



# Hello October

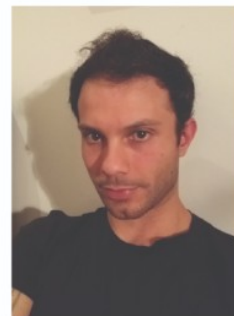
## The STURGE-WEBER FOUNDATION eNEWS Edition 2 | Issue 10

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### Lisa's Research Fellowship Awarded to Dr. Davide Zecchin, Ph.D.

The Sturge-Weber Foundation is honored to announce awarding Dr. Davide Zecchin, Ph.D., University College, London, the 2018 Lisa's Research Fellowship (\$50,000). This award will provide the necessary funding needed for Dr. Zecchin's research - "Genetic Therapy for the Sturge-Weber Mutation - Proof of Concept Study."

Dr. Zecchin proposes to demonstrate that Sturge-Weber syndrome (SWS) could potentially be treated by genetic therapy. This genetic therapy would not only be aimed at the skin, but at all GNAQ-mutant cells in the body. The approach is to use gene therapy to correct the GNAQ mutation, working in cells derived from patients. It is thought that gene therapy could be used effectively after birth with the potential to prevent epilepsy, neurodevelopmental delay, and glaucoma.



*Dr. Davide Zecchin*

[Read More](#)

### LIVE! LEARN! LOVE!

*by Karen Ball*

October is Anti Bullying Month. Sadly, we in the SWS and Birthmarks community know all too well about bullying and the impact it has on our lives and of those we love. The SWF and Positive Exposure have been partnering for years to celebrate our differences and leading awareness campaigns. We have directly and intimately seen the impact of celebrating our differences on the lives of our kids/young adults. They have blossomed into confident individuals who are giving back to the next generation with what they have learned so far in life.

**"IF PEOPLE  
ARE TRYING  
TO BRING YOU  
DOWN  
IT ONLY MEANS  
THAT YOU ARE  
ABOVE THEM"**

[READ MORE](#)

## WE NEED YOUR HELP!

The Sturge-Weber Foundation is working on a Matching Gifts Campaign to increase the value of our member donations. We need your help! By providing the name of your employer, we are able to research the company to see if they participate in matching gifts programs for donations you send to the foundation.



**Helping is easy - please follow the link below, fill out the short form with your name and your employer (company) name. That's it - we will do the rest!**

Question? Contact Susan Finnell, [sfinnell@sturge-weber.org](mailto:sfinnell@sturge-weber.org).

[MATCH YOUR GIFT!](#)

## SWF EDUCATION CONFERENCE IN NORTH CAROLINA

**November 10, University of North Carolina, Chapel Hill, NC**  
Guest speakers will discuss - Medical genetics, ophthalmology, dentistry, neurology, dermatology, oncology and hematology.

*To register, click the button below!*



[REGISTER!](#)

## REMINDER TO OUR GENEROUS DONORS

Many SWF donors use their banks or employers to send us monthly or periodic donations. These are much appreciated and are efficient ways to keep a steady donation stream coming to the SWF.

However, since the SWF office moved October 2016, the address for donations may not have been updated. If you make donations this way - via bank or employment draft - please notify them of the correct mailing address:

**The Sturge-Weber Foundation**  
**12345 Jones Road, Suite 125**  
**Houston, TX 77070-4958**

**Thank you for your continued support!**



## MEMBER MOMENTOUS MOMENTS

*From Sherrie Harleman*

My son Jesse who is 13, almost 14 years old and has type one SWS. He has never been able to tie his shoes, snap a button, or zip a zipper. The little things we all take for granted. Today Jesse did the zipper on his hoodie!!!! He was so proud of himself. I am over the moon proud of him!! For most parents, this is a mild accomplishment but for me, it means the world!!!

*From Leslie Greene*

This is Connor with Caitlin Lawrence- Lovelace, receiving the Chief Scout Award. She is the grand daughter of Roland Michener, and my very best friend from Ontario college of Art & Design University.



The Chief Scout's Award is the highest award which can be achieved at the Scout level in Scouts Canada (Same as US Eagle Scout). It was inaugurated in 1973 by then Governor General of Canada, Roland Michener. The award was created to provide recognition for Scouts when the Scout program was divided into the Scout and Venturer sections.

*From Julie Luby (Allie Shepard's Stepmother)*

At the end of August 2018, Allie Shepard graduated from Nursing School at Eagle Gate College in Salt Lake City, UT with a Bachelor of Science in Nursing. This is her second Bachelors degree (she also has a Bachelors degree in Health Education & Promotion from the University of Utah). A month after she graduated, she successfully passed her NCLEX exam (National Council Licensure Examination) so she is now licensed as a registered nurse (RN).



It was a busy time for Allie--during the last four years, she worked hard to financially support herself while going to school, and was married in April 2017. All of her family members are so proud of all of her hard work and so happy that she can now pursue her dream of being a nurse. Her graduation day photo is attached.

## ON THE ROAD . . . MAKING AN IMPACT!

October is a busy month for the Foundation. All staff members have been traveling across the US to attend conferences and education days at SWF CCNs. Check out where they have been!

- Karen Ball and Brian Fisher attended the Child Neurology Society Conference, October 14-17, Chicago, IL
- Susan Finnell attended the Education Conference at Cook Children's Hospital, October 20, Ft. Worth, TX
- Karen Ball and Brian Fisher attended PeDRA Conference, October 24-25, Denver, CO
- Karen Ball and Brian Fisher attending the American Academy of Ophthalmology Conference, October 26-30, Chicago, IL



*CNS Conference in Chicago*



*Cook Children's Hospital Ed Day*



*Chanel the Cook's Child Assistant*



*Webster at Cook Children's Hospital*

**WHAT'S COMING UP . . .**

**November 10** - SWF Ed Conference, SWF Ed Conference,  
University of North Carolina, Chapel Hill, NC  
**November 22-23** - Thanksgiving, SWF Office Closed  
**November 27** - **GIVING TUESDAY!**



**WE ARE BETTER TOGETHER. SUPPORT!**

STAY CONNECTED:

**SWF CONNECTION by INSPIRE**



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