Hypospadias and Epispadias Association

Current Stream

Newsletter for HEA

July 2009

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www.heainfo.org

What HEA Means To Me

Several years ago I began looking for information about hypospadias, sure I knew what it was but I wanted to understand the nuts and bolts of the condition. When I was little going thru all my operations I hadn't been told much and never asked questions, so I wanted to know more.

My search led me to a yahoo HS group that I stayed with for a bit but, soon left because of spam on the message board and such. Then a few years ago I found HEA, it looked well put together and offered serious information. I posted on the message board and, before long I had made friends with Chris Arnold and several others. For the first time I could explain what I went through without being embarrassed and to my shock there were others who understood and had similar stories to tell. War stories were shared, experiences told and tips given. I posted a lot in the beginning, just wanting to share myself and maybe, just maybe, be of help to others.

> *"For the first time I could explain what I went through without being embarrassed and to my shock there were others who understood and had similar stories to tell"*

A conference was coming up in New York, I wanted to go but, due to one excuse after another I backed out. I really don't think I was ready yet, and then came Norfolk. All my life I had been pretty much silent on my condition, only telling my very best friend and hating it when my mother shared it with others. Growing up I had been shy and kept to myself but here I was sharing my very personal story with complete strangers who let me know that it was okay and they understood. I met a lot of great, caring people who I now call friend and feel comfortable doing so.

In August we have another conference which I look forward to going to. I think I have started coming out of the shell I had built around myself, I'm not quite where I want to be but, I am getting there. I think that is part of what HEA can offer someone, a place where at your own pace you can give of yourself, be accepted, feel better and maybe, just maybe, find peace. When one does that then maybe they can lend a hand to others looking for a light out of the darkness.
That is what HEA means to me.

Todd Elliott
HEA Board Member

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The value of connections

As a person who grew up with hypospadias, I know very well one of the most difficult parts of this condition is not the physical details of the structure of the urethra, but the fact that we often feel completely alone and isolated.

The feelings of secrecy and shame attached with differences in the genitals can be very overpowering and despite the reportedly high incidence rate only one time in all my years in hospitals did I ever meet another person with hypospadias... until I found HEA.

The huge feeling of relief in being able to safely chat with someone else online who knew exactly what I was talking about when I expressed my feelings and frustrations having grown up with HS was overwhelming. It was safe and anonymous, and perfect.

But then I wanted more. I actually wanted to meet another real live person with HS to make sure they really did exist, not just as an email address or online person but in real life.

I was terrified but determined. I had no idea what to expect when I walked into the hotel in San Jose, California. Would I know who 'they' were? Would they have name tags? Would they have a "HS" or "ES" on their forehead? I didn't know, but I was both scared and excited to find out.

I arrived and I saw them...

people with hypospadias and epispadias!
They were real... and they were a lot like any other person... a lot like me. All different ages, shapes and sizes, cultural backgrounds. Truly diverse.

What did I think we would all look like? I don't know. I had just never before met so many people like me. It was overwhelming. Immediately I felt like I was with friends or family.

As the conference progressed I listened to some speakers and then I attended sessions where we sat in a big circle and just talked, about having HS, about the pain growing up, about our fears.

We knew what the others were feeling, we knew exactly what it was like.

We nodded our heads, we laughed, we cried. I didn't want to go back to my hotel room at the end of the day, I just wanted to stay with these great people every moment. It had taken me 37 years to find them and I was so relieved.

Since then, I had the pleasure of attending another conference in Norfolk, VA and it was a very similar experience, but this time I remembered many of the friends I'd met in San Jose.

Chris Arnold,
President, HEA

New HEA Buttons!

These will be distributed at the 2009 Conference

Shame and Hiding in School-Aged Kids

By Betty Engel

Many of the people with hypospadias or epispadias who have shared their stories have mentioned how tough school was for them. They felt a lot of shame about the appearance of their genitals and tried to hide, especially when in gym and swimming classes, locker rooms, and bathrooms. Some people with special requirements such as needing catheters or incontinence equipment felt that the arrangements made with the school made their differences too visible to their peers. Many parents are worried that their children will be easy targets for teasing or bullying.

We all know that shame is really painful. We probably wouldn't wish it on our worst enemies. We try to hide, but hiding brings isolation and can make shame even worse if we're discovered. We certainly don't want our children to suffer from shame or to feel the need to hide. But isn't shame an inevitable part of life? In my opinion, most of the situations which cause children to feel shame can be prevented.

Shame-making situations fall into two classes. First, interactions where the child is made to feel "not normal" or "defective" will bring on feelings of shame and therefore attempts to hide. Preventing such interactions requires changing attitudes. Attitude change is difficult but not impossible. A lot of what HEA does is about attitude change. We try to help people realize that being different is not being defective.

The second type of shame-making situation is when a person is teased or bullied for having a certain trait or condition. Being teased can sometimes feel good when it is an expression of love. More often, though, it feels awful because the teaser is deliberately trying to humiliate us. Bullying can feel even worse, because it usually involves public humiliation and can include physical assault. Traditionally, teasing and bullying among children were considered to be unavoidable: humans by nature were thought to want to feel more powerful than everyone else. Sometimes, it was believed that being the target of teasing and bullying would make the person stronger, less sensitive, and more assertive. Sometimes bullies were admired for their supposed strength and competence, while the victims were pitied for their supposed weakness and incompetence. Bystanders were encouraged to find humor in bullying and to enjoy the excitement of watching aggression happen.

Research has shown that the traditional conception of teasing and bullying as an inevitable and mostly harmless part of childhood is wrong. Teasing and bullying are not indications of strength or superiority but rather are examples of social abuse and symptoms of psychological problems. Furthermore, these behaviors hurt both victims and bystanders by creating a climate of fear, callousness, and disrespect for everyone involved. Children who tease and bully often become perpetrators of greater violence. Children who are teased or bullied often become withdrawn, depressed, fearful, and afraid of school. Children who witness teasing and bullying feel powerless and anxious—they may attempt to feel more powerful by becoming bullies themselves.

In the past decade, 40 states in the US have required that schools institute anti-bullying programs. The best of these programs change the climate of the school. The US Department of Health and Human Services Health Resources and Services Administration has established a wonderful web site on what we can do to stop bullying.

(http://stopbullyingnow.hrsa.gov/adults/default.aspx)

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The TOP 10 Reasons To Register For The 2009 HEA Conference!

1 **You will get to meet many of the great people from HEA that you chat with online.**
Wouldn't it be great to finally put a face to the screen names you have come to know so well?

2 **You will get to hear updates and information from people and organizations from around the world that deal with HS/ES**
We will have people speaking about their work related to HS/ES in Africa, Australia, the UK, South America, Canada, and the USA.

3 **You will get to listen to some Doctors who are experts in the field of HS/ES**
Dr. Kennedy from Stanford University, Dr. Alvarez from The Institute for Hypospadias in the Caribbean, as well as other Doctors talking about Epispadias, Surgical complications, Treatment options and more.

4 **You will get to explore the psycho-social aspects of HS/ES with some knowledgeable experts.**
Attend sessions on Sex and Dating, Talking to Your Kids about HS/ES, Issues for Fathers.

5 **You will get to learn about medical privacy rights, and helping your child deal with issues in school.**
Lead by some passionate advocates from the USA and Australia, there will be sessions on informed consent and medical privacy, if you are preparing for your surgery or the surgery of your child. Also a session specifically on advocating in the schools for children with genital differences.

6 **You will get to participate in discussions on a wide variety of topics.**
There will be opportunities for discussions in the group sessions, and during social events. Participate to whatever degree you feel comfortable, or just listen.

7 **You will get to attend a fabulous banquet and awards dinner with all your new friends and colleagues.**
The banquet will be open to all conference attendees and jointly held with our friends at the ABC organization (Assn. For the Bladder Exstrophy Community) who are the joint sponsors of this year's conference.

8 **You will get to take home some cool conference goodies, like pens, buttons, brochures, and other exciting resource information.**
HEA is sponsoring the participant registration bags this year, and we also plan to have some exciting resources available at the HEA info table for people to take home.

9 **You will get to learn about some exciting new projects that HEA will be working on in the upcoming year.**
Learn more about our work in the area of Epispadias. Learn about the International Symposium on Hypospadias in Toronto that HEA will be attending. Learn about a new training / educational program being developed by HEA Executive Director, Billy Deegan on DSD's. Learn about some possible work and partnerships in other countries that HEA is pursuing. Learn about the possibility of a professional documentary being produced through a partnership between HEA and a roduction company in Texas.

10 **You will get to experience the city of bridges... Pittsburgh PA!**
Did you know that Pittsburgh has more bridges than any other city in the world aside from Venice, Italy?
Did you know that Pittsburgh was the birthplace of McDonald's Big Mac, and Heinz Ketchup?
Did you know that Pittsburgh also has attractions such as the Carnegie Science Center, the National Aviary, an exciting Arts and Theatre district, the Andy Warhol Museum, the Phipps Conservatory and Botanical Gardens, The Pennsylvania Trolley Museum, The Pittsburgh Zoo and Aquarium, The Sandcastle Water Park, and much more!

HEA is here for you. It is an organization with a purpose of providing support and education, and this annual conference is one of the main ways we achieve this goal. We would love to see you in Pittsburgh and have you help make this the biggest and best HEA conference yet!

Register today!

Ask Tiger

Dear Tiger

"I struggle trying to tell someone I am dating about my hypospadias. Sometimes it comes out like I am saying I expect to die by next week. Sometimes I say it too casually and they are taken aback as it is more serious. I know that there is no "canned response" but can you help me think of a way to approach this?"

Jason

Dear Jason

This depends on how you conduct your sex life; If you are pursuing casual sex, then telling your partner all about hypospadias is probably a waste of their time. They just want to have sex, and so do you, and getting each other off is what its all about, not about talking before hand. Or sharing some kind of intimacy.

If you are dating someone you have feelings for and might want to get more seriously involved with, then sitting them down and telling them that you want to be sexual with them, and that sex has meaning to you (involves intimacy and trust) and that you need to talk about that before you get naked together. If they are responsive to that and want to talk, then tell them that you were born with a genital difference that is very common, and that you wanted to tell them about it before just showing it to them.

I would spare people the diagnosis name (hypospadias) and instead just describe your genitals "my pee hole is larger than usual and goes down my shaft a bit" or "my pee hole is at the base of my penis and my penis has a curve when its hard" or "I have some scars on the underside of my penis from where they fixed a hole" and that your penis gets hard and feels good and you have orgasms and enjoy sex. Let them know they can ask you questions if they want, and that you want them to take a look with you if they want to go ahead and have sex. Be prepared that there are people that want a perfect partner with a perfect penis and that just this much talk might be enough for them to withdraw from you as a potential sex partner.

Although you might feel hurt, I would argue that its better to be hurt on the basis of this little bit of information being exchanged than having them look at your penis and rejecting you at that point. Keep the language simple and don't bore them with a bunch of science and activism "let me tell you about HEA" unless you are very interested in them and they are very interested in you.

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One of their tip sheets describes what changes to the school climate would look like:

> To reduce bullying, it is important to change the climate of the school and the social norms with regard to bullying. It must become "uncool" to bully, "cool" to help out students who are bullied, and normative for staff and students to notice when a child is bullied or left out. This requires the efforts of everyone in the school environment–teachers, administrators, counselors, other non-teaching staff (such as bus drivers, nurses, school resource officers, custodians, cafeteria workers, and school librarians), parents, and students. ("Best Practices in Bullying Prevention and Intervention," Stop Bullying Now!, http://stopbullyingnow.hrsa.gov/adults/tip-sheets/tip-sheet-23.aspx, accessed 7/8/09

Imagine going to school in a place where people notice if you're bullied or left out and where it's "cool" for people to help you out. Can we make it happen for our children and the children in our communities? I think so.

HEA

Hypospadias and Epispadias Association

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2008-2009 Board of Director's Year In Review!

It is with great pride that the HEA board presents a fantastic year's worth of accomplishments! It is amazing what a group of people with common goals can accomplish despite everyone's busy, busy lives. This year HEA was able to celebrate the following successes:

- Registration with Goodsearch / Goodshop
- Registration with Ebay Giving Works
- Completed the formal legal incorporation in NY of HEA Inc. NY
- Three Amazingly successful HEA Newsletters!
- Spanish Translations!
- A fantastic, and well attended Online Open House!
- Successful membership drive that moved paid members from under 30 to almost 100!
- Corporate contributions from three different companies (thanks Ed, Bill, Chris)
- Representation at the Chicago DSD Conference organized by Jim Lake, and featuring our own Billy Deegan as a speaker!
- Planning of joint ABC/HEA International Conference in Pittsburgh
- Redesign and launch of a spectacular new Website format!
- Jim's Walk! Raised over $1000.00 for HEA.
- Link with the online birth defects Website www.birthdefects.org
- Starting process for a professionally produced documentary on HS/ES
- Support, education and outreach provided for many individuals and parents through the HEA website!
- Official HEA Buttons & Mugs (to be revealed at the conference!)

We are looking forward to another fantastic year for HEA in 2009/2010. Be a part of it...we're always happy to have help, ideas, and energy from new volunteers.