

The Current Stream

The Newsletter of The Hypospadias & Epispadias Association

Winter 2011 Issue

2011 HEA Conference Chicago, Illinois

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**The HEA Online Open House will be held on Sunday, December 4, 2011, from 11am to 11pm Eastern Standard Time.
Come to HEAinfo.org at any time during that period to join our online party!**

A Message from HEA's President

By Ed Weaver
HEA President

As we enter the holiday season, it's natural for us to reflect back upon the year that we've had and begin planning for the year ahead. 2011 was a year of both challenges and successes.

Many members of our community endured surgeries, serious medical situations, hospitalizations, employment or financial issues, existential concerns, family transitions, etc., in addition to the normal stressors of everyday life. As difficult as this year was for many of us, when I look back, something is very clear to me: ***we are a very caring and supportive community!*** For those of us who faced such challenges, what may have initially felt shocking or overwhelming was made bearable because of the encouragement and support that we received from other HEA members.

As an organization, HEA was able to provide top-notch newsletters for our members, improve our website services by upgrading our provider and tools, execute successful fundraisers (via the Night of a Thousand Meatballs, HEA Walk/Runs, and Facebook Causes drives), expand our professional partnerships and network with other experts and organizations, and organize an amazing conference in Chicago.

Looking ahead to 2012, there are many possibilities and new opportunities for HEA. Our level of individual investment in HEA will determine our level of organizational success next year. There are many ways to invest in HEA: time, suggestions, networking, talent, skill, and—yes—money.

One of the ways that you can support HEA is by offering your time and talent. Last year, we set up committees to help HEA run more effectively; however, we were not successful in getting them operational. Utilizing active committees will free the board from some of its tactical (day-to-day) efforts and allow it to focus on strategically leading HEA into the future. These committees will include:

- **Membership/Outreach** (primarily responsible for contact with and support of our members). This would include monitoring the message board, participating in chats, welcoming new members, monitoring membership renewals, maintaining the membership database, organizing membership drives, and so forth.
- **Website/Publications** (primarily responsible for website development, improvement, content, and layout; the newsletter; and future publications). This would include such functions as brainstorming on ways to improve our website; providing assistance with the layout, updating, and functioning of the website; organizing and preparing our newsletter; and preparing new brochures.
- **Fundraising/Grant** (primarily responsible for organizing and driving fundraisers and pursuing grants). This would include developing, organizing, and implementing fundraising initiatives; identifying sources of grants and writing grant proposals; etc.

- **Networking/Media** (primarily responsible for identifying ways to get the word out about HEA). This would 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.

If you have talents, resources, connections, and/or interest in one of these areas, please contact me (Ed Weaver, edubsjr@hotmail.com) by December 31, 2011. 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.

Thank you for the support that you have already provided HEA. I appreciate the efforts made to keep this amazing organization alive for the hypospadias/epispadias community. As it is the holiday season, I would also like to wish you all Happy Holidays and peace in the New Year!

2011 HEA Conference Thank You Letter

By Jim Lake

HEA Treasurer and 2011 Conference Co-coordinator

I just wanted to take a moment to thank all of the participants of this year's conference. It was truly a coordinated effort as two locations were used. I have received excellent reviews for the DSD training which was held at the Doubletree Hotel in Mundelein, IL. Participants from the Lake County Health Department as well as persons from other area social service agencies were awarded 5.5 Ceu's for their attendance. This was the second time that such training was provided, but the first time where membership also attended. A meet and greet was held at the Doubletree in Schaumburg, IL followed by the remaining weekend of the member only conference. Breakfast, lunch, and beverages were provided as presenters shared information with attendees. There was also plenty of

free time for members to bond, sightsee, or relax. New friendships were made and old acquaintances rekindled.

The next conference logistics are currently in the works. I want to thank each of our presenters: Billy



Deegan, David Sandberg, Barbara Neilson, Tiger Devore, Ed Weaver, Bill Kennedy, Mohan Gundeti and Alice Dreger for volunteering their time and expertise to provide information to HEA members, including parents, children and adults.

I did want to make sure that Chris Arnold received special recognition for once again providing program printing as well as advertising specialties, including HEA Stress Doctors and numerous other items. He also contributed to conference scholarships. Special Thanks as well to Alice Dreger and who donated to the general conference fund as well as providing scholarships and to Zach H. who also provided donations for scholarships. I also want to thank my co-coordinator, Nancy Mayginnnes, for her amazing job of organization as well as conference donations and for listening to me whine during our weekly planning meetings. I love working with HEA and look forward to many wonderful activities in the New Year.



My 2011 Conference Story

*By Chris
HEA Member*

I was thrilled to be able to attend the 2011 HEA conference in Chicago recently. This was my fifth HEA conference, and each one has been an amazing experience. Chicago was no exception (thank you, Jim and Nancy!). As I think back on the Chicago conference, it is clear to me that there are many reasons why these small conferences pack such a punch of value for those of us lucky enough to attend. Let me try to list some of these reasons.

Shame and secrecy are things of the past for one weekend.

Those of us with hypospadias or epispadias are very familiar with the issue of shame and secrecy in our lives. For some of us it is something that we have found some good coping strategies to deal with, but for others it is still a very significant issue in their lives. Even our closest coworkers and friends may not know about our life with HS or ES. There is something very liberating to be able to spend two or three days surrounded by people you don't have to have any secrets with. You just cannot imagine how good this feels unless you have experienced it. Connections online are wonderful, but that connection in person is just something amazing.

Solidarity.

Solidarity is defined as “a union of interests, purposes, or sympathies among members of a group; fellowship of responsibilities and interests.” Those of us at the HEA conference experience this solidarity. It is a strong and powerful force. It brings us together. There is something so personal that unites us. This is a strong bond indeed. We have a responsibility, and it creates a strong union.

Education and support.

Every year, we learn something new. Dr. Bill Kennedy is an amazing speaker who just knows how to answer any question thrown at him, and every time we see his presentations there are new nuggets of information. It might be a burning question from a parent of a child with HS or a very personal question from an adult who needs some knowledgeable insight into their condition. The education provided at the HEA conferences is not something you can just Google.

This year we knew that a number of us were facing surgery soon or possibly facing it on the horizon, so we had a group session just to deal with that. In the two weeks following the conference, three of the people in that session underwent surgery. They didn't do it alone. Even though we were all back home miles apart, there was a network of e-mails, phone calls, text messages, and Facebook friends checking in to offer encouragement and find out how things went. This would not have happened without these connections made through HEA.

Friendships so strong.

From the first moment I see my friend, my brother, Ed in the airport, then Tony, to the moment when we walk into the hotel after a long day of travel and in the distance we see Nancy and Willie, there is a joy and a warmth at seeing these friends that is hard to explain. It is so much more than simply seeing an old friend. It is not really even the same as seeing a dear family member. You see, even the most loved family member does not share what we share with our HEA family: that deep connection that is just hard to explain. My HEA friends mean so much to me, even if I see them only once a year. You are a powerful force in my life. I can't imagine it without you.

Newbies!

Now that I have been to a number of conferences, I can tell you that one of the parts I find the most rewarding is to see those new attendees each year! Remember, these conferences have quite a small attendance, maybe 35 to 50 people on average, and there are many repeat attendees, but it is the four or five guys who are brave enough to show up for the first time who are really awesome to see. You can almost see the fear and apprehension in their eyes that first morning as people register and move into the

conference room. Then, because of the warmth and security and support that fill the room immediately, if you are watching you can start to see that fear and apprehension start to cautiously drift away. They will never be the same. We know that, because we were them at a previous conference. We had four or five newbies in Chicago, and I was so happy to be able to be there to see them and meet them.

Growth.

After acknowledging the importance of the newbies, we can then talk about those who were newbies last year and are returning this year as seasoned pros: Rod, Steve, Tony, Jim from Texas, Jim from California, Joseph, Josephine, Chris, and others, I'm so glad you returned. You are very important to us, and you are now part of changing the lives for new people this year. It's also great to catch up and see how people's lives have changed since that first introduction to HEA the previous year.

To sum it all up...

There is never enough time. I never want the weekend to end. Those three days don't provide enough hours for me to ever spend the time I wish I could spend just being with each one of you, talking with you and getting and offering support and friendship. Maybe we will have a bit more time next year. I hope so. Maybe we can keep in touch now and then over the next year, but if not, I can't wait to see you again at the next HEA conference. Where will it be? When? I can't wait! If you are reading this and you have never been to an HEA conference, please consider going next year. Your life will be changed for the better, I promise. I look forward to meeting you!



I thought that the HEA Conference was great!

By Keyan Mayginnnes (age 11)

I thought that the HEA Conference was great! I was able to talk to so many people who are living with the same thing as me. Barbara (Neilson) showed me and my brother an awesome video of a camp that I can go to where I will meet other kids like me. You do all kinds of cool things like zip lining! I think that I will go to next years conference because it was very cool.

Options

By Tiger Devore

HEA Vice President

For many years I have been advocating for people to talk to their doctors about all the options possible in their own health care. Too often we respond to the authority and trust we give to our physicians and just go along with what they recommend, presuming that they "just know best." I just got reminded how wrong that attitude can be.

Every time I go to an HEA conference I learn more from the participants than I could ever teach to them. At this meeting, we had a group for men who are facing upcoming surgery or considering surgery. As I listened to what all of the men around that table had to say, I heard how individual and customized each of their cases and considerations really were. In all of their descriptions, one thing was consistent, the expected outcome of a functioning penis, that urinates out of the tip, and has no leaks or urine coming from anywhere else on the penis.

It got me thinking about the standards of care that urological surgeons practice under. Is there an imperative that this outcome be the only option for hypo/eppi patients? In my work with transsexuals, there was a time when all patients had to complete the transformation from "one sex to the other" and any other outcome really wasn't either considered or seen as ethical and appropriate for the providers to allow. Almost 30 years later, trans people can begin and end their treatment where they see fit, creating a spectrum of outcomes allowable instead of a "must be this or that" kind of model.

So I walked up to our invited expert urological surgeon, Bill Kennedy, and asked him straight out "what if I don't want to have another graft and all the risk that comes along with that, what if I asked you to allow me to urinate out of the base of the penis instead of the tip? Can you and would you do that?" He was fast in answering that the patient gets what they ask for, that there aren't rules that would prevent him or any urological surgeon from allowing for a "not peeing out of the tip" desired outcome.

There's the most important thing: "what the patient asks for." As I listened to the men at the upcoming surgery group talk about what they were facing, each one talked about re-repair and how previous repairs have a life expectancy (success is 5 to 20 years but that is also changing to "never") and then fail and need surgery again. My urologist has been letting me know that its going to be "sooner than later" for my own 30 year old urethra to need "revision" (means surgery). I am a "no unnecessary surgery" kind of guy, so I have been considering alternatives. Last week my doc presented his plan for my next surgery. After we had talked about that, I asked him if I could use some kind of successive dilation to keep the urethra open for as long as possible, either with a metal "sound" or a plastic catheter. I would do this myself at home and see him to make sure that no strictures or tissue collapse was making surgery necessary. He raised his eyebrows and tilted his head, and said "I think you could get some good mileage out of that" which I accepted as "yes."

So my catheters in three different sizes come in the mail this Wednesday. I will let you know if I am successful in getting more "miles" out of my current urethra.

The HEA Open House Is Coming Up!

By Betty Engel

HEA Webmaster and Forum Administrator

The HEA Online Open House has been rescheduled and will be held on Sunday, December 4, 2011, from 11 a.m. to 11 p.m. eastern standard time. Come to HEAinfo.org at any time during that period to join our online party.

The HEA Online Open House is a chance for us to show off some new HEA website features, kick off our membership drive, and encourage everyone in our community to share information and support through our chat rooms.

Our website will have a somewhat different look, with a new menu to help people find the information they are looking for. We are also improving security and redesigning our online forms.

On December 4 only, people who come to our website will be able to support HEA by becoming a member at the reduced price of US \$25 for a full year's membership. Don't miss this 30% reduction in membership dues.

A new benefit of membership will be previewed during the Open House: we are putting up videos of past conference presentations. We are just setting up this new feature, so we will be giving everyone (members and nonmembers) a preview on December 4. Soon, members will be able to watch Tiger Devore, Bill Kennedy, Barbara Neilson, Billy Deegan, and other health care leaders in the area of hypospadias and epispadias present useful and accurate information about these conditions.

We will also be running our chat rooms throughout the Open House. That's 13 hours of opportunities to ask questions, express concerns, celebrate breakthroughs, and hang out with other folks in the HEA community. We're hoping to have some knowledgeable guests joining us for some hypospadias/epispadias questions and answers. Sign on and sign off to the chat rooms at your convenience. And, of course, it's free for everyone.

Details are posted in the News section of the HEA website homepage, and new information will be available there as it becomes available. The newsletter will also contain complete instructions on how to sign on to and use the chat rooms. Participating in the chat rooms is easy, anonymous, and safe.

See you at HEAinfo.org on Sunday, December 4!

McHEUNOR.com by T. McCracken



"Doctor, I just can't seem to relate to my computer equipment these days."
Cartoon used with permission.

Here's your chance to improve your relationship with your computer.

Plus get answers to your questions about hypospadias and epispadias. And get some support, too!

HEA Online Open House

December 4, 2011
11am to 11pm Eastern Standard Time

Online at HEAinfo.org

HEA Hypospadias & Epispadias Association, Inc.

Helping HEA While Surfing the Web

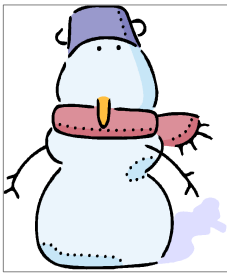
By *Bill Bickerstaff*

The website GoodSearch.com has created some new innovations on its basic theme of rewarding user-selected nonprofit organizations for Internet activity conducted through its Yahoo-based search engine. If you go to GoodSearch.com and enter the Hypospadias and Epispadias Association as your designated nonprofit, GoodSearch will donate approximately one cent to HEA (the exact amount may vary) every time you do a Web search on the GoodSearch website. Even if you know your Web destination, using the GoodSearch website and entering your search term there will earn a donation for HEA. (But don't type in the actual Web address of your destination site as the search term, because the fine print on GoodSearch's website says that no donations are made for certain kinds of searches, such as image searches and searches where a URL or a very well-known site such as Facebook is the search term.) These donations can mount up when enough people use GoodSearch. Since most of us use the Internet, this small effort can provide a painless source of funds for HEA.

In addition, if you use GoodShop.com and choose HEA as your designated nonprofit, when you shop online, a percentage of every purchase you make is donated to HEA. GoodShop connects to more than 2,500 major-brand websites and issues more than 100,000 discount coupons for you to benefit from, while donating a percentage of every purchase to HEA. GoodShop provides an especially easy and convenient tool for your holiday shopping while financially aiding HEA. No premiums or add-ons are ever charged to you, and you can shop directly at the merchant's official website, which you enter through GoodShop.

GoodSearch recently created GoodDining.com as a way for members and friends of participating nonprofits to support their cause just by going out to eat. HEA can earn up to a 6% donation on every dollar you spend when you register a credit or debit card and use it when you dine in or take out at any of more than 10,000 restaurants, bars, and clubs across the United States. The website allows you to type in a zip code or a city and state to find a list of participating establishments in your area. Everything is processed “behind the scenes” so that you never have to tell the restaurant that you are participating in the program.

We hope that you will visit and use GoodSearch, GoodShop, and GoodDining and help HEA as you surf, shop, and eat your way through the holidays and beyond.



Have a joyful holiday season