

KSEC Newsletter

To the Kidney Stone Community



The Kidney Stone Engagement Core was convened in January 2021 as an advisory group of patients, caregivers, advocates, clinicians, and researchers dedicated to enhancing the patient-voice in research for kidney stone disease. This newsletter, our first, provides us an opportunity to update you – the kidney stone community – on our work to date.

Our efforts to found KSEC were rooted in the believe that patients and their families should have a substantial voice in determining not only what we research but how best to design research studies and report upon the findings in a way that would generate the greatest impact for people who suffer with kidney stone disease. We garnered funding from the Patient Centered Research Outcomes Institute (PCORI) in order to develop a research agenda for the management of kidney stone disease, work that has recently been published in the Journal of Urology. This list reflects priorities of the kidney stone community and seeks to address gaps in management regarding ureteral stent use and pain management, ureteral stent removal, observation or intervention for asymptomatic kidney stones, diet or medical prevention, and care plans for repeated interventions. This list, however, represents the beginning, not the end, of our work. As we are actively engaging researchers to answer these important questions, we also recognize that this list may be incomplete and does not address important questions regarding why kidney stones form, why certain groups are at a greater risk than others, and how to incorporate the newest technologies to care for kidney stones.

Samantha Jacklin

I am a research coordinator for Jonathan Ellison at Children's Wisconsin with the Medical College of Wisconsin, the director of the KSEC. I have a Bachelors of Science degree in Biology. I am also an engagement manager for the Kidney Stone Engagement Core.



We are dedicated to changing the burden of kidney stones for patients and caregivers while creating a relationship between caregivers, patients and clinicians. On weekends or after work hours, I spend a lot of time traveling, spending time outdoors and on the golf course with my husband and my two sons.

KSEC Member Spotlight

Katherine Parker

I am the research coordinator, project and engagement manager for the Kidney Stone Engagement Core at the Medical College of Wisconsin and Children's Wisconsin. I have a degree in Neuroscience/ Psychology and have worked in research for 8 years with 4 years of clinical research in pediatric urology. Our team is dedicated to lessening the burden of kidney stones for patients and families by building partnerships with patients, caregivers, researchers and clinicians by developing research and clinical tools to improve their experience. Outside of my work, I am a martial artist, taekwondo instructor, amateur photographer, and mother.



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Since completing our initial project, KSEC has continued to engage the research community in a number of ways. We have provided feedback on several grant proposals regarding surgical and medical management of kidney stone disease, of which four have been awarded funding. Additionally, we have worked with kidney stone researchers and advocates to better understand how to best engage the kidney stone community. To this end, we would like to share with our readers a new online resource - <https://stonecollab.org/> - that we feel would be of interest to the kidney stone community.

Finally, we are always looking for ways to improve our process and better engage the kidney stone community. If you have any ideas, feedback, or interest in further engagement, please don't hesitate to reach out. You can find us at our new website, kidneystonecentral.org.

Wishing you well until our next communication,

Jon Ellison

Active KSEC Funding

"PATIENT-CENTERED
RESOURCE BUNDLE FOR
CHILDREN UNDERGOING
KIDNEY SURGERY":
CHILDREN'S RESEARCH
INSTITUTE

"PERSONALIZED OUTCOMES
OF NEPHROLITHIASIS IN
YOUTH": NATIONAL INSTITUTE
OF DIABETES AND DIGESTIVE
AND KIDNEY DISEASES

"USDHUB: COMMUNITY
RESOURCE FOR URINARY
STONE DISEASE RESEARCH":
NATIONAL INSTITUTE OF
DIABETES AND DIGESTIVE
AND KIDNEY DISEASES