

## National Kidney & Urologic Diseases Information Clearinghouse (NKUDIC)



## Directory of Kidney and Urologic Diseases Organizations

This directory lists Government agencies and professional and voluntary associations that provide information and resources related to kidney and urologic diseases. Some of these organizations offer educational materials and other services to patients and the general public, while others primarily serve health care providers.

### NIDDK-funded George M. O'Brien Kidney and Urologic Research Centers

#### **George M. O'Brien Kidney Center at Yale**

Peter Aronson, M.D., Director  
Yale School of Medicine  
P.O. Box 208029  
1 Gilbert Street, TAC S255  
New Haven, CT 06520-8029  
Phone: 203-785-4184  
Fax: 203-785-7068  
Email: [peter.aronson@yale.edu](mailto:peter.aronson@yale.edu)  
Internet: <http://obriencenter.yale.edu>

#### **George M. O'Brien Urology Research Center at the University of Pennsylvania**

Samuel K. Chacko, D.V.M., Ph.D., Director  
University of Pennsylvania  
Glenolden Research Laboratory  
500 South Ridgeway Avenue  
Glenolden, PA 19036-2307  
Phone: 267-350-9603  
Fax: 267-350-9610  
Email: [chackosk@mail.med.upenn.edu](mailto:chackosk@mail.med.upenn.edu)  
Internet:  
[www.uphs.upenn.edu/surgery/Research/urology/Chacko/george\\_obrien\\_program.html](http://www.uphs.upenn.edu/surgery/Research/urology/Chacko/george_obrien_program.html)

**Mayo Clinic O'Brien Urology Research Center**

John C. Lieske, M.D., Director  
Mayo Clinic  
200 First Street SW  
Rochester, MN 55905  
Phone: 507-266-7960  
Fax: 507-266-9315  
Email: Lieske.John@mayo.edu  
Internet: [www.mayo.edu/research/labs/nephrolithiasis/overview](http://www.mayo.edu/research/labs/nephrolithiasis/overview)

**Pittsburgh Center for Kidney Research**

Thomas, Kleyman, M.D., Director  
Email: [kleyman@pitt.edu](mailto:kleyman@pitt.edu)  
Internet: [www.kidneycenter.pitt.edu/index.html](http://www.kidneycenter.pitt.edu/index.html)

**UAB-UCSD O'Brien Core Center for Acute Kidney Injury**

Anupam Agarwal, M.D., Director  
University of Alabama/University of California at San Diego  
Phone: 205-996-6670  
Email: [agarwal@uab.edu](mailto:agarwal@uab.edu)  
Internet: [www.uab.edu/medicine/obriencenter/](http://www.uab.edu/medicine/obriencenter/)

**NIDDK-funded Research Centers of Excellence in Pediatric Nephrology**

**Center of Excellence in Pediatric Nephrology at the Medical College of Wisconsin**

Ellis D. Avner, M.D., Director  
Children's Hospital Health System  
8701 Watertown Plank Road  
Milwaukee, WI 53226  
Phone: 414-955-2573  
Fax: 414-955-6329  
Email: [eavner@mcw.edu](mailto:eavner@mcw.edu)  
Internet: [www.chw.org/research](http://www.chw.org/research)

## **Government Agencies and Professional and Voluntary Organizations**

### **Alport Syndrome Foundation (ASF)**

1608 East Briarwood Terrace  
Phoenix, AZ 85048-9414  
Phone/Fax: 480-800-3510  
Email: [info@alportsyndrome.org](mailto:info@alportsyndrome.org)  
Internet: [www.alportsyndrome.org](http://www.alportsyndrome.org)

**Mission:** To educate and support patients and families that have been affected by Alport syndrome with the goal of funding research to find more effective treatment protocols and a cure.

#### ***Services provided:***

Patient registry  
Resources  
Support groups

### **American Association of Clinical Urologists (AACU)**

Two Woodfield Lake  
1100 East Woodfield Road, Suite 350  
Schaumburg, IL 60173  
Phone: 847-517-1050  
Fax: 847-517-7229  
Email: [info@aacuweb.org](mailto:info@aacuweb.org)  
Internet: [www.aacuweb.org](http://www.aacuweb.org)

**Mission:** To promote and preserve the professional autonomy and financial viability of our members and to inform members of the issues affecting their practice and profession, and then to work directly to influence the resolutions of these issues.

#### ***Services provided:***

Advocacy and public policy  
Educational meetings and events for health care providers

## **American Association of Genitourinary Surgeons (AAGUS)**

Loyola University Medical Center  
Department of Urology  
Fahey Building 54, Room 267  
2160 South First Avenue  
Maywood, IL 60153  
Phone: 708-216-5100  
Fax: 708-216-8991  
Email: [jsofia@lumc.edu](mailto:jsofia@lumc.edu)  
Internet: [www.aagus.org](http://www.aagus.org)

**Mission:** To promote the study of diseases of the genitourinary system.

### ***Services provided:***

Educational meetings and events for health care providers

## **American Association of Kidney Patients (AAKP)**

2701 North Rocky Point Drive, Suite 150  
Tampa, FL 33607  
Phone: 1-800-749-2257 or 813-636-8100  
Fax: 813-636-8122  
Email: [info@aakp.org](mailto:info@aakp.org)  
Internet: [www.aakp.org](http://www.aakp.org)

**Mission:** To improve the quality of life for kidney patients through education, advocacy, and fostering patient communities.

### ***Services provided:***

Advocacy and public policy  
Educational programs and events for health care providers  
Publications for patients  
Resources  
Support groups

## **American Association of Sexuality Educators, Counselors, and Therapists (AASECT)**

1444 I Street NW, Suite 700  
Washington, D.C. 20005  
Phone: 202-449-1099  
Fax: 202-216-9646  
Email: [info@aasect.org](mailto:info@aasect.org)  
Internet: [www.aasect.org](http://www.aasect.org)

**Mission:** To promote sexual health by developing and advancing the fields of sexual therapy, counseling, and education.

**Services provided:**

Continuing education  
Publications for patients  
Resources

**American Board of Urology (ABU)**

Gerald H. Jordan, M.D.  
Executive Secretary  
American Board of Urology  
600 Peter Jefferson Parkway, Suite 150  
Charlottesville, VA 22911  
Phone: 434-979-0059  
Fax: 434-979-0266  
Email: denise@abu.org  
Internet: www.abu.org

**Mission:** To ensure high-quality, safe, efficient, and ethical practice of urology by establishing and maintaining standards of certification for urologists.

**Services provided:**

Certification activities  
Publications for health care providers

**American Kidney Fund (AKF)**

11921 Rockville Pike, Suite 300  
Rockville, MD 20852  
Phone: 1-800-638-8299  
Internet: www.kidneyfund.org

**Mission:** To fight kidney disease through direct financial support to patients in need, health education, and prevention efforts.

**Services provided:**

Advocacy and public policy  
Continuing medical education (CME)  
Free kidney health screenings  
Publications for patients  
Resources

### **American Nephrology Nurses' Association (ANNA)**

East Holly Avenue, Box 56  
Pitman, NJ 08071-0056  
Phone: 1-888-600-2662 or 856-256-2320  
Fax: 856-589-7463  
Email: [anna@ajj.com](mailto:anna@ajj.com)  
Internet: [www.annanurse.org](http://www.annanurse.org)

**Mission:** To promote excellence in and appreciation of nephrology nursing in order to make a positive difference for people with kidney disease.

#### ***Services provided:***

Advocacy and public policy  
Certification activities  
Chapter locator  
Continued nurses education (CNE)  
Educational programs and events for health care providers  
Publications for health care providers and patients

### **American Prostate Society**

10 East Lee Street, Suite 1504  
Baltimore, MD 21202  
Phone: 1-877-850-3735 or 410-837-3735 (Tuesday and Friday only)  
Fax: 410-837-8510  
Email: [info@americanprostatesociety.com](mailto:info@americanprostatesociety.com)  
Internet: [www.americanprostatesociety.com](http://www.americanprostatesociety.com)

**Mission:** To increase knowledge of all three prostate diseases plus erectile dysfunction through quarterly newsletters and responding to individual questions or requests for help.

#### ***Services provided:***

Resources

### **American Society for Histocompatibility and Immunogenetics (ASHI)**

15000 Commerce Parkway, Suite C  
Mt. Laurel, NJ 08054  
Phone: 856-638-0428  
Fax: 856-439-0525  
Email: [info@ashi-hla.org](mailto:info@ashi-hla.org)  
Internet: [www.ashi-hla.org](http://www.ashi-hla.org)

**Mission:** To advance the science, education, and application of immunogenetics and transplant immunology.

**Services provided:**

Accreditation activities  
Certification activities  
Continuing education activities  
Educational programs and events for health care providers  
Publications for health care providers

**American Society of Nephrology (ASN)**

1510 H Street NW, Suite 800  
Washington, D.C. 20005  
Phone: 202-640-4660  
Fax: 202-637-9793  
Email: [email@asn-online.org](mailto:email@asn-online.org)  
Internet: [www.asn-online.org](http://www.asn-online.org)

**Mission:** To lead the fight against kidney disease by educating health professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients.

**Services provided:**

Advocacy and public policy  
Continuing medical education (CME)  
Educational programs and events for health care providers  
Publications for health care providers  
Research

**American Society of Pediatric Nephrology (ASPN)**

3400 Research Forest Drive, Suite B-7  
The Woodlands, TX 77381  
Phone: 281-419-0052  
Fax: 281-419-0082  
Email: [info@aspneph.com](mailto:info@aspneph.com)  
Internet: [www.aspneph.com](http://www.aspneph.com)

**Mission:** To promote optimal care for children with kidney disease through advocacy, education, and research; and to disseminate advances in clinical practice and scientific investigation.

**Services provided:**

Advocacy and public policy  
Educational programs and events for health care providers

### **American Society of Transplantation (AST)**

15000 Commerce Parkway, Suite C  
Mt. Laurel, NJ 08054  
Phone: 856-439-9986  
Fax: 856-439-9982  
Email: [info@myAST.org](mailto:info@myAST.org)  
Internet: [www.myast.org](http://www.myast.org)

**Mission:** To advance the field of transplantation and improve patient care by promoting research, education, advocacy, and organ donation.

#### ***Services provided:***

Advocacy and public policy  
Educational programs and events for health care providers  
Publications for health care providers and patients

### **American Society of Transplant Surgeons (ASTS)**

2461 South Clark Street, Suite 640  
Arlington, VA 22202  
Phone: 703-414-7870  
Fax: 703-414-7874  
Email: [asts@asts.org](mailto:asts@asts.org)  
Internet: [www.asts.org](http://www.asts.org)

**Mission:** To foster and advance the practice and science of transplantation for the benefit of patients and society; guide those who make the policy decisions that influence the practice and science of transplantation; increase organ donation; define and promote training and the career-long education of transplant surgeons, scientists, and physicians; and advance the professional development and careers of transplant surgeons, scientists, and physicians.

#### ***Services provided:***

Advocacy and public policy  
Continuing medical education (CME)  
Educational programs and events for health care providers  
Publications for health care providers and patients

### **American Urogynecologic Society (AUGS)**

2025 M Street NW, Suite 800  
Washington, D.C. 20036  
Phone: 202-367-1167  
Fax: 202-367-2167  
Email: [info@aug.org](mailto:info@aug.org)  
Internet: [www.augs.org](http://www.augs.org)

**Mission:** To promote the highest quality patient care through excellence in education, research, and advocacy.

**Services provided:**

Advocacy and public policy  
Educational programs and events for health care providers  
Publications for health care providers and patients

**American Urological Association (AUA)**

1000 Corporate Boulevard  
Linthicum, MD 21090  
Phone: 1-866-RING-AUA (1-866-746-4282) or 410-689-3700  
Fax: 410-689-3800  
Email: [aua@auanet.org](mailto:aua@auanet.org)  
Internet: [www.auanet.org](http://www.auanet.org)

**Mission:** To promote the highest standards of urological clinical care through education, research, and the formulation of health care policy.

**Services provided:**

Advocacy and public policy  
Clinical guidelines and policy statements  
Continued medical education (CME)  
Educational programs and events for health care providers  
Publications for health care providers and patients

**Amyloidosis Foundation, Inc.**

7151 North Main Street, Suite 2  
Clarkston, MI 48346  
Phone: 1-877-AMYLOID (1-877-269-5643)  
Email: [info@amyloidosis.org](mailto:info@amyloidosis.org)  
Internet: [www.amyloidosis.org](http://www.amyloidosis.org)

**Mission:** To increase education and awareness of amyloidosis within the community, leading to earlier diagnosis and improved treatment.

**Services provided:**

Patient information and publications  
Educational meetings and events for health care providers  
Research  
Resources

### **Amyloidosis Support Groups, Inc.**

232 Orchard Drive  
Wood Dale, IL 60191  
Phone: 1-866-404-7539 or 847-350-7540  
630-350-7539 (evening)  
Fax: 847-350-0577  
Email: [muriel@finkelsupply.com](mailto:muriel@finkelsupply.com) or [mangelamy@yahoo.com](mailto:mangelamy@yahoo.com)  
Internet: [www.amyloidosisupport.com](http://www.amyloidosisupport.com)

**Mission:** To provide peer group support to patients, caregivers, families, and friends of those touched by amyloidosis.

#### ***Services provided:***

Patient information and publications  
Resources  
Support

### **ASAIO (Formerly the American Society for Artificial Internal Organs)**

7700 Congress Avenue, Suite 3107  
Boca Raton, FL 33487-1356  
Phone: 561-999-8969  
Fax: 561-999-8972  
Email: [info@asaio.com](mailto:info@asaio.com)  
Internet: [www.asaio.com](http://www.asaio.com)

**Mission:** To advance the research, development, and medical application of bionic technologies.

#### ***Services provided:***

Educational programs and events for health care providers  
Resources

### **Autosomal Recessive Polycystic Kidney Disease & Congenital Hepatic Fibrosis (ARPKD/CHF) Alliance**

P.O. Box 70  
Kirkwood, PA 17536  
Phone: 1-800-708-8892 or 717-529-5555  
Fax: 1-800-807-9110  
Email: [info@arpkdchf.org](mailto:info@arpkdchf.org)  
Internet: [www.arpkdchf.org](http://www.arpkdchf.org)

**Mission:** To educate, advocate, support, and advance research specific to ARPKD/CHF and improve the lives of those affected.

***Services provided:***

Publications for health care providers and patients  
Public service announcements (PSAs)  
Support groups

**Cystinuria Support Network**

Internet: [www.cystinuria.com](http://www.cystinuria.com)

***Mission:*** To support persons with cystinuria and their families, friends, and caregivers.

***Services provided:***

Resources

**Endourological Society**

4100 Duff Place, Lower Level  
Seaford, NY 11783  
Phone: 516-520-1224  
Fax: 516-520-1225  
Email: [michelelij@aol.com](mailto:michelelij@aol.com)  
Internet: [www.endourology.org](http://www.endourology.org)

***Mission:*** To facilitate scientific dialogue among endourologists worldwide in the form of annual meetings, circulation of scientific literature, and surgical skill training courses/hands on laboratory sessions.

***Services provided:***

Educational programs and events for health care providers  
Publications for health care providers and patients

**Fistula First Breakthrough Initiative**

I PRO ESRD Network Coordinating Center  
1979 Marcus Avenue, Suite 105  
Lake Success, NY 11042  
Phone: 516-209-5306  
Fax: 516-326-7805  
Email: [FFBI@ncc.esrd.net](mailto:FFBI@ncc.esrd.net)  
Internet: [www.fistulafirst.org](http://www.fistulafirst.org)

***Mission:*** To improve the survival and quality of life of hemodialysis patients by optimizing vascular access selection—which for most patients will be an AV fistula—to lower infection, hospitalization, and mortality rates while preserving vital Medicare resources.

***Services provided:***

Resources

**Hereditary Nephritis Foundation (HNF)**

Internet: [www.cc.utah.edu/~cla6202/HNF.htm](http://www.cc.utah.edu/~cla6202/HNF.htm)

***Mission:*** To promote research into the causes of and cures for hereditary nephritis and to provide up-to-date general information about Alport syndrome and related conditions to patients, families, and physicians.

***Services provided:***

Resources

**IgA Nephropathy Foundation of America**

P.O. Box 1322  
Wall Township, NJ 07719  
Phone: 732-770-7377  
Email: [info@iganephropathy.org](mailto:info@iganephropathy.org)  
Internet: [www.iganephropathy.org](http://www.iganephropathy.org)

***Mission:*** To eradicate IgA nephropathy while also addressing the many problems faced by the patients and their families.

***Services provided:***

Resources

**IgA Nephropathy Support Network**

89 Ashfield Road  
Shelburne Falls, MA 01370  
Phone: 413-625-9339  
Internet: [www.igansupport.org](http://www.igansupport.org)

***Mission:*** To assist patients with IgA nephropathy and their families, serve as a clearinghouse for dissemination of information about IgA nephropathy, and promote research for a possible cure.

***Services provided:***

Resources

### **International Pediatric Nephrology Association (IPNA)**

10833 Le Conte Avenue, A2-383 MDCC  
Los Angeles, CA 90095-1752  
Phone: 310-694-8250  
Fax: 310-694-3552  
Email: [suzanne@ipna-online.org](mailto:suzanne@ipna-online.org)  
Internet: [www.ipna-online.org](http://www.ipna-online.org)

**Mission:** To disseminate knowledge about kidney diseases in children in the areas where care is needed most.

#### ***Services provided:***

Educational programs and events for health care providers  
Publications for health care providers

### **International Society of Nephrology (ISN)**

340 North Avenue, 3rd Floor  
Cranford, NJ 07016-2496  
Phone: 567-248-9703  
Fax: 908-272-7101  
Internet: [www.theisn.org](http://www.theisn.org)

**Mission:** To advance the diagnosis, treatment, and prevention of kidney diseases in the developing and developed world.

#### ***Services provided:***

Continuing medical education (CME)  
Educational programs and events for health care providers  
Publications for health care providers

### **International Transplant Nurses Society (ITNS)**

8735 West Higgins Road, Suite 300  
Chicago, IL 60631  
Phone: 847-375-6340  
Fax: 847-375-6341  
Email: [info@itns.org](mailto:info@itns.org)  
Internet: [www.itns.org](http://www.itns.org)

**Mission:** To promote excellence in transplant clinical nursing through the provision of educational and professional growth opportunities, interdisciplinary networking and collaborative activities, and nursing research.

***Services provided:***

Educational programs and events for health care providers  
Publications for health care providers and patients

**Interstitial Cystitis Association (ICA)**

1760 Old Meadow Road, Suite 500  
McLean, VA 22102  
Phone: 703-442-2070  
Fax: 703-506-3266  
Email: [icamail@ichelp.org](mailto:icamail@ichelp.org)  
Internet: [www.ichelp.org](http://www.ichelp.org)

***Mission:*** To promote early diagnosis and optimal care with dignity for people affected by IC.

***Services provided:***

Educational programs and events for health care providers  
Publications for health care providers and patients

**Kidney & Urology Foundation of America**

2 West 47th Street, Suite 401  
New York NY 10036  
Phone: 1-800-633-6628 or 212-629-9770  
Fax: 212-629-5652  
Internet: [www.kidneyurology.org](http://www.kidneyurology.org)

***Mission:*** To provide care and support of patients, address the concerns of those at risk, educate the community and medical professionals, develop methods of prevention, and improve treatment options.

***Services provided:***

Resources

**Kidney Cancer Association (KCA)**

P.O. Box 96503 #38269  
Washington, D.C. 20090-6503  
Phone: 1-800-850-9132 or 847-332-1051 (international)  
Fax: 847-332-2978  
Email: [office@kidneycancer.org](mailto:office@kidneycancer.org)  
Internet: [www.kidneycancer.org](http://www.kidneycancer.org)

**Mission:** To fund, promote, and collaborate with the National Cancer Institute, American Society for Clinical Oncology, American Urological Association, and other institutions on research projects to educate families and physicians, and serve as an advocate on behalf of patients at the state and federal levels.

**Services provided:**

Educational programs and events for health care providers  
Publications for health care providers and patients  
Support group locator

**Kidney Disease: Improving Global Outcomes (KDIGO)**

Email: [KDIGOcommunications@kdigo.org](mailto:KDIGOcommunications@kdigo.org)  
Internet: [www.kdigo.org](http://www.kdigo.org)

**Mission:** To improve the care and outcomes of kidney disease patients worldwide through promoting coordination, collaboration, and integration of initiatives to develop and implement clinical practice guidelines.

**Services provided:**

Clinical practice guidelines  
Publications for health care providers  
Resources

**Medical Education Institute, Inc. (MEI)**

414 D'Onofrio Drive, Suite 200  
Madison, WI 53719  
Phone: 1-800-468-7777 or 608-833-8033  
Fax: 608-833-8366  
Internet: [www.meiresearch.org](http://www.meiresearch.org), [www.lifeoptions.org](http://www.lifeoptions.org), [www.kidneyschool.org](http://www.kidneyschool.org),  
[www.homedialysis.org](http://www.homedialysis.org)

**Mission:** To help people with chronic diseases learn to manage and improve their health.

**Services provided:**

Continuing medical education (CME)  
Publications for health care providers and patients

**NATCO** (Formerly the North American Transplant Coordinators Organization)

P.O. Box 15384  
Lenexa, KS 66285-5384  
Phone: 913-895-4612  
Fax: 913-895-4652  
Email: natco-info@goAMP.com  
Internet: www.natco1.org

**Mission:** To support, develop, and advance the knowledge and practice of its members and to influence the effectiveness, quality, and integrity of donation and transplantation.

**Services provided:**

Advocacy and public policy  
Certification activities  
Continuing education activities  
Educational programs, meetings, and events for health care providers  
Publications for health care providers

**National Association for Continence (NAFC)**

P.O. Box 1019  
Charleston, SC 29402-1019  
Phone: 1-800-BLADDER (1-800-252-3337) or 843-377-0900  
Fax: 843-377-0905  
Email: memberservices@nafc.org  
Internet: www.nafc.org

**Mission:** To improve the quality of life of people with incontinence, voiding dysfunction, and related pelvic floor disorders, and to be the leading source for public education and advocacy about the causes, prevention, diagnosis, treatments, and management alternatives for incontinence.

**Services provided:**

Educational programs and events for health care providers  
Information for the media  
Publications for health care providers and patients  
Support groups

**National Association of Nephrology Technicians/Technologists (NANT)**

11 West Monument Avenue  
Dayton, OH 45402  
Phone: 1-877-607-NANT (1-877-607-6268) or 937-586-3705  
Fax: 937-586-3699  
Internet: www.dialysistech.net

**Mission:** To promote the highest quality of care for chronic kidney disease patients through education and professionalism.

**Services provided:**

Educational programs and events for health care providers  
Publications for health care providers

**National Diabetes Education Program (NDEP)**

1 Diabetes Way  
Bethesda, MD 20814–9692  
Phone: 1–888–693–NDEP (1–888–693–6337)  
TTY: 1–866–569–1162  
Fax: 703–738–4929  
Email: [ndep@mail.nih.gov](mailto:ndep@mail.nih.gov)  
Internet: [www.ndep.nih.gov](http://www.ndep.nih.gov) or [www.yourdiabetesinfo.org](http://www.yourdiabetesinfo.org)

**Mission:** To improve the treatment and outcomes for people with diabetes, to promote early diagnosis, and to prevent or delay the onset of diabetes.

**Services provided:**

Community outreach programs  
Information for the media  
Publications for health care providers and patients  
Public service campaign materials

**National Diabetes Information Clearinghouse (NDIC)**

1 Information Way  
Bethesda, MD 20892–3560  
Phone: 1–800–860–8747  
TTY: 1–866–569–1162  
Fax: 703–738–4929  
Email: [ndic@info.niddk.nih.gov](mailto:ndic@info.niddk.nih.gov)  
Internet: [www.diabetes.niddk.nih.gov](http://www.diabetes.niddk.nih.gov)

**Mission:** To increase knowledge and understanding about diabetes among patients, health care professionals, and the general public. To carry out this mission, the NDIC works closely with the NIDDK's Diabetes Research Centers; the National Diabetes Education Program (NDEP); professional, patient, and voluntary associations; Government agencies; and state health departments to identify and respond to informational needs about diabetes and its management.

**Services provided:**

Publications for health care providers and patients  
Resources

### **National Foundation for Transplants (NFT)**

5350 Poplar Avenue, Suite 430  
Memphis, TN 38119  
Phone: 1-800-489-3863 or 901-684-1697  
Fax: 901-684-1128  
Email: [info@transplants.org](mailto:info@transplants.org)  
Internet: [www.transplants.org](http://www.transplants.org)

**Mission:** To empower patients to create futures with hope.

#### ***Services provided:***

Publications for health care providers and patients  
Resources

### **National Hospice and Palliative Care Organization/Caring Connections**

1731 King Street  
Alexandria, VA 22314  
Phone: 1-800-658-8898 or 703-837-1500  
Fax: 703-837-1233  
Email: [caringinfo@nhpco.org](mailto:caringinfo@nhpco.org)  
Internet: [www.caringinfo.org](http://www.caringinfo.org)  
[www.nhpco.org](http://www.nhpco.org)

**Mission:** To lead and mobilize social change for improved care at the end of life.

#### ***Services provided:***

Advocacy  
Continuing education  
Information for the media  
Resources

### **National Kidney Disease Education Program (NKDEP)**

3 Kidney Information Way  
Bethesda, MD 20892  
Phone: 1-866-4-KIDNEY (1-866-454-3639)  
TTY: 1-866-569-1162  
Fax: 301-402-8182  
Email: [nkdep@info.niddk.nih.gov](mailto:nkdep@info.niddk.nih.gov)  
Internet: [www.nkdep.nih.gov](http://www.nkdep.nih.gov)

**Mission:** To reduce the morbidity and mortality caused by kidney disease and its complications and to raise awareness of the seriousness of kidney disease, the importance of testing those at high risk—those with diabetes, high blood pressure, or a family history of kidney failure—and the availability of treatment to prevent or slow kidney failure.

**Services provided:**

Information for the media  
Publications for patients, health care providers, and laboratory professionals

**National Kidney Foundation (NKF)**

30 East 33rd Street  
New York, NY 10016–5337  
Phone: 1–800–622–9010 or 212–889–2210  
Fax: 212–689–9261  
Internet: [www.kidney.org](http://www.kidney.org)

**Mission:** To prevent kidney and urinary tract diseases, improve the health and well-being of individuals and families affected by kidney disease, and increase the availability of all organs for transplantation.

**Services provided:**

Advocacy and public policy  
Continuing medical education (CME)  
Educational programs and events for health care providers  
Publications for patients, health care providers, and laboratory professionals  
Public service announcements (PSAs)  
Publications for patients, health care providers, and laboratory professionals

**National Organization for Rare Disorders (NORD)**

55 Kenosia Avenue  
Danbury, CT 06810  
Phone: 1–800–999–6673 or 203–744–0100  
Fax: 203–798–2291  
Internet: [www.rarediseases.org](http://www.rarediseases.org)

**Mission:** To help people with rare “orphan” diseases and assist the organizations that serve them. The NORD is committed to the identification, treatment, and cure of rare disorders through education, advocacy, research, and service programs.

**Services provided:**

Advocacy and public policy  
Publications for health care providers and patients  
Rare disease database

**NDI Foundation** (*Formerly the Nephrogenic Diabetes Insipidus Foundation*)

Main Street  
P.O. Box 1390  
Eastsound, WA 98245  
Phone: 1-888-376-6343  
Fax: 1-888-376-6356  
Email: info@ndif.org  
Internet: www.ndif.org

**Mission:** To support education, research, treatment, and a cure for NDI and to create a communication channel to serve the entire NDI community: patients and their families, researchers, physicians, and other health care providers.

**Services provided:**

Resources

**The NephCure Foundation**

15 Waterloo Avenue  
Berwyn, PA 19312  
Phone: 1-866-NephCure (1-866-637-4287)  
Email: info@nephcure.org  
Internet: www.nephcure.org

**Mission:** To support research seeking the cause of the potentially debilitating kidney diseases nephrotic syndrome and focal segmental glomerulosclerosis, improve treatment, and find a cure.

**Services provided:**

Educational programs and events for health care providers  
Support groups

**Oxalosis and Hyperoxaluria Foundation (OHF)**

201 East 19th Street, Suite 12E  
New York, NY 10003  
Phone: 1-800-OHF-8699 (1-800-643-8699) or 212-777-0470  
Fax: 212-777-0471  
Internet: www.ohf.org

**Mission:** To promote research to find a cure for oxalosis, primary hyperoxaluria, and related stone diseases and improve the care and treatment of those they affect.

**Services provided:**

Advocacy and public policy  
Resources

**PKD Foundation**

8330 Ward Parkway, Suite 510  
Kansas City, MO 64114  
Phone: 1-800-PKD-CURE (1-800-753-2873) or 816-931-2600  
Fax: 816-931-8655  
Email: [pkdcure@pkdcure.org](mailto:pkdcure@pkdcure.org)  
Internet: [www.pkdcure.org](http://www.pkdcure.org)

**Mission:** To promote programs of research, advocacy, education, support, and awareness in order to discover treatments and a cure for polycystic kidney disease and improve the lives of all it affects.

**Services provided:**

Advocacy and public policy  
Educational programs and events for health care providers  
Publications for patients

**The Prostatitis Foundation**

1063 30<sup>th</sup> Street  
Smithshire, IL 61478  
Phone: 1-888-891-4200 or 309-325-7184  
Fax: 309-325-7189  
Internet: [www.prostatitis.org](http://www.prostatitis.org)

**Mission:** To provide support to men with prostatitis and to push for prostatitis research funding.

**Services provided:**

Support groups

### **Renal Physicians Association (RPA)**

1700 Rockville Pike, Suite 220  
Rockville, MD 20852  
Phone: 301-468-3515  
Fax: 301-468-3511  
Email: [rpa@renalmd.org](mailto:rpa@renalmd.org)  
Internet: [www.renalmd.org](http://www.renalmd.org)

**Mission:** To represent and serve the interests of nephrology practitioners in their pursuit and delivery of quality renal health care.

#### ***Services provided:***

Advocacy and public policy  
Educational programs and events for health care providers  
Publications for health care providers

### **Renal Support Network (RSN)**

1311 North Maryland Avenue  
Glendale, CA 91207  
Phone: 1-866-903-1728 or 818-543-0896  
Fax: 818-244-9540  
Internet: [www.rsnhope.org](http://www.rsnhope.org)

**Mission:** To help patients develop their personal coping skills, special talents, and employability by educating and empowering them—and their family members—to take control of the course and management of the disease and to provide lawmakers and policymakers with the patients' perspective on the needs and capabilities of people with chronic kidney disease.

#### ***Services provided:***

Advocacy and public policy  
Information for the media  
Publications for patients  
Resources  
Support groups

### **The Simon Foundation for Continence**

P.O. Box 815  
Wilmette, IL 60091  
Phone: 1-800-23-SIMON (1-800-237-4666) or 847-864-3913  
Fax: 847-864-9758  
Email: [info@simonfoundation.org](mailto:info@simonfoundation.org)  
Internet: [www.simonfoundation.org](http://www.simonfoundation.org)

**Mission:** To bring the topic of incontinence out into the open, remove the stigma surrounding incontinence, and provide help and hope to people with incontinence, their families, and the health care professionals who provide patient care.

**Services provided:**

Educational programs and events for health care providers  
Publications for health care providers and patients

**Society of Government Service Urologists (SGSU)**

1950 Old Tustin Avenue  
Santa Ana, CA 92705  
Phone: 714-550-9155  
Fax: 714-550-9234  
Email: info@govurology.org  
Internet: www.sgsu.org

**Mission:** To represent and educate urologists employed in federal service, mainly by hosting the James C. Kimbrough Urological Seminar, an annual educational meeting.

**Services provided:**

Educational programs and events for health care providers

**Society of University Urologists (SUU)**

1100 East Woodfield Road, Suite 350  
Schaumburg, IL 60173  
Phone: 847-517-7225  
Fax: 847-517-7229  
Email: info@suunet.org  
Internet: www.suunet.org

**Mission:** To promote high standards in the urology field by acting as a forum for the interchange of ideas and materials relative to university urology educational programs and by fostering a balance of all phases of academic work in urology.

**Services provided:**

Continuing medical education (CME)

**Society of Urodynamics, Female Pelvic Medicine & Urogenital Reconstruction (SUFU)**

1100 East Woodfield Road, Suite 350  
Schaumburg, IL 60173  
Phone: 847-517-7225  
Fax: 847-517-7229  
Email: info@sufuorg.com  
Internet: www.sufuorg.com

**Mission:** To improve the art and science of urology through basic and applied clinical research in urodynamics and neurourology, voiding function and dysfunction, female urology and pelvic floor dysfunction, and to disseminate and teach these concepts; and to foster interdisciplinary dialogue and communication and promotion of the development of young scientists, and the development of scientific, educational, and professional activities through publications, meetings, and original activities to assist in the establishment of standards of care.

**Services provided:**

Educational programs and events for health care providers  
Publications for health care providers  
Resources

**Society of Urologic Nurses and Associates (SUNA)**

East Holly Avenue, Box 56  
Pitman, NJ 08071-0056  
Phone: 1-888-TAP-SUNA (1-888-827-7862)  
Email: suna@ajj.com  
Internet: www.suna.org

**Mission:** To enrich the professional lives of our members and improve the health of our patients and their families through education, research, and evidence-based clinical practice.

**Services provided:**

Certification activities  
Continued nurses education (CNE)  
Educational programs and events for health care providers  
Publications for health care providers and patients

## **The Transplantation Society (TTS)**

International Headquarters  
1255 University Street, Suite 605  
Montreal, QC, Canada H3B 3V9  
Phone: 514-874-1717  
Fax: 514-874-1716  
Email: [info@tts.org](mailto:info@tts.org)  
Internet: [www.tts.org](http://www.tts.org)

**Mission:** To provide the focus for global leadership in transplantation through the development of the science and clinical practice, scientific communication, continuing education, and guidance on ethical practice.

### ***Services provided:***

Continuing medical education (CME)  
Educational programs and events for health care providers  
Publications for health care providers

## **Transplant Recipients International Organization (TRIO)**

2100 M Street NW, Suite 170-353  
Washington, D.C. 20037-1233  
Phone: 1-800-TRIO-386 (1-800-874-6386) or 202-293-0980  
Email: [info@trioweb.org](mailto:info@trioweb.org)  
Internet: [www.trioweb.org](http://www.trioweb.org)

**Mission:** To improve the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness.

### ***Services provided:***

Publications for health care providers and patients

## **United Network for Organ Sharing (UNOS)**

P.O. Box 2484  
Richmond, VA 23218  
Phone: 1-888-894-6361 or 804-782-4800  
Fax: 804-782-4817  
Internet: [www.unos.org](http://www.unos.org)

**Mission:** To advance organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology, and policy development.

**Services provided:**

National transplant waiting list  
Publications for health care providers and patients

**United Ostomy Associations of America, Inc. (UOAA)**

2489 Rice Street, Suite 275  
Roseville, MN 55113-3797  
Phone: 1-800-826-0826  
Email: [info@ostomy.org](mailto:info@ostomy.org)  
Internet: [www.ostomy.org](http://www.ostomy.org)

**Mission:** To improve the quality of life of people who have, or will have, an intestinal or urinary diversion; to provide information, advocacy, and service to, and for, its affiliated support groups, their members, and the intestinal/urinary diversion community at large.

**Services provided:**

Advocacy and public policy  
Educational programs and events for health care providers  
Support group locator

**Urology Care Foundation** (*Formerly the American Urological Association Foundation*)

1000 Corporate Boulevard  
Linthicum, MD 21090  
Phone: 1-800-828-7866 or 410-689-3700  
Fax: 410-689-3998  
Email: [info@urologycarefoundation.org](mailto:info@urologycarefoundation.org)  
Internet: [www.UrologyHealth.org](http://www.UrologyHealth.org)

**Mission:** To support urology research and provide patients, healthcare professionals, and caregivers with accurate and up-to-date educational materials about urologic problems.

**Services provided:**

Advocacy and public policy  
Publications for health care providers and patients  
Research  
Resources

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## **National Kidney and Urologic Diseases Information Clearinghouse**

3 Information Way  
Bethesda, MD 20892-3580  
Phone: 1-800-891-5390  
TTY: 1-866-569-1162  
Fax: 703-738-4929  
Email: [nkudic@info.niddk.nih.gov](mailto:nkudic@info.niddk.nih.gov)  
Internet: [www.kidney.niddk.nih.gov](http://www.kidney.niddk.nih.gov)  
[www.urologic.niddk.nih.gov](http://www.urologic.niddk.nih.gov)

The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health of the U.S. Department of Health and Human Services. Established in 1987, the Clearinghouse provides information about diseases of the kidneys and urologic system to people with kidney and urologic disorders and to their families, health care professionals, and the public. The NKUDIC answers inquiries, develops and distributes publications, and works closely with professional and patient organizations and Government agencies to coordinate resources about kidney and urologic diseases.

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May 2014