

## **FAMILIES IMPACTED BY HYPOSPADIAS AND EPISPADIAS BENEFIT FROM EDUCATION AND SUPPORT GROUP**

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Several years ago a small group of men with hypospadias created an online community. These men soon discovered much more in common than their physical condition—most shared a feeling of shame and isolation that had swelled up during a lifetime of secrecy. Many had never discussed the condition with their parents, and some did not even know the medical term “hypospadias.” Expressing a desire for sound advice and emotional support, parents whose sons had been recently diagnosed with hypospadias soon joined the group and learned from one another and from the experiences of men with hypospadias. Realizing the strong need for an education and support group with broad outreach, the informal group (by this time also including men with epispadias) organized into the Hypospadias and Epispadias Association (HEA) and obtained 501c3 tax-exempt status. The organization’s mission to educate and support people born with hypospadias or epispadias, their families, and loved ones is carried out via its interactive website at HEAinfo.org, annual international conferences, and outreach to the medical community and the general public. The website, which receives more than 50,000 unique visitors per year from more than 100 different countries, includes message boards, real-time discussions including guest medical speakers, and links to medical information. The organization has so far hosted five annual conferences which include leading medical experts, social workers, psychologists, and interactive workshops for all members of the family. As membership has grown to more than 400 message board users and nearly 150 paid members, HEA has begun expanding its outreach. Toward that goal, HEA has created brochures for distribution to medical professionals and public service announcements to help ensure that no individual or family need ever struggle alone to find answers, solutions, and comfort.

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