

Kidney Disease

Research Updates

National Kidney and Urologic Diseases Information Clearinghouse

Spring/Summer 2007

NIDDK Explores Key Clinical Research Opportunities in Kidney Disease

With kidney disease continuing to take a rising toll on public health and medical costs, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) turned to the extramural research community for input on designing studies to help reverse the trend.

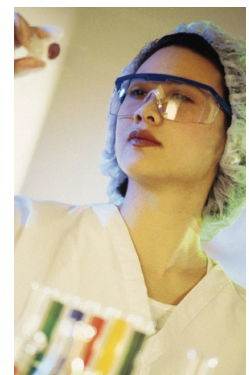
At a recent 2-day meeting of the researchers in Bethesda, MD, Robert Star, M.D., acting director of the NIDDK's Division of Kidney, Urologic, and Hematologic Diseases, stressed the sizable public health burden of all forms of renal disease.

A study from the U.S. Renal Data System for the Centers for Medicare and Medicaid Services found that treatment for people with chronic kidney disease (CKD) accounted for 19 percent of Medicare expenditures in 2002; treatment for people with end-stage renal disease (ESRD) accounted for another 7.8 percent.

In 2004, ESRD cost Medicare \$20 billion. The incidence of acute kidney injury (AKI) is increasing, according to Star, accelerating kidney function decline in some people with CKD. In addition, cardiovascular disease (CVD) accounts for half of all deaths among people with kidney failure.

With 10 large kidney studies scheduled to end between fiscal year 2007 and 2009, the NIDDK is seeking the most promising, compelling, and feasible opportunities that address what research is needed to reduce the morbidity and mortality of kidney disease.

In recommending topics for the NIDDK to study, participants were asked to consider if a concept addresses a profound public health concern in adults or children, will have a large potential economic impact, is answerable and feasible to start in 1 to 3 years, and is not likely to be addressed by others.



Meeting participants met in three groups to identify clinical research opportunities in key areas: AKI, CKD, and ESRD.

Acute Kidney Injury

The key challenges with AKI are identifying people at risk in order to carry out evaluation and undertake possible preventive measures; developing preventative and therapeutic agents; improving surveillance and care management of all patients, especially those who are high-risk;

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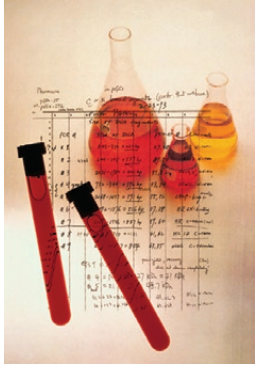


National Institute of
Diabetes and Digestive
and Kidney Diseases



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and gaining a better understanding of the natural history of AKI and how it accelerates CKD. The concepts participants recommended included

- studying treatment for patients with established AKI, involving, for example, careful volume resuscitation; and
- studying two observational cohorts to validate biomarkers with opportunities for targeted interventional studies to test new therapies. Patients would be studied with either timed AKI—for example, following cardiovascular surgery—or untimed injury, such as sepsis.

Chronic Kidney Disease

Although CKD rates have both improved and stabilized, awareness of CKD is low and implementation of secondary prevention is poor. The key challenges participants identified were the need for better diagnostic tests and use of current testing strategies, better understanding of group and individual variation, and testing new therapies targeting both progression of the renal disease itself as well as CVD.

The concepts recommended by the CKD group included

- determining whether treating systolic blood pressure to a lower goal than currently recommended reduces CVD illness and mortality in people who don't have diabetes but have at least one CVD risk factor
- developing improved renal functional measurements to better monitor CKD as well as genetic tests to identify people who are at risk

- determining if a therapy that lowers nocturnal blood pressure reduces CKD progression and CVD mortality
- examining the efficacy of novel drugs such as anti-fibrotic or cytoprotective agents to slow progressive renal decline
- testing whether bicarbonate preserves muscle mass, limits bone disease, and slows CKD progression

End-Stage Renal Disease

The key challenge in treating ESRD is that mortality remains stubbornly high, especially in the first year of hemodialysis. Studies have failed to show that increased dialysis dose improves outcomes. While fistula use in dialysis is associated with lower morbidity, mortality, and cost, 25 to 50 percent of fistulas fail to mature, increasing the risk of sepsis from temporary catheters.

The ESRD group proposed

- determining if the mortality and cardiovascular event rate could be reduced by beta blockers and renin angiotensin system blockers
- conducting an observational study to identify determinants of fistula maturation
- assessing the need for the invasive pretransplant evaluation of CVD in transplant candidates with a randomized, controlled study

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Kidney Disease Research Updates

Kidney Disease Research Updates, an email newsletter, is sent to subscribers by the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC). The newsletter features news about kidney disease, 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 www.kidney.niddk.nih.gov/about/newsletter.htm.



Executive Editor: Andrew Narva, M.D.

Andrew Narva, M.D., is the director of the National Kidney Disease Education Program (NKDEP) within the National Institute of Diabetes and Digestive and Kidney Diseases. Dr. Narva, a graduate of Harvard Medical School and board-certified in internal medicine and nephrology, served with the Indian Health Service before joining the NKDEP. He also was a member of the National Kidney and Urologic Diseases Advisory Board, the Renal Community Council of the U.S. Renal Data System, the Medical Review Board of End-Stage Renal Disease Network 15, and the National Kidney Foundation's Minority Outreach Committee, which he chaired.



Rodgers Named NIDDK Director

National Institutes of Health (NIH) Director Elias A. Zerhouni, M.D., announced the appointment of Griffin P. Rodgers, M.D., as director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) effective April 1, 2007.



Rodgers, who was appointed deputy director of the NIDDK in January 2001, has been the Institute's acting director. Rodgers also has served as chief of the NIDDK's Clinical and Molecular Hematology Branch since 1998.

As NIDDK director, Rodgers oversees an annual budget of \$1.8 billion and a staff of 650 scientists, physician-scientists, and administrators. The Institute conducts and supports research on many of the most serious health issues affecting the public, including diabetes, endocrinology, and metabolic diseases; digestive diseases and nutrition, including obesity; and kidney, urologic, and hematologic diseases.

"Griff Rodgers is an outstanding physician-scientist and molecular hematologist," said Zerhouni. "He has made singular contributions to the study of globin disorders and is internationally recognized for his contributions to the development of effective therapy for sickle cell disease and other genetic diseases of hemoglobin. In addition to his research experience, Dr. Rodgers is a dedicated and knowledgeable clinician and a first-rate research administrator. He has all the qualities we seek in an Institute director."

Rodgers received his undergraduate, graduate, and medical degrees from Brown University. He completed his residency and chief residency in internal medicine at Barnes Hospital and the Washington University School of Medicine. His fellowship training in hematology/oncology was in a joint NIH program with George Washington University and the Washington DC Veterans Affairs Medical Center.

In addition to his medical and research training, Rodgers earned a master's degree in business administration, with a focus on the business of medicine, from the Johns Hopkins University in 2005.

As a research investigator, Rodgers is widely recognized for his contributions to the development of the first effective—and now U.S. Food and Drug Administration-approved—therapy for sickle cell disease. He was a principal investigator in clinical trials to develop therapy for patients with sickle cell disease and also performed basic research that focused on understanding the molecular basis of how certain drugs induce gamma-globin gene expression. He was honored for his research with numerous awards, including the 1998 Richard and Hinda Rosenthal Foundation Award, the 2000 Arthur S. Fleming Award, the Legacy of Leadership Award in 2002, and a Mastership from the American College of Physicians in 2005.

"It is truly an honor to be given the opportunity to lead an organization with a mission as far-reaching and varied as the NIDDK's," said Rodgers. "While the NIDDK has a long and distinguished history of accomplishment as an Institute, we must look to the future to capitalize on the opportunities for disease prevention that new technologies and discoveries are giving us. The health problems we face as a nation are real and the results of research offer substantive promise for solving the difficult questions faced by millions of Americans every day and the health professionals who treat them." ■

"Dr. Rodgers is a dedicated and knowledgeable clinician and a first-rate research administrator. He has all the qualities we seek in an Institute director."

Elias A. Zerhouni, M.D.
NIH Director

NIDDK Welcomes Seven New Members to Advisory Council

Seven new members have joined the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Advisory Council, which met in Bethesda, MD, on February 21. The Council meets three times a year to advise the NIDDK about its research portfolio.

Advisory Council members, who come from the scientific and lay communities, serve 4-year terms and provide second-level peer review of grant applications scored by scientific review groups. Council members are an important liaison between the research communities they represent and the NIDDK, which supports each community's research efforts. The new members are

Charles O. Elson, III, M.D., vice chair for research in the department of medicine and the Basil I. Hirschowitz chair in gastroenterology at the University of Alabama at Birmingham. Elson joins the Digestive Diseases and Nutrition (DDN) Subcommittee.

James W. Freston, M.D., Ph.D., the Boehringer Ingelheim chair of clinical pharmacology and professor emeritus at the University of Connecticut School of Medicine in Farmington. Freston, a member of the NIDDK-funded National Drug-Induced Liver Injury Network, joins the DDN Subcommittee.

Mark A. Magnuson, M.D., the Earl W. Sutherland Jr. professor of molecular physiology and biophysics and director of the center for stem cell biology at the Vanderbilt University School of Medicine in Nashville, TN. Magnuson joins the Diabetes, Endocrinology, and Metabolic Diseases Subcommittee.

William E. Mitch, M.D., the Gordon A. Cain professor of medicine and director of the division of nephrology at Baylor College of Medicine in Houston. Mitch joins the Kidney, Urologic, and Hematologic Diseases (KUH) Subcommittee.



NIDDK Director Griffin P. Rodgers, M.D. (standing front row, second from left), meets with new council members (front row from left) Lisa H. Richardson; William E. Mitch, M.D.; and (back row from left) Anthony J. Schaeffer, M.D.; Mark A. Magnuson, M.D.; James W. Freston, M.D., Ph.D.; Charles O. Elson, III, M.D.; and Patrick Tso, Ph.D.

Lisa H. Richardson, national emeritus chairperson of the board and volunteer for the Crohn's and Colitis Foundation of America. Richardson joins the DDN Subcommittee.

Anthony J. Schaeffer, M.D., the Herman L. Kretschmer professor and chairman of the department of urology at the Feinberg School of Medicine at Northwestern University in Chicago. Schaeffer joins the KUH Subcommittee.

Patrick Tso, Ph.D., professor of pathology, associate director of the Cincinnati Obesity Research Center, director of the Cincinnati Mouse Diabetes Phenotyping Center, and director of the Center for Lipid and Atherosclerosis Research at the University of Cincinnati College of Medicine. Tso joins the DDN Subcommittee. ■

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NKUDIC Answers More Than 8,000 Queries in 2006

The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) responded to 8,244 inquiries in 2006. About half of the inquiries were from the general public, patients, and their families or friends, while 22 percent were from nurses and dietitians.

Most of the inquiries—4,178—came through online orders. The NKUDIC also responded to 1,962 email messages; 1,462 phone calls; and 397 letters.

The NKUDIC inventory includes 125 publication titles. Last year, the Clearinghouse produced 10 new publications. The most popular Clearinghouse publications were

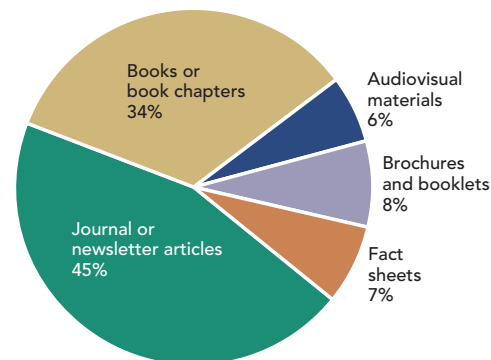
- *Your Kidneys and How They Work*
- *Kidney Failure: Choosing a Treatment That's Right for You*
- *High Blood Pressure and Kidney Disease*
- *Interstitial Cystitis/Painful Bladder Syndrome*

NIDDK Reference Collection

New items about kidney and urologic diseases are added continuously to the National Institute of Diabetes and Digestive and Kidney Diseases

(NIDDK) Reference Collection. More than 2,900 resources in the Reference Collection pertain to kidney and urologic diseases. The chart below depicts the kind of kidney and urologic diseases materials that are available through the Reference Collection. ■

Kidney and Urologic Diseases Materials Available From the NIDDK Reference Collection



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- conducting an observational study to determine the causes of the high mortality and morbidity in the first 90 days of dialysis
- developing optimal techniques to reduce the calcium-phosphorus product by dialysis and optimize use of vitamin D to reduce vascular calcification and CVD
- studying pediatric ESRD patients with a focus on adherence and neurocognitive function

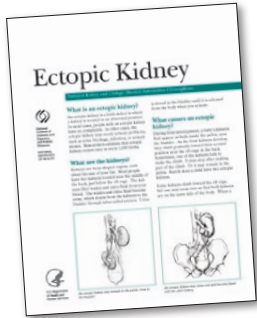
The NIDDK will review, clarify, and further develop these concepts for potential incorporation into the Institute's research agenda. For information about NIDDK clinical trials for kidney disease, visit www.kidney.niddk.nih.gov/clinicaltrials. ■

The large kidney studies scheduled to end between fiscal year 2007 and 2009 are the

- African American Study of Kidney Disease and Hypertension (AASK)
- Family Investigation of Nephropathy of Diabetes (FIND)
- Acute Renal Failure Trial Network (ATN) Dialysis Study
- Dialysis Access Clinical Trials Consortium (DAC)
- Frequent Hemodialysis Network (FHN)
- Folic Acid for Vascular Outcome Reduction in Transplantation (FAVORIT)
- Focal Segmental Glomerulosclerosis (FSGS)
- Randomized Intervention for Children With Vesicoureteral Reflux (RIVUR)
- Chronic Kidney Disease in Children Prospective Cohort Study (CKid)
- Chronic Renal Insufficiency Cohort (CRIC)

Ectopic Kidney

The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) has a new fact sheet about ectopic kidney, a birth defect in which a kidney is not located in its normal position. The five-page fact sheet provides an explanation of the condition, available tests, complications, and treatments. Researchers estimate that ectopic kidney occurs once in every 1,000 births. With proper testing and any necessary treatment, an ectopic kidney should not cause serious long-term health problems. To order a copy of the fact sheet, go to www.kidney.niddk.nih.gov.



Hemodialysis

The NKUDIC has updated the Spanish version of *Eat Right to Feel Right on Hemodialysis*. This booklet, part of the NKUDIC's Kidney Failure Series, helps people on dialysis work with their dietitians to choose the right foods for optimal health. The publication 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. Go to www.kidney.niddk.nih.gov/spanish/pubs/eatright for a copy of the booklet. ■



To order, please call
1-800-891-5389 or visit
<http://catalog.niddk.nih.gov>.

Featured in the NIDDK Reference Collection

Autosomal Recessive Polycystic Kidney Disease

Polycystic kidney disease (PKD) comes in two hereditary forms: autosomal dominant PKD, the most common of all life-threatening genetic diseases; and autosomal recessive PKD, or ARPKD, a relatively rare disease often causing significant mortality in the first month of life.

Your Child, Your Family, and Autosomal Recessive Polycystic Kidney Disease, a 26-page brochure from the PKD Foundation, answers basic questions about ARPKD, categorizing the topics into seven areas: general information, genetics, diagnosis, prenatal diagnosis, medical care, family supports, and research efforts. The brochure also briefly summarizes the goals and work of the PKD Foundation, a nonprofit organization devoted to research programs to determine the cause of PKD and to improve clinical treatment and discover a cure. The brochure is available for \$15—\$10 for members—from the PKD Foundation, 9221 Ward Parkway, Suite 400, Kansas City, MO 64114, 1-800-PKD-CURE (753-2873), pkdcure@pkdcure.org.

For additional resources about kidney disease, visit the NIDDK Reference Collection at <http://catalog.niddk.nih.gov/resources>. The Reference Collection is a free, online, searchable database to help health care professionals, health educators, patients, and the general public find educational materials not typically referenced in most databases. ■

NKDEP Forms Federal Kidney Network

The National Kidney Disease Education Program (NKDEP) is spearheading an effort to improve coordination in the Federal response to chronic kidney disease (CKD) care with the creation of the Kidney Federal Agency Network (KFAN).



As the KFAN coordinator, the NKDEP creates and distributes a quarterly newsletter, *KFA News*, highlighting Government CKD activities.

The KFAN is an informal group of Government professionals involved in CKD activities. The network also includes those who serve populations at risk for CKD, such as people with diabetes, African Americans, and older adults. The purpose of the network is to share knowledge and tools to help coordinate goals, messages, and activities related to CKD.

“Many agencies and divisions within the Health and Human Services Department lead some aspect of the multifaceted response to CKD, such as surveillance, detection, treatment, health

care quality and access, transportation, and dialysis,” said NKDEP Director Andrew Narva, M.D. “To date, these efforts have been mostly uncoordinated, creating some contradictions, redundancies, and gaps.”

As the KFAN coordinator, the NKDEP creates and distributes a quarterly newsletter, *KFA News*, highlighting Government CKD activities, and convenes meetings for KFAN members to discuss goals and ways to work together. For a copy of *KFA News*, contact the NKDEP at nkdep@info.niddk.nih.gov. ■

Upcoming Meetings, Workshops, and Conferences

NKUDIC Information Available at National Exhibits

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) distributes materials and information from its clearinghouses at various conferences throughout the year. Look for the NIDDK or the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) exhibit booth at the following upcoming conferences:

American Academy of Physician Assistants 35th Annual Conference

May 26 to 31 in Philadelphia. For more information, visit www.aapa.org/annual-conf/index.html.

American Academy of Nurse Practitioners 22nd National Conference

June 20 to 24 in Indianapolis. For more information, visit www.aanp.org/Conferences/2007+Conference/2007+Conference.asp.

American Academy of Family Physicians Scientific Assembly

October 3 to 6 in Chicago. For more information, visit www.aafp.org/online/en/home/cme/aafpcourses/conferences/assembly.html.

American Academy of Pediatrics National Conference and Exhibition

October 26 to 30 in San Francisco. For more information, visit www.aap.org/profed/precfa.htm.

American Society of Nephrology Renal Week

October 31 to November 5 in San Francisco. For more information, visit www.asn-online.org. ■