



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 revitalize the CAIRIBU Urobiome Research Interest Group in 2023.

5/3/2023

Attendance:

Nicole De Nisco – UT Dallas

Michael Neugent – UT Dallas

Kristina Penniston – CAIRIBU Interactions Core

Jennifer Allmaras – CAIRIBU Interactions Core

Mariana Coughlin – CAIRIBU Interactions Core

Short-term goals:

(1) Discuss revitalizing the CAIRIBU Urobiome Research Interest Group

Summary:

- **Kris:** Discussed the CAIRIBU approach to incorporating investigators in the CAIRIBU community (current and prior funded centers, others involved in CAIRIBU initiatives). Reviewed the Urobiome Research Interest Group, what was done before and where it could go now. Reviewed CAIRIBU Connect as a landing page for meeting minutes, the urobiome “mind map”, summaries of NIH grants obtained by people in the URIG (needs updating since last meeting in 2022), links to recordings of various talks). Discussed Aaron Miller P01 multi-center grant idea. Discussed collaboration with UTI Health Alliance patient advocacy group and plans for a patient/researcher dialogue with an opportunity to build stakeholder engagement aspects to grant applications.
- **Nicole:** Mentioned UTIGA (UTI Global Alliance) and Sheryl Justice (?). UTIGA holds a UTI hour (Nicole hosting a talk in July on diagnostics)
- **Kris:** Plans to have CAIRIBU IC promote UTIGA events
- **Nicole:** Mentioned involving patients around metagenomic diagnostics and the problems these tests present
- **Nicole:** Mentioned Society for inflammation and infection and Keymora Scott(?)
- **Kris:** We (CAIRIBU) want to make more connections with these groups. Do we want to identify “buckets” of people and call for another meeting?
- **Michael:** Mentioned the importance of facilitating structured conversation. Mentioned at CAIRIBU Annual Meeting there was a focus group on urobiome and that it was difficult to fit everyone’s questions because they are all coming at it from different perspectives, that is why it is important to incorporate structure into the conversations.
- **Kris:** Yes, CAIRIBU IC can aim these conversations. Stones, infection, everyone has a stake in the game in urobiome. Aaron’s idea to assess urobiome as it relates to each condition. Would you say one goal is to define or articulate a research agenda for urobiome?
- **Nicole:** Yes, we can come up with a list of diseases/organs that include urobiome.
- **Kris:** Also, as a way to “coerce” NIH as what topics they should fund. Mentioned NIH workshops, that kind of went out the window with covid, CAIRIBU could do a version of this. Small working groups an option within each topic?
- **Nicole:** Mentions there will be lots of sub-topics, this is a large umbrella. Multiple aspects of disease, but also aspects of methodologies. Technologies beyond sequencing? “Who” is there and is associated with these diseases? We are behind in figuring out mechanistically what these are doing. Understanding metabolites using metabolomics(?) Struggle with transcriptomics given the nature of urine.
- **Kris:** Asks what is the challenge?
- **Nicole:** Answers urine is hostile environment for RNA. How can we get RNA from urine besides what has been doing. Filled with Ecoli is possible, but otherwise not so much right now. This is a real struggle. If we

figure out how to get that to work, we could figure out what genes microbiota are expressing. Linked with metabolomic data, as well as proteomics, but the databases are not as great given the limited characteristics.

- **Kris:** Discussed Alan Wolfe grant, central clearing house for information and data/resources useful to urobiome research community. What could CAIRIBU Interactions Core step into help with this? Links to resources?
- **Nicole:** Agrees, it is better to come from a third party (CAIRIBU) who is not invested as a competitor.
- **Kris:** Asks is there any organization that does this already?
- **Michael:** Answers there is a large consortia of databanks in cancer (cancer genome atlas). Suggests global urobiome project sponsored by a third party that publishes large consortia papers that identifies gaps in the field.
- **Kris:** Mentions that in benign prostate, leaders are looking at what cancer genome atlas did as well.
- **Michael:** Adds that cancer genome atlas is incredibly well organized.
- **Kris:** Mentions this tasks requires more than CAIRIBU could do. Could be an additional grant. Another problem is submitting supplemental data materials.
- **Nicole:** Adds that these are usually submitted to NCBI. Adds there is a potential need in other areas of data reporting.
- **Kris:** Ask Nicole to summarize this need in an email and send to CAIRIBU Interactions Core. Not everyone submits their data to NCBI, understood that kind of data as supplements to manuscripts, not true? Is it possible to pull from every journal and put it in one spot? Would this be helpful?
- **Michael:** Intermediate file set database?
- **Nicole:** Yes, like figshare.
- **Kris:** Raw data should all be in sequence read archive. The process data is usually submitted to each journal, difficult to curate especially if the journal is not open access. If no usefulness or utility will not pursue. Who could we get to talk about data access, standardizing how we collect data?
- **Nicole:** Could ask Julie Barthold if she knows someone?
- **Michael:** Suggests dkNET
- **Kris:** Adds that CAIRIBU IC already meets monthly with dkNET. Suggests we could ask at our next meeting with them. The problem is there is so much there. What is available? What could we share with our community?
- **Michael:** Identified the difference between standardizing methodology and standardizing reporting.
- **Kris:** Agrees, standardizing methodology, cool but how do we innovate? Brings the conversation back to U-RIG. We have a relatively large group of people who were ever interested in working on this. We should take the whole list and add these other individuals/groups? Can we pull out people (from UTIGA(?)) just doing urobiome work?
- **Nicole:** Not sure if we could or even should just pull out urobiome researchers.
- **Michael:** Adding others helps with translating mechanisms.
- **Kris:** Put together list, organize meeting, work out structured agenda with conversation and announce a meeting. Suggests June.
- **Nicole:** Suggests July or last week of June.
- **Kris:** Asks for ideal time of day?
- **Nicole:** Lunch meetings are good.
- **Michael:** MVIF research shows 3pm CT is really good in the US. Or 1 pm CT. This group puts on a monthly conference (virtual)next meeting next Wednesday. 9am ET. Open to anybody. Keynote, 3-4 selected talks and discussion afterwards. Run by Levy Watson in US, Nicholas Suggota (?). People from human microbiome project. Very few percentage are urobiome researchers. Maybe 3 people. Includes Lisa Karstens.
- **Kris:** Brought up next steps, schedule a meeting, follow up with this group to discuss a conversation structure, CAIRIBU specific goal is to get people to write grants, even thinking of how we can provide money to get investigators together to discuss a grant.
- **Nicole:** Agrees with big intro meeting with one or two big topics followed by smaller breakout sessions (immediately following(?)) where people can get to know each other better, interest in physical meetups for grant and paper writing purposes.
- **Kris:** Mentioned prior iteration of URIG not wanting CAIRIBU to be named as the organizer but recognized there is always going to be a need for broker. Will move forward with the CAIRIBU U-RIG.

SUMMARY

- History of the U-RIG and plans for revitalizing
 - Materials from prior U-RIG meetings and other resources from U-RIG participants available on CAIRIBU Connect
 - CAIRIBU IC to continue to curate list of interested investigators
 - Discussed related/interested societies including UTIGA and Society of for Inflammation and Infection, MVIF
- How to structure the meeting
 - Requires structured conversation, many different investigators with different interests
 - Possibility for breakout groups that stem from a larger meeting, discussion around diseases or organs that would be interested in the urobiome
- Technologies beyond sequencing in urobiome research
 - Metabolomics (?), transcriptomics, proteomics
 - Data handling and reporting as an issue within this topic
- Data handling in microbiome research
 - Sequencing data vs intermediate file sets (analysis files)
 - Is there room for CAIRIBU to help?
 - Methodology standard vs reporting standards
 - Cancer Genome Atlas as a model?
 - Discussed a challenge regarding open access from journals
 - Potential collaboration with dkNET for future CAIRIBU programming, will follow up in next meeting with dkNET
- Future directions
 - Interdisciplinary, collaborative publications and grants
 - Possibility for CAIRIBU funding for getting groups together

Suggested next steps:

- **Develop conversation structure for first large group U-RIG meeting to be scheduled sometime in the late-June/early-July**



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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



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7/28/2023

ATTENDANCE

Aaron Miller, Alan Wolfe, Mike Neugent, Nicole De Nisco, Chelsie Armbruster, Emily L Coffey, Julie Barthold, Laura Preves Helgeson (patient), Lindsey Burnett, Lisa Karstens, Mangesh Suryavanshi, Tanya Sysoeva, Lindsey Burnett, Megan Bradley, Nazema Siddiqui, Sonali Advani, Vanessa Hale, Kristina Penniston, Jennifer Allmaras

2 newly published papers including authors Linda Brubaker and Alan Wolfe in Frontiers in Urology

a. **Beyond the Usual Suspects:** <https://www.frontiersin.org/articles/10.3389/fruro.2023.1212590/full>

b. **Tarnished Gold:** <https://www.frontiersin.org/articles/10.3389/fruro.2023.1206046/full>

GOALS FORMED FROM THIS MEETING

- **Develop ongoing community of researchers that meets regularly**
 - **Learn more about each other's work** to identify common themes, connections, and how to bridge gap between research (e.g. between human and animal models)
 - **Monthly knowledge exchanges** (3rd or 4th Friday of month); begin in September; possibly alternate times; 3 people to present work each time with time at end for discussion – **Michael Neugent to organize**; will send out Google Sheet with sign up times
 - **Form groups to write manuscripts together and/or science communication materials** – to do before writing grants together
 - **Collaborative manuscript on the epidemiology of UTIs needed**; Aaron Miller encourages collaborative process to begin building precedent for future research applications
 - **Science communication papers** – see below for snip from prior meeting (available on CAIRIBU website under “CAIRIBU Research Interest Groups”
 - Importance of developing materials for providers was discussed.
 - Develop materials first then address strategy to disseminate
 - Another area to add to topics is **how antibiotics are not a no-consequence therapy.**
 - **Involve UTIGA in development of materials?** – Sheryl Justice (from UTIGA) has an interest in developing these materials
 - Also involve Lenny Ackerman talk on diagnostics – recording available here once posted: <https://utiga.org/past>
 - **After developing materials, think about dissemination strategy** – talks for YouTube or Podcast
 - Nazema Siddiqui also interested in technical and experimental workflows group (see CAIRIBU website [HERE](#) – page 2 – for list of people interested in various small writing groups)
- **Create more opportunities for U-RIG to connect at in person meetings** – CAIRIBU meeting, AUGS, etc.
 - Invite each other to speak at each other's things

Science communication papers. Patients and clinicians are envisioned as initial target populations. Those interested in working on these include: *Michael Neugent, Katie Forster, Lenore Ackerman, Tanya Sysoeva (also has students who may be interested), John Lee.*

- Is there a urobiome?
- Brief history (in layperson's terms) of urinary microbiome research and knowledge
- Description of the evidence that supports existence of a urinary microbiome
- How do we study the urobiome (e.g., technical aspects, tools, equipment, processes)?
- What is the terminology associated the urobiome and urobiome research?
- Is there an infection if a UTI is asymptomatic?
- How should we use (or not use) antibiotics?
- What are probiotics? What are prebiotics?
- What are the technical aspects of how we study the urobiome?
- What urobiome-related clinical trials are currently underway?