



Association for the Bladder Exstrophy Community

Centers of Excellence (COE)

Application Requirements for Designation – Updated September 2024

INTRODUCTION: The Center of Excellence designation is given out to those facilities/institutions that demonstrate excellent patient care in the areas of bladder and cloacal exstrophy.

Designation is determined by a consensus of the A-BE-C medical advisory board. The process of COE designation consists of:

1. The Facility applications and additional documentation
2. An **annual** administration fee of \$2000.00 USD
3. Virtual Interview with Clinical Psychologist, Social Worker, and/or Patient Care Coordinator

COE designation is in effect for five years.

Quality Improvement and Evaluation is to be repeated every 5 years

Application Deadline for 2025 Designation:

Applications can be submitted any time. The administration fee is due with the application. Send completed application to: Pamela.artigas@bladderexstrophy.com or mail to: A-BE-C, 505 Beachland Blvd. #1-180 Vero Beach, FL 32963. Attn: Pamela Artigas, Executive Director

Application Checklist:

Please ensure that you complete the full application provided below and have included all appropriate additional documentation needed as a part of this application. Additional documents needed:

1. CVs
2. Summary of any patient satisfaction survey results within the most recent 12-month period
3. Educational material available to patients



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Facility Application

Please complete the following application for your facility.

Institution/Facility Name: _____

Institution/Facility Street Address: _____

Institution/Facility City: _____

Institution/Facility State: _____

Institution/Facility Zip: _____

Institution/Facility Website: _____

Institution/Facility Contact Name: _____

Institution/Facility Contact Email Address: _____

Institution/Facility Contact Phone Number: _____

Evidence of Overall Commitment to Clinical Program Excellence

CASE VOLUME OF EXPERIENCE AND SCOPE OF PRACTICE

Overall Facility Experience

Facilities applying for a Center of Excellence designation must have ample experience in treating patients with bladder and bowel health issues. Each applicant physician must have a database of:

At least 50 cases of exstrophy



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A physician who does not perform surgery may apply as part of a Center of Excellence but there still must be at least two applicant surgeons present. Non-surgeons applying for a COE designation must still meet the case volume requirements.

ROLE OF MEDICAL DIRECTOR

Medical Director Job Description

The applicant maintains a single designated physician as Medical Director for the organization's center. A qualified, board certified surgeon, appointed through the facility's administrative/medical staffing process, should hold this position.

Please provide the following information regarding your Center's Medical Director:

1. *Name the institution's/facility's physician medical director of the Center responsible for chief oversight of the Center's patients:* _____

2. *Please indicate if this physician:*

a. Is currently Board Certified: Yes/No

b. Has completed at least 5 years post-fellowship training in pediatric urology: Yes/No

c. Regularly participates in administrative meetings of the institution/facility: Yes/No

3. *Describe the role of the Medical Director at your facility:*

TEAM MEMBERS AND REFERRAL NETWORK

Team Members CVs and Referral Network Links

As a Center of Excellence, it is important to provide patients with care related to all areas of bladder and bowel health. Areas may include gynecology, radiology, orthopedic surgery, pediatric anesthesiology, plastic surgery, neurosurgery, physical therapy, occupational therapy, clinical social work, clinical psychology, child life, and patient care coordinators. These areas may be supported through a referral alliance or may be comprised of staff members within the applying organization including NPs/PA's.

Physicians and non-physician providers that will support the designated Center of Excellence are asked to submit a CV along with this application, to verify their role in the proposed Center. These staff



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members should have clinical experience in managing all aspects within their designated specialty, including:

- Pre-operative evaluation for surgical readiness
- Post-operative adverse events
- Management of a compromised patient until he/she is sufficiently stable to be discharged from the facility
- Psychosocial assessment and intervention along the medical, surgical and developmental spectrum of care

Please answer the following questions regarding support staff members and referral alliances:

1. Please verify that you maintain staff consultative services, or referral alliances, in the following areas.

If the individual is a staff member, circle "On Staff", and provide that individual's name below, as well as a CV with this application. If the individual is a referral alliance, circle "Referral Alliance", and provide the name, along with a link to the physician's website, verifying their status.

a. Gynecology: On Staff/Referral Alliance

b. Radiology: On Staff/Referral Alliance

c. Orthopedic Surgery: On Staff/Referral Alliance

d. Pediatric Anesthesiology: On Staff/Referral Alliance

e. Pediatric Surgery: On Staff/Referral Alliance

f. Neurosurgery: On Staff/Referral Alliance

g. NP's/PA's: On Staff/Referral Alliance

h. Additional Staff: On Staff/Referral Alliance



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DEDICATION OF THE TEAM MEMBERS

The applicant utilizes designated nurses or other allied health professionals who are formally trained and dedicated to caring for patients with the bladder exstrophy-epispadias complex and cloacal exstrophy

Please provide answers to the following questions regarding the support team:

1. Number of professionals dedicated to BE patients: _____
2. Number of professionals who hold advanced specialized training in catheterization and irrigation management: _____
3. Category of these health professionals: _____
4. Number of professionals trained in urodynamics: _____

PSYCHOSOCIAL TEAM

Psychosocial team members may include clinical social work, clinical psychology, child life and patient navigation. They often serve as a liaison between the physicians and their staff/facility, particularly on matters pertaining to access, psychosocial wellbeing, educational and support resources, etc for BE patients and their families. **Their role is essential to the success of any Center of Excellence. Therefore, an interview with these team members is required.** While roles may differ or be shared, functions of the team include provision of: behavioral health interventions; mitigation of psychosocial high-risk factors, adverse childhood events and barriers to care; school consultation; clinical care coordination; access to peer, camp, and group supports; transition of care interventions; multi-modality education; and management of patient/family advisory councils).

Please provide the following information regarding the Psychosocial Team Members :Describe the services provided by the above named team members:

EVALUATION AND QUALITY IMPROVEMENT



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Research

Centers designated as a Center of Excellence should be engaging in research that is patient-centered and family-centered. Preferably this research is interdisciplinary and engages multiple centers.

Provide details of the research that your center is engaged in currently and what research and outcome studies your center has been involved in in the past.

1. Current research including collaborators: _____

2. List your program's publications relevant to patient and family-centered outcomes for the BE population: _____

Patient Education

Providing appropriate patient education and promoting support groups is an important part of being a Center of Excellence.

1. Program Website: _____

2. Attach educational material available to patients with this application.

4. List authored or co-authored, self-published patient-education materials on relevant topics, or source of patient education materials from third parties (printed and/or online):

Please answer the below questions regarding patient education provided at the facility:

5. Does the institution/facility have evidence of written practice policy statements requiring that patient education be provided to all patients? Yes/No



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6. In what ways does your facility provide patient education? (Circle all that apply):

- a. 3rd Patient Brochures in waiting room
 - b. Facility Branded patient brochures in waiting room
 - c. Exam room brochures
 - d. Physician or nurse facilitated education to patient (discussion only)
 - e. Physician or nurse facilitated education to patient (with the use of illustration or electronic aids)
 - f. Online education provided on facilities website
 - g. Post-operative education materials provided to patient
 - h. Other online or print education offered to patient (please describe):
 - i. Local Support groups
 - j. Information on A_BE-C Annual Conference
 - k. Information on B.E.S.T. Campout
 - l. Information on Youth Rally
 - m. Additional Information:
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7. Who generally provides the above patient education?

ACTIONABLE REPORTING OF OUTCOMES

Outcomes

The applicant utilizes a uniform, computerized system for analyzing, reporting, and acting upon patient outcomes. In addition, the applicant provides documentation that the Center is dedicated to a goal of long-term patient follow-up of at least two years with a monitoring and tracking system for outcomes in a manner consistent with HIPPA regulations and FDA requirements for post-market surveillance of pharmaceuticals and implanted devices. The applicant is asked to describe the process by which the team adheres to such longitudinal follow-up, including how it seeks to stay in touch with past patients. Additionally, the center should be prepared to make quality improvements stemming from such data analysis including patient satisfaction input. There should be a defined procedural process for taking action for quality improvement as part of this application (as discussed in section 11.1).

Please answer the following questions regarding outcome reporting:

1. Does the institution/facility have in place a uniform system for the reporting of all patient outcomes?
Yes/No

2. Please describe the reporting system:



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3. Please describe the process in which the facility stays in touch with past patients:

EVIDENCE OF A COMMITMENT TO TOTAL QUALITY IMPROVEMENT AND EVALUATION

Quality Improvement

The applicant should be able to demonstrate that it is routinely making efforts to improve the quality of patient care and safety throughout the organization. If the applicant is part of an academic medical center, continuous quality improvement should be integral to the institutional culture. This will be assessed during the onsite visit and should be visible and verbalized at all levels of the organization. Policies and procedures should be in place, or at the very least, established protocols at the clinic level, with the goal of pursuing total quality improvement.

Please answer the following questions regarding quality improvement measures:

1. What methods exist to ensure that the institution/facility regularly take part in Continuous Quality Improvement (CQI) initiatives?

2. Does the institution/facility routinely conduct patient satisfaction research focused on patient "experience of care"? Yes/No

A. If yes, who is responsible for this research? _____

B. If yes, how often is this research conducted? (Circle one) I. After each patient's discharge

II. Quarterly

III. Bi-yearly

IV. Annually

C. If yes, how is this research utilized?



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D. How is it shared with physicians applying for Center of Excellence designation?

3. What methods are in place for making improvements based on outcomes measures or patient satisfaction ratings? _____ 4.

Does the facility have a Patient Safety Officer or equivalent? Yes/No

Additional Questions:

1. What additional outstanding features, activities, or accomplishments of this institution/facility especially qualify it for a Center of Excellence designation by the Association for the Bladder Exstrophy Community?

2. Does the institution/facility attest that all the information contained herein is true and correct to best of your knowledge? Yes/No

Signed by: _____

Title: _____

Date: _____



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Disclaimer:

The "Center of Excellence" designation is not an accreditation or certification, by the Association for the Bladder Exstrophy Community (A-BE-C) and should not be held out to, or understood by, the public or any third party as indicative of A-BE-C's opinion that those who attain it have met any standard of quality or achievement. Designation is self-reported and peer reviewed by A-BE-C's medical advisory board and staff.