



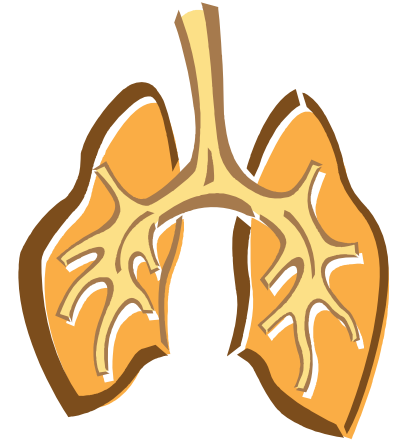
Toll Free 1-877-315-6855  
www.theadvocacyalliance.org

# IT'S YOUR HEALTH SPRING 2010

## MAY IS NATIONAL ASTHMA AND ALLERGY AWARENESS MONTH

### Gaining Control Over Asthma

Asthma is a chronic respiratory disease affecting over 20 million Americans and becoming more serious, requiring more people to be hospitalized. It is often linked to allergies, heredity, and environment. It affects all ages but 50% of the cases are children under age 10 (boys with asthma outnumber girls). In adult-onset asthma, women are more often affected than men.



Airway inflammation causes spasm of the air passages followed by swelling and thickening of lung secretions. This decreases or closes off air to the lungs with wheezing, coughing, chest tightening and labored breathing. It is known that these asthma attacks are caused by certain triggers.

Some common asthma triggers include dust, pollen, animal dander, breathing cold air, cigarette smoke, certain chemicals, perfume, medications, infection and even exercise. These triggers vary from person to person, and the length and severity of the attack vary with each episode.

### Signs of a medical emergency which may require emergency or urgent care may include:

- Difference in breathing-faster, slower, more shallow
- Cough or wheeze that will not stop
- Bluish fingernails or lips



- An asthma attack should be treated as quickly as possible to open the airway. Sit upright during an attack and follow the plan prescribed by your physician. Don't wait to get emergency help if symptoms are not responding to your emergency rescue treatment.
- Asthma attacks may be prevented if the factors that trigger them are identified and avoided. This is sometimes difficult to determine.

- Avoid known allergens and air pollutants. Watch for the Air Quality Index (AQI) during your local weather report. It offers you information every day on whether air quality in your area could be a health worry.
- Take prescribed medications regularly; don't omit them when you feel well. Most treatment plans include daily and emergency (rescue) medications.
- Avoid aspirin.
- Investigate and avoid triggering factors.
- Do relaxation and airway clearing exercises (health practitioner can assist with these).
- Stay active, but avoid sudden bursts of exercise. If an attack follows exercise, sit and rest; sip warm water. Use bronchodilator for exercise-induced asthma.
- Swimming is excellent exercise for people with asthma.
- Drink plenty of fluids to keep secretions loose.



These practical tips will help you understand and better plan how to manage your asthma. With an individualized action plan in place you should be sick less, breathe easier and enjoy life more.

Resource: <http://www.health.nih.gov>

## Do What You Can For Those You Can

A Zen monk was seen by his disciple by the sea, where the tide had washed ashore hundreds of starfish. It was clear that they would soon die from exposure. The monk was tossing the starfish, one at a time, back into the sea, in a slow and meditative manner. "Why are you bothering?" the disciple asked the monk. The young disciple looked at the large number of starfish that were succumbing. "It won't make any difference." The monk stopped for a moment, and looked down at the starfish in his hand. "It will to this one," he replied."



**Check out these websites mentioned in this edition of "It's Your Health".**

[www.getpalliativecare.org](http://www.getpalliativecare.org)

<http://www.health.nih.gov>

<http://www.liveyourlifewell.org>

[www.getpalliativecare.org](http://www.getpalliativecare.org)

# Dual Diagnosis Services and Supports Update

The Developmental Disabilities Council is federally funded and established in 55 states and territories to engage in systems change, advocacy and capacity building. Each year Pennsylvania's Council identifies requests for proposals that reflect the priorities of the Commonwealth.

The Dual Diagnosis Services and Supports Grant is a two-year grant that was funded in October 2008 and is comprised of a statewide coalition of eight Health Care Quality Units. For the purposes of this grant, dual diagnosis is defined as intellectual/developmental disabilities and mental illness. The primary mission of the grant is to: determine how people with dual diagnosis want to be supported, identify ways the support systems could be more responsive, provide a comprehensive review of best practices from existing literature, advocate for increased collaboration between systems that support people with dual diagnosis, create public awareness to increase acceptance, and educate one and all to improve outcomes.

On September 29, 2009, Pennsylvania's Health Care Quality Units (HCQU) hosted a statewide stakeholders' meeting as part of the *Dual Diagnosis Services and Supports* project funded by the Pennsylvania Developmental Disabilities Council. At the meeting, findings of focus groups and consensus meetings conducted across the Commonwealth were presented. In addition, workgroups were formed to begin developing a roadmap for improved services and guide project efforts going forward.

Nearly one hundred stakeholders gathered in Mechanicsburg for a full-day session. Opening speakers included Secretary Estelle Richman, Department of Public Welfare, Deputy Secretary Kevin Casey, Office of Developmental Programs (ODP), Sherry Snyder, Office of Mental Health and Substance Abuse (OMHSAS), and Graham Mulholland, Executive Director of the Pennsylvania Developmental Disabilities Council. Participants were encouraged by the speakers to continue their work to improve services and supports for people with intellectual disabilities who also have mental illness.

On behalf of the HCQU Coalition, Dina McFalls, Director of Philadelphia Coordinated Health Care, presented a summary of findings of the focus groups and consensus meetings. During the afternoon, four workgroups met to develop goals or mission statements and to begin identifying action steps for ongoing work. The four workgroups include: 1) Access to Behavioral Health Services; 2) System Integration (ODP & OMHSAS); 3) Public Awareness; and, 4) Education. These areas represent the summation of input from over 500 people during the focus group and consensus meetings held in Year One. Each workgroup will be chaired by two HCQU directors: Group 1 by Lynn Libby and Joanne Cook; Group 2 by Dina McFalls and Kevin McElligott; Group 3 by Star Long and Heather Coleman; and, Group 4 by Sharon Falzone and Mary Nau. Each group determined an agenda based upon the themes that were presented as their focus and each group will establish various projects to undertake over the next year. Updates of group progress will be reported throughout the year.

The Public Awareness Workgroup will have several press releases throughout the upcoming year in order to keep you current on the goals and projects of the grant workgroups. Please contact Heather Coleman (610) 435-9050 or Star Long (717) 835-2275 with any ideas, questions or concerns.

## IS YOUR ENVIRONMENT HEALTHY?

National Poison Prevention Week, was recently held the week of March 14-20, 2010. The main point of this week is to highlight many factors we need to consider to keep our environment healthy.

### Indoor air has been shown to be more harmful than outdoor air.

Since we spend most of our time indoors, even when spring has finally arrived, there are important considerations to keep in mind. Many substances that are present within our homes, as well as those items that we purchase and use indoors, present risks to our health and safety. Asbestos, heating fuel, lead, mold, radon and PVC all pose potential health concerns. Furniture, carpets, personal products and plastics are examples of things that may potentially emit harmful chemicals.

Asthma is a prevalent condition in Pennsylvania, with over 1,000,000 adults reported as having the diagnosis as of 2004. Mold, commonly found in basements and other damp areas, is a trigger for asthma.

Lead is present in many homes built prior to 1978; it leaches harmful chemicals but is odorless and tasteless. Found in dirt, dust, new toys and old house paint, lead affects the developing nerves and brains of unborn and young children. It causes irritability, aggressive behavior, headaches, anemia and constipation. High levels may cause vomiting, staggering gait, muscle weakness, seizures, or coma. Lead causes lung cancer; these symptoms are delayed.

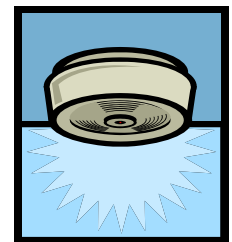
Radon also causes lung cancer. It enters the home from the ground and is therefore found in basement areas. It is recommended that homes be checked for the presence of radon. Kits can be purchased from hardware stores or obtained from the American Lung Association.

Carbon monoxide can be produced by gas water heaters, unvented kerosene and gas space heaters, wood stoves and fireplaces, as well as improperly maintained furnaces and blocked chimney flues. Symptoms of low levels of concentration include fatigue and chest pain in those with heart conditions. High levels cause headache, dizziness, confusion and nausea. Carbon monoxide poisoning can be fatal. Keep gas appliances properly adjusted and chimney flues clean. Furnaces should be inspected and properly maintained. Install carbon monoxide detectors. Be sure not to idle your car in the garage.



Research done by NASA and the Landscape Contractors of America identified a list of plants that appear to help remove harmful substances from the air. These include the bamboo palm, Chinese Evergreen, English ivy, Gerbera Daisy, Corn plant, Mother-in-Law's Tongue, pot mum, peace lily, and Janet Craig, Marginata and Warneckii Dracaena. The plant should be in a 6 inch pot, or larger, and the soil should be exposed to the air. One plant per 100 square feet is recommended.

There are many potentially harmful products in the kitchen. Plastic and styrofoam release harmful chemicals when heated. PVC is vinyl (plastic #3) and should be avoided whenever possible.



- Glass or ceramic containers are recommended for cooking and food storage.
- Reduce exposure by using vinegar or baking soda for cleaning whenever possible.
- In the bathroom, a new vinyl shower curtain when hung emits odors and gives a good example of harmful chemicals present in the items we purchase.
- Shampoos, soap, makeup and lotions may contain potentially harmful ingredients.
- Look for products containing shea butter, beeswax, Vitamin C and B5 and hyaluronic acid, a sugar compound that occurs naturally in skin cells.
- To help minimize exposure to harmful substances, avoid using hazardous products, except when bleach solutions are required.
- Use essential oils and purchase fragrance-free products.
- Have your home checked for lead and radon.
- Purchase a carbon monoxide detector.



- Replace smoke alarm batteries when daylight savings time begins and ends.
- Buy cotton and wool which are naturally fire-resistant.
- Vacuum regularly and open windows often.
- Small changes can help keep you and the people you support safe and healthy.

## TEN WAYS TO LIVE YOUR LIFE WELL

The following Ten Tools are from Mental Health America's wellness campaign. They are ten research-based tools that can help you cope better with stress and create more of the life you want. To take the Stress Test and learn more go to <http://www.liveyourlifewell.org/>.

### The 10 Tools

(These proven tools can help you feel stronger and more hopeful.)

1. **Connect with others.** *Fight stress with friendship.*
2. **Stay positive.** *Take steps to increase optimism. Foster gratitude.*
3. **Get physically active.** *Exercise can make you happier.*
4. **Help Others.** *Reach out...realize how fortunate you are.*
5. **Get enough sleep.** *Being tired can hurt your health and your relationships.*
6. **Create joy and satisfaction.** *Laugh and find some fun.*
7. **Eat well.** *The right foods can boost mood and brain function and fight disease.*
8. **Take care of your spirit.** *Praying, meditating and connecting with your deepest self can enrich your life.*
9. **Deal better with hard times.** *Coping tools can help you through a rough patch.*
10. **Get professional help if you need it.** *Don't hesitate to explore this possibility.*

Information taken from Mental Health America's <http://www.liveyourlifewell.org/>.



# STURGE WEBER SYNDROME

## History

In 1879, Dr. William Allen Sturge, presenting to the Clinical Society in London, described the case of a patient who began experiencing episodes of “twitching” on left side of her body. The episodes began when the child was six months of age, worsened over time, by becoming stronger, spreading to the other side of her body, and including periods of unconsciousness. Curiously, the child possessed a deep purple colored skin lesion on the right side of her head and face. The lesion blanched when pressure was applied, was demarcated in the midline and involved the upper lip, nose, and forehead, scalp, back of neck, chin and upper part of her sternum. The child’s lips, gums, tongue, roof of mouth, floor of mouth, uvula, and pharynx were all similarly affected, on the right side. Her right eye was larger and vascular malformation was present. Dr. Sturge named the lesion a “port-wine” stain, and postulated the patient’s neurological deficit could be explained by a lesion existing on the surface of the same side of the brain.

In 1922, Dr. Frederick Parkes Weber, who was well known for his comprehensive knowledge of rare disorders, attributed radiologic features of brain “atrophy” to what is now identified as Sturge-Weber syndrome.

## What is SWS?

Sturge Weber Syndrome (SWS), also known as encephalotrigeminal angiomasia, is a rare congenital disorder resulting in neurological and dermatologic (skin) disorders. The syndrome is present at birth and presents as seizures accompanied by a large port wine stain birthmark on one side of the face. The birthmark may vary in color from light pink to dark purple and usually affects the forehead and eyelid on one side of the face and may extend to the cheek, nose, or upper lip. The birthmark is caused by the formation of excess capillaries around the ophthalmic area of the trigeminal nerve, located just beneath the surface of the skin. Additionally, there is malformation of blood vessels in the tissues surrounding the brain, on the same side as the presenting birthmark. This causes calcification of tissue and loss of nerve cells in the cerebral cortex of the brain. (Grey matter or covering of the cerebrum pictured in green).

## Symptoms

Seizure activity begins in infancy and may worsen with age. Seizures typically begin as partial motor seizures involving jerks on the side of the body opposite the birth mark. They may evolve into drop attacks, myoclonic seizures, or infantile spasms. Prolonged or frequent seizures usually result in hemiparesis or weakness of the body on the affected side. Some children will have developmental delays and mental retardation. Most persons with Sturge Weber Syndrome will have or develop glaucoma (increased pressure in the eye). The increased eye pressure can cause the eye to enlarge or bulge from its socket (buphthalmos). Other symptoms may include: delayed cognitive and motor skills, visual abnormalities, behavioral difficulties, headaches and or migraines. Other organs are rarely involved.

## Diagnosis

Diagnosis can be made by a qualified physician using supporting tests such as a CT-scan MRI, or PET scan to identify the abnormal blood vessels and calcium deposits in the brain. EEGs may also be used to identify seizure activity.

## Causes

SWS is not hereditary. It is thought to result from spontaneous mutation of cells during fetal development. It is believed that one cell is affected and as that particular cell divides, the error is duplicated in subsequent cells. If a cell is affected during the early stage of development, the effects will be more severe, because more cells will carry the error.

## Treatment

Treatment for Sturge-Weber Syndrome is based on the person's presenting symptoms. Laser treatment may be used to lighten or remove the birthmark. Anticonvulsant medications or surgery may be used to control seizures. Eye drops or surgery may be necessary for more serious cases of glaucoma. Physical therapy should be considered for those with muscle weakness or paralysis. Educational therapy is often prescribed for those with intellectual and developmental disabilities. Annual monitoring for glaucoma is recommended.

## Prognosis

Although it is possible for the birthmark and atrophy in the cerebral cortex to be present without symptoms, most persons will develop seizures during their first year of life. The risk of intellectual impairment is increased when the onset of seizures begins before 2 years of age and when seizures are resistive to treatment. Most cases of Sturge-Weber are not life-threatening. Quality of life depends on how well the symptoms can be prevented or managed.

## Resources

The Sturge-Weber Foundation (SWF) was founded by parents, Kirk and Karen Ball, who began searching for answers, after their daughter Kaolin, was diagnosed at birth with Sturge-Weber Syndrome. The organization was incorporated as a non-profit organization in 1987, and their mission is to improve the quality of life and care for people with Sturge-Weber syndrome and associated Port Wine Birthmark conditions.

For more information on Sturge-Weber Syndrome or other port wine birthmark conditions contact:

### **Sturge-Weber Foundation (SWF)**

P.O. Box 418  
Mt. Freedom, NJ 07970  
[SWF@sturge-weber.org](mailto:SWF@sturge-weber.org)  
<http://www.sturge-weber.org>  
Tel: 973-895-4445 800-627-5482

### **National Organization for Rare Disorders (NORD)**

P.O. Box 1968  
(55 Kenosia Avenue)  
Danbury, CT 06813-1968  
[orphan@rarediseases.org](mailto:orphan@rarediseases.org)  
<http://www.rarediseases.org>  
Tel: 203-744-0100  
Voice Mail 800-999-NORD (6673)  
Fax: 203-798-2291

### **National Eye Institute (NEI)**

National Institutes of Health, DHHS  
31 Center Drive, Rm. 6A32 MSC 2510  
Bethesda, MD 20892-2510  
[2020@nei.nih.gov](mailto:2020@nei.nih.gov)  
<http://www.nei.nih.gov>  
Tel: 301-496-5248

### **Vascular Birthmarks Foundation**

P.O. Box 106  
Latham, NY 12110  
[hvbf@aol.com](mailto:hvbf@aol.com)  
<http://birthmark.org>  
Tel: 877-VBF-4646 (823-4646)

I am only one, but I am one.

I cannot do everything, but I can do something.

And I will not let what I cannot do interfere with what I can do.

~Edward Everett Hale~

P.O. Box 1368  
846 Jefferson Avenue  
Scranton, PA 18501



## IDEAS FOR OUR NEWSLETTER?

Contact:

Sharon Falzone, Ph.D., Director  
Northeastern PA Health Care Quality  
Unit Toll-free at 1-877-315-6855 or  
[sf@theadvocacyalliance.org](mailto:sf@theadvocacyalliance.org).