

# THE STURGE-WEBER FOUNDATION eNEWS

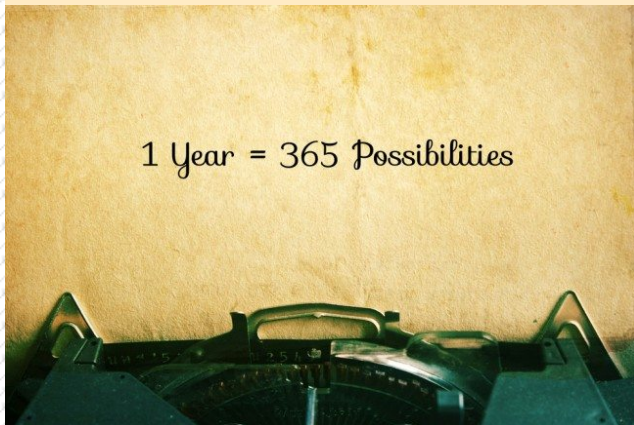


January 21, 2020 | Edition 4, Issue 1



## Research Task Force - Moving FORWARD!

On January 15th the SWF and researchers from the SWF International Research Network (SWFIRN) and the SWF Clinical Care Network (CCN) had the first Animal Model Research Task Force Meeting. These meetings will be a place for researchers to present their research and have the ability to collaborate with other researchers to gain more guidance. Dr. Sarah Wetzel-Strong and Dr. Doug Marchuk (pictured left) are the first to present. Dr. Sarah Wetzel-Strong presented her work to the group. The discussion that followed was very exciting. Dr. Wetzel-Strong was awarded a grant from the SWF last year to further her work. Great job Dr. Marchuk and Dr. Wetzel-Strong, thank you for your work!



## Ring in the New - Cherish the Old

The New Year brings such hope and promise for all our hopes and dreams! I just put Derek on the plane back home to Montana to his group home, Lighthouse Christian Home. I understand when all these years my mom would always say the house is so quiet after we would leave to go home to NJ.

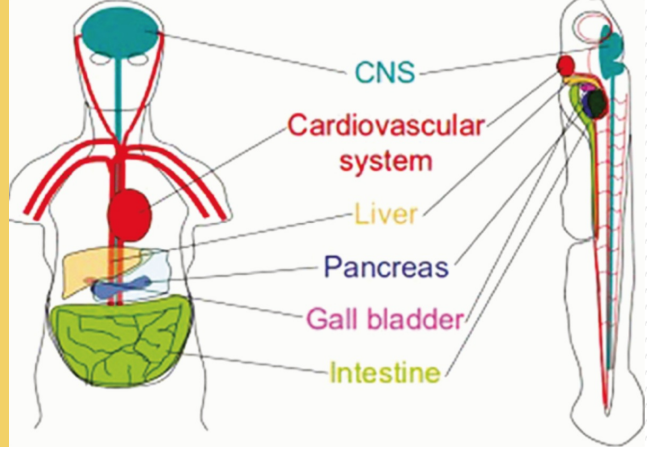
[Read More](#)

## ZEBRAFISH IN RESEARCH

As mentioned in the December/January Branching Out, two of the research projects have to do with the use of Zebrafish. We know of mice and monkeys in medical research, but have you ever heard of Zebrafish?

[Find Out More!](#)





### Wanderers

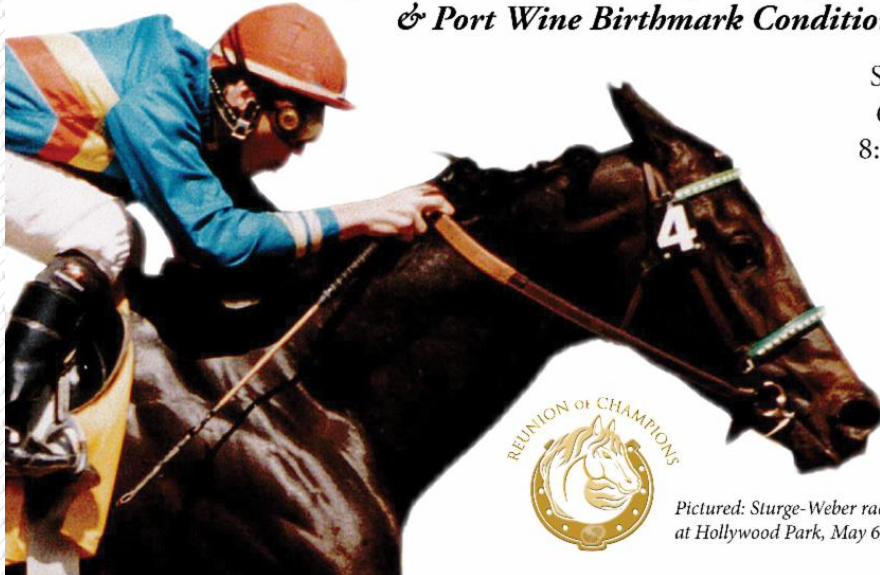
We often suggest to our SWF community, that they look for useful information on other special needs websites. One of the most helpful is the eParent Weekly Newsletter - an arm of the Exceptional Parent Network. This recent issue has an article on wandering - also called elopement.

[More Details](#)

# SAVE THE DATE!

## THE STURGE-WEBER FOUNDATION 2020 REUNION OF CHAMPIONS FRIDAY, MARCH 20, 2020

*Impacting Patients and Research for Sturge-Weber Syndrome  
& Port Wine Birthmark Conditions*



Seawell Ballroom, Denver, CO  
6:30 PM - Cocktail Reception  
8:00 PM - Dinner and Program

### 2020 HONOREES

**Dr. Henry Hin Lee Chan**  
*Hong Kong Dermatology  
& Laser Centre*

**Dr. Jill S. Waibel**  
*Miami Dermatology  
& Laser Institute*

*Pictured: Sturge-Weber racing  
at Hollywood Park, May 6, 2001.*



[Off to the Races](#)

### The Military Experience

Are you a US military family? If so and you would like to share your experiences with other SWF families, please let us know.

What in the military experience helps you deal with the pressures and challenges of coping with medical situations? How have you been able to deal with changing medical providers as you move or relocate? Is it easier or harder to form relationships with other families?

You have the answers. Please consider sharing. Contact: [ahoward@sturge-weber.org](mailto:ahoward@sturge-weber.org).

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