



Dear Interested Participant,

We are conducting a research study to look at the health care costs associated with Marfan syndrome, how they affect overall medical care, and the feelings in the Marfan syndrome community about these costs. The study aims to assess all of the facets of health care including insurance, cost of medications and the effects on peoples lives of these costs.

The study involves filling out a survey (that will take approximately 25 minutes) regarding your own experiences with the costs of medical care. Our goal is that this information will lead to greater lobbying and policy reform in the area of health care for chronic conditions.

If you are currently 18 years or older, English-speaking and have a medical diagnosis of Marfan syndrome or have a child with a medical diagnosis of Marfan syndrome please consider participating by visiting,

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

to get further information regarding the study. Should you require a paper copy of the survey, feel free to contact us and a survey with a return envelope will be mailed to you for your completion.

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. If you have questions regarding this study, please contact Jilliane Miller at the contact information below.

Thank you! Your participation is greatly appreciated.

Sincerely,

Jilliane Miller, BS
Genetic Counseling Graduate Student
jilliane@bu.edu

Maureen Flynn, MS, LGC
Genetic Counselor
(617) 638-5908
gc4dna@bu.edu