Urologic Diseases

Research Updates

National Kidney and Urologic Diseases Information Clearinghouse

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NIDDK Releases Comprehensive Report on Urologic Diseases

he National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has released a groundbreaking comprehensive analysis of urologic diseases in America in an ambitious effort to quantify the burden of these diseases on the U.S. economy and public.

Americans spend nearly \$11 billion annually—exclusive of medication expenditures—on medical care for urologic diseases, including visits to office-based physicians and hospital outpatient clinics, visits to emergency rooms, and hospital stays, according to *Urologic Diseases in America 2007*, a 700-page report that is the culmination of 5 years of work by the NIDDK, RAND Health, and the University of California, Los Angeles (UCLA).

The report incorporates current and retrospective data on all aspects of the epidemiology, practice patterns, costs, and impact of urologic diseases in the United States and is intended for use by public officials, nongovernment organizations, the media, academic researchers, health professionals, and the public.

Most Important Effort

"Accurately describing the burden of urologic disease on the American public is one of the most important efforts undertaken by the NIDDK at the dawn of the new millennium," said the report's authors, Mark S. Litwin, M.D., M.P.H., and Christopher S. Saigal, M.D., M.P.H., professors at UCLA's David Geffen School of Medicine and researchers at UCLA's Jonsson Comprehensive Cancer Center. "Documenting

trends in epidemiology, practice patterns, resource utilization, technology diffusion, and costs for urologic disease has broad implications for quality of health care, access to care, and the equitable allocation of scarce resources, both in terms



of medical services and research budgets."

The report incorporated information from three data categories: Medicare data, derived from the Centers for Medicare and Medicaid Services; utilization, cost, and prevalence data, extracted from the Agency for Healthcare Research and Quality and the National Center for Health Statistics; and data on special populations and topics of interest, culled from various organizations including the Veterans Health Administration. The report noted that for many urologic conditions, population-based datasets had limited information on true prevalence.

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UDA Project Publishes Key Findings

Key findings from the *Urologic Diseases in America 2007* (UDA) project that were published in several academic journals include the following:

- Gender, age, race, and socioeconomic status influence the type of bladder reconstruction a person with bladder cancer receives; younger men are more likely to get the most sophisticated types of reconstruction. These findings appeared in a July 2006 issue of the journal Cancer.
- The lifetime risk for urinary tract infections (UTIs) in women is greater than 50 percent. Between 1988 and 1994, the overall lifetime prevalence of UTIs was estimated to be 53,067 per 100,000 women. Composite data revealed that overall spending for treating UTIs in U.S. adult women, excluding spending on outpatient prescriptions, was about \$2.5 billion in 2000. Findings were published in an April 2005 issue of the *Journal of Urology*.
- Treatment of men with benign prostatic hyperplasia (BPH) puts a significant burden on employees and their employers through direct medical costs and lost work time. Direct and indirect private sector costs related to BPH treatment are an estimated \$3.9 billion. These findings also were published in the April 2005 issue of the *Journal of Urology*.
- Data from the 2001 to 2002 National Health and Nutrition Examination Survey showed that Hispanic/Latino men were about twice as likely as Caucasian men to report erectile dysfunction (ED) after controlling for risk factors other than race known to be associated with ED, including diabetes, obesity, and hypertension. The report also found the prevalence of ED increased dramatically with advanced age—three quarters of men age 75 and older report some level of ED. The findings appeared in the January 2006 issue of the Archives of Internal Medicine.

Urologic Diseases Research Updates

Urologic Diseases Research Updates, an email newsletter, is sent to subscribers four times a year by the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC). The newsletter features news about urologic diseases, special events, patient and professional meetings, and new publications available from the NKUDIC and other organizations.

If you would like to subscribe, send an email to niddk@info.niddk.nih.gov. You can read or download a PDF version of the newsletter at http://kidney.niddk.nih.gov/about/newsletter.htm.

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Dr. Nyberg is the director of urology and urology centers programs at the National Institute of Diabetes and Digestive and Kidney Diseases, part of the National Institutes of Health (NIH) in Bethesda, MD. Dr. Nyberg is a graduate of Tufts University in Boston, Columbia University in New York, and the University of Massachusetts Medical School in Worcester and completed residency training in urology at The Johns Hopkins Hospital in Baltimore.

He has also held faculty positions in urology at The Johns Hopkins Medical School, in urology and biochemistry at the Medical University of South Carolina, and in urology at the University of Connecticut. Dr. Nyberg received the Distinguished Service Award from the American Urological Association for significant clinical and research contributions to urology. He also received the NIH Directors Award for excellence for the development of urology research programs at the NIH.

REPORT, from page 1

Conditions Analyzed

The extensive report covers definitions, risk factors, prevalence and incidence, utilization trends, economic impact, and recommendations on the following conditions:

Prostate

- Prostatitis
- Benign prostatic hyperplasia
- Prostate cancer

Bladder

- Interstitial cystitis and painful bladder syndrome
- Urinary incontinence
 - Adult male and female bladder cancer
 - Upper and lower tract transitional cell carcinoma

Kidney

- Urolithiasis
- Ureteropelvic junction obstruction
- Kidney cancer

Pediatric

- Vesicoureteral reflux
- Undescended testis
- Hypospadias
- Ureterocele
- Posterior urethral valves
- Urinary incontinence and urinary tract infection in children

Male Health

- Male infertility
- Erectile dysfunction and Peyronie's disease
- Urethral stricture
- Testicular cancer

Infections

- Urinary tract infection
 - Adult male and female
 - Sexually transmitted diseases

You can find a report compendium or download the full report at http://kidney.niddk.nih.gov/statistics/uda. You also can order the report in book form for \$10 or on CD-ROM for \$5 at www.catalog.niddk.nih.gov/materials.cfm?CH=NKUDIC.

Researchers Explore New Frontiers in IC Research

esearchers gathered in Bethesda, MD, last October to share research progress and explore "future frontiers" in the field of basic and clinical interstitial cystitis (IC) research.



"One major goal for the basic science network is to promote increased collaborations and interactions with the clinical community so that the basic science can be even more focused on questions of relevance to developing preventative strategies or clinical treatments."

Chris Mullins, Ph.D.

Director of basic cell biology programs in the NIDDK Division of Kidney, Urologic, and Hematologic Diseases

The "Basic Research in Interstitial Cystitis: Second Investigators Meeting," held on October 25, 2006, convened investigators who received funding from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health to promote a range of basic cellular, molecular, and genetic research and translational studies relevant to IC.

"One major goal for the basic science network is to promote increased collaborations and interactions with the clinical community so that the basic science can be even more focused on questions of relevance to developing preventative strategies or clinical treatments," said Chris Mullins, Ph.D., director of basic cell biology programs in the NIDDK Division of Kidney, Urologic, and Hematologic Diseases.

On October 26 and 27, a broader forum focused on the current research and clinical treatments and where they are headed during the "Frontiers in Painful Bladder Syndrome and Interstitial Cystitis 2006 International Symposium."

In 2003, the NIDDK began funding the IC Clinical Research Network (ICCRN), a cooperative network of 10 clinical research centers in the United States and Canada, along with one datacoordinating center. The purpose of the ICCRN is to propose, prioritize, develop, and conduct multicenter, clinical trial protocols related to IC and painful bladder syndrome (PBS) treatments and to conduct related ancillary research studies.

Baffling Condition

IC is a chronic, debilitating condition that affects about 1 million people, most of them women. Symptoms include pelvic, bladder, or perineal pain and an urgent and/or frequent feeling of having to urinate, sometimes as often as 18 times

a day. Treatments for IC are limited, as are their effectiveness.

Because IC symptoms and severity can vary greatly, most researchers believe IC is not one, but several diseases. In recent years, scientists have started to use the term PBS to describe cases with painful urinary symptoms that might not meet the strictest definition of IC.

The term IC is used alone when describing cases that meet a list of NIDDK-established criteria. The term IC/PBS includes all cases of urinary pain that cannot be attributed to other causes, such as infection or urinary stones.

Difficulties defining IC have contributed to problems in determining IC prevalence, said Philip Hanno, M.D., assistant clinical professor of urology at the Hospital of the University of Pennsylvania, during an epidemiology session on October 26. Wide ranges in prevalence estimates—from 1.6 per 100,000 women to 158 per 100,000 women—can be attributed to lack of a uniform definition of IC/PBS and readily available diagnostic marker(s), unknown etiology, uncertain pathophysiology, lack of standardized methodology, differences in the populations studied, and overlapping conditions and definitions.

Hanno said IC epidemiology could be improved through

- evidence-based, symptom-specific definitions
- studies of true incidence, prevalence, natural history, and risk factors
- the ability to differentiate IC/PBS from other causes of voiding dysfunction and bladder pain

IC RESEARCH, from page 3

Some of the IC studies underway include

- Events Preceding Interstitial Cystitis
 (EPIC)—a case-control study involving only
 women and designed to identify IC/PBS risk
 factors
- Boston Area Community Health Study—a study to
 - determine the prevalence of PBS by age, gender, race or ethnicity, and socioeconomic status
 - estimate the extent to which PBS symptoms overlap with psychosocial factors, such as sexual abuse or depression
 - determine the relative effects of PBS on quality of life
 - estimate the probable future magnitude of PBS
- RAND IC Epidemiology Study (RICE)—a study to
 - develop a case definition for IC in women for patient screening and epidemiological studies
 - develop and validate a symptom questionnaire to identify female IC patients through self-report
 - develop IC-specific self-report measures of functional status and disease burden
 - conduct first- and second-stage IC screening
 - describe the impact of IC on qualify of life compared with other diseases

Basic Research Progress

One of the goals of the basic research group that met on October 25 "is to gain a greater understanding of the disease at the molecular and cellular level," said Mullins. "An area that appears to hold promise for understanding the pathophysiology of IC, and possibly for defining the disorder, is biomarker discovery."

"A number of groups at the meeting presented work that uses cutting-edge approaches to identifying factors that appear differentially regulated in IC cells versus normal cells," Mullins said. "One such study presented by Brian Liu

of Brigham and Women's Hospital/Harvard Medical School described results identifying a number of autoantibodies that appear to be differentially expressed in IC patients versus non-IC patients, based on a 'reverse capture' immunoproteomics approach."

Other promising areas of research include characterizing urothelial cells and the impact of central nervous system changes on susceptibility to inflammation associated with IC.

Some of the key areas the group identified for further research include

- increased investigation of the crosssensitization process and better understanding of the central sensitization process, including somato-visceral and viscero-visceral convergence
- greater understanding of the comorbidity of PBS and other disorders
- determining which receptors are involved in bladder mast cell migration
- studies on urothelial differentiation, including molecular and functional markers, translation to clinic, and identifying whether IC subset has aberrant differentiation and if differentiation defects are associated with the disease
- etiopathology of other bladder dysfunctions and the relationship to IC/PBS
- new IC models based on dysfunction of urothelial differentiation, including tissue culture models and new animal models
- urothelial stem cell biology and cell heterogeneity
- development of several hypotheses regarding tissue- and disease-specific targets in IC
- investigations of glycosaminoglycan synthesis and degradation
- intravesical IC therapy challenges
- mechanisms of nociception in IC
- the search for other molecule targets
- case definition and pathogenesis of IC

A report summary of the October 26 to 27 meeting is available at www.niddk.nih.gov/fund/other/niddkfrontiers/frontiers%20in%20PBS%20 Summary%20Report.pdf.

NIDDK Website Offers New Resources

Interactive Health Education Tools and Image Library Now Live

ould you like to watch a video on your computer of a live surgical procedure to correct urinary incontinence? Or maybe you're interested in taking an interactive, online tutorial about erectile dysfunction.



With a new, interactive section of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) website, http://kidney.niddk.nih.gov/resources/HealthTools, you can do those things and much more.

- Test your health knowledge with online quizzes.
- Download digital recordings of radio broadcasts from the National Institutes of Health (NIH).
- Listen to audio files from NIH Research Radio.
- Monitor your health using online diet and exercise tools.



The Image Library, an online, searchable database of original full-color and black-and-white illustrations, is produced by the National Kidney and Urologic Diseases Information Clearinghouse and other NIDDK information clearinghouses.

These tools and resources from the NIH and the National Library of Medicine about urologic and kidney diseases are compiled into one section of the NIDDK website for ease in finding and accessing all that is available. Interactive tools are also available for diabetes at http://diabetes.niddk.nih.gov/resources/ Health Tools and digestive diseases at http://digestive.niddk.nih.gov/resources/HealthTools.

Image Library Live

Another new section of the NIDDK website is the Image Library, http://catalog.niddk.nih.gov/ImageLibrary, an online, searchable database of original full-color and black-and-white illustrations produced by the National Kidney and Urologic Diseases Information Clearinghouse and other NIDDK information clearinghouses. The library organizes the drawings into instructional, anatomical/medical, and lifestyle/activity categories. These illustrations are available copyright-free to the public at no cost, although the NIDDK should be credited as the source of each downloaded illustration. The illustrations are available in high, medium, and low resolutions.

New NIDDK Website Makes Debut

he National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) unveiled a new and improved website in September, offering the National Institutes of Health staff, researchers, and the general public more online information and resources in an easier-to-use format.

The website redesign features an improved look, better navigation, and more user-friendly functions. Users who visit www.niddk.nih.gov will now enjoy

- new "Scientific Areas" sections that enable researchers to easily find funding areas and opportunities in their field of interest with up-to-the-minute information about
 - special NIDDK initiatives
 - upcoming conferences
 - research resources
 - NIDDK staff contacts
- easier navigation for finding information about the kinds of science the NIDDK funds and instructions necessary for completing the grant application process
- a redesigned health education section for the public with basic information on diseases, along with statistic

diseases, along with statistics, links to additional resources, Spanish translations, and lists of available NIDDK publications

Many website improvements also occurred behind the scenes. "The new website now has a database-driven content management system, giving us much better tools to maintain it as a truly living document," said Maren Laughlin, Ph.D., senior adviser for integrative metabolism at the NIDDK. "The new, improved site structure should allow website visitors to more easily see all that is available to them." Laughlin served on the NIDDK 18-member content committee, one of two committees set up to rework the website's extramural sections.

More To Come

The recent facelift is only phase one of a three-part plan to revamp the entire NIDDK website. While the first phase focused on site architecture and updated content, phases two and three will put design and color to work to give the home page and other parts of the site a fresh look.

Final improvements include the addition of multimedia content and more database tools, such as

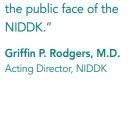
> an automated event calendar and an organizational chart to make finding staff contact information easier. Professional and NIDDK web staff also will have new, interactive, electronic tools to help update and maintain the website.

A user survey—the American Consumer Satisfaction Index—reported an 82 percent overall satisfaction rate with the health

information sections of the NIDDK website for November 2005 through January 2006.

That score is among the highest achieved by all participants in the survey, which is administered jointly by ForeSee Results and the University of Michigan. The NIDDK redesigned the health information sections 3 years ago and set the standard for this effort.

"Our website is truly the public face of the NIDDK," said NIDDK Acting Director Griffin P. Rodgers, M.D. "It facilitates the conversation that takes place among biomedical researchers at our universities and small businesses, the American public, and the Institute. With this new website, we hope to invite greater participation and better serve our mission of improved health for the American people."



"Our website is truly



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Updated NIDDK Publications

Kidney Failure: Choosing a Treatment That's Right for You

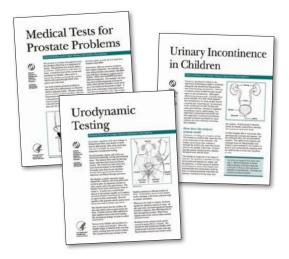
This booklet looks at three treatment options for people who develop kidney failure: hemodialysis, peritoneal dialysis, and kidney transplantation. It also explains the pros and cons of these treatments and the consequences of refusing or withdrawing from treatment.

Imaging of the Urinary Tract

This fact sheet explains imaging of the urinary tract, why it is done, the different available imaging techniques, how to prepare for the test, and what to expect during and after the test.

Medical Tests for Prostate Problems

Digital rectal examinations, prostate-specific antigen blood testing, urinalysis, and ultrasound are some of the medical tests doctors use to diagnose prostate problems. This fact sheet explains the tests and how to prepare for them and includes questions to discuss with health care providers.



To order, please call 1–800–891–5390 or visit www.kidney.niddk.nih.gov.



Peritoneal Dialysis Dose and Adequacy

Peritoneal dialysis removes wastes from the blood when the kidneys can't do the job. This fact sheet describes the two types of peritoneal dialysis—continuous ambulatory peritoneal dialysis and continuous cycler-assisted peritoneal dialysis—and how they work to help the body remove wastes.

Urinary Incontinence in Children

Many children experience occasional incontinence, and urinary incontinence in young people usually disappears over time. This resource explains how the urinary system works, the causes of daytime and nighttime incontinence, and available treatments.

Urodynamic Testing

Urodynamics is a study that assesses how the bladder and urethra are performing their job of storing and releasing urine. Urodynamic tests help your doctor or nurse see how well your bladder and sphincter muscles work and can help explain symptoms such as incontinence, frequent or painful urination, or recurrent urinary tract infections. This publication explains the testing process from pretest preparation through follow-up.

Publications, from page 7

Urinary Incontinence in Women

Millions of women have urinary incontinence, or loss of bladder control. Women experience urinary incontinence twice as often as men due to pregnancy and childbirth, menopause, and the

structure of the female urinary tract. Both women and men can become incontinent from neurologic injury, birth defects, strokes, multiple sclerosis, and physical problems associated with aging. While older women experience

incontinence more often than younger

women, it is not inevitable with age—incontinence is treatable and often curable at all ages. This fact sheet explains the different kinds of incontinence and how they are evaluated and treated. It also includes resources for finding more information.

Eat Right to Feel Right on Hemodialysis

This publication, part of the NIDDK's *Kidney Failure Series*, helps people on dialysis work

with their dietitians to choose the right foods for optimal health. It covers things to know about calories, diet supplements, fluids, phosphorus, potassium, and protein, and includes a list of cookbooks and other resources for more information.

Featured in the NIDDK Reference Collection

Bladder Training to Help Correct Urinary Incontinence

Urinary Incontinence

in Women

This online article describes bladder training, a behavior modification therapy for managing urinary incontinence. Bladder training can help the bladder hold urine better and decrease the urge to urinate by following a timetable to store and release urine. The article explains the basics of bladder training, the various causes of poor bladder control, urge suppression techniques, lifestyle guidelines to improve bladder control, and goals that can be achieved with bladder training. Some of the urge suppression techniques include different types of Kegel exercises and mental tricks to distract one's attention away from the urge to urinate.

Bladder control tips include drinking moderate volumes of fluid, emptying the bladder completely before bedtime and before and after sexual intercourse, reducing caffeine and alcohol intake, and not going to the bathroom unnecessarily. Readers are encouraged to learn to control their bladders, rather than letting their bladders control them.

Information about how to obtain a copy of the article is available on the NIDDK Reference Collection website at http://catalog.niddk.nih.gov/resources.