



## **Credit, Attribution, and Use of Program Materials**

### **Program Ownership and Authorship**

All programs, products, designs, intellectual property, branding, and associated materials related to BE-DRY® are the sole property of the Association for the Bladder Exstrophy Community (A-BE-C), unless otherwise specified in writing.

BE-DRY® was developed, funded, and led by A-BE-C, and all public, academic, media, and promotional references must accurately reflect A-BE-C as the program originator and lead organization.

### **Permitted Attribution**

Partners, donors, hospitals, manufacturers, and collaborators may be acknowledged only as supporting, implementing, or collaborating entities, using language such as:

- “Supported by...”
- “Implemented in collaboration with...”
- “With manufacturing support from...”
- “With philanthropic support from...”

No partner or donor may represent themselves as the creator, developer, owner, or lead of BE-DRY® or any of its components.

### **Prohibited Representation**

Without prior written approval from A-BE-C, partners may not:

- claim authorship, development, or leadership of the BE-DRY® program or product
- list BE-DRY® as a personal, institutional, or organizational initiative
- use BE-DRY® materials, images, or data for CVs, academic publications, presentations, or media without explicit attribution language approved by A-BE-C
- submit BE-DRY® work as independent research, innovation, or design

### **Media and Public Communications**

All press releases, social media posts, publications, presentations, and public communications referencing BE-DRY® must be reviewed and approved by A-BE-C in advance to ensure accuracy of attribution and program history.

## Staffing and Governance

Financial contributions or material support do not confer governance authority, staffing roles, advisory positions, or decision-making power within A-BE-C or its programs, unless explicitly agreed upon in writing.

## Violation of Attribution Standards

Failure to adhere to this attribution policy may result in:

- withdrawal of partnership recognition
- revocation of permission to reference the program
- termination of collaboration

## Research, Data Use, and Publication

### Research Oversight and Approval

Any research activities, evaluations, data collection, or clinical studies involving BE-DRY® must be reviewed and approved in advance by A-BE-C, including study design, methodology, data use, and intended outputs.

Approval by a hospital, academic institution, or ethics committee does not supersede A-BE-C's authority over program-related research.

### Data Ownership and Use

All data generated through the use, evaluation, distribution, or implementation of BE-DRY®—including clinical outcomes, patient-reported outcomes, quality-of-life measures, photographs, and testimonials—are jointly stewarded by A-BE-C and the implementing clinical partners, with A-BE-C retaining primary ownership and control of program-related data.

Data may not be reused, shared, or repurposed for secondary analyses without written approval from A-BE-C.

### Publications and Presentations

Any abstracts, posters, manuscripts, case reports, presentations, or academic publications referencing BE-DRY® must:

- Accurately credit A-BE-C as the program developer and lead organization
- Be submitted to A-BE-C for review and approval prior to submission or presentation
- Include appropriate acknowledgment of A-BE-C's financial, intellectual, and operational contributions

Authorship order, acknowledgments, and institutional affiliations must be agreed upon in writing in advance of submission.

### Prohibited Research Representation

Partners may not:

- publish BE-DRY® data as an independent or institution-led innovation

- list BE-DRY® as a personal or institutional research initiative
- use BE-DRY® outcomes to advance academic credentials, grants, or promotions without explicit approval and attribution

#### Media, Conferences, and External Reporting

All public dissemination of research findings—including conferences, workshops, media interviews, and social media—must be coordinated with A-BE-C to ensure accuracy, ethical representation, and protection of patient dignity.

#### Non-Compliance

Failure to comply with this research and publication policy may result in:

- withdrawal of permission to use BE-DRY® materials or data
- exclusion from future research collaborations
- termination of partnership agreements