APGNN
The Association of Pediatric Gastroenterology and Nutrition Nurses

March 2008

Volume 18 Issue 1

President's Message

Groundhog's Day, February 2, 2008

Well, Punxsutawney Phil says six more weeks of winter! I know some people aren't pleased to hear that news but in New England having only six more weeks of winter doesn't sound too bad. Thinking of spring and summer, I want to call your attention to the abstract submission deadline of, March 31st, 2008, for The Third World Congress of Pediatric Gastroenterology, Hepatology and Nutrition, WCPGHAN3. It will take place at Iguassu Falls, Brazil, August 16-20th, 2008. Please visit the website and view the program for the Multiprofessional Congress http://www.wcpghan2008.com/index.php . Regrettably, due to the world congress we are not having our annual APGNN meeting. I realize going to Brazil is not a realistic option for the majority of our members but if you will be attending, please let me know ahead of time so we can plan to get together.

Last month, as your representative, I attended CDHNF (Children's Digestive Health and Nutrition Foundation, the research and public awareness arm of NASPGHAN) and NASPGHAN's winter business meetings in Fort Lauderdale Florida. It was very apparent that the members of NASPGHAN and CDHNF truly value our experience and perspective. They are eager to have APGNN representation on their subcommittees. As you know, Addie McDuffie is co –Chair of the NASPGHAN Family Education Committee. Recently other APGNN members joined some of the scientific advisory committees (SAB). Deborah Whitehurst and Millie Boettcher (APGNN Clinical Practice members) serve on the IBD committee. Dee Galacki (APGNN Patient and Family Education committee member) is on the Hepatitis committee. Marge Friedhoof (APGNN Patient and Family Education committee member) just joined the GERD committee. On behalf of all the other APGNN members, I want to say thanks to Millie, Deborah, Dee and Marge for volunteering to participate in the scientific advisory committees (SAB) of CHDNF. Their involvement helps APGNN fulfill its mission by promoting the recognition of pediatric nurses as experts in their field while promoting excellence in the care of families with children with Gastroenterology/Nutrition illness. I have already heard from Dr. Bousvaros, chair of IBD committee, that the addition of Millie and Deborah has been a great asset. If you are interested in participating sometime in the future, please join the APGNN Clinical Practice committee or the Patient and Family Education committee so you will be kept abreast of any future opportunities. (cont. pg 2)

President's Message Continued

I'm pleased to report that the plans for the APGNN CDHNF research grant are moving right along and I hope that at this time next year some of you will be submitting your research grant applications. So get your research hats on because it's never too soon to start planning! I'll tell you more about the grant in the near future.

CDHNF and NASPGHAN are holding a special conference on Wednesday, November 12 through Saturday, November 16, 2008 in San Diego, California to celebrate the 10th anniversary of the founding of CDHNF. Although we are unable to hold a full APGNN meeting, we will hold an APGNN leadership retreat during that time. If there is interest and room available we may organize focus groups during this meeting. The APGNN executive board will be discussing this during their next conference call.

On the final note, our APGNN secretary, Kristin Peterson has been invited to be a speaker for SGNA's March conference as an APGNN member. She will be teaming up with a dietician to give a presentation on celiac disease. The audience will include both adult and pediatric gastroenterology nurses. She plans to tell them about APGNN and distribute our APGNN fact sheet. This is a great opportunity to increase professional awareness of our organization. Don't miss an opportunity to do the same when you're invited to give presentations, let the audience know you belong to APGNN and spread the word! It is my hope that APGNN remains active throughout the year, not just at our annual meeting.

Mary-Alice Tully

President APGNN

Membership Committee Report

APGNN Welcomes New Members

Janis Arnold, SW	Boston, MA
Karen Avant, RN	St Louis, MO
Tricia Curley, RN	Denver, CO
Thomas Fay, RN	Iowa City, IA
Dolores Galacki, RN	Boston, MA
Catherine Ortscheid, PNP	Marshfield, WI
Sue Weides, RN	Park Ridge, IL

Past President's Report

2008 APGNN ELECTIONS:

Seeking APGNN Members willing to become involved in this exciting and growing organization. Please consider sharing your time and expertise by nominating yourself or a peer for the upcoming 2008 Elections for:

Secretary
Clinical Practice Committee Chair
Membership Committee Chair
Newsletter Committee Chair
Program Committee Chair

Contact Addie McDuffie at addie.mcduffie@chkd.org or call 757-668-9793 for more information.

Program Committee Report

The Program Committee will begin planning for the 2009 conference in the Fall. Look for updates in the September Newsletter.

Patient and Family Education Committee Report

We want to welcome our newest members:

Susan Miller at susan.miller@echmc.org; Leah Bowers at LNBowers1128@yahoo.com; Beverly Gursky at bsgursky@aol.com; Marge Friedhoff at mfriedho@mcw.edu; Tricia Curley at tkcwyo@yahoo.com.

Two brochures that we have reviewed and edited for the Public Education Committee were Inflammatory Bowel Disease and Ulcerative Colitis.

Communication has been sent to members to submit their suggestions on development of Feeding Tube Brochures.

Respectfully submitted,

Lillian Sablan and Karen Sherry

Congratulations to Paula Stanley 2007 Winner of the APGNN Excellence in Education Award Recognizing Educational Programs of Distinction Sponsored by TAP

Paula received the Excellence in Education Award at the Annual Meeting in Salt Lake City last year. Here is an overview of her educational program of distinction.

The purpose of this project is to provide simple information pamphlets to patients and parents in the Gastroenterology Department of Children's Hospital of Pittsburgh of UPMC who require a procedure to diagnose and plan treatment for their medical condition. Pamphlets were created for common Gastroenterology procedures including: colonoscopy, esophagogastroduodenoscopy, capsule endoscopy, liver biopsy, and PH probe testing. The goals of the project were to:

1. Increase compliance with pre procedure preparation
2. Decrease the number of patients requiring rescheduling
3. Provide patients and their family's clear expectations of their experience during their procedures.
4. Improve patient and family education and understanding of various procedures.

This project was launched to meet the educational needs identified by families and recognized by the staff regarding patient procedures. A significant number of phone calls from confused parents were received regarding preps for the colonoscopy procedure. Procedures were often cancelled due to inadequate preps, required rescheduling, and even hospital admissions to successfully complete a clean out that could easily be performed at home. The pH probe study patients' confusion was in the time and date of the procedure as well as not following instructions about their antacid medications. Coming late would cause the patient to miss their prescheduled appointment in radiology for placement verification of the pH probe. Valuable OR and radiology time was being lost due to cancellations and rescheduling issues all stemming from poor patient and family education and communication.

APGNN Excellence in Education Award Continued

Educational sheets were developed thoroughly explaining each Gastroenterology procedure along with what the family should expect the day of the procedure. The colonoscopy and pH probe procedures were specifically addressed although other common procedures were included in the project as well (EGD, capsule endoscopy and liver biopsy).

The procedure education pamphlets were placed in every exam room in the Gastroenterology clinic as well as in the waiting area with other educational information, readily accessible for parents and patients. Physicians and Nurse Practitioners were asked to distribute the pamphlets to patients and families if the decision was made to have a procedure. The medical assistants were also asked to give the pamphlets upon discharging patients if a procedure was ordered. To again ensure that families obtained the educational material, the secretary who schedules procedures would ask parents if they had received the pamphlet. If they did not, the secretary would mail the information to their home. Compliance with the procedure instructions was then calculated and compared with previous months.

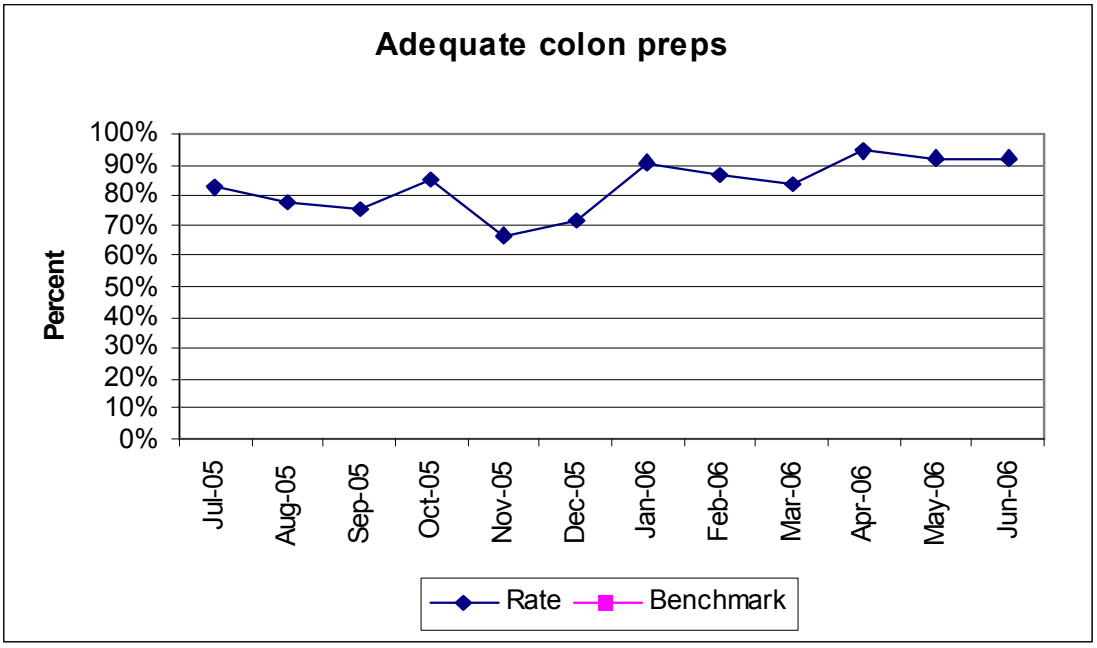
As noted previously there were two procedures that compliance issues impacted on our daily schedule. As part of the hospital quality improvement, we chose to track quality indicators to quantify the adequacy of the outpatient colonoscopy preps, and the completion of pH probe studies from July 2005 -June 2006. Our results are depicted below:

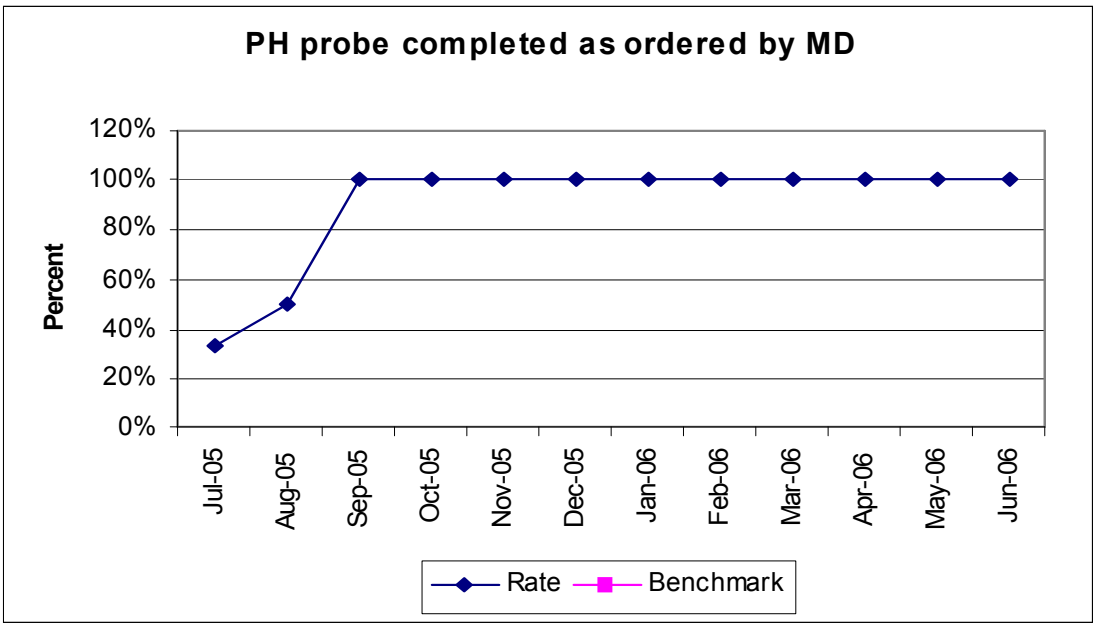
Specifically ,our outcomes are the following:

1. From July 2005 to June 2006, there is an upward trend from 78% to 93% adequate colon preps, which has resulted in an overall 15% increase.
2. From July 2005 to June 2006, a significant increase from 33% to 100% of ph probe test completion as ordered by physician.

While this small study only addressed patient compliance with clean out preparations and instructions prior to a pH probe, the educational material provided to patients and families provided valuable information regarding the procedure. While physicians discuss the procedure at length, the patient and family are often overwhelmed and don't recall what had been said. The accurate and easy to read pamphlet provided them with information that could be accessed at their leisure.

APGNN Excellence in Education Award Continued





What's in a Name? A Short History of Crohn's Disease

By: Clare Ceballos, MA, APRN-BC, PNP, WOCN

Crohn's disease is named for a Mount Sinai Hospital physician, Burrill B. Crohn, who along with his colleagues Gordon D. Oppenheimer and Leon Ginzberg, first described a series of patients with regional ileitis in 1932. However, their work was predated by several earlier observations and case series.

In 1612 Gullielmus Fabricius Hildenus recorded an autopsy finding of a boy who had suffered with subhepatic pain. He noted that the boy's cecum was contracted and invaginated into the ileum and that upon extracting the cecum, it was ulcerated and fibrous (1). Similar reports at autopsy continued to be made in the next century, including further autopsy descriptions by Giovanni Battista Morgagni in 1769, detailing an illness with intestinal inflammation and abdominal mass, which was a different entity than syphilis, actinomycosis or tuberculosis. In 1806 Coombe & Sanders reported what is widely regarded as the first case of Crohn's disease to the Royal College of Physicians in London. In 1823, John Abercrombie, a physician who worked from 1804 as a general practitioner in Edinburgh, Scotland, documented 144 cases highlighting differences between ileal and colonic disease. He was most likely recording Crohn's disease and ulcerative colitis. In addition to his general practice, Dr. Abercrombie was also a skilled pathologist and published a book in 1827 entitled "Pathological and Practical Researches on Diseases of the Stomach, the Intestinal Canal, the Liver and other Viscera of the Abdomen" (2).

One of the earliest descriptions of what we would call Crohn's disease was made by a Scottish surgeon, Thomas Kennedy Dalziel, in 1913. Dalziel was trained in surgery and pathology and in 1891 he joined the staff of the Royal Hospital for Sick Children in Scotland. His observations, of thirteen patients, were published in the British Medical Journal in 1913 (3). He noted on autopsy that these patients had disease involving the jejunum, mid ileum and transverse and sigmoid colon. Histology showed transmural inflammation, submucosal edema, multiple eosinophils and scattered giant cells.

Further progress was made in describing this disease entity by two physicians, from Mount Sinai Hospital in New York, Eli Moschcowitz and Abraham Wilensky. In 1923 (4) they reported a series of four patients, who developed an abdominal mass and obstruction after an episode of "acute appendicitis". The surgical specimens were all characterized by presence of multiple giant cells leading the two to conclude that granuloma of the intestine was a different entity than tuberculosis. Also at Mount Sinai Hospital Leon Ginzberg and Gordon Oppenheimer cared for another twelve patients also with distal ileal disease that could not be attributed to amebiasis, syphilis, actinomycosis or intestinal tuberculosis. These physicians were joined by Burrill Crohn who in 1930 was caring for a teenage brother and sister with fever and right sided lower abdominal mass. Since all these physicians were working at the same hospital they were encouraged by the hospital pathologist, Paul Klemperer and the surgeon who had operated on all the patients, A A Berg, to coauthor work describing their experience with these patients. (continued on page 8).

What's in a Name? A Short History of Crohn's Disease Continued

The work of Crohn was predated by many previous observations and case series. If Dr. Berg had opted to be included in the original paper, with its alphabetical listing of authors, Crohn's may have been Berg's disease; and if Dalziel had presented his paper at a time when Europe was not in the throes of starting World War I, he may have credited with Crohn's disease too.

References:

1. Kirsner JB. (1997). Crohn's disease: yesterday, today and tomorrow. Gastroenterology 112: 1028-1030
2. Abercrombie J (1827). Pathological and Practical Researches on Diseases of the Stomach, the Intestinal Canal, the Liver and other Viscera of the Abdomen. Edinburgh, Waugh & Innes
3. Dalziel TK. (1913). Chronic intestinal enteritis. Br Med J 2: 1068-1070
4. Moschowitz E, Wilensky AO. (1923). Nonspecific granulomata of the intestine. Am J Med Sci 166:48-66
5. Crohn BB, Ginzburg L, Oppenheimer GD. (1932). Regional ileitis: a pathological and clinical entity. JAMA 99: 1323-1329

Questions and Answers about the World Congress Conference

One APGNN member had the following questions about the 2008 conference:
"I understand the world congress is in Brazil. I am interested in sending a vignette or case study poster but am unsure if APGNN will be represented. The deadline for abstract submission is 2/28/08. I don't understand if I submit to NASPGHAN website or via APGNN. I would also like to know if APGNN is meeting in Brazil."

Due to the world congress, we are not having our usual APGNN meeting. However there will be a 'Multi-professional Congress'. Please visit the website and view the program for the multi-professional congress http://www.wcpghan2008.com/index.php and also note that the abstract submission deadline is now listed as March 31st, 2008. You should submit your abstract directly to "The 3rd World Congress of Pediatric Gastroenterology, Hepatology and Nutrition" website.

Good Luck to all APGNN members planning to go to Brazil!

Pediatric GI List Serve

A Google (trademark) Groups account has been set up for pediatric GI nurses and other health care providers to utilize in sharing information or making inquiries into care practices. Some recent examples of postings are: what practice are other institutions doing for NG tube verification? How are others educating patients/families on Humira administration. This list serve provides the opportunity to obtain info from the very people who are at the leading edge of determining best practices. However, it only works if it is being utilized. So…we encourage all APGNN members to join and see how it works for each of you.

In order to utilize this resource an individual has to set up a personal Google account (there is no charge to this). Once you set up your account you can make adjustments to how you receive (if any) notifications of postings by members. These notifications can go to any email account you choose. The name of the group is APGNN Peds GI Nurse and currently there are 44 people who have created accounts.

To create your account go to http://groups.google.com/group/apgnn-peds-gi-nurse. Once on the site you will need to create your own Google account (there is a prompt to do this on the page). Some tips for creating the account: Your email account that you list is where any notification will be sent. Your password is needed to access from other sites, but you can tell it to remember you on the computer you register (do this only if it is your primary computer you utilize). The nickname is the name that will appear on any posting to people so "be friendly".

Once the account is set up you will then be able to view the posting list for any activity on the site. You can adjust your notification setting by going to "edit my membership" tab. If you want to post an inquiry there is a tab that says "+new post" . A text box will appear for you to send your message. This sends it to anyone currently on the list. If you receive an inquiry notification via email, please note, YOU CAN NOT REPLY TO THIS EMAIL FROM YOUR PERSONAL EMAIL ACCOUNT. In order to reply, you need to log into your google groups page and click on the posting and reply accordingly.

Please note: currently this account is set up that anyone can join. Thus, it is also open to advertisement and job search postings. At some point the discussion may need to occur that we make the join invite only (which means that a member has to send an invite to someone). This will then minimize the number of unwanted people who come across this account on the web and join "just for fun".

Good luck and I hope everyone finds the list serve helpful and informative. If you have any questions or if you are having any difficulty setting up your account, feel free to contact ***Deb Wallner at dwallner@chw.org.***

Pediatric GI Zebra

A 17 year old Caucasian female presented to the clinic on August 27, 2007, with a four week history of fatigue, arthralgias, mylagias, low grade fevers and intense pain in her wrists, fingers, ankles, legs and knees. She was having trouble walking as well as holding her cell phone due to the intense pain. Her mother reported a 10 pound weight loss over the past month before presenting. She experienced some nausea and anorexia but no vomiting. She had a recent history of Chlamydia diagnosed one week before her GI visit that was treated with high dose Azithromycin. She also had her HPV vaccination 3 weeks before this visit at which time her ALT was 167 and AST 117. Zoloft 50mg was started 6 weeks before presenting and 2 weeks before her arthragias and myalgias began.

She had not been able to go to school due to her symptoms. She spent every day in bed and was becoming weaker. She had several visits with her PCP and extensive laboratory analysis before she was referred. Because of the obscure symptoms and elevated LFT's as noted above, more laboratory work-up followed. Infectious hepatitis studies for A,B, and C were negative, a monospot was negative, HIV nonreactive, hemoglobin, WBC and platelets normal, CMV and EBV titers were negative. The follow-up liver panel completed 5 days before the GI visit revealed an albumin that was low at 3.2 (range 3.7-5.1) but globulin, bilirubin were normal, ALT was 196 and AST 140. Subsequent labs drawn 3 days before our visit revealed a liver panel with ALT at 1124, AST at 1177, alk phos 207, total bili 1.4 (range 0.2-1.3) direct bili 0.5 (range 0-0.3), albumin 3.2 (unchanged), CRP normal, CBC essentially normal, INR 1.1, negative PPD, Ultrasound with Doppler studies 2 days before visit shows mildly prominent spleen at 13.4 cm otherwise normal.

Medications: Zoloft discontinued at visit on 8/27/07, no OTC or herbal remedies, no alcohol for 4 weeks.

Past Medical History: Unremarkable except for mood swings, Zoloft started recently (mid July/07).

Personal/Social History: Senior in high school, uses alcohol on weekends but uncertain of the amount, sexually active no barrier method in place, recently started on birth control in the beginning of August.

Physical: 99.1, 103, 20, 99/63, BMI at the 10th%

Dermatologic examine no rashes, no spider angiomata or petechiae

Sclera nonicteric, no thyromegaly

Cardiovascular/Pulmonary exam unremarkable

Abdominal exam nontender, nondistended, no ascites, organamegaly, or masses

No visible swelling of joints, clubbing, cyanosis, or edema

Further labs at GI visit:

A1 Antitrypsin Phenotype: MM value:192 (100-200 normal range)

ANA: negative, ANA IgG: detected

Anti Smooth Muscle Antibody: 1:80 (<1:20 normal)

Anti Liver Kidney Antibody: 0.7 (0-20 negative)

Anti Mitochondrial Antibody: 0 (0-0.9 normal)

Serum Protein Electrophoresis: Unremarkable except slightly low albumin

Copper/Ceruloplasmin: Negative

Acetaminophen level: <1

Pediatric Zebra Continued

Ion, TIBC, Iron Saturation: normal

Beta HCG: Negative

CMP: Lytes, BUN, creatinine normal, Albumin 3.2, Globulin normal, Indirect bili 1.6 (0-1.1), Direct bili 0.6, Alk Phos 338, AST 1367, ALT 1372

CBC: WBC 6.2, HGB 11.4 (12-15.6), Platelet 287

UA: Normal

Sed Rate: 10 (0-20)

Celiac Markers: Negative

Liver Biopsy: Chronic hepatitis with moderate inflammatory activity (Grade 3) with lymphoplasmacytic infiltrate and no bridging fibrosis

(Stage 1)

LFT's elevated in a Hepatocellular Pattern

Differentials: Autoimmune hepatitis(AIH) (low level ANA titer detected and positive smooth muscle antibody), drug or toxin induced hepatitis related to Zoloft, HPV vaccine, high dose Azithromycin, infectious hepatitis (negative A,B,C, CMV, EBV), Wilson's Disease (negative ceruloplasmin, copper), hemachromotosis (normal iron studies), less likely primary biliary cirrhosis or primary sclerosing cholangitits because only slightly elevated bili and alk phos.

Final differential after second opinion with Hepatologist:

Drug induced hepatitis was high on the list because just by discontinuing the Zoloft, the LFT's started to trend down. Drug induced hepatitis can give similar findings to that seen on her liver biopsy. However, Zoloft is noted to cause arthralgias and hepatitis in less than 1% of cases but can produce an autoimmune hepatitis-like picture.

AIH is also likely because of a positive ANA titer and smooth muscle antibody. However, given the fact that the ANA titer was only slightly elevated and with normal globulin levels this made the diagnosis of AIH less clear. But her presentation and age favored AIH. The liver biopsy showed plasma cell infiltration consistent with AIH and no features of cholestatic disease.

Clinical Course: It was decided that Autoimmune Hepatitis was the more likely diagnosis for this patient. She was started on Prednisone and Immuran. Her LFT's trended downward for the next several months. On October 29, at her follow-up visit the ALT, AST, Alk Phos and bili were normal. By November 15, her Prednisone was discontinued and she remains on Immuran. Last LFT check on Jan 30, 2008 showed all LFT values to be within normal range. Her arthralgias/myalgias, fevers and anorexia have resolved without subsequent reoccurrence.

Autoimmune hepatitis can be triggered by viral, drug, toxic, or environmental agents. Most cases have no identifiable trigger. Forty percent of cases have an abrupt onset with fulminate presentation more likely in younger people. Type 1 AIH is characterized by smooth muscle antibodies and antinuclear antibodies, and is the most common type in the US. It is more common in females with a ratio of 3.6:1. All ages can be afflicted. Often patients with AIH have other autoimmune disease processes with thyroiditis being the most common.

Common symptoms at presentation include fatigue (85%), jaundice (46%), myalgias (30%), frequent physical findings hepatomegaly (78%), increased ALT/AST (100%), increase globulin (90%), mild hyperbilirubinemia <3 (83%), positive ANA, ASMA, LKM1 (87%).

Editor's Note

Happy almost Spring!! Being in Nebraska, I have to be optimistic despite what Punxsutawney Phil says.

First I want to start by thanking everyone that submitted material for this edition of the APGNN Newsletter. I am thrilled that we have so many members who are willing to share their expertise with other members. We will continue to contact members and ask for their support in this way. We will also be interviewing members about hot topics and publishing the transcripts. What an exciting way to keep up to date on the latest happenings in our specialty. Be prepared to be contacted in the future. If you can identify someone that you think would be appropriate to interview, contact me at kocovskyd@boystown.org so I can approach them. Look for the next edition of the newsletter in June. Until then, think Spring!

Diane Kocovsky

Newsletter Committee Chair

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