



#BeautyIsNotRare

A Campaign by EB Research Partnership, Lucy Beall, & Olivia Vedder

everyone is beautiful -

whether you have a visible disease, like Epidermolysis Bullosa (EB), or are unapologetically showing your scars, acne, or individual insecurities. The standard society holds women and girls to, especially in the day of social media, proves extremely harmful. We want to flip the script - transforming social media into a positive space, and validate the fact that #BeautyIsNotRare.



plan

Lucy Beall and Olivia Vedder will kickstart the #BeautyIsNotRare campaign by participating in isolation photoshoots via FaceTime with reknowned fashion photographers. The women will post their shots to Instagram (suggested caption below) with instructions on how to participate, set up FaceTime photoshoots, and spread the message. Each participant will be asked to nominate 3 friends to partake, and individuals who tag @ebresearch will have the opportunity to be featured on EBRP's social media channels and website.



audience

Women on Instagram, ~500M Active Accounts Monthly ¹

¹ source: Statista & Sprout Social



suggested caption

I'm joining @ebresearch, @lucy_beall, & @oliviavedder in challenging conventional beauty standards because #BeautyIsNotRare. I nominate [insert 3 friends] to join us. Click the link in my bio for instructions on how to take part in a FaceTime photoshoot, post your image to Instagram, and tag @ebresearch for a chance to be featured. [Insert personal #BeautyIsNotRare story here].



about eb research partnership

Founded by a dedicated group of parents and Jill and Ed Vedder (Pearl Jam), EB Research Partnership (EBRP) is the largest 501(c)(3) nonprofit dedicated to funding research aimed at treating and ultimately curing Epidermolysis Bullosa (EB), a group of devastating and life threatening skin disorders that affect children from birth. EBRP utilizes an innovative business model of venture philanthropy. When making a grant to a research project they retain the added upside of generating a recurring revenue stream if the therapy or product is commercially successful, then use the return on investment to fund additional EB research until a cure is found.

To learn more about EBRP visit www.ebresearch.org.

contact



Olivia Vedder is a junior at Seattle Academy in WA. She acts as an ambassador for both Global Citizen and the youth-led climate organization, Zero Hour. Olivia became aware of Epidermolysis Bullosa (EB) at a young age through Mikey Fullmer, a family friend who was born with the disorder. Her parents, Jill and Eddie Vedder, co-founded EB Research Partnership to find a cure for EB and Olivia has become a passionate advocate for the cause by meeting EB families, visiting research labs where scientists are actively testing potential therapies, and interning at EBRP.

“When I was 11 or 12, Mikey and his family came to Seattle. At one point, we went to get ice cream, and Mikey was in agonizing pain. It was so hard to watch, knowing this is just one instance of what he, and everyone else with EB, deal with on a daily basis. Since then, I have been inspired to do whatever I can for this cause.”

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Instagram: [@oliviaavedder](https://www.instagram.com/oliviaavedder)



Lucy Beall is a young woman seeking to change how society views differently-abled individuals. Although she has Epidermolysis Bullosa, a genetic skin condition currently without a cure, Lucy has defied stigmas surrounding disabilities by being a full time student at University of St. Andrews, working in London art auction houses and by modeling for publications such as Vogue Italia. Through her modeling, speaking, and writing, Lucy hopes to develop the discussion on visible disabilities and how those with disabilities are portrayed by the media.

Email: lucy@ebresearch.org

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**For EB Research Partnership,
please contact Stephanie Ishoo, Director of Communications, at stephanie@ebresearch.org or 646.844.0902**

Lucy Beall, as seen in

VOGUE BBC

THE  TIMES
THE SUNDAY TIMES

GLAMOUR

TEDx



When I was 17, on a hot day in Santa Fe, I wore shorts to pick up my dog from the vet. The woman I sat down next to immediately looked me over and said, "You look like you've been mauled by a gorilla. What happened to you?" I could have told her how the only thing separating us was a simple miscommunication in my cells that causes my condition: Recessive Dystrophic Epidermolysis Bullosa (RDEB).

That day, I realized I saw a different body than most people did. Yes - I saw the scars across my legs that bloom red and stubborn as poppies, but I did not see my "otherness". I saw beauty in my own strength and eventually grew to feel lucky to display my strength on my body like art.

At the University of St. Andrews in Scotland, I studied art, thousands of years of it, and what we as a society collectively consider to be beautiful. **But, I realized that I did not see myself anywhere.** Not in painting, photography, or sculpture. I have since been advocating for those with EB and have had the honor of sharing my story and image with the world.

I think of the woman at the vet and how that conversation ended. "At least your face was spared," she said. She may not have thought much of my body, but I do. My hands are scarred, but they allow me to write. My feet can bleed, but I have walked to stand in the images you see of me. My arms develop blisters, but allow me to hug those I love. My eyes wound themselves overnight, but I can see that there will be change, soon, due to the work of brilliant EB researchers.

I am overcome by the beauty of that.

#BeautyIsNotRare.