

From the Chair

Mary Emerson,
MS, RD, LDN



Many exciting things are happening within DDPD right now. It is my pleasure to welcome Andrea Shotton as our new Legislative Chair. I want to thank Daria Polanchik for her serving as Legislative Chair over the last two and half years. Andrea represented DDPD at the Public Policy Workshop in Washington D.C. in March. The listserv has been active with some great practice oriented questions and lots of ideas being exchanged. I urge those who haven't joined to consider checking out this valuable resource for your practice, as well as the opportunity to provide guidance to a colleague. The listserv also has a number of announcements of upcoming events and ADA postings.

The publication of *Children with Special Health Care Needs* in collaboration with the Pediatric DPG was debuted at FNCE. This publication is designed to be a practical resource for practitioners that may see a small number of children with special health care needs in their practice setting, as well as a manual for those of us who work in these settings on a daily basis.

The ADA Quality Management Committee has approved for DDPD to develop Registered Dietitian Standards of Practice and Standards of Professional Performance in Behavioral Health Nutrition Care. Committee members are Terry Girard Anderson, Renee Hoffinger, Paula Kerr, Maria Soler, Susan Zabriskie and myself. Ellen Pritchett, ADA's Director, Quality and Outcomes, is assisting us. The development of these Standards of Practice will define the basis of competent Behavioral Health nutrition practice, reflect current, evidence-based

practices, encourage consistency in Behavioral Health nutrition practice, and be the framework upon which future DDPD DPG education projects are based to challenge registered dietitians to move beyond experience-based practice to reach a higher level of evidence-based practice. If you have any questions or concerns about this project please do not hesitate to contact one of the members or myself.

Susan Zabriskie is working on a group home menu project. Rosalind Wilkins, Chair of Nominating Committee with her nominating committee has developed a wonderful slate of candidates. This has been our first year with on-line voting. Lee Wallace, our Chair-elect, is busy making arrangements for FNCE 2005 in St. Louis. So as the snow falls here in New England I know there is a lot of activity within DDPD underway and I encourage all members to be involved.

Children with Special Health Care Needs Nutrition Care Handbook

Lynn Grieger, MS, RD

Children with Special Health Care Needs Nutrition Care Handbook is an ADA publication from authors in the Pediatric Nutrition DPG and DDPD. The original Pocket Guide was published in 1997, and is now updated and expanded in this new version. The handbook is designed to meet the needs of nutrition professionals who serve children with special health care needs such as developmental disabilities, mental retardation, birth defects, low birth weight, metabolic disorders, and other disorders. More of these children are now seen in all areas of community health services, with over 50% having health problems that place them at nutritional risk. WIC and Head Start nutritionists, dietitians in community hospitals, and community health dietitians will find essential and practical information in this Handbook.

The Handbook is organized by common functional nutrition problems instead of diagnosis, because typically the presenting nutrition concern - poor growth, inadequate diet, feeding difficulty - is the nutrition professional's primary concern. Chapters on growth, diet, feeding, and fluid and

bowel management include information on both healthy infants and children and children with special health care needs. Case examples discuss both assessment and intervention techniques. The chapter on community services and programs outlines the variety of resources available in most communities. Topics are cross-referenced between chapters, and a glossary includes most terms used throughout the book. A very helpful resource list includes books, manuals, Internet sites, newsletters and magazines for additional information.

The Handbook is designed as a resource for any nutrition professional who works with children with special health needs. I often refer to my original copy of the Handbook, and look forward to using the updated information. The handbook is \$30 for ADA members and can be ordered from ADA's Member Service Center at 800-877-1600 ext. 5000 or through ADA's Web site at <http://www.eatright.org/Public/ProductCatalog/104.cfm>.

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tion between neurological disorders and diet was strengthening as success was being reported with dietary interventions excluding gluten and casein.

Another component, which provided fuel for the Opioid Excess Theory, was the idea that unusual brain opioid activity might be causing problem behaviors typically seen in individuals with ASD. This idea strengthened when an animal study postulated that the injection of opiate drugs produced some of the same and most common behavioral problems seen in the disorder.⁹ This at first seemed to be an unusual correlation; however, if autistics were acting like opioid addicts, the study raised the question as to whether or not the opioid system was involved in the etiology of ASD. Around this same time, a case study, believed to be the first documented attempt to determine the effect of food on autistic behavior, was also published showing that wheat and oats had long-term effects on the behavior of an autistic child.¹⁰ It seemed as though these fragmented, early studies had common relevance. They all revealed an interesting connection between neurological disorders, diet, and the opioid system of the brain responsible for certain problematic behaviors.

Although many of the earliest studies did not look at ASD specifically, they set the groundwork for future studies that later identified the neurochemical theory, known today as the Opioid Excess Theory, introduced by Jaak Panksepp in 1979.¹¹ He was the first to propose that ASD could be a neurochemical disorder stimulated by brain opioid dysfunction.¹¹ Sahley and Panksepp,¹² building on the earlier studies of Gillberg,¹³ who also discovered a unique urinary peptide pattern in adults with ASD, later hypothesized that the discovered brain opioids may come from an exogenous source. The dietary proteins, gluten and casein, were the suspected sources that had potential to saturate and deregulate areas of the brain responsible for the behavioral deficits observed.¹² In the 1980's researchers further identified these urinary peptides in the urine and cerebrospinal fluid of autistic individuals.¹⁴⁻¹⁵ Other studies in the 1990's continued the quest to explore the Opioid Excess Theory and its relationship with autistic tendencies.¹⁶⁻²¹ As more studies were published, the explanation of how these urinary peptides found in the urine of autistics could realistically come from the incomplete breakdown of gluten and casein was formulated.

To further understand the Opioid Excess Theory one must first consider the normal digestion process. In most individuals, proteins are broken down to individual amino acids in the intestinal lumen. In individuals with ASD, however, there may be a damaged intestinal gut with impaired permeability.²²⁻²³ When the two structurally similar proteins, gluten and casein are not completely

digested they can pass through the intestinal wall and into the bloodstream as partially digested peptides.²¹ Excessive amounts of these peptides that have escaped the intestinal lumen may also travel to the urine where they can be detected and measured as well as into the cerebrospinal fluid. Because these exogenous peptides, known as gliadomorphin and casomorphin are structurally very similar to the naturally occurring endorphins in the brains they have the ability to bind to the endorphin receptor sites in the brain. As a result, they may mimic the natural occurring endorphin activity by deregulating the CNS and acting as neurotoxins.^{12, 24} Because opiates are addictive, this could explain why so many children with ASD are self-limiters and eat only a handful of foods as if they are addicted.²⁵ A diet excluding gluten and casein seems to decrease the opioid activity in the brain²¹ thereby leading to a decrease in autistic tendencies, as well as a resolution of many of the gastrointestinal and immunological symptoms as reported by Wakefield et al.²⁶⁻²⁷ More recent research has also looked at dietary intervention and its effects on behavior and urinary excretion of exogenous peptides thought to come from the incomplete digestion of gluten and casein in children with ASD.^{22-26, 28-29} Two more recent studies reported significant reductions in autistic behaviors in children following the GFCF diet.^{20,30}

In addition to the behavioral consequences, the GFCF diet also addresses the gastrointestinal symptoms commonly reported. Gastrointestinal issues are common to many developmentally disabled children, but autistic children appear to have a unique pathology.²⁶ Intestinal inflammation has been reported in children with ASD, and improvement has been noted upon following a GFCF diet.²⁶ Another recent study reported behavioral and gastrointestinal improvements on a gluten free, casein free, and soy free diet in 56 of 61 participants with ASD.³¹ If peptides are leaking through the gut, it is likely that other unintended food particles are also exiting, thereby setting the stage for food intolerances, allergies, and nutritional deficiencies. In addition to the detrimental effects this has on health, a leaky gut can also encourage bacterial growth, which may intensify the gastrointestinal symptoms that may already be present.²³ It should also be noted that gastrointestinal distress in itself might play a role in behavioral attributes especially due to the autistic child's inability to communicate his or her needs to the caregiver.

Growing recognition of anecdotal reports, along with the studies supporting the Opioid Excess Theory and the influx of more recent research, has indeed led to a greater understanding of emerging biomedical interventions. Proponents of the GFCF diet have never suggested

a cure for ASD but rather have introduced an option for parents when considering treatments for their children. The anecdotal reports that have often been scrutinized as not being scientifically based, are, in fact, very important and must not be overlooked. Parents should not be dismissed, as they are vital members of the team of experts that is required in the care and treatment of any individual with ASD.

Unfortunately Autism is a highly stigmatized disorder, but parents and professionals are discovering daily that proper intervention can allow these individuals to reach their fullest potential. Autism deserves the attention of the medical community and nutritional professionals should play an important role in the treatment of these children as a GFCF diet, although challenging, can provide the essential nutrition that is often lacking in autistic children. While it is crucial to demand and evaluate science behind any diet, any parent will tell you that their child's success on a GFCF diet, whether it is an improvement in behaviors, intestinal health, or nutritional status, is all the scientific proof they need.

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LEGISLATIVE NEWS

Submitted by Andrea Shotton, MS, RD, LDN, DDPD Legislative Chair

Federal

Support Needed for the Newly Introduced Direct Support Professionals Fairness and Security Act

Many dietitians in the DDPD Practice Group train direct support staff who assist people with severe disabilities to prepare and to eat meals. Proper training makes direct support professionals key to initiating dietary changes and initiatives in their homes and communities. Support staff hourly wages are low while the job is often very demanding; consequently a high turnover rate is common. Many of the direct support professionals seek less demanding jobs in fast food and retail industries instead. This attrition causes a cycle of retraining for the dietitian. Such turnover decreases in clients' nutritional gains, which could jeopardize the client's health.

The Direct Support Professionals Fairness and Security Act, H.R. 5197, has been introduced in the House of Representatives by Reps. Lee Terry (R-NE) and Lois Capps (D-CA). It would provide funds to States to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities under the Medicaid program. The new Act will contribute to an improved national policy on the financing of long-term services and supports, which may include a salary increase for direct support staff. Take the initiative and contact your representative to urge him/her to co-sponsor the Direct Support Professionals Fairness and Security Act if and/or when it is reintroduced in Congress. The Act will ensure that persons with disabilities will be better served by a direct support staff providing continuity of care. This is more likely to occur when wages are fair.

Statewide

New York -- Health Services in Jeopardy for People with Developmental Disabilities

The NY State Department of Health is proposing rule changes that would effectively close part-time Article 28 clinics (including all part-time clinics serving children and adults with developmental disabilities). Full-time Article 28 clinics would then need to expand to cover the patient load; however, most expansion has been halted. Additionally, switching to Article 16 clinics wouldn't provide the same range of medical services, not to mention that most already have waiting lists

and cannot serve new patients. For those individuals who are able to locate alternative health care, Medicaid expenses would probably increase for transportation.

Indiana - Attend Public Forum on Funding Services!

Legislators and candidates are being invited to learn about successes and needs in their district. They will have an opportunity to make comments. DDPD members in Indiana can make a difference to participants by advising them on nutritional needs for the developmentally disabled community. For more information and public forum locations, contact The Arc of Indiana (317) 977-2375 or 1-800-382-9100 or www.arcind.org.

Tennessee - Proposed TennCare (State's Medicaid program) Waiver Revisions of Concern to DDPD Members

In August, the Governor released a draft waiver proposal that would implement an overly restrictive formulary for pharmacy coverage. Gastric acid reducing medications will no longer be covered for adults including those with disabilities. Dietitians working with people who have mental retardation and other developmental disabilities have a significantly greater need for patients to be continually covered for GERD (Gastroesophageal reflux disease) medication to control swallowing difficulties.

DDPD has a vacancy for the 2005-2006 Assistant Newsletter Editor. This is an opportunity to work with our incoming Editor Joan Guthrie Medlen as well as our incoming Chair, Lee Wallace, herself a former DevelopMental Issues Editor. This is an opportunity to network with enthusiastic, fun members.

Contact Mary Emerson for a copy of the job description, as well as any questions.

Mary Emerson, MS, RD, LD • 207-761-2378

Report From the Chair-Elect on FNCE Activities

Lee Shelly Wallace, MS, RD, LDN, FADA

I arrived at our DDPD Executive Committee meeting on Saturday, October 2, only slightly late - getting from the East Coast to Anaheim in the morning proved to be a challenge for several of us! It was good to meet some of the newer Committee members in person. We had a chance to catch up on progress as a DPG, and begin to look forward towards next year.

While I always knew there was lots of networking going on at FNCE in addition to the many educational sessions, I never realized until this year just how much went on behind the scenes. As a past Newsletter Editor and Treasurer, I only knew there were training sessions to help people in those position get a better grip on needed skills, but that was just the tip of the iceberg!

As the Chair-Elect, I was also invited to participate in several meetings, and really enjoyed the opportunity to do so. I wanted to give at least a short report back to you, DDPD members, to let you, too, know some of the information behind the scenes. So let me tell you about 3 particular meetings: (1) DPG Best Practices Forum, (2) DPG Foundation Lunch - to discuss endowments, and (3) DPG Chair, Chair-Elect/PID meeting

DPG Best Practices Forum

The Best Practices Forum met during a light lunch. It was a chance for the DPG Chairs and Chairs-elect to get together to discuss best practices. There was a brief time for general networking as lunch was served beginning at 12:30, and the planned program agenda did not begin until 1:00.

The planned agenda was introduced by Lori Porter, Director of ADA's Practice Team. Speakers were officers from a variety of the DPGs. They offered examples that their practice groups had found beneficial in relation to several areas (noted below). We also had a chance for discussion (questions and answers) on each topic.

- DPG membership recruitment and retention
Recruitment and retention are a concern for all the DPGs - which each exist to provide services to their members and to help keep the particular interests of the DPG's members in mind for planning ADA's strategic goals.
- Successful FNCE Program Planning
Getting started early seemed to be the key point - especially for proposing a priority session and funding it! Also schedul-

ing other meetings, which might include an Executive Committee meeting, breakfast or evening reception or other networking opportunities for the DPG members.

- Strategies for securing sponsorship and advertising funds
Money is always needed: for meetings, for member resources, to bring in speakers, provide receptions and networking for DPG members, develop educational materials, expand newsletters, etc. Several of the DPGs have a specific person delegated to this task, such as a Fund-raising Chair or a Coordinator to develop partnerships with companies related to the practice of the DPG.

One of the discussion topics was that some DPGs are more "allied" to some funding sources than others because of the nature of the group: The Diabetes Care & Education dietetic practice group came to mind - companies that provide medical supplies or food items aimed at diabetics are an easier connection and tie-in. Some of us, and I think our DPG is included, need to work a little harder to find the connections.

- Successful collaboration between DPGs
Sharing resources was the key here - for example, several of the DPG's join together to offer a big evening reception for members could pool their resources, and they spoke about their experiences, both good and bad - it requires a lot of coordination and preplanning! (Our DPG has done this in the past - both for FNCE program planning and for member receptions.)

DPG Foundation Lunch

The ADA Foundation invited us to a luncheon to explain what the ADA Foundation does as the philanthropic arm (501(c) 3) of ADA, to recognize the DPGs who currently offer scholarships or awards through the Foundation or who are 21st Century Club members, and to share their plans for the future and opportunities for partnership.

From the Foundation's report: "What does the ADA Foundation Do?" their mission is to improve the nutritional health of the public by focusing on three things:

1. giving scholarships and awards to dietetics students and professionals.
2. funding dietetics research by dietetics professionals.
3. promoting healthy weight for kids public awareness program."

Information about the Foundation is available at www.adaf.org

Suggestions for DPG involvement included: letting members know about the Foundation's activities, contributions to an existing scholarship or award or to establish a new one, contributing a basket to the Silent Auction, making a donation to honor a colleague or the memory of someone, making a donation to the research endowment and healthy weight for kids initiative and encouraging participation of DPG members in FNCE events: buy tickets to the Gala, participate in the 5K run, yoga, or the Silent Auction.

DPG Chair, Chair-elect, and PID meeting

An afternoon meeting was also arranged for the DPG Chairs, Chairs-elect, and the Professional Issues Delegates (PID). We had assigned seating in a roundtable format, so DPG and PID could be seated together. We were provided an update on ADA services and new initiatives, including generational diversity and the strategic goals of ADA. Then, each table was given a large note-taking pad and the task to discuss one or two of the following topics (their choice) and provide feedback to the entire group. These topics/questions included:

1. DPG/PID Relationship
 - a. Fall HOD Meeting Outcomes
 - b. Current PID/DPG Structure/Process (evaluate how the process and structure of the PID/DPG system is working as it relates to professional issues being represented in the HOD)
2. DPG support of the Association's diversity initiatives - brainstorm methods of how to support the Association's diversity initiatives
3. Current projects to benefit the Association based on the ADA Strategic Plan
4. Professional Issues which will impact the Association

After a good time of talk and brainstorming at each table, the entire group then heard from a spokesperson from each table who summarized the results and discussion at each table. Having only a few minutes to summarize, it went too fast for me to take notes on all of it, but a representative did take the sheets we had written on, and kept additional notes, so we hope that information from this session can -and will! - be used by ADA.

If you have any particular questions about any of the above, please ask me - email works well, but you can leave a message on my phone, too.

I appreciated the opportunity to represent DDPD at these meetings, and really learned a lot about how DPG's work, and how we can all work together to increase our visibility and worth as dietetics professionals.

Counseling Tips for Nutrition Therapists

Molly Kellogg, RD, LCSW

Tip #9 - Dealing With Resistance

Integrity is when what you do, who you are, what you say, what you feel, and what you think all come from the same place.

— *Madelyn Griffith Haney*

It is frustrating when our clients do not appear to accept responsibility for their behaviors or do just the opposite of what we know is good for them. It may be helpful to look at the issue from the perspective of resistance.

What does resistance sound and look like?

- “Yes, but...”
- “Well, I guess I could try.”
- The client returns for the next visit and has not done what you thought he had agreed to.
- The client does not return for a scheduled visit.
- Body language that looks like reluctance.

Resistance is what happens when we expect or push for change when the client is not ready for that change. Resistance is not something that exists in clients in a static sense. It arises as a normal, expected product of the interaction. When resistance emerges, there always are good reasons why the client is not ready to change in the way we are asking. The reasons may not be clear to us or to the client, but they exist. Ignoring them gets us nowhere.

Ways to lessen the chances of eliciting resistance:

When we emphasize personal choice and control, resistance will be minimized.

Examples:

- When working with bulimics to brainstorm other ways to

cope with strong emotions, urging them to include bingeing and purging as one of the options demonstrates their degree of choice.

- When clients want to pursue a behavior you do not believe will work or disapprove of, before putting in your opinion, begin with: “That is one of your choices.”
- I often use this approach when clients are berating themselves. I don’t believe self-criticism helps at all, but arguing with them tends to bring up resistance. I begin with, “you can choose to call yourself those names and focus on what you dislike about yourself. Does it lead to the results you want? If not, would you be interested in other ways to talk to yourself?”
- When addressing lack of a change you expected, be willing to look at what happened without judgment: “Oh, that’s interesting! I wonder how that came about.”

Our clients’ behaviors are indeed much more in their control than in ours, so it makes sense to acknowledge this out loud and get back to what we can do to help them reach their goals. Unless they have contracted with you to be their food police and follow them around all day, leave them with the choice and control and stay in a consultant role.

Another important strategy is to track closely a client’s readiness and check in along the way. (See Tip # 7 archived at www.mollykellogg.com) Carefully exploring how important the change is to her and her confidence in doing it can save time and aggravation later.

Approaching each possible behavior change as an experiment (see tip #3) can lessen the chance that resistance will emerge. When you take that approach, the only accountability clients have to you is to run the experiment. You are not asking them to commit to the change forever.

How to respond once resistance surfaces:

The general approach that works here is to back off and come alongside your client. The sooner you catch it and respond by backing off, the sooner you two can get back to work. As long as you push when resistance is present the work will get nowhere.

This may sound like:

- I can tell I’ve gotten us off track here. Can you help me review what is important to you right now? (Going back to checking on importance and meaning)
- I agree, there’s no point in trying something that’s not going to work. (mirroring client’s low confidence to change)

- I see; you really do hate gyms. Since you would like to be more active, would you like to brainstorm other ideas together? (Acknowledging the resistance and coming alongside)
- I sense you aren’t ready to work on this right now. That’s fine with me. This is your session. (emphasizing personal choice and control)
- Thanks for reminding me that we need to do this in ways that will work for you.

Some thoughts about eating disorders:

With eating disorders the ambivalence about change is often deeper, and more subconscious than with medical nutrition therapy clients. There may be significant medical consequences of the client’s choices, so we and their families feel a strong temptation to push. Control issues often are a central theme in the psychological picture of an eating disorder. It’s clear why resistance can be powerful.

Work with this population demands that we pay careful attention to not provoking resistance. No matter what we do it will still come up. We will be most effective if we clearly acknowledge resistance as soon as it comes up and then work with it. Fighting an eating disorder head-on always leads to failure. Finding ways to come alongside eating disordered clients is one of the most challenging and gratifying aspects of the work.

When resistance doesn’t surface:

There may be a few clients out there for whom plain old accountability really works. These tend to be the clients who are clear about the importance of change, and have confidence. They just need input on how to accomplish it. All they need is someone to report to and help with making plans for the next step. After a while the changes become habit and they end with you. Boy, those clients are great and every now and then, we get lucky and one walks in.

Hope this is helpful.

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Summary of DDPD Planned Session Behavioral Therapy in the Treatment of Eating Disorders,

Molly Kellogg, RD, LCSW

Presented at the ADA Food & Nutrition Conference & Expo in Anaheim, California, October 3, 2004. Submitted by Jessica Setnick, MS, RD/LD, DDPD Eating Disorders Resource Professional.

Molly Kellogg is an experienced dietitian, therapist, and diabetes educator, chosen by DDPD for her expertise with eating disordered clients. Over the course of her session, Molly discussed the dietitian's best strategies for helping eating disordered clients change even if they at first appear not to be interested in what we have to say.

Molly emphasized that in these situations, the process between dietitian and client is as important as the nutrition education that we provide. If our clients are not ready to change, nutrition counseling will not be fruitful in forcing them to do so.

Why would our eating disordered clients not want to change? It seems obvious to everyone around them that their illness is harmful. Molly asked us to think back to the beginning of the eating disorder, when it was "just" a diet. At first, eating disorder behaviors, such as restrictive eating, overexercising, binging, or purging, actually "work" to decrease the pain of life stresses. If the behaviors cause weight loss, the individual may also get positive reinforcement from other people and media messages, which encourage continuing the behaviors. Over time, the behaviors become at the very least a habit, and possibly an identity.

Once behaviors have become this ingrained, there are lots of reasons not to change - this is expressed by our clients as resistance. Resistance can be expressed in body language, in ambivalence, in disagreeing with our recommendations, or in denial that their problem is serious.

The key to addressing resistance and/or ambivalence is to talk about it with your client, instead of pushing against it, which is often our instinct. For example, saying "You sound reluctant to make that change," even if the patient has not specifically said so. Naming the resistance and recognizing it takes away its power to upset you or control the session. Molly calls this "Backing Off."

Once you have identified that your client is resistant to a certain recommendation, "Unpacking" the details of the problem helps your client express the fears that your suggestion produced.

Then if you can find something that you do agree on, or that your client is willing to say that they do want to change, you can move forward with your client, instead of against them. Molly calls this "Coming Alongside." Coming Alongside also includes asking your client if they would like to hear your suggestions, rather than just demanding that they make a change.

Sometimes our clients do not make an observable change, and this can make the dietitian feel useless or helpless. But if we remember that changes only occur when all the pieces are in place, then we can recognize that helping to gather the pieces is in fact very helpful.

Our clients change under three circumstances.

- When they want to, or have a good reason to change.
- When they have the knowledge and resources to change.
- When they feel confident that they can change.

Often our clients do not meet these criteria, therefore they are not able to change just because we educate or make recommendations. Instead of giving out more information, or giving up from frustration, we can actually encourage eventual change by "keeping ourselves out of the way." Molly gave the dietetics professionals in attendance additional strategies and examples of Mirroring, Experimenting, and Giving Permission, that we can keep in our toolbox and use in a variety of patient situations.

DDPD is grateful to Molly for generously sharing her expertise with our membership.

*For more of Molly's nutrition counseling techniques, join her email newsletter, **Counseling Tips for Nutrition Therapists**, or order her book of the first 25 Tips at www.mollykellogg.com. To order an audiotape or CD of **Behavioral Therapy in the Treatment of Eating Disorders** or other FNCE 2004 educational sessions, visit <http://www.conferecmedia.net/>*

FNCE 2004

Mary Emerson MS, RD, LDN

I attended FNCE 2004 in Anaheim as Chair of Dietetics in Developmental & Psychiatric Disorders (DDPD) Practice Group. I was very fortunate to be a presiding officer for one particular program on Behavioral Therapy of Eating Disorders. Molly Kellogg, LCSW, RD was the speaker on "Behavioral Therapy in the Treatment of Eating Disorders." Molly is well known for her training, supervision and coaching of nutritional professionals working with clients with eating disorders. Please check out her Web site, www.mollykellogg.com. She has some great counseling tips that she e-mails out free of charge to colleagues who register (see "Counseling Tips for Nutrition Therapists," page 7). She started her presentation discussing the client's readiness to change and how to obtain this from the client using motivational interviewing. She went on to discuss resistance of clients to change, which is an inherent part of the condition, and our role in working with the resistance. She covered psychotherapeutic skills that apply in nutrition work with eating disorder clients, identifying benefits of professional supervision for the dietitian working with eating disorders and describing the treatment team approach to eating disorders and how it improves the quality of patient care. After all the eating disorder is the symptom of underlying issues that need to be identified and dealt with in therapy. She provided examples of specific language that the dietitian can use in dealing with resistance to behavior change, such as acknowledging resistance, shifting into tracking readiness, promoting client control, mirroring ambivalence, and working with experiments so the client can make some gains towards a larger goal.

DDPD also sponsored a member breakfast with Kathryn Moseley, MS, RD from the Children's Hospital of Los Angeles speaking to us about the phenylketonuria (PKU) diet in the adult client. She presented the history and specific metabolic pathways that are blocked in PKU and its manifestations. Ms. Moseley told the audience about the differences between the phenylalanine (Phe) restricted diet and the new therapy using large neutral amino acids (LNAA). The PreKunil tablets contain LNAA which cross the blood brain barrier and has been shown to decrease brain Phe and allow for utilization of the other LNAA needed for protein and neurotransmitter synthesis. The treatment requires taking approximately ten tablets three times each day with meals and minimal protein restriction.

She discussed the challenges of diet adherence with children after the age of six to eight years old, due to high cost, need to prepare most foods at home, and restrictiveness of diet. She discussed the use of biochemical tests such as the phenylalanine/tyrosine ratio and use of Phe test kits for monitoring blood levels. She discussed the potential for finding patients initially diagnosed with PKU and now non-compliant with the diet. She showed a video (which is available at <http://www.pkulatetx.com>) that shows a woman with PKU who was untreated and severely affected and had been institutionalized for over 40 years with no treatment. The woman had significant behavioral issues, including head banging and out of control behavior. After her placement into a group home dietary intervention began. She was weaned off of all her medications and her behavior improved significantly. Kathryn discussed the pending studies with BH4 therapy in the US to help individuals with PKU be able to metabolize Phe. This presentation was extremely informative and also very hopeful about the use of diet in behavioral management with adults with PKU.

DDPD Audio-Visual Library

DDPD members can receive one tape per order. A deposit of \$15 for one tape (\$20 for two-tape series) should be sent. Make check payable to ADA-DPG 12. The deposit will be returned if tapes are received within one month of the date mailed. Include your name, address, and daytime phone number along with the name of the tape ordered. Send request and deposit to the AV Librarian:

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507 Chestnut St
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If the ordered tape is out on loan, your name will be placed on a waiting list and mailed when the loan is returned. ADA-DDPD is not responsible for damages to tape player that may occur. Please carefully inspect tapes to make sure they are not damaged.

Please contact the AV Librarian for updated listings or more detailed information about any of the tapes listed.

ADA FNCE Meeting tapes are generally one hour per tape.

NEW ADDITIONS

Kathryn Moseley's presentation at the DDPD Breakfast Meeting October 4, 2004 entitled: **"Phenylketonuria: New Approaches and Insight Treatment"**. Also available is a 5 minute video that shows a woman

with PKU who was untreated and severely affected and had been institutionalized for over 40 years with no treatment. The woman had significant behavioral issues, including head banging and out of control behavior. After her placement into a group home dietary intervention began. She was weaned off of all her medications and her behavior improved significantly. The video shows her behavior before treatment and four years later ending in a trip to Disneyland. The video is in a CD form that plays on an IBM compatible computer.

EATING DISORDER RESOURCES

Eating Disorders. (audio 2 tapes plus 32 page study guide) Alexander Lucas, MD and Diane Huse, RD, 1986 *Exploration of anorexia & bulimia nervosa*. ADA study kit.

Counseling the Dysfunctional and Noncompliant Patient. (audio 2 tapes) Lisa Beckley-Barrett, RD, from ADA 1988 Annual Meeting. *Good for professional working with substance abuse patients.*

Gentle Eating. (audio, 3 tapes) Marel Hanison, MS, RD. *A new approach to disordered eating.*

Eating Disorders: Interventions and Guidelines. (video, part 1 is 80 min, part 2 is 62 min) From ADA Seminar, LaRue Carter Hospital, August, 1993.

Current Perspectives in the Treatment of Obesity. (audio) ADA 1993 Annual Meeting.

Eating Disorders in Special Populations. (audio) ADA 1994 Annual Meeting.

The Latest in Nutrition Counseling: Experts Share Secrets of Success. (audio) ADA 1994 Annual Meeting.

Afraid to Eat: Eating Disorders & the Student-Athlete. (17 min video) Karol Video. *Interviews with student-athletes, coaches, and medical personnel to define anorexia and bulimia and provides information about the incidence rates. Covers the characteristics and warning signs and dramatically show the consequences of eating disorders.*

Diabetes and Eating Disorders. (audio tape) Claudia Plaisted, 1999 SCAN meeting session recording about assessing and treating clients with diabetes and eating disorders.

International Association of Eating Disorders Professionals: Families, Healing & Diversity. (8 audio tapes), San Diego, CA, August 10-13, 2001.

DEVELOPMENTAL DISABILITIES RESOURCES

The Fitness Program. (video 2 tape series & teaching guide) ORDER SEPARATELY. Fitness for all, exercising safely & effectively, fitness testing, fitness can be fun, fitness routines, teaching strategies, aerobic and muscle-

continued

DDPD A/V Library *continued*

building routine by students with developmental disabilities.

Team Approach to Feeding Problems. (audio 2 tapes plus 32 page study guide) Harriot Cloud, MS, RD. ADA study kit 1987. *Focuses on identifying, assessing and treating feeding problems.*

Home Gastrostomy Care for Infants and Young Children. (video 27 minutes, manual test pkg.) University of Colorado School of Nursing, 1989. *Principles, techniques, ADL's.*

Assessment of Growth and Development. (video) William Chumlea, PhD. Cincinnati Production. *Demonstration of anthropometric measurement and explanation of developmental physical expectations.*

Dimensions of Feeding Techniques. (3 tape video series—30 minutes each) Rosalind Benner, RD ORDER SEPARATELY

1. Chewing & Swallowing—the basics
2. Feeding the patient
3. Progressing to independent feeding.

Nutritional Assessment. (video) Ross Laboratories. *Anthropometry in the home. A 15 minute tape on the basics of anthropometry, particularly for practitioners making home visits.*

Nutrition Assessment of Children with Disabilities. (video 60 minutes) Boling Center for Developmental Disabilities, University of Tennessee at Memphis. Copyright 1988. Hosted by Elizabeth Emerick, MS, RD, Nutritionist. *All aspects of nutrition assessments for children with developmental disabilities including behavioral, clinical, feeding skills, and biochemical aspects of assessment are reviewed on the VHS tape.*

When Feeding is a Problem. (video, 15 min) The center for Human Nutrition, Omaha, Nebraska, 1990. *The VHS tape presentation provides a basic introduction to aspects of oral motor feeding problems such as tongue thrust and lip retraction.*

Oral Structure, Swallowing and Digestion: Normal and Abnormal. (video, 16 min) Texas Department of Mental Health and Mental Retardation, Austin, Texas, 1991. *The VHS tape presents an overview of the basics of swallowing; provides demonstrations of dysphasia in adults with developmental disabilities.*

A History of Mental Retardation. (video, 17 min) The Shriver Center—Massachusetts Department of Mental Retardation, 1989. *Presented as "progression of time" through modes of thought/ treatment of MR. Excellent resource for staff, students, and professionals new to the field of MR.*

Obesity in Special Populations. (audio, 2 tapes) McCamman, Palmer, Devlin, 1991 ADA Annual Meeting. *Nutrition intervention strategies for individuals with Prader Willi Syndrome; treatment of weight gain in psychiatrically impaired individuals on psychotropic medications; and twelve step intervention in compulsive eating.*

New Direction in Dysphagia. (audio) Hartiage, Panther & Lewis. 1992 ADA Annual Meeting. *Case studies and applications at a facility. Details diet, with some emphasis on fluids, compliance after discharge.*

A New Home. (audio) Lewis, Garfield, Hunter, 1993 ADA Annual Meeting. *The shift of services of patients with developmental delay and psychiatric disorders away from hospital or institutional setting to community-based facilities is reviewed.*

Nutritional Needs of Children with Chronic Diseases. (audio) ADA 1994 Annual Meeting.

"Feeding and Swallowing." (video, 3 tapes, ORDER TAPES SEPARATELY) University of Nebraska, approx. 1995.

1. Feeding and Swallowing: Positioning, oral hypersensitivity, behavioral approaches, direct therapy strategies.
2. Feeding and Swallowing: Indirect management development of early skill, identification of medically related issues.

continued

DDPD A/V Library *continued*

3. Feeding and Swallowing:
Parents perspective on decision to place a G-tube and life after placement of G-tube.

Mothers of Developmentally Delayed/Special Needs Children Talk About WIC, etc. (video, 1 hour) Texas Department of Health, 1994. *Interview of mothers explaining situations and feelings associated with assistance programs/referrals.*

An Introduction to the Ketogenic Diet- A Treatment for Pediatric Epilepsy. (video, 1 hour) The Charley Foundation, 1994. *Interview of professional, parents, children. Diet, monitoring, long-term follow-up.*

Nutrition for Infants and Toddlers with Special Needs. (video, 24 min and viewers guide) University of Colorado School of Nursing, 1989. *Basic nutrition, feeding plans, relationships.*

Feeding Infants and Young Children with Special Needs. (video 26 min and viewers guide) University of Colorado School of Nursing, 1989. *Techniques to alleviate feeding problems of special needs clients.*

NHANES III Anthropometric Procedures. (video, 30 min) CDC/NCHS. *Outlines standardized anthropometric procedures. Explanation and demonstration only.*

The Missing Link. (video, 17 min and training guide) Frances Stern Nutrition Center, New England Medical Center Hospital, 1996. *Designed to help Early Intervention professionals appreciate the importance of nutrition and feeding concerns in children with special health care needs.*

Consuming Concerns— Nutrition Concerns in Early Intervention. (slide/video, 20 min training guide) Frances Stern Nutrition Center and Eunice Kennedy Shriver Center UAP, 1996. *Inservice training on specific nutrition issues and concerns of special needs children from birth to 3 years of age.*

Marketing MNT to MCOS. (Written material, audio and slides) Workshop 3/17/96 ADA & Ross. *Background/program and planning; presentation resources.*

Winning the Managed Care Game. (Written material, audio and slides)

Nutrition Screening Initiative. ADA, AAFP, NCA, 1993. Slides/written material presenting screening initiative for older Americans.

Dimensions in Food Textures, Preparation & Feeding Techniques for Special Needs Children. ORDER TAPES SEPARATELY. Anderson Benner Video. Part 1. The Basics: IEP Legislation, Phases of chewing/Swallowing, Textures.

- Part 2. Food Processing Techniques: Thickeners, Recipes, Panning, Plating.
Part 3. Feeding children with Special Needs: Positioning, Feeding, Jaw/Tongue Dysfunction, Adaptive Equipment Cards, Environment.

SUBSTANCE ABUSE RESOURCES

Fetal Alcohol Syndrome and Fetal Alcohol Effects: The Effects of Drinking During Pregnancy. (video, 15 min) The Shriver Center—Massachusetts Department of Mental Retardation, 1987. *Overview of diagnosis, assessment, and the Shriver Center's treatment.*

Assessment for Alcohol Exposure in Utero: Diagnostic Implications for Fetal Alcohol Effects & Fetal Alcohol Syndrome. (video, 56 min) The Shriver Center—Massachusetts Department of Mental Retardation. *Very specific and thorough techniques and methods of identification; recommendations for continuum of assessment and care.*

Substance Abuse & Nutrition. (20 min video & written materials) National Health Video. *Explains how substance abuse may lead to malnourishment; vitamin & mineral depletion; appetite loss, poly-drug use; immune system effects; role of nutrition in the recovery process tailored to food guide*

continued

DDPD A/V Library *continued*

pyramid choices appropriate for recovering substance abuse clients.

Fetal Alcohol Syndrome. (13 min video) National Health Video. *Describes how alcohol affects unborn child; no known safe level of alcohol during pregnancy.*

PSYCHIATRIC RESOURCE

Skill Development: Assessing the Nutritional Status of the Elderly. (audio, 3 tapes) 1991 ADA Convention Panel: *Includes us of lab data for screening; effect of prescription and non-prescription drugs; implications in malnutrition; application for dietitians in assessment of institutionalized and non-institutionalized elderly.*

Diet and Behavior. (audio) Dwyer, Lachance, Wender & Black, 1991 ADA Annual Meeting. *Misconceptions and current scientific information about the relationships between diet and behavior. Public education strategies that assist alleviating misconceptions.*

Skill Development: Counseling Strategies for Those Who Don't Want to Hear What You Have To Say. (audio, 3 tapes) Hall & Salas. 1991 ADA Annual Meeting.

Key Issue Nutrients: Nutrient, Neural Function & Behavior. (audio) Blass & Fernstrom, 1992 ADA Annual Meeting. *Tape begins with animal/infant studies, then applies to human physiology/psychology.*

Adverse Food Reactions with Special Emphasis on Food Allergy. (audio) ADA 1994 Annual Meeting.

Geriatric/Extended Care: Undernutrition—A Case Mix - Quality of Care Issue. (audio) ADA 1994 Annual Meeting.

The Function of Dysfunction. (audio tape) Monika Woolsey, 1999 SCAN meeting session recording about Axis II disorders and counseling clients with these type of diagnosis.

Food & Mood. (book) Elizabeth Somer, Henry Holt & Co, NY, 1999.

Helping Someone with Mental Illness. (book) Rosalynn Carter, Three Rivers Press, NY, 1999.

Managing Your Mind & Mood Through Food. (book) Judith Wurtman, Harper & Row, NY, 1988.

The Serotonin Solution. (book) Judith Wurtman, Fawcett Columbine, NY, 1997.

I Am Not Sick, I Don't Need Help: Helping the seriously mentally ill accept treatment (book) Xavier Amador, Vida Press, 2000.

Eight Leading Experts Answer the Five Most Common Questions About Chronic Depression. (video) National Depressive Manic Association, 30 min, 1998.

Chronic Depression Video Series Volumes I-IV. (video) National Depressive Manic Association, 30 minute each, 1998.

Dark Glasses & Kaleidoscopes. (video) National Depressive Manic Association, 33 minutes, 1997.

DDPD Advertising Policy

The Dietetics in Developmental and Psychiatric Disorders Dietetic Practice Group accepts advertisements for our newsletter, *DevelopMental Issues*, under these guidelines:

- Advertisements will be limited to products and services that are of interest to our members, consistent with the goals for the dietetic practice group, and which promote sound nutrition of the patients we serve.

We reserve the right to evaluate all statements in advertisements and to refuse to accept any copy that does not follow guidelines established through the American Dietetic Association.

We require the following disclaimer in each issue of the newsletter: "The publication of an advertisement in *DevelopMental Issues* should not be construed as an endorsement of the advertiser or the product by the American Dietetic Association or this dietetic practice group.

Rates: \$2500 to sponsor an entire issue (which includes recognition at our Annual Meeting, a full page ad, a recognition notice, and one year complimentary subscription)

\$ 500 for a full page

\$ 350 for a half page ad

\$ 250 for a quarter page

\$ 125 for an eighth page (business card size)

Dietetic Practice Group members are entitled to a 20% discount.

Advertisements may be submitted any time and advertisers will receive notification of acceptance within 30 days of submission, at which time scheduling for placement will be arranged.

Advertisements must be received in camera-ready form by the designated deadline for publication along with payment in full made payable to The American Dietetic Association/DPG #12 and sent to: Melissa Altman-Traub, Newsletter Editor, Nutrisolutions@aol.com, 1556A Stoney Lane, Philadelphia, PA 19115. Phone: 215-969-0652.

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Resource Professionals

*Do you have a professional
question you need help with?
Contact the appropriate
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