

The Current Stream

The Newsletter of The Hypospadias & Epispadias Association

Winter 2010 Issue

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2010 HEA Conference San Antonio, Texas

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*By Ed Weaver, HEA Board Member,
Secretary and Conference Organizer*

**Our thanks to Ken
for editing the
articles.**

The theme for this conference was "Healing...Empowering...Advocating." Our goal was to provide a relaxed, safe, and supportive environment in which to learn more about hypospadias and epispadias. Downtown San Antonio and the Menger Hotel provided us with a wonderful setting for this event, and the weather couldn't have been better! Our time at the Jasper hacienda allowed us to share a meal, connect with one another, support each other, and network. Approximately 40 people participated in this conference; it was a nice mix of veterans and first-timers.



Billy and Chris

Healing. The healing that occurred in San Antonio was *extremely* powerful! We watched a brave young man express himself, identify a goal in life, and travel further along the path toward peace during the difficult transition to adulthood. We supported a determined, loving single mother in her quest for information to evaluate the best course of action for her young son. We witnessed the power of a safe, supportive community as an adult man realized that he was not alone and that life is still worth living. We listened as a man freely shared his lifelong struggle with hypospadias, the impact it has had on him, and the progress he has made with his recovery. And these are only some of the stories! We came together as a loving, supportive community; it didn't matter whether you were a parent, a professional, or someone who has hypospadias (HS) or epispadias (ES). It was very apparent that we are all in this together! Many thanks to all of the participants for creating a loving, safe, and supportive community, as well as for sharing something so deeply personal and painful. I am humbled by both your courage and your compassion.

Empowering. They say that knowledge is power—and we had some of the best professionals available to strengthen us. Whether we were learning about the current trends in and studies of these conditions, the power of resiliency, the medical causes and options, knowing our rights regarding medical treatment, strategies for finding peace, or finding the “Courage to Shine,” this conference had something for everyone. Our members may not realize this, but the caring, dedicated professionals who were there to support us did so at their own expense; these amazing people freely shared their expertise and time with us because they understand our struggles! One parent told me that he had been researching hypospadias for a year and that everything he needed to know was provided at this conference! Many thanks to HEA's professional friends for their expertise, time, and compassion. Your dedication and commitment to HEA make a difference in the lives of others. An organization can have no better friends than you!



Advocating. Applying what we have learned for the benefit of ourselves, our child, and others in need is critical. For those affected by HS or ES, I hope that you learned more about these conditions, felt accepted within the HS/ES family, and realized a greater sense of self-worth. We deserve understanding, acceptance, happiness, and peace, but we need to remember that we have no greater advocate than ourselves. For the parents, I hope that you gained the knowledge necessary to understand how HS or ES can affect your child and what you can do to best support him or her.

Communication is vital. And, remember, your child's condition is not your fault! For the professionals, I hope that you have gathered more insight into the effects that HS and ES can have on individuals and families. You are an important resource for others, and your willingness to further your understanding only makes you a more valuable advocate. From what I witnessed, we are a strong, resilient, talented, intelligent, compassionate, and capable group; I know that we can be strong advocates for ourselves, our children, and others in need.

We experienced the significant impact that HEA can have on people's lives. HEA is a nonprofit organization, operating on a shoestring budget and driven mainly by the volunteer Board members. During the second night of campfire groups, HEA made an appeal to the group. In order for our association to survive, grow, and thrive, we need the support of our members. HEA has a plan. Part of our plan is to establish working committees to assist the Board in strengthening HEA. These committees include the following: Membership/Outreach (primarily responsible for contact with and support of our members), Website/Publications (primarily responsible for website development and improvement, website content and layout, the newsletter, and future publications), Fundraising/Grant (primarily responsible for organizing and driving fundraisers and pursuing grants), and Networking/Media (primarily responsible for identifying ways to get the word out about HEA). If you have talents, resources, connections, and interest in one (or more) of these areas, please contact me. We need your help! Many hands make light work. Together, we can do anything.

Thank you! Thank you! Thank you! Thanks to the wonderful team of HEA Board volunteers who put in countless hours to plan and execute such a wonderful conference. Special thanks to Doug for his down-home Texas hospitality and generosity. Thanks to our professional friends who provide us with such great information and support so freely. And thanks to you, our members, for your participation, compassion, and support. This event would not have been such a success without your involvement.

"Healing...Empowering...Advocating." I believe that we achieved our objective! I am looking forward to an even greater conference next time!



Willie and Rod

"Special thanks to Doug for his down-home Texas hospitality and generosity"



Jim and Betty

Quotable Conference Quotes

*By Chris Arnold, HEA Board
Member and President*

As I thought back on the 2010 HEA conference in San Antonio, I was trying come up with a good and thoughtful story that would help those who were not able to attend to get a feeling for what it was all about. What really stuck in my mind throughout this conference were the number of memorable and moving quotes I heard people saying. I can't remember them all, but there were many real gems. Going back through my notes and memory, I've compiled a sample of some good ones.

We heard a great deal of discussion about secrecy and the harm and pain that can result from it. During her presentation, Barbara Neilson from Sick Kids in Toronto said:

"Privacy is okay; secrecy is not."

One of the first-time attendees said:

"We just never talked about it at home, ever."

After this, a number of other attendees said that statement was true in their families as well. One of the parents who was attending for the first time told the group that she had considered the idea of just having her son's hypospadias repaired and not telling him—but after being with all of us, she knew that would be the worst thing she could do, and because of this information she would make sure she was open about her son's hypospadias. This will truly make a difference in the life of this young guy.

Another of the first-time attendees said:

"I felt so alone. I felt so ashamed. Now I know I'm not alone."

Again, this is something that came up over and over, even from some of the older attendees who talked about how lucky the kids with hypospadias are now with the changing attitudes to secrecy and increased access to information for them and their parents.

During the introductions on the first day, one attendee said his name and then followed that with:

"I have hypospadias...that is the first time I've ever said that out loud in front of people."

It was so moving to hear the sound of relief in his voice. This secret and burden that he had been carrying with him his whole life had just been taken off his shoulders and met with a roomful of loving support and understanding.

With the openness that was experienced one attendee said he wanted to ask the whole group a question:

"With a show of hands, how many of you sit to pee?"

Amongst some chuckles, a large number of the guys (and of course all the women in the group) put up their hands. The chuckles were because we could all relate to the feeling of being less of a man because we had to sit to pee. Looking around the group, it was supportive to see that there were several real men in the same situation. It was comforting, and I was happy that these questions could be asked in a safe group like this.

I too used a few quotes in my presentation on Monday morning. Two in particular that seemed to strike a chord with a number of people were the following:

“It took me a long time to stop judging myself through other people’s eyes.”—Sally Field

“I can see peace instead of this.”

The comment on peace is in reference to the conflict, shame, and fear which those of us with hypospadias or epispadias often spend our lives feeling. We have the power to choose how we react. We have the power to choose how we perceive things that happen around us. We could choose to see peace instead of the alternative.

And finally, there were many great and funny quotes heard as well. Not all are appropriate for this story, but some of the more memorable ones include these:

“Deep in the heart of Testes!”—Travis

“One day, at HEA camp...”—MFAR

“Being at the HEA conference is like being at a family reunion where you actually like the people!”—Captain Dan

With eight first-time conference attendees and four new parents, along with board members and returning HEA members, this really was a small but powerful event. The lighter theme than in previous years was wonderful, as was the good ol’ Texas BBQ at Doug’s place. I know that once again we changed lives, and you can quote me on that!

Our First HEA Conference

*By Joseph
Teen Participant*

My name is Joseph Santigate, and I attended the HEA conference in San Antonio at the Menger Hotel. It’s the first time I attended anything like this, and I didn’t know what to expect. The conference consisted of time spent listening to doctors and a lot of time sharing. This was when the men were able to share their experiences and feelings with the rest of the people at the conference, and there was also time for the parents who attended to discuss their feelings and experiences. This is the first time I have spoken openly with people about my hypospadias.

From a teen’s perspective the first day was an uninteresting medical explanation day. But the night of the first day was filled with family fun, food, and giant centipedes. The second day was a blessing in disguise where I was able to feel that I am normal and that other men have already gone through the hardships I have to go through and they have come out of it strong and successful. The nights were spent at the Jasper ranch. This is where I felt like I became more and more a part of the HEA family. Being the only teen at the conference, I felt like there was a lot of focus on me, but it felt good to know that all these people care and want to help me with my problems.

*By Maria
Joseph's mother*

My husband and I had the pleasure of attending the HEA conference in San Antonio with our son, and we are both so happy that we did. From a parent's view, dealing with a child who has a chronic condition had its ups and downs, none of which are nearly as overwhelming as what our child deals with everyday of his life. However, not being able to "make it better" is a difficult reality for parents. This experience allowed us to see the strides real people have made and how they have learned to deal with what are sometimes life-altering experiences. We were so pleased to meet the professionals who had a wealth of information but most of all were kind and caring, unlike the way many professionals treat the issue. Our feelings were listened to, and we were able to impart some of our experiences to parents of young children, with their many questions. All around, it was a very cathartic experience where we were also able to learn and recharge. We are thrilled to be a part of HEA and its membership.

A Mother's Experience at the 2010 HEA Conference

By JP's Mom

Being a mother to a child born with hypospadias (HS), I wanted to make an educated decision regarding surgery for my son. I began to spend countless hours researching and trying to decipher complex medical publications about HS, yet I still found it difficult to make a decision. I realized there was another side to this condition that I also needed to understand: the human aspect of hypospadias. What does it really mean to have HS, how do men feel about surgery and their penises, how do other parents feel, what have they done or not done for their son's HS, and what is the best surgery option for my son? Before finding HEA and attending the conference in Texas, I didn't think I would ever find any clarity to these questions.

While at the conference, I was finally able to hear other parents' experiences, talk to other people who actually have HS, and have a chance to put HS on the table and discuss it for what it is, and is not, with caring and knowledgeable doctors. This has become invaluable information to me in my search for a complete understanding of HS. I felt a huge burden lifted, being able to share my experiences, cry, and ask questions about what the best surgery techniques are. Most important was the comfort I felt just spending time with all of the wonderful people who were brought together from all over North America to one place by the common thread of hypospadias. I was able to return home with a greater understanding of and a different perspective on HS than what I arrived with. I feel a renewed strength in my resolve to make the best possible decision for my son. Thank you, HEA, for your existence and for a great conference!



Billy, Joe, Maria
and Joseph



Holiday Gift Giving

Dear Friends of HEA:

This time of year, organizations appeal for funds with the hope of raising money to start new programs or enhance old ones. I would guess that at least three of the letters in your mailbox this week were probably from organizations whose objective is to advance causes that we are all keenly aware of and might even financially support. When the holiday spirit grips us, we try to give generously to others: maybe our old alma mater receives a modest donation, or perhaps the Leukemia Foundation following the death of a loved one.

For many of us, hypospadias or epispadias has been a lifelong medical and psychological issue. I would wager that you have never received a solicitation on the phone or a single commemorative stamp asking you to support this vital cause. That isolation, my friends, is the principal reason HEA exists: to bring awareness to others who struggle and have struggled alone.

This year HEA proudly continues to grow. If, when you count your blessings this year, you find that you have more than you need, please consider sending a tax-deductible donation to:

**Hypospadias & Epispadias Association Inc.
240 West 44th Street Suite 2
New York, NY 10036**

Your generous gift will enable us to reach out everywhere to members who have felt isolated and afraid. Our goal is to educate and support individuals and families who struggle with hypospadias or epispadias. Please help us help others...so that no one is alone.

Sincerely,

Billy Deegan
Executive Director
HEA

What's In a Name?

*By Tiger Devore, HEA Board Member
and Vice President*

I remember an older patient I had been working with for a couple of years telling me a story about his childhood, when his mother was always upset with how wet the bathroom floor was after he stood to pee. She felt he just didn't know what he was doing, and she charged his father with teaching the boy how to get it in the bowl. The father saw that he made a lot of spray and just told him to do the best he could or sit down. They never took him to a doctor or thought that what he had needed to be fixed.

I asked him if he had ever been told a name for the genital difference he was talking about or wanted to know what that was called. His answer was clear and simple: "No and no."

There are times when naming something gives that thing a life and meaning that it would never have had without that naming. Sometimes that is good, but sometimes it isn't.

Hypospadias, epispadias: medical-sounding diagnostic names.

Hermaphroditism, intersex, disorders of sexual development (DSDs): descriptive names, but each with a history and set of implications that can be really stigmatizing to the person who is so categorized.

Medical diagnoses typically imply a need for treatment. Descriptive names imply a category, a type, even an identity.

Like the patient I described above, most people, I think, just want to go about the business of their lives as a person without having to live under the weight of being "a hermaphrodite with hypospadias" or any combination of the above names. So despite all the current discussion about which of these names and categories are the most currently "correct," let me offer up a simple guide to this nomenclature minefield.

Your medical history is your most private information. Your diagnosis is probably important to the doctor who cares for you, but that probably is about as far as that goes. You are not your diagnosis. How your diagnosis affects how you think about yourself, and how you talk about yourself and your history to your closest intimates, is much more important than getting that diagnostic title correct. There is a lot to say about this, but not in this short article.

Are you a hermaphrodite? Are you an intersex person? Sure, if that fits for you. The diagnosis gives credence to that idea, but if that isn't how you know yourself, then it doesn't fit, no matter what any expert or medical records may say. (There's more here, too, for another time.)

Do you have a disorder of sexual development? If you believe that nature makes males and females, penises and vaginas, that either are perfectly formed or otherwise are "disordered," then yes, you have a DSD. Science, with its wish for neat categories and deterministic reduction, likes "this or that and nothing in between" kinds of naming. Society and culture like this kind of binary definition so that we can function as a group with cooperative rules about who does what; men do certain things, and

women do other things. If those categories blur, it's a lot of trouble for a lot of people.

Nature doesn't care about science or culture or society or even religion. Nature came before, and will exist long past, all of those constructs that we have made up.

So, how do you want to name yourself? For me, I am Tiger.

More Thoughts from Massimo Di Grazia

Massimo Di Grazia

Counselor in sexual matters, Italy

In the beginning of the journey, in order to establish a relationship with our bodies, we need to remove the barriers that we create ourselves. These barriers were certainly built for our need for protection, for our security, in order for us not to be recognized as different in such an intimate part of our bodies. We can see these barriers like masks that we put on every time we interact with others and that are based on whom we meet. Often, when we meet others, we talk to them with great ease and we offer security, friendliness, and warmth. But we wear these masks in many relationships, in particular the one with ourselves and our body. Often we forget we have them or pretend to forget to remove them. What is the reason we wear one for ourselves also? Why does this happen? Why can't we be free in the relationship with ourselves and our body? What binds us to live with the shadow of these masks? Why are we always in a pervasive falsehood? We can try to make some broad reflections about these questions. From these considerations may start many others by people with different experiences, and this can provide a new perspective. That is the beauty of human relationships.

Here are some reflections. It may be easier to have the mask on for ourselves so that we don't see and live the reality. Maybe it is more comfortable to live with the shadow of this mask and not ever have to relate to others or to human sexuality. Maybe we can stay in our own shell that we know very well, even if it causes suffering. This leads to not having a fight with the unknown. Maybe if we expose ourselves to others, we feel judged. Maybe contacting human sexuality is like contacting the unknown, a jump in the dark. In my opinion, we fear it because we ourselves create this darkness, this unknown, with our minds. It is as if we make a movie but we already know the plot before it happens; there is its start, the middle, and the ending. If we don't enter the plot, we don't have the opportunity to enjoy the view that life gives us.

For this we wear the mask so we can anesthetize our human needs: human sexuality and relationships with each other. Wearing our mask, we can avoid situations where we will be humiliated or judged, where we will need to defend ourselves, to invent. With this mental trick, we lose the best thing that life gives us, relationships with other people. Often people with urogenital anomalies wear this mask like an anesthetic, as a means without which one can't go out and one can't have relationships with other people. In my opinion, this doesn't lead to a healthy

person. It doesn't lead to freshness inside but rather leads to an closing off, and it doesn't allow genuine emotions or feelings but allows one to live in repression only.

In order to start a conscious process, it may be very useful to watch the movie that we make with our mind to see when and how to set off the mechanism that leads to us to wear the mask, how we wear it, and how it blends into us. Often it makes it difficult to see our face, and sometimes it becomes a second skin that is tattooed on and is indelible, masking the external from the internal world. I think we need to try to learn, to see through the eyes of the observer. This may seem like a drop in the ocean, but the sea is made of many drops.

Plan Your “Try”Athlon!

*By Jim Lake, HEA Board Member
and Treasurer*

To start, I was asked to write a paragraph about fundraising and the annual HEA Walk. I do not know how to write a paragraph and have given the editors free rein in doing their job!

Picture this: Year 1 for first annual HEA Walk! That was a year and a half ago on May 2, 2009. Two wonderful friends joined me in walking at Moraine Hills State Park near McHenry, Illinois. It was a mostly sunny, cool day, and we had a great time. Most importantly, about \$1,000 was raised for HEA!

One of the responsibilities of the HEA treasurer is to raise funds. I joined the HAA (Hypospadias Association of America) in 2002 at its second conference. The name was changed to HEA (Hypospadias and Epispadias Association) to be inclusive of those with epispadias as well, and I haven't missed a conference since! I became treasurer in 2004. (I love this job. Does anyone want to learn how to be treasurer? I'm trying to share the love. I was thinking about making a run for vice president because I want someone to yell, “Jetson!” I digress, back to my letter.)

Various fundraisers have been held around the country. However, since HEA is an organization whose membership is worldwide, it's hard to invite people to get on the same page, let alone on the same continent, for a special event. I thought about it, had a few original thoughts, decided to keep those to myself, and decided to try something proven. Yes, I copied from all of those other organizations which had walks for fundraisers.

I went through my address book and e-mail list of family, friends, coworkers, and acquaintances. I was a bit apprehensive at first, but as I went through the list, I kept it comfortable. Initially I had on the list only those who knew about my condition so that I felt comfortable discussing it, at least superficially. I wrote a not too generic form letter about my intentions and asked each person to donate \$1 per mile, or \$10. I did not send the e-mails to the whole list at the same time; rather, I sent them individually, as I did not want them to be read as spam. That way I could also customize the letter briefly to the individuals. I started sending out the first e-mails at the end of February, leaving about two months for follow-up and collection. I sent out “thank you” e-mails as I received donations through PayPal and the mail.

I was amazed at how a first effort could generate so much interest. About a month before the walk, I sent out a second e-mail to those who stated they would contribute but had not, as well as to those who had not responded. I received several more responses and prepared to walk. I sent out a third request one week before the walk (how's that for persistence?).

Before I go too far, I want to share what happens with some of these funds. Our office space in New York has been donated by the executive director, Billy Deegan, for years! The president, vice president, and other board members are not paid and also have offices set-up to conduct business. They are usually on one or more committees to assist in pushing HEA forward with the assistance of our membership. As treasurer, I set up and maintain the bank account, home office space, computer, and office supplies at no charge to HEA. Hey, good deal so far....

The major expenses are the ways we make HEA accessible to you: the website; the newsletter; the conferences; office supplies (including lots of postage for sending correspondence and information, not to mention "thank you" cards after your walk is complete to all who donated); legal bills for incorporation; phone bills; and one salary, for our executive director, who has been paid sporadically since the establishment of HEA and who has not been paid at all this year because of other pressing needs.

Volunteers do a great deal of work behind the scenes. No one works harder than our webmaster, Betty Engel, who ensures website content and maintenance and is a full-time cheerleader to the board. I have the pleasure of working with some of the most amazing people who want nothing more than to be a part of making HEA accessible for those who need it, whether for a short time or a lifetime. If you would like to donate some time and talent, please contact us.

This year I made a commitment to bring the conference to the Chicago area in 2011. It will be different than other conferences, as we will be working with the Lake County Health Department to conduct training for counseling and nursing staff on the first day. We want to provide scholarships to those who would like to attend but could not afford to do so. We would like to reduce the cost of the conference in order to make it affordable to individuals and families and to provide as much as possible during the conference, including child care and activities for the young. With those few statements made, you can see that HEA needs your help!

I have received numerous comments over the years asking, "What can I do?" First, mark your calendar for Saturday, May 7, 2011. That is the date (set in stone, unless someone changes it) for the next HEA "Try" Athlon! I am wording it that way because I haven't told you about what happened earlier this year. After the success of the first walk there was much interest among the board and membership who were solicited for the 2009 walk. There were walks, not only in the Chicago area, but in St. Augustine, Florida; Vancouver, British Columbia; New York City; and somewhere in England. The "Try" Athlon came about because some of the participants wanted to do other activities besides walk. Billy wanted to sit on a bench and watch Betty walk, while David Foulds in England did a mountain bike ride and collected money. We collected over \$5,000 for our combined efforts last May.

Others wanted to join with the Chicago walk this year, but few wanted to walk 10 miles. Once again, I solicited my \$1 per mile, but I did the 10-mile walk with a few

close friends the week before the HEA Walk. On the day of the publicized walk, I had the pleasure of meeting two area families and friends. We walked, had lunch (donated by an HEA supermom), and celebrated the day with special T-shirts and our own version of a 5K. Money was collected through relatives, friends, and businesses.

If you like to do any other kind of physical activity (such as running or swimming), then this event allows the freedom to do your fundraising your way. If you continue to prefer to watch others participate, we won't tell! Please think about ways you would like to get involved, whether it be fundraising or volunteering on a committee. Also look for information regarding how you can host your own "Night of 1,000 Meatballs," coming in February. Involvement conquers isolation...when you're ready, we can help with the first step.

We, as Humans, are Joiners

Billy Deegan
Executive Director, HEA

Some by choice; others by birth; and still, others by default. We are born into kinship groups or primary groups where we often share much commonality. Family, ethnicity, geography, religion, neighborhood, and social status, to name a few, are assigned at birth. Some can be changed, such as location, but others like place of birth remain the same forever. Secondary groups are most often chosen, such as YMCA, bowling league, and employment; while others are chosen for us, like private school. Default groups are the groups we don't necessarily or actively participate in joining, but automatically are members of these groups such as honor roll, airline passengers, or cancer survivor. As we grow, we learn that there are groups for "us" and for "them"; "in" crowds and "out" crowds, groups that generate pride, and groups that cause us shame.

Being born with a genital difference is a group no one chooses. It was assigned at birth. Now, it gets very interesting and the subgroups begin to evolve. Some disorders of sexual development are extremely rare and unheard of while others are very common. Some require immediate medical care and others do not. Some have formal educational support organizations in place, and others do not. Quality medical care varies from poor to miraculous; some families cope with openness and honesty while others inadvertently teach shame and secrecy. Some meet others like themselves while others go almost a lifetime never meeting another person with their condition. For some, this is a very minor issue in the course of their lives and for others, it is a challenging lifelong issue.

Nearly a decade ago, a support group for hypospadias was formed in Denver, Colorado. It evolved into what we know today as The Hypospadias and Epispadias

Association Inc. a 501c3 tax-exempt organization with a mission to provide education and support to individuals and families of people with hypospadias or epispadias. We maintain a state of the art website and produce an annual conference at a variety of international locations. We write and distribute a quarterly newsletter and provide a phone number whereby interested people can call the HEA office and learn where they might get the help they need.

Who is HEA trying to target when we say we do outreach to this community? We know that hypospadias occurs in 1 in 125 male births, and epispadias in 1 in 125,000 male births and 1 in 500,000 female births. It is estimated that there are over 151 million males in USA alone. Simple math says there are conservatively over one million men and boys in America who have a hypospadias. They in turn have parents, partners, health care providers and teachers who are directly touched by these issues. Since HEA hung its shingle, we have had tens of thousands of people visiting our website. We have produced conferences in seven major cities, and we produce a brochure, supported by the American Pediatric Urologists and are distributed nationally. And yet, our paid active membership yearly seldom breaks 100 members. Why is that?

I believe one of the principal reasons more people don't join HEA is we are still unknown to the very people who are directly impacted by hypospadias or epispadias. Not a day goes by where we are not contacted on our website or phone from someone saying they just found us on the web. So much more work has to be done promoting us and advertising our existence.

HEA is an all volunteer grassroots organization with a small budget and limited hands to do the work. We had many growing pains and too often frustrated members with website difficulties. Few, if any, reminders of membership expiring asking for renewal, and intermittent letters to members appreciating their contributions. Please understand we are trying to do so much work, with so few people, that unfortunately, too often, professionalism was replaced by best intentions falling through the cracks. We have improved. We will now have a master database of all our contacts, an automated system of membership acknowledgement, and renewal advisory. Very shortly, we will be sending out emails and letters to all of the contacts we have accumulated asking if the demographic information is still correct and whether or not you would like to be contacted in the future.

Why join when you get the contents of HEA's website for free? In the interest of compassion, we decided years ago to not make a members' only section a privilege to paid members only. We had hoped that after getting the help that was requested, people would feel a desire to support the organization. Sadly this was not the case and we had underestimated the fear and shame factor.

HEA is not a group anyone waited a lifetime to join. It is not the sought after, prestigious group everyone hope to one day be accepted into. We are the "them", the "outcrowd", the group that shame, secrecy, and isolation prevent potential

members from signing their name. Self help groups, by their very nature attract few. They are courageous people who are sick and tired of being sick and tired and wanting to no longer feel alone. They walk in frightened and embarrassed. What keeps some people in self help groups is both their new found sense of well being and their commitment to the future families. They often report to feeling for the first time “I am meeting people who think and feel as I have thought and felt. I no longer have to struggle with this alone. It is here I get education and support and learn so many tools for successful happy living”. Also, people stay because they feel an obligation to help newcomers walking in the door. They are committed to breaking the cycle of shame and isolation.

It is because of you we exist. It is because of those who remained that we have not had to close our doors. These few dedicated men and women have worked hard to keep our website fresh, plan our conferences, publish our newsletters, and be a voice and ear for so many who have never had a safe place to share. Our yearly budget has been generated by members, donors, fundraisers, and grants. As the economy has declined so has our yearly budget. The last two years have been tough but we have been so grateful to our membership for still joining, our fundraisers are fun and successful, and some grants have arrived. It is important for you to know however that 63% of our budget has year was largely out of the wallets of our board members who so generously give our their time but now their money so we can remain the voice of the Hypospadias Epispadias Community.

So here's the pitch:

- If you are a member of the default group hypospadias, epispadias or for that matter any genital difference, please join HEA.
- If you are a support person for someone with a hypospadias or epispadias, please join HEA.
- If you are a health care, education or advocate professional, please join HEA.
- If you think HEA is the organization that will make a difference in the lives of people with hypospadias or epispadias please join HEA.
- If you have previously been a member of HEA and have been dissatisfied with the service we promised, contact me at 212 382 3471 and I will give you a free membership for one year
- If at this holiday season and end of year charitable tax gifts are being considered, please consider helping us make a difference in the lives of so many people.

We have the cause. We have the leadership to get this vital work done. Now all we need is your support with a financial contribution, or by rolling up your sleeves and pitching in with the work -- or both. Your support will insure that no one with a genital difference will feel alone again. No parent with a child born with a genital difference will have to go through this alone. Thank you, thank you, thank you!

Night of a Thousand Meatballs



Date: February 26, 2011

Location: Your home or favorite restaurant

Dear Friends of HEA,

I had an idea for an amazing fund raiser and public awareness educational night. When I was a child, my family, even when we weren't eating, sat around the kitchen table talking. So for me, breaking bread is strongly connected to camaraderie and deeply meaningful conversation. It is the sole reason I got my master's degree in group work.

My idea is that on February 26, 2011, across the country and the world, in every time zone, HEA people are meeting in someone's home or restaurant, sharing a bowl of spaghetti and meatballs family style. Each host would invite family, friends and even health professionals to their home or favorite restaurant, to share a meal for a great cause. Spaghetti / meatballs / salad / bread / dessert and BYO/wine would cost the host a small advance to be recouped upon receipt of the donations.

We ask each participant to pay \$25 to attend or \$25 above the dinner price in a restaurant. During dessert you could begin a short discussion about hypospadias/epispadias. You might ask a question, "Did you know how common these conditions are?," or "When did you first hear the word hypospadias or epispadias?," or "What can we do so that no child ever grows up believing he/she alone is feeling such share, secrecy, and isolation?"

Host Planning

- How many people can your home accommodate?
- Who would you invite?

- Is it better for you to host the event in your home or a local restaurant?
- Are you, like me, excited about the concept that all over the world on this day families and friends are coming together to make a difference by breaking down barriers of secrecy and isolation, and having fun doing it? To get inspired, check out this [YouTube Video](#). Like this group of amazing musicians, we too will be participating in a global event.

Please let me know ASAP if this dinner might work for you and how many people you anticipate inviting. Thank you for your continued support in keeping this organization available for people all over the world.

My best,

[Billy Deegan](#)

Executive Director, HEA

Billy's Menu

Spaghetti
Sauce
Meatballs (10 meatballs per lb of ground meat)
Salad
Garlic Bread
Sour Cream Cherry Pie

Spaghetti

I buy # 7 medium thick pasta or medium shells.

Sauce

3 large cans of tomato sauce, 1 large can of whole peeled tomatoes. I peel down to nothing one large carrot. Add meatballs and bring to boil. Reduce flame to low, cover and simmer for 2 hours. Careful not to bring to second boil or you'll burn the bottom.

Meatballs

I combine 1 lb of ground beef, pork, and/or lamb, add finely chopped onions to taste, breadcrumbs, 1/2 tsp salt, pepper and oregano. Hand roll into 2 inch balls and in frying pan with thin coat of oil I brown these balls by gently rocking them in pan. Add to sauce gently.

Garlic Bread

Bake 4 large garlic cloves wrapped in aluminum foil in oil in oven at 450 degrees for 15 minutes. Mash in pan and add butter, spread across long French bread, heat in oven at 350 degrees for 10-12 min.

Sour Cream Cherry Pie

1 unbaked pie crust
2 c. pitted sour cherries
3/4 c. sugar
2 tbsp. flour
1 c. sour cream
1 egg, well beaten
1/2 tsp. vanilla
1/8 tsp. salt

Topping

1 tsp. cinnamon
3/4 c. flour
1/2 c. sugar
1/3 c. butter

Mix $\frac{3}{4}$ cup sugar, 2 tablespoons flour, 1 cup sour cream, 1 egg, $\frac{1}{2}$ tsp vanilla, and $\frac{1}{8}$ tsp salt together. Beat until smooth. Add cherries and put in pie crust. Bake 15 minutes in hot oven (425 to 450 degrees). Lower oven temperature down to 325 degrees and bake 30 minutes.

Topping: Combine 1 tsp cinnamon, $\frac{3}{4}$ cup flour, $\frac{1}{2}$ cup sugar, and $\frac{1}{3}$ cup butter; sprinkle on top of pie and bake 20 minutes longer at 325 degrees.

The Hypospadias & Epispadias Association

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