

"I'm a mother whose son was born with epispadias. HEA is more than support and information to us.

It's family."

— Amanda



HEA's Mission

- We create and nourish a community that promotes a positive body image and healthy emotional lives for those affected by hypospadias and epispadias.
- We act as a center of information and lived experience for parents and adults who are considering available treatment options.
- We provide a forum for an open exchange of information between people impacted by hypospadias and epispadias and our health care providers.
- We educate the public at large about the prevalence of hypospadias and epispadias and remove the stigma, isolation and shame associated with these conditions.
- We promote healthy sexual lives, and identities, of adults affected by hypospadias and epispadias.

HEA

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HEA

Understanding Hypospadias & Epispadias

Ever heard of hypospadias or epispadias? Few people have, yet hypospadias is one of the most common birth defects in male babies. The Hypospadias and Epispadias Association (HEA) exists to help build knowledge and community around these conditions.

HEA is open to anyone affected by, or interested in congenital conditions relating to variances in genital development and related physical and psycho-social issues.

We also welcome and encourage parents, family members, spouses/partners and health care professionals and educators to get involved, to learn from us, and to offer their insight and support.

1 in 200 boys are born with hypospadias each year.

Source: Centers for Disease Control and Prevention (CDC)

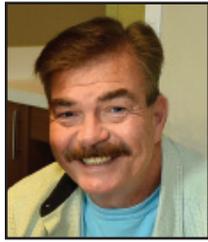
Getting Informed Through HEA

If you are looking for resources and educational information about the conditions hypospadias and epispadias, the HEA website (www.heainfo.org) provides articles, personal accounts and other exclusive content for all stages of development.

HEA also has a Facebook group for adults and parents of children affected by HS/ES at www.facebook.com/groups/HypospadiasEpispadiasHEA/.

* The Facebook group is "closed," which means administrators must approve member's requests for inclusion and only group members can see posted content.

A Message From Our Executive Director



Originally formed as a meeting between health care professionals, the first meeting of the Hypospadias Association of America was held in 1999. The next meeting grew to a conference including parents, children, adults, social workers, counselors, psychologists, psychiatrists, nurses and doctors needing questions answered regarding these conditions, including Epispadias, as few outside of the medical profession had heard of these terms until confronted by these birth differences, which are not rare.

The name of the organization was changed to the Hypospadias and Epispadias Association, Inc. in 2002 to be inclusive of those with Epispadias, and to share medical information, provide education and support to all affected.

Our conferences have been held almost annually, in a number of cities in the US and Canada, in order to be available to our members. Many have never met anyone with these differences and now have a place to be safe to speak up and ask questions and more importantly, end the isolation and secrecy of having a difference of sexual development.

HEA has events other than the conference that you can take part in. We have an annual picnic which involves community awareness as well as other fundraising activities, including a walk.

We are constantly working to improve our website and have a closed Facebook group where you can discuss your thoughts and concerns.

We are here to ensure you are not alone, and we will continue to work with the health care community as we have discovered that we all need education, support and understanding across the line.

Always my best!

—*Jim Lake, executive director*



Barbara Neilson, MSW, speaks to attendees during a breakout session at the 2017 HEA conference in Dallas, TX.

"I was alone and felt so different; then I found HEA."

— HEA Member

What Are Hypospadias & Epispadias?

Hypospadias and epispadias are birth anomalies that affect the formation of the penis during embryological development. When the urethra (the tube that services as a conduit through the penis for the passage of urine and semen) fails to develop properly, the urethral opening is formed on the underside (hypospadias) or top side (epispadias) of the penis, instead of at the tip.

According to the Centers for Disease Control (CDC), approximately 1 in 200 males are born with hypospadias annually, making it one of the most common birth defects in the world. Epispadias, which is often more severe than hypospadias, occurs much less frequently.

How to Support HEA

BECOME A MEMBER For only \$36 a year, become a member and support those affected by hypospadias and epispadias and help us to continue to educate the community and raise awareness about these conditions. Your membership fee helps us promote HEA and its conference and other events throughout the year.

DONATE! HEA offers various events throughout the year that will benefit from your support. These fundraising events include an annual walk that has been held at various locations around the US over the years; and an annual picnic held in scenic Franklin, PA which brings together families and men affected by HS/ES. Other fundraisers include HEA support bracelets which can be purchased from the HEA website or at the conference and other HEA events.

Consider donating to the conference scholarship fund which assists our local and international members in attending the HEA conference.

JOIN US Attend the HEA conference and meet and support others affected by HS/ES, including family members. Speak with medical professionals and discuss the latest treatment options. The HEA conference is a great opportunity to meet wonderful people, network and enjoy social activities.



Attendees at the 2017 HEA conference in Dallas, TX.