

The Current Stream

The Newsletter of The Hypospadias & Epispadias Association

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Join Us In Chicago! 2011 HEA Conference

By Jim Lake, HEA Board Member
and Treasurer

I do want to spend a moment with an update on the 2011 HEA Conference in the Chicago suburbs, to be held Friday-Sunday, October 21-23. I have had a lot of support locally to make this the best conference yet. Nancy Mayginnnes and I have been working on negotiations with hotels for conference space and the lowest possible room rates. We picture the conference portion to be in Schaumburg, Illinois. It is near large malls, parks, dining, and public transportation for those of you who want to check out the city sometime over the weekend. Nancy is planning a meet-and-greet function at her home to kick off the event on Friday, October 21. Transportation will be provided by the hotel.

This year's event will also include training for doctors, nurses, and counselors on Friday, October 21, before the conference begins. The training will be an overview of disorders of sex development (DSDs).



**"On May 14-15,
we had the first of our third
annual HEA**

**Walk/Run/Bike events in
Chicago, IL, Albany, NY,
and Manchester, UK. The
New York City event will
be on June 12. There's still
time to plan and hold
events in Boston, Orlando,
Norfolk, London,
Vancouver, Denver,
Toronto, and several other
cities around the globe. If
you are interested, we have
developed a planning kit to
help you start your very
own event."**

I understand that many dislike the nomenclature, but several differentiations will be discussed. It allows HEA and partners to reach out to medical and counseling professionals who may not otherwise be given the opportunity to be aware that we are out here. Three years ago, Billy Deegan (HEA), Arlene Baratz (Accord Alliance), David Sandberg (Accord Alliance), Franci Newhouse (former HEA board member), and I presented a full day of training to the Lake County Health Department and received amazing reviews. Attendees were given continuing educational credits for attendance. We are currently planning a curriculum for the upcoming training. Members can also attend, and we will provide any additional information you may need online and in the next newsletter.

As far as the conference, Friday night (10/21) will be the meet-and-greet, while Saturday and Sunday (10/22-10/23) will be the conference. We are also working on programs for children, parents, and adult attendees with hypospadias or epispadias. Looking forward to seeing everyone!

HEA News and Plans

By Billy Deegan
Executive Director, HEA

I am told that this is the Year of the Rabbit in the Chinese calendar. I herald from the Year of the Tiger. It is predicted that this year could bring a lot of success to career ventures I have been working on. It further predicts that financial gains can come primarily from outdoor events and social gatherings—which brings me to my missive.

It has been almost a decade since I first traveled to Denver to a conference with the founders of a Yahoo support group for men with hypospadias. Who could have imagined that we would be pioneering advocacy and social support for a condition that has been with us for ages? As your executive director, I have the job of securing and stabilizing this organization, increasing its membership, and raising funds. After nine years of countless committee and board meetings, nine conferences (in Denver three times; Toronto; San Jose, California; New York City; Norfolk, Virginia; Pittsburgh; and San Antonio); presentations to pediatric urologists in Vancouver, Rome, Istanbul, and London; the creation of a professional public service announcement; an HEA brochure; a thrice-yearly newsletter; a state-of-the-art website; and over a quarter of a million dollars raised, what have we accomplished?

We have saved lives. We have allowed mothers and fathers to sleep at night. We have been a beacon of light sent to eliminate isolation, secrecy, and shame. We have taught the medical profession that hypospadias and epispadias affect more than just the urethra, but also the spirit. We have been true to our motto: "You are not alone."

I have not done this. *We* have done this. Who are *we*? Everyone who has ever contributed a dollar, an hour of service, or the gift of their knowledge. But I have heroes. A hero is defined as:

-noun, plural -roes; for 5 also -ros.

1. a man of distinguished courage or ability, admired for his brave deeds and noble qualities.
2. a person who, in the opinion of others, has heroic qualities or has performed a heroic act and is regarded as a model or ideal: He was a local hero when he saved the drowning child.

Doug Jasper, Jim Lake, Franci Newhouse, Alice Twombly, Travis Harrison, Greg Sonnenberg, Tiger Devore, Dr. William Kennedy, and Barbara Neilson have been with us almost from the beginning, tirelessly offering their time, finances, and services. These are men and women who say only, "What can I do to help?" A list of HEA heroes would be incomplete without mentioning Willie Sears, our unofficial ambassador to the newcomer. Willie has devoted countless hours listening to and supporting new members. Along our journey, we found Chris Arnold, Bill Bickerstaff, Desmond Dutcher, Sue and David Foulds, Ken April (our newsletter editor), Scott Mallalieu, Nancy Mayginnes, Betsy Morgan, Cherise O'Kennedy, Jenny Parada, John Sunderland, Ino ter Haar, and Ed Weaver. This year, we are pleased to have the help and support of our newest board member, Josephine Prince. Our website was created and developed through the hard work of Travis Harrison, who passed the baton on to Betty Engel. She volunteers 40 hours a week to update and develop this site. A special thanks to attorney Domenic Romano, a friend and New York City not-for-profit specialist, who, at a greatly reduced fee, found us a great accountant. Together, they secured our permanent tax-exempt 501(c)(3) status. These are the men and women who plan our conferences, create our newsletters, raise our money, safeguard our finances, appear on television and radio, advocate for informed consent and patient rights, write letters to immigration authorities to obtain medical visas so children can get medical care, answer phones and correspondence requesting information, write and present articles educating us, travel to international conferences to make our voices heard, and, without hesitation, open up their wallets and give, give, give to keep our projects and ultimately our organization alive and afloat.

Already, as I write this, it is February 2011, and I am hoping we can get a lot more work done this year. Let me tell you about our plans as well as my wish list.

On Saturday and Sunday, February 26 and 27, we had our Nights of a Thousand Meatballs. I started this event last year as a way to raise money, provide awareness, let local members gather, and give members a less intimidating way to get involved. I

asked people around the world to consider hosting a spaghetti-and-meatball dinner in their homes or local restaurants. Depending on individual comfort levels, they could invite family, friends, and/or health professionals to gather for an evening of dining, as well as to educate others on the issues facing our community. Not many people hosted this event, but those of us who did found it fun and enlightening. Not to mention that it raised much needed donations.

On Saturday-Sunday, May 14-15, we had the first of our third annual HEA Walk/Run/Bike events in Chicago, IL, Albany, NY, and Manchester, UK. On Sunday, June 12, we will be having the New York City event. I am hoping that this year we can also have this event in Boston, Orlando, Norfolk, London, Vancouver, Denver, Toronto, and several other cities around the globe. If you are interested, we have developed a planning kit to help you start your very own event.

On Sunday, July 24, we will have our website open house. This is an opportunity to show off our website improvements and have a membership drive. We did this several years ago, and it was very successful. We will have medical and mental health experts scheduled all day to present material and run a question-and-answer session in our chat rooms.

On Friday-Sunday, October 21-23, our annual HEA conference will be held in the Chicago area. Not only is Jim Lake planning this, but he arranged for continuing education credits for physical and mental health and addiction professionals who participate in the conference, and the state of Illinois will sponsor this event. Save the date!

These events will happen, and if we are fortunate, they will pay for our office rental, telephones, fax, Internet connections, website expenses, board liability insurance, postal charges, and legal and accounting fees. That is, if we are able to generate more funds. In addition, the following are my wishes for 2011.

1. September 17 to 19: The Fourth World Congress on Hypospadias and Disorders of Sex Development will convene in London. I attended and gave presentations at earlier congresses in Istanbul and Rome but, due to a lack of finances, was unable to attend in Toronto. I think it is crucial that we are represented at this conference and our concerns are heard. Anyone have extra frequent flyer miles?

2. In order of priority, I would like us to write, produce, and distribute three brochures. The first would be a brochure for parents discussing how to decide on surgical options and what to expect after surgery. The second would be for adults considering a re-repair, and the third would be a second edition of HEA's brochure explaining who we are and what we do.

3. We created and produced a 30-second and a 60-second public service announcement. We need to begin a strategic campaign to get these aired on the radio.
4. We have a terrific website. We need to link this site to as many health websites as we can.
5. I would like to see our website translated into Spanish, French, Italian, German, and Chinese.
6. I am developing a project where I do video interviews of members of HEA to document their stories. My vision is to create as many videos as possible for the HEA library and for streaming on our website, thereby documenting our history as well as our lives. The cost would be travel expenses and a camera operator and equipment.

Thanks for reading this. That's the plan. If you'd like to help, I'm sure we could use the extra hands.

The Future of HEA

By Ed Weaver
HEA Board Member and President

We have all experienced the knowledge, support, acceptance, and love of the HEA family! For many of us, finding HEA has been a positive, life-altering event. The impact that HEA has had on us is significant; that is why we support the organization through our membership and continue to pay it forward to others in need.

HEA is a nonprofit organization, operating on a shoestring budget and driven mainly by the volunteer Board members, executive director, and webmaster. Historically, both the leadership and manpower for HEA have come from these individuals, with the support of a few dedicated members. However, we've come to realize that, in order for us to survive, grow, and thrive, we need to harness the support of more of our members. HEA has a plan.

Part of our plan is to establish working committees to assist the board in strengthening HEA. Utilizing active committees will free the board from the tactical (day-to-day) efforts and allow them to focus on leading HEA into the future! These committees will include the following.

- Membership/Outreach (primarily responsible for contact with and support of our members). This will include monitoring the message board, participating in chats, welcoming new members, monitoring renewal memberships, maintaining the membership database, organizing membership drives, etc.
- Website/Publications (primarily responsible for website development/improvement, website content/layout, the newsletter, and future publications). This will include brainstorming ways to improve our website; providing assistance with the layout, updating, and functioning of the website; organizing and preparing our newsletter; preparing new brochures; etc.
- Fundraising/Grant (primarily responsible for organizing and driving fundraisers and pursuing grants). This will include developing, organizing, and implementing fundraising initiatives, identifying grants and writing proposals, etc.
- Networking/Media (primarily responsible for identifying ways to get the word out about HEA). This will include combing the Internet to identify and connect with organizations and resources that share HEA's mission, as well as pursuing various avenues of getting the word out.

We need your help!

If you have talents, resources, connections, and/or interest in one (or more) of these areas, please contact me (Ed Weaver, edubsjr@hotmail.com). Committee involvement would require participating in a monthly "meeting," volunteering your time to ensure results, and communicating effectively with your committee. I would like to ask for a one-year commitment, but I would be grateful for anything you can offer. Thanks for your consideration! I look forward to working together to make a difference for our HEA family.

HEA Committee Updates

[Website/Publications](#)

By Betty Engel
HEA Webmaster

At the San Antonio Conference last October, I was privileged to receive many ideas about how the HEA website, HEAinfo.org, could be improved. Thanks to all the presenters and attendees for giving me a better appreciation of what you need from our website.

We now have a new message board that runs faster, looks better, and is error-free. All of the user names and posts from the old board were translated so that nothing was lost. Many people (including Erin, Willie, Ken, Ino, John, Niels, and Chris) have been sending me suggestions for improving the message board and I've tried to incorporate their suggestions where possible. New features include the following:

- Users can communicate with each other in more ways (email, private messages, ICQ, Jabber, Instant Messenger, and website) while maintaining desired levels of privacy.
- Individual profiles now include information about where users are and why they are interested in HS and ES.
- User names of those currently signed into the board are listed.
- General information about HEA and its activities, such as discussions about the HEA conference, are viewable by message board guests, while all other posts are viewable only by registered users.
- Users can make a list of "friends" for sending emails or private messages more easily.
- Posts can now be longer.
- Users can take longer to compose their posts.
- Board-wide announcements can be posted and replied to.
- Icons can be attached to posts to make them stand out.
- Attachments can be added to posts.
- Users can change the look of their message board by clicking on User Control Panel → Board Preferences → My Board Style. Current choices are Charcoal, envision, Minimal, prosilver, RedSilver3, and subsilver2. My personal favorite is envision, while folks with color vision problems might like RedSilver3 or Minimal.

We are working on expanding the information about hypospadias and epispadias on the website by establishing a wiki on hypospadias and epispadias. This section would be a collection of articles written *by* our community *for* our community. Some of us have more medical knowledge about these conditions than most doctors and we can pass on this information through the wiki. Personal stories can be incorporated into factual articles so that the content has depth and relevance. More information about the HEA Wiki will be posted soon on the website.

Do you have other suggestions about the website? Please [email me!](#)

By Nancy Mayginnes
HEA Board Member

Together we have completed another fantastic HEA Newsletter. I want to thank

everyone who contributed articles. I encourage HEA members to participate in writing articles for the upcoming newsletters. Please email me at Mayginnes@comcast.net if you are interested.

Networking/Media

By Ed Weaver

HEA Board Member and President

One of the significant goals for HEA in 2011 is to increase awareness of hypospadias, epispadias, and HEA as an organization. As we all know, there is very little awareness of conditions such as hypospadias and epispadias in our society. And, oftentimes, we find that even doctors, therapists, urology-oriented professionals, and like-minded support groups have never heard of our valuable community! Therefore, HEA is creating a Networking/Media Committee.

This committee will be primarily responsible for identifying ways to get the word out about hypospadias, epispadias, and HEA. This will include combing the Internet to identify and connect with organizations and resources that share HEA's mission, as well as various other professionals. This committee will also be charged with brainstorming and pursuing a variety of avenues for increasing awareness. Committee members will be needed to volunteer a few hours a month (or whatever you can spare) for some individual work and participate in brief monthly committee contacts.

This is a vital initiative, and HEA will need your assistance! Currently, this committee consists of Board members Tiger Devore, Ph.D., John Sunderland, and Ed Weaver (chair); however, these Board members cannot tackle this task alone! If you have any media connections, contacts, skills, ideas, suggestions, and/or time that you would be willing to share with HEA, please contact me at edubsjr@hotmail.com. This committee will officially start tackling this initiative as of April 1, 2011.

We need your help! Please consider supporting HEA by volunteering on this committee!

The HEA Message Board and Chat Rooms

By John

Member of HEA

How blessed we are these days to have the Internet and the possibility to "meet up" with people from all over the world. Make no mistake, we who live in countries where there is reasonable access to medical care and psychological help are really very blessed indeed.

Like all need in the world, we see only that which is presented to us in the media and

now on the Internet; that makes it real, and without those elements we would not be as easily aware of the needs of people living in countries with little or no social outreach. So it is more important for us at HEA to react when we find a person out there who is isolated and needs our support and input, whatever it is we can offer.

Some young people affected by hypospadias or epispadias are born into a situation where there is only one parent in their household, or they are in a remote part of a country and thus have little expert medical help and also very little chance of getting to know someone who may be like them and will appreciate something of what life is handing out to them. I am just exploring how we can best be a continuing support to such people as these.

Over the last few years, there have been members of HEA who really cherished the continued back-and-forth banter of the message board and chat rooms, comparing notes, as it were, and it is only later when they seem to be much more open, happy etc. that they reduce the frequency of contact. The odd mail from them from time to time suggests that a settled situation has developed.

I suppose that what I am really advocating is that our posting boards and chat rooms be used more, to help where we can. It is my daily routine, when I am at home, to check the HEA site and, when it is appropriate, reply to a posting. If more of us were able to do that, we might increase the outreach that HEA seeks to give and make that difference to someone who is like us. If you are able, please give it a try.

When Memories of Trauma Are Triggered

By Tiger Devore
HEA Board Member and Vice President

Whenever I am at a conference for people who are sexually different, I am always watching for signs of participants who are having unexpected feelings triggered as a result of the material being presented. Sometimes it is really obvious, like when a surgeon is explaining a technique for removing scar tissue and he makes a sweeping movement with his hands that indicates snipping away all the damaged tissue, and all the men who have had genital surgery in the audience groan and grab their stomachs or even run out of the room. That is retraumatization. The surgeon doesn't mean to upset the audience; he is showing them how all the old damage can be removed and the repair can be made with fresh skin and better healing than ever before. The participants all react to the memory of pain in the genitals from having had surgery there before, and without any conscious thought, they demonstrate all the physical responses associated with that pain or the fear of that pain.

The retraumatization reaction isn't always so obvious or immediate. Sometimes something that is said or seen will stick in the unconscious of the participant, only to show up sometime later (this can take years). I remember a presenter talking about kids being in the hospital preparing for genital surgery, and how sometimes a kid who is being placed on the operating room table can muster the adrenaline to get up and run out of the surgical suite, even though he was sedated before being wheeled to the operating room for the procedure. This presenter said that when the emotional support team is called to reassure and calm these kids, the kids are referred to as "runners." I listened to the presentation with interest, enjoyed the information she was presenting, went along to the next session, and didn't notice anything out of the ordinary as I went through the rest of the conference. Two years later, someone was describing to me how they had once been held down by an assailant and they were struggling to get free of being pinned. Like a wave sweeping over me, a memory came back of how I struggled to get free while nurses were trying to hold me still and anesthetize me for surgery when I was less than 7 years old. It wasn't just a memory, it was like being there all over again. I remembered the presenter talking about "runners," and for the first time realized that I was a "runner" several times when I was hospitalized as a kid. I was triggered by the story I was hearing and recategorized the memory on the basis of the presentation from the conference.

For any of us who have a history of trauma, we may find that unexpected events that are otherwise innocuous but still trigger memories of past trauma may occur in our daily environment. For many men with hypospadias, bathrooms can be a source of all kinds of anxiety and retraumatization. Think of how you may react if you are someone who has to sit to pee, and you walk into a public bathroom and see that the stalls have no privacy door. It is pretty common for us to remember being teased or embarrassed for being exposed sitting on the toilet in the bathroom when all the other boys were standing. As adults, we may just walk out of a bathroom with no privacy and wait to pee or go in search of a bathroom that does have privacy. All of that discomfort and waste of time is about retraumatization. This reaction can get more subtle. What goes on in your mind when you see a men's underwear ad and the model has a more than ample genital bulge? All of these triggers for having the kind of genitals that "normal" men have (standing to pee, filling out their underpants a certain way) put us back into our trauma about being genitally different.

My guess is that as you read this, many of you can recall events which make you have that feeling of discomfort and differentness. I hear men say over and over that as a result of contacting HEA or being at an HEA event, they are so relieved to hear stories like the ones I have mentioned above because for the first time they are not the "only ones." I realize that some of you may have been thrown into uncomfortable feelings just from reading this article. I encourage everyone who is affected by this material to talk it out with someone who you trust. If you feel moved to share your own experience of being surprised by something in your day-to-day life that triggered a trauma memory, please write back to me through HEA (anonymously if you prefer) and let me know if you would be willing to share it with the HEA community through this column. We help each other to feel comfortable with what we've been through by sharing these experiences and finding out how common they are, even if we don't attach our names to the descriptions.

A New Perspective

By Dott. Massimo Di Grazia

Changing the perception we have of ourselves can be helpful. Let me explain. Is it true that we have the belief that others don't accept us or might not accept us? If we easily believe that they don't, we make it a real problem. Certainly this problem is evident, and we can't hide from the objective evidence. But I want to briefly show you a new perspective or at least try to give you a chance to experience it. A typical perspective may be to observe that one's genital organ is different from the norm and that it has small size, visible scars, little sensitivity, problems in maintaining erections, and many other things that I don't want to list here. Where can we find a different perspective on this very difficult situation?

Here is my proposal to regain confidence with this body that has suffered and tolerated many humiliations and pains. With this confidence one can believe again in one's own body, hear it and feel like one is part of it, feel every little element so vital and full of energy. Take a place and a time where you can stop, observe, and listen. I think the process of gaining a new perspective on one's body needs a place and time that allows one the opportunity to introduce this to oneself and then to others. Now, with a new energy, this can be developed through the instrument of meditation. This instrument allows us to retake contact with our bodies and to have the correct openness that helps us to transform and make free our inner energy that is incarcerated in us. Meditation creates a direct connection between mind and body; it recreates the fusion that often, in a conscious or unconscious way, we try to dismiss and denigrate. When I speak of meditation, I speak about a moment in which one stays in a place where one feels good and one tries to calm one's mind and experience one's body as a mass. We feel our breath; we try to experience this air that enters and leaves as a way that allows us to feel every part of our bodies, even those parts we don't want, which we denigrate and we hate. This process allows us to have an intimate space where we make contact with mind and body, where we can observe our wounds to see them not as a bad thing but as a positive energy to be released. Certainly this is a complicated process—it needs exercise, it needs practice—but it allows us to take confidence in ourselves, and as I mentioned in a previous article, to codify our inner states of pain, our anger that comes from a physical condition.

It comes from a condition that is not normal in such an intimate and delicate part of the person which includes sexuality, reproduction, intimacy, pleasure, feeling like a man or a woman, and feeling normal. I firmly believe that this moment dedicated to oneself through meditation can open a new perspective on how one appears to oneself as well as to someone with whom one shares a sexual relationship. In my opinion, this may be the key to enter our body that we often hate and insult. If we are not the first to change the perception we have of ourselves, we cannot create the right condition for others to accept us in their emotional and sexual sphere.

Does HEA Have an "Official" Policy on Surgery?

By Doug Jasper
HEA Board Member

I receive a lot of messages sent to HEA which either ask that question or are from people seeking advice before deciding whether to have surgery. Since this often involves making this decision for our children, obviously the stress and the feeling that we don't have enough information can be overwhelming.

Clearly, the necessity for surgery depends completely on the case at hand, and there is no yes-or-no, one-size-fits-all answer to this question. This decision is completely between the patient and the health care provider. So the quick answer is that no, HEA does not advocate for or against surgery in any way.

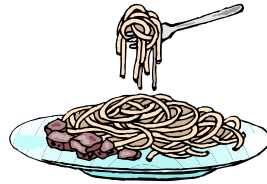
HEA's position follows its mission; we wish to educate and inform those in the hypospadias/epispadias community with accurate and unbiased information and let the patient or his family decide. We also seek to forge an alliance with hypospadias/epispadias specialists and be a resource for their patients "outside the doctors office."



Spotlight on Josephine-New HEA Board Member!

By Josephine
HEA Board Member

Josephine is the mother of a wonderful little boy with hypospadias. This condition does not define him, of course, but his mother was concerned enough about his future that she joined HEA to learn as much as she could about hypospadias. Having a child with hypospadias and being involved with HEA have profoundly affected and changed her life in many different ways. She is now dedicated to the future of this wonderful organization, which has offered help, hope, and understanding to so many throughout the United States and elsewhere. Josephine enjoys working part-time as an office administrator and at home taking care of her son, and she feels it is a honor to now serve on the board.



Night of 1,000 Meatballs

The Night of 1,000 was a big success! Members and supporters gathered, shared, laughed and ate well. Thanks to everyone who held the dinners and who participated and contributed!



Our thanks to Ken April for his hard
work editing the articles!