular systems. Detailed information can be found at the Marfan Foundation website at www.marfan.org.

If you are being referred to rule out Marfan syndrome, we require the following:

1. Cardiology evaluation with echocardiogram
   a. Pediatric cardiology appointments at the Johns Hopkins University can be scheduled by calling 410-955-9714.
   b. Adult cardiology appointments can be scheduled by calling 443-997-0270
   c. Your primary care physician may have other local resources of Cardiologists for you to consider.

2. Ophthalmology evaluation to assess for lens dislocation. We recommend that you let the scheduler know that a slit lamp exam with dilated eyes required.
   a. Appointments through Wilmer Eye Clinic can be scheduled by calling 410-955-5080.
   b. Your primary care physician may have other local resources of Ophthalmologists for you to consider.

****If echocardiogram shows no dilation of the aorta and eye exam does not show lens dislocation, and if there is no family history of first degree relative with aneurysm/dissection, you/your child would NOT meet criteria for Marfan syndrome and an appointment is likely not indicated.**

Other referrals: If you are being referred for any of the following reasons, you must obtain an echocardiogram prior to scheduling an appointment. These conditions can be associated with aortic disease and will help us triage if you need a genetic counseling appointment versus medical appointment. Please talk to your PCP about a cardiology referral to rule out aneurysm:

1. brain aneurysm
2. arterial aneurysm or dissection (carotid, splenic for example)
3. pneumothorax
4. bowel rupture
5. fibromuscular dysplasia

   -Pediatric cardiology appointments at the Johns Hopkins University can be scheduled by calling 410-955-9714.
   -Adult cardiology appointments can be scheduled by calling 443-997-0270
   -Your primary care physician may have other local resources of Cardiologists for you to consider.

This questionnaire is to be completed if you/your child was referred to the CARDIOVASCULAR CONNECTIVE TISSUE CLINIC. If you/he/she was supposed to be referred a general clinic or another specialty clinic, please contact our office at 410-955-3071 option 1 to be sent another questionnaire.

Patient's Name: ____

Patient's Date of birth: _____/_____/________ **Phone:** ____________________

Name of referring doctor (indicate self-referral if no referring doctor):
Doctor Name: ________________________ **Phone:** ____________________
Address: ____

Reason(s) for appointment:____

Type of appointment requested: ___Genetic Counseling ___Medical evaluation ___Both

1. Has the patient ever seen a genetics specialist before? Yes / No (circle one)
If **YES**, please list the name and the location of this specialist(s) and attach evaluation notes:

____

2. Does the patient have medical records through Johns Hopkins University? Yes / No (circle one)

3. Does the patient have a confirmed diagnosis of a genetic syndrome or is this a rule-in/rule-out appointment request? <u>If there is a confirmed genetic diagnosis, please attach genetic testing results.</u> Please circle the appropriate box:

No confirmed diagnosis
Confirmed diagnosis of:

Marfan syndrome
Vascular Ehlers Danlos Syndrome
Aortic dilation, unknown diagnosis
Loeys Dietz Syndrome
Bicuspid aortic valve and aneurysm
Familial Thoracic Aneurysm
Other: ____

4. It is helpful for us to better understand the patient's <u>MEDICAL PROBLEMS</u>. Please circle YES, NO or NOT SURE for each of the following:
Cardiac and Vascular history:

Recent echocardiogram Yes / No / Not sure
(MUST BE ATTACHED TO SCHEDULE APPOINTMENT)

Recent MRA, CTA or other imaging of the aorta or arteries
(if yes, please attach results) Yes / No / Not sure

Aortic root aneurysm or dilation Yes / No / Not sure
Other aneurysm Yes / No / Not sure
(if yes, which artery? ______________________________)

Aortic dissection Yes / No / Not sure
(if yes, at what age? ______________________________)

Other arterial dissection Yes / No / Not sure
(if yes, which artery and at what age? ____________________)

Ocular problems

Has the patient had a recent eye exam? (if yes, please attach results)	Yes / No / Not sure
-myopia (nearsightedness)	Yes / No / Not sure
-lens dislocation	Yes / No / Not sure
-retinal detachment	Yes / No / Not sure
-eye muscle problem	Yes / No / Not sure

Musculoskeletal problems

-joint hypermobility	Yes / No / Not sure
-joint dislocation or subluxation	Yes / No / Not sure

Skeletal or craniofacial features

-pectus (chest wall) deformity	Yes / No / Not sure
-contractures	Yes / No / Not sure
-scoliosis	Yes / No / Not sure
-hip dysplasia	Yes / No / Not sure
-tall stature, height>97%	Yes / No / Not sure
-clubfoot	Yes / No / Not sure
-craniosynostosis	Yes / No / Not sure
-bifid/broad uvula/cleft palate	Yes / No / Not sure

Other

-postural orthostatic tachycardia syndrome (POTS) or neurally mediated hypotension (NMH)	Yes / No / Not sure
-pneumothorax (collapsed lung)	Yes / No / Not sure
-organ rupture	Yes / No / Not sure
(If yes, which organ and at what age?________________________)	
-recurrent hernias	Yes / No / Not sure
-food allergies or inflammatory bowel disease	Yes / No / Not sure

5. Please list any additional <u>MEDICAL DIAGNOSES</u> that you have (use back of form if necessary)

- ____
- ____
- ____
- ____
- ____

6. Please list any <u>SURGERIES</u> that you have had and age and/or year (use back of form if necessary)

- ____
- ____
- ____
- ____
- ____

7. Has the patient ever had any <u>NON VASCULAR IMAGING</u> (e.g. MRI, CT, X-rays, dexa scans) or <u>LAB TESTS</u> that were abnormal? Yes / No (circle one). If **YES***, *Please include a copy of any abnormal imaging reports and/or lab test results with this and provide details:*

- ______________________________
- ______________________________
- ______________________________

8. Please list ALL doctors/specialists who this patient sees and the reason(s):

- ______________________________
- ______________________________
- ______________________________
- ______________________________

9. It is helpful for us to better understand the patient's <u>FAMILY HISTORY</u>:

Is there anyone else in the family with major health, developmental or cardiovascular concerns? Especially family history of aortic aneurysm, dissection, aortic surgery or sudden unexplained death. If so, please provide information about these concerns and how each person is related to the patient.

a. ______________________________
b. ______________________________
c. ______________________________
d. ______________________________
e. ______________________________

10. Please list medications:

11. Please list allergies:

12. Is there any other important information about the patient we should know prior to scheduling his/her appointment? Please describe:

13. What are the patient's goals for the visit?

JOHNS HOPKINS INSTITUTIONS

AUTHORIZATION FOR RELEASE OF MEDICAL RECORDS TO THIRD PARTIES

- **NOT TO BE USED TO RELEASE PATIENT'S OWN RECORDS TO PATIENT (USE HIPAA FORM A.6.2) OR FOR BILLING RECORDS (USE HIPAA FORM A.2.1.w).**
- **NOT TO BE USED IN CONNECTION WITH HEALTH INFORMATION FROM SUBSTANCE ABUSE TREATMENT PROGRAMS.**
- **AN AUTHORIZATION MAY NOT BE USED TO GRANT DIRECT ACCESS TO ANY ELECTRONIC PATIENT RECORD.**

All items on this authorization must be completed or the request will not be honored. Use "N/A" if not applicable.

For this authorization, "My Health Information" is:

___ Complete Record (other than billing)

___ Other:

For the date(s) of service starting: ____

[insert date(s) of service requested]

I authorize _____ ____

[insert entity]

to disclose My Health Information to _____Institute of Genetic Medicine ______________________________
for GENETIC TESTING/EVALUATION AT JOHN HOPKINS HOSPITAL

My Health Information should be faxed to ___410-614-9246________________________ **OR** sent to:

GRETCHEN MACCARRICK
JOHNS HOPKINS HOSPITAL
BLALOCK 1008
600N. WOLFE STREET
BALTIMORE, MD 21287

I understand there is a charge for copying and handling my request. I understand that all fees will be in compliance with applicable Maryland State guidelines. By signing this authorization, I agree to pay these fees at the time this request is made.

This authorization is valid for one year from date signed, unless I revoke this authorization, or unless an earlier date is specified here: _______________.

I understand that once My Health Information is disclosed as requested in this authorization My Health Information may no longer be protected by federal and state privacy laws and potentially may be re-disclosed by the person who is receiving my information.

I am not required to sign this authorization. Johns Hopkins does not condition treatment, payment, benefit eligibility or enrollment activities on the signing of this form. If I do not sign this authorization, Johns Hopkins will not disclose My Health Information as requested. I will receive a copy of this authorization upon signature.

I may revoke this authorization at any time in writing by following the guidelines set forth below.

Patient Name: ____
(first) (m. initial) (last)

Signature: ______________________ **Date:** ______________

Address: ____
(street address)

____
(city) (state) (zip code)

Phone: ____
(area code) (home phone number)

Medical Record #: ____

Birth Date: ____________________

For healthcare agent/court appointed guardian/surrogate/parent/informal kinship care relative or Personal Representative of the deceased,
(circle one of the above)

I, ______________________ **confirm that I am the representative for the patient as circled above.**
(insert your name)

Representative's Signature: ____

Address: ______________________________________ **Phone:** ______________

If you are the healthcare agent, court appointed guardian, relative providing informal kinship care or court appointed Personal Representative of the deceased, please attach proof of your authority to act on behalf of the patient.

By signing this authorization, I understand that medical records released may contain information related to HIV status, AIDS, sexually transmitted diseases, mental health, drug and alcohol abuse, etc. I understand that release of psychotherapy notes requires an additional authorization.

I may revoke this authorization by mailing or faxing my written request along with a copy of the original authorization to the clinic or department where my authorization was made or to:

Johns Hopkins Privacy Officer
5801 Smith Avenue
McAuley Hall, Suite 310
Baltimore, MD 21209
Fax 410-735-6521

If I am unable to provide a copy of the original authorization with my request to revoke, I will provide the following information.

- Date of the authorization,
- Name,
- Address,
- Phone number,
- Medical record number,
- Date of birth,
- Purpose of authorization,
- A description of the health information covered by the authorization,
- The person or entity authorized to use the data.

If the form was signed by my representative, the request will also include:

- The representative's name,
- Relationship,
- Address and
- Phone number.

I understand that if I am unable to provide all of the above information, Johns Hopkins may not be able to honor my revocation request.

Request for E-mail Communications Between Johns Hopkins Provider and Patient

Patients Are Advised to Think Carefully before Choosing to Send or Receive Personal Information by E-Mail

E-mail is a common and useful form of communication; it is used by almost everyone. However, there are some concerns with using unencrypted e-mail as a means to communicate health information and other personal information.

Before choosing to communicate with your provider by e-mail, you should understand that unencrypted e-mail is not secure—that means that it could be intercepted and seen by others. In addition, there are other risks associated with unencrypted e-mail, such as:

- misaddressed/misdirected messages
- e-mail accounts that are shared with others
- messages forwarded on to others
- messages stored on portable devices having no security

A balance must be struck between making information available and the risk of data loss, misdirection or theft. Judgment should be exercised in all instances when deciding whether to send or receive personal information by unencrypted e-mail. If the decision is to send and receive personal information by e-mail, common sense steps should be taken:

- verifying the correct e-mail address each time used
- if the address is pulled from a directory, double checking to make sure the correct person's address is inserted, particularly with fairly common names
- sending only the minimum amount of information necessary to achieve the purposes of the communication
- considering carefully using alternative forms of communication if you are going to discuss sensitive information
- if you do not wish to have your personal information sent to you by e-mail, contact the sender immediately

If you choose to communicate with more than one provider at Johns Hopkins, you must complete a separate Request for E-Mail Communications form for each provider. Similarly, if you wish to terminate communication by E-Mail, you must contact each provider with whom you have previously submitted a Request form.

Johns Hopkins reserves the right to deny a request for e-mail communication under circumstances permitted by law.

If you still want to arrange to communicate with one or more Johns Hopkins' providers by unencrypted E-Mail, please proceed to page 2.

If this request is being signed in a face to face meeting with your provider, complete Parts 1 and 2 and return the request to the provider or provider's representative.

If this request is being submitted remotely, then Parts 1, 2 and 3 must be completed and the completed form submitted to the provider.

In either case, the provider or provider's representative will complete Part 4 and give a copy of the form to you.

PART 1

Date: ______________________

Patient's Name (print name): ____

Patient's email address (print): ____

Provider's Name (print name): ____

Part 2

The undersigned, being the patient named above, acknowledges that I have received, reviewed and understand the advice to think carefully about using E-mail to communicate personal information. In exchange for the convenience of this form of communication, I am willing to accept the associated potential risks. I represent that I am the patient named above.

Patient's Signature: ____

Part 3

In order to verify the identity of the person communicating remotely, the patient is required to provide some additional personal identifying information, as follows:

Medical Record Number: ____

Date of Birth: ____

Address: ____

Phone Number: ____

Last 4 digits of Social Security Number: ____________________________________

Mother's Maiden Name: ____

Part 4

Provider's email address (print): ____

Provider's Signature: ____