

## Epidermolysis Bullosa Eye Disease Survey Recruitment Statement

Version: 2/1/18

Subject Line: EB Eye Disease survey with thank you gift card

Hello EB Community Member,

We are doing a survey to help us understand how much eye problems affect kids and adults with Epidermolysis Bullosa (EB). Learning more about your experience will help us develop better treatments for EB eye diseases.

We have heard from our patients that some people are in such pain from abrasions and other eye problems that they stay in a darkened room until they feel better. Many EB kids and adults are in pain for days. Many people do not find relief with eye ointments that are typically recommended. We do not know how often this happens or how many individuals and families suffer from eye problems.

We want to hear about this affects caregivers and kids. Does it disrupt your regular routine? If so, how much?

By answering this survey, you will be helping us inform the research community about the needs and experiences of families facing this condition.

### Here is some quick information about the survey:

- The survey is anonymous.
- It begins with screening questions that take 5 minutes or less.
  - o If you qualify, the survey may take 20 minutes to complete. As a thank you, we will send you a \$15- [amazon.com](https://www.amazon.com) gift card.
  - o If you do not qualify, we will send you a \$5- [amazon.com](https://www.amazon.com) gift card.
  - o At the end of the survey we will ask for your email, which will be used to send you the gift card.
- If you have already completed the survey, we will be contacting you directly by email.
- If you would like to participate, please click on one of links below:
- If you are answering for yourself, please click here: <https://collaborate.tuftsctsi.org/redcap/surveys/?s=XLY89WNXMW>
- If you are answering on behalf of a child, please click here: <https://collaborate.tuftsctsi.org/redcap/surveys/?s=HYNKCEFRY4>

Our survey involves research and participation is voluntary. It is entirely anonymous. You may stop participating at any time without penalty. The alternative to participating is not completing the survey. It should not take longer than 25 minutes to finish. There is a risk of loss of confidentiality and a risk of participating in the study is that it could be upsetting to think about the effect of eye symptoms on your

family. You will not receive a direct benefit for participating in this study. However, all participants will be offered early access to the results and an emailed copy of the study when it is published.

We simply request that it is completed only once by each family, unless more than one person in your household has EB. This will help us to be sure the results represent the EB community as a whole. Your contact information may be used to reach you for future studies.

This study has been reviewed by the Tufts Health Sciences IRB.

Thank you very much for your kind help with this survey. If you are interested in the results, or if you have any questions or concerns, please feel free to email Dr. Vicki M. Chen at [vchen@tuftsmedicalcenter.org](mailto:vchen@tuftsmedicalcenter.org).

Best regards,

Vicki M. Chen, MD

Pediatric Ophthalmology  
Tufts Medical Center, Boston, MA