

**An Urgent Appeal to the Friends of ASHA:  
Your donation today helps ensure  
another 25 years of service.**



## *Celebrating 25 Years of Service: The Herpes Resource Center*

**D**ear Friends: In the fall of 1979—before AIDS, before safe antiviral drugs—genital herpes was big news. And bad news.

Health care providers across the country were seeing tens of thousands of new cases every month. The diagnosis was received by many as a sort of “life sentence”—the closing of a chapter, an end to feeling fully healthy. Treatment was literally nonexistent.

The advice columnist Ann Landers ran a special column about herpes that year. In it she referred readers to the American Social Health Association (ASHA) for information. Afterwards, ASHA’s small staff in Palo Alto, CA, journeyed to the post office daily to retrieve sacks of mail the size of a sailor’s duffel. Picture a room full of those. As bag after bag piled up, it became clear that ASHA needed to respond with more than free brochures.

Under the aegis of a Herpes Resource Center (HRC), ASHA rolled out a series of programs and services.

Over the next two decades, this Resource Center accomplished remarkable things. It generated hundreds of thousands of dollars for research fellowships at leading herpes research centers, published the best educational materials available, and advocated for more government action in finding a cure by forming a lobby group of patients and establishing a presence on Capitol Hill.

The HRC is now turning 25 years old. A look at the timeline on page 3 shows that we’ve come a long way in making herpes a manageable condition. And ASHA’s HRC is proud of our part in that:

- We’ve served as a voice for patients. We’ve made clear the damage that can be done if people are not treated with sensitivity and respect when they are diagnosed—when they are not given information and choices.
- We’ve helped set a higher standard for patient counseling.
- We’ve helped accelerate research.

- We’ve kept the issue on the radar screen at key government agencies such as the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH).

Perhaps most important of all, the HRC has given a helping hand or a comforting voice, a dose of sane facts, to over a million people. Over the phone. At local meetings. Over the Internet.

We’ve done it—you’ve done it—by paying it forward. People get free help. And to make sure that the same service is there for the next person, they give. They buy a book, take a newsletter subscription, make a donation.

So far it’s worked.

But at 25 years old we’re facing serious challenges. Upwards of 70,000 people still call for counseling or referrals, but we can answer only a third of them. Why? We can’t afford to increase staffing. Undoubtedly, there are many factors at play. Charitable giving in the U.S. is down. The Internet creates expectations of free information on demand. But we’re not comfortable with the status quo—or with the idea of turning people away.

If you can, please help us to sustain the Resource Center. You have already played a key role in paying it forward, and we honestly thank you. We wish we could say our work was done. But on the occasion of the HRC’s 25th anniversary, we have to come to you once more. Your tax-deductible donation can make a real difference. Please see page 3 for further details about the campaign. We hope you’ll join us in making sure there’s a helping hand ready for the next 70,000 people who call—and, if necessary, the next million after that.

– The HRC Staff

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## Life on the Herpes Hotline

**M**y daughter does not want to tell people where I work. This is because she is 17 and I work at the National Herpes Hotline. Herpes is considered an embarrassing word these days. To my daughter, even a professional connection with it is something to hide.

Of course, any embarrassment I had is long gone. I have been at the hotline for over four years now. My daughter's attitude just brings it home to me what the stigma is like, and what our callers go through in just that aspect of herpes. Shame and embarrassment are very real to a person recently diagnosed with herpes. We can help with this. De-mystifying herpes helps to destigmatize it, and treating the caller gently and with empathy help build feelings of self-worth. I was once told by a caller: "My sister was just diagnosed with genital herpes. Can you talk to her? I want you to tell her the same things you told me seven years ago when I was diagnosed. It helped me get through it."

We're only hotline counselors trained in one subject, but we take a lot of pride in what we do. There is great satisfaction in feeling that you know all you need to know to help someone. To our knowledge, there is no service like this one anywhere. We know our information is accurate and up to date. To put it in popular jargon, we're thought of by many as the "go-to guys" about herpes.

We make a difference in people's lives. It may seem a surprising role for an STD hotline, but on many occasions, we even help maintain the bonds between families. Sometimes parents call us because their grown children have just been diagnosed with genital herpes. They fear that younger children or others in the family may contract the virus through bathrooms, dishes, or through casual contact. Accurate information about transmission may make it possible—almost literally—for an adult or teenage child to come home again.

Sometimes the school nurses are at a loss as to what to do about a child with herpes; they call to ask if the child should be isolated or treated with some extra caution. We make sure they know children should be treated normally. We will probably never know how many children are in school today because we were able to reassure the school nurse that herpes is not transmitted through books, toys, or bathrooms.

We are not marriage counselors, but it is likely that we help save a marriage now and then. It is not terribly unusual for genital herpes to be diagnosed in a spouse after years of monogamy. The first thought that both partners may have is that there has been infidelity, but a herpes diagnosis does not necessarily mean that. Most people who have herpes are not aware of it, and it might be many years before there is a

noticeable symptom. A couple may not receive accurate information from their health care providers.

A year or two ago, I spoke with a couple in their seventies. They were deeply in love, and each knew that they had been faithful all their lives, but information they had received told them that there must have been a recent third party involved. Actually, while discussing it, it became apparent that the husband had likely been having unrecognized symptoms for a number of

years. This is a call we get fairly regularly, but I think I will remember this one because the emotion in their voices made it evident that this call had changed their lives. The husband was in tears from the moment I said that the diagnosis did not necessarily mean infidelity. Crying, he asked me, "Are you sure about this? This is really true?" and when I answered him with truth and confidence he broke down completely, saying "Oh, thank you, God. Thank you, God. And thank you." Dramatic, I know, but these were his exact words.

Not very often, thankfully, we get a caller who talks about ending his or her life because of herpes. What they "know" about herpes is that it's a shameful thing, as we discussed above. The power of the stigma can be so strong, it makes living with the virus seem unbearable. We are able to talk in a calm and reassuring tone, provide solid facts, and empathize with the feelings they are having now. They usually have a greatly exaggerated idea of what herpes is and what will happen to them. Facts help, and the knowledge that they can get all the information they need and rely on that information, makes a big difference.

I never expected to work in the field of herpes, and I would never have expected it to be so meaningful. Yes, it can be difficult at times. But taking everything into account, I wouldn't miss this for the world.



## Your Donations at Work

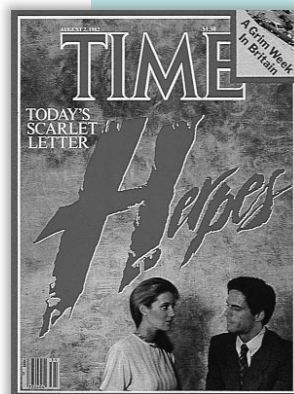
The American Social Health Association is committed to maintain the HRC's core services and also to fulfill its role as advocates for Americans concerned to see the government do its part to prevent herpes. This means more research, more education, and ultimately a vaccine or a cure.

A successful 25th anniversary campaign will generate \$500,000 from individuals and organizations. With these funds, we can:

- Expand National Herpes Hotline staff and increase service so that virtually every caller gets answered quickly
- Expand Web-based services such as Herpes Email Response and increase hours for the moderated Chat room
- Hold a national training conference for local group leaders and medical advisors, so that they get the latest in training
- Fund the next research fellowship in HSV through the ASHA Research Fund.
- Continue to provide free educational packets to those in need of accurate, reliable information
- Update herpes educational materials
- Translate our herpes materials into Spanish
- Be a voice for the thousands who can not speak for themselves, to push for research on treatments, vaccines, and new approaches to prevention.

Your tax-deductible contribution or subscription to *the helper*, our quarterly journal on HSV issues, will enable us to continue proactive patient advocacy work, and communicate the newest scientific findings to interested individuals via the ASHA Web site, the National Herpes Hotline, and *the helper*. If you would like to make a donation, or order a subscription, please use the enclosed reply card and envelope. You can also donate online via ASHA's secure Web site by visiting [www.ashastd.org](http://www.ashastd.org).

Continuation of our services depends on contributions from generous individuals like yourself. For this reason, we ask you once again for your loyal support.



**1979:** ASHA founds the Herpes Resource Center

**1979:** *the helper* publishes its first issue; support groups are launched

**1980:** ASHA launches the National Herpes Hotline

**1982:** "Scarlet H" appears on the cover of *TIME Magazine*

**1985:** Oral Zovirax® is approved by the FDA

**1987:** ASHA HELP (Herpes Support) Groups reach 100

**1994:** ASHA publishes *Managing Herpes: How to Live and Love with a Chronic STD*

**1995:** Valtrex® and Famvir® are approved by the FDA for treatment of genital herpes

**1998:** First prime-time direct-to-consumer antiviral ads are placed on TV

**1999:** The first accurate, type-specific HSV blood tests are approved by the FDA

**2000:** ASHA goes online with a herpes Web site

**2001:** ASHA introduces *Herpes Patients' Bill of Rights*

**2001:** ASHA hosts the first Global Herpes Diagnostic Summit

**2001:** ASHA launches the Herpesnet Email Response Service and Herpes Chat Room

**2002:** *Managing Herpes* 2002 is published

**2002:** ASHA hosts the Herpes Vaccine Summit

**2002:** ASHA launches two new HSV test counseling initiatives; the four-month Herpes Observational Prevalence Study (HOPS), and the two-year Herpevac Clinic Trial for Women test counseling service

**2003:** ASHA hosts Herpes Prevention Summit

**2004:** The Herpes Resource Center celebrates its 25th anniversary



# Reaching Out at the Community Level

"Help! I need somebody / Help! Not just anybody  
Help! You know I need someone / **HELP!**"

Most of us know these words as the beginning of the Beatles' tune "Help!" They also hold true for many people searching for answers after a herpes diagnosis. While it's difficult enough to find answers to all of the medical questions that arise, patients and their partners also have a range of emotional concerns that are equally valid and need to be addressed. Both aspects of dealing with HSV are challenging and they're often made more stressful by social stigma and a reluctance to discuss matters of sex and sexual health that is fueled by stigma. Health care providers are not exempt from being uncomfortable when discussing these matters, either.



In 1980, ASHA established a support services program to directly address both the medical and psychosocial elements of herpes. Through the Herpes Resource Center, ASHA currently affiliates 59 HELP (herpes) Support Groups across

North America and Australia. This network of local support (HELP) groups for people concerned about herpes simplex virus offers a safe meeting environment where reliable information is provided and fears, frustrations, and feelings can be shared confidentially. Each group is run by volunteers and must have an affiliated medical advisor (such as a physician or nurse) to answer questions and ensure that HSV information is consistent and accurate. HELP Group coordinators are required to successfully complete an HRC examination to demonstrate a baseline of knowledge about herpes, counseling, and available resources in their community. HELP Groups meetings are free of charge and open to all wishing to participate.

The HRC provides each group with an extensive annual allotment of free materials that includes books, brochures, and a library of back issues of our quarterly herpes newsletter, *the helper*. These days, most HELP groups naturally want a presence on the Internet, so the HRC provides guidance for Web site design and content.

Being diagnosed with an STD is never easy, but ASHA and the HRC are committed to providing programs and services to offer both comfort and information to individuals and partners coping with herpes. Knowledge is indeed power, and our HELP Group program continues to offer both.

## The Herpes Resource Center's Services

The Herpes Resource Center (HRC) focuses on increasing education, public awareness and support to anyone concerned about herpes. The HRC has helped more than 1 million people since 1979, and many more people contact us each year through the HRC's various services:

- **National Herpes Hotline (NHH) (919.361.8488)**

Trained Health Communication Specialists are available to address questions related to transmission, prevention and treatment of herpes simplex virus (HSV). The NHH also provides support for emotional issues surrounding herpes. The hotline is open from 9am to 6pm, ET, Monday through Friday.

- **Herpes Chat Room**

<http://wagner.ashastd.org/chat/world/html/logintest.html>

A resource for people to discuss issues surrounding HSV.

The Chat Room is monitored at all times by a Herpes Resource Center staff member, who is available to answer your questions and keep the conversations on track. Chat is free and *anonymous*, 5pm to 6pm, Monday, Tuesday, Thursday and Friday.

- **Herpesnet E-mail Response Service**  
[herpesnet@ashastd.org](mailto:herpesnet@ashastd.org)

An innovative e-mail response service, this resource provides the public an opportunity to receive information, support, and referrals through the privacy of e-mail.

