

## HEA's mission is to:

- Increase public awareness of hypospadias and epispadias and issues related to the conditions
- Work within the medical community to improve the quality of care for people affected by these conditions
- Relieve the secrecy and isolation that these conditions can impose on boys and men
- Provide information about treatment options and alternatives
- Help men with hypospadias and epispadias create positive body images
- Promote healthy emotional and sexual lives

**"We recommend HEA as a valuable information source on hypospadias and epispadias."**

—American Society for Pediatric Urology

## WEBSITE RESOURCES at HEAinfo.org:

### Members helping members

- FORUM – Internet message board
- CHAT – Regularly scheduled online discussions
- LOCAL INFO – International member database

### Library

- ARTICLES – Exclusive articles covering topics such as embryological development and dealing with emotional effects of surgery
- MEDICAL RESEARCH – Layman summaries of medical articles
- GLOSSARY – Common explanation of medical terminology
- SURVEYS – Comprehensive HEA studies

### Other Resources

- FAQ – Frequently asked questions
- LINKS – To other organizations

## Understanding Hypospadias & Epispadias

Ever heard of hypospadias or epispadias? Few have, which is why a safe and confidential cyberspace was created where anyone can log on and relate freely with others to gain support, information and knowledge.

The Hypospadias and Epispadias Association is open to anyone affected by or interested in the many physical and emotional issues stemming from congenital conditions relating to variances in male genital development.

We also welcome and encourage health care professionals and educators to get involved to both learn from us and to offer their insight and support.

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

– HEA member

# HEA Hypospadias & Epispadias Association



These conditions affect the entire family.

## What are hypospadias and epispadias?

Hypospadias and epispadias are birth anomalies that affect formation of the penis during embryological development. When the urethra (the tube that serves 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. Physical and emotional problems commonly stem from these conditions. According to a study published by the Centers for Disease Control (CDC) in 1997, approximately 1 in 125 males is born with hypospadias, making it one

of the most common birth variances. Epispadias, which is often more severe than hypospadias, occurs much less frequently.

## How we began . . .

The Hypospadias and Epispadias Association started in 1999 as a forum for men, their families, and friends, sharing information on the internet. HEA has hosted several successful international conferences with members and health care professionals. We have subsequently expanded our objectives to include changing the perception of hypospadias and epispadias and lessening the isolation and stigma experienced by the men and boys living with these conditions.

## A message from our Executive Director . . .

The Hypospadias & Epispadias Association does not exist simply to help a parent decide if his or her child requires surgery or to help a desperately alone adult find comfort.

HEA brings people together to learn about these conditions and to share our collective experience and wisdom.

We are committed to building an organization whose mission is to erase the shame and secrecy of genital anomalies. We will teach ways to build healthy and open communications within families.

Our health care providers will continue to provide excellent quality care as we learn together. Our goal is that hypospadias and epispadias are no longer just talked about in medical offices. We are discovering daily that life with friends is wonderful and that we are no longer alone.

— Billy Deegan



Children are born every day with these conditions, but the reality is that most people outside of the medical community have never heard of them.