

ASPN ~ CLB Update

ASPN Mission Statement

The American Society of Pediatric Nephrology is an organization of pediatric nephrologists and affiliated health care professionals. Our primary goals are to promote optimal care for children with kidney disease through advocacy, education and research; and to disseminate advances in clinical practice and scientific investigation.

Importance of ASPN-CLB Relationships

The CLB is comprised of corporate partners engaged in the care of pediatric nephrology patients. Importantly, the collaborative relationship between ASPN and the CLB members provides channels for discussion of any issues of importance to the pediatric nephrology and industry communities as they arise.

Key ASPN Committees:

Clinical Affairs and Practice Management Committee

Responsible for identifying, evaluating, and disseminating information about issues relevant to current clinical care of children with kidney disease.

Serves as a liaison to other professional groups and organizations developing clinical guidelines, consensus statements, or educational materials related to the care of children with kidney disease.

This committee also works with the Public Policy committee to educate ASPN members about clinical practice issues, especially those related to quality care, expected standards of care, and reimbursement.

Council Liaison: Jodi Smith/Blanche Chavers

Program Committee

Responsible for soliciting, reviewing, and developing topics for symposia and workshops for the ASPN annual scientific meeting, and for recruiting and coordinating speakers and moderators for those sessions. The committee works with alliance organizations, IPHA, ASN, NKF and others to optimize the educational scope of the program to meet the needs of our members.

Council Liaison: Don Batisky

Public Policy Committee

Responsible for gathering, analyzing and disseminating information on public policy issues pertinent to the practice of pediatric nephrology. This committee advocates for public

policies and programs that advance the interests of our members, patients and their families before the U.S. Congress, federal agencies, national regulatory groups, and voluntary health organizations. Committee members have developed and produced advocacy materials, webinars related to ESRD quality and payment, and training and educational sessions at the ASPN annual meeting to promote advocacy among our members.

Council Liaison: Asha Moudgil
Washington Representative: Erika Miller

Research Committee

Responsible for identifying clinical and basic science research priorities in the pediatric nephrology community, and for developing new strategies for encouraging and supporting research in the area of pediatric nephrology. This committee serves as a liaison with other organizations (e.g. ASN, NIH) that promote and support research, and keeps our members informed about research consortia and funding opportunities relevant to pediatric nephrology.

Council Liaison: Rasheed Gbadegesin.

Training and Certification Committee

Responsible for working with ASPN membership, fellowship training program directors and other organizations to facilitate training and certification of future pediatric nephrologists and to support the ongoing certification needs of

practicing pediatric nephrologists.
Council Liaison: Don Batisky

Examples of ASPN-CLB Collaborative Efforts:

- ASPN has served an advisory role to several CLB members to facilitate understanding of the pediatric nephrology landscape for clinical trials and product development. In this arena, ASPN is the representative for pediatric kidney disease related therapies and thereby has the opportunity to advance missions of joint interest with the members of the CLB.
- ASPN is available to and has partnered with industry in areas where our missions are aligned, and looks forward to ongoing cooperative efforts to advance our common goals. .
- The ASPN, through its Research Committee, assists CLB members in identifying individuals and research networks in the pediatric nephrology community willing to participate in clinical trials of products for children. In such situations, ASPN serves as an advisor and conduit for communication, but does not have an active role in conducting trials. ASPN also provides links to content experts that may be of great benefit to CLB members as new products are moving towards clinical trials
- Pediatric Nephrology trainees have received grant support from several CLB members to attend a variety of conferences over the years. Efforts such as these not only benefit fellows directly, but also benefit the broader ASPN membership by providing high quality core curriculum for training programs, which then acquire new knowledge brought home by their trainees. Similarly, programming support at the annual PAS/ASPN meetings furthers our mission of diverse education for ASPN members.
- The ASPN and CLB share a joint interest in assuring that patients have access to appropriate therapy. CLB members continue to work with the

ASPEN on strategies to improve patient access to therapy.

Other ASPEN Initiatives of Interest to CLB:

Kidney Health Initiative

- ASPEN has board-level representation on the Kidney Health Initiative (KHI) project developed by the ASN and the FDA (<http://www.asn-online.org/khi/>). The first work product of the KHI is a white paper on pharmacokinetics in pediatric continuous renal replacement therapy. In addition, ASPEN has representation on the vascular access registry and a new project in which medical providers, the device industry, regulators, and patient advocacy groups will work to incorporate patient input into the processes of product development and regulatory decision making for new medical products in kidney disease. The ASPEN is also represented by a Telehealth initiative in CKD and Transplantation. A white paper from this group is expected in the beginning of the new year.

Therapeutics Development Workgroup

- ASPEN has organized a Therapeutics Development Workgroup. This workgroup includes representatives from ASPEN, CLB members, the FDA, patient advocacy groups, and the NIH. The fundamental goal of this workgroup is to eliminate barriers and improve the process for conducting clinical trials in children with kidney disease. Much progress has been made, including the development of roadmaps for conducting clinical trials to benefit industry and investigators.

Leadership Development Course

- ASPEN has conducted Leadership Development Courses for members of ASPEN since 2011.

Each course extends over 18 months, and involves pre-course reading, leadership inventory (360) workshops, and lectures/workshops conducted by ASPEN members and outside trainers, including some from CLB partners. The next session will be in the Fall of 2017.

Multi-Disciplinary Meeting

- ASPEN has developed an annual meeting designed for nurses, nurse practitioners, social workers, and dietitians who work with pediatric nephrology patients. The fourth annual meeting was held in Cincinnati in October 2016. There were over 100 attendees. The meeting was very successful and well received. Next year's meeting will be held in Dallas, October 19/20, 2017.

Responsibilities of the CLB:

- Active participation in meetings and conference calls.
- CLB members are encouraged to share with ASPEN leadership their needs and challenges regarding identification and clinical trial development of drugs, devices, or other products that might benefit children with kidney disease. ASPEN is positioned to assist each CLB member with identification of resources to further their efforts to advance patient care.
- Assisting ASPEN leadership with education of our members regarding each CLB member's interest in the care of children with kidney disease. This includes brief articles in our bimonthly newsletter (Kidney Notes) to introduce the CLB member and give our members your perspective on our collaborations.
- Mutual sharing of expertise and experience in those areas where collaboration between ASPEN and CLB can further our objectives and improve potential outcomes.
- Timely payment of annual dues

Long-term Goals:

- Development of a robust, multifaceted program for effective communication with all of our members, training programs, relevant professional and patient-oriented organizations, and other friends of ASPEN.
- Expansion of the educational opportunities available to our members, patients and patient families, using diverse materials, including web-based and interactive programs

New & Ongoing Initiatives:

- Enhanced fund-raising opportunities under the auspices of the new ASPEN 501c3 Foundation. .
- ASPEN has a monthly interactive renal pathology webinar/discussion. This major effort in web-based education, and has been well received and by all accounts a great success. Web-based education provides another opportunity for collaboration between ASPEN and CLB members.
 - ASPEN communications and website committee will be utilizing real time social media commentary and end of the day wrap up highlights at the PAS meeting in San Francisco to improve communication and identify key findings, updates and partners in support of our ASPEN scientific sessions.
 - Creation of a taskforce to commemorate the 50th anniversary of ASPEN in 2019. We anticipate a gala celebration at the PAS in May, 2019 and an effort to formally record the history of pediatric nephrology in America and the history of ASPEN.
 - Creation of a new ASPEN committee focused on international medicine. There are currently a number of ASPEN members who are actively engaged in supporting pediatric nephrologists in other countries. This committee will foster and expand these efforts.

Calendar of Events:

Spring CLB Conference Call:	TBD
ASPEN meeting at PAS Annual Scientific Meeting:	May 6-9, 2017, San Francisco
Council meeting at PAS	May 5, 2017
ASPEN Summer Council Meeting	June 22-23, 2017, Atlanta
CLB meeting with Council	June 22, 2017, Atlanta
Fall CLB Conference Call:	TBD
ASPEN Multidisciplinary Meeting (for Affiliates)	October 19-20, 2017, Dallas
ASN Meeting	October 31 – November 5, 2017, New Orleans
Council Meeting at ASN	November 1, 2017, New Orleans
CLB meeting with Council	November 1, 2017, New Orleans