

Dear members of *DEBRA*,

We are writing to tell you about a virtual research volunteer opportunity with Dr. Amy Paller, Dr. Antonia Reimer-Taschenbrecker (both at the Department of Dermatology), and Dr. Abel Kho (Institute of Augmented Intelligence in Medicine, I.AIM) at Lurie Children's Hospital and Northwestern University, Chicago. We are looking for people with recessive dystrophic epidermolysis bullosa (RDEB) and history of squamous cell carcinomas (SCCs) who are willing to contribute photographs of their skin lesions.

What is the study about?

SCCs which rapidly metastasize are the main cause of death in adults with RDEB. The earlier an SCC is recognized, the easier it can be removed and the better the outcome. AI leverages computer science to perform tasks that typically require human intelligence and has recently been used to identify skin cancers based on images. We are currently developing an AI approach for early detection of SCC and distinction of malignancy from chronic wounds and other RDEB skin findings. The aim is to create a web application for patients with RDEB to upload images of their skin and get an output as to SCC present/ no SCC. This will be especially valuable for patients with difficult access to medical expertise and those who are hesitant to allow full skin examination at each visit, often because of fear of biopsies. Thus, this project will directly benefit patients by allowing early recognition of SCCs and will empower patients and their families by providing a home use tool.

So far, we have mainly used professional images (photographs taken in hospital settings by physicians, nurses, and clinical photographers) of both SCCs in RDEB and images of RDEB skin without SCC to develop and train the AI model. The images that we expect in a real-life setting will mostly be pictures taken by patients or family members with their phones or digital cameras. These images have different properties regarding resolution, focus, lighting, and backgrounds. Incorporating such images will be crucial in the upcoming phases of model development—testing and validation—for the web application to be a success for patients. **This is what we need your help with!**

Who is this study for?

This project will enroll adolescents and adults with RDEB and history of at least one SCC. The survey and consents will be provided in English, Spanish, German, French, Arabic, Chinese, Russian, and Hindi. We are inviting people with RDEB around the world to participate and are hoping that approximately 100 people will provide images.

What will you do if you participate?

If you qualify and decide to participate, you will be asked to complete the survey and upload photographs of your SCC(s) using the links below. Depending on the number of SCCs you've had and the number of photos you want to provide, the survey will take approximately 15-20 minutes to complete. We hope that you will consider participating in this study. Participation is entirely voluntary.

What should you do if you are interested in participating?

To participate in this study, please follow this link:

<https://redcap.nubic.northwestern.edu/redcap/surveys/?s=JH9LHR4CC4R4H3HN>

This study is Lurie Children's IRB 2023-5810, "Developing a Novel Artificial Intelligence Patient App to Recognize Squamous Cell Carcinoma in Recessive Dystrophic Epidermolysis Bullosa," PI: Dr. Amy Paller. The content of this e-mail has been approved by the Lurie Children's IRB.