

Inaccurate Photo of Infant with Stevens-Johnson Syndrome Used in Posts about Fauci's 1980s HIV Clinical Drug Trial

Stevens-Johnson Syndrome Foundation dispels harmful rumors

DENVER (Nov. 2, 2021) - It has come to the attention of the Stevens-Johnson Syndrome Foundation that photos of our founder's daughter have been circulating the web featuring inaccurate information. These photos feature the founder's daughter during SJS. They are paired with false claims and lead the reader to believe that nevirapine caused the reaction during the National Institutes of Health and Dr. Anthony Fauci's 1980s clinical drug trials to treat children with HIV/AIDS. These claims are <u>false and unfounded</u>.

"The photos shared via social media and in numerous web-based articles are not photos of a child from Dr. Fauci's clinical HIV/AIDS trial. Instead, these are photos of my daughter, Julie McCawley, who had Stevens-Johnson Syndrome to Phenobarbital for Pediatric Epilepsy," said Jean McCawley, Founder, Stevens-Johnson Syndrome Foundation. "I have never met Dr. Fauci, nor has my daughter participated in any of his trials. I am saddened that anyone would share these photos in an attempt to defame Dr.Fauci and inappropriately use these photos of my daughter during her illness."

While it is true that Nevirapine can cause SJS and the photos do depict an infant with SJS, the images do not show a child reacting to Nevirapine. Instead, these photos feature the founder's daughter, <u>Julie</u>, during SJS caused by Phenobarbital, an anticonvulsant used for Pediatric Epilepsy. The photographs were taken in Denver Children's Hospital by William Farrell of The Photo Works, Julie's great-uncle, during her reaction, in 1994 at the age of 11-months-old.

These photos were initially authorized for use by the <u>Journal For Pharmacist's Education</u> for an article published in April of 2001. However, the social media posts and articles including these photos do not have permission to use them unless directly granted by the Stevens-Johnson Syndrome Foundation.

"SJS is a horrible reaction that I wouldn't wish on anyone. But more than that, the photos of my daughter during SJS are meant to be used for education and not as a weapon of destruction," said McCawley. "SJS is a life-threatening reaction that has taken countless lives. Instead of sharing these photos for destruction, we should be sharing them to raise awareness of the harm that all medications can cause."

About the Stevens-Johnson Syndrome Foundation:

The Stevens-Johnson Syndrome Foundation is a non-profit organization that aims to provide

the public and medical communities with information on adverse allergic drug reactions. The SJS Foundation was founded in 1995 after the founder, Jean McCawley's daughter, Julie, suffered from SJS at 11-months-old. After Jean did agonizing research on SJS and desperately searched for others who had experienced SJS and came up empty-handed, she decided to create the foundation to provide others like her and Julie with the support they need during and after SJS. The SJS Foundation offers services including support for adults and children with SJS, bereavement groups for those who lost loved ones to SJS, patient information, information for medical professionals, a registry to log reported cases of SJS and research being completed from partners of the foundation. To learn more, visit http://sjsupport.org/.

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