



# SJS Foundation March 2022 Newsletter

<http://sjsupport.org/>

Hello, SJS Families and Friends!

## 100 years of SJS

2022 marks the 100th anniversary of the discovery of Stevens-Johnson Syndrome. In 1922, Dr. Albert Stevens and Dr. Frank Johnson discovered SJS after two children presented with fever, conjunctivitis, red/purple spots and inflamed mucous membranes.

74 years later, the Stevens-Johnson Syndrome Foundation was founded by Jean McCawley after her 11-month-old daughter suffered a severe case of SJS. For the past 26 years, the SJS Foundation has worked continuously to bring public awareness and research to SJS and Toxic Epidermal Necrolysis, a more severe form of SJS.

“When we started the Stevens-Johnson Syndrome Foundation, we were the only resource for those who suffered from SJS and TEN. We started as a small online support group, and have grown to reach hundreds of thousands of people from around the world,” says Jean.

The SJS Foundation is a valuable resource to families and physicians. We have reached around the world connecting families that have suffered from SJS/TEN together for emotional support. Over the years we have shared hundreds of thousands of SJS fact sheets with hospitals and patients along with information packets on treatment and side effects.

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**Vanderbilt University Medical  
Center Research Updates**



The SJS Foundation is excited to assist Dr. Elizabeth Phillips with Vanderbilt University Medical Center by connecting patients to volunteer for genetic research.

In August 2021, Vanderbilt held a [virtual scientific symposium](#) and invited SJS survivors to participate. It was a successful endeavor bringing scientists from around the globe to collaborate.

"I would like to thank all survivors and families that participated in SJSTEN 2021," says Dr. Phillips. "It is survivors and families like you that are the inspiration and catalysts for past, current and future research and progress."

The SJS Foundation is happy to participate as co-authors on Vanderbilt's white paper which will be published in *Frontiers in Medicine*, a medical journal. The white paper will feature SJS/TEN community concerns, current research projects and future research projects.

"There is a lot to do but much to look forward to," says Dr. Phillips. "The next year will continue to see SJS/TEN research centered around prediction and prevention, earlier diagnosis, supportive care and treatment and more targeted treatments."

**To learn more about SJS/TEN research through Vanderbilt, [click here](#).**

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## **SJS Family Spotlight**

Angela Wanpen Anderson was born on March 17, 1993, to Paul and Wanpen Anderson in Urbana, Illinois. Her mother struggled with infertility for 14 years but was able to conceive two children with the help of an infertility procedure called GIFT. Her son Timothy was born three



years before Angela in 1990.

Angela was a shy but bright child, dedicated to her education, with a passion for music. As she grew older, she came out of her shell and became the life of the party. Angela became a kind, caring young woman who emitted sunshine anywhere she went. There wasn't a place Angela went, where people didn't know and love her.

On Christmas Eve, 2015, Angela presented with an eye infection and flu-like symptoms at Carle Hospital in Illinois. Unfortunately, Angela was not diagnosed in time and didn't receive the proper treatment. Angela passed away on December 28, 2015, four days after being admitted to the hospital. She is greatly missed by her parents, brother, friends and everyone she met.

Following Angela's death, her parents asked for donations for SJS research in lieu of flowers at her funeral. After Angela's funeral, more donations came pouring in in memory of Angela. Wanpen and Paul desperately searched for someone doing SJS research, and after almost a year, they got in touch with just the right team to complete their search.

"Finally, Dr. Elizabeth Phillips at Vanderbilt University Medical Center answered the call and wanted to start a research project specifically dedicated to SJS/TEN research. Wanpen and I met with her and her team at VUMC and liked what they had to say. By this time a year had passed and we had received even more donations. So, in December of 2016, we donated \$22,000 to the SJS/TEN research fund in memory of Angela Anderson," says Paul.

The Andersons believe, as so many do in our community, that SJS/TEN awareness and research are essential for getting SJS into the public eye. The Andersons hope to one day see a test for earlier identification of SJS, to eliminate the "guesswork out of the diagnosis, so doctors could treat it quickly."

To learn more about Angela's story, [click here](#).

In honor of what would have been Angela's 29th birthday, please donate to the



## 10forTEN

SJS/TEN survivor, Louis Chaix, is rollerblading across America from Los Angeles to New York City to raise awareness of Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis. Louis had suffered from TEN when he was six years old and had over 80% of his body burned.

18 years after having TEN, Louis decided he wanted to raise awareness and funds for SJS/TEN. He reached out to Jean McCawley, Founder of the SJS Foundation, who got him in contact with Vanderbilt University Medical Center.

Louis and VUMC have collaborated on his campaign for raising SJS/TEN awareness. He is asking for \$10 donations for TEN awareness.

“My mission is to inspire and give hope to people. Through the 10forTEN expedition, we are trying to build a very strong community in order to Give Hope One Stride at a Time,” says Louis.

To learn more about 10forTen or to donate, [click here](#).

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## Company News

We have been hard at work updating our website! Some notable features include a new web design, new logo, accessibility features and a language selection tool.

To check out our website, visit [Stevens-Johnson Syndrome Foundation](#).

## Online Support Group Meetings

We hope you can join us for our monthly online support group meetings on the last Saturday of each month from 8 p.m. - 9 p.m. EST. Please visit our [Facebook Page](#) to access our Zoom meeting link.



Stevens-Johnson  
Syndrome Foundation

## About the SJS Foundation

The Stevens-Johnson Syndrome Foundation was founded by Jean McCawley over 25 years ago and provides the public and medical communities with information on adverse drug reactions.

The SJS Foundation's goal is to make the public aware of SJS and Toxic Epidermal Necrolysis so that a quick diagnosis may be made and the offending drug stopped as soon as possible. Allergic drug reactions are the fourth leading cause of death in the United States.

The SJS Foundation is working with medical professionals on SJS research to identify causes, genetic markers and treatment plans. The SJS Foundation also provides emotional support for people with SJS and TEN.

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