



# BHN Newsletter



## **Serving the Aging Developmentally Disabled Population**

**Summary By: Lester Y. Rosenzweig, MS, RD, CDN**

There are approximately 4.5 million individuals with intellectual and developmental disabilities (IDD) in the United States (1). The majority of persons with IDD (about 3 million) are children living with family or adults, married or single, with or without children, who live on their own. The remainder lives in large state-operated facilities (institutional care), group homes, family home or a supervised apartment (2).

Only 30 years ago, most persons with IDD were in the shadows of society. They were cared for at home or if more severely disabled, cared for in state-operated institutions. Today, we see a major shift from institutionalization to integration within the community. Better care for these individuals from birth through adulthood has resulted in a better quality of life and greater longevity (3).

The successes of better care of persons with IDD can be credited to the advocacy efforts of families and organizations that provide care to these individuals in the community. Children and adults with IDD and their family or caregivers now have available a variety of support and health services through local service agencies. These services may include medical care, health and wellness counseling (including nutrition), psychiatric care, social work, life skills training and job placement.

All individuals, living with or without a disability, have or are at risk of developing one or more chronic diseases. These diseases include heart disease, obesity, hypertension, diabetes, and depression. The IDD population has a higher risk of developing these conditions, although often for the same reasons as the non-disabled population: heredity, poor lifestyle habits, poor nutrition, little physical activity, smoking, lack of health related knowledge or understanding, limited income, etc. (4). Functional decline in adults with IDD often occurs for the same reasons as the non-disabled population: the side effects of medications, stroke, depression, disruption in sleep, heart disease, hypertension, diabetes, sensory loss, pain, arthritis, osteoporosis, dental problems and nutritional deficits (5). Therefore, screening, assessment and the provision of services to promote a healthy lifestyle (including nutrition and physical activity) can benefit persons with IDD (4).

As individuals with Down's syndrome age, they have more gastrointestinal problems, an increased risk of leukemia, a decreased immune system with more infections, as well as, hypothyroidism which decreases their activity level and body temperature. Their probability of developing Alzheimer's disease is 3-5 times greater than the general population. It occurs earlier, has a shorter duration and there is no inevitability about onset. The average onset age is about 53 for people with Down's syndrome, compared to the late 60s for non-Down's syndrome

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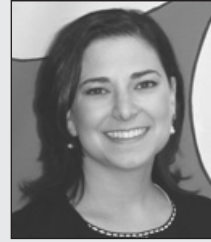
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## From the Chair

Jessica Setnick, MS, RD, CSSD



I am just back from a fabulous ADA Food & Nutrition Conference & Exposition (FNCE) in Chicago, where Behavioral Health Nutrition (BHN) events were the belle of the ball! I was absolutely thrilled to meet so many of you in person, and if you weren't there, take it from me, BHN made a splash like never before! Our Nutrition and Addictions session was a home run with attendees, one of whom told me afterward that it was the best presentation of FNCE 2008 and one of the best she has attended in 25 years of FNCE! Our BHN member reception and first ever BHN Awards Ceremony was both touching and inspirational, with family members of the award winners in attendance, and awardees including founding members of BHN/DDPD. Our BHN booth at the DPG showcase was mobbed, signing up new members and selling our publications. The Adult with Intellectual and Developmental Disabilities CD was a hot item, and The Nutrition and Addictions book sold out in just a few hours with members still lining up to buy! Don't fret if you don't have your copy yet, we have lots more available, and our pre-FNCE workshop on Psychiatric Medications will be available on CD in the coming months. Also at FNCE we met for the first time Regan Wilson, our Student Liaison Committee Chair, and unveiled our new student membership category, with a reduced fee of \$10, to give more students the opportunity to get to know our DPG. The final BHN event of this FNCE, the session to contribute to the Standards of Practice for Dietetics in Eating Disorders, IDD, Addictions, and Mental Health, was well-attended and conclusive – our profession is taking the lead in the nutrition care of individuals with these conditions, and we need to shout it from the rooftops! You will hear much more about the findings of this session in the months and years to come. As amazing as it seems, my term as chair is now half over, but what we have accomplished in this half a year will set the stage for many future accomplishments. Planning for FNCE 2009 in Denver is already underway, and if you would like to get involved with BHN, now is a great time to start! Please contact me or any of the BHN Executive Committee members, as we look forward to hearing from you.

#### Your chair,

Jessica Setnick

## BHN Practice Area Standards in Planning Process

Members working in the four areas of behavioral health nutrition, Intellectual and Developmental Disabilities, Eating Disorders, Mental Illness, and Addictions met at the Food & Nutrition Conference & Expo (FNCE) in Chicago to discuss practice standards for each area of practice. Paula Kerr, MS, RD, CD, with the assistance of Renee Hoffinger, MHSE, RD, LD, and BHN Resource Professionals Paula Cushing, RD, Roberta Pearle Lamb, MPH, RD, and Linda Venning, MS, RD, directed each small group in the discussion of 1) skills unique to assessment and education in each specialty practice area; 2) skills and tools you wish you had when entering this area of practice; and 3) skills or tools you still seek. Participants in this session were invited to discuss the need for development of standards of practice for their individual practice areas. The Eating Disorders Workgroup formed in December is developing their Standards of Practice and Standards of Professional Performance. Mary Tholking, MEd, RD, LD, is chair of this workgroup. If you are interested in being part of a workgroup, contact the BHN Resource Professional in your area of practice. Current Standards of Practice and Standards of Professional Performance for RDs in Behavioral Health Care can be accessed at [www.bhndpg.org](http://www.bhndpg.org), members only/practice standards.

## Serving the Aging

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individuals (6). These conditions can negatively impact their food choices and consumption requiring nutrition interventions.

As individuals with Cerebral Palsy age, there tends to be a decrease in muscle strength (after many years of no changes) and an increase in the occurrence rate or severity of osteoporosis, osteoarthritis, locked joints, seizures, swallowing difficulties, and/or fatigue. Greater frailty leads to further loss of mobility and food intake, requiring the need for more specialized nutrition care and feeding assistance (6).

The prevalence of psychiatric disorders is higher in people with IDD than the non-disabled population and increases with age. Afflictions such as depression, schizophrenia, and anxiety can impact food choices and intake. Medications to treat these conditions often affect appetite (positively or negatively), which can result in weight gain or loss. The increased frequency of dementia is responsible for much of the psychiatric disorders seen later in life (7).

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### **"700,000 Americans over 60 have some form of IDD and this number will double by 2030"**

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The average life expectancy of the non-IDD population in the U.S. was 78 in 2004 (8). The life expectancy of those with IDD increased from 19 in the 1930's to 66 by 1993 (9). Current estimates are that 700,000 Americans over 60 have some form of IDD and this number will double by 2030 (8).

The majority (60%) of individuals with IDD lives with their families, and in 25% of these households the primary caregiver is over age 60. The number of two-generation elderly households where the parents age 80 plus are caring for an older child with IDD is growing. Most of these families will remain intact as long as possible due to choice or the lack of satisfactory alternatives. However,

these arrangements are likely to be compromised by the parents' own diminished health and abilities (9). Therefore, appropriate care and resources for both older family members and their sons/daughters in care must be available.

Government agencies, service providers and advocates for people with IDD and the aging population are addressing these needs. The federal Older Americans Act encourages local and state aging units to jointly plan and develop services for older adults with IDD. Such agencies are establishing committees and task forces to plan for and develop programs to meet the needs of caregivers and individuals with a disability. These groups are addressing issues of care, respite care, retirement, funding, etc. They are funding demonstration projects, establishing networks for the dissemination of best practices, and single point of entry resource centers (9).

At the provider level, institutions, group homes, and day programs are being assessed to determine the adequacy and need for various services as well as physical accessibility. Specially designed programs and classrooms addressing dementia and Alzheimer's disease are being implemented. Group homes are being remodeled to be more accessible as their residents get older. They have become a model for community-based care of the general older adult population (versus nursing home or institutional care) (5).

The ability to "age in place" within one's own home is a goal that may be desirable for everyone regardless of their disability. "Home" may be the group home, the supportive living apartment, the family residence or the "institution." Service providers are working to keep their consumers (and their caregivers) as independent and healthy as possible, providing a full spectrum of support and/or health services. They are sensitive to the many factors that shape a person's physical and emotional needs and are addressing their consumers' needs as they grow older. To be successful, we must continue to provide the compassionate care and variety of services that have brought this population into the

mainstream, increased their longevity, and improved their quality of life.

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# A Wealth of Information at Pre-FNCE Workshop

By Karen Jircitano, RD, LDN

BHN is proud to have sponsored the Pre-FNCE Workshop “What Dietitians Need to Know about Psychiatric Medication—Including Weight Gain, Nutrient Interactions, and Pediatric Issues,” held on Saturday, October 25, 2008 at the Hyatt Regency Chicago. Our speakers were BHN’s own Zaneta M. Pronska, MS, RD, LDN, FADA, and her associate and editor, Dean Elbe, BSc (Pharm), BCPP. With an impressive list of publications and speaking engagements, Zaneta is well-known as the author of *Food Medication Interactions*, now in its 15<sup>th</sup> edition. She is the consultant dietitian to several LTC facilities, including facilities for MH/MR. Dean has edited the 11<sup>th</sup> to 15<sup>th</sup> edition of *Food Medication Interactions*. He is the clinical pharmacy specialist in child and adolescent psychiatry at Children’s & Women’s Health Centre of British Columbia. Zaneta and Dean have co-presented numerous times, including BHN’s Priority Session 2007 in Philadelphia, “Psychotropic Drugs—Food Interactions: What RDs Need to Know.”

Chair-elect Andrea Shotton, MS, RD, LDN, introduced Zaneta and Dean to the forty workshop participants. Zaneta began by advising the audience to know their client’s diagnosis and how it has changed over time. She cited ADA’s position of using Medical Nutrition Therapy (MNT) first and then if necessary, combining MNT with pharmacotherapy in a team approach

to treatment. Dean explained that it is hard to extrapolate the results of adult drug trials to the pediatric population. The brain continues to develop until about twenty-five years old, so certain medications are inappropriate for children. For example, tricyclic antidepressants are less expensive to use as generics and are well tolerated, but their safety and efficacy raise concern. Because the serotonin system in the brain matures faster than the norepinephrine system, secondary amines such as Norpramin, Pamelor, and Vivactil are somewhat safer and better tolerated than the tertiary amines. Secondary amines are less likely to cause weight gain and are less sedating with fewer anticholinergic effects (dry eyes, blurred vision, glaucoma, dry mouth, sedation, confusion, constipation, etc.).

Dean and Zaneta also gave mini-case studies and asked the participants to choose the most appropriate medication based on the scenario. For example, a nine-year-old with major depression might do well on Prozac (SSRI) as it increases serotonin and is less apt to cause sedation. Zaneta reminded the group that “it’s the food that causes weight gain, not the drug” and that the drug “makes the head want to eat more food that the body doesn’t need.” Medications that influence overeating are Zyprexa, Clozaril and Abilify. The medications used in ADHD, such as Concerta, Ritalin LA, and Adderall XR, are



long-acting so they don’t require dosing at school and work long enough to allow after-school activities and homework. Zaneta also reviewed behavioral approaches to combating the weight gain associated with many of the mood-altering drugs. When providing nutrition education, always consider the education level/learning ability/reading level of the client. Keep it simple! Focus on basic nutrition, portion control and snack education.

The presentation could easily have extended for another hour, as Zaneta and Dean had a wealth of information and advice between them. The workshop participants came away with a better understanding of the efficacy of medications used for children, a marvelously detailed handout, and a well-stocked goody bag provided by BHN.

## Depression and Nutritional Deficiency

Webinar Review: By Ruth Leye-Wallace PhD, RD

Robert Hedaya, MD, FAPA, a psychiatrist in Chevy Chase, Maryland recently presented a ninety-minute webinar titled “Depression and Nutritional Deficiency: State of the Science and Treatment” sponsored by The Institute For Functional Medicine (IFM) in Gig Harbor, Washington. At his clinic Dr. Hedaya practices what he terms “whole psychiatry”, encompassing antecedents, mediators, and triggers of depression as we currently understand them. He describes depression as a final common pathway. This path may include: digestion, nutrition, detoxification,

immune dysregulation, oxidative stress and energy balance and metabolism, neuro-endocrine signaling, genetics, developmental experience and challenges, spiritual, cognitive and depth psychological constructs as well as cultural, economic, and other environmental factors.

Nutritional aspects in his treatment of depression include amino acids (tryptophan and tyrosine), minerals (deficiencies of zinc, calcium, copper, iron, magnesium, potassium and excesses of calcium, magnesium, vanadium),

B vitamins (B12, folic acid, pyridoxine, riboflavin, thiamine, and biotin), EPA’s (EPA and DHA), and vitamin D. After reviewing examples of scientific evidence, Dr. Hedaya reported his protocols for diagnosis and nutritional interventions as well as several case studies.

A monograph titled *Depression: Advancing the Treatment Paradigm*, by Robert Hedaya, MD, and Sheila Quinn is available for \$59.95 through the Institute for Functional Medicine at <http://www.functionalmedicine.org/>

# “From Addiction to Recovery” Priority Session a Smashing Success

By Jessica Setnick, MS, RD, CSSD

BHN's session at the ADA Food & Nutrition Conference & EXPO (FNCE) in Chicago was a smashing success! Dr. Kevin McCauley, MD and BHN member Theresa Stahl, RD, LDN informed the audience about the latest info on addictions and nutrition for addictions.

## ***“Is addiction really a disease?”***

Dr. McCauley started the session explaining his quest to answer the question, “Is addiction really a disease?” He detailed several possible theories of addiction, including the common beliefs among the general public that addictions are willingly chosen, and those who chose addiction are morally weak. In contrast to this opinion, Dr. McCauley has determined that individuals who become addicted to substances and/or behaviors have both a genetic vulnerability and a stress-activated hypofunctionality of the frontal cortex. Therefore drug use in the experimental stage “feels” different for “pre-addicts” vs. people who do not become addicted. Once the addiction has been triggered, additional stress activates the midbrain, the part of the brain responsible for survival, and use of the drug feels as if it is essential for survival.

Later in the addiction, dopamine release during drug use changes the brain's “hedonic set point,” making it unable to enjoy once pleasurable activities or cope with stress without drug use. With this explanation of addiction as a

dysfunction of the midbrain, Dr. McCauley concluded, addiction fits the medical model of disease. With this issue settled, medical care in the treatment of addiction can progress at a faster pace.

Theresa Stahl, RD, then took the stage to report on the latest practices in dietetics in alcohol and drug abuse treatment settings. In addition to recommending screening tools, she emphasized that nutrition assessment should incorporate questions about drug and alcohol use in a non-judgmental and non-threatening manner. She noted that nutrition can be impaired in a rehab patient due not only to appetite changes, but also by damage to the gastrointestinal tract and liver, including reflux; chronic nausea, vomiting, and/or diarrhea; lactose intolerance; and hepatitis. Other health issues that may have started before or after the addiction are anemia, HIV and AIDS, and eating disorders.

Because the recovery process may be in essence starting a new life for many patients, they need support from the dietitian in many basic areas. Theresa advises that group nutrition classes are an effective way to provide information on nutrition supplementation, grocery shopping, weight management, food safety, and mindful eating. Education for patients who are avoiding alcohol should include an explanation that although the health benefits of alcohol are often touted in the media, it is a better choice for them to avoid it altogether. This includes avoiding foods that have been cooked with alcohol, as very little of the alcohol is lost in the cooking process.



Theresa also provided general nutrition goals for recovery: spacing of meals every few hours, with no more than 4-5 hours between eating opportunities; moderate or limited use of caffeine and sugar; increased intake of complex carbohydrates, including fiber, and protein; and vitamin/mineral supplements as needed, with particular emphasis on B vitamins. She encouraged dietitians to help patients set small, achievable goals, to educate support persons if possible, and to allow plenty of time for questions.

The speakers then took questions from the audience, allowing for great interaction. After the session was over, many attendees commented that it was one of the best sessions at FNCE, and was a very needed topic for them professionally and personally. A huge thanks to our talented speakers and to the BHN membership for providing the funding for this session. We have proposed two BHN sessions for next year's FNCE and will continue with our mission of educating even non-BHN dietitians and nutrition professionals about the important practice areas we represent.

## **UPDATE ON THE HOUSE OF DELEGATES- Working for Members**

The House of Delegates met in Chicago on October 24-25, 2008 to discuss the following issues: 1) Nutrition Informatics; 2) Draft Revised Code of Ethics for the Profession of Dietetics; 3) Identifying Mega Issues; and, 4) Nutritional Genomics. To read more information on these and other issues visit HOD under Governance on [eatright.org](http://www.eatright.org) or [http://www.eatright.org/cps/rde/xchg/ada/hs.xsl/governance\\_16681\\_ENU\\_HTML.htm](http://www.eatright.org/cps/rde/xchg/ada/hs.xsl/governance_16681_ENU_HTML.htm)

# Discovering Research and Practice in Behavioral Health Nutrition at FNCE Poster Sessions

By Regan Wilson, BHN Student Liaison

What are nutrition professionals finding in their practice in behavioral health? I perused the poster sessions at FNCE 2008 and found a number of presentations of particular interest to BHN members. The following is information from four poster presentations in the area of disordered eating.

## **Re-Feeding Potential: Nutritional Management of Adolescents with Anorexia Nervosa.**

Author April Hackert, MS, RD discussed her research in the practice of treating adolescents at HOPE (Honesty, Openness, Practice and Education) at the Center for Anorexia and Bulimia at Alta Bates Summit Medical Center in Berkeley, CA. According to their Web site <http://altabatesummit.org/eatingdisorders/index2.html>, HOPE at Herrick "is the Bay Area's only full-spectrum, psychiatric eating disorder program for both adolescents and adults. The program bridges outpatient and inpatient levels of care and is successful at treating individuals who have failed in their past attempts to heal."

Many nutrition professionals in the behavioral health nutrition field are very aware of the immense number of calories that are required for a young person to regain weight when they are refusing to maintain 85% of their ideal body weight. It was educational for me to learn that on average, females require 3500 kcals per day and males require 4000 kcals per day with a goal of gaining .36 pounds per day.

Traditional treatments for increasing calorie intake have focused on sheer number of calories regardless of macronutrient ratio. Ms. Hackert's study focused on individualizing the macronutrient ratio to meet individual metabolic needs. In general the individualized diets have followed a 50% carbohydrate, 30% lipid, and 20% protein ratio and tended to be structurally similar to DASH menus. The study found that the individualized menus enhanced weight gain to .67 pounds per day resulting in a quicker return to ideal body

weight status. Ms. Hackert postulated that the food ratio may decrease volume which would decrease both physical and psychological discomfort and thus lead to greater weight gains.

## **The Wellbody Program Reduces Binge Eating and Improves Nutrition, Exercise, and Body Image through a Non-Diet Approach.**

As the title indicates, researchers Molly Vetter-Smith, MEd, RD, and Julia Tobias, MEd, RD, along with others at the University of Missouri at Columbia wanted to assess how a non-diet approach could help participants with subclinical, maladaptive patterns of eating. The cost effective Wellbody program was designed to assist participants to address emotional eating, improve nutrition, respond to physiological hunger cues, engage in enjoyable physical activity, increase awareness to socio-cultural physical appearance beliefs and address barriers to change.

The Wellbody program research revealed decreased binge eating, increased consumption of nutritious food and decreased body dissatisfaction. Though not statistically significant, the researchers did find that participants increased physical activity by participating in the program. Despite encouraging men to participate, only 3 participants were male. According to their research, "Wellbody appears effective for helping participants make lifestyle changes necessary for improved long-term health and well-being."

## **Parent, Peer and Media Influences on Body Images of Caucasian Girls Ages 9-11 Years Old.**

Melaina Hammond-Lane, MS, RD, Department of Food and Nutrition, Southern Illinois University, Carbondale, IL, wanted to examine body image issues among younger, Caucasian girls. In her research, Melaina surveyed sixty-nine 9-11 year old girls living in Illinois and participating in the Girl Scouts. The purpose of this study was to investigate the

relationships among parent, peer, and media influences and body image. She hypothesized that parents, peers, and media would all have a strong impact on the body images of the girls with parents having the most positive influence. Her results indicated that parents were indeed the largest positive influence and media the largest negative influence for the responses of independent variables. For the scale-response questions, media was found the largest positive influence and peers the largest negative influence.

Results indicated there was a statistically significant relationship between the influences and body image with a significant correlation between parents, peers, and media and body image.

## **A Modified Obesity Proneness Model Describes How Mothers May Influence the Development of Disordered Eating Behaviors and Obesity.**

In the past, research has focused on components of the obesity proneness model from a parent's perspective. Presenter Jennifer Nickelson PhD, RD, Department of Public Health, University of Northern Florida in Jacksonville, FL, along with other researchers, wanted to look at the perceptions young women have of their mothers' beliefs and behaviors and the "students' own weight concerns, inability to self-regulate eating, and weight status."

Ms. Nickelson explained the phenomenon as "eating guilty." In the eating guilty scenario, as I understand it, parents, or in this case mothers make comments about their child's weight or food consumption and then restrict the child's eating. The child then internalizes the concerns, but because of the past restrictions, the child doesn't learn to regulate her or his eating. The results of the research were extensive - "...girls were more likely to think mothers were concerned about their weight than were boys. Students who perceived mothers to be concerned about their weight were likely to think mothers

## **FNCE Poster Sessions**

*continued from page 6*

perceived them as heavier, valued weight highly, had restrictive feeding practice, and made comments about their weight. Students with greater internalized concern about weight were likely to think mothers made comments about their weight and were heavier. Students' perceptions of mothers' restrictive feeding practices were related to students' inability to self-regulate eating. These findings suggest that obesity and eating disorder prevention efforts may need to address the restrictive feeding practices and comments mothers make about their daughters' weight."

# **Mental Health Parity Bill Passes the House and Senate!**

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

Recently, the House and the Senate came together to pass the Mental Health Parity Bill legislation, (H.R. 1424, Sec. 512), part of the Emergency Economic Stabilization Act. This bill will help to eliminate discrimination in health care coverage against people suffering from mental disorders. This bill requires group health plans that currently offer coverage for mental health and substance-use disorders to provide those benefits in the same manner as benefits provided to all other medical and surgical procedures covered under the plan. It also prohibits group health plans from imposing discriminatory annual/lifetime dollar limits, co-pays and deductibles, or day and visit limits unless similar limitations or requirements are imposed for other medical and surgical benefits. The law will change the way insurance companies handle coverage in this field for children who are in life-threatening situations.

We at BHN would like to applaud both the Congress for passing this bill and the Eating Disorders Coalition for their tireless advocacy to get this bill passed.

For More Information: Eating Disorders Coalition for Research, Policy, and Action, (EDC), David Jaffe, Executive Director, [manager@eatingdisorderscoalition.org](mailto:manager@eatingdisorderscoalition.org), 202-543-9570.

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### **Student Liaison Committee Chair**

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The American Dietetic Association is the world's largest organization of food and nutrition professionals. ADA is committed to improving the nation's health and advancing the profession of dietetics through research, education, and advocacy.

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## 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.

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

## **The BHN Nominating Committee is Pleased to Announce – The 2009 Slate of Candidates**

### **Chair Elect -**

Kathryn Russell, MS, RD

### **Treasurer -**

Janice Scott, MS, RD, CSP, LD

### **Nominating Committee**

(2 members) -

Therese Shumaker, MS, RD, LD

Sharon Lemons, MS, RD, LD

Much appreciation to these volunteers who are willing to share the knowledge and excellent experience they bring to the team.

Voting will take place 1st February through 3rd March, 2009, the same timing as ADA voting.