



CAIRIBU Interactions Core

*Collaborating for the Advancement of
Interdisciplinary Research in Benign Urology*

The CAIRIBU Interactions Core is working with Dr. Nicole De Nisco and Dr. Michael Neugent of UT-Dallas to keep the CAIRIBU Urobiome Research Interest Group going.

6/21/2023

Attendance:

Nicole De Nisco, PhD – UT Dallas; Michael Neugent, PhD – UT Dallas; Kristina Penniston, PhD – CAIRIBU Interactions Core; Jennifer Allmaras, MPH – CAIRIBU Interactions Core; Mariana Coughlin, MS – CAIRIBU Interactions Core

Short-term goals:

1. Conversation starters for CAIRIBU Connections: “UTI Through the Lifespan - Patient Perspectives”
2. Discuss structure for follow-up panel of scientists and clinicians
3. Discuss next steps for CAIRIBU Urobiome Research Interest Group (U-RIG)

Discussion:

- **Penniston:** Discussed **outline for patient panel happening on June 28, 2023**. Mentioned time for questions and answers and queried for list of questions in case discussion needs direction.
- **De Nisco:** Example questions: **1) What would you want us to focus on as researchers**, i.e. types of therapies, more antibiotics, treatment that is not antibiotic based, something preventative? **2) What kind of therapies are patients interested in?** Gave the example of intravesical deliveries, going into an office, having an agent delivered directly into the bladder and having to sit and wait. **Are these treatments desirable?**
- **Penniston:** **Should we do a patient survey on the most desirable attributes of treatment?** Gave an example of a similar study done in BPH treatment.
- **De Nisco:** Agreed patient preference is most important
- **Neugent:** **We want to know about their relationships with clinicians throughout their journey.** How long did it take them to find someone who will listen to them? Have they found that? Are they confident in the level of medical attention they received? Mentions that on Twitter, there is mention of a great need for scientists who are willing to pay attention to women suffering from rUTI. What are the obstacles to sufficient medical care? Do they feel they have been misled or made to feel not important?
- **De Nisco:** Adds, are they seeing a urologist? If not, they may be just getting whatever antibiotic is prescribed. Noted the burden of having to seek out specialized care. Noted the gap between scientific discovery and clinical implementation and patient frustrations with this fact. What can we do to expedite this process?
- **Penniston:** Agrees with the distinction between “guideline care” vs specialized care, need to do away with guideline-based treatment regimens (one size fits all) and towards precision care.
- **Neugent:** **Need to push back at concept that rUTI is a single disease.** UTIs are heterogenous, and people respond differently to different treatments.
- **Penniston:** Patients require education on this as well as are often confused about this distinction.
- **De Nisco:** Agrees, adds that it is the clinician’s job to communicate.
- **Penniston:** Agreed, but many urologists don’t appreciate the nuances of UTIs.
- **De Nisco:** Agrees, **important to refer to clinicians with appropriate expertise.**
- **Penniston:** Back to planning for next steps following the patient panel.....
- **De Nisco:** **Suggests follow up panel of scientists and clinicians to address patients’ questions.** Suggests we hold this event in September rather than July or August. Suggests we engage clinicians in

promoting the event to ensure good patient attendance as well as participation of groups such as UTIGA and UTI Australia.

- **Penniston: Suggests another meeting of the U-RIG to take place in late July or early August.**
Reminds group of the idea for patient or clinician facing written materials, could this turn into a work group that comes out of the U-RIG?

SUMMARY

- CAIRIBU Connections: UTI Through the Lifespan – A Patient Perspective
 - June 28, 2023 at 2 PM ET (1 PM Central | 11 AM Pacific)
 - Questions to stimulate discussion (if needed)
 - What do patients want researchers to focus on?
 - Types of therapies (e.g., antibiotics, non-antibiotic therapies, Intravesical deliveries)
 - Prevention
 - What are the most desirable attributes of treatment options?
 - What has been your experience with clinicians? How long did it take to find a provider who made you feel confident in the level of medical attention you received?
 - What are the obstacles to sufficient medical care?
 - Do you feel you have been misled or made to feel unimportant?
 - Are you seeing a Urologist? How long did it take to get connected with a specialist and what were the barriers?
- Follow up panel of scientists and clinicians
 - To be scheduled sometime in September
 - Designed to address the questions that patients have around the topic of UTIs
- Next meeting of the CAIRIBU Urobiome Research Interest Group (U-RIG)
 - To be scheduled sometime in late July or early August, between patient panel and researcher panel
 - To discuss topics to be addressed at researcher panel and engage scientists in clinicians in participating.
 - To discuss potential for work groups potentially to create patient or clinician facing written materials

Suggested next steps:

1. **Dr. Penniston to moderate June 28th patient panel.** Dr. De Nisco and Dr. Neugent to plan to attend and engage in interactive Q&A session.
2. **Schedule next CAIRIBU U-RIG meeting** (Mariana) to occur in late July/early August based on Nicole's and Michael's availability and that of others who responded to poll.
 - Discuss next steps for small writing groups, grant proposal development groups, potential patient preferences survey(?), other ideas for sustaining action around UTIs and other aspects of urobiome research
3. **Set up a follow up panel of scientists and clinicians to be scheduled sometime in September.**
 - Will require additional discussion to identify appropriate panelists, targeted outreach and promotion approaches, and focus on patient participation