President’s Corner

Dear Colleagues,

Thanks to all staff and members involved we had a very successful Annual Meeting of the American Society of Pediatric Nephrology. It was held in conjunction with the Pediatric Academic Societies meeting in Washington, DC, May 14-17. Approximately 300 pediatric nephrologists, trainees and allied health-care professionals attended (the exact figures are not yet available). More significantly, 148 abstracts were submitted, representing a 50% increase in the number over the past few years. The PAS organizers were extremely helpful in permitting us to present as many of these as possible in platform and poster sessions.

ASPN sponsored four symposia: Urolithiasis and Mineral Metabolism, Glomerulonephritis in 2005, Acute Renal Failure, and The Next Steps in Pediatric Renal Transplantation. We also sponsored a workshop on Chronic Kidney Disease. ASPN co-sponsored symposia with the International Pediatric Hypertension (IPHA) on Development of Hypertension in the Newborn; with IPHA and the Lawson Wilkins Pediatric Endocrinology Society (LWPES) and IPHA on Consequences of Metabolic Syndrome in Children; and with LWPES on Transitioning Complex Pediatric Patients to Adult Care. ASPN member Bruder Stapleton hosted a “Meet the Professor” Breakfast, and ASPN member Lisa Guay-Woodford gave the SPR Presidential Address at the conclusion of her services as president.

Some of our events were a bit less scholarly and a bit more celebratory. A luncheon was held to serve as the ASPN business meeting, and to recognize Russell Chesney as recipient of the ASPN Founder’s Award and Adrian Spitzer as recipient of the Henry L. Barnett Award from the AAP Section on Nephrology. A highlight of the meeting was the annual ASPN Reception/Dinner at the Hotel Washington, which was well attended despite a sudden downpour just as it was scheduled to start. At the reception, Greg Gorman, Ashu Syal and Daryl Okamura were recognized with the ASPN Research Trainee Awards for work submitted to this meeting.

At the conclusion of the Annual Meeting, members of the ASPN Public Policy Committee went to Capitol Hill to meet with their own representatives and with selected key legislators who are working on issues of importance to our Society. Such involvement by our members is essential to support the work being accomplished by our Washington representatives, Dom Ruscio and Jennifer Shevchek. We hope to sponsor more Capitol Hill Days in the future as this is a very effective way to enhance the work on the initiatives that further the mission of the ASPN. More information about these initiatives can be found in the Washington Report on pages 5 and 6.

Photos from events in Washington are on page 2 of this issue of KIDney NOTES.

Your council recently had a very productive retreat in Chicago and we are ready to move ahead with projects and initiatives for 2005-2006, as well as plans for the 2006 Annual Meeting in San Francisco, April 29 – May 2, 2006. We will keep you posted and, of course, invite input from the entire membership.

Sandy

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ASN Renal Week—Resident Travel Grant Information

Guidelines regarding application for a Resident Travel Grant to the 2005 ASN Renal Week Meeting in Philadelphia can be found at http://www.asn-online.org/about/committees/TPD%20Files/tpdinfo.aspx. Please share this information with any interested residents in your program. This is a great opportunity to introduce prospective pediatric nephrologists to our profession. The deadline for applications is August 5, 2005. The award is $800.
ASPN President, Sandy Watkins, opens the meeting

**ASPN Annual Meeting**
**Washington, DC**
**May 14-17, 2005**

Former Founders Award, John Lewy, 2005 Barnett Award winner, Adrian Spitzer, and 2005 Founders Award winner, Russell Chesney

**ASPN Reception at Hotel Washington**
The National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH) announces an intramural research protocol to investigate ARPKD/CHF. The objective is to produce comprehensive longitudinal data on the kidney and liver disease in ARPKD/CHF to provide the groundwork for more focused studies and novel therapeutic interventions. The protocol enrolls children and adults with a clinical diagnosis of ARPKD/CHF, which requires: 1) Characteristic kidney involvement based upon clinical or biopsy findings; and 2) Either liver involvement or a normal parental renal ultrasound and family history compatible with autosomal recessive inheritance. Infants under 6 months of age and medically fragile patients are excluded. Patients who have received a kidney or liver transplant and have stable graft function without severe complications are eligible.

This study requires patients to be admitted to the NIH Clinical Center for 4-5 days, with follow up visits every 1-2 years. No change in the patient’s therapy is made during the protocol admissions, and routine medical care continues to be provided by the referring nephrologist. Laboratory tests include 24-hour urine collections for determination of renal tubular and glomerular function. Blood tests include measurement of renin, aldosterone, erythropoietin, cystatin C, norepinephrine, PTH, Vitamin D, IGF1 and IGF-BP3. Imaging studies include high-resolution ultrasound, Doppler measurements of blood flow, MRI of the kidneys and the liver, MR cholangiography and Echocardiogram. Twenty-four hour ambulatory blood pressure monitoring is performed on hypertensive patients. The families and referring physicians are provided with copies of the test results at the end of each visit. Any medical findings that requires a change in the patient’s treatment regimen is discussed with the referring physician. To date, approximately 30 patients have been evaluated, and we would like to expand this experience. There are no medical expenses for the patients, and travel can be provided.

We welcome any recommendations regarding specific investigations of this patient population, and invite your referral of patients to participate in this comprehensive clinical research study. For more information or for patient referrals please contact Dr. Meral Gunay at 301 594 4181 or mgaygun@mail.nih.gov.
TRIANG INGRAM INFORMATION UPDATE
The Training and Certification Committee would like to utilize the American Academy of Pediatrics online directory of Ne-
phrology Training Programs as a portal for ASPN members to contact/explore fellowship training programs. For this to be
effective, significant participation is needed. To add or update your program:

Go to: http://www.aap.org/training/nephrology/
Proceed to the Administration Page by entering your User ID (e-mail address) and Password (nephrology001)
(If you have difficulty logging on, please contact Laura Laskosz at laskosz@aap.org or 800/433-9016, ext. 4928)
Select your program to edit.
Details on the new portal will follow soon.

Membership Research Interests Database
The new ASPN Research Survey-Database is now online. This Survey-Database builds on the "Table of Membership Re-
search Interests" that the ASPN assembled ~1 1/2 yrs ago - it can now be easily updated, browsed, and searched by all members.
This should facilitate identifying colleagues with similar research interests, potential abstract/manuscript reviewers, etc. However,
we ask all members to restrict the use of the database expressly for their own purposes.
To maximize the utility of the website, we ask each of you to:
1. Log in. The survey site URL is http://www.aspneph.com/interests.html. The "user name" and the "password" are the
same as for entry into the members-only portions of the ASPN web site but need to be entered separately here.
2. Complete the form with your entries. An automatic notification will be sent to the ASPN office each time an entry is
made.
3. Browse the site...try to "search" for some info and become familiar with the options.
Should you have any questions, please contact the aspn office at aspn@northwestern.edu <mailto:aspn@northwestern.edu>.
While we plan to monitor the content of this database, ASPN is not responsible for inaccuracies or for changes that are incorrectly
applied.
Use of the information contained in this electronic database for commercial or solicitation purposes is expressly prohibited.
Please also visit the "Funding Opportunities" links on the ASPN Research website.

Pediatric Nephrology Database of Clinical Trials and
Multi-Center Studies
A major thrust of the new NIH Roadmap is to support translational studies and better understand the clinical relevance of different
treatment options. This mission is likely to be accomplished only through broad participation in multicenter collaborative stud-
ies. Accordingly, the ASPN would like to post a list of currently active clinical trials and multicenter studies relevant to the care of
children with renal disease. The goal is to advise membership of the availability of these trials/studies and stimulate enrollment of
our patients. The list would be updated quarterly. ASPN members interested in "advertising" their clinical trials/multi-center studies
on the ASPN website are asked to submit the ASPN office (address information on last page of this newsletter) the following
information:
1. TITLE OF STUDY
2. SITE
3. PI
4. CONTACT INFO: coordinator name, snail and e-mail ad-
dresses, telephone numbers, web site
5. BRIEF DESCRIPTION OF STUDY - 1 paragraph such as
the following: The Mayo Clinic Hyperoxaluria Center is a
clinical care and research center staffed by physician scientists
devoted to the study of the hyperoxalurias, with an emphasis
on inherited Primary Hyperoxaluria. The center facilitates
collaborative research to better understand this disorder. The
center will compile statistics on outcomes of patients and the
NIDDK will house an international patient registry to collect
and analyze data on pediatric and adult patients with inherited
forms of calcium stone disease, including Primary Hyperox-
aluria and Dent's disease.
6. INCLUSION/EXCLUSION CRITERIA FOR ENROLL-
MENT

Dialysis Survey Results Presented
The results of the dialysis survey were presented at the ASPN membership luncheon. Approximately 80 programs
provided information on nearly 1330 children receiving dialysis at ASPN members’ programs. 47.7% of these chil-
dren were on HD, and 53.3% on PD.
About 10% are 0-2 years old, 28% 2-11 years old, 57% 12-19 years old, and 5% were 20+ years old. 45 programs (56%)
have a dedicated pediatric dialysis unit.
The mean number of patients per pro-
gram was 15, and there is a wide distribu-
tion in program size. 42 (54.5%) of dialy-
is program directors receive salary sup-
sport for dialysis administration, and 24
programs (30.3%) have an exception.
The vast majority of programs are billing
dialysis using the new ‘G’ codes, al-
though a few are not. There is widespread
skepticism among ASPN members re-
garding the benefits of new CMS regula-
tions. A more complete analysis of the
data is in preparation and will hopefully
be published in a peer-reviewed journal.
HOUSE ADOPTS PARED-DOWN LABOR-HHS-EDUCATION BILL: HEALTH AND HUMAN SERVICES IS HARD-HIT

The budget crunch in social services spending was on display for two days, as the House of Representatives debated and subsequently passed H.R. 3010, the Labor-HHS-Education appropriations bill for fiscal year 2006. The $142.5 billion measure, which was adopted by a vote of 250 to 151, calls for the termination of 57 programs, including health professions training, rural emergency medical services and a raft of school improvement programs; several more are flat-funded or reduced. All told, an estimated $2.8 billion would be cut from ongoing programs in an effort to trim back the federal budget deficit.

Action on the Labor-HHS-Education bill was part of a larger effort by the House to complete its work on all 11 appropriations bills before the July 4 recess. A Senate subcommittee is expected to take up the measure on July 12.

Technically, the reductions contained in the bill total about $163 million. But House appropriators included significant increases—most notably $890 million in start-up costs for the 2003 Medicare prescription drug law and $1 billion to raise the maximum Pell grant to $4,100—which had to come out of the hide of other domestic programs.

HHS programs, representing the largest portion of the bill's discretionary budget, would be funded at about $63.2 billion, or $632 million below last year, slightly less than proposed by the president. Within that total, the National Institutes of Health would see less than a ½ percent increase over last year, the lowest growth in 36 years. At $28.5 billion, the House bill largely tracks the president’s request.

ASPN is happy to report that the House passed bill did include the Society’s report language regarding chronic kidney disease research at the National Institute of Diabetes and Digestive and Kidney Disease and the National Children’s Study at the National Institute of Child Health and Human Development.

SENATE FINANCE COMMITTEE WORKS ON DRAFT LEGISLATION REGARDING PAY-FOR-PERFORMANCE: PEDIATRIC NEPHROLOGY RECOGNIZED

ASPN has recently learned that the Senate Finance Committee (SFC) is in the process of introducing pay-for-performance (P4P) legislation. On June 23, Jennifer Shevchek, ASPN’s Washington Representative attended a meeting where SFC allowed organized medicine to review their draft legislation regarding implementation of a pay-for-performance, or what the bill coins “value-based purchasing” for Medicare. Of major interest to the Society is that the draft bill includes ASPN’s recommendations to exclude pediatric facilities, those providing care at least 50 percent of patients 18 years of age or younger, from a value-based purchasing system. In addition, the legislation requires a Medicare Payment Advisory Committee (MedPAC) study on P4P in pediatric facilities. Overall the draft legislation includes value-based purchasing systems for a number of provider types, including hospitals, physicians, nursing homes, and ESRD facilities. For ESRD facilities, there will be a value-based purchasing system implemented for the composite rate, as well as a Sense-of-the-Senate provision on fixing the annual adjuster issue with the composite rate. The bill also calls for a chronic kidney disease demonstration project.

The philosophy behind a value-based purchasing system is to try and accomplish P4P within the structure of the current system, and give the Secretary of HHS fairly wide jurisdiction to make decisions where things are not specifically addressed. There will be a pay-for-reporting requirement for calendar years 2006 and 2007. The SFC staff indicated that the bar for what has to be reported would be set low, with the expectation that reporting will be easy for practitioners to qualify for a 2 percent bonus payment. However, those practitioners who do not satisfy the requirement will pay a 2 percent penalty. Actual P4P will begin in 2008, paid for by a withhold that will increase in quarter percentage increments from 2008 to 2012 i.e. 1 percent in 2008, 1.25 percent in 2009, 1.5 percent in 2010, 1.75 percent in 2011, and 2 percent in 2012.

Unfortunately, of serious concern to most medical societies is that the Sustainable Growth Rate (SGR) cut of 4.3 percent scheduled for 2006 is addressed through non-binding “Sense-of-the-Senate” language that only “calls” for a physician payment fix, rather than statutorily reversing the cut or fixing the formula. According to SFC staff, the bill does not include binding language due to the reluctance of Congress to open up Medicare legislation this year. It is rumored that the House version of the bill will include language to fix the SGR.

To move this legislation forward, it must be reconciled with whatever bill is developed by the House Ways and Means Health Subcommittee. However, it is still unclear as to whether a House pay-for-performance bill will adopt language excluding pediatric ESRD facilities from such a value-based purchasing system. ASPN will continue to keep its membership informed on any future developments.
The following article details the filing of an amicus brief on behalf of the RPA’s lawsuit against the Centers of Medicare and Medicaid Services (CMS) regarding dialysis facility medical director fees. **INSIDE CMS — www.InsideHealthPolicy.com — June 16, 2005**

**PHYSICIAN GROUPS LEND SUPPORT TO RPA EFFORT TO OVERTURN STARK II RULE**

Nephrologists’ effort to prevent CMS from effectively fixing dialysis facility medical directors’ fees by delineating what levels of payments are safe from legal scrutiny has been bolstered by the engagement of multiple physician groups in a lawsuit seeking to block the policy.

On June 10, the American Medical Association (AMA), the American College of Physicians (ACP) and the Infectious Diseases Society of American (IDSA) filed an amicus brief in support of the Renal Physicians Association’s (RPA) lawsuit regarding the use of safe harbor payment methodologies to determine dialysis facility medical director reimbursement. The lawsuit is being heard in the federal district court for the District of Columbia.

An industry source said large dialysis chains are renegotiating contracts for medical directors based on the CMS rules implementing the Stark self-referral law. “To our knowledge, yes, the large dialysis chains are renegotiating medical directors’ contracts using the safe harbor methodology. We believe that, if enforced, the rule will dramatically cut reimbursement,” the source said.

The physician self-referral interim final rule is part of regulations for the statute authored by Rep. Pete Stark (D-CA), ranking member on health subcommittee for the Ways and Means Committee. The rule, issued in March 2004, establishes a safe harbor provision to determine dialysis facilities’ medical directors reimbursement. In the rule, CMS says the same safe harbors also apply to other medical director positions.

A representative of IDSA said that medical directors’ reimbursement at infectious control centers has been cut in half since the beginning of 2005.

“The amicus brief lets the court know that the case is important to broader entities outside of dialysis centers,” a representative of AMA said.

The Stark law requires that compensation paid to physicians who, under exemptions in the law, refer patients to designated facilities not exceed fair market value. To implement that mandate, CMS established a safe harbor provision in the rule. The provision requires that any payment rate that meets the level of compensation determined by two methodologies is automatically considered fair market value.

The first methodology requires that the hourly payment to the physician be less than or equal to the average hourly rate for emergency room physician services in the relevant physician market, provided there are at least three hospitals providing emergency room services in the market. The second methodology is an hourly rate based on the median nationwide salary for nephrologists.

The physician groups argue if facilities are forced to implement the rule’s methodologies for determining fair market value, medical directors will be underpaid. The RPA representative said the rule’s ramifications stretch beyond payment cuts and into patient care. The physician groups backed up that point saying, “If medical directors of outpatient dialysis centers and other specialists cannot be fairly compensated for their training and expertise, there will be fewer specialists available to provide the necessary health care,” the brief states.

“Infectious disease physicians provide state of the art care for patients with diverse, complex conditions such as HIV, hepatitis, meningitis and other infectious diseases...Infection control medical directors are responsible for developing and enforcing procedures and policies aimed at preventing, treating, and containing hospital acquired infections. The compensation rates for these physicians should reflect the additional and distinct duties” the brief states.

In addition, the groups, including RPA, are disputing CMS’ claim that the safe harbor rule is voluntary. “Because of the enormous pressure to comply with the Stark Law, as well as the myriad other regulations, a bright line safe harbor rule, if available, becomes an almost compulsory standard,” the amicus brief states.

In order to participate in Medicare, dialysis facilities must have medical directors responsible for administrative and clinical oversight. Prior to the rule, director fees were negotiated between nephrologists and facilities with little federal oversight.

**ASPN EFFECTIVELY TARGETS VISITS WITH CONGRESSIONAL OFFICES DURING THE SOCIETY’S ANNUAL MEETING IN WASHINGTON D.C.**

On May 17th, members of ASPN spanned out over Capitol Hill to educate lawmakers about pediatric kidney disease the Society’s legislative priorities regarding biomedical research funding, Medicare physician reimbursement, and pediatric kidney transplantation. As a result of these visits, Senators Christopher Dodd (D-Connecticut) and Mike DeWine (R-Ohio) are in the process of sending a letter to the Government Accountability Office (GAO) requesting a study to examine the current Medicare guidelines surrounding kidney transplantation and to quantify the impact pediatric kidney transplant failure has on our federal health care system. ASPN hopes that a GAO study will allow the transplant community to work with Congress in the development of sound federal policy that promotes successful organ transplantation. ASPN looks forward to continuing a dialogue with key congressional offices in an effort to build working relationships that will allow the Society to be an influential player in the development of new Medicare ESRD and kidney transplantation policies.
**Meeting Announcements**

**FASEB SUMMER RESEARCH CONFERENCE —CALCIUM OXALATE IN BIOLOGICAL SYSTEMS**

**Dates:** July 16-21, 2005 in Tucson, Arizona

Mary Alice Webb, Purdue University
Vincent R. Franceschi, Washington State University
Craig Langman, Northwestern University

This FASEB Summer research conference will focus on the medical and other scientific sides of oxalate, including of course, Oxalosis and Primary Hyperoxaluria, Kidney Stones, and a host of wonderful science from around the world. It is very valuable for trainees, encourage their attendance and poster presentations.

For additional information, please visit our website: [http://src.faseb.org](http://src.faseb.org)

**Don't Miss Out! International Pediatric Transplant Association (IPTA)**

Mark Your Calendar: IPTA 3rd World Congress, August 6-9, 2005, Innsbruck, Austria

Email: ipta@ahint.com; Web: [www.IPTAonline.org](http://www.IPTAonline.org)

A variety of formats are planned that will encourage the exchange of new scientific & clinical information & support an interchange of opinions regarding care & management issues relevant to organ & tissue transplantation in children. This Congress will:

- Highlight the most recent advances in clinical & basic sciences related to pediatric transplantation.
- Provide a forum for exchange of new scientific & clinical information relevant to pediatric solid organ & tissue transplantation.
- Create an arena for the interchange of ideas regarding care & management of pediatric organ & tissue transplant recipients.
- Facilitate discussions of the socioeconomic, ethical & regulatory issues related to pediatric solid organ, tissue & cell, transplantation.

Scientific material will be presented through symposia, oral abstracts, small group sessions designed for in-depth exploration of both clinical & basic science topics, & poster presentations.

The IPTA 3rd World Congress is approved to offer CME credits for physicians.

Visit [www.IPTAonline.org](http://www.IPTAonline.org) to view the scientific program & register for the congress

**FASEB SUMMER RESEARCH CONFERENCE —NEW INSIGHTS IN POLYCYSTIC KIDNEY DISEASES: MOLECULAR PATHWAYS, PATHOGENIC MECHANISMS, AND TRANSLATIONAL APPLICATIONS**

**Dates:** August 6-11, 2005 in Saxtons River, Vermont

**Conference Topics:** The Functional Role of Cystoproteins in Epithelial Differentiation • Epithelial Polarity, Transport, and Cell Signaling: The Role of Cystoproteins • Cilia/Centrosomal Dysfunction and PKD Pathogenesis • PKD Pathways: Lessons from Comparative Genomics • PKD as a Complex Trait • Other Cystic Diseases and Convergent Pathways • PKD: Extra-Renal Disease • Biomarkers for Disease Progression • Innovative Targeting in PKD Therapeutics

For additional information, please visit our website: [http://src.faseb.org](http://src.faseb.org)

**THE AMERICAN SOCIETY OF NEPHROLOGY—RENAI WEEK 2005**

**November 8 - 13, 2005**

Pennsylvania Convention Center; Philadelphia, Pennsylvania

**Advances in Research Conference:** Nov. 8-9; **Postgraduate Education Courses:** Nov. 8-9;

**Annual Meeting & Scientific Exposition:** Nov. 10-13

**Registration:** Attendees—[Click here](http://www.aspneph.com/market.html)

**Housing:** Attendees: Reserve Housing Online OR Submit PDF Form
4th International Conference on Pediatric Continuous Renal Replacement Therapy (PCRRT)  
Feb. 23 – 25, 2006, Zurich, Switzerland

This conference brings together in one forum caregivers of children who require extracorporeal therapies including CRRT and plasmapheresis. The course will discuss basics, use of PCRRT in sepsis, acute renal failure, multiorgan dysfunction syndrome and non-ARF indications. Research in drug clearance, nutrition, liver support and outcome will be presented. There will be a call for abstracts that will be published in Pediatric Nephrology.

Sponsors for the program are University of Zurich, University of Alabama School of Medicine, DeVos Children’s Hospital, Grand Rapids, Michigan; and PCRRT Foundation. Physician and Nursing credit will be available.

For preliminary information go to www.pcrrt.com and click on 2006 program or contact timothy.bunchman@spectrum-health.org or cmalone@pclnet.net.