

Hello EB community member!

We are conducting an important new research study to validate questions used in our original EB Eye Survey.

This study includes **three shorter surveys- one that is 10 minutes long, and two that are five minutes**. We are comparing responses to the three surveys to "validate" the questions. We will ask you to complete these twice, to validate the responses. **You will receive the surveys a second time a week after completing them the first time.**

Validation is an important step in the clinical research process. It allows us to be confident that the questions we ask, and the answers you give, really reflect the impact of EB eye disease. After validation, **this survey may be used in development of therapies for EB.**

If you are a patient with EB, please complete the surveys. If you are the parent of a child with EB, please complete the surveys for your child.

Participation is voluntary and you may stop participating at any time without penalty. You may find some of the questions uncomfortable. The alternative to participating is to not participate. There is no benefit to you and you will not be compensated for your participation. There is no cost to you to participate. There is a potential risk for loss of confidentiality, but your personal information will be coded to protect your data.

This study has been reviewed by the Tufts Health Sciences IRB. If you have questions about the rights of research subjects, please contact the Tufts Health Sciences IRB administrator at (617) 636-7512 or IRBOffice@tuftsmedicalcenter.org.

If you would like to participate, you may open the survey in your web browser by clicking the link below:

<https://j.mp/2AxhGyN>

If the link above does not work, try copying the link below into your web browser:

<https://collaborate.tuftsctsi.org/redcap/surveys/?s=CN8HA738F3>

If you do not wish to be contacted for this or future studies (to unsubscribe) or if you have any questions about this research study, please email Dr. Chen at vchen@tuftsmedicalcenter.org.

Thank you for helping us to understand your experience with EB eye disease.

Warm regards,

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