



FOR IMMEDIATE RELEASE

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Association for the Bladder Exstrophy Community announces first eight U.S. “Centers of Excellence”

Designees are meeting rigorous standards to be leaders in bladder and cloacal exstrophy treatment and care

St. Petersburg, FL, August 21, 2018 — Association for the Bladder Exstrophy Community (A- BE-C), a global nonprofit organization providing education and support to bladder exstrophy patients and their families, today announced the following inaugural U.S. recipients of its new “Centers of Excellence” designation:

- Boston Children’s Hospital
- Children’s Hospital Los Angeles
- Children’s Hospital of Philadelphia
- Children’s Hospital of Wisconsin
- Cincinnati Children’s
- Johns Hopkins Medical Institutes
- Riley Children’s Health
- Seattle Children’s

A-BE-C's Centers of Excellence program is the first to identify centers of care that report meeting the highest standards of treatment, including post-operative and long-term care for bladder and cloacal exstrophy.

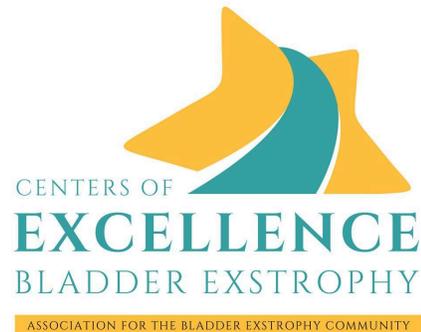
“These Centers of Excellence were selected after their completion of a rigorous application process that was reviewed by peers and colleagues across disciplines, and we are confident that families affected by exstrophy will find comprehensive and highly skilled care at these institutions,” says Aseem R. Shukla, M.D., a bladder exstrophy surgeon and clinical advisory board chair for A-BE-C. “We believe that this COE framework will be adopted by other leading academic medical centers to guide their progress from good care to best-in-class.

Bladder exstrophy is a rare birth defect in which the bladder has not formed correctly at birth. In most cases, the bladder and genitals are split in half, turned inside out and sit outside the body. Treatment requires surgical reconstruction. With surgery and other treatment, children born with exstrophy can lead normal, healthy and active lives.

“The diagnosis of bladder exstrophy is initially frightening for parents, especially since many primary care physicians, gynecologists and obstetricians have never heard of it, says Pamela Block, executive director of A-BE-C. “The Center of Excellence program is all about helping patients and families quickly find the quality care they need.”

About A-BE-C’s Centers of Excellence Program

The widely anticipated Centers of Excellence, a program of the Association for the Bladder Exstrophy Community (A-BE-C), has been established to address the challenge parents of children born with bladder or cloacal exstrophy face in finding accurate information and expert treatment. The program aims to provide families with the information they need to connect with experts who can guide them through the treatment of this complex and chronic health condition.



Center of Excellence designees report meeting rigorous criteria for comprehensive care, delivery, professional education and patient outreach services. Each is required to renew annually and undergo a "Quality Improvement and Evaluation" every five years to maintain the designation.

Key dates

- Applications due: December 31
- Recipients announced: July/August

About Association for the Bladder Exstrophy Community (A-BE-C)

A-BE-C is dedicated to supporting people worldwide who are affected by bladder exstrophy. Founded in 1995, the organization works to ensure all who live with this rare and life-altering condition have the opportunity to realize their greatest purpose and potential. Funding for the 501(c)(3) nonprofit’s work comes from contributions from members, individual and corporate donors, and sponsors. www.bladderexstrophy.com