

# The Current Stream

The Newsletter of The Hypospadias & Epispadias Association

Summer 2011 Issue

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Our thanks to Ken  
for editing the  
articles



## HEA

Hypospadias & Epispadias Association  
**International Conference**

Friday-Sunday, October 21-23, 2011

Held in the outskirts of the beautiful city of Chicago, Illinois

**The Conference Registration Forms are now online!**

HEA is very excited about the topics and format of this year's conference. We look forward to providing education, support and time for healing for all participants.

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❖ HEA has reserved a block of rooms at the Schaumburg DoubleTree Hotel, 800 National Parkway, Schaumburg, Illinois 60173 (phone 1-847-605-9222). We were able to secure the very reasonable rate of \$59.00 + tax per night. The DoubleTree Hotel offers local-area transportation, on-site dining, room service, a lounge, a full fitness center, and a year-round indoor pool. It is also within walking distance of several restaurants.

- ❖ The HEA Conference will begin on Friday, October 21 at the DoubleTree Hotel in Mundelein, Illinois. This training will be medically and psychologically based and will include counselors, therapists, nurses, psychiatrists, and physicians from the Lake County Health Department and other agencies and individuals from the Chicago area. The training will center on DSDs (disorders of sex development), and 6 CEUs or MEs will be awarded to professionals in attendance. HEA members and other interested families and individuals affected by DSDs are invited to attend this concentrated training from 9 am until 4 pm. A continental breakfast and afternoon snack as well as beverages will be provided. A buffet luncheon will also be included with your registration.
- ❖ Transportation to the Mundelein DoubleTree Hotel, where Friday's training will take place, will be provided. The remainder of the conference will take place at the Schaumburg DoubleTree Hotel.
- ❖ After Friday's training, a meet-and-greet party will be held from 6 pm to 10 pm at HEA Board member Nancy Mayginnes' home. Heavy appetizers will be served, and babysitting will be provided. Transportation from the DoubleTree Hotel will also be provided at no charge. This event will provide attendees and presenters with the opportunity to speak in an informal setting, meet new friends, and reconnect with those you haven't seen for a while.
- ❖ The HEA Conference will continue on Saturday, October 22, and ½ day on Sunday, October 23, at the DoubleTree in Schaumburg. A brief outline of the conference is as follows:

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## Conference Schedule

### **Thursday evening, October 20, 2011**

Early conference registration at the Doubletree Hotel in Schaumburg, Illinois

### **Friday, October 21, 2011**

**8:30-9:00** Continental breakfast provided

**9:00-11:30** Welcome, Housekeeping Issues, Warm-Up Exercise.  
Discussion of boundaries, confidentiality, and creating a safe place.

Overview of DSDs  
Overview of Family Needs  
Overview of Adult Needs  
Finding Resources

**11:30-12:30** Lunch (buffet at hotel)

**12:30-1:30** Choose your group:  
A more in-depth look at helping families  
A more in-depth look at helping adults

**1:30-2:45** Discovering... Exploring... Changing... Gender... Sexuality

**2:45-3:00** Break

**3:00-3:30** Break into small groups. Pick one of the following scenarios and in dyads in front of your group try to identify with your clients.

1. You have been seeing someone special for a few dates. The relationship is progressing, and you need to tell them about your DSD.
2. Your child has just been diagnosed with a DSD. Choose someone in your life you would like to tell, and try it.
3. Your patient has just given birth to a baby with a DSD. You need to tell the parents. How do you do this? Parents: evaluate delivery, tone, substance.... Was the medical professional reassuring? Alarming? Did he/she convey a sense of tragedy?

**3:30** How do we continue this with friends, family, and coworkers?

**4:00** Evaluations and certificates for health provider training

**6:00** Party at Nancy Mayginnnes' house (babysitting will be provided)

### **Saturday, October 22, 2011**

**8:30-9:00** Continental breakfast (included in conference fee)

**9:00-10:00** HEA: Where have we been, where are we going?

**10:00-11:30** Medical Issues in Children  
Medical Issues in Adults  
Medical Issues in People with Epispadias

**11:30-12:30** Lunch (included in conference fee)

**12:30-1:30** Concurrent sessions:

Parent Workshop

Wrath of Grapes (and Other Dry Goods): Addiction

**1:30-2:30** Where I've Been, What I've Seen, Where I'm Going

**2:30-2:45** Break

**2:45-4:00** Discussion Groups

- A. Is hypospadias or epispadias still an issue after surgery, or is it fixed and over with? How do I discuss this with my child at age 5, 8, 13, 17, 25?
- B. Restimulation, retraumatization, chronic conditions: It's hard to keep on trucking when my ass keeps falling off!

**4:00-5:00** Workshop

**Dinner in restaurant in vicinity (not included in conference fee)**

**Sunday, October 23, 2011**

**9:30-10:00** Continental breakfast (included in conference fee)

**10:00 -11:00** Board of Directors Panel: Why I got involved, how it has helped me personally  
Small Group Discussion: How Can You Help?

**11:00-12:00** Elections and Formation of Committees

**12:00-1:00** Open Microphone: Gratitude and Goodbyes

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**HEA Annual Walk**



**The Illinois walk was a great success! Thank you to those who participated and donated.**



## Getting Men to HEA

By Tiger Devore, HEA Board Member  
And Vice President

I recently was part of a documentary called "The Truth of My Sex." It was produced by the BBC and broadcast here in the US on the Oprah Winfrey Network. Although I have done documentaries for PBS, National Geographic, and even the Discovery Channel, I have never gotten so many e-mails that made it possible to invite men from around the country to come and join HEA in Chicago at this year's conference. Call it the Oprah factor....

These e-mails almost always speak to the shame, isolation, secrecy, and fear these men have about their genital difference. Many of them report such poor medical care that they avoid doctors completely. Often, they avoid relationships because they don't know how to tell a prospective partner about their genital difference. Lingering resentment toward or alienation from their families can add to their lack of support.

Some of these people come to the conference. More about them in a moment. Others cannot face the idea of standing in front of other people and admitting to their genital difference, even knowing that they are at a conference full of men who share that difference. The fear and the shame are so deep, the secret so carefully kept for so many years, that they simply cannot attend, even though they want to and they know it would be good for them. Sometimes they will come in another year; sometimes they will ask to be dropped from the mailing list because the reminder that someone "knows" about them is too much to bear.

The ones who make it to the conference, the ones who face their fears and deal with how frightening it is to imagine talking about something they have kept hidden for so long, almost universally have the experience of the greatest relief they may ever have known. To hear other men telling a story they thought was only their own; about the family shame, the scary hospital memories, the teasing from other kids, the intrusion of multiple genital exams. As well as the stories that bring a smile of recognition: peeing on the toilet seat, always looking for a toilet with a door and a lock, remembering to drink a lot of cranberry juice. This experience of belonging, the one thing that has been impossible to achieve previously in their lives, is finally theirs. What a relief to be surrounded by others who know what you've been through without having to go into an uncomfortable explanation that might never be really understood.

Hypospadias is the most common congenital difference in human beings. Epispadias is more rare. There are millions of men living with them.

I know that coming to HEA can literally be a lifesaver. When I was a young doctoral student in 1984, I chose to appear on television to talk about genital difference. I was told by a researcher who had studied more people like me than anyone had before that I was the first he knew of who was willing to be seen and known as (what it was called then) a hermaphrodite. I did it not only to reach out to other people who had been born like me, and suffered as I had, but also to reduce my own sense of stigma, to stop feeling that I could never tell anyone and that if anyone did find out, I would simply die of embarrassment. I couldn't have that hanging over my head, so I took control of the secret and let it out on national television.

So many people look at the HEA website. So few ever come to a conference, let alone join this organization.

If what I have written here has touched you, please come to a conference if you never have. Please write to the doctors who have treated you and encourage them to tell their patients about HEA. If you know someone with a genital difference who is still in isolation, please invite them to a conference. And please support HEA by becoming a member; it is so inexpensive in comparison to the good that this organization does for so many who come and have that great moment of belonging, as well as those who can look at the website but still believe that they can never let themselves be known.

## Preface

By John L. Sunderland, HEA Board Member

I am writing this short preface before seeing the next article by Massimo Di Grazia, one of our regular contributors to the newsletter, because we met in May 2011 and had a great time together, mixing pleasure and quite a bit of business centered around DSDs. Massimo would like his articles to be meaningful for individuals, and while previously they have been of a general nature, he would like his future articles to be a little more specific (this may be apparent in the following article) and address areas he thinks are important.

Of course what *we* think is important is also in his mind, and to that end he asked that I mention his wish to write the article after this one, based on a particular area someone would like help with. We do not need to be apprehensive with our questions and can ask anything that might be troubling us and that would benefit all of us, including those too shy to ask. If someone is unhappy doing that, it is always possible to send him a private message, since Massimo is a member of HEA.

With his recent degree in psychology and diploma in sex therapy, I think we can expect frank and helpful input from Massimo. He is also coming from a position where he understands DSDs, having such a condition himself.

Just to finish, I thought it might be useful for us to know what happens in Italy when the DSD group led by Massimo meets each year. The group has three different meetings, covering the north, center, and south of the country, and at least one session is reserved for the young members of the group (one assumes with consent), the parents going elsewhere for a meal. This is the chance for the young to ask those awkward questions that they may not feel comfortable with at home. There are no holds barred, and it is popular with the young, as one would expect. I know we set up a teen's space online and try not to abuse it, but it is open for all to see, and that is where the private sessions seem to be an improvement.

## The Knowledge of Ourselves

By Dott. Massimo Di Grazia

The knowledge of ourselves is connected to the binomial mind-body, which exists to enjoy all that life gives us. The awareness of this binomial is an important passage in one's sexuality. In fact, we can think of human sexuality as the energy motor in males and females. To fully enjoy this life energy, it is necessary to have an awareness of this binomial, which involves the experience of masturbation.

Masturbation is an experience which permits us to discover and perceive the hormonal and physical changes of our body, to have our first erotic experiences, and to develop a deeper intimacy with ourselves. Moreover, it allows us to know emotions and instincts that are part of human life and to start to familiarize ourselves with erotic and sexual thoughts. We have to know these feelings and accept them; masturbation is a way to practice the binomial mind-body.

Masturbation is very important in the early knowledge of human development.

This awareness encourages an approach to the binomial mind-body.

Masturbation is a part of one's entire life: it starts during the preadolescent age, becomes more frequent in adolescence with its hormonal storm, and continues during adulthood, obtaining in each phase a specific meaning.

Males and females live this experimentation, each one in a different way, but the thing common to everyone is that this experimentation is connected to the perception transmitted by the mind and the body.

The flow of erotic and sexual thoughts and bodily changes can be followed by fear, shame, and embarrassment. For these reasons, masturbation is not considered to be part of the growth process. In my opinion, it is important that

we know the meaning of this process and be better in how we practice it. We have to consider masturbation positively, quietly, and freely because it gives us more awareness of our mental and physical needs. The act of masturbation permits us to know our sexuality, to accept erotic thoughts and desires, and this is the first step toward sexual activity. We have to think of masturbation as a healthy experience: we must not punish it, we must not feel guilty about it, because masturbation is not a dirty thing or a thing not to do. It is not a consolatory action for something which we miss, and we don't think about practicing it systematically. In my opinion, masturbation must exist in our life; if it becomes the only way of achieving sexual satisfaction and is practiced compulsively, we have to investigate, but I don't want to talk about that now. On the contrary, I want to think of masturbation not as an exclusive experience, but as a useful approach to sex, also for people affected by urogenital pathologies, including disorders of sex development. In this article I will not discuss these urogenital pathologies or the different surgical operations performed to restore urological and genital functionality. These aspects will be considered in future articles.

In my opinion, what is important is not how a person masturbates but how the liaison with the binomial mind-body is present and active. If we let the mind's desires, the hormonal instincts, and all the energies flow, we get in contact with our bodies, and masturbation encourages and produces experience and knowledge.

Then, the genitals (penis or vagina) are not important even if they do not have a normal aspect or dimensions, as anatomy books describe or as our collective imagination and individual patients think. Yet it is important to have a global vision of the binomial mind-body, to let the energy flow, and to try to open the paths to receive our and someone else's sexuality. It is especially important to people with genital differences to restore these instincts and these desires.

I would like to emphasize that what is important is not how one masturbates but how one feels the sensations inside oneself, receives them, and practices autoeroticism. I want to use this word and cease to say masturbation. The term "autoeroticism" gives stronger foundations and fortifies the meaning of human sexuality, because it involves not just the genitals but also the binomial mind-body. We have to appropriate our instincts and fancies and let them flow because we want to reach the knowledge of ourselves.

With this article, I hope I have given you another point of view about this issue. If you have any questions, please contact me at my e-mail address: [mdigrizia2@alice.it](mailto:mdigrizia2@alice.it). I am at your full disposal.

# HEA

Hypospadias & Epispadias Association

## International Conference

Friday-Sunday, October 21-23, 2011

Held in the outskirts of the beautiful city of Chicago, Illinois

Complete information about the conference can be found on the HEA website. Information about accommodations is also posted there. Go to <http://heainfo.org/conference.html>  
Please keep checking the website for changes and updates to the conference program, speakers, and activities.

### Conference Fees

<b>Note:</b> People who are HEA members at the time of registration get a \$25 discount. The discount is not applicable for those registering for Friday only.	<b>Early Registration (through August 31, 2011)</b>	<b>Regular Registration (after August 31, 2011)</b>
<b>Friday-Sunday 3-Day Conference</b> (includes 6 meals plus Friday night party at home of Nancy Mayginnnes plus beverages)	Individual: \$150 (\$125*) Family: \$180 (\$155*)	Individual: \$175 (\$150*) Family: \$205 (\$180*)
<b>Saturday-Sunday 2-Day Conference</b> (includes 4 meals plus beverages)	Individual: \$100 (\$75*) Family: \$130 (\$105*)	Individual: \$125 (\$100*) Family: \$155 (\$130*)
<b>Friday Daytime Conference Sessions/Training</b> (includes 2 meals plus snack)	Individual: \$50	Individual: \$50
* Indicates \$25 discount for HEA members.		

### Your Information (All information will be kept strictly confidential.)

Name: \_\_\_\_\_

Street Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zipcode: \_\_\_\_\_ Country: \_\_\_\_\_

Email: \_\_\_\_\_ Phone: \_\_\_\_\_

Number of family members attending: \_\_\_\_\_ Names/ages of children: \_\_\_\_\_

Main Topic of Interest: \_\_\_ HS \_\_\_ ES \_\_\_ both \_\_\_ other (specify \_\_\_\_\_)

Please enclose a check made payable to HEA and mail this form to HEA Treasurer,  
P.O. Box 475, Wauconda, IL 60084. Or register using the online form and PayPal at

<http://heainfo.org/conference.html>.