

ASSOCIATION FOR THE
BLADDER EXSTROPHY
COMMUNITY

GLOBAL CARE 2020

Annual Fundraising Campaign





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BLADDER EXSTROPHY

DEFINITION

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. If you can imagine a balloon that has been cut in two, opened up so that the inside of the balloon is visible, you will have a picture of what has happened.





WHO ARE WE?

ABOUT A-BE-C

The Association for the Bladder Exstrophy Community (A-BE-C) is an international support network for patients and families living with bladder exstrophy. We are united in a commitment to ensuring that all people affected by bladder exstrophy have the opportunity to realize their greatest life purpose and potential.

CAUSES



WHEN DOES EXSTROPHY OCCUR?

The cause and nature of the faulty development is not exactly certain. It is 4 to 5 weeks after conception that the various organs and different types of muscles and tissues of the body begin to form from layers of cells that separate, divide and fold. One theory suggests that something goes wrong during this early folding and separation, causing the cloacal membrane to fail to close, leaving the bladder outside of the abdominal wall. A second theory proposes that the layer of skin which forms over the bladder at this stage is thin and unable to hold in the bladder. It pulls apart, again leaving the bladder inside out.

HOW MANY CHILDREN ARE BORN WITH BLADDER EXSTROPHY?

Bladder exstrophy is a rare disorder that happens in about 1 in 30,000 births. It is more likely to occur in boys than in girls. Cloacal exstrophy (another form of exstrophy) happens in about 1 in 50,000 to 100,000 births.





WHOM DO WE SERVE?

OUR COMMUNITY

Our community includes individuals living with bladder exstrophy, parent-exstrophy support groups, health care providers who work with patients and families living with bladder exstrophy, and others who share our commitment.

We assist patients and families living with bladder exstrophy by providing education, support, and resources to help them navigate the medical and psycho-social issues relating to exstrophy.

WHAT IS OUR "WHY"?

TO ELIMINATE THE STIGMA ASSOCIATED WITH BLADDER EXSTROPHY.

TO ALLOW EACH CHILD BORN WITH THIS CONDITION TO HAVE ACCESS TO PROPER CARE, SUPPLIES, AND RESOURCES, AND HELP THEIR FAMILIES NAVIGATE THE COMPLEXITIES OF THIS LIFELONG CONDITION.

TO GIVE EACH INDIVIDUAL A CHANCE TO LIVE A LIFE TO THEIR GREATEST PURPOSE AND POTENTIAL.



ONGOING TREATMENT

A LIFETIME OF CHALLENGES

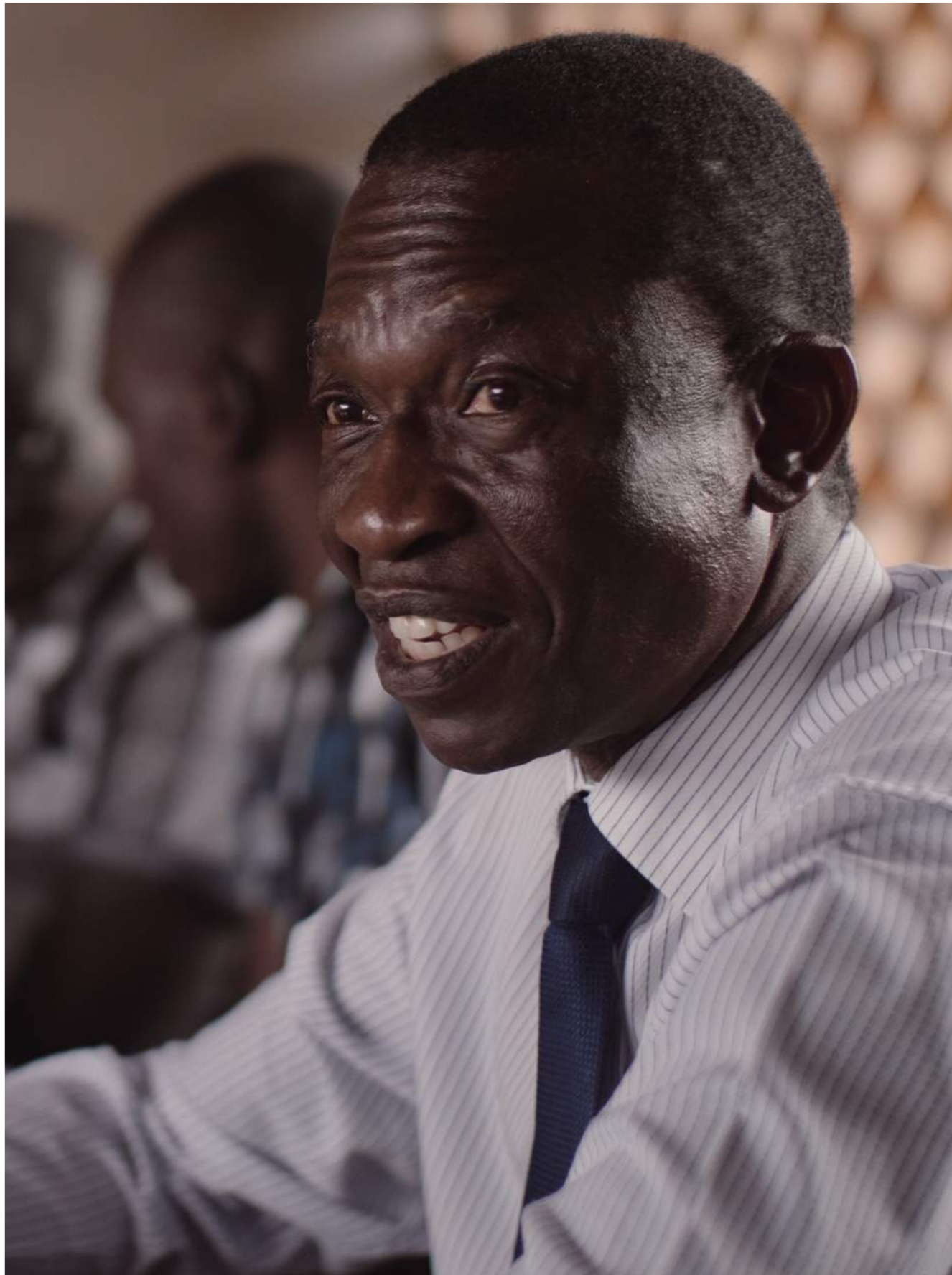
The surgical management of bladder exstrophy remains challenging. Patients require life-long follow-up even when there is successful reconstruction.

Reconstruction typically requires multiple stages for completion. Patients in resource poor countries face additional challenges including lack of access to trained personnel to manage perioperative care.

Long-term incontinence in exstrophy is a source of significant embarrassment and significantly compromises their quality of life.

SOMETHING TO THINK ABOUT

In many parts of the world, children born with bladder exstrophy are left untreated, or an attempted repair is unsuccessful, resulting in a lifetime of pain and suffering.



THE IMPACT

FIVE YEAR COMMITMENT

A-BE-C has committed to a five year initiative designed to treat under-served children and adults and extend access to surgical interventions and other treatments through the training of physicians in Uganda and other under served areas.



EXPANDING OUR REACH

A-BE-C AND UROCARE HOSPITAL COLLABORATE FOR ANNUAL EXSTROPHY WORKSHOP

A-BE-C recently established an annual workshop to train healthcare workers in the various techniques and procedures to treat bladder exstrophy. Urologists, Surgeons, Fellows and students from Uganda and 14 surrounding countries joined a team of American surgeons and physicians to learn valuable skills, strengthen partnerships and create a greater awareness about the exstrophy condition and care.



URO CARE HOSPITAL

A UNIQUE OPPORTUNITY

Over the past 3 years A-BE-C has helped facilitate surgeries for children with bladder exstrophy in Uganda, and trained Ugandan surgeons in India with the goal to work with Uro Care Hospital to build a medical facility where children can both undergo surgeries and receive follow up treatments.

Standard of Care

Safe, affordable and timely treatment should be a standard of care for anyone in the world born with bladder exstrophy. It is not. In many parts of the world, children born with bladder exstrophy are left untreated, or an attempted repair is unsuccessful, resulting in a lifetime of pain and suffering. A-BE-C is working with others to change that. You can help.



[click here to watch the videos](#)



Partner with A-BE-C



MAKE A DIFFERENCE

With the support of our corporate partners we can more effectively fight for access to resources, proper care and life changing procedures.



TAKE A STAND

This isn't just a bladder exstrophy issue. It's a social justice issue. Children are missing out on education and a brighter future, simply because they cannot stay dry.



BUILD AWARENESS

Imagine if your child or a child you know lived in pain every single day simply because they didn't have access to a surgery that could change their life?



ADVOCATE FOR CHANGE

In areas of the world where there are minimal resources, the children with special needs often go unheard. Be their voice. Be their change.

**READY TO
MAKE A
DIFFERENCE?**

CONTACT US TODAY

PHONE NUMBER

425-941-1475

EMAIL ADDRESS

admin@bladderexstrophy.com

WEBSITE

bladderexstrophy.com

aacc

