

President's Message

Dear APGNN Colleagues:

I just returned from the DDW meeting at which I attended the CDHNF Board meeting as well as the NASPGHAN Executive Council Meeting. The following are highlights of my report to them and it serves as a good update as to where we are as an organization.

We have spent time in conference calls reviewing & updating our *Strategic Plan*. Our **stated objectives are to:**

1. Be recognized leaders in pediatric GI by providing various educational resources
2. Educate, stimulate & recognize excellence in pediatric GI nursing
3. Build interest, confidence & competence in pediatric GI nursing research

The various ways we have met these objectives during the last year have included:

A. Providing the Annual Conference which every year grows in attendance:

Last year 203 registered, 131 were APGNN members and 72 were non-members. Objectives were rated as "highly met" for all presentations with speakers being rated 4 & 5's on a 5-point scale w/regard to expertise & effectiveness

We have continued the attitude of focusing on a theme for our annual meeting: last year's was "Searching for Evidence" and this year we are "Working Toward Adherence"

Also at the request of membership for more networking time, we have decided to add an evening reception on Friday night.

Increased conference fees will help to cover the costs for larger meeting rooms and amenities.

B. Continuation of funding for our award programs:

Most specifically, the *Excellence in Education Award* which honors GI nursing colleagues who have been judged by a specially appointed committee to be providing excellent educational opportunities to either patients/families, peers or to the community. The award recipient has funding to attend the meeting (including the PG Course) and presents the project which provides all attendees with new ideas & thoughts they can take back to their own facilities. The total budget for this award is \$2000 and in the past TAP has funded this program but we are committed to continuing this event

We also will continue the awards for *Posters of Distinction in Research* as well as *Clinical Practice* and the *Mentoring Award*.

APGNN Board and Committee Chairs EXECUTIVE BOARD

President:

Rosemary Young

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Adelina McDuffie

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Treasurer:

Patricia Bierly

COMMITTEE CHAIRS

Membership:

Lisa Philichi

Newsletter:

Robin Shannon

Patient/Family Education:

Karen Sherry & Lillian Sablan

Program:

Lindsay Wilson

Research/Publication:

Lynn Mattis

Clinical Practice:

Helene Bacha

PRESIDENT'S MESSAGE CONTINUED

C. Developing an Ethics Statement and use of Disclosure Statements for all Board/Committee Members (we have been using them for speakers at our annual meeting already)

D. APGNN involvement in NASPGHAN Patient Education Committee: Addie McDuffie, our current Past President, is Chairperson of this committee

E. Continuation of work on the Clinical Handbook: chapters are under review and we hope to have the book available for distribution at the fall meeting. \$ 36,000 of the \$ 50,000 needed have been raised

F. Our quarterly newsletter is now sent out electronically, thanks to the assistance of the NASPGHAN home office. We have added sections to the newsletter to include invited articles of topical interest as well as added a medication update section.

We added a **New Objective** this year:

4. To work on revising our structure to maximize effectiveness

This was added to recognize the fact that as we become a larger group our organization needs to work in a more streamlined fashion to provide benefits to all members. We are striving to ensure members obtain benefits from their participation in the group. To accomplish this we have:

* Asked all committees to develop action plans with specific objectives and timelines

Enabled electronic membership renewal and are working on electronic voting for offices & bylaw changes

NEW INITIATIVES FOR THE COMING YEAR include:

1. Bylaw changes: membership and dues
2. Enhancement of our website and use of Pediatric GI nursing Listserv
3. Ways to increase & enhance membership: we had a significant number of attendees at our annual meeting who are not members. However, since the last meeting we now have 260 members with 62 joining in the last year
4. Exploration & possible development of a Pediatric GI Nursing Research Grant

Continued Administrative support from NASPGHAN is greatly appreciated and instrumental in allowing us to keep connected via conference calls, mailings and up to date on all the fine details involved in planning the October conference. Thanks to Margaret Stallings, Sandy Fasold and Kim Rose for all of their assistance!

None of the above would have been possible without the combined efforts of APGNN's current Board & Committee Chairs

Looking forward to seeing you all in Salt Lake City in October!

Rosemary Young, MS, RN

APGNN President



3rd Annual APGNN *Excellence in Education* Award sponsored by TAP Medical Affairs

I am Delighted to report that TAP has once again funded the *APGNN Excellence in Education Award*. Recall that this award is designed to honor, recognize and promote excellence in pediatric GI nursing educational activities that improve patient care.

Any APGNN member or other pediatric gastroenterology nurse who has designed and implemented an educational activity (patient/family, peer or community) that addressed an unmet need is eligible. The project may be an individual or collaborative effort where the applicant has held a leadership role or been an integral part of the endeavor.

The Award provides funding for attending the APGNN Conference including Travel Expenses, and one year's annual dues. The winner also receives an engraved crystal object in recognition of this achievement.

Applications will be emailed to all APGNN members in the very near future. Please take advantage of this wonderful opportunity to share your Educational Program with all of us at APGNN.

Addie McDuffie, MS, CPNP
APGNN Past President
addie.mcduffie@chkd.org



ANNUAL MEETING AND
POSTGRADUATE COURSE
.....
GRAND AMERICA HOTEL SALT LAKE CITY UTAH
.....
OCTOBER 25-27, 2007

The APGNN Annual Meeting is Friday October 26th and Saturday October 27th



The APGNN Excellence in Mentoring Award

This award recognizes a mentor that has provided guidance and direction toward nursing excellence to an APGNN member during the past 36 months. The only exclusion criterion is that one can not be a recipient for two consecutive years. The mentor who is selected as the recipient of the award will be honored with a check in the sum of \$250 - to be presented by his/her nominating APGNN member during the Annual Meeting.

If you have a special Mentor in your career, please consider submitting a letter summarizing how your mentor has fostered your professional development to Lisa Philichi, Membership Chair at lisa.philichi@multicare.org. Additional information regarding the mentor nomination process is included in the accompanying guidelines. The APGNN Board/Committee Chairs will then blindly review all submissions and select a recipient. Wouldn't it be nice for your mentor to be able to list *The Beverly J Yandell Mentor Award* on his /her CV from now on-I can't think of a better way to say thank you, can you?

Your President,

Rosemary Young, RN, MS, CGRN

PLEASE SEE THE LAST PAGE OF THIS NEWSLETTER FOR THE OFFICIAL GUIDELINES FOR SUBMISSION/EVALUATION OF A NOMINEE FOR THE EXCELLENCE IN MENTORING AWARD

DEADLINE FOR SUBMISSION: 8/31/07

DISEASE INFORMATION

Is There an Acceptable Minimal Gluten Exposure? A Review and Commentary on a Recent Study

Celiac disease (CD) is an immune-mediated intestinal inflammatory condition caused by the ingestion of gluten—the major protein fraction contained in the cereals wheat, rye, and barley. CD is a life-long disorder affecting 0.5–1% of the general population worldwide and occurs in genetically susceptible persons. Characteristically, the treatment of celiac disease (CD) has been based on the strict avoidance of gluten-containing food.

It was been quite difficult to determine if there is an acceptable tolerable exposure particularly when factoring in low level exposure over a long period of time. It has been previously shown that celiac disease patients who ingested 200-1000 mg gluten/day for 4 weeks demonstrated measurable changes in the architecture of the small-intestinal mucosa (1). Only limited data are available on the toxicity of lower doses of gluten (2-4). The article entitled “A prospective, double-blind, placebo-controlled trial to establish a safe gluten threshold for patients with celiac disease was written by a group of respected American and Italian gastroenterologists and recently published in the American Journal of Clinical Nutrition. In this study the group attempted to determine if there was an acceptable level of gluten ingestion which in the short term would not produce any identifiable inflammation or symptomatology (5).

This was a multi-center, double-blind, placebo-controlled, randomized trial in 49 adults with biopsy-proven CD who were being treated with a gluten-free diet (GFD) for 2 years or longer. This group was compared to a control group of patients who also had celiac disease but received no additional gluten. After a baseline evaluation, all patients were assigned to ingest daily, for 90 days, a capsule containing 0, 10, or 50 mg gluten. Symptoms, laboratory tests and small intestinal biopsy results were obtained at baseline and 90 days after ingestion of the assigned product. Of interest at baseline a significant number of participants demonstrated damage of the small intestinal mucosa and higher intraepithelial lymphocyte counts in the tissue (a common indicator of active celiac disease status) as compared to controls. Only one patient developed a symptomatic relapse during the study. After 90 days of ingestion of the various gluten levels, the placebo group demonstrated an improvement in the villous height/crypt depth group, however the other 2 groups demonstrated worsening of the same indicator. The group receiving 10mg/day of gluten demonstrated a 1% decrease and the 50 mg group demonstrated a 20% decrease in the villous height/crypt depth ratio.

As noted the treatment of CD involves the consumption of a gluten-free diet (GFD) which over several months results in clinical, serologic, and histological remission. However, the diet is difficult to maintain because gluten contamination is considered somewhat common in food. Hidden gluten may be found in commercially available products including those specifically targeted to people with CD. This primarily occurs due to contamination/processing in a facility that uses wheat products in other foods.

Whether there is a safe threshold for gluten ingestion in patients with celiac disease is a topic of major concern due to the rising incidence of celiac disease. Better screening tools and enhanced awareness of the problem is helping to identify many patients who were previously undiagnosed. The recent National Institutes of Health Consensus Conference position on CD estimated that as many as 1 in 133 people in the United States are affected by CD(7). Therefore, the Food Allergen Labeling and Consumer Protection Act (FALCPA) provided food labeling requirements that took effect on January 1, 2006. The law now requires food manufacturers to clearly state if a product contains any of the eight major food allergens responsible for over 90% of all allergic reactions; those allergens are milk, eggs, peanuts, tree nuts, fish, shellfish, wheat, and soy. In addition, the law requires that the Food and Drug Administration conduct inspections and issue a report within 18 months to ensure that the food manufacturers comply with practices to reduce or eliminate cross-contamination of a food with any major food allergens that are not intentional ingredients of the food (8). This however does not mandate absolute restriction as many of the items can be labeled as free of the ingredient if below a certain threshold level.

It was quite interesting that the study finding reported an abnormal small-bowel tissue existed in a significant proportion of CD patients already on a gluten free diet despite full resolution of their symptoms. This has been documented in other studies (9-11) and is likely due to the ongoing ingestion of gluten, either deliberate or inadvertent, causing persistent inflammation in the small-intestinal mucosa (12, 13). These observations are supported by the results of this study indicating a significant improvement in the intestinal architecture in the placebo group after 3 months merely as a result of strict monitoring of the diet to avoid any gluten consumption. Despite the wide individual variability noted in the current study, the overall response was that ingestion of 50 mg gluten/d for 3 months was sufficient to cause a significant decrease the small intestinal villi. Because of a limited number of patients, the study was unable to reach firm conclusions about the potential toxicity of 10 mg gluten/day. Additionally the quality of the gluten ingested may alter the type of intestinal inflammation and hence could not be factored into this study.

This study concludes that abnormal small bowel cellular changes persist in a significant proportion of CD patients being treated with a GFD, most likely because of the persistent ingestion of trace amounts of gluten. The dedicated intake of 50 mg gluten/day produced significant damage in the architecture of the small intestine however, the sensitivity to trace intakes of gluten showed large inter-patient variability, a feature that should be addressed in future studies. This is all of extreme importance as it has been thought that long term gluten exposure in those with CD may result in intestinal cancers. The authors wisely suggest that these multiple factors require further clarification. The take home message is that the determination of "safe" levels of gluten ingestion have not yet been established and therefore it should be recommended that strict adherence to a gluten free diet for all patients with celiac disease be continued.

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*All APGNN members are invited to develop a future article submission for either “**Disease Information**” or “**Medication Update**”. These new recurring columns will be a great opportunity to share your knowledge and/or develop your writing skills. Please contact your Newsletter Committee Chairperson for more information:*

Robin Shannon
rspnp@comcast.net

CALL FOR ABSTRACTS

*If you are interested in submitting an abstract for our Annual Meeting in Salt Lake City, please contact: **Lynn Mattis** lmattis@jhmi.edu or call her at 410-955-9166*

Deadline for submissions: August 1, 2007

Abstracts submitted may summarize clinical outcomes research or unique case study experiences (“Clinical Research” or “Clinical Vignette”

Please contact Lynn for important information including guidelines for submission and abstract submission forms

COMMITTEE REPORTS

MEMBERSHIP COMMITTEE

If you have any questions about membership or becoming a member, please contact Membership Committee Chair, **Lisa Philichi** at Lisa.Philichi@multicare.org Please make sure to contact Lisa if any of your contact information changes so that you continue to receive important information from APGNN. When updating your membership profile, please list only 2 professional titles to help keep our information stream-lined.



APGNN Welcomes New Members

Lorileen Bautista, CPNP	Willow Grove, PA
Vance Coleman, RN, BSN	San Francisco, CA
Jodi Klekotka, CPNP, APRN	Hartford, CT
Kristin Philipp, MSN, APRN	Hartford, CT
Kimberly Ritenour, CPNP	Richmond, VA

PROGRAM COMMITTEE

SALT LAKE CITY, OCTOBER 2007

The theme for the 2007 Salt Lake City APGNN meeting is “Working Towards Adherence”. The agenda for the course is almost set and it is shaping up to be an informative and exciting conference. Confirmation letters have gone out to speakers and once we get all information back we will be applying for CEUs via SGNA. We are applying for funding from different sources for speakers not already attending the conference. Any APGNN member interested in presenting a ZEBRA should contact Lindsay Wilson at: lwilson@jhmi.edu

CLINICAL PRACTICE COMMITTEE

We are happy to say that since the last newsletter we were able to recruit a new member for the committee. We hope that this will encourage others to join us so that we can create new clinical guidelines. One of the objectives of this committee is to encourage, support and guide any member who wishes to submit a **clinical vignette**. Each year we are amazed with the expertise & creativity of the submissions. If this interests you, we can facilitate your submission!

A few examples of previous topics: G-tube Complications; LFT reduction with decreased BMI and Lymphopenia & Fever with IBD & 6-MP. Members of this committee have also suggested a good article that may help & guide you in this process: “Call for Abstracts: Are You Ready?” by JoAnne M. Youngblut & Dorothy Brooten, Journal for Specialists in Pediatric Nursing, 12 (2): 115-118, April 2007.

These are just a few tools that might facilitate the process. Another suggestion that might be available is if anyone has already submitted in the past and wants to help guide new submitters please feel free to volunteer your services.

With all of this, we are looking forward to receiving your submissions in preparation for the next Annual Meeting in Salt Lake City!

Helene Bacha, Bsc.N.CGN (C)

Chair, Clinical Practice Committee

helene.bacha@muhc.mcgill.ca

FAMILY RESOURCES

At your fingertips! The Public Education Committee is delighted to report that there are now **50** Patient/Family education brochures on the newly designed, easily navigated NASPGHAN website. The majority of these brochures are available not only in English but also Spanish, French and Portuguese. Thanks to the efforts of Kevan Jacobson and his 2005-2006 Committee, **7 new brochures** were recently approved & posted: ***Breast feeding, Eosinophilic Esophagitis, Fundoplication, Healthy Eating, My Child is Overweight, NASH and Nutrition & CF.*** One additional brochure, Autoimmune Hepatitis, is in development. Please take a few moments to check this Family Resource Center: the link is highlighted by a family picture on the new NASPGHAN Home Page. A BIG thank you to those responsible. The Committee will soon be exploring ways to better GET THE WORD OUT about these valuable resources. We welcome all ideas from Membership (e-mail the Committee Chair at addie.mcduffie@chkd.org)

Currently, the Public Education Committee is focusing on assuring that the large numbers of education brochures now available remain current. A 3-year review cycle has been initiated. We anticipate adding Publication/Revision dates to each brochure. Content experts from NASPGHAN membership will be asked to assist us in this important endeavor. We thank you for your time and expertise!

At the upcoming DDW Meeting, we will be discussing ways to collaborate with the National Digestive Diseases (NIDDK) Information Clearinghouse in developing materials and providing access. How best to assure strong collaboration with the Clinical Practice Committee and CDHNF will also be explored. One joint venture with CDHNF is already under consideration: securing funding to develop an educational video on G-Tube Feeding.

In closing, on behalf of myself and *all APGNN* members, I thank Phil Sherman, John Barnard and the Executive Council for the privilege and opportunity to Chair this Committee.

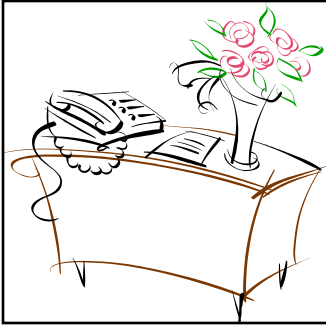
Addie McDuffie, MS, CPNP

APGNN representatives on the NASPGHAN Public Education Committee are Karen Sherry & Lillian Sablan.

Resource for Transplant Patients & Their Families

Camp Sunshine on Lake Sebago in Casco, Maine, is a camp for children with life-threatening illnesses and their families. The camp offers over 30 sessions throughout the year, when families can come and just have fun in a beautiful full service camp. Among many of the benefits of this camp are that it is free and it is for the whole family so parents and siblings have the opportunity to enjoy themselves too. The camp has a solid organ transplant session every year, as well as a mixed diagnosis session. If you care for families where a child has had a liver or small bowel transplant, consider referring them for this wonderful experience. For more information check out the camp website at www.campshine.org or contact Jennifer Cavage, family coordinator for Camp Sunshine at 207-655-3800.

FROM THE EDITOR



PLEASE REMEMBER: This is YOUR newsletter!! Contact me if you would like to “publish” an article or contribute in any way. We are always looking for new ideas and perspectives!

Robin Shannon, Newsletter Committee Chair

Isn't it time YOU considered serving on the Board of APGNN?

*Please consider taking a more active role by nominating yourself or a peer for the upcoming 2007 elections. Offices this year that need to be filled are: **1) Treasurer***

2) Patient/Family Education Committee Chair

3) Research & Publications Committee Chair

Kindly contact **Addie McDuffie at 757-668-9793** or addie.mcduffie@chkd.org



APGNN Executive Board & Committee Contacts

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rjyoung@tconl.com

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APGNN Excellence in Mentoring Award Guidelines for Submission/Evaluation

Deadline for submission of nominations: August 31, 2007

Purpose

The mentor award was established to honor mentors of APGNN members who support nursing excellence and professional development; to identify role model mentors; to heighten awareness of the need for mentoring; and to encourage broader mentoring participation in pediatric gastroenterology and nutrition.

Eligibility

Served as a mentor to an APGNN member during the past 36 months

Submission Criteria-All nominations must include

- ❖ Two-page (typed, approximately 250 words) letter of nomination that enumerates the ways in which the mentor reflects the purpose of the award; fostering your career development through scholarship, teaching and advocacy
- ❖ Curriculum vitae of nominee
- ❖ Your name and contact information

Award Process

Award to be determined by current APGNN Board/Committee Chairpersons. The recipient will be awarded a commemorative plaque or certificate and a check in the sum of \$250.00 during the annual APGNN meeting to be presented by his/her nominating APGNN member.

Criteria Used In Evaluating Nominees

- ❖ Respects goals and assists in professional development; inspires, encourages, supports essential strategies for life success
- ❖ Actively guides and assists with clinical work, research and/or education; articulates and encourages high standards
- ❖ Accessible for advice and assistance; takes time to ensure guidance is provided
- ❖ Actively seeks financial or other support for education, research or clinical activities
- ❖ Actively involves APGNN member in clinical, educational and/or research activities
- ❖ Actively involves APGNN member in professional conferences and/or publications
- ❖ Provides assistance to overcome problems or barriers to ongoing professional development
- ❖ Helps to 'network' with other relevant professionals
- ❖ Alerts to career opportunities; helps secure and/or advance employment opportunities
- ❖ Is a strong advocate for pediatric GI/nutrition nurses

- ❖ Provides excellent model of professionalism