



Dialogues in Pediatric Urology

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Multi-Center Collaborations in Pediatric Urology

FROM THE GUEST EDITORS

**Christopher Jaeger
Valeska Halstead**

"Alone we can do so little; together we can do so much." Helen Keller was perhaps ahead of her time in recognizing that progress is dependent on collaboration. Pediatric Urology has clearly embraced this truism, boasting numerous multi-center collaborations that study everything from spina bifida to information technology. One might think that these collaborations are just another excuse to catch up with friends who share similar topics of interest across the world. Although that may be at least partially true, collaborations have spawned as a result of a collective effort to improve the quality of research previously defined by single-institution, retrospective studies with small cohorts.

In its history, the practice of Pediatric Urology has arguably been more dominated by dogma passed down from giants in the field than it was based upon good science. Yet, we practice in a specialty defined by rarity and complexity. How are we supposed to realistically study rare diseases such as bladder exstrophy or spina bifida with a handful of cases per year on average at each institution? Thankfully leaders in our field have embraced this challenge and turned it into an opportunity to produce impactful research through collaboration. This spirit of collaboration is infectious and excites many in our field to seek answers to difficult questions but to do it in step with "competitors," oftentimes in one's region of practice. It is inspiring and it was one of the many reasons we chose to become Pediatric Urologists.

In this edition of Dialogues in Pediatric Urology, we chose to highlight some of the most prominent and impactful multi-center collaborations in our field today. We asked each team to share insights on the most important elements of a successful collaboration and common obstacles faced based on their experiences. We were unfortunately not able to include all collaborations in existence, but we are in awe of all the work being done across the specialty. We hope you enjoy this edition updating you on the work of the leaders among us.

FROM THE ASSISTANT EDITOR

Jason Van Batavia

I want to thank Christopher Jaeger and Valeska Halstead for putting this edition of DPU together. Their "collaboration" and coordination amongst the various groups highlighted here required dedication and persistence, and the final product is one that I know each reader will enjoy. The stories of each of these successful pediatric urology collaborations is important for all of us, from urology residents to senior faculty, to understand; not only to shine light on the amazing accomplishments of our colleagues but also to serve as a guide for future endeavors. I hope these collaborations will serve as inspiration and be the springboard for many more in our field!

Societies for Pediatric Urology

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A Decade of UMPIRE

The inception of the CDC-funded **U**rologic **M**anagement to **P**reserve **I**nitial **R**enal function (UMPIRE) protocol for infants and young children with Spina Bifida (SB) was a result of the early successes of the multi-center National Spina Bifida Patient Registry. In 2012, the CDC convened a working group of pediatric urologists, pediatric nephrologists, clinical epidemiologists, research methodologists, community advocates, and CDC personnel to develop and test a standardized protocol to optimize urologic care of children with SB from the newborn period through the first 5 years of life. The organizing committee evaluated several potential study design options and determined that a randomized controlled trial (RCT) would be impractical and at high risk for contamination and noncompliance among participating centers. Just as important, the relatively small, proposed budget meant that a RCT would have been unlikely to achieve an adequate sample size and duration.

Instead, an iterative quality-improvement protocol was selected.¹ The concept was that participating institutions would agree to prospectively treat all eligible newborn children with SB using a single, consensus-based protocol that specified the timing of subject follow-up visits, the type and frequency of diagnostic tests, and the type and nature of any treatment-related interventions. After 2 years of development and planning, the CDC solicited a collective funding application, and nine centers were eventually funded in 2014. Each center obtained IRB approval, and accrual into UMPIRE began in 2015. The protocol has since been extended to cover children with SB from 0-10 years of age, and the project was competitively renewed for an additional 5 years in 2019. An unforeseen challenge of this competitive renewal process was that one of the original centers was not renewed, meaning that longitudinal data on that center's enrolled patients were lost. As with all large, multi-institutional groups, funding issues have not been the only issues that UMPIRE personnel have needed to address. Turnover of key personnel at each institution, protocol implementation and data entry issues, defining a viable plan for leadership succession, differences of opinion on analysis priorities were somewhat predictable challenges, and a worldwide shortage of ^{99m}Tc-DMSA (and multiple local bans on compounded replacements)² have challenged the UMPIRE collaborative.

Despite these challenges, the collaborative has published findings from its collective efforts following years of data accrual. In 2019, Stacy Tanaka and her co-authors were the first to demonstrate that the majority of infants with SB have normal kidneys on ultrasound (55.9%) or mild hydronephrosis (40.4%) at baseline.³ This study showed that many children with SB have normal anatomy at birth but yet are known to carry a high lifetime risk of renal damage and chronic kidney disease. This study was the first of its kind to validate the proactive approach to genitourinary surveillance featured in the UMPIRE protocol. In 2021, Chad Wallis and his co-authors showed that infants with SB had a low rate of UTI's (4% in the first 4 months of life), challenging the notion that routine antibiotic prophylaxis is indicated for all children with SB.⁴ Urodynamics has been the most recent focus of the participating institutions in UMPIRE. Clinical experts from participating intuitions recently came together to review over 150 urodynamics tracings, highlighted in a study written by Stacy Tanaka et al.⁵ Interestingly, investigators found substantial differences in interpretation of tracings and categorization of bladder risk across sites

Jonathan Routh, Michelle Baum, Elizabeth Roth,
Stacey Tanaka, Chad Wallis, Elizabeth Yerkes

– highlighting a profound need for updated standardization of risk stratification. Much deliberation within the group resulted in changing the risk categorization scheme and eliminating detrusor-sphincter-dyssynergia as a defining variable in the scheme. The inherent challenges underlying the need for urodynamics standardization across sites was summarized nicely in a 2021 article written by Elizabeth Yerkes et al.⁶

A critical underlying concept of UMPIRE's design is the recognition that the protocol may not be one-size-fits-all and may need to be modified to meet the needs of some patients. Each center is therefore free to deviate from the protocol if s/he feels that a deviation is warranted to benefit the patient's health – just so long as those deviations are documented, including a specific rationale behind each deviation. Analyses of those deviations to determine whether they suggest that the protocol should be modified for some or all patients is currently ongoing.

Reflections on Challenges & Opportunities of Being Part of a Large, Funded Collaboration: Additional Viewpoints from the UMPIRE Membership

The UMPIRE investigators have published or are actively investigating topics relevant to the first few years of life such as baseline imaging, baseline urodynamics, urinary tract infections and need for CIC. With UMPIRE, we have increased awareness of the risk of CKD/ESKD in those with spina bifida. As the cohort ages into the second phase of the protocol, there will be opportunity to look at silent acquired renal scarring and trajectories of eGFR, as well as best measures for assessing renal function in spina bifida.

With the intense work we have done together across sites to standardize urodynamics and interpretation thereof, we will be able to identify any subtle findings that may predict evolution to unfavorable bladder dynamics, upper tract risk, or continence. Through iterative assessment and changes in the protocol as the children grow, we hope to tailor medical testing and interventions to the individual without compromising renal and bladder outcomes. Essentially with

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Figure. UMPIRE collaborators representing multiple participating institutions.

UMPIRE (continued from previous page)

the power of this collaboration, we will set the stage for answering the gaps in knowledge identified in the Guidelines for Care in Spina Bifida.

From a personal and professional standpoint, despite the challenges associated with funding and limited time, there are many benefits and opportunities associated with being part of a collaboration like UMPIRE:

- As a junior member: contribution to projects, networking with other urologists and non-urologists with whom they might otherwise not have close contact, forming relationships that lead to collaborations outside of spina bifida care.
- For mid-career and senior members: transition to various leadership roles, satisfaction of longer-term relationships within urology and other spina bifida specialties, opportunity to represent UMPIRE nationally and internationally.
- For all: exposure to different ways of looking at ambiguities and complexities in the urologic care of children with spina bifida and having opportunities to then share ideas outside of UMPIRE.
- For all: shared commitment to answer important questions together and hopefully elevate care, even when reaching a consensus means that some long-held individual practices are not part of the protocol.

With a collaboration of this size, nothing moves as fast as one

might think it should. However, to work together is a privilege and worth the effort to see progress over time. Time and energy spent working through the friction of differing viewpoints ultimately makes for better, more thoughtful collaborations and contributions to the field.

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Pediatric Urology Midwest Alliance (PUMA): A Multi-Center Research Collaborative

Rama Jayanthi
Molly Fuchs

A few years ago, at one of the national Pediatric Urology meetings, the senior leadership of several Midwestern programs got together to discuss how they may be able to work together. The initial impetus was an interest in trying to improve outcomes with bladder exstrophy. Though each of these programs were national leaders and had significant experience with complex reconstruction including primary exstrophy, there was a recognition that by being humble, open-minded, and willing to learn from others, each program, and thus all surgeons, could benefit.

This was the genesis of the Pediatric Urology Midwest Alliance (PUMA) consisting of the Departments of Urology from Nationwide Children's Hospital, Riley Children's Hospital, Lurie Children's Hospital, Cincinnati Children's Hospital, and the Mayo Clinic. Surgeons would travel to other PUMA sites to observe exstrophy cases. PUMA protocols permit each location to maintain control over intraoperative decision making but having other experienced surgeons in the operating room allowed for real time discussions, not to mention seeking opinions and asking for advice!

So far, between April 2017 and July 2023, thirty cases of bladder exstrophy have been closed in a collaborative fashion (20M:10F). Of the 20 males, 13 underwent CPRE and 7-staged repair. Median age at surgery was 7.3 months, with average follow up of 32 months. Post-operative immobilization was with external fixation in 16, hip spica casting in 10 and an orthotic brace in 4. Length of hospital stay varied considerably with a range of 5 to 33 days and a median of 25 days.

We demonstrated that with a unity of purpose and a culture of collaboration, a multicenter consortium could be created. Our model

allows for local control of clinical decision-making while simultaneously providing for real-time intraoperative consultation. No child had a dehiscence despite different institutional protocols, suggesting that bladder plate dissection and careful tension free closure may be of greater importance than the method of post-operative immobilization. Our data suggest that early discharge is likely safe, that long post-operative hospital stays may not be necessary or beneficial.

It was apparent early on that in addition to our collaborative exstrophy project, PUMA should have a significant research component. Indeed, PUMA did publish the first reported use of intraoperative laser angiography during exstrophy closure, assessing penile blood flow at various stages of the procedure.¹

We realized that PUMA would offer a unique opportunity to study uncommon problems, that combining data from several large institutions might allow for meaningful conclusions. To make this work however, there were a few rules we had to follow. First, since we were doing retrospective studies, we wanted to answer simple questions. Second, we could only try to answer questions with binary answers, a simple yes or no. Third, we wanted the academic output of the research program to support the careers of our junior faculty, so we decided that for most papers, no department chief would be an author, and that we would limit authorship to two individuals per site.

In all honesty, our first attempt at academic output was a test case. Would we be able to work together? Would people support a project where their respective institutions would not get primary credit? Would individuals and institutions subjugate their egos for

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PUMA (continued from previous page)

the greater good? Fortunately, our first project was a resounding success winning best clinical paper in the 2017 Fall Congress of the SPU and was subsequently published in the *Journal of Urology*.² This landmark paper validates the experience of most pediatric urologists, that long term follow-up demonstrates that the majority of adults with bladder exstrophy require intermittent catheterization, that few are voiding and continent.

Though PUMA began with an interest in classic bladder exstrophy, we have since branched out to other conditions. Using the strength of the collaborative, we have shown that the overwhelming majority of patients with cloacal exstrophy do not have a functional urethra, calling into question surgical protocols that emphasize recreating “normal” anatomy.³ In addition to classic and cloacal exstrophy, PUMA has studied other conditions such as posterior urethral valves.⁴ Our multicenter study on the risk of renal failure showed that those with nadir creatinine less than 0.4 usually maintained renal function, and those greater than 1 had a much higher risk of ultimately requiring renal replacement therapy. We demonstrated the novel finding that children with a serum nadir creatinine in the first year of life between 0.4 and 0.99 mg/dL showed a variable course, suggesting this patient subset may benefit the most from future study of factors that affect disease progression. In addition, PUMA centers have very active minimally invasive surgery programs and have published studies on complex robotic surgery.^{5,6}

PUMA members have been very proud of what we have accomplished to date, but we acknowledge that there are significant hurdles that we face as we look to the future. The pandemic created major challenges, making it very difficult to travel to other institutions for exstrophy closures. We did live stream cases to allow other PUMA sites to observe and offer advice and guidance, but a virtual presence pales compared to standing in the operating room, looking over the surgeon’s shoulder.

Time is our most important commodity, and everyone has numerous competing interests: clinical productivity, RVU pressures, ensuring quality outcomes, academic advancement, etc. Furthermore, complex prospective multi-institutional studies would require external funding, which is getting harder to obtain. Should valuable academic time offered, and paid for, by an institution be used to support the collaborative or the home department/institution? Ultimately, everyone in the consortium needs to see value in the group, for themselves and for their department.

Regardless, it is clear that such multicenter entities are of great importance. As the number of Pediatric Urologists grows, concern has arisen regarding adequacy of exposure to uncommon index conditions that require a high level of expertise in their management. One concept to address this is creation of regional collaborations in which treatment algorithms for rare conditions are openly discussed and shared. To this end we established the Pe-

diatric Urology Midwest Alliance with the goals of harnessing the collective experience to coach one another, providing patients and their families a level of expertise that enhances that of any one institution, identifying new areas of research, and importantly providing mentorship to the next generation of surgeons.

Additional Reflections:

We think the most important thing to do to have a successful collaboration is to have a culture of humility. It is very important for participating institutions and physicians to acknowledge that they do not have the answers to complex questions. Along with that humility there needs to be a drive to answer those questions. PUMA started because we were not satisfied with what we were hearing from “experts” at national meetings. Our strength was that we decided that we were not going to claim we were experts, despite the fact each institution had significant experience, and that we were all equals.

There are many hurdles, one of biggest being divided loyalties. Do we work for PUMA or do we work for our home institution? Another related hurdle refers to funding. PUMA has no funding so with the limited time one has, what kind of projects can one work on? Ideally, local senior leadership needs to understand that promoting PUMA simultaneously promotes the home institution.

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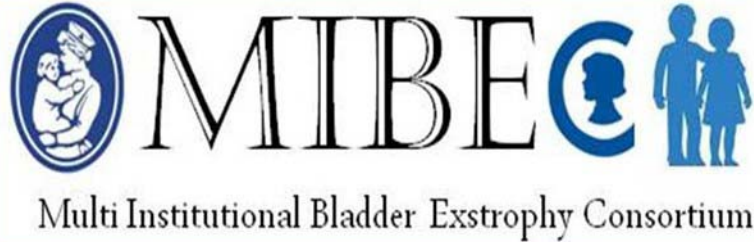
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PUMA collaborators representing the Cincinnati Children’s Hospital, Nationwide Children’s Hospital, Riley Children’s Hospital, and Mayo Clinic – Rochester.



The Multi-Institutional Bladder Exstrophy Consortium (MIBEC)



Ted Lee, Dana Weiss, Elizabeth Roth, Karl Godlewski, Travis Groth, Richard Lee, Aseem Shukla, Joseph Borer, Michael Mitchell

Bladder exstrophy (BE) is a rare diagnosis that presents complex anatomical and reconstructive challenges. Goals of surgery are to recreate normal anatomical and physiologic bladder, bladder neck and urethra for purposes of maintaining upper urinary tract health, urinary continence, sexual function, and cosmesis. Grady and Mitchell first described the complete primary repair of bladder exstrophy (CPRE) procedure in 1999.¹ Initial outcomes following CPRE were reported by several authors with substantial variability in results and limited follow-up time. In an effort to refine and optimize CPRE technique, patient care and provide long-term outcomes, the Multi-Institutional BE Consortium (MIBEC) was formed in 2013 and continues currently.

The MIBEC consists of pediatric urologic surgeons with a specific interest and dedication to the care of patients with exstrophy-epispadias complex enlisted from Boston Children's Hospital, Children's Hospital of Philadelphia, and Children's Hospital of Wisconsin. One of the three institutions alternately serve as the host site for scheduled surgery, with observation, commentary, and critique by visiting surgeons. The surgeries are also broadcasted live in both closed circuit and distant live broadcast in order to facilitate real-time observation and teaching. Technical details of the surgery are discussed in real time and recorded for analysis, retrospective review, and critique. Videos are edited to produce streamlined playback images of each surgery and these videos are used for pre-operative preparation. Of note, travel was paused during travel restrictions pertaining to the coronavirus pandemic. Informed consent is obtained for each patient participating within this consortium prior to initial surgical intervention.

In the first 2 years of the MIBEC alone, exposure to CPRE increased by greater than 10-fold per surgeon when contrasted to prior years. Over the past 10 years, over 200 cases of bladder exstrophy, cloacal exstrophy, or epispadias have been included within the collaborative. Revisions and alteration of technique were achieved at several venues, including: (1) on-site meetings prior to each surgery, (2) intraoperative discussion, (3) review of operative video, and (4) bimonthly agenda driven meetings. Through this iterative process, the CPRE technique has been continuously refined.²⁻⁵

Patients are followed prospectively. During the course of the MIBEC, a common protocol for patient management and evaluation has been developed. Case report forms (CRF) for pre-operative, intraoperative and postoperative details of care are used to record data. For example, the intraoperative CRF is used to record measurements of the exstrophied bladder (width, length and depth), urethra and genitalia. Postsurgical outcomes, long-term functional outcomes, results from diagnostic studies (e.g., ultrasonography, voiding cystourethrogram and urodynamics), and health related quality of life measures are recorded and stored within a secure online database pro-

spectively. This collaboration has yielded significant contributions for exstrophy-epispadias complex and resulted in growth in academic productivity among the participating institutions.⁶⁻¹⁰ As we reach the second decade of this collaboration, we hope to provide additional insights pertaining to long-term bladder development, continence, and health related quality of life.

The MIBEC proved beneficial toward increased surgeon exposure and expertise. Refinement of the CPRE technique will continue with this unique model of continuing surgical education in perpetuity for the betterment of patient, teacher and pupil. This collaborative model can be transferred to other rare, complex surgical procedures to maximize and share collective expertise, standardize/refine technique, and analyze outcomes to ultimately benefit patient care and outcome.

Additional Reflections

The most important thing to do to ensure a successful collaboration is to place trust in your colleagues with a shared passion for excellence in the comprehensive care and optimal outcome of the patient population.

The biggest hurdle or obstacle to overcome in a collaboration is proudful and dismissive postures. This highlights the importance of humility, the desire and freedom for each individual to contribute their unique perspective in a non-judgmental environment, and to provide and accept constructive critique, all in the spirit of pursuing perfection.

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SaFE-NC – A Chicago-Area Collaboration to Improve Neonatal Circumcision Care

Emilie Johnson, Paula White, Stacy Laurent, Catherine M. Seager, Derek J. Matoka, Mark Potter, Jane L. Holl

Introduction

Circumcision is the most common pediatric surgical procedure in the United States (US); about half of newborn boys undergo circumcision.¹ Neonatal circumcision care is provided by many specialties (most commonly obstetricians and pediatricians) through different care models, largely dependent on local practice patterns and practitioner availability. Also, many families encounter difficulty accessing desired neonatal circumcision for their infant boys.^{2,3} As a result, these boys will often undergo more costly, higher risk, less health beneficial circumcision in the operating room later in infancy or young childhood. Through a shared interest in optimizing newborn circumcision care delivery, our multi-specialty, multi-center collaborative group was formed.

Goals of the Collaboration

The Agency for Healthcare Research and Quality (AHRQ) is providing four years of funding for our team to design and implement an improved model for newborn circumcision care. First, our team will work together to design and implement a Safe, Feasible, and Equitable Neonatal Circumcision (SaFE-NC) Program at three Chicago-area hospitals. The World Health Organization (WHO) has published Standards and Procedures for neonatal circumcision; we will be adapting these WHO Standards to the US context. The project involves evaluating the current neonatal circumcision care model at each of the three participating hospitals, designing and implementing an improved care model based on the WHO Standards, and evaluating the effectiveness of the new model (**See Box 1 – Study Aims**).

Box 1. Study Aims

Aim 1: Design & Implement SaFE-NC at 3 diverse hospitals through a Learning Collaborative Approach
Aim 2: Evaluate implementation and effectiveness of SaFE-NC
Aim 3: Cost analysis of SaFE-NC implementation and maintenance

Key Players and Study Locations

The team consists of physicians and researchers from 5 institutions in the Chicago area (**Figure – SaFE-NC Team**). Areas of expertise represented include pediatric urology, general pediatrics, family medicine, obstetrics, health services and outcomes research, health economics, biostatistics, and global health. Loyola Medicine, The University of Illinois at Chicago, and Ann & Robert H. Lurie Children's Hospital of Chicago are the 3 clinical sites. These high-volume neonatal circumcision sites were selected based on diversity of patient demographics, specialties performing circumcisions, and hospital type, which will help to optimize generalizability of our study findings to other institutions locally and nationally.

Current State

Learning collaborative teams have been assembled at each clinical site, and our second all-site meeting will occur in the coming weeks. During these collaborative meetings, participants (physicians, nurses, medical assistants,

administrative professionals, and more) exchange ideas about how to improve the way we provide newborn circumcision care. We are also currently working to define the current process for newborn circumcisions at each hospital. Observations of inpatient and outpatient newborn circumcisions are being performed at all three hospitals. Detailed process maps that include components like personnel, workflow, equipment, and locations are being drafted and reviewed with team members.

Future Directions

We are beginning to envision improvements to the current neonatal circumcision care model at each hospital, inspired by the WHO Standards and Procedures. Each site will soon refine and finalize their version of SaFE-NC for roll-out and evaluation. We then envision developing a “SaFE-NC Toolkit” that gives ideas and guidance for other hospitals who are looking to improve and streamline their neonatal circumcision.

Additional Reflections

The most important thing to do to ensure a successful collaboration is to touch base regularly and keep it fun! Collaborations are a lot of work, and engagement is so much better if participants know what to expect and have a good time working together.

What is the biggest hurdle or obstacle to overcome in a collaboration? The biggest hurdle or obstacle to overcome is coordination. Even if folks are motivated, coordinating competing schedules to maintain regular communication is no small feat!

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The Pediatric KIDney Stone Surgery (PKIDS) Trial: Improving Surgical Outcomes through Patient-centered Collaboration

Lydia Briggs, Greg Tasian, Jing Karchin, Brian Augelli, Jonathan Ellison



The horizon of surgical innovation is constantly shifting due to emerging technological advancements, with costs and risks of early adaptation of these advancements and barriers to dissemination of high-level evidence limiting rapid translation from knowledge generation to implementation. Randomized Controlled Trials (RCTs), the “gold-standard” of study design, are limited in surgery due to these factors. These limitations are further compounded by the relative rarity of pediatric disease.¹ We present the Pediatric KIDney Stone (PKIDS) Care Improvement Network, a community of patients, caregivers, and clinicians across 30 pediatric healthcare systems throughout North America as a model of collaboration for pediatric urologic disease. This network strives to overcome traditional hurdles of surgical trials such as identifying relevant patient-centered outcomes, optimizing patient accrual and enrollment, and incorporating new knowledge into clinical practice across a diverse healthcare landscape.² Currently, PKIDS is conducting a prospective observational trial comparing the effectiveness of three surgical modalities in pediatric nephrolithiasis, with a focus on stone clearance and lived patient experiences. Having successfully accrued 1290 patients to the trial, we will garner valuable information based upon a network-wide consensus definition of stone clearance as well as patient-prioritized outcomes related to the lived experience, specifically Patient Reported Outcome Measures Information System (PROMIS) questionnaires measuring physical emotional and social health at baseline and pre-specified postoperative inter-

vals (pain intensity, pain interference, anxiety, peer relationships, psychological stress experiences, and sleep disturbances). The foundation for this engagement depends upon a multi-faceted system of centralized regulatory infrastructure and broad-based stakeholder engagement.

The regulatory aspect of collaboration, while rarely inspiring sparks of investigative enthusiasm, is essential to high-level and effective multi-institutional study design.³ PKIDS has a designated data coordinating center (Children’s Hospital of Philadelphia) which is able to leverage a single IRB framework under the Common Rule, wherein collaborating IRBs agree to “rely” upon the designations put forth by the central IRB. The Common Rule refers to the federal regulations on Protection of Human Subjects issued by the U.S. Department of Health and Human Services. Combined with an infrastructure of data use agreements across PKIDS, institutions are able to share information between themselves and the coordinating center in a way that optimizes both knowledge generation (with a centralized evaluation for all trial activities) and stakeholder engagement (creating mechanisms for a decentralized pursuit of secondary study analyses). Importantly, PKIDS has centralized leadership structure and standardized process of approval for use of trial data in secondary studies. This system, supported by a Publications and Study Initiation Committee comprised of PKIDS investigators, invites collaborators to submit proposals for secondary analyses and provides constructive feedback to strengthen these proposals, ensuring meaningful engagement and feasibility of such activities.

Stakeholder engagement arises from this central infrastructure, with intentionally designed committees aimed to create opportunities for cross-pollination across varied fields of expertise and experience. These committees include the Clinical Engagement Committee (comprised of clinicians across a broad array of specialties), the Private Sector Advisory Committee (comprised of industry and payer stakeholders), and perhaps most uniquely, the Patient and Family Partners (PFP). Notably the PFPs, as a committee of patient and caregiver

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PKIDS collaborators with patient and family seen together at the 2021 SPU Fall Congress in Miami, FL.

PKIDS (continued from previous page)

representatives, provide continuous input into what is, at its core, the guiding light for PKIDS – patient-centered care improvement. These groups were created upon the inception of PKIDS and involved in processes of grant proposal, study design, and trial implementation, creating a culture of co-ownership across the PKIDS Trial.

While this culture of co-ownership was intentionally created, PKIDS has also relied on organic evolution of a collaborative culture throughout the study period. Specifically, we identified perceived barriers to recruitment from coordinator-based feedback and utilized the community of researchers, clinicians, and patient and family partners to best address these barriers. A culture of transparency and support has been molded by facilitating de facto breakout sessions to our coordinators, enabling them to procure advice from our PFPs in order to facilitate recruitment strategies. We have granted patients opportunities to complete study materials at home with the intent of decreasing longitudinal continuation burnout secondary to unnecessary commutes. Most notably, we identified that coordinators broaching the matter of studying surgical outcomes sometimes created inner turmoil within patients, perhaps even creating a level of distrust in the procedure. Thus, we encouraged our investigators and coordinators to advocate for the research and procure certitude that their engagement in PKIDS was not a factor in the participant's level of care, which was identified as a key barrier to participation. Coordinators were available with information pre-operatively, streamlining the engagement with our studies and further reinforcing the community of PKIDS. This tribe of patient-centered medical education has indubitably created a culture of families continuously engaging and wanting to facilitate the growth of the PKIDS network, as evidenced by the large proportion of

families who have indicated interest in participating in future PKIDS studies. Ultimately, we strive to create a hub where researchers can access valuable data and work within stream-lined regulatory, disseminate timely post-surgical outcomes to the urology community, and collaborate with stakeholders such as patients, caregivers, researchers, and clinicians to optimize the impact and feasibility of this work.

Additional Reflections

The most important thing to do to ensure a successful collaboration is to have opportunities for engagement (career advancement, mentorship, etc.) coupled with interpersonal relationships and a multitude of communication strategies (email / large group meetings / small group meetings / one on one chats) to support these relationships.

The biggest hurdle or obstacle to overcome in a collaboration is the competing demands of time, resources, and priorities. We start our meetings with the mission statement of PKIDS, identify and communicate what we are laser focused on for that specific time-frame, and address competing demands through understanding individual priorities, goals, and opportunities for engagement in the network.

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The Pediatric Urologic Oncology Working Group

Kathleen Kieran, Jonathan Routh, Nicholas Cost

The Pediatric Urologic Oncology Working Group (PUOWG) became a formal committee of the SPU in 2012 based on the prior framework of the AAP SOU Oncology Working Group. The goal of the new group was to provide a professional development hub for urologists interested in pediatric oncology. Many urologists played key early roles in the group, including Drs. Nicholas Cost (founding Secretary), Michael Ritchey (founding President), and Jonathan Ross (past President). The American Cancer Society estimates that nearly 10,000 American children aged 15 years and younger will be diagnosed with cancer this year; cancer is second only to accidental trauma as a cause of death for American children. Improvements in pediatric cancer care now allow more than 85% of children to survive more than 5 years after their cancer diagnosis. Many of these children will have primary urologic cancers or urologic sequelae of their treatment, making knowledge of pediatric oncology critical for pediatric urologists.

Since its inception, PUOWG has established itself as an educational resource for clinicians at all levels. It hosts periodic case presentation conferences at the spring and fall Societies for Pediatric Urology meetings, at which case presentations are solicited and the top four selected for publication in *Urology* (the Gold Journal). This fall, PUOWG has also directed urologic oncologic content for the Section

on Urology's return to the annual American Academy of Pediatrics National Conference and Exhibition. Children's Hospital Colorado hosts an annual Pediatric, Adolescent and Young Adult (PAYA) Urologic Oncology Conference that fosters networking and collaboration, in addition to providing continuing medical education in the form of clinical updates on oncologic topics pertinent to pediatric urologists. Finally, PUOWG encourages multicenter collaborative research projects aimed at improving the urologic oncologic care of children; a selection of publications from these efforts is listed below.

PUOWG has been hailed by members of the SPU Executive Committee as a prime example of a new organization that brings value to pediatric urologists. PUOWG's success reflects, in large part, its focus on collaboration (rather than competition) with other medical and surgical subspecialties, and its commitment to providing pediatric urologists with specialty-focused oncology-oriented medical education. Several PUOWG Executive Committee members sit on Children's Oncology Group (COG) committees (Renal, Soft Tissue Sarcoma, Germ Cell, and Survivorship/Late Effects), in which capacity they influence clinical trial protocol development, analyze existing data, and develop formal clinical recommendations and guidelines. Pediatric urologists with an interest in pediatric urologic oncology are encouraged to be-

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come members of COG (<https://www.childrensoncologygroup.org>) and to attend the COG Fall Group Meeting (usually held in September). PUOWG's alliance with COG helps members develop relationships with medical oncologists, radiologists and radiation oncologists, and pediatric surgeons such that the urologic perspective is intentionally incorporated into COG protocols and pediatric oncologic care, helping research and clinical work move forward efficiently while minimizing redundant and duplicated efforts. Additionally, national and local collaborations assist pediatric urologists interested in oncology to become involved at their own institutions.

PUOWG's Organizational Aims:

(1) Involvement in the cooperative oncology groups, such as the Children's Oncology Group (COG), which lead large-scale, prospective, pediatric oncology research.

(2) Developing and fostering sub-specialty oncology interest amongst pediatric urologists via our existing professional organizations such as the American Urological Association (AUA) and the Society of Pediatric Urology (SPU).

(3) Continuing education of the pediatric urology community on oncology-related issues.

(4) Conducting and leading high-impact clinical and translational research in a multi-institutional and collaborative manner amongst interested pediatric urologists.

(5) Focusing on quality improvement to ensure that as pediatric urologists we are providing safe, reliable, and state-of-the-art oncology care to this patient population.

Additional Reflections:

As with most things, successful collaboration is a function of high-quality and consistent communication. There should be clear goals, clear timelines, and clear accountability. Scheduled and ad hoc check-ins to ensure that everything is going as planned (and what isn't working if not) are also important.

The biggest obstacle to overcome in a collaboration is—literally—the one that no one mentions. Creating a space that is safe and respectful where people can speak up and say what is or isn't working, and hold others accountable, is incredibly important. Very little goes perfectly as planned, but being able to take stock and to pivot is what distinguishes successful and unsuccessful endeavors.

Selected PUOWG Publications

Peard LM, Morin J, Flores V, et al. Gonadal tumors in a contemporary cohort of patients with differences in sex development undergoing surgery - A multi-site study from the Pediatric Urologic Oncology Working Group of the societies for pediatric urology. *J Pediatr Urol* 2023 Apr 13; S1477-5131(23)00136-5. doi: 10.1016/j.jpuro.2023.04.008.

Peard L, Gargollo P, Grant C, et al. Validation of the modified Bosniak classification system to risk stratify pediatric cystic renal masses: An international, multi-site study from the pediatric urologic oncology working group of the societies for pediatric urology. *J Pediatr Urol* 2022; 18: 180.e1-7. doi: 10.1016/j.jpuro.2021.12.001.

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PUOWG faculty and attendees of the 1st annual Pediatric, Adolescent and Young Adult Urologic Oncology Conference held in Aurora, CO in June 2022.