Urology Interagency Coordinating Committee (UICC)
Updates from MAPP and LURN
May 17, 2019
9:00 a.m. - 12:00 p.m.
6707 Democracy Blvd. Room 7050, Bethesda, MD
Meeting Minutes

Dr. Tamara Bavendam, the Women's Urology Program Director within KUH, opened the meeting and meeting participants introduced themselves, also noting their agency affiliations.

Background on Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

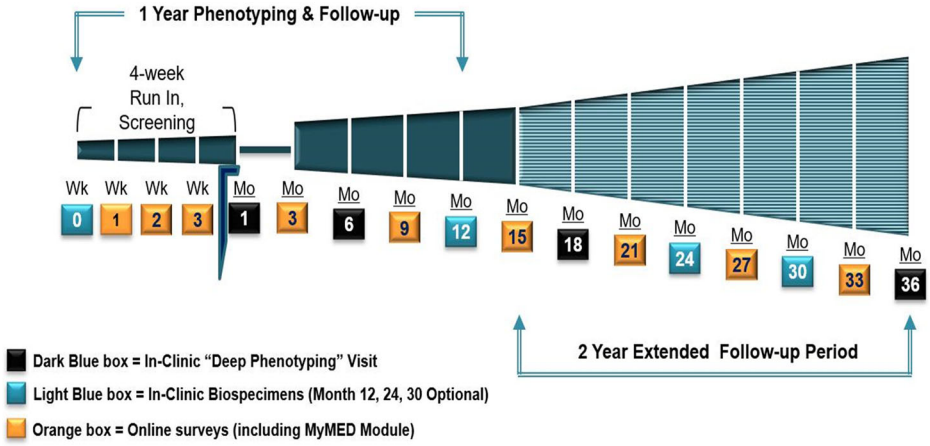
Dr. Mullins discussed the NIDDK's research interest in urologic chronic pelvic pain syndrome and NIDDK's funding history for benign urologic diseases. NIDDK's funding history for urologic chronic pelvic pain syndrome (UCPPS) detailed that many current therapies are infective in randomized trials and UCPPS patients have associated co-morbidities, suggesting that these are systemic disorders requiring a multi-system, multidisciplinary approach. The MAPP Research Network was established by the NIDDK in 2008, as a novel study of UCPPS. Dr. Mullins noted that what differentiated MAPP from other studies in urologic research, was that the MAPP Research Network approaches UCPPS as a systemic disorder and assesses urologic and non-urologic contributions using a highly-integrated study design. Within the Network, study goals include to:

- Better understand the **treated natural history** (progression) of UCPPS
- Identify factors that define clinically relevant patient **sub-groups**
- Address underlying disease **pathophysiology**
- **Inform** future clinical studies (e.g., trials) and improve clinical management

Dr. Mullins noted that another advantage of MAPP is the large, diverse group of PIs throughout the country. The MAPP Research Network includes Phase 1 and Phase II studies:

- **MAPP Phase I (July 2008 - June 2014)**
    - 12-month cohort study (Epidemiology and Phenotyping Study)
    - 424 UCPPS participants
        - Biweekly internet-based questionnaires
        - "Deep phenotyping" at baseline, 6 and 12 months
- 415 controls and 200 "positive controls"
    - Single 'deep phenotyping' visit

MAPP Phase II (July 2014 - June 2022)
- 36-month cohort study (Symptom Patterns Study)
- 620 UCPPS participants
    - Internet-based questionnaires every 3 months
    - 'Deep phenotyping' at baseline, 6, 18 and 36 months



- Repeated neuroimaging and quantitative sensory testing

Dr. Mullins noted that the MAPP Phase II studies used different cohorts and dedicated patients to progressive visits at different timed intervals. In the MAPP Phase II study, many "phenotyping" domains were studied, including: urologic, non-urologic, psychosocial, quantitative sensory testing, microbiome, molecular phenotyping, animal models, and neuroimaging. Dr. Mullins noted that two new domains were added: an ATLAS to investigate new treatment monitoring and mHealth Mobile, an app on the user's mobile phone that allows the individual to access a daily survey. Dr. Mullins noted that an integrated approach to systemic phenotyping for UCPPS, beyond bladder and prostate research, to include psychosocial factors, microbiome profiles, and sensory testing.

Currently, the MAPP Research Network is scheduled to enter a 3-year year extension (2020) to extend patient follow up for 1 year, extend data analysis for 3 years, and transition basic studies within the Network to R01s. Dr. Mullins noted that a meeting will be held on September 24-25 at the Wardman Park Marriott in Washington, DC. The meeting, titled "Research Advances for Urologic Chronic Pelvic Pain Syndrome: Informing the Next Generation of Clinical Studies," will focus on four major themes (1) Mechanisms to Novel Therapy, (2) Clinical Sub-Grouping, (3) Improved Definitions/Outcomes, (4) Novel Trial Designs and feature presentations, moderated discussions, and recommendations.

In conclusion, Dr. Mullins cited two resources for the public:

- Clemens JQ, Mullins C, Ackerman AL, Bavendam T, van Bokhoven A, Ellingson BM, Harte SE, Kutch JJ, Lai HH, Martucci KT, Moldwin R, Naliboff BD, Pontari MA, Sutcliffe S, Landis JR; MAPP Research Network Study Group. Urologic chronic pelvic pain syndrome: insights from the MAPP Research Network. Nat Rev Urol. 2019 Mar;16(3):187-200.
- **www.MAPPNETWORK.ORG**

Update and Relevance of MAPP Findings

Dr. Mullins introduced Dr. Pontari, MAPP Network Co-Chair for CP/CPPS, and Professor and Vice-Chair of the urology department at the Lewis Katz School of Medicine at Temple

University. Dr. Pontari welcomed participants and provided an update on MAPP Network Findings. Below is the citation to the most recently published MAPP findings:

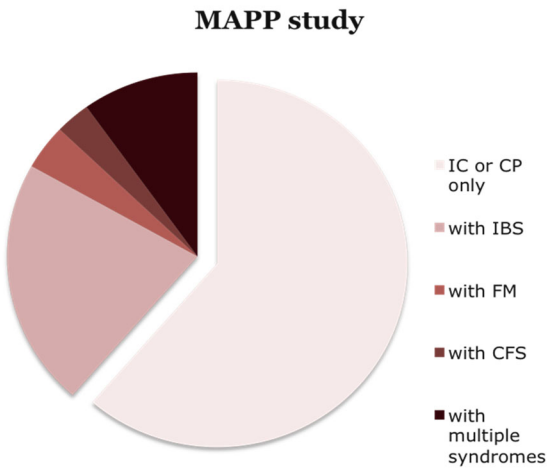
- Clemens JQ, Mullins C, Ackerman AL, Bavendam T, van Bokhoven A, Ellingson BM, Harte SE, Kutch JJ, Lai HH, Martucci KT, Moldwin R, Naliboff BD, Pontari MA, Sutcliffe S, Landis JR; MAPP Research Network Study Group. Urologic chronic pelvic pain syndrome: insights from the MAPP Research Network. Nat Rev Urol. 2019 Mar;16(3):187-200.

Dr. Pontari detailed locations of reported pain from the body map within the MAPP Epidemiology-Phenotyping Study and noted that the pain is not always restricted to the pelvis. Of the participants:

- **Pelvic Pain Only**
  - 26%
- **Pelvic Pain and Beyond**
  - 74%
  - More severe UCPPS symptoms
- **"<u>Centralized" pain phenotype</u> in the majority of UCPPS patients**

Within the MAPP Epidemiology-Phenotyping Study Widespread Pain Phenotype study, he noted that results indicated clinicians should consider giving a body map to patients to help characterize the distribution of pain, which may not be limited to the pelvic area. Dr. Pontari described upper chronic pelvic pain (UCPPS) and chronic overlapping pain conditions (COPCs) within the MAPP Epidemiology-Phenotyping study:

- **Chronic overlapping pain conditions (e.g. irritable bowel syndrome, fibromyalgia, chronic fatigue syndrome) common in UCPPS patients**
  - 43% females, 30% males (F > M) have ≥1 COPC
  - 10% two or more COPCs
  - More severe UCPPS symptoms
  - Worse QOL
  - More psychosocial symptoms



Key:
IC-Interstitial Cystitis
CP-Chronic Prostatitis
IBS-Irritable Bowel Syndrome
FM-Fibromyalgia
CFS-Chronic Fatigue Syndrome

Dr. Pontari summarized by stating that for some UCPPS pts, the pelvic pain may be part of manifestation of systemic pain and COPC can be a modifying factor. Within the bladder phenotype of this study, Dr. Pontari noted that, in questions from the RAND Interstitial Cystitis Epidemiology Study (RICE) Interstitial Cystitis (IC)/Bladder Pain Syndrome (BPS) patient questionnaire, patients where asked to respond to inquiries about "Painful urgency" (urinary urgency due to pain/pressure/discomfort) and "Painful bladder filling" (Pain is worse with bladder filling.). Results from the study showed positive responses from 88% of women, which indicated that bladder hypersensitivity is a key feature of IC/BPS and 75% of men indicated positive responses for a bladder phenotype for chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS). Dr. Pontari noted that this suggests an overlap in symptoms between IC/BPS and CP/CPPS in men. The bladder phenotyping component to this study determined that patients who tested positive for a bladder phenotype were associated with more non -urologic pain and a worse quality of life (QOL). In summary, male IC/BPS may be under-appreciated, many men with CP/CPPS actually have bladder & IC/BPS symptoms, and physicians should query CP/CPPS patients about their bladder & IC/BPS symptoms. An affirmative response may lead to change in diagnostics and treatments.

The MAPP Epidemiology-Phenotyping study also looked at 12-month symptom trajectories in individuals with urologic pain severity and urinary severity. This study showed symptom progression was impacted by widespread pain (measured with a body map) and the severity of bladder-focused symptoms after a 4-week period. The predictors of longitudinal symptom trajectory showed that patients who were evaluated using a body map showed an increased likelihood of improvement in pain within 12 months and were associated w/older age, less widespread pain symptoms at baseline, better overall physical health at baseline (higher SF-12 physical, sleep, fatigue) and better overall mental health at baseline (higher SF-12 mental, pain catastrophizing, perceived stress evaluated the use of a symptom assessment tool). Patients who were diagnosed and treated using a body map were also more likely to show improvement in urinary symptoms in 12 months. These patients showed less widespread pain symptoms at baseline and better overall physical health at baseline (higher SF-12 physical, sleep, fatigue). The symptom assessment tool was developed using baseline questionnaire where responses were examined using principle components and exploratory factor analysis. This two factor solution provided the best psychometric description of pain symptoms urinary symptoms and determined the formation of MAPP Pain and Urinary Indices:

- MAPP Pain Severity = Sum of Pain subscale from the GU Pain Index, plus Item 4 from the IC Symptom Index
- MAPP Urinary Severity = Sum of Urinary subscale from the GU Pain Index plus Items 1-3 from the IC Symptom Index

This study, using the symptom assessment tool, demonstrated that pain symptoms were associated with symptoms of depression, urinary symptoms were not associated with depression symptoms, and longitudinal analysis showed that pain and urinary symptoms track differently. These findings suggest pain and urinary symptoms should be assessed separately using two indexes, rather than assessed by a "composite score" that combines both pain and LUTS (e.g. ICSI). When MAPP PIs looked at psychosocial difficulties in UCPPS patients, they discovered psychosocial difficulties were worse than controls when compared to factors such as mood, life stress, coping skills, personality traits, and widespread pain symptoms. Psychosocial difficulties

were similar in UCPPS subjects and "positive" controls with fibromyalgia, IBS, and CFS. The study showed more psychological difficulties in UCPPS patients compared to controls, and the level of psychosocial problems was solely attributable to the severity of UCPPS symptoms. Dr. Pontari noted that treating these symptoms may not be enough to help the problem and both sexes (UCPPS patients) showed psychosocial issues.

The MAPP II Symptom Patterns Study focused on 1-year phenotyping and follow-up for patients. During this time, patients were required to be screened at 4 weeks. After week 3, patients were scheduled for a "deep phenotyping" visit. Patients were also scheduled for deep phenotyping visits at months 6, 18, 36 and in the interim, in-clinic biospecimens were collected at months 12 and 24 with a patient option for month 30. Patients were also able to complete online surveys throughout the study using their MyMED module. Shortly after the 12 month period were data was collected, the study shifted focus to a 2-year extended follow-up period. The MAPP II bladder -specific symptoms found: 363 women with IC/BPS, 55 men with IC/BPS alone or IC/BPS and CP/CPPS, and 127 men with CP/CPPS only. Another symptom, pain with bladder filling, was reported 3/5 instances from 76% of men or women with IC/BPS and 40% of men with diagnosis of CP/CPPS. MAPP PIs studied the Association of Painful Bladder Filling (PBF) and UCPPS Symptom Severity, Chronic Overlapping Pain Conditions (COPCs), Anxiety and Depression. MAPP PIs found PBF associated with PBF associated with: more severe UCPPS symptoms and more severe depression and anxiety scores. There is also a four-fold greater likelihood of being diagnosed with a COPC (fibromyalgia, IBS, chronic fatigue syndrome), These findings provide strong support for PBF as a marker which distinguishes subgroups within UCPPS, regardless of the diagnoses of CP/CPPS or IC/BPS.

While the MAPP 1 body map evaluated 45 pain sites in 7 regions using baseline only and no severity measures, the MAPP II body map includes 76 pain sites and includes pain severity and 5x/week patient interaction. In MAPP II, patients are asked to provide responses to a brief pain inventory. Patients were to select each area on the body map where they have had pain and tenderness over the past 7 days and indicate the intensity of pain in that area (scale of 1-10). MAPP PIs collected data on the widespread pain propensity score during the run-in period when patients' visits occurred as well. Patients were also studied to find out if widespread pain correlates with UCPPS severity; through this effort, the study has emphasized the importance of capturing the severity of widespread pain. Another component of the MAPP II study was the "Analysis of Therapies During the Longitudinal Assessment of Symptoms (ATLAS)". Prior to the 12-week period, patients received a pre-therapy (up to 4 weeks before week 0) that includes a dipstick urinalysis/culture, biospecimens, Q-Sym Data, MyMED (data diary for patients), deep phenotyping, neurological scans, and QST measures. Following the pre-therapy, patients submitted data for 12 weeks using MyMed and Q-Sym Data. After the 12-week period, patients received post-therapy, which included the same diagnostics as the pre-therapy. Other MAPP features include evaluations for pelvic floor muscle tenderness and Hunners Lesions.

Dr. Pontari noted that the MAPP Quantitative Sensory Testing (QST) study focused on pain sensitivity using the application of standardized, quantifiable sensory stimulus. The team's goal was to systematically assess the somatosensory response. This study showed pain sensitivity in UCPPS patients and healthy control cohort. An increased pain sensitivity was associated with increased UCPPS symptom severity as well as an increased risk of symptom progression. This

study demonstrated evidence of global pain hypersensitivity in the UCPPS patient cohort. The UCPPS patient neuroimaging cohort also demonstrated associations with widespread pain, showing the UCPPS dysfunction is not limited to the pelvis. Dr. Pontari described the breakthrough study that showed voluntary contraction of PFM and GMM, transcranial magnetic stimulation. The citation for this study is:

- Yani MS et al. Distributed representation of pelvic floor muscles in human motor cortex. Scientific Reports 8:7213, 2018

The MAPP I Biomarker Study focused on a molecular phenotyping effort and results showed:

- UCPPS higher urinary concentrations than controls in:
    - VEGF (women)
    - VEGF, VEGF-R1, MMP-9 (men)
- Pain severity associated with:
    - VEGF, VEGF-R1, MMP-9, MMP-2, MMP-9/NGAL complex (women)
    - MMP-9, MMP-9/NGAL complex (men)
- Urinary severity associated with:
    - VEGF, MMP-9, MMP-2, NGAL, MMP-9/NGAL complex (women)
    - VEGF-R1, MMP-9, MMP-9

*MMP = matrix metalloproteinase
NGAL = neutrophil gelatinase-associated lipocalin

In addition to the MAPP Biomarker Study, several other MAPP projects include inflammatory phenotyping, metabolomics, and microbiome studies. In closing, Dr. Pontari reiterated the need for clinical phenotyping of UCPPS patients should focus on at least 3 important factors:

- Pain localization on body map – Widespread Pain Phenotype
- Presence of Chronic Overlapping Pain Conditions (COPCs)
    - Refer to appropriate other specialists: GI, Neurology, PMR, Rheumatology
- Bladder Phenotype especially in men

Current insights for treatment as a result of MAPP research activities include:

- Tailoring existing treatments to more specific phenotypes
- Results of ATLAS study
- Biomarkers
- Pelvic floor dysfunction
    - Meds
    - TMS- Yani et al Motor cortical neuromodulation of pelvic floor muscle tone: potential implications for the treatment of urologic conditions Neurourology and Urodynamics 2019; 1-7. https://doi.org/10.1002/nau.24014
        - Repetitive trans cranial magnetic stimulation (rTMS) of the PFM representation in the SMA
        - Different response for low (increased) and high frequency (relaxed) for pelvic floor tone

Discussion

- Dr. Narva commented that this is a complex challenge for physicians. Dr. Narva queried what translation efforts where underway and if primary care providers are able to use these tools and questionnaires? Dr. Pontari noted that he would like to develop a 1-page FAQ on assessment tools. Dr. Narva advised Dr. Pontari to consider using overlapping pain conditions and non-urologic conditions such as back pain and fibromyalgia to discuss urologic concerns with patients.
- Dr. Bavendam queried the use of the physical therapy module. Dr. Mullins noted many patients participant in physical therapy and commented that this is the best opportunity to phenotype patients.
- Dr. Rankin queried how the data integrated between neuroimaging and biomarkers and the use of animal models. Dr. Pontari noted that DCC is working to integrate this data for neuroimaging biomarkers. There has been progress on the animal models, but nothing has been developed as of yet.
- Dr. Bavendam queried the group if the MAPP study could expand to include the study of other female pelvic organs such as the uterus. Dr. Pontari noted that data is not collected in this area. Dr. Bavendam also queried what data is being collected on Hunner's lesions? Dr. Mullins noted that histological data is being collected.

Background on LURN

Dr. Kirkali discussed the Symptoms of Lower Urinary Tract Dysfunction Research Network (LURN). Many challenges exist within the current research framework, including a lack measurement tools for LUTS and a need to improve patient phenotyping efforts. To address important research obstacles that will improve the field, the NIDDK funded the LURN. A year later LURN was expanded to include 3 additional research sites to a total of 6 research sites and the data coordinating center (DCC).The goal of the LURN is to increase the understanding of LUTS by: 1) improving the measurement of patient experiences of lower urinary tract symptoms (LUTS), 2) identifying and explaining the important subtypes of LUTS patients, and 3) disseminating data, research tools, and biosamples to the research and clinical communities. Dr. Kirkali noted that all samples are banked into the NIDDK repository and are available to the broader research community.

Update and Relevance of LURN Findings

Dr. Kirkali introduced Dr. Claire Yang, co-chair of the LURN. Dr. Yang noted that LUTS involves the bladder, urethra, prostate, and pelvic floor. The Network also studies LUT functions in terms of storing and emptying urine. LUTS is characterized by incontinence, urgency, frequency, nocturia, slow stream, and a sensation of incomplete bladder emptying. While LUTS is not a generally a life or health threatening condition, the prevalence of this condition increases with age, has a significant negative impact on the patient's quality of life (QOL), and represents a huge economic burden within the United States. Many LUTS treatments are not effective for patients because current treatment paradigms are based on a single or predominant symptom and patients have more than a single or predominant symptom.

Dr. Yang noted several efforts within the LURN 1 study:

- Development of Comprehensive Assessment of Self-Reported Urinary Symptoms (CASUS)—The most comprehensive and evidence-based self-reported measure of LUTS to date.
- Multiple Self-Reported Measures Qualitative Assessment
- Discovering Refined Clinical Subtypes using Novel Analytical Techniques
- Subgrouping/Phenotyping efforts
    - Phenotyping Observational Cohort
    - Phenotyping Neuroimaging and Sensory Testing
    - Biomarker Pilot Project
    - Phenotyping Organ-Based Pilot

The CASUS self-report measure of LUTS was born from a need for a comprehensive self-reported measurement tool in urology. The development process consisted of interviews with 88 people with LUTS at different sites. PIs used study results of the self-reported measures qualitative assessment to develop the following self-reported measurement questionnaires:

- CASUS: a comprehensive, granular tool
    - Used for Subgrouping
    - CASUS questionnaire administered to subjects enrolled in Observational Cohort for validation
- LURN SI-10
    - "Short form" for clinical use
- LURN SI-29
    - Research tool for outcomes

Dr. Yang described the self-reported measures recall study and noted that the primary objective for this study is to recommend a single recall period for the LURN battery that has evidence for validity (with regard to recall) and is longer than 1-day. Subjects who experience at least one of the targeted symptoms randomized into one of three groups: Frequency, nocturia, urgency, incontinence, weak stream, feeling of incomplete emptying, and post void dribble. The study gathered data (bladder diary) at 3-,7-, and 30-day periods. In general, recalled reports tracked well with average daily reports for men and women. Systematic bias was minimal, supporting the use of 7- and 30-day recall periods.

Another area of success within the LURN 1 study was subgrouping/phenotyping efforts. The goal was to identify clinically relevant subgroups of patients with LUTS for better diagnosis as well as better treatments. The PIs noted the following areas of assessment in the Observational Cohort Study:

- Collection of demographic and clinical data, self-reported outcome measures, and biosamples
- Target enrollment of 500 males and 500 females
- Interval data collection up to 1 year

In this effort, 1064 men and women reported back at selected time intervals. Dr. Yang noted significant differences in the data collected in this cohort versus traditional LUTS cohorts:

Symptom Cluster	Symptom
Storage	Daytime frequency
	Nocturia
	Urgency
	Incontinence/leakage (various types)
	Poor or absent sensation of bladder filling
Voiding	Slow/weak stream
	Splitting or spraying
	Intermittent stream/Double voiding
	Hesitancy
	Straining
	Dribbling at the end of flow
	Paruresis (i.e., shy bladder, shy bladder syndrome)
	Poor or absent sensation of urethra during void
Post-micturition	Feeling of incomplete emptying
	Post-micturition dribble (delayed)
Other or Poorly Characterized	Abnormal bladder or urethral sensations

Dr. Yang noted that patient data was collected according to the following visit schedule:

	Initial Visit	Initial and/or Baseline Visit	3 Month Visit	6 Month Assessment	9 Month Assessment	12 Month Visit
Eligibility assessment	X					
Demographics	X					
General clinical information	X					
Physical exam findings	X					
Clinic testing (urine analysis)	X					
LUTS Tool (one month recall)	X					
LUTS Tool (one week recall)		X	X			X
CASUS	X					X
3-Day voiding diary		X				
Self-report questionnaires		X	X			X
Biosample collection (Blood, Urine, Saliva)		X	X			X
Perineal/Vaginal swab		X				
Interval treatments			X	X	X	X

In addition to the Phenotyping Observation Cohort, LURN 1 studied neuroimaging and sensory testing. The primary objective was to investigate urinary urgency through neuroimaging and quantitative sensory testing methods. This study used survey responses, fMRI, multi-modal automated sensory testing (MAST), audiometer testing, and biosample collection. The study recruited targeted participants who had urinary urgency, +/= incontinence, and who were co-enrolled in the Observational Cohort Study. By pointing to the need for better phenotyping, Dr. Yang emphasized phenotyping efforts in this study as opposed to efforts in previous MRI studies:

Previous functional MRI studies	LURN neuroimaging studies
fMRI studies that focused primarily on the activation/deactivation of cortical areas	(a) Connectivity studies using resting state fMRI to examine alterations in brain networks and abnormal communication between cortical areas involved in bladder control; (b) diffusion tensor imaging (DTI) to examine structural alterations in brain white matter tracts.
Mostly women	Men and women (1:1 ratio)
Predominantly elderly	Across all age groups
Mostly with urgency incontinence	Patients across a spectrum of urgency, with or without urgency incontinence
Small no. of participants, typically single site studies	Large no. of participants across six LURN sites (n=256 for this proposal)
Repeated bladder filling and withdrawal via a catheter (invasive and artificial)	Use a diuresis protocol to fill bladder without a catheter (natural filling)
	Integration with detailed phenotyping data available through the umbrella LURN Observational Cohort Study
	Integration with quantitative sensory testing (QST) as part of this protocol

Dr. Yang noted the site visit schedule for patients:

	Screening Assessment	Neuroimaging & Sensory Testing Visit
Eligibility assessment	X	
Screening demographics	X	
LUTS Tool (one month)		X
AUA Symptom Index		X
Self-report questionnaires		X
Urine analysis (dipstick)		X
Pregnancy test		X
Biosample collection (blood, urine, saliva)		X
Genital swab collection		X
DNA collection		X
fMRI		X
MAST testing		X
Auditory stimulation		X

In addition to these phenotyping efforts, LURN 1 PIs studied the role of the urethra in an organ-based pilot study. The primary objective was to determine the feasibility of performing an extended and extensive urodynamic test sequence in healthy female controls. In this pilot, urethral tests such as uroflowmetry and bladder tests such as rapid fill-rate cystometry were used as assessment tools. The pilot enrolled 10 healthy females at Duke University and demonstrated feasibility for procedures, data collection, and transfer.

While several efforts were underway to advance phenotyping in urology, LURN 1 also collected the following biosamples: whole blood, plasma, serum, urine, saliva, vaginal / perineal swab. Dr. Yang noted that, in the first phase, the goal was to develop signatures for biomarkers to identify subgroups of people. Dr. Yang noted that data was also collected on non-urologic factors such as caffeine, fluid intake, tobacco, diet and alcohol. Results showed weak data to support eliminating non-urologic factors that may impact LUTS. Efforts are now underway to analyze the data collected. Other efforts include using cluster analysis on data (symptoms) and mathematical modeling, without bias of accepted clinical diagnosis to discover refined clinical subtypes using the LUTS assessment tool.

In closing, Dr. Yang noted that the LURN study resulted in six year of data collection, 17 publications, 26 abstracts, and 75K biological samples that are banked in the NIDDK repository. Next steps for this group will include further development of self-reported measurement tools with a focus on transdisciplinary efforts. LURN II will further phenotyping and subtyping efforts through variable clustering, a longitudinal study, and further assessment on how non urologic factor impact LUTS.

Discussion

- Dr. Narva noted the importance of establishing consistent descriptions for symptoms and conditions.
- NIA Marcel noted geriatric comorbid conditions. And asked what exclusions. Dr. Yang noted that pain was the only exclusion (b/c of MAPP network). He suggested linking this information to drug data for Medicare patients. Dr. Kirkali noted that all data will be deidentified and available in the repository.
- Dr. Rankin queried readiness of questionnaires. Dr. Yang noted these are still in development, but the feedback has been positive from PIs to use. Dr. Mullins noted that the short form is only for physicians. Dr. Yang noted the PI could identify the subtype identified as many patients present with multiple symptoms.

Closed Federal Discussion

- A representative from the FDA commented that there is a vast amount of data being applied to problems. The key for FDA is to view targeted data and identify what really works in a multifactorial disease process.
- A representative from NICHD noted overlap between LURN and some of their programs. Currently, they are interested in female pelvic pain research areas and expressed strong interest in a collaboration with MAPP Network.

- A representative from AHRQ commented on their efforts using systematic evidence reviews in conjunction with opioids. AHRQ also expressed interest in joining MAPP.
- Dr. Bavendam noted ongoing efforts with PLUS (in its 4th year) as well as efforts in underactive bladder research within LURN.

Agency Updates

- A representative from NICHD noted many efforts are on hold due to the development of a strategic plan.
- A representative from FDA noted drug evaluation efforts for underactive bladder conditions.
- A representative from NIA noted little progress has been made on deprescribing drugs deemed not appropriate for the geriatric population. This new effort will focus on patient populations such as Alzheimer's.
- A representative from AHRQ noted efforts to study urology symptoms from prostate cancer.
- Dr. Bavendam noted that a joint KICC and UICC meeting will be held in October. Also, October 7-8 meeting will focus on uncovering the burden of genitourinary conditions.