



Changing The Face of Sturge-Weber Syndrome



## Awareness Activity

### Project Title: Sponsor a Sturge-Weber Foundation Awareness Event at your School

**Background:** Some people have a disease or disability that no one can see so they don't have to share information about their appearance every time they go out in public. Often, that is not the case for individuals with Sturge-Weber syndrome or associated Port Wine birthmark conditions. Sharing information about yourself, your family member or a friend can help others understand the differences and challenges faced daily. Sharing information about The Sturge-Weber Foundation make you a champion for those we serve. The Vision of the Sturge-Weber Foundation is that in all areas of life – public, professional, personal – the following goals will be achievable for our members:

- *In Awareness* – when the public will be able to see past the disability to the person.
- *In Empowerment* – when families and individuals will be able to obtain the medical care, employment, education, respect and personal achievement they seek.
- *In Research* - when the pace of discovery will not be hampered by lack of resources and will lead continually toward a cure and advances in treatment.

### What you do:

1. Contact the appropriate administrator at your school to see if you can have an event
2. Discuss the best way to share your awareness presentation. Would it be better in a small classroom setting? An assembly? Maybe even a table at back to school night to engage parents too?
3. Once you have permission and know how you plan to share information, contact Bonnie at [bayers@sturge-weber.org](mailto:bayers@sturge-weber.org) or 973-895-4445 x 103 to order any supplies you would like to use from The SWF office to help you share your story and the Sturge-Weber Foundation story.
4. **Get Credit!** ☺ Please take pictures of your event so they can be included in The SWF Branching Out Newsletter and/or on the SWF Website. Pictures should be emailed to Bonnie Ayers at [bayers@sturge-weber.org](mailto:bayers@sturge-weber.org). Also, tell us about your event! We'd love to hear all about it!

### Supplies available:

SWF Brochures  
Check it Out Cards  
Someone Special Booklet

Color Me The Same Coloring Books  
Kids Guide to Sturge-Weber syndrome  
Teen Guide to Sturge-Weber syndrome

Posters  
Wristbands  
Vimeo Presentations

**Other idea:** Make your presentation at a local community group such as Kiwanis, Rotary, your local or place of worship.