Association for the Bladder Exstrophy Community

A Statement from the Medical Advisory Committee of The Association for the Bladder Exstrophy Community

Timely and expert patient and family centered clinical care is critical for children with bladder exstrophy and epispadias. There are several options for pursuing care. Surgical approaches and options may vary among different children's hospitals in the United States.

To guide families affected by bladder exstrophy and to ensure that all patients receive honest, evidence-based, and ethical care from pediatric urologists and surgical teams, we offer the following guidelines and best practices.

1. **The importance of peer-reviewed data**
   Families deserve accurate information when making decisions about surgery for a child with bladder exstrophy. Treatment outcome data that is published in peer-reviewed medical journals undergoes independent review by the scientific community through accepted processes. Insist that your surgeons share not only their personal impressions of their surgical results, but also treatment outcome data that comes from research published in peer-reviewed medical journals to ensure you are receiving validated information.
2. **Scientifically grounded counseling**
   There has not been a scientific study directly comparing nor establishing the superiority of any of the different surgical approaches to repairing bladder exstrophy currently performed around the world. Your surgeon should explain all treatment options and possible risks in a fair and balanced way. It is reasonable for your surgeon to describe one's level of experience and offer an opinion as to why they prefer a certain approach to surgical repair of exstrophy. But claims that a particular technique or center offers superior results cannot be considered accurate until those claims are rigorously tested and reviewed.
3. **Social Media Solicitation**
   Claims made on social media platforms – such as Facebook, Instagram, or TikTok – are not always supported by available information and may be biased by individual experiences. We encourage exercising caution in relying on the accuracy of information gleaned from such platforms. While general educational posts and webinars may have educational value, we encourage using discretion when these posts engage in direct promotion or patient solicitation – a tactic that runs contrary to the ethical standards of our community.
4. **Transparency and Collaboration**
   Providers and families benefit when surgeons and hospitals collaborate openly and share scientific data responsibly. We encourage families to consider enrolling in institutional review board approved multi-center studies to advance care as long as the opportunity is presented in a transparent and ethical manner. These studies are critical to gain knowledge that can give rise to innovative approaches and offer hope for other children born with bladder exstrophy.

We, as members of the Advisory Committee for the Association of the Bladder Exstrophy Community, believe that these general guidelines and best practices will ensure that pediatric urologists, patient advocates and affected families work together to ensure every child with bladder exstrophy receives care grounded in evidence, integrity, and respect.