

## Digestive Diseases

## NEWS

National Digestive Diseases Information Clearinghouse

Fall 2007

## NIH Launches Study to Assess Bariatric Surgery in Teens

The National Institutes of Health (NIH) launched an observational study to assess the benefits and risks of bariatric surgery in teenagers. Bariatric surgery can decrease the amount of calories and nutrients the body absorbs by reducing stomach size. The Teen-Longitudinal Assessment of Bariatric Surgery (Teen-LABS) study will help determine whether the surgery is an appropriate treatment option for extremely overweight teens.

During the next 5 years, researchers will enroll 200 extremely overweight teens scheduled for bariatric surgery at the participating clinical sites and compare their pre- and postoperative data to 200 adults scheduled for bariatric surgery who have a history of obesity since their teen years. Researchers will collect information on the preoperative and 2-year postoperative status of participants, including measures of body composition, cardiovascular risk factors, sleep apnea episodes, diabetes indicators, depressive symptoms, quality of life, eating habits, and nutritional status. Investigators will also store serum, plasma, urine, and genetic samples for future studies.

Teenagers between the ages of 14 and 19 who are scheduled for bariatric surgery are eligible for the study, but younger patients could be considered if they meet clinical criteria for surgery at one of the participating centers. The study pays for data collection but not for the surgery and related patient care.

The Teen-LABS protocol parallels that of the adult LABS study, an observational study evaluating the benefits and risks of bariatric surgery and its impact on the health and well-being of

extremely obese adults. The 200 teens who will be enrolled in Teen-LABS will also be participants in adult LABS.



Launched in 2003, the six clinical centers for the adult LABS have already enrolled more than 4,000 patients in a series of short-term and longer-term studies. These studies will collect information about patient characteristics, types of surgeries, medical and psychosocial outcomes, economic factors, and other topics. The adult LABS study is expected to continue through 2008.

Recent data show that nearly 17 percent of U.S. youth between the ages of 6 and 19 are considered overweight. Overweight youth are more likely to develop serious health problems, such as type 2 diabetes and heart disease. The goal for overweight teens is to slow the rate of weight gain by eating fewer calories and increasing physical activity, but these changes are very difficult for severely overweight youth to achieve.

**BARIATRIC SURGERY**, continued on page 2

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National Institute of  
Diabetes and Digestive  
and Kidney Diseases





Bariatric surgery can decrease the amount of calories and nutrients the body absorbs by reducing stomach size.

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“We know that bariatric surgery is not an easy way out for teens to control weight,” said Mary Horlick, M.D., project scientist for Teen-LABS and director of the Pediatric Clinical Obesity Program in the Division of Digestive Diseases and Nutrition (DDN). The DDN is part of the National Institute of Diabetes and Digestive and Kidney Diseases, the sponsor of Teen-LABS at the NIH. “We hope to learn whether or not bariatric surgery is suitable for extremely overweight teens and if it will help them remain at a healthy weight over the long-term.”

For more information about weight control and physical activity in children and teens, go to

The Teen-LABS study is under way at the following medical centers:

- Texas Children’s Hospital, Houston
- Children’s Hospital of Alabama in Birmingham
- University of Pittsburgh
- Cincinnati Children’s Hospital Medical Center (Data Coordinating and Clinical Center)

[www.win.niddk.nih.gov/publications](http://www.win.niddk.nih.gov/publications) and [www.win.niddk.nih.gov/publications/take\\_charge.htm](http://www.win.niddk.nih.gov/publications/take_charge.htm). To learn more about Teen-LABS, visit [www.cincinnatichildrens.org/research/project/teen-labs](http://www.cincinnatichildrens.org/research/project/teen-labs). For information about the adult LABS study, visit [www.niddkLABS.org](http://www.niddkLABS.org). ■

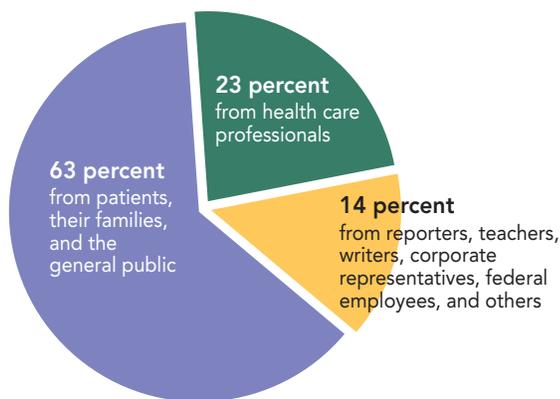
## Facts About Inquiry Response September 1, 2006, to August 31, 2007

### Clearinghouse Handles More than 8,700 Inquiries, Most from Patients and Families

The National Digestive Diseases Information Clearinghouse responded to 8,798 inquiries between September 1, 2006, and August 31, 2007, according to this breakdown:

Amount	Inquiry Method
3,282	email messages
2,474	online publication orders
2,402	telephone calls
445	mailed letters
130	faxes
65	conferences

Most of those inquiries were from patients and their families:



Digestive Diseases  
**NEWS**

*Digestive Diseases News*, an email newsletter, is sent to subscribers by the National Digestive Diseases Information Clearinghouse (NDDIC). The newsletter features news about digestive diseases, special events, patient and professional meetings, and new publications available from the NDDIC and other organizations.

If you would like to subscribe, send an email to [niddk@info.niddk.nih.gov](mailto:niddk@info.niddk.nih.gov). You can read or download a PDF version of the newsletter at <http://digestive.niddk.nih.gov/about/newsletter.htm>.



**Executive Editor: Stephen P. James, M.D.**

Stephen P. James, M.D., is the director of the Division of Digestive Diseases and Nutrition within the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). As director, Dr. James oversees planning, implementation, and evaluation of a national research effort focused on gastrointestinal, pancreatic, hepatobiliary, and nutrition diseases and conditions. Before joining the NIDDK in 2001, Dr. James directed the division of gastroenterology at the University of Maryland’s School of Medicine for 10 years.



## NIDDK Director Addresses Physicians and Scientists During Digestive Disease Week

Agency-wide initiatives throughout the National Institutes of Health (NIH) have great potential to advance digestive diseases research, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Director Griffin P. Rodgers, M.D., told attendees who gathered in Washington, DC, during Digestive Disease Week.



“Collectively, digestive diseases represent an enormous public health burden.”

Griffin P. Rodgers, M.D.  
NIDDK Director

These initiatives include research on the human microbiome and epigenetics, as well as new awards to support vulnerable members of the research community, such as new investigators.

“Collectively, digestive diseases represent an enormous public health burden,” Rodgers told participants at the world’s largest annual gathering of researchers and physicians in the fields of gastroenterology, hepatology, endoscopy, and gastrointestinal surgery on May 21. “Research progress in combating these complex digestive diseases requires coordination across scientific disciplines, organizations, and approaches.”

Rodgers said this includes coordinating research among NIH and federal partners and developing partnerships with academia, government, industry, private foundations, practitioners, patients, and the community.

In addition to focusing on such public health challenges as chronic conditions, the aging population, and health disparities, the NIH is responding to changing needs within the scientific community with a number of new programs, according to Rodgers. These include the

- NIH Director’s New Innovator Award to support highly innovative research by new investigators
- Pathway to Independence Award, which provides 1 to 2 years of support for mentored postdoctoral research plus up to 3 years of independent research support upon attainment of a faculty position

- NIH Director’s Bridge Award to provide continued but limited funding for new and established grantees who have submitted a competing renewal grant application for a highly meritorious project
- NIH Clinical and Translational Science Awards, designed to overcome current obstacles to performing clinical research, including challenges associated with interdisciplinary collaboration and other barriers

Related to these NIH initiatives, Rodgers said the NIDDK will work to ensure that new investigators realize their full potential as innovative researchers by promoting mentorship activities and special consideration for new investigator funding.

### Core Principles

As the NIDDK director, Rodgers said he will pursue the following core principles:

- maintain a vigorous investigator-initiated research portfolio
- support pivotal clinical studies and trials on a range of digestive diseases with substantial involvement of minorities as study leaders and participants
- support exceptional research training and mentoring opportunities for physician scientists and Ph.D. scientists at the undergraduate, graduate, and postgraduate levels
- preserve a stable pool of talented new investigators

## AGA Honors Freston, Podolsky for Distinguished Service, Achievement

The American Gastroenterological Association (AGA) honored two digestive diseases experts for their outstanding contributions to the field during Digestive Disease Week (DDW) held in Washington, DC, May 19 to 23. DDW is the world's largest annual gathering of researchers and physicians in the fields of gastroenterology, hepatology, endoscopy, and gastrointestinal surgery.

James W. Freston, M.D., a member of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) National Advisory Council, received the 2007 Julius Friedenwald Medal for Distinguished Service for his lifelong contributions to the field of gastroenterology. The award, created in 1941, is the highest honor the AGA bestows on a member.

David K. Podolsky, M.D., director of the National Institutes of Health-funded Center for the Study of Inflammatory Bowel Disease and external expert for the National Commission on Digestive Diseases, was awarded the AGA's 2007 Distinguished Achievement Award. The AGA created the award to recognize individuals who have made a major specific accomplishment in clinical or basic research in gastroenterology.

Freston is professor of medicine emeritus and the Boehringer Ingelheim chair of clinical pharmacology at the University of Connecticut School of Medicine, Farmington. His contributions in clinical research have been in the area of clinical pharmacology of gastrointestinal drugs, with a focus on acid-related disorders.

Podolsky, the Mallinckrodt professor of medicine at Harvard Medical School and chief of gastroenterology at Massachusetts General Hospital, made many contributions to the field through the study of epithelial biology and mucosal immune defense.

NIDDK Director Griffin P. Rodgers, M.D., publicly congratulated the awardees during his address to the AGA Presidential Plenary Session. ■

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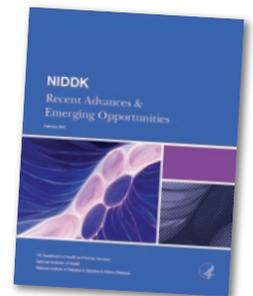
### CORE PRINCIPLES, from page 3

- disseminate science-based knowledge to health care providers and the public through national campaigns, an information clearinghouse, and an annual compendium entitled *NIDDK: Recent Advances and Emerging Opportunities*

NIDDK-supported digestive diseases research efforts already under way include the

- Inflammatory Bowel Diseases Genetics Research Consortium
- Gastroparesis Clinical Research Consortium
- Nonalcoholic Steatohepatitis Clinical Research Network
- Pediatric liver disease consortia on biliary atresia and cholestatic liver injury

This compendium is a web-based publication, which is also presented to the NIDDK's National Advisory Council in printed form each February.



The NIDDK has also provided leadership and support for trans-NIH research planning efforts related to digestive diseases, including the

- Trans-NIH Action Plan for Liver Disease Research
- National Commission on Digestive Diseases—see related story on page 8. ■

## NIDDK Unveils Website Makeover

**D**ynamic graphics and an enhanced layout define the redesigned website launched by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

The NIDDK's website reformat is aimed at best directing the site's users—scientists, health care professionals, and the general public—to the topics and sections they seek.

While the fundamental architecture of information remained stable in the redesign process, the committee advancing the design sought to update the website's look and feel and improve the immediate success of information seekers.

“Our new design should save researchers, health professionals, and the public valuable time finding important scientific and consumer health information,” said NIDDK Director Griffin P. Rodgers, M.D. “We are continually striving to make our resources more readily available to a wider audience and in the latest formats. The website plays a key role in helping to disseminate this information.”

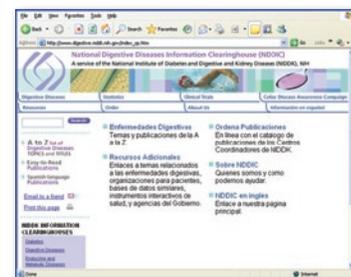
## NIDDK Website Features Health Information in Spanish

**T**he National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has launched a new portal to feature Spanish-language digestive diseases materials and resources on its website.

People looking for information about digestive diseases in Spanish can now go directly to the Spanish-language portal page, where they will find an A to Z list of topics and titles. The online system for ordering NIDDK materials now includes descriptions in Spanish of available publications to help visitors choose the resources they want. The National Digestive Diseases Information Clearinghouse has 10 publications about digestive diseases in Spanish and will be adding more in the future, including one-page fact sheets that are part of the NIDDK's Awareness and Prevention Series.

The NIDDK website, which receives nearly 2 million visits per month, scored an 83 out of 100 possible points on the American Customer Satisfaction Index (ACSI) for March to June 2007, making it a top-performing site. The ACSI measures the performance of about 200 private-sector companies and many government agencies. Visitors rate government websites on various components of overall satisfaction, such as ease of search and navigation, look and feel, functionality, and content. Ratings are converted to a score on a 100-point scale using ACSI methodology.

The website features a reference collection, an interactive health tools portal, an image library, and portals containing health information in Spanish. ■



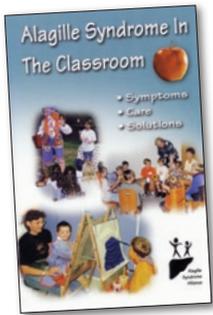
The website features a reference collection, an interactive health tools portal, an image library, and portals containing health information in Spanish.

To visit the site, go to [www.niddk.nih.gov](http://www.niddk.nih.gov).

The new Spanish-language portal is available at [www.digestive-espanol.niddk.nih.gov](http://www.digestive-espanol.niddk.nih.gov).

The NIDDK website also links to the Spanish-language portal for MedlinePlus and the NIDDK Reference Collection, a free, online database that includes 78 resources in Spanish.

To help people order materials in Spanish, two full-time bilingual information specialists respond to requests for health information in Spanish. Between July 15, 2006, and June 27, 2007 more than 17,500 Spanish-language publications were ordered through the three NIDDK clearinghouses. The NIDDK responded to more than 700 information requests in Spanish during that time. ■



To order this brochure, contact the Alagille Syndrome Alliance.

## Featured in the NIDDK Reference Collection

### Alagille Syndrome

A brochure from the Alagille Syndrome Alliance helps parents and educators understand issues that can arise when children with Alagille syndrome (AGS) are part of a standard classroom.

The 12-page publication, *Alagille Syndrome In The Classroom*, addresses the symptoms of the disorder, the use of medication and nutrition to treat AGS, liver function tests to monitor the disease, guidelines for children taking medication during school hours, pancreatic enzymes in AGS, vitamins, hospitalizations, communication between family and school, and hints for teachers and staff.

Treatment focuses on increasing bile flow from the liver with medication, preventing or correcting nutritional deficiencies such as vitamin malabsorption, and maintaining normal growth and development, often through supplemental feeding. A final section considers legal factors, as established by the Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act of 1973. The brochure also notes the activities and goals of the Alagille Syndrome Alliance.

AGS is a rare, multisymptomatic, genetic liver disorder characterized by a reduced number of small bile ducts within the liver combined with abnormalities in other organs including the heart, eyes, spine, kidneys, lungs, and pancreas. To order the publication, contact the Alagille Syndrome Alliance at 10500 SW Starr Drive, Tualatin, OR 97062, 503-885-0455, [alagille@alagille.org](mailto:alagille@alagille.org), or visit [www.alagille.org](http://www.alagille.org).

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Reference Collection is a free, online database that helps health care professionals, health educators, patients, and the general public find educational materials not typically referenced in most databases. To find more digestive diseases resources, visit [www.catalog.niddk.nih.gov/resources](http://www.catalog.niddk.nih.gov/resources).

## Additional Resources

### Easy-to-read Booklets

The National Digestive Diseases Information Clearinghouse (NDDIC) has published two new easy-to-read booklets. *What I need to know about Crohn's Disease* explains what the disease is, who is at risk, the symptoms, and how the condition is diagnosed and treated. Crohn's disease causes parts of the digestive tract to become inflamed. Although the disease can affect any area of the gastrointestinal tract, it most often affects a part of the small intestine called the ileum. Crohn's disease is most common in men and women between the ages of 20 and 30.



Diverticular disease is made up of two conditions: diverticulosis and diverticulitis. Diverticulosis occurs when bulging pouches called diverticula form in the colon. Diverticulitis occurs if the pouches become inflamed. *What I need to know about Diverticular Disease* provides people with the information they need to understand and manage the disease.

To view or order a copy of the booklets, visit [www.digestive.niddk.nih.gov/ddiseases/a-z.asp](http://www.digestive.niddk.nih.gov/ddiseases/a-z.asp).

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To view or order a copy of the booklets, visit [www.digestive.niddk.nih.gov/ddiseases/a-z.asp](http://www.digestive.niddk.nih.gov/ddiseases/a-z.asp).

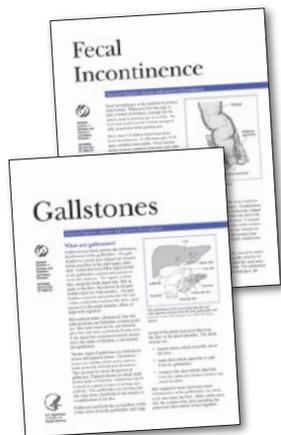
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## Updated Fact Sheets

The NDDIC has updated the following fact sheets:

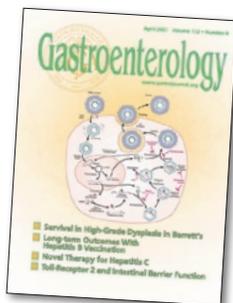
- *Fecal Incontinence*
- *Gallstones*
- *Gastroparesis*
- *Heartburn, Gastroesophageal Reflux (GER), and Gastroesophageal Reflux Disease (GERD)*
- *Primary Biliary Cirrhosis*

The fact sheets are available at [www.digestive.niddk.nih.gov/ddiseases/a-z.asp](http://www.digestive.niddk.nih.gov/ddiseases/a-z.asp).



## Digestive Diseases Research

The April 2, 2007, issue of *Gastroenterology* features an article by Stephen P. James, M.D., director of the National Institute of Diabetes and Digestive and Kidney Diseases' (NIDDK) Division of Digestive Diseases and Nutrition, about the outlook for digestive diseases research at the Institute. According to the article, the NIDDK has taken a number of steps to offset the effects of budget limitations, such as delaying or diminishing commitments to new, Institute-solicited research projects other than those of highest priority such as essential clinical trials or critical core resources. The NIDDK also has taken steps to ensure new investigators receive special consideration for their application funding. The NIDDK accounted for about 30 percent of reported expenditures by the National Institutes of Health for digestive diseases research in fiscal year 2005. "Opportunities and Challenges at NIDDK in Digestive Diseases Research" can be found in *Gastroenterology* 2007;132:1219–1220.



## Liver Disease

*Action Plan for Liver Disease Research: Progress Review for 2006* is a report on progress made toward reaching goals laid out in the *Action Plan for Liver Disease Research* 2 years after the action plan's adoption. The annual review is intended to help implement the 2004 Action Plan through an ongoing assessment of progress and the need for further efforts to promote liver and biliary disease research. The report is available at [www2.niddk.nih.gov/AboutNIDDK/ResearchAndPlanning/Liver\\_Disease/ActionPlanforLiverDiseaseResearchProgressReview.htm](http://www2.niddk.nih.gov/AboutNIDDK/ResearchAndPlanning/Liver_Disease/ActionPlanforLiverDiseaseResearchProgressReview.htm).



## Workshop Proceedings

Summaries of two digestive diseases workshops have been published in professional journals:

- "New Therapies and Preventive Approaches for Necrotizing Enterocolitis: Report of a Research Planning Workshop," was published in the July 24, 2007, issue of *Pediatric Research*. The workshop, coordinated by the National Institute of Diabetes and Digestive and Kidney Diseases' (NIDDK) Digestive Diseases Interagency Coordinating Committee and the National Institute of Child Health and Human Development, addressed basic and translational mechanisms of approaching necrotizing enterocolitis (NEC) and recommendations for clinical studies to reduce the incidence of NEC, a gastrointestinal disease that primarily affects premature infants.
- "Screening and outcomes in biliary atresia: Summary of a National Institutes of Health Workshop," was published in the August 2007 issue of *Hepatology*. The NIDDK workshop addressed issues related to outcomes, screening, and pathogenesis of biliary atresia, the most common cause of end-stage liver disease in infants and the leading pediatric indication for liver transplantation in the United States.

ADDITIONAL RESOURCES,  
continued on page 8

ADDITIONAL RESOURCES, from page 7

### New Interactive Tools

New to the Interactive Health Education Tools section of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) website are:

- July 13 podcast entitled “Celiac Disease Awareness Campaign Marks First Anniversary”
- April 24 video entitled “Demystifying Medicine—Hepatitis C: Comes of Age Globally and in Culture”

The interactive tools section consolidates all the tools and resources about digestive diseases from the National Institutes of Health (NIH) and the National Library of Medicine. To access these resources, visit [www.digestive.niddk.nih.gov/resources/HealthTools](http://www.digestive.niddk.nih.gov/resources/HealthTools).

## Upcoming Meetings, Workshops, and Conferences

### Fecal and Urinary Incontinence

The National Institutes of Health will convene a State-of-the-Science Conference on fecal and urinary incontinence from December 10 to 12, 2007. Attendees will assess available scientific evidence about

- the prevalence, incidence, and natural history of fecal and urinary incontinence in the community and long-term care settings
- the burden of illness and impact of this problem on individuals and society
- risk factors and prevention strategies
- those at risk and those who have fecal and urinary incontinence
- research priorities

For more information and to register, go to <http://consensus.nih.gov/2007/2007IncontinenceSOS030main.htm>.

### Liver and Digestive Diseases

The National Institute of Diabetes and Digestive and Kidney Diseases will hold a research workshop entitled “Nuclear Receptors in Liver and Digestive Diseases” from November 7 to 8 in Rockville, MD. The meeting goals are to present state-of-the-art knowledge about nuclear receptors, promote cross-fertilization among basic, translational, and clinical investigators, and integrate current understanding of nuclear receptor biology and current clinical challenges for a variety of digestive and liver disease states.

For more information about the workshop, go to [www3.niddk.nih.gov/fund/other/nuclear07/index.htm](http://www3.niddk.nih.gov/fund/other/nuclear07/index.htm).

### NCDD Progress on Research Agenda Continues

The National Commission on Digestive Diseases (NCDD) will hold its next meeting on November 19, 2007, in Chicago. The Commission held its third meeting on June 18 and 19 to continue work on a report outlining a 10-year plan to address important goals for digestive diseases research and to make recommendations to the Director of the National Institutes of Health and to Congress.

Commission members who chaired working groups that have been meeting since last November presented their groups' research recommendations for specific digestive diseases along with challenges and steps to achieve the proposed goals. Revised recommendations based on feedback from Commission members are posted on the NCDD website and will form the basis of the report chapters. Following the Commission's November meeting, the public will have an opportunity to comment on the recommendations before the Commission completes the final report in 2008.

All Commission meetings are announced in the Federal Register and are open to the public. For more information about the Commission, including a list of members and working group topics, visit [www.niddk.nih.gov/federal/ncdd/mtg-info.htm](http://www.niddk.nih.gov/federal/ncdd/mtg-info.htm). ■