



The American Neurogastroenterology and Motility Society Newsletter-April 2008

Message from ANMS President: Henry Parkman, MD

Recent 2008 ANMS Clinical GI Motility Course

Elated! That is how I felt during our recent 2008 ANMS Clinical GI Motility Course held February 29 to March 2, 2008. This was our fourth Biennial Course in Gastrointestinal Motility. Each one has gotten better and better, thanks to the ongoing efforts of Richard McCallum and Satish Rao. Taking into account the comments given by the previous years' participants, separate breakout sessions were held for nurses/medical assistants and physicians. For the nurses, GI motility procedures were demonstrated. For the physicians, there were case-based discussions. What a successful meeting! The 337 registered participants interested in GI motility included 134 physicians, 45 GI Fellows, 86 nurses, and 72 medical assistants. The reviews are in from the participants, and the overall quality of the program was considered excellent. The exhibitors thought this course was thriving – allowing interaction of their group with the participants. At this course, we unveiled our Auxiliary Membership category for Nurses and Medical Assistants.

Future Specialized Meetings

Our next ANMS scientific meeting will be the 2008 Joint meeting November 6-9, 2008 in Lucerne Switzerland. Our ANMS representatives on the program committee, Gianrico Farrugia and Jay Pasricha, helped to plan this meeting with the other societies and groups. The European Society of Neurogastroenterology and Motility (ESNM) is the host sponsor for this second joint society meeting. The abstract deadline is June 20, 2008.

Plans are underway for the ANMS/AGA Workshop on Gastroparesis and Functional Dyspepsia. This symposium will be held January 15-17, 2009 to be held in Orlando, Florida. This meeting is being organized by our AGA Nerve Gut officers, Gianrico Farrugia and Emeran Mayer.

ANMS Research Grants

This year the ANMS invites members to submit Clinical & Basic Science Research Proposals on the area of <u>Esophageal Motility</u> and <u>Esophageal Disorders</u>. Applications are intended to support work up to \$30,000 that will contribute to development of data to support applications for extra mural funding and career development, especially our younger members. **Application deadline is July 1**st, 2008.

Succession

On a final and personal note, I am going into retirement! No, not from research or clinical practice. In November 2008, I will be stepping down as President of our society. At the Joint Meeting in November 2008, I will be turning over the torch to Michael Camilleri, MD who will be our new president. We are in great hands! Onward and upward!

Upcoming Meetings:

Digestive Disease Week. May 17-22, 2008. San Diego Convention Center, San Diego, CA. Visit our ANMS Booth #4446 in Foundation Row.

American Gastroenterological Association

Advancing the Science and Practice of Gastroenterology

native of distributions,

Sixteenth International Workshop on Electrogastrography



(EGG). May 21-22, 2008 in San Diego, CA. This meeting brings together physicians and basic scientists who share a common interest in EGG, electrical stimulation of the gut for gastroparesis and obesity, gastric motor dysfunction.

Symposium on Esophageal Pain - Friday May 16, 2008 UCSD Moores Cancer Center Auditorium in San Diego, CA. Organized by Ravinder Mittal MD. For information contact Dr R.K. Mittal at mittal@ucsd.edu or Jennifer Wan at jiwan@ucsd.edu

8:00 am: Introduction: Heartburn and Esophageal Pain -Scope of the Problem -John Dent MD, PhD

Basics of Pain

8:30 am Nature of the Pain Receptors -Ashley Blackshaw PhD.
9:00 am Vagal and Spinal Pathways of Esophageal Pain -Raj Goyal, MD
9:30 am Central Mechanisms of Pain Amplification-Emeran Mayer, MD

Stimuli Leading to Pain

10:15 am Biomechanics of Esophageal Sensation–Hans Gregersen MD, PhD 10:45 am Longitudinal Muscle Contraction, TLESR, Reflux & Pain - Ravinder Mittal MD

11:15 am Role of Esophageal Mucosa in Heartburn and Chest Pain - Roy Orlando MD

11:45 am Role of Neutral Reflux (weakly acid or alkaline) in Typical and Atypical Esophageal Symptoms - Daniel Sifrim MD, PhD 12:15 pm Non-Erosive Reflux Disease, Functional Heartburn & Chest Pain –What is it? Ronnie Fass MD

Mechanisms of Sensitivity and Hypersensitivity

 $1:\!30~\mathrm{pm}\,$ Mechanism and Peripheral Stimuli of Visceral Pain – Sushil Sarna PhD

2:00 pm Molecular Pathways and their Sensitization- Jay Pasricha MD 2:30 pm Sensitization of the Spinal and Cortical Pain Pathways: Qasim Aziz MD PhD

3:00 pm Cortical Pathways of Pain -Reza Shaker MD

${\it Diagnosis~\&~Management~of~Esophageal~Pain}$

3:45 pm Diagnostic Strategies for Esophageal Pain - Peter Kahrilas MD

4:15 pm How to Treat Esophageal Pain – Satish Rao MD, PhD.

4:45 pm Drugs on the Horizon for Esophageal Pain - Anders Lehman PhD

2008 Joint International Meeting in Neurogastroenterology





and Motility will be held November 6-9, 2008 in Lucerne Switzerland. ESNM are the host sponsors for this 2nd meeting of the American Neurogastroenterology and Motility Society, Functional Brain-Gut Research Group, European Society of Neurogastroenterology and Motility, International Group for Neurogastroenterology and Motility. Abstract deadline is June 20, 2008.

Welcome to Lucerne, Switzerland

Joining forces in the field of neurogastroenterology and motility, the American Neurogastroenterology and Motility Society (ANMS), the European Society for Neurogastroenterology and Motility (ESNM), the Functional Brain Gut Research Group (FBG) and the International Group for the Study of Neurogastroenterology and Motility (ISNM) decided to continue the successful model of joint international meetings and chose Switzerland to host the 2nd Joint International Meeting. The Neurogastroenterology and Motility 2008 meeting will take place in Lucerne, Switzerland on November 6-9, 2008.



The convention center (Kultur- und Kongresszentrum am See Luzern), a modern architectonic masterpiece built by the architect Jean Nouvel opened its doors in 2000 and is perfectly integrated in the famous picturesque city of Lucerne in the centre of Switzerland.



The Scientific, Steering and Local Organizing Committees put together an exciting and comprehensive program covering major topics from bench to bedside emphasizing the exchange of ideas between basic researchers and clinicians. In addition to the established topics of gastrointestinal dysfunction, sensitivity and sensation the program includes plenary sessions on the stress response and the bowel, feeding and weight control and new topics in inflammation and allergy. Furthermore, presenters will

detail recent progress in understanding the role of gasomediators, development and neuropharmacology of the enteric system and conditioned gastrointestinal disorders.

In order to encourage interactions between experts and young investigators, ample time slots have been reserved for poster sessions. Complementing the core program, satellite symposia will provide our partners from the industry opportunities to present latest developments and directions of future research.

Participants are the most important part of any successful meeting. The NGM 2008 faculty includes well-renown opinion leaders in our field. The abstract submission site is open (www.ngm2008.com). Both basic scientists and clinicians are invited to submit abstracts for presentation at NGM 2008 by June 20, 2008.

We are looking forward welcoming you in Lucerne Michael Fried Mark Fox Radu Tutuian

2008 ANMS Satellite Symposium at the Society for Neurosciences meeting, November 14, 2008 to be held in

Washington, DC. This symposium will emphasize "Neurogenic



Inflammation and Visceral Pain," and will cover the evolving areas related to the interaction between inflammatory mediators and the enteric nervous system and implications on mechanisms of visceral pain and pain pathways. For additional

information on the program, visit the ANMS website http://www.motilitysociety.org

ANMS/AGA Workshop on Gastroparesis and Functional **Dyspepsia January 16-17, 2009.** This symposium, proposed by



the ANMS to the AGA, will be a joint symposium by the AGA and ANMS and will is cosponsored by the FBG and the Gastroparesis and Dysmotilities Association (GPDA). Organized by Gianrico Farrugia and Emeran Mayer. Stay tuned!

American Gastroenterological Association Advancing the Science and Practice of Gastroenterology

Publications from the ANMS

Consensus Recommendations for Gastric Emptying

Scintigraphy. This consensus statement from members of the American Neurogastroenterology and Motility Society and the Society of Nuclear Medicine was jointly published in the Journal of Nuclear Medicine Technology (2008;36:44-54) and the American Journal of Gastroenterology (2008;103:753-63) in March 2008. A standardized method is recommended for measuring gastric emptying by scintigraphy (GES). A low-fat, egg white meal with imaging at 0, 1, 2, 4 hours after meal ingestion, as described by a published multicenter protocol, provides standardized information about normal and delayed gastric emptying. Adoption of this standardized protocol will resolve the lack of uniformity of testing, add reliability and credibility to the results, and improve the clinical utility of the gastric emptying test.

Cyclic Vomiting Syndrome in Adults

This manuscript, appearing in the April 2008 issue of Neurogastroenterology and Motility (2008;20(4):269-84), was derived in part from the proceedings of two expert panel meetings on adult CVS sponsored by the Cyclic Vomiting Syndrome Association and the American Neurogastroenterology and Motility Society. Cyclic Vomiting Syndrome (CVS) was initially described in children but can occur in all age groups. CVS is increasingly recognized in adults. The lack of awareness of CVS in adults has led to small numbers of diagnosed patients and a paucity of published data on the causes, diagnosis, and management of CVS in adults. This article is a state-of- overview on CVS in adults and is intended to provide a framework for management and further investigations into CVS in adults.

Research Committee; Chaired by Yvette Taché, PhD

2008 ANMS research Grant Program for junior investigators. Deadline: July 1, 2008. Following the successful launch of this program last year, the ANMS will continue to offer research grants in 2008. This year the ANMS invites ANMS members to submit Clinical & Basic Science Research Proposals on the Esophageal Motility and Esophageal Disorders. Applications are intended to support work up to \$30,000 that will contribute to extra mural funding and promote career development. Electronic submission deadline for application is July 1st, 2008 and award notification will take place in the fall. For detail information on selection criteria, eligibility, please consult the website http://www.motilitysociety.org

ANMS Sponsored Symposium at the Society for Neuroscience

The objective of this initiative is to increase the awareness of, and attracting neuroscientists to the field of neurogastroenterology. In order to expose PhD students, MD/PhD students, MDs and postgraduate fellows to the enteric neurosciences, a satellite symposium series "A Window into Enteric Neurosciences" will be held before each annual meeting of the Society for Neurosciences. This first ANMS Society for Neuroscience (SFN) satellite symposium was held in November 2007 entitled "A Window into Enteric Neurosciences," sponsored by the ANMS. This program exposed neuroscientists to the field of enteric neurosciences and covered evolving areas related to signaling in sensory transduction of nutrients, stress-related visceral pain, the role of endocannabinoids in the ENS, and genes involved in the process of ENS differentiation as detailed in the program below: Yvette Taché and Gianrico Farrugia, Presiding

Henry Parkman: Integration of neurosciences to the field of gastroenterology: Training and career opportunities

Yvette Taché: CRF signaling pathways in central and enteric nervous systems: Implications in the gut response to stress.

Helen Raybould: Sensory transduction of nutrients in visceral afferents Michelle Southard-Smith: The development of the enteric nervous system in health and in Hirschsprung disease

Keith Sharkey: Endocannabinoids and their receptors in the enteric nervous system.

Presenters and organizers of the ANMS Neuroscience Symposium:



Mentoring Program in Neurogastroenterology Research. The objective of the program is to provide guidance and networking to individuals at an early stage of their career who are considering or have just entered the field of neurogastroenterology and gastrointestinal motility. This program will help young clinicians and scientists in the fields of clinical and basic sciences related to neurogastroenterology and gastrointestinal motility. In this program, mentors will be matched with mentees to help provide mentees with suggestions, guidance and assistance. This can be performed through a variety of ways including email, telephone calls, and meetings. Mentors meet with their mentee during the ANMS and AGA meetings. A breakfast meeting for mentors and mentees is planned at the Joint International Meeting of Neurogastroenterology and Motility in Luzern Switzerland. If you are interested in becoming a mentor or mentee, please visit our website at http://www.motilitysociety.org/ and fill out the appropriate form.

ANMS at the OESO meeting April 2008.

The OESO is a world organization for specialized studies on Diseases of the Esophagus. This meeting focuses on esophageal disorders with presentations varied into specialized symposia, topic fora, and a unique aspect of this meeting – presentations of detailed answers to specific questions related to the esophagus. Several members of our ANMS council participated in this meeting: Yvette Taché, Henry Parkman, and Lori Ennis.

Membership Committee; Jim Galligan, PhD

ANMS had 274 members during 2007 and this number has fairly stable during between 2003 and 2007. The Membership Committee has initiated a membership drive during 2008 with the goal of recruiting 100 new members. A component of this effort will require personal contact between current members and their colleagues working in research and clinical areas relevant to the ANMS. ANMS Council members will be sending personal invitations to colleagues in an effort to increase awareness of the benefits of ANMS membership. Council members may also call on the ANMS membership to help in this membership drive, so we encourage you to identify colleagues at your own institution, or elsewhere, who would benefit from ANMS membership.

ANMS Memberships

Ask your colleagues to join the ANMS. They can easily join on the ANMS website. For the membership fee of only \$125 for Regular membership and \$50 for trainees, you get a \$250 value journal subscription to Neurogastroenterology and Motility! In addition society members receive copies of the Recorder, and get reduced registration fees to ANMS meetings. Share this information with your colleagues. Note there are now three types of memberships for our society:

Regular Member

Training Member – For individuals in graduate school or postgraduate training (GI Fellows, Post-docs)

Auxiliary Member – Nurse, technician, nurse practitioner, physician assistant that assists in the practice of GI motility and functional GI disorders.

Articles on Neurogastroenterology and Motility

As a service to the ANMS membership, the ANMS council, spearheaded by our secretary Tony Bauer, will offer an e-blast of publication highlights each month. A list of 5-7 articles with individual summaries pertaining to the field of neurogastroenterology and motility will be chosen to keep our membership abreast with the latest developments in our field. These will be selected from various top tier journals. Both

clinical and basic scientific articles will be selected. We hope that this will become a valuable service to our membership to keep you informed of important articles in enteric neuroscience, neurogastroenterology and GI Motility.

Education Committee. Chaired by Satish Rao, MD

The ANMS Clinical Training Program for GI Fellows has been expanded and revised extensively for the academic year 2007-8. In addition to the original five centers (Cedars Sinai Medical Center, Temple University, University of Kansas, University of Iowa, and University of Michigan) which participated in the program for the year 2006-7, this year five new sites were added: Medical College of Wisconsin, Milwaukee, Northwestern University, Chicago, Columbus Childrens Hospital at Ohio State University, Columbus, University of North Carolina at Chapel Hill, and Wake Forest University, Winston Salem. This year, 25 GI Fellows will be spending a one month rotation at one of these 10 GI Motility Centers of Excellence to learn the art and practice of neurogastroenterology with special emphasis on learning the various GI motility procedures that are used to evaluate patients with these disorders. This should provide a strong foundation for a better understanding of GI motility problems and its treatment. So far, the program has received excellent reviews by both the GI Fellows and the faculty. Plans are underway for seeking applications and securing funding for the year 2008-9. The ANMS is committed to continue this training program. This program was made possible through unrestricted grant support from Takeda Pharmaceuticals North America and Sucampo Pharmaceuticals Inc.

Clinical Practice Committee

ICD-9 Adds a Fifth Digit to the Dysphagia Diagnosis Code Effective Oct. 1, 2007, there are now six ICD-9 codes to describe dysphagia. They are as follows:

- 787.20 Dysphagia, unspecified
- 787.21 Dysphagia, oral phase
- 787.22 Dysphagia, oropharyngeal phase
- 787.23 Dysphagia, pharyngeal phase
- 787.24 Dysphagia, pharyngoesophageal phase
- 787.29 Other dysphagia (Cervical dysphagia)

Some insurance companies have already begun to deny claims that do not include the fifth digit. To prevent denials, amend your encounter forms and any other charge-capture mechanisms you use, as well as your computer files, to reflect the new codes.

An updated Registry of GI Motility Laboratories is posted on our ANMS website (www.motilitysociety.org). The purpose of this registry is to have a listing of GI Motility Laboratories that perform good quality GI motility testing that can be relied on by other physicians. This will help both physicians who what to refer patients as well as patients who might need to find a local laboratory that does this procedure. In the future, this registry may be useful for quality assurance and pay for performance.

The ANMS Journal: Neurogastroenterology and Motility

The field of gastrointestinal motility has undergone phenomenal growth and change in the past three decades since it emerged as a distinct specialty. Our Journal, Neurogastroenterology & Motility, is the official Journal of the American Neurogastroenterology and Motility Society, the European Society of Neurogastroenterology and Motility, and the Functional Brain-Gut Research Group. It is now one of the top ten leading journals in gastroenterology and has an impact factor of

3.38 and is rising. The Journal provides a forum where current issues and advances relating to the motor function of the GI tract can be presented and discussed. It is of interest to both clinicians and researchers. The Journal publishes original research and review articles, abstracts of symposia and meeting reports. Neurogastroenterology and Motility encourages papers on all basic and clinical aspects of gastrointestinal motility and its control by myogenic, neural, hormonal and chemical mechanisms. Papers on the way motility interacts with other gastrointestinal functions including absorption, secretion and immunology are also encouraged. The journal is published monthly and will be increasing its page numbers in the near future. ANMS members on the Journal Management Committee are Ann Ouyang and Michael Camilleri.

American Neurogastroenterology and Motility Society (ANMS):

A society dedicated to research and the practice of medicine in gastrointestinal motility, the brain-gut axis, and related enteric sciences.

Mission of ANMS:

Advance the study of neurogastroenterology, GI motility and related enteric sciences

Translate the scientific advances to patient care
Disseminate the knowledge to patients and care-givers in order to
improve the diagnosis and treatment of patients with GI
motility and functional GI disorders

Officers of the American Neurogastroenterology and Motility Society (ANMS)

| Henry P. Parkman, MD | President | 2004-2008 |
|----------------------------|-------------------------------|-----------|
| Michael Camilleri, MD | President-Elect | 2006-2008 |
| Anthony Bauer, PhD | Secretary | 2006-2010 |
| John Wiley, MD | Treasurer | 2006-2010 |
| Gianrico Farrugia, MD | Councilor | 2004-2008 |
| Yvette Taché, PhD | Councilor | 2004-2008 |
| Jay Pasricha, MD | Councilor | 2004-2008 |
| James Galligan, PhD | Councilor | 2006-2010 |
| Emeran A. Mayer, MD | Councilor | 2006-2010 |
| Gary M. Mawe, PhD | Councilor | 2006-2010 |
| Satish S. C. Rao, MD | Clinical Practice Committee | |
| Ann Ouyang, MD | Representative to NGM | |
| Nancy Norton | Ad hoc councilor | |
| Chung Owyang, MD | Immediate Past-President | |
| Robert W. Summers, MD | Past-Past-President | |
| Joseph H. Szurszewski, PhD | Past-Past-Past President, NGM | |
| Lori Ennis | Executive Director | |
| | | |

New Council members will be chosen in 2008. If you are interested in serving, please let us know.

Digestive Diseases National Coalition (DDNC) Hill Day

The DDNC is a broad-based coalition advocating for important public health initiatives in digestive diseases and is composed of 27 organizations that represent health professionals and patients. The ANMS participated in the Digestive Diseases National Coalition (DDNC) Hill Day. On March 10, 2008, Henry Parkman went to several congressional offices including Arlen Spector of Pennsylvania with several messages: 1) requesting increase funding for the NIH; 2) awareness of upcoming report of the National Commission of Digestive Diseases. The DDNC was advocating a 6.5% increase for the NIH as well as a proportional increase for NIDDK. The current President's proposal is to continue the trend of near level funding for the NIH. On 3/13/2008, the Senate voted 95 to 4 in favor of adopting the "Specter/Harkin" amendment to the Senate's fiscal year (FY) 2009 budget resolution. This amendment authorizes an additional

\$2.1 billion for the National Institutes of Health (NIH) in FY 2009, bringing the agency's total potential funding level up to \$32.2 billion. This is an important first step to increasing funding for NIH in FY 2009.

At the DDNC board meeting, Henry Parkman, secretary of the DDNC and chair of the educational committee, discussed plans for the committee to develop a slide set on irritable bowel syndrome to help educate the public and congress on the importance of this disorder and need for funding. During the luncheon, the DDNC Distinguished Public Servant Award was presented to Senator Tim Johnson (D-SD) for his service for digestive disease awareness.

Lunch session at Dirksen Senate Office Building. Senator Tim Johnson with Henry Parkman, secretary of DDNC, Peter Banks, President of DDNC, Maurice Cerulli, prior President of DDNC.



Henry Parkman discusses issues of Irritable Bowel Syndrome with Senator Tim Johnson.



News from the NIH NIDDK

The NIH State-of-the-Science Conference: Prevention of Fecal and Urinary Incontinence in Adults was held December 10-12, 2007. For the synopsis of this meeting, go to http://consensus.nih.gov/2007/2007IncontinenceSOS030main.htm http://consensus.nih.gov/2007/2007IncontinenceSOS030html. Potential funding opportunities may arise from this meeting! Conclusions of the meeting include the following: Fecal incontinence and urinary incontinence are common, affecting more than one-fourth of all American adults during.

affecting more than one-fourth of all American adults during their lives.

Fecal incontinence and urinary incontinence may have serious

Fecal incontinence and urinary incontinence may have serious effects on the lives of the many individuals who suffer physical discomfort, embarrassment, stigma, and social isolation, and on family members, caregivers, and society. Financial costs are

substantial and may be underestimated because of underreporting.

The lack of standardized definitions of both fecal and urinary incontinence is a major impediment to the development of reliable estimates of prevalence, incidence, and burden.

Little is known about the course (natural history) of fecal incontinence. Although more is known about the course of urinary incontinence, its natural history over several years has not been well studied.

Although many factors that contribute to incontinence have been identified, the underlying biologic causes and how they interact with comorbid conditions and a person's living situation have not been elucidated. Knowledge of the multiple causes of incontinence would inform prevention and treatment.

Systematic evaluation is needed of the many measures that characterize fecal and urinary incontinence and their impact. Such evaluation would identify measures that may be most useful for detection of these conditions and measurement of their severity and effects.

Many risk factors for fecal and urinary incontinence have been proposed, but further studies are needed to test hypotheses about the etiologic role of specific risk factors and to develop tools to classify persons according to their future risk of fecal or urinary incontinence.

Fecal and urinary incontinence may be prevented by lifestyle changes, such as weight loss and exercise.

Effective approaches to the short-term prevention of urinary incontinence have been identified in particular groups.

Innovative approaches are needed. Information is needed about the comparative effects of different preventive approaches, their longer term effects, and their relative costs.

Organized approaches to improve clinical detection are needed and require rigorous evaluation. Raising public awareness may also promote disclosure and care seeking.

NIDDK issued in January 2008 their annual Recent Advances and Emerging Opportunities which illustrates recent NIDDK-supported scientific advances.

NIDDK points out that ANMS members might consider R21 applications for Pilot and Feasibility Clinical Research Studies in Digestive Diseases and Nutrition. See the program information NIDDK PA06-301.

National Commission on Digestive Diseases issued its draft document for public commentary, which ended March 8, 2008. The Overarching Research Goals for this report are:

Increase the Fundamental Knowledge Base for Understanding Health and Digestive Diseases

Translate Fundamental new Knowledge for the Direct benefit of Individuals

Develop Research Resources and Infrastructure Maintain a Pipeline of Research Investigators for the Future

Group 2 of this document is entitled Functional Gastrointestinal Disorders and Motility Disorders and is chaired by Kenton Sanders, PhD and Co-chaired by Nancy Norton. We owe a debt of gratitude to these Kent and Nancy for leading this initiative. The general research goals for this area are:

Improve our understanding of normal motility and secretory activities of the GI tract.

Discover the physiologic changes that lead to functional GI disorders and GI motility disorders

Develop more effective therapies to prevent, treat, or reverse these disorders

Information from Patient Support / Physician Liaison Groups

International Foundation for Functional GI Disorders (IFFGD)

IFFGD continues to be active in advocacy and legislative activities this year. We have been engaging members of Congress to enlist support for a 6.5% funding increase for the National Institutes of Health in fiscal year 2009; urging them to support a funding increase of \$75 million for the Department of Veterans Affairs Medical and Prosthetic Research Program; and working to enact substantial funding increases for the Food and Drug Administration. Most excitingly, IFFGD has been working with the office of Congressman Eliot Engel (D-NY-17th) to draft legislation which would create an NIDDK-coordinated research network for IBS.

IFFGD's President and Founder, Nancy Norton, has been working with the NIDDK's National Commission on Digestive Diseases, as Vice Chair of the Commission's Functional Gastrointestinal Disorders and Motility Disorders Working Group and of the Diseases of the Colon and Rectum Working Group, to draft a Long-Range Research Plan for Digestive Disease Research. The Research Plan will provide guidance to the NIH, the investigative community, and the voluntary health community in pursuing promising avenues to address digestive diseases.

In December 2007 the NIH convened a State-of-the-Science Conference to identify best practices and strategic interventions to prevent fecal and urinary incontinence in adults. Nancy Norton presented at this conference. Since then, IFFGD has been working to see that the report's conclusions are publicized and supported by Congress.

IFFGD continues to further patient education by hosting a family of eight websites, providing a continually updated, reliable, and credible internet resource. Our new Video Corner section features top researchers discussing key topics of interest to patients.

Be sure to save the date for our 8th International Symposium on Functional Gastrointestinal Disorders, which will be hosted by IFFGD on April 17-19, 2009 at the Pfister Hotel, in Milwaukee, Wisconsin. IFFGD will also be providing content for the Neurogastroenterology & Motility 2008 Joint International Meeting, which will be held on November 6-9 2008, in Lucerne, Switzerland.

IFFGD is pleased to offer two Research Grants in 2008, of \$50,000 each, available to investigators for research related to functional gastrointestinal and motility disorders and neurogastroenterology. The deadline for submitting applications is June 2, 2008. We are also pleased to announce that we are seeking applications/nominations for Research Awards, for active investigators who have a record of research interest in basic mechanisms or clinical aspects of functional gastrointestinal and motility disorders and neurogastroenterology. The deadline for receipt of applications is October 20, 2008. Details and applications for both Grants and Awards can be found online at www.giresearch.org.

Nancy Norton President, IFFGD http://www.iffgd.org/

Henry Parkman, President of ANMS with Nancy Norton, President of IFFGD at the US Capital during the recent IFFGD Hill Day to increase awareness and funding for Irritable Bowel Syndrome.



Cyclic Vomiting Syndrome Association (CVSA)

International Affiliates: CVSA continues to grow on the international scene with the addition of the Denmark association. There are now five affiliate associations around the globe – Australia, Denmark, Italy, United Kingdom and USA/Canada. New articles: "The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition Diagnosis and Management of Cyclic Vomiting Syndrome – A Consensus Statement" will be in print in the Journal of Pediatr Gastroenterol & Nutr. in July 2008. This is an important landmark accomplishment for CVS patients and their caregivers. The manuscript on CVS in adults by CVSA advisor Henry Parkman, MD is now in press in Neurogastroenterology and Motility. This paper resulted from 2 meetings - CVS Across the Ages - June 2006 at the Medical College of Wisconsin Milwaukee and CVS in Adults - A Satellite Symposium held September 2006 following the Joint International Neurogastroenterology and GI Motility Meeting. CVS is now being diagnosed more commonly in adults and there is high need to meet the call for more informed and effective care.

Meetings: Dr. Richard Boles, M.D., a medical geneticist at Childrens Hospital Los Angeles and Associate Professor of Pediatrics at the Keck School of Medicine at USC will be presenting Pediatric Grand Rounds at Children's Hospital of Wisconsin/Medical College of Wisconsin May 16, 2008 at the invitation of Dr. B U.K. Li. Dr. Li is the Director of the CVS Program at Children's in Milwaukee. In addition to clinical care for CVS. Dr. Boles has done extensive research on the connection between Cyclic Vomiting Syndrome, other functional disorders (migraine, depression, chronic fatigue, irritable bowel and others) and mitochondrial function. While in Milwaukee, Drs. Li and Boles and Kathleen Adams will be doing preliminary work on grant writing for a conference grant for the 3rd International Scientific Symposium on CVS. This is much on our minds since we all recognize the need for bringing together our next interdisciplinary set of experts to present and then collaborate on investigations about CVS. This cross specialty approach to the science of CVS remains a hallmark of our work.

CVSA will be hosting the Bi-annual International Family & Adult Conference June 27 - 29, 2008 at the Sheraton Colonial Hotel in Wakefield, MA just outside of Boston. Please inform you patients about this opportunity.

Outreach for Diagnosis and Care: Dr. Thangam Venkatesan, M.D. Director of the Program for the Care of CVS in Adults at the Medical College of Wisconsin, joined the CVSA Medical Advisory Board in 2007. Her primary research interest at the moment is the care of CVS in the Emergency Room. Her abstract, "To ER is human: emergency room use in cyclic vomiting syndrome" will be presented at the DDW. Her conclusion based on surveys: "There is a sub-group of adult and pediatric CVS patients with a high utilization of ER services that suffers due to a lack of awareness of the disorder in the ER. Recognition of CVS in the ER may serve to decrease utilization of acute care services and improve patient outcomes."

<u>Call for subjects:</u> Richard G. Boles, MD, Department of Medical Genetics, Childrens Hospital Los Angeles and CVSA has launched a collaborative study. This retrospective pilot study is on the efficacy and tolerability of co-enzyme Q10, L-carnitine and amitriptyline in cyclic vomiting syndrome.

CVSA is here to see that all benefit by the work going on out in the field. Kathleen Adams, BSN, RN kadams@mcw.edu www.cvsaonline.org

Association of Gastrointestinal Motility Disorders, Inc. (AGMD)

Since our July 2007 AGMD Digestive Motility Symposium, our organization has moved forward on many levels in serving as an advocate, drawing more awareness, and providing education, resources, and support for those affected by digestive motility diseases and disorders.

Our website now offers an Online Community where people can gather together in support of each other. We are also making many new updates to our site in order to provide as many resources and help to those in need. AGMD now holds Monthly Educational Support Group Meetings in Massachusetts. What makes these meetings unique is that part of the session focuses on education of digestive motility diseases and the other part of the session focuses more on support and providing resources. We are also extremely excited about the prospect of expanding the Pediatric Division of AGMD with the assistance of Dr. Alex Flores at the Tufts Medical Center Floating Hospital For Children in Boston, MA. AGMD is hoping to hold its next AGMD Digestive Motility Symposium in 2009. We will be posting updates as plans progress.

AGMD was honored to participate in the Digestive Disease National Coalition (DDNC) Annual Public Policy Forum which was held March 9 & 10, 2008 at the Hotel George in Washington, D.C. Nicola Migliacci served as our representative at the Forum and she reported to us that the enthusiasm, dedication, input, and responses from all those who participated was inspiring. She will continue to work closely with AGMD in assisting us in lobbying congress for more critical funding for research in digestive motility diseases and disorders.

In drawing awareness to digestive motility diseases and disorders, AGMD is passionate about including some of the more rare forms in the spotlight such as chronic intestinal pseudo-obstruction (CIP). According to Dr. Brian Lacy, Ph.D., M.D., "The exact prevalence of CIP remains unknown, although it is estimated that approximately 100 infants are born each year in the U.S. with congenital pseudo-obstruction. This number, however, significantly underestimates the total number of new cases each year, as it does not include the large number of adult patients who develop pseudo-obstruction later in life." Currently, there is no cure for patients with CIP and the quality of life of this patient population is extremely poor. It is our hope that we can provide patients like these more answers, treatments, and hope through our organization.

Mary-Angela DeGrazia-DiTucci, President/Patient/Founder

E-mail: <u>digestive.motility@gmail.com</u>
Website: http://www.agmd-gimotility.org

Zelnorm Update: Novartis has decided to close the Tegaserod Treatment IND program. No additional sites or patients will be added to the program. Those sites enrolled in the tIND program will be closing out in the near future. For patients who have an urgent need for Zelnorm based on a life-threatening or severely debilitating condition serious enough to require hospitalization, there may be an alterative option through the FDA. Physicians may inquire about this potential Emergency IND by contacting the FDA at (301) 796-3400 or www.fda.gov/cder.

Gastroparesis and Dysmotilities Association (GPDA)

As the month of May approaches, the Gastroparesis and Dysmotilities Association (GPDA) will once again be encouraging our members to find unique ways to reach out into their communities and initiate awareness activities regarding digestive motility diseases and disorders. Our annual awareness campaign began in 2006 when GPDA circulated to the 50 State governors and all 13 Canadian provinces/territories our proclamation declaring May as Digestive Motility Awareness month. Coupled with this action was the production and circulation of our first public service announcement (PSA) for gastroparesis. The PSA featuring former NFL quarterback Archie Manning has renewed interest related to Archie's sons Super Bowl successes.

Proclamations commonly are devised for single entity diseases, but it remains important for our organization to instruct the public and our patient group that disorders of motility are often a collection of problems. Many of our members are struggling against more than one functional and motility disorder, frequently having been diagnosed with gastroparesis, GERD, and IBS. Starting in mid April, patients and the public will be able to request a Digestive Motility Awareness package from GPDA. The package will contain buttons, pamphlets and a suggestion list to help individuals get started with raising awareness in their schools, churches and local physician's offices.

GPDA's grass roots action on awareness will continue striving to introduce the term digestive motility into society's lexicon. Our efforts will remain vital until a pharmaceutical reaches the market for the treatment of more severe motility disorders enabling wide-ranging marketing campaigns.

Jeanne Keith-Ferris

Gastroparesis and Dysmotilities Association (GPDA) http://www.digestivedistress.com/main/page.php?page_id=1