EMERGENCY PREPAREDNESS KIT

Patient Name:

This kit is your tool to help you be prepared in the event of an emergency. We suggest putting the completed packet in a brightly colored envelope or folder so it is easy to find. At home, keep it near the door so it is handy for Emergency Medical Services (EMS) and perhaps tack it up on the wall at work. Also provide a copy of this packet to your Power of Attorney and Healthcare Proxy. Portable USB drives can hold all this information and can be carried on a key chain. Some medical alert services have these drives available with their logo or you can purchase them in any office supply store.

Many people put emergency contact information in their cell phone filed under ICE (In Case of Emergency). Use ICE1, ICE2 and so on. EMS personnel are trained to look for this on your cell phone.

If you need emergency care, it may be helpful for you to call your primary care provider to call ahead on your behalf and notify the doctor in charge of the ER of a possible aortic dissection before you arrive. You or someone close to you may also want to call the ER before you arrive.

CHECKLIST

We recommend that you complete these documents so they are available in case of an emergency. Some of these documents may not apply to you (for instance, not everyone will want a Do Not Resuscitate Order). Remember to update your information regularly.

	Last Updated
Personal Information Form	____________
Medical History	____________
Genetic Testing Results	____________
Medical note/summary from your last appointment with your doctor	____________
Doctor(s) Information	____________
Insurance Information	____________
Family Medical History	____________
Power of Attorney	____________
Healthcare Proxy	____________
Living Will	____________
Do Not Resuscitate Order	____________

Include a copy of the most recent version of each of the following from your doctor

Ultrasound with Written Report	____________
MRI/MRA with Written Report	____________
CT/CTA with Written Report	____________
Blood Work Results	____________

Other resources

Marfan Syndrome Fact Sheet	____________
Medical Alert Bracelet Information	____________
Emergency Alert Card	____________

PERSONAL INFORMATION

First Name: ______________________ Last Name: ______________________

Date of Birth: ______________________ Social Security Number: ________ – ________ – ________

Gender: Male Female Marital Status: ______________________

Contact Information

Home Address: ______________________

City: ______________________ State: ____________ Zip: ____________

Home Phone: ______________________ Work Phone: ______________________

Cell Phone: ______________________ Email: ______________________

Occupation: ______________________ Employer: ______________________

Work Address: ______________________

City: ______________________ State: ____________ Zip: ____________

Health-related Information

Height: ______________ Weight: ______________ Blood Type: ______________

Normal Blood Pressure: ______________ Resting Heart Rate: ______________

Alcohol Consumption (number of drinks consumed): ________ per day per week

Smoking: Non Smoker 1 pack or less/week 2–3 packs/week 1 pack/day More than 1 pack/day

Former Smoker / Date Quit: ______________

Language Information

Language spoken at home: ______________________ Do you need an interpreter? Yes No

If you need an interpreter and the hospital is temporarily unable to provide one, who can they contact to provide assistance?

First Name: ______________________ Last Name: ______________________

Home Phone: ______________ Work Phone: ______________ Cell Phone: ______________

Emergency Contacts

Contact 1 First Name: ______________________ Last Name: ______________________

Address: ______________________ Relationship: ______________________

City: ______________________ State: ____________ Zip: ____________

Home Phone: ______________ Work Phone: ______________ Cell Phone: ______________

Contact 2 First Name: ______________________ Last Name: ______________________

Address: ______________________ Relationship: ______________________

City: ______________________ State: ____________ Zip: ____________

Home Phone: ______________ Work Phone: ______________ Cell Phone: ______________

First Name: ____________________ Last Name: ____________________

Diagnosis

Marfan Syndrome Age at diagnosis: ________

Notes/comments: ____________________

Current Medications (include vitamins/supplements)

1. **Name:** ________ Dosage: ________ Schedule: ________
   Reason: ________
2. **Name:** ________ Dosage: ________ Schedule: ________
   Reason: ________
3. **Name:** ________ Dosage: ________ Schedule: ________
   Reason: ________
4. **Name:** ________ Dosage: ________ Schedule: ________
   Reason: ________
5. **Name:** ________ Dosage: ________ Schedule: ________
   Reason: ________
6. **Name:** ________ Dosage: ________ Schedule: ________
   Reason: ________

If you have additional medications, please list them on page 7 of this form.

Allergies

1. ________
2. ________
3. ________
4. ________
5. ________
6. ________

Cardiac History (Heart)

What cardiac issues do you have or have you previously had? *(e.g., mitral valve prolapse, aortic regurgitation or aortic aneurysm/dissection, etc.)*

Please attach most recent imaging studies.

MEDICAL HISTORY *(continued)*

Ocular History (Eyes)

What ocular issues do you have or have you previously had? *(e.g., lens dislocation, retinal detachment, strabismus, cataracts, etc.)*

Please attach most recent imaging studies.

Orthopedic History (Bones & Joints)

What skeleton and joint issues do you have or have you previously had? *(e.g., scoliosis, dislocations, etc.)*

Please attach most recent imaging studies.

Pulmonary History (Lungs)

What lung issues do you have or have you previously had? *(e.g. asthma, pneumothorax, pulmonary blebs, etc.)*

Please attach most recent imaging studies.

Recent Surgeries /Procedures

What surgeries/procedures have you had? *(e.g., aortic repair, eye surgeries, pectus surgeries, etc.)*

1. Surgery/Procedure: ____________

Location: ____________ Date: ____________

Doctor who performed surgery: ____________ Doctor's phone: ____________

2. Surgery/Procedure: ____________

Location: ____________ Date: ____________

Doctor who performed surgery: ____________ Doctor's phone: ____________

3. Surgery/Procedure: ____________

Location: ____________ Date: ____________

Doctor who performed surgery: ____________ Doctor's phone: ____________

MEDICAL HISTORY *(continued)*

4. Surgery/Procedure: ______

Location: ______ Date: ______

Doctor who performed surgery: ______ Doctor's phone: ______

5. Surgery/Procedure: ______

Location: ______ Date: ______

Doctor who performed surgery: ______ Doctor's phone: ______

6. Surgery/Procedure: ______

Location: ______ Date: ______

Doctor who performed surgery: ______ Doctor's phone: ______

7. Surgery/Procedure: ______

Location: ______ Date: ______

Doctor who performed surgery: ______ Doctor's phone: ______

8. Surgery/Procedure: ______

Location: ______ Date: ______

Doctor who performed surgery: ______ Doctor's phone: ______

If you have additional surgeries/procedures, please list them on page 8 of this form.

Additional Current Medications (include vitamins/supplements)

7. **Name:** ______ Dosage: ______ Schedule: ______

   Reason: ______

8. **Name:** ______ Dosage: ______ Schedule: ______

   Reason: ______

9. **Name:** ______ Dosage: ______ Schedule: ______

   Reason: ______

10. **Name:** ______ Dosage: ______ Schedule: ______

    Reason: ______

11. **Name:** ______ Dosage: ______ Schedule: ______

    Reason: ______

MEDICAL HISTORY *(continued)*

12. **Name:** ________________ Dosage: ________________ Schedule: ________________
    Reason: ____
13. **Name:** ________________ Dosage: ________________ Schedule: ________________
    Reason: ____
14. **Name:** ________________ Dosage: ________________ Schedule: ________________
    Reason: ____
15. **Name:** ________________ Dosage: ________________ Schedule: ________________
    Reason: ____
16. **Name:** ________________ Dosage: ________________ Schedule: ________________
    Reason: ____
17. **Name:** ________________ Dosage: ________________ Schedule: ________________
    Reason: ____
18. **Name:** ________________ Dosage: ________________ Schedule: ________________
    Reason: ____
19. **Name:** ________________ Dosage: ________________ Schedule: ________________
    Reason: ____

MEDICAL HISTORY *(continued)*

First Name: ______________________ Last Name: ______________________

Additional Recent Surgeries /Procedures

What surgeries/procedures have you had (e.g., aortic repair, arterial repair, intestinal surgery, etc)?

9. Surgery/Procedure: ______________________

Location: ______________________ Date: ______________________

Doctor who performed surgery: ______________________ Doctor's phone: ______________________

10. Surgery/Procedure: ______________________

Location: ______________________ Date: ______________________

Doctor who performed surgery: ______________________ Doctor's phone: ______________________

11. Surgery/Procedure: ______________________

Location: ______________________ Date: ______________________

Doctor who performed surgery: ______________________ Doctor's phone: ______________________

12. Surgery/Procedure: ______________________

Location: ______________________ Date: ______________________

Doctor who performed surgery: ______________________ Doctor's phone: ______________________

13. Surgery/Procedure: ______________________

Location: ______________________ Date: ______________________

Doctor who performed surgery: ______________________ Doctor's phone: ______________________

14. Surgery/Procedure: ______________________

Location: ______________________ Date: ______________________

Doctor who performed surgery: ______________________ Doctor's phone: ______________________

15. Surgery/Procedure: ______________________

Location: ______________________ Date: ______________________

Doctor who performed surgery: ______________________ Doctor's phone: ______________________

16. Surgery/Procedure: ______________________

Location: ______________________ Date: ______________________

Doctor who performed surgery: ______________________ Doctor's phone: ______________________

DOCTOR(S) INFORMATION

First Name: ____________________ Last Name: ____________________

Primary Care Physician

First Name: ____________________ Last Name: ____________________

Address: ____

City: ____________________ State: __________ Zip: __________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Geneticist

First Name: ____________________ Last Name: ____________________

Address: ____

City: ____________________ State: __________ Zip: __________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Cardiologist

First Name: ____________________ Last Name: ____________________

Address: ____

City: ____________________ State: __________ Zip: __________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Cardiac Surgeon

First Name: ____________________ Last Name: ____________________

Address: ____

City: ____________________ State: __________ Zip: __________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Ophthalmologist

First Name: ____________________ Last Name: ____________________

Address: ____

City: ____________________ State: __________ Zip: __________

Cell Phone: ______________ Pager: ______________ Fax: ______________

DOCTOR(S) INFORMATION *(continued)*

Orthopedist

First Name: ______________________ Last Name: ______________________

Address: ______________________

City: ______________________ State: __________ Zip: __________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Other Specialist

First Name: ______________________ Last Name: ______________________

Medical Specialty: ______________________

Address: ______________________

City: ______________________ State: __________ Zip: __________

Cell Phone: ______________ Pager: ______________ Fax: ______________

If you have additional doctors, please list them on page 11 of this form.

DOCTOR(S) INFORMATION *(continued)*

First Name: ______________________ Last Name: ______________________

Other Specialist

First Name: ______________________ Last Name: ______________________

Medical Specialty: ______________________

Address: ______________________

City: ______________________ State: ____________ Zip: ____________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Other Specialist

First Name: ______________________ Last Name: ______________________

Medical Specialty: ______________________

Address: ______________________

City: ______________________ State: ____________ Zip: ____________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Other Specialist

First Name: ______________________ Last Name: ______________________

Medical Specialty: ______________________

Address: ______________________

City: ______________________ State: ____________ Zip: ____________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Other Specialist

First Name: ______________________ Last Name: ______________________

Medical Specialty: ______________________

Address: ______________________

City: ______________________ State: ____________ Zip: ____________

Cell Phone: ______________ Pager: ______________ Fax: ______________

Other Specialist

First Name: ______________________ Last Name: ______________________

Medical Specialty: ______________________

Address: ______________________

City: ______________________ State: ____________ Zip: ____________

Cell Phone: ______________ Pager: ______________ Fax: ______________

INSURANCE INFORMATION

First Name: ____________________ Last Name: ____________________

Primary Health Insurance

Type of Policy: EPO HMO PPO POS Other, please specify: ____________________

Authorization required: Yes No Authorization No.: __________ Effective Date: __________

Insurance Company: ____________________

Address: ____________________ Phone: ____________________

City: ____________________ State: __________ Zip: __________

Subscriber: Self Spouse Other, please specify: ____________________

Subscriber First Name: ____________________ Subscriber Last Name: ____________________

Subscriber ID Number: ____________________ Subscriber Date of Birth: ____________________

Subscriber Employer: ____________________

Employer Address: ____________________ Group number: ____________________

Address: ____________________ Phone: ____________________

City: ____________________ State: __________ Zip: __________

Secondary Health Insurance

Type of Policy: EPO HMO PPO POS Other, please specify: ____________________

Authorization required: Yes No Authorization No.: __________ Effective Date: __________

Insurance Company: ____________________

Address: ____________________ Phone: ____________________

City: ____________________ State: __________ Zip: __________

Subscriber: Self Spouse Other, please specify: ____________________

Subscriber First Name: ____________________ Subscriber Last Name: ____________________

Subscriber ID Number: ____________________ Subscriber Date of Birth: ____________________

Subscriber Employer: ____________________

Employer Address: ____________________ Group number: ____________________

Address: ____________________ Phone: ____________________

City: ____________________ State: __________ Zip: __________

FAMILY MEDICAL HISTORY

First Name: ______________________ Last Name: ______________________

Father

- Aortic Dissection
- Aneurysm
- Stroke or TIA
- Asthma
- Blood Disorder (e.g., anemia)
- Congestive Heart Failure
- COPD (chronic obstructive pulmonary disease)
- Coronary Artery Disease
- Diabetes
- Malignancy
- Neuromuscular Weakness
- Obstructive Sleep Apnea
- Pancreatitis
- Peripheral Artery Disease
- Renal Dysfunction
- Seizures
- Thyroid Disease
- Other (please specify): ______________________

Mother

- Aortic Dissection
- Aneurysm
- Stroke or TIA
- Asthma
- Blood Disorder (e.g., anemia)
- Congestive Heart Failure
- COPD (chronic obstructive pulmonary disease)
- Coronary Artery Disease
- Diabetes
- Malignancy
- Neuromuscular Weakness
- Obstructive Sleep Apnea
- Pancreatitis
- Peripheral Artery Disease
- Renal Dysfunction
- Seizures
- Thyroid Disease
- Other (please specify): ______________________

Grandparents

- Aortic Dissection
- Aneurysm
- Stroke or TIA
- Asthma
- Blood Disorder (e.g., anemia)
- Congestive Heart Failure
- COPD (chronic obstructive pulmonary disease)
- Coronary Artery Disease
- Diabetes
- Malignancy
- Neuromuscular Weakness
- Obstructive Sleep Apnea
- Pancreatitis
- Peripheral Artery Disease
- Renal Dysfunction
- Seizures
- Thyroid Disease
- Other (please specify): ______________________

Other Relatives

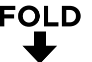
- Aortic Dissection
- Aneurysm
- Stroke or TIA
- Asthma
- Blood Disorder (e.g., anemia)
- Congestive Heart Failure
- COPD (chronic obstructive pulmonary disease)
- Coronary Artery Disease
- Diabetes
- Malignancy
- Neuromuscular Weakness
- Obstructive Sleep Apnea
- Pancreatitis
- Peripheral Artery Disease
- Renal Dysfunction
- Seizures
- Thyroid Disease
- Other (please specify): ______________________

THE MARFAN FOUNDATION

EMERGENCY ALERT CARD

Print out card for every member of household. Fill in patient name and contact information. Cut along dotted line. Fold vertically and horizontally. Carry this card at all times.

FOLD



EMERGENCY ALERT CARD

DO NOT SEND THIS PERSON HOME
UNTIL THE POSSIBILITY OF AORTIC DISSECTION IS RULED OUT.

This patient has Marfan syndrome or a related condition, which places him/her at 250 times greater risk for aortic dissection than the general population.

FOLD

Symptoms of aortic dissection can be variable, relatively minor, and nonspecific. **Chest pain** is the most common symptom, but **pain can also occur in the back and/or abdomen**. The pain may be described as severe or vague, constant or intermittent, migratory, tearing, tightness, or fullness. Other signs and symptoms can include **cardiovascular instability, pulselessness, parasthesia, paralysis, syncope,** or a sense that "something is terribly wrong."

22 Manhasset Ave., Port Washington, NY 11050

800-8-MARFAN | Marfan.org

PATIENT NAME: ____________________

EMERGENCY CONTACT: ____________________

PHONE: ____________________

PHYSICIAN: ____________________

PHONE: ____________________

MEDICAL NOTES: ____________________

☐ MARFAN SYNDROME ☐ RELATED DISORDER, SPECIFY: ____________________

The most definitive tests for aortic dissection are: **CT scan, Transesophageal echocardiogram and MRI.** Choose the one that is most readily available, and expertly performed and interpreted. A normal X-ray does **NOT** rule out the possibility of aortic dissection.

50% OF PATIENTS WITH UNDIAGNOSED AORTIC DISSECTIONS DIE WITHIN 48 HOURS.
Please do not discount aortic dissection until it has been definitively ruled out.

Individuals with Marfan syndrome and related conditions are at **increased risk for rapid progression and poor outcome** from acute ascending or descending aortic dissection. Specialized and aggressive medical and surgical practices that are tailored to this patient population may be needed. If diagnosed with AD, this patient **must be transferred to a tertiary care center** with the capability of definitive surgical management immediately upon stabilization for transport. This is the consensus opinion of the Professional Advisory Board of The Marfan Foundation, and is in keeping with evidence-based guidelines established by the American College of Cardiology Foundation and American Heart Association in collaboration with eight other professional organizations.