Bladder Exstrophy Task Force

When the task force met first in 2019 at the Fall SPU conference the initiative that was proposed was to create a bladder exstrophy multi-institutional registry (to be available and used by all SPU members) that evaluates the short and long term outcomes of BE surgery, with the eventual hope of (potentially) standardizing surgical and pre- and post-operative practices.

The John Hopkins RedCap database was used as a template to create a database that will include standardized measurements of initial findings such as bladder plate width, length depth, width of bladder neck, width of urethral plate. Stay tuned for more details about where and how this database can be accessed by the SPU membership.

An important aspect identified by the group was that patient reported outcomes are critically important and any database should be designed to answer questions in bladder exstrophy that have been identified as important by the patients and their parents.

Dr. Anthony Schaeffer was designated as the lead to start working on identifying patient reported outcomes. It was also felt that pediatric urologists who have knowledge in patient-centered outcomes and comparative effectiveness research should join the task force such as Drs Konrad Syzmanski and/or Dr. Jennifer Dodson.

Dr. Schaeffer participated in the Bladder Exstrophy yearly support group that is lead by the Association for the Bladder Exstrophy Community (ABeC) which was sponsored and hosted by the Children’s Hospital of Los Angeles in June 2019. This survey was an informational survey to guide future patient-centered research interests (as discussed in more detail below). Here are the results:

Dr. Schaeffer had planned to broaden the reach by surveying patients and families with BE at other camps such as the Youth Rally and other Bladder Exstrophy Support groups but unfortunately this was not able to be achieved because of the pandemic.

In an effort to formalize a patient-centered research initiative in BE, a Letter of Intent for the Eugene Washington Engagement Award was submitted to the Patient Centered Outcomes Research Institute (PCORI) in November 2019. The goal of this initiative was to formalize a group of diverse and engaged persons with bladder exstrophy (and parents of children with BE) working together with BE health professionals to formulate research objectives and become active participants in patient-centered research. Some readers may be familiar with the extremely successful Bladder Cancer Advisory Network (B.C.A.N.), which served as an exemplary organization around which to model ours. The proposal was co-written by Anthony Schaeffer, Assistant Professor of Urology and the University of Utah, and Pamela Artigas, Director of the Association for the Bladder Exstrophy Community (ABeC). This initiative was in response to the BE community voicing a desire for research that is more responsive to their needs. We requested $100,000 to organize and run the inaugural in-person meeting of this group, called the Bladder Exstrophy Advisory Network (B.E.A.N.). Our proposal was not accepted, but we received excellent feedback and are seeking alternative sources of funding.

Dr. Merguerian has handed the steering of the group to Dr. Schaeffer. Over the course of the next year the task force hopes to 1) publicize and widely disseminate the BE task force’s pre-, intra- and post-operative database and 2) resubmit the B.E.A.N. proposal, with a potential first meeting to be held in the fall of 2022.