



## Are you or your child diagnosed with Marfan syndrome?

Boston University is conducting a study to determine the impact of health care costs in people living with Marfan syndrome. The study aims to assess all of the facets of health care including insurance, cost of medications and the effects on people's lives of these costs. This information may lead to better health care policy for chronic conditions like Marfan syndrome.

The study entails filling out a 25 minute anonymous survey regarding your own experiences with health care costs. You must be 18 years or older and diagnosed with Marfan syndrome or have a child diagnosed with Marfan syndrome to participate in this free survey.



This survey can be accessed at

<http://people.bu.edu/jilliane/>

For more information or a paper copy of the survey please email [marfanhealthcostsurvey@gmail.com](mailto:marfanhealthcostsurvey@gmail.com) or call (617) 638-5908.

Thank you! Your participation is greatly appreciated.

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You may learn more about your rights as a research participant by calling the office of the Institutional Review Board of Boston University Medical Center at (617) 638-7202