Advances in the Treatment of PKU

Sandra Simons, MA, RD, CHES

Phenylketonuria (PKU) is an autosomal recessive inborn error of phenylalanine metabolism that is caused by a deficiency of the liver enzyme phenylalanine hydroxylase (PAH). The PAH enzyme is responsible for the breakdown of phenylalanine into tyrosine. Tetrahydrobiopterin (BH4) is a known cofactor to facilitate the conversion of phenylalanine to tyrosine by the PAH enzyme (Figure 1).

Due to the deficiency in PAH enzyme to effectively break down phenylalanine, PKU if left untreated, results in a toxic build up of phenylalanine, a deficiency of tyrosine and its downstream products including melanin, L-thyroxine and catecholamine neurotransmitters (1). Untreated PKU is characterized by mental retardation, microcephaly, speech and developmental delays, behavior abnormalities, seizures and poor skin pigmentation. PKU has an incidence rate of about 1 in 15,000 infants in the United States (2). There are several classifications of PKU that are a result of the specific gene mutation inherited by the patient. These classifications are assigned at the time of diagnosis based on blood/phenylalanine concentrations (Table 1).

The standard treatment protocol for PKU is a low phenylalanine diet, which correlates to a diet very low in natural protein. A typical diet for the treatment of classical PKU, allows for only 200-500mg of phenylalanine from food (approximately 4-10g of protein) per day. Therefore the diet must be supplemented with phenylalanine free amino acid modified medical food, commonly referred to as PKU formula, to meet daily protein needs. The overall goal of treatment is to maintain blood PHE concentrations of 120-360 µmol/L for those age 12 and under and between 120-900 umol/L for teens and adults, although the National Institute of Health (NIH) strongly encourages even lower phenylalanine levels (120-600 umol/L) during adolescence (2).

The objective of this article is to provide a historical look at critical advances in the treatment of PKU, and highlight current and emerging therapies that may improve treatment, quality of life or even lead to a cure for PKU.

A Historical Look at PKU

The history of Phenylketonuria is not a long one, but one marked by rapid advances and discoveries. PKU was first reported in 1933 by a Norwegian doctor named Asbjorn Folling. He noticed that several mentally retarded patients had a similar musky smell and deduced that the odor was from ‘phenylacetic acid’ (1). These patients also had a high level of ‘phenylketones’ in their urine leading to an identifiable condition termed ‘Phenylketonuria’. The future of PKU dramatically changed in 1962 by Dr. Robert Guthrie and the development of the ‘Guthrie’ test. The

Table 1. Classifications of PKU

<table>
<thead>
<tr>
<th>Classification of PKU</th>
<th>umol/L</th>
<th>mg/dL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Classical PKU</td>
<td>&gt;1200</td>
<td>&gt; 20</td>
</tr>
<tr>
<td>Mild PKU</td>
<td>600-1200</td>
<td>10-20</td>
</tr>
<tr>
<td>Non-PKU Hyper-PHE</td>
<td>120-599</td>
<td>2&lt;10</td>
</tr>
</tbody>
</table>

(3)
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From the Chair
Andrea D. Shotton, MS, RD

It is with great pleasure to see the new strategic plans for BHN fall into place this year and for years to come empowering members to be experts in behavioral health nutrition. The plans include two webinars performed in 2009 and two more in place for 2010. Beth Sobel, MS has graciously volunteered her time and talent at becoming BHN’s first Webinar Coordinator. Please welcome her. She is a great addition to the Executive Committee and has jumped in full steam to complete the rest of the year’s webinars. You may access the webinars on our website at www.bhndpg.org. Additionally, you will find the link to our new Facebook page on BHN’s home website www.bhndpg.org. Become BHN’s fan on Facebook!

Please visit the home website often, our Publications Chair, Paula Kerr, MS, RD, is constantly working overtime to keep it updated with all BHN’s new advances, resources and information in behavioral health. With that said, we are still in need of a Website Editor position on the Publications Committee.

As the year wraps up, we begin nominations for the 2009-2010 awards that are presented annually at the Food and Nutrition Conference & Expo. Do you wish to nominate a BHN Member for their excellence in practice in any of the four focus fields?

- Eating Disorders
- Intellectual and Developmental Disabilities
- Addictions
- Mental Illness

Please email Andrea Shotton at asotton@nutritionalvoices.com with name, credentials, field of practice, location of practice, and how the individual has shown excellence in the given field.

BHN continues to move forward with increasing membership numbers, webinars, standards of practice and professional performance development and educational publications. This leads to many positions available for BHN members to volunteer their expertise and skills. Contact our volunteer coordinator, Cary Kreutzer, MPH, RD at ckreutzer@chla.usc.edu.

How amazing it is to share with other Dietetic Practice Groups and ADA members our talented individuals in BHN. I encourage all of you to remember BHN’s new mission and be empowered to be the food and nutrition experts in behavioral health care.

Your Chair,
Andrea D. Shotton

The Renfrew Center Foundation Presents Advanced Professional Training Seminars

**Insatiable Hungers: Eating Disorders, Chemical Dependency and Depression in Women**

Presented by: Adrienne Ressler, MA, LMSW, CEDS
National Training Director, The Renfrew Center Foundation
May 14 – Long Island, NY
May 21 – Cleveland, OH

**Hungers of the Soul: Spirituality, Hope, and Forgiveness in the Treatment of Eating Disorders**

Presented by: Jennifer Nardozzi, PsyD
National Training Manager, The Renfrew Center Foundation
April 16 – Indianapolis, IN
April 30 – Albany, NY
June 4 – Boston, MA

http://renfrew.org/news-events/events/springseminar.html
Advances in Treatment of PKU

Guthrie test was a simple and inexpensive bacterial inhibition blood assay conducted on a dried blood spot taken from newborns, allowing the rapid detection of PKU and initiation of a low phenylalanine diet supplemented with PKU formula. Neurological changes have been documented within one month of birth (1), so the earlier treatment begins the better the potential outcome. Newborn screening was rolled out across the USA during the late 1960’s and 1970’s. Advances in technology and the development of tandem mass spectrometry now allows for newborn screening of a single blood spot to include many more conditions than just PKU. Information on newborn screening can be found on state newborn screening websites.

Before newborn screening, patients with classical PKU had a bleak prognosis, often leading to boarding in mental institutions or group homes for the less severely affected. Even after newborn screening and early initiation of diet, some clinicians felt that the PKU dietary regimen was only necessary through childhood, when neural development is maximal (1). Many children with managed PKU were taken off diet between ages 4-12 during the 70’s and early 80’s, which was thought safe and without repercussions. This was found not to be true (2). Several studies outlined either a decline in mental ability for those taken off the diet or major differences in intelligence and neurologic function when compared to those who remained on treatment (1,4).

From 1967-1983, the Maternal and Child Health Division of the Public Health Services funded a collaborative study to follow 211 infants from 15 clinics nationwide until the age of 10 years. A follow up study, initiated in 1998 evaluated patients who remained on full diet treatment and compared to those who did not. The results illustrated that subjects remaining on a PHE restricted diet had fewer reported problems, including mental disorders, hyperactivity, headache, eczema and asthma than those who ceased the diet. Quantitatively, test results also showed lower intellectual and achievement scores were associated for those with higher blood/plasma phenylalanine levels as children and adults (4). This led to the 2000 NIH Consensus Development Conference Statement that metabolic control and ‘diet for life’ is necessary across the lifespan of individuals with PKU (2). In addition, the support for ‘diet for life’ has spurred, an on-going nationwide movement to return individuals that are off-diet, late diagnosed or born before newborn screening back to the PKU diet.

Advances in Diet Therapy

Supplementation with amino acid modified medical food (PKU formula) and low protein food is necessary on a daily basis for successful PKU management. As emerging research in the late 90’s solidified PKU as lifelong dietary treatment, it became apparent that improvements in palatability of PKU medical food were necessary to facilitate dietary adherence. In 1997, Prince, et al. documented that changing the form of amino acids used to create the ‘protein substitute’ would enhance taste, palatability and acceptability of the PKU medical food and ultimately lead to improved dietary compliance (5). These findings led to an expansion within the PKU formula marketplace with increased variety and flavors. PKU medical foods are now available as drinks, bars and tablets that range from nutritionally complete, all-in-one products providing phenylalanine free protein, fat, carbohydrate, all essential vitamins and minerals

### Table 2. Low Protein Food Cost Comparison Chart

<table>
<thead>
<tr>
<th>Food Item</th>
<th>Quantity</th>
<th>Low Protein Cost</th>
<th>Average Cost in Supermarket#</th>
</tr>
</thead>
<tbody>
<tr>
<td>White Bread</td>
<td>16 slices</td>
<td>11.99*</td>
<td>$2.00</td>
</tr>
<tr>
<td>Bagels</td>
<td>6 bagels</td>
<td>8.89**</td>
<td>$3.29</td>
</tr>
<tr>
<td>Dinner Rolls</td>
<td>6 rolls</td>
<td>7.89**</td>
<td>$2.99</td>
</tr>
<tr>
<td>Spaghetti</td>
<td>1 - 8 oz box</td>
<td>6.49*</td>
<td>$1.09</td>
</tr>
<tr>
<td>Fettuccine</td>
<td>1 - 8.75 oz box</td>
<td>10.59*</td>
<td>$1.09</td>
</tr>
<tr>
<td>Blueberry Muffin Mix</td>
<td>Approx. 12 muffins</td>
<td>7.33****</td>
<td>$3.79</td>
</tr>
<tr>
<td>Sugar Cookies Mix</td>
<td>Approx. 18 cookies</td>
<td>6.55****</td>
<td>$3.49</td>
</tr>
<tr>
<td>Chocolate Chip Cookies</td>
<td>16 cookies</td>
<td>15.95***</td>
<td>$2.50</td>
</tr>
<tr>
<td>Imitation Cheese Slices</td>
<td>32 slices</td>
<td>11.99*</td>
<td>$3.29</td>
</tr>
</tbody>
</table>

*www.cambrookefoods.com
**www.dietspec.com
***www.pkuperspectives.com
****www.dietforlife.com
# Shoprite, Branchburg, NJ – average of multiple brands on 1/12/10
to modular units that provide only the amino acid protein to allow for greater flexibility in the diet. The low phenylalanine diet permits only a small amount of fruits and vegetables, supplemented with specialized low protein foods like bread and pasta that are quiet expensive compared to their regular counterpart (Table 2). Although advances in PKU formula and low protein foods has resulted in a wide selection of products that allow for greater choice and variety, the dietary treatment for PKU remains a challenge for many (6).

Recent and Future Treatment Advances

Glycomacropeptide (GMP)

A new dietary treatment option is emerging that may serve as an alternative to amino acid modified medical food or even a replacement. GMP or glycomacropeptide is an intact protein that comprises 15-20% of the protein in bovine milk whey, which is a byproduct of cheese making. GMP, as a nutritional product for PKU has promise, because GMP in its pure form is void of phenylalanine (6). GMP alone does not possess a suitable amino acid profile for PKU treatment, but when supplemented with the limited indispensable amino acids: histidine, leucine, tryptophan and tyrosine, becomes a viable alternative to traditional amino acid modified medical food for PKU. Research conducted at the University of Wisconsin-Madison reported that PKU mice fed with a low phenylalanine (PHE) diet supplemented with GMP had an 11% decrease in plasma phenylalanine concentrations and 20% lower brain phenylalanine levels, than mice fed an amino acid based diet (6). GMP products aim to provide a more palatable alternative with increased variety for the low-PHE diet. In a recent GMP study, 10 out of 11 subjects reported a preference for the GMP diet to the amino acid diet (7). The same study reports improved protein retention, higher plasma insulin and phenylalanine utilization with the GMP diet. GMP has been clinically tested with PKU patients in the forms of shakes, puddings, and sports drinks. Products containing GMP are not yet commercially available, but are anticipated in 2010.

Large Neutral Amino Acid Therapy (LNAA)

Large Neutral Amino Acid (LNAA) therapy is an emerging alternative treatment for older individuals with PKU. This type of treatment for PKU is based upon amino acid competition at the blood brain barrier. Research conducted in the 1980’s indicated that high levels of phenylalanine in the blood inhibit the transport of tyrosine, tryptophan and other amino acids into the brain. The decreased transport of these amino acids result in impaired synthesis of dopamine and serotonin, the neurotransmitters that regulate mood, appetite, sleep and other normal brain functions (8). Large neutral amino acids (arginine, histidine, isoleucine, leucine, lysine, methionine, phenylalanine, threonine, tryptophan, tyrosine and valine), share common transporters across the intestinal cell membrane and blood-brain barrier (3,8). Supplementation with LNAA blocks the uptake of phenylalanine by actively controlling cell receptor sites, effectively reducing phenylalanine concentration in the brain (8,9). Koch, et al., found that the brain concentration of phenylalanine decreased toward the carrier level within six months of LNAA use despite increased intake of natural protein (10). Treatment with LNAA helps to protect the brain from acute toxic effects of elevated phenylalanine levels and has been shown to have a positive effect on executive function, verbal generality, cognitive flexibility, and self-monitoring (11). These potential benefits make this form of treatment an alternative for teens and adults who are off diet, individuals who were not diagnosed early in life and those struggling to maintain low blood PHE levels.

Although LNAA treatment does not completely replace the phenylalanine-restricted diet it does help ease the dietary restriction for treated individuals by allowing for a larger amount of natural food protein (Figure 2). While diet treatment is always very individual, the LNAA diet may allow the inclusion of regular bread, rice, pasta, and other grains eliminating the need to purchase costly low protein foods (Table 2). Treatment with LNAA can be especially useful for those living in group environments with set menus and for those struggling with dietary compliance (12).

The ‘relaxed diet’ associated with LNAA therapy, not only improves the dietary options for those living in long-term care environments, but also quality of life. Significant improvements in concentration and decreased self-injurious behavior have been reported in previously untreated adults on a normal diet and LNAA supplementation (11). A study by Moseley documented that untreated adults living in group homes not only demonstrated improvements in daily living skills, but also had a reduction in use of medications while using LNAA therapy. This resulted in significant cost savings for the organizations responsible for the care of these individuals (12).

Tetrahydrobiopterin (BH4)

BH4 is the cofactor for the hydroxylation of phenylalanine to tyrosine by phenylalanine hydroxylase (PAH), the defective enzyme in PKU (11) (Figure 1).
Sapropterin hydrochloride, branded as KUVAN®, is a synthetic form of BH4 and was approved by the FDA in 2007. It works to boost the enzymatic action of PAH and stimulate the breakdown of phenylalanine to tyrosine resulting in lower blood phenylalanine. Currently, over 400 mutations have been identified for the PAH gene which leads to varying degrees of PAH deficiency and degrees of PKU severity. There is a strong correlation between patients that are BH4 responders and non-responders; dependent on the type of mutation they possess (13). Studies have suggested that those with most mild forms of PKU (hyper-phe and mild PKU) possess mutations that are more likely to respond to this form of treatment (11,13). A study conducted by Matalon, Koch, Michals-Matalon, et al. explored the response rate to BH4 in classical and atypical PKU. Of the 36 patients in the study, 21 responded with a decrease in blood phenylalanine of which 12 had classical PKU. The remaining 15 patients (14 with classical PKU), were reported as non-responders (13). BH4 responsive patients, often have an improved tolerance to dietary phenylalanine, suggesting diet liberalization and a reduced reliance on specialty low protein food and medical food. In some cases, PKU medical food may no longer be necessary, although this is rare (11).

Phenylalanine Ammonia Lyase (PAL)

Since not everyone with PKU is BH4 responsive, especially those with the most severe forms of PKU (1), the quest for a more comprehensive alternative treatment remains on-going. For over a decade researchers in Canada have been examining phenylalanine ammonia lyase (PAL) as an alternative therapy. PAL is proposed as an enzyme substitute for PAH. PAL is a nonmammalian enzyme produced through recombinant DNA techniques. It is anticipated to reverse hyperphenylalanemia by converting excess phenylalanine to trans-cinnamic acid and trace amounts of ammonia (14). Using PAL with a mouse model, short term studies have shown a reduction in blood and brain concentrations of phenylalanine (11,14). One caveat to long-term treatment is an immune response recognizing PAL as a foreign protein. To resolve this, researchers found that pegylating or linking polyethylene glycol to PAL creates a protective coating decreased immunogenicity resulting in PEG-PAL (14). Phase 1 clinical trials on humans with PEG-PAL are currently underway.

Gene Therapy

Gene therapy is also being explored in animal models and although wrought with challenges has shown some promise for possible future treatment. There has been documented success with introducing the PAH gene into a mouse liver that resulted in expression of the enzyme and reductions in blood phenylalanine (1,11). Due to the death of a patient with a urea cycle disorder who was enrolled in a clinical trial, human investigations utilizing gene therapy have been on hold (11). Gene therapy is an exciting prospect for the future, but is in the early stages requiring additional work and study to be considered a viable alternative treatment for PKU.

Summary

The research that Asbjorn Folling began in the early 30’s continues today with great fervor and passion. The progress made in PKU research has led to more palatable formula, alternative options to the traditional PKU diet and a better understanding of the disease. The ultimate quest is for a cure, but for now research has led to many viable options to aid dietitians and other medical professionals to implement diet plans to improve patient quality of life. Those with PKU currently enjoy a better prognosis and outcome. PKU is no longer the debilitating disease it once was. PKU patients have now become college graduates, doctors and other professionals in our society. We look toward the future with great excitement and continue the quest for a cure, but for now accept PKU as ‘Diet for Life’.

About the Author:
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Applied Nutrition Corp. is a medical food company that manufacturers products for the dietary management of Phenylketonuria (PKU) and Maple Syrup Urine Disease (MSUD).

References
ADA Updates Position Paper on Nutrition Services for People with Developmental Disabilities and Special Health Care Needs


Abstract

It is the position of the American Dietetic Association that nutrition services provided by registered dietitians (RDs) and dietetic technicians, registered (DTRs), are essential components of comprehensive care for all people with developmental disabilities and special health care needs. Nutrition services should be provided throughout life in a manner that is interdisciplinary, family-centered, community-based, and culturally competent. People with developmental disabilities and special health care needs frequently have nutrition concerns, including growth alterations (failure to thrive, obesity, or growth retardation), metabolic disorders, poor feeding skills, medication-nutrient interactions, and sometimes partial or total dependence on enteral or parenteral nutrition. Individuals with special needs are also more likely to develop comorbid conditions such as obesity or endocrine disorders that require nutrition interventions. Poor health habits, limited access to services, and long-term use of multiple medications are considered health risk factors. Health maintenance and avoidance of complications can be promoted by timely and cost-effective nutrition interventions. Public policy for individuals with special needs has evolved over time, resulting in a transition from institutional facilities and programs to community living. The expansion of public access to technology and health information on the Internet challenges RDs and DTRs to provide accurate scientific information for those with developmental disabilities and special health care needs. Nationally credentialed RDs and DTRs are best prepared to provide appropriate nutrition information for wellness and quality of life.

The full version of the position paper is available at ADA’s website.

Shortcut to: http://www.eatright.org/About/Content.aspx?id=8379

BHN members participating in the position update:

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Reviewers: Harriet Holt Cloud, MS, RD; Shirley Ekvall, PhD, RD, LS, FAAMD, FACN; Mary Hager, PhD, RD, FADA

Association Positions Committee

Workgroup: Suzanne Geerts, MS, RD, LD (content advisor)

INCIDENCE OF CEREBRAL PALSY ON RISE IN UNITED STATES


MAYWOOD, Ill. -- Cerebral palsy (CP) has increased in infants born prematurely in the United States, according to data presented by researchers from Loyola University Health System (LUHS). These findings were reported at the 30th Annual Meeting of the Society for Maternal-Fetal Medicine in Chicago. They also were published in the latest issue of the American Journal of Obstetrics & Gynecology.

Researchers reported that CP is associated with inflammation of the connective tissue in the umbilical cord. This inflammation is more common in premature births from preterm labor and premature rupturing of the amniotic sac versus early deliveries due to preeclampsia. Premature births from preterm labor and rupturing of the amniotic sac also are often associated with infections while preeclampsia is not.

“These findings are valuable, as we continue to study the link between premature births and cerebral palsy,” said John Gianopoulous, MD, chair, Mary Isabella Caestecker professor and chair, Department of Obstetrics & Gynecology, LUHS. “While further investigation is needed, managing inflammation may reduce the risk of certain complications in these infants.”

CP is a disorder that impairs movement due to brain damage. This condition typically develops by age 2 or 3. More than 500,000 Americans have CP, and it is one of the most common causes of chronic childhood disability.

Researchers evaluated 222 preterm placentas for this study. Reasons for preterm births were categorized into four groups: premature rupture of the amniotic sac or preterm labor; preterm preeclampsia; maternal disease related to heart complications; and uncompleted births of multiples. Of those patients who went into preterm labor or had their amniotic sac rupture early, 30 percent had an inflamed umbilical cord compared with only 3 percent of patients with preeclampsia.

LUHS maternal-fetal medicine specialists conducted this study. These physicians work in conjunction with neonatologists, geneticists and obstetrical anesthesiologists to provide care for patients with medical or surgical complications during pregnancy.

Loyola University Health System is a nationally recognized leader in providing health care and in conducting groundbreaking research to treat heart disease, cancer, organ transplantation and neurological disorders.
New Study Details Complex Health Care Needs of Medicaid’s Highest-Need, Highest-Cost Populations

Center for Health Care Strategies, Inc. Released October 20, 2009

Hamilton, NJ, and Oakland, Calif. - Medicaid beneficiaries with disabilities frequently have multiple chronic conditions, and very high rates of psychiatric illness and cardiovascular disease, according to a study released today by the Center for Health Care Strategies. As national policymakers debate health reform, The Faces of Medicaid III: Refining the Portrait of People with Multiple Chronic Conditions provides insights for targeting efforts to improve care and control spending for Medicaid’s highest-need, highest-cost beneficiaries. These insights are relevant and applicable to other populations and patients with multiple complex co-morbidities. The study was funded through a grant from Kaiser Permanente.

Building on an earlier analysis that examined one year of national Medicaid diagnostic data, this new study adds two data sets -- pharmacy claims and five years of diagnostic data -- to further refine what is known about Medicaid beneficiaries with chronic needs. The study, conducted by Rick Kronick, Ph.D., and Todd Gilmer, Ph.D., both from the University of California, San Diego, sought to expand the knowledge base regarding the prevalence and patterns of chronic conditions among Medicaid beneficiaries.

"Analyzing prescription drug use in addition to diagnostic claims identifies considerably more beneficiaries with co-morbidities, and notably, a significant increase in patients with behavioral health issues," said Dr. Kronick. "By expanding these insights into the population’s complex needs, this work can help Medicaid stakeholders in designing tailored care management interventions for patients with multiple chronic conditions."

Compared to solely looking at diagnostic data, the addition of pharmacy data reveals higher rates of co-morbidity among Medicaid beneficiaries with disabilities, including significantly higher prevalence of psychiatric illness and cardiovascular disease. Following are highlighted findings resulting from the addition of pharmacy data:

- The proportion of Medicaid beneficiaries with disabilities who are diagnosed with three or more chronic conditions increases from 35% to 45%;
- The frequency of psychiatric illness among Medicaid beneficiaries with disabilities increases from 29% to 49%. Similarly, the prevalence of cardiovascular disease increases from 32% to 44%; and
- Costs for Medicaid-only beneficiaries with three or more chronic conditions increases from 66% to 75% of total spending for beneficiaries with disabilities.

Pharmacy data was particularly valuable in illustrating the prevalence of psychiatric illness among high-cost Medicaid beneficiaries. In examining diagnostic and pharmacy data together, psychiatric illness is represented in three of the top five most common pairs of diseases among the highest-cost 5% of Medicaid-only beneficiaries with disabilities. This was not apparent using diagnostic data alone.

"These patients account for much of the cost and use of services in Medicaid, and require special attention, considerable resources, and an intensive approach to care management," said Raymond J. Baxter, PhD, senior vice president, Community Benefit, Research and Health Policy, Kaiser Permanente. "This report contributes significantly to the body of information about how to understand and improve the care of patients with complex, chronic conditions."

The Faces of Medicaid III: Refining the Portrait of People with Multiple Chronic Conditions is the third edition in CHCS’ Faces of Medicaid series. It is available for download at www.chcs.org/facesofmedicaid.

The Center for Health Care Strategies (CHCS) is a nonprofit policy resource center dedicated to improving health care quality for low-income children and adults, people with chronic illnesses and disabilities, frail elders, and racially and ethnically diverse populations experiencing disparities in care. CHCS works with state and federal agencies, health plans, and providers to develop innovative programs that better serve Medicaid beneficiaries. For more information, visit www.chcs.org.

BHNewsletter reaches more than 1300 members quarterly.

Do you have a product or service you would like to publicize? Have you written an evidence-based article you would like to share?

BHNewsletter reaches more than 1300 members quarterly.

Let me know! Diane Spear, BHNewsletter Editor
www.newsletter@bhn.org

It is BHN Awards Time!

Time to spotlight those among us who have shown Excellence in Practice and to celebrate one BHN member as recipient of our Distinguished Member Award. go to www.bhndpg.org/about/awards.asp for BHN awards criteria, guidelines, and forms to nominate members you know to be deserving of recognition.

Application Deadline is June 1, 2010.
Women with bulimia nervosa (BN), when compared with healthy women, showed different patterns of brain activity while doing a task that required self-regulation. This abnormality may underlie binge eating and other impulsive behaviors that occur with the eating disorder, according to an article published in the January 2009 issue of the *Archives of General Psychiatry*.

**Background**

In the first study of its kind, Rachel Marsh, Ph.D., Columbia University, and colleagues assessed self-regulatory brain processes in women with BN without using disorder-specific cues, such as pictures of food.

In this study, 20 women with BN and 20 healthy controls viewed a series of arrows presented on a computer screen. Their task was to identify the direction in which the arrows were pointing while the researchers observed their brain activity using functional magnetic resonance imaging (fMRI).

People generally complete such tasks easily when the direction of the arrow matches the side of the screen it is on—an arrow on the left side pointing to the left—but respond more slowly and with more errors when the two do not match. In such cases, healthy adults activate self-regulatory processes in the brain to prevent automatic responses and to focus greater attention on resolving the conflicting information.

**Results of the Study**

Women with BN tended to be more impulsive during the task, responding faster and making more mistakes when presented with conflicting information, compared with healthy controls.

Patterns in brain activity also differed between the two groups. Even when they answered correctly to conflicting information, women with BN generally did not show as much activity in brain areas involved in self-regulation as healthy controls did. Women with the most severe cases of the disorder showed the least amount of self-regulatory brain activity and made the most errors on the task.

**Significance**

Altered patterns of brain activity may underlie impaired self-regulation and impulse control problems in women with BN. These findings increase the understanding of causes of binge eating and other impulsive behaviors associated with BN and may help researchers to develop better targeted treatments.

**What’s Next**

The researchers are currently conducting further studies on brain functioning in teens with BN, which would offer a closer look at the beginnings of the illness. They also recommend studying people in remission from an eating disorder. Comparison studies with impulsive people who have healthy weight and eating habits could also provide more information about which patterns of brain activity are most directly related to eating disorders.
It is well known that alcohol consumption is pervasive throughout college culture, but what is known about the role of dietitians in addressing excessive alcohol intake among college students? It has been estimated that four out of five U.S. college students drink, with two in five students reporting they drank five or more drinks on one occasion within the previous two weeks (1). Approximately 1,700 college students between the ages of 18 and 24 die every year from alcohol-related injuries (2). One recent research study has shown two brief interventions by primary care providers to be effective in helping high-risk students significantly reduce their alcohol consumption and high risk behaviors over time. The two 20-minute intervention sessions were delivered by a trained provider and were based on motivational interviewing techniques (3). Another recent study found that two 10-minute web-based interventions composed of motivational personalized feedback also have a positive effect for high-risk students. After six-months, those who received the two web-based sessions were found to drink less often and smaller quantities than the control group (4).

While these studies suggest the approaches to be effective in reducing alcohol abuse within college communities, they do not mention the role of the dietitian. I wanted to learn how dietitians are currently involved in alcohol abuse prevention and interventions at colleges and universities. My first thought was to look at the universities that have excellent alcohol abuse prevention programs in place and then see how the dietitians that work for those universities are involved, if at all. My research of alcohol abuse prevention programs at universities brought me to the for-profit organization Outside the Classroom, which works to promote alcohol prevention by providing educational institutions with the resources and tools needed to develop their own research and prevention programs (5). The organization does not promote abstinence, but works to help institutions reduce alcohol-related risk and prevent harm. Outside the Classroom is the largest funder of alcohol prevention research in the U.S. The organization’s online program, AlcoholEdu, is widely taken by first-year students at four-year universities. Every year the organization gives their Prevention Excellence Awards to individuals, institutions, and Greek organizations that have developed exceptional alcohol prevention programs (multiple awards are given each year).

Bentley University in Waltham, Massachusetts has been a winner of Outside the Classroom’s Prevention Excellence Award every since the 2006-2007 school year. Deanna Busteed, MS, RD, LD, is the dietitian at Bentley University for the student body of approximately 4,000 undergraduate students and 1,400 graduate students. Deanna is involved with many different avenues of alcohol prevention at the university. Throughout the school year she offers a dormitory educational session on healthy eating, titled “Be Healthy and Fit at Bentley,” during which she covers the topic of alcohol consumption and the effects of excessive intake on health. Another avenue where Deanna has talked to students about alcohol consumption is the 12-week freshmen seminar offered the first semester of every school year; however, most of her time is spent in individual appointments with students during which she asks questions about substance abuse and addresses the issue. She refers students to counseling and/or clinic staff as needed. Deanna also specializes in working with student athletes and provides individual sessions, lectures and team meetings for the athletes. These sessions include a discussion about the harmful effects alcohol can have on performance. Coincidentally, Deanna Busteed is the wife of Brandon Busteed, the founder and CEO of Outside the Classroom.

Emory University in Atlanta, Georgia was one of the 2008-2009 winners of the Prevention Excellence Award from Outside the Classroom. Carol Kelly, RD, LD, is the dietitian for Emory University. Carol collaborates with the substance abuse counselors on campus, and the counselors consult her about the nutritional consequences of abusing alcohol, with a focus on cognitive performance in academics. Carol works one-on-one with the students to develop low-risk options for low to moderate alcohol consumption. In addition to her clinical duties, Carol delivers presentations to student athletes and team coaches about the effects of alcohol and drugs on physical and mental performance. She is also involved with a variety of school programs and events throughout the year, during which she frequently addresses the issue of nutritional consequences of alcohol abuse, which is often by request of the students. Some of these opportunities include acting as a regular guest lecturer for the department of physical education and dance, moderating a panel for Body Acceptance Week held every semester, and giving presentations to the residence halls and Greek organizations.

All enrolled Emory students (approximately 13,000 undergraduate and graduate students) are eligible for fifteen nutrition counseling appointments without charge each academic year, after which students can continue to see Carol for paid sessions. According to Carol, she had over 700 clinic appointments last school year.

In summary, alcohol consumption is an area of concern on college and university campuses. Dietitians are important resources for students who wish to safely and healthfully include alcohol in their diet. There are many different ways that dietitians can become involved in the alcohol abuse prevention process, as shown by the work of Deanna and Carol. Dietetics students can also benefit from the resources and knowledge university dietitians have to offer regarding how alcohol consumption can be a part of a healthy, balanced diet.

About the Author: Deonna Hughes, BS is a student member of BHN and the BHN Student Assistant Newsletter Editor. She is currently a graduate student of

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the Nutritional Sciences Program at the University of Washington (UW) and is enrolled in the UW Dietetic Internship. She currently works as a dietetic technician at Seattle Children’s Hospital.

References:


Eating Disorders Related Legislation Pending

By Charlotte Caperton-Kilburn, MS, RD, LDN
BHN Public Policy Chair

In February, ADA’s Legislative and Public Policy Committee (LPPC) requested the opinion and expertise of BHN on eating disorders related legislation that is pending in six states. These bills are supported by the National Eating Disorders Association (NEDA), which has asked ADA to consider supporting the bills.

The intent of the legislation is to increase access to treatment for eating disorders by expanding insurance coverage. NEDA focuses its work in the states. Currently, 30 states provide limited services for eating disorders. These services typically do not cover the services of an RD.

The bills brought to ADA for support are introduced in the state legislatures in California, Florida, Missouri, New York, Pennsylvania, and Rhode Island. NEDA has asked ADA to support any or all of the bills. Five of the bills (California, Florida, Missouri, Pennsylvania, and Rhode Island) require that insurance providers cover treatment for eating disorders. The Missouri bill also requires access to nutrition counseling and dietitian services and creates a state council to educate the public on eating disorders. The New York bill differs from the others in that it does not include insurance provisions, but requires licensed practitioners to take course work in eating disorders in order to improve the prevention and early-diagnosis of eating disorders.

Jessica Setnick, MS, RD, CSSD, 2009 Chair of BHN, and I asked for input from BHN members and we are happy to report that over 100 comments were sent to ADA in regard for these bills. Thanks to those of you who read the bills and sent along your thoughts. In March The LPPC took those comments into consideration in deciding whether ADA would support the bills.

For those of us who work in the eating disorder field on a daily basis, it is clear that we need insurance coverage for nutritional services as well as health care coverage.

BHN PUBLICATIONS

**The Adult with Intellectual and Developmental Disabilities**

This resource tool is designed to provide an overview of nutrition in individuals with intellectual and developmental disabilities. The resource guide is contained on one CD-ROM as a 209 page PDF file.

*BHN Member Price: $28.00*

**Psychiatric Nutrition Therapy**

This resource guide is intended for anyone working in the 4 practice areas within Behavioral Health Nutrition: mental illness, eating disorders, addictions, and those with intellectual and developmental disabilities who also require psychiatric care. The resource guide is contained on one CD-ROM as a 170-page PDF file.

*BHN Member Price: $28.00*

**Nutrition & Addictions**

This is a 244-page manual of information about addiction and drugs of abuse, including legal, illegal and pharmaceutical drugs, alcohol, nicotine, caffeine, and more. Patient educational handouts on nutrition and recovery topics are also included.

*BHN Member Price: $24.95*

To order, visit http://www.bhndpg.org/publications/index.asp

Would you like to receive a free copy of one of our publications? Submit a review to a newsletter or Web site that you belong to, and when it is published, we will refund your purchase price! Submit your published review to Paula Kerr, MS, RD, LD at pkerr1493@gmail.com
2010 ADA Member Benefits Update

By becoming one of the more than 70,000 members of the nation’s largest organization of food and nutrition practitioners, you give yourself access to a wide variety of benefits, including information resources, educational opportunities, public policy initiatives, practice-based research, networking connections, and promotional tools. As a member of a dietetic practice group (DPG), you’re well aware of at least one major benefit of ADA membership, but there are dozens of others—with new and improved offerings every year—that you might not know about. Of course, ADA wants you to take full advantage of all the opportunities that membership provides. Below is a listing of some of the newer resources ADA provides for its members, as well as those of particular interest to DPG members, accompanied by brief descriptions of their function. Please feel free to share this list with your colleagues.

For a more extensive list of benefits, visit the members-only section of ADA’s Web site at www.eatright.org or call the Member Service Center at 800/877-1500, ext 5000, Monday through Friday, 8:00 AM to 5:00 PM Central Standard Time.

NETWORKING & PROMOTION RESOURCES

Member Interest Groups (MIGs)

Member Interest Groups are groups of ADA members who have a common interest. Unlike dietetic practice groups or affiliates, member interest groups focus on areas other than the practice of dietetics or geographic location. As divisions of the national organization, MIGs reflect the many characteristics of ADA’s membership and the public it serves. Current MIGs include the National Organization of Men in Nutrition (NOMIN), Chinese Americans in Dietetics and Nutrition (CADN), Latinos and Hispanics in Dietetics and Nutrition (LAHIDAN), the National Organization of Blacks in Dietetics and Nutrition (NOBIDAN), Fifty-Plus in Nutrition and Dietetics (FPIND), Filipino Americans in Dietetics and Nutrition (FADAN), and the newest addition, Muslims in Dietetics and Nutrition (MIDAN).

National Nutrition Month® Materials

National Nutrition Month® (NNM), celebrated every March, is an annual nutrition education and information campaign created by ADA that’s designed to focus attention on the importance of making informed food choices and developing sound eating and physical activity habits. ADA provides food and nutrition professionals with access to a wide variety of supporting materials to help convey this important message, including fact sheets, flyers, classroom guides and games, recipes, press releases, and event ideas.

Registered Dietitian Day

March 10, 2010 was the third annual Registered Dietitian Day. This special occasion was created by the American Dietetic Association to increase the awareness of registered dietitians as the indispensable providers of food and nutrition services and to recognize RDs for their commitment to helping people enjoy healthy lives. Registered Dietitian Day promotes ADA and RDs to the public and the media as the most valuable and credible source of timely, scientifically-based food and nutrition information.

Find a Registered Dietitian Online Referral Service

ADA’s Find a Registered Dietitian online referral service is free to Active category members representing their own private practice, group practice or employer. Consumers and businesses search this Web-based site to connect with members who provide nutrition consulting service expertise.

Me, Inc., Online Branding Toolkit

ADA has developed this online branding toolkit to provide you with the resources needed to improve your brand, including communication tips, downloadable promotional flyers, developing your online presence and much more.

INFORMATION RESOURCES

www.eatright.org

Newly redesigned, ADA’s Web site is faster, more user-friendly, offers a more powerful search function, and can be personalized to meet your needs. The new eatright.org features five sections specifically targeted to members, students, the public, the media, and other health professionals, making it easier for all visitors to access the content they want. Build your MyADA profile and get involved with quick links to blogs, forums, surveys, and online communities—and get connected by easily subscribing to and sharing e-newsletters, RSS feeds, podcasts, and videos. And as always, eatright.org keeps you informed with 24/7 access to scientific and professional resources, and links that are essential for any food and nutrition practitioner. The secure, member-only site can be accessed using your member ID and password, and provides a wealth of information and programs in a location that guards your privacy.

ADA NewsBytes

This monthly e-newsletter from ADA’s Board of Directors informs members of developments affecting food, nutrition, and health topics, as well as ADA’s legislative and regulatory priorities.

Daily News

Opt in to receive this key resource for keeping abreast of the top news stories concerning dietetics and the profession. Delivered to your e-mail inbox every weekday morning, ADA’s Daily News is a quick review of the nation’s leading food, nutrition, and health headlines, with links directly to the articles.

On the Pulse

More government-focused than ADA’s Daily News, On the Pulse is a weekly e-newsletter on ADA’s legislative and regulatory priorities in both Washington, DC, and state legislatures. It also addresses reimbursement, research findings, and practice-related issues.

ADA New in Review

Formerly a section of the Journal, the new online exclusive ADA New in Review compiles abstracts and citations from nearly 200 different scientific and professional publications to convey fundamental knowledge in nutritional science that spans specialty practice. The monthly ADA New in Review e-mail alerts mem...
PRACTICE RESOURCES

MNT Practice Resources
There is a wealth of information on ADA's Medical Nutrition Therapy (MNT) Web page to help members understand the business of dietetics. Consider it your one-stop shop for practice management education. Learn about codes for nutrition services, how to become a Medicare provider, private insurance reimbursement, tips to expand MNT coverage, telehealth, and more. Popular advocacy materials available for download include the MNT Works marketing toolkit, ADA's payer brochure for increasing MNT coverage, and a step-by-step billing presentation called "Cracking the Code: Billing Potential beyond Medical Nutrition Therapy." Access these resources at www.eatright.org/mnt.

Hot Topics
Hot Topics are timely, one-page science-based answers to members' questions and issues that have a significant impact on consumer health. Responses are written in consumer-friendly language and are designed to clarify a controversy or debunk a nutrition myth. Some current hot topics address organic foods, bottled water, probiotics, stevia, and superfoods.

Eat Right Messages
The Eat Right Messages Program is an online and print nutrition education program that is available on ADA's Web site as print-ready, two-page handouts in PDF format. Content includes a statement promoting registered dietitians and a special section where members can include personalized contact information.

Evidence-Based Nutrition Practice Guidelines and Toolkits
Located in the Evidence Analysis Library, these guidelines provide disease-specific nutrition recommendations using a systematic approach that assures nutrition care is based on scientific evidence. Toolkits accompany the guidelines and provide Medical Nutrition Therapy tools used for documenting patient encounters and collecting outcomes.

EDUCATIONAL RESOURCES

Center for Professional Development
The premier choice for lifelong learning, the Center for Professional Development offers conferences, workshops, meetings, lectures, live phone teleseminars and webinars, e-learning, CD-ROM and online courses, and audiocassettes. ADA's professional development opportunities are easily accessed through the Center under the Professional Development tab on the Member section of eatright.org.

Leadership Institute
ADA's Leadership Institute is an integrated, intensive, multifaceted training program in the theory and practice of leadership in dietetics. The purpose of the program is to enhance the leadership competencies of ADA members both conceptually and interpersonally, through a combination of information, skill development, and practice-based educational experiences.

Free Online Journal Continuing Professional Education (CPE)
Since January 2008, ADA members have been able to easily complete their Journal CPE quizzes online at www.eatright.org. See which quizzes you've already completed and take one that's still available to complete for credit. Quizzes are scored automatically online, and once all questions are answered correctly, CPE credit for completed quizzes may be added directly to your Professional Development Portfolio.

Have you had thoughts or questions for BHN experts about the field of work?

Please submit interviewing questions to Andrea Shotton at ashotton@nutritionalvoices.com.

The questions will be used to create a BHN you-tube video for the general public and students of all health care professions to understand and identify the BHN Registered Dietitian and dietetics professional and where and how to locate one.
The House of Delegates governs the profession. On May 1-2, the House will be discussing two mega issues affecting the profession. Share your ideas and concerns about these issues with your delegates.

- Health and Nutrition Literacy
- Management and Leadership Across Practice

For more information on these topics visit http://www.eatright.org/HODMegaIssues/

Submit your comments by April 30th using the Member Input Form

HOD Delegate Contact Information
Leslie P. Schilling, MA, RD, CSSD, LDN is the delegate for the BHN DPG and can be contacted at leslie@schillingnutrition.com or 901.628.8102.
**Behavioral Health Nutrition**

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A complete list of BHN Executive Committee members and volunteers is available at www.bhndpg.org

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**BHN: Setting the Standard for Nutrition in Behavioral Healthcare**

**Vision:** Impact the nutrition of the behavioral health populations we serve.

**Mission:** Empower BHN members to be the experts in

- Intellectual and Developmental Disabilities
- Eating Disorders
- Mental Illness
- Addictions

**Goals:**

1. The public recognizes, trusts, and chooses our members as the experts in behavioral health nutrition.
2. Members and prospective members view BHN as essential to their professional success.

ADA website: http://www.eatright.org
BHN website: http://bhndpg.org