SOUTH CENTRAL PENNSYLVANIA
HEALTH CARE QUALITY UNIT

It's Your Health

Winter 2007

the Advocacy Alliance
Toll Free 1-877-315-6855
www.theadvocacyalliance.org

January is National Glaucoma Month

Glaucoma is a vision disorder in which pressure in the eyeball increases, damaging the optic nerve and causing vision loss, from slight loss to total blindness. Over 80,000 Americans are blind from glaucoma. Usually glaucoma has no known cause, though it sometimes runs in families. It is important to see an eye doctor (ophthalmologist or optometrist) regularly to measure the eye pressure using a simple, painless procedure called tonometry.

If the outflow channels of the eye are open, the disorder is called open-angle glaucoma. Progressive loss of peripheral or side vision, tearing, headaches, and blurred vision are indicators of open-angle glaucoma. If the channels are blocked by the iris, the disorder is called closed-angle glaucoma. Sudden onset of severe eye pain, facial pain, loss of vision, rainbow halos around lights, redness of the eye and dilated pupils are symptoms of closed-angle glaucoma. These symptoms may be accompanied by nausea and vomiting. If these symptoms occur it is a medical emergency and immediate medical attention is necessary.

An elevated intraocular pressure does not always indicate glaucoma if the optic nerves are not enlarged. Increased pressure without optic nerve damage is called ocular hypertension and is monitored by the eye doctor at regular intervals. A test called a visual field is performed to test for loss of peripheral vision.

Treatment for glaucoma is likely to be more successful if started early. Medicated eye drops will oftentimes control glaucoma. Individuals not responsive to medications may be candidates for laser therapy. Eye medications have some alerts that may cause aggravation to certain heart or lung conditions. It is important to give your healthcare provider a thorough health history. In addition, other prescribed medications a person may be taking can aggravate glaucoma. It is always wise to be aware of side effects and observe for them any time prescribed medications or over-the-counter medications are taken.

It is important that glaucoma screening for early detection and prevention be done annually on people over age 35, especially those with family histories of glaucoma.

Resources: www.webmd.com; www.emedicine.com; www.health.allrefer.com

Prader- Willi Syndrome

Prader-Willi Syndrome (PWS) is a complex genetic disorder involving chromosome 15 with a segment of genes missing or "inactive." In 1956, the characteristics of PWS were identified by three Swiss physicians, Prader, Willi, and Labhart. All individuals with PWS have some degree of intellectual impairment and many medical issues and concerns.

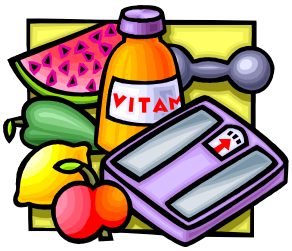
PWS is a serious medical disorder that interferes with the body's appetite control center. Individuals with PWS do not feel full or satiated after eating. They experience an uncontrollable drive to forage and hoard food. Their metabolism is approximately one half the rates of their peers. Persons with PWS gain weight easily and at a fast rate.

Medical issues and concerns include diabetes, heart failure, osteoporosis, sleep disorders, dental cavities, body temperature abnormalities, and respiratory complications. Additional issues and concerns include gastric complications, skin infections, rectal bleeding, bowel and bladder incontinence, edema and fluid retention, and adverse medication reactions.

Early symptoms of the disorder in infancy are low muscle tone ("floppy" baby) weak reflexes, poor sucking ability, delayed motor development, and a weak, infrequent cry. Excessive and rapid weight gain begins between one and six years of age. Physically, the children possess a high vomiting threshold and decreased gag reflex, small stature, unstable body thermoregulation, incomplete sexual development, speech and language difficulties and an insatiable appetite.

Behavioral characteristics include temper tantrums, stubbornness, food foraging, difficulty with change, self-injury (often skin picking), and sleep disturbances. Skin picking occurs in about 80% of situations, and requires vigilant skin care and monitoring to prevent serious infection.

All individuals with PWS have some degree of intellectual impairment. Early intervention, particularly physical therapy, may improve muscle strength and encourage achievement of developmental milestones.



Life-long food vigilance is extremely important for those with Prader-Willi Syndrome. Food needs to be inaccessible and diets carefully managed. Consequently, the environment has to be modified to limit access to food. Pantries, refrigerators and cupboards are often locked. Outings require close supervision and avoidance of proximity to food stores and eating establishments. Regular exercise is a cornerstone of treatment for weight management and promotion of improved health. Exercise is medically necessary to maintain metabolism and muscle tone.

Medications should be limited due to decreased metabolism. Appetite suppressants are not effective. Medications that may be helpful include vitamin and mineral supplements, and growth hormone replacement therapy to stimulate skeletal growth, increase lean muscle mass, and aid in sexual development. Other medications may be indicated to address self-injurious, explosive, and obsessive compulsive behaviors, but it is important to consider that individuals with PWS have unpredictable responses to many medications. It is a good practice to initiate one-fourth to one-half the usual dosage, and increase in small increments.

Consistency and structured routines which provide predictability work best for individuals with PWS. Physical safety is an important focus of care. Prevention of overeating and monitoring and treatment of open wounds require vigilance by caregivers. Individuals with Prader Willi Syndrome are prone to anxiety. Family involvement and understanding support with transition and change are positive components to effectively manage the ramifications of PWS. Due to the complexity of PWS, it is important to have all individuals with Prader-Willi Syndrome wear medical alert identification.

Prader-Willi Syndrome cannot be cured and it is important to remember that it is a life-threatening condition.

Happy Holidays

. . . Not Always

The holiday season is upon us! The music, the lavish decorations in the malls, the bright lights adorning homes and businesses can stir joy and happiness in our hearts. But this does not hold true for everyone.

Consider those who have lost loved ones during the past year or who are suffering with illness that limits their usual celebrations. Sadness, loneliness, and anxiety may better describe their feelings about the impending holiday season. Holiday memories and lost traditions can magnify one's depressed mood. Others with unrealistic expectations for the holiday, the perfect gifts, the perfect decorations, perfect parties and family gatherings, may become overwhelmed with stress.

Additional expenses that occur during the holidays lead to mounting pressure on those with financial problems. Time becomes more precious with additional "duties" such as decorating, baking, shopping, and entertaining. Fatigue results, stamina decreases, and "the holiday blues" take hold.

But, there is good news! You can cope with holiday stress by pacing yourself and setting realistic expectations!

Prioritize. Define what you want to accomplish during the holidays. Gather input from immediate family members and determine what is most important to you.

Plan. Determine what you can and cannot do. Spread out activities.

Budget. Be realistic. Set limits on gifts, cards, entertainment, decorations.

Express your emotions. Accept that it is okay to feel sad or lonely. Express your emotions and talk about the past. However, focus on the present and creating new memories and traditions.

Simplify. Holiday fun doesn't have to be expensive. Take a drive to look at the neighborhood lights/decorations, attend free concerts and holiday programs at schools and churches, volunteer to aid others, tour a garden center with decorated trees, play in the snow and sing with gusto!

Share the labors. Assign duties and responsibilities so the work is not on only one person. Communicating and working as a team builds mutual respect and shared pride in accomplishments.

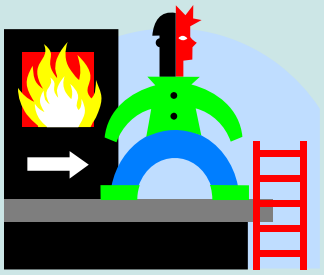
Smile! It can make a person's day and yours too!

Special Populations Fire-Safety Checklist

More than 4,000 Americans die each year in fires and approximately 25,000 are injured. Special populations such as older adults, people with disabilities, and people with hearing and visual impairments can significantly increase their chances of surviving a fire by practicing proven fire safety precautions.

Special populations are at risk for a number of reasons:

- Decreased mobility, health, sight, and hearing limit a person's ability to take the quick action necessary to escape during a fire emergency.
- Depending on physical limitations, a person may require help from a caretaker, neighbor, or outside sources.



The United States Fire Administration (USFA), a directorate of the Federal Emergency Management Agency (FEMA), encourages individuals with special needs to use this fire safety checklist to help protect themselves and their home from fire.

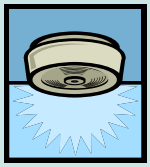
- It is vitally important to make and practice escape plans. In the event of a fire, remember, time is the biggest enemy and every second counts.
- Involve the assistance of support staff, family members, or a trusted friends when practicing your fire escape plan.
- Know at least two exits from every room.

- If you use a walker or wheelchair, check all exits to make sure they get through the doorways.
- Practice opening locked or barred doors and windows.
- When a fire occurs, do not waste any time saving property. Leave the home immediately. Once out, stay out.
- People with mobility difficulties should be encouraged to have their bedroom on the ground floor and as close as possible to an exit.
- If necessary, have a ramp available for emergency exits.
- Unless instructed by the fire department, never use an elevator during a fire.

- Be sure your street address is clearly marked and visible from the street.
- Have local emergency service numbers posted or memorized.

  - Contact your local fire department on a non-emergency telephone number and explain your special needs.
  - Your local fire department will be able to help you with your escape plan and may be able to perform a home fire safety inspection and offer suggestions about smoke alarm placement and maintenance.
  - Ask emergency providers to keep your special needs information on file.

- Working smoke alarms installed on every level of your home dramatically increase your chances of survival.
- Special fire safety devices, such as smoke alarms with a vibrating pad or flashing light for the deaf and hard of hearing, are available. In addition, smoke alarms with a strobe light outside the house can catch the attention of neighbors or others who might pass by.
- Smoke alarm batteries need to be tested every month and changed at least once a year. If you can't reach the test button on your smoke alarm, ask someone to inspect it for you.



Resource: www.usfa.fema.gov

Links to Check Out

www.usfa.fema.gov

www.ninds.nih.gov/disorders/swallowing_disorders/swallowing_disorders.htm www.beckydorner.com

www.webmd.com

www.pcoscampaign.com

www.emedicine.com

www.health.allrefer.com

February is Polycystic Ovary Syndrome Awareness Month

Polycystic ovary syndrome, PCOS, is a common hormonal condition in which women produce a surplus of androgens (sometimes called male hormones), causing irregular ovulation, or even lack of ovulation. PCOS affects approximately one of every 10 women. Researchers predict that more women will develop PCOS as obesity becomes a bigger problem throughout the world.

The causes of PCOS are not completely understood, though it is likely that a genetics tendency is involved. Women with PCOS can have a wide spectrum of signs and symptoms, which may include:

- Irregular or absent menstrual periods
- Heavy vaginal bleeding
- Oily skin and acne
- Excessive hair growth on the face, chest, abdomen, or thighs
- Thinning of hair on the crown of the head
- Type 2 diabetes
- Obesity
- Cardiovascular problems, including high cholesterol
- Multiple tiny ovarian cysts

PCOS is diagnosed on the basis of signs and symptoms. There are no blood tests to diagnose PCOS, but can be used to confirm the diagnosis, by ruling out other conditions that have similar symptoms. There is no cure for PCOS, but it can be controlled with varying degrees of success. With healthy lifestyle choices, from appropriate diet and exercise choices, women can experience improvement in the signs and symptoms of PCOS. Treatment options include oral contraception that counteract the androgen levels and establish regular periods. For women with PCOS and insulin resistance, medication to improve insulin sensitivity may be useful.

Women are often very frustrated as this condition is slow to be diagnosed. Regular gynecological examinations are important along with a detailed conversation with the medical consultant, in order to give a complete health history. Advocate groups hope with greater community and medical awareness about PCOS, earlier diagnosis of women with this syndrome will be identified.

Resources: www.webmd.com; www.pcoscampaign.com

Dysphagia: A Matter of Life

At any stage of the normal swallowing process in which food or liquid moves from the mouth, through the back of the throat, into the esophagus, and finally into the stomach, difficulty may be experienced. Swallowing disorders or dysphagia can occur in all age groups, though more commonly in older individuals.

Complications of undiagnosed or untreated dysphagia range from poor appetite, weight loss, choking, pneumonia, behavioral changes to potentially fatal conditions. In many cases, dysphagia can be partially or completely corrected, while in some cases it can be life-threatening and require aggressive interventions, such as a feeding tube.

Dysphagia is more common in individuals with:

- Neurological disorders—such as Parkinson's Disease and Multiple Sclerosis, or sudden neurological damage from a stroke, spinal cord or head injury
- Disorders affecting muscle strength or coordination—such as Muscular Dystrophy or ALS
- Gastro esophageal Reflux Disease (GERD)
- Tumors or cancer of the head, neck, mouth or throat
- Medication side effects and interactions

Other considerations that may lead to dysphagia include structure abnormalities, poor or missing teeth, ill-fitting dentures, esophageal narrowing, improper positioning while eating or drinking, behaviors such as eating or drinking too quickly, and poisoning or burns from swallowing household cleaners.

It is important that support staff who work with individuals at risk for dysphagia be observant of signs and symptoms indicative of swallowing difficulties that can develop at any time.

Statistics indicate over 6 million Americans are affected by dysphagia. Treatment many include medication and/or surgery, though many people can be helped by changing diets and learning new techniques to promote safe swallowing. Mealtime and gathering around the table with family and friends can be one of the most satisfying times of the day. It can also be a very dangerous time. Understanding dysphagia and how to manage this condition may be a matter of life.

For further information on this condition contact your local HCQU nurse.

Resources: www.ninds.nih.gov/disorders/swallowing_disorders/swallowing_disorders.htm;

www.beckydorner.com

When indicators of dysphagia are observed, it is important not to dismiss them as insignificant because "they have always eaten like this." Some indicators include:

- **Abnormal positioning/movement of head/body during drinking or eating**
- **Frequent respiratory infections/ pneumonia**
- **Weight loss**
- **Unexplained elevated temperature**
- **Refusal to eat**
- **Excessive tongue movement or thrusting**
- **Prolonged or effortful chewing**
- **Eating rapidly**
- **Swallowing food whole**
- **Spitting out food**
- **Pocketing food or drink in mouth**
- **Regurgitation of food from nose or mouth, or vomiting**
- **Coughing or choking**
- **Wet, gurgly voice**
- **Excessive drooling or not managing saliva**
- **Weak cough**

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Ideas for Our Newsletter?

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