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Welcome to the first edition of the Living Sphere Newsletter.

The Living Sphere project began with the desire to create a comprehensive online resource for people living with the herpes virus. The initial idea was generated by an informal 'wish list' developed from the comments posted by members of several online herpes support groups. The idea slowly evolved and grew into the exciting, full-featured, interactive site it is today.

In our first Newsletter we'd like to highlight some of the features of the Living Sphere website, let you in on a few of the ideas currently on the drawing board and invite you to get involved on a more personal level.

We have also included Dr Stuart Aitken's informative article on genital herpes, featured the supportive friendship rings program and provided a listing of Australian Herpes Self-Help and Support groups.

We hope you enjoy the Newsletter and encourage you to get in touch with any ideas, comments or suggestions you may have. As with all aspects of the Living Sphere website and its associated projects, your feedback is encouraged and highly valued.

Jeannie and Damion



Know herpes

International Herpes Week
31st October - 6th November 2005

International Herpes Week is an initiative of the International Herpes Alliance. The aim is to promote herpes awareness and to lessen the social stigma by educating people about the virus.

Various organisations around the world participate by producing herpes awareness resources, presenting talks and holding workshops, etc. In Australia the national herpes gathering, Hevent 2005, will be held to coincide with IHW.

To learn more visit the International Herpes Alliance's website > www.herpesalliance.org



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info@livingsphere.com

Living Sphere is proud to present Australian's National Herpes Gathering:

Hevent 2005

The herpes self-help community will come together in Sydney during International Herpes Week for Australia's third national herpes gathering: Friday 4th to Sunday 6th November.

Hevent 2005 is a weekend social event providing opportunities for people living with the herpes virus to come together, share stories and experiences, to strengthen existing friendships and to form new friendships in a casual, relaxed, holiday atmosphere.

Coming to terms with sharing your life with the herpes virus can be an emotionally traumatic experience for some. Dealing with the physical aspects is often a minor issue in comparison to the emotional impact and fear of the stigma. Through meeting people with the same condition, sharing experiences, exploring fears and emotional issues, skills for coping with and managing the virus are developed. Herpes social functions can play a major part in assisting people regain their social confidence and consciously deciding to get on with their lives in a positive manner.

A fun-filled weekend of entertainment, adventure, wining and dining is scheduled, with plenty of time to just relax and chat also included.

Hevent2005 is a non-profit function planned and organised by a team of dedicated volunteers. All funds raised are used for promotional and administration expenses only (eg. advertising, printing, postage, etc.).



The 2005 registration fee schedule is as follows:

Regular Registration Fee: **\$30**
Early Bird Special - payment received by 30 August: **\$25**
Late Registration - payment received after 30 September: **\$40**

Note: All accommodation, meals, drinks and tours are additional to this fee.

Payments are accepted by cheque, money order, or secure online payment via PayPal or Paymate (instructions for online payments will be emailed upon receipt of your official registration).

To register you can print the registration form below, complete it and mail it with your cheque / money order to the address below. Or you can email your details to the team.

Hevent 2005
PO Box 674
Helensvale Q 4212
Australia

Please feel free to email the team with any queries you may have:

hevent2005@yahoo.com.au

Or visit the Hevent 2005 website:

http://au.geocities.com/australian_hevent/

Hevent 2005 Registration Form

Name: _____

Address: _____

Phone: _____

Email: _____

Attending: Friday Saturday Sunday

Payment Method: Cheque Money Order

PayPal Paymate

Additional Info: _____

Hevent 2005, PO Box 674, Helensvale Q 4212

Note: Please make cheques / money orders payable to: 'Living Sphere'

Genital Herpes - A Medical Perspective

by Dr Stuart Aitken

Genital herpes is a condition affecting the genital skin of many people.

The diagnosis of genital herpes can be stressful, but getting factual information can help people and their partners put herpes in perspective and get on with their lives.

If you or your partner has genital herpes, it is worthwhile arming yourself with the knowledge you need to make the choices that are right for you. Read widely, ask questions, and don't be afraid to be critical of the information you come across.

Talking about genital herpes with someone who understands can help. Your general practitioner or a sexual health clinic is often a good place to start.

What is genital herpes?

Genital herpes is a skin condition caused by the Herpes Simplex Viruses. Most of us are familiar with the appearance of 'cold sores': those sores that appear around the mouth or nose during times of stress, when people get run down, or have a cold or flu.

'Classic' genital herpes is a similar concept: recurrent blisters, splits or sores, that occur on genital skin, rather than around the lips.

What causes genital herpes?

Genital herpes is caused by the Herpes Simplex Viruses, conveniently abbreviated to HSV.

These viruses come from a larger family of viruses, the herpes viruses. The herpes family of viruses contains some other well-known viruses, such as the virus that causes chicken pox and shingles, and the virus that causes glandular fever. Throughout our lives, most humans will come into contact with some of these viruses from the herpes family.

There are two types of HSV: Herpes Simplex Virus Type One (HSV-1) is the virus that commonly causes cold sores around the mouth or nose. Herpes Simplex Virus Type Two (HSV-2) usually affects the genital area. However, either of these viruses can affect either site. That is, HSV-1 can cause genital herpes, and (less commonly) HSV-2 can cause cold-sores around the mouth.

What are the symptoms of genital herpes?

Classic outbreaks of genital herpes occur as a series of skin changes over seven to ten days. Tingling, numbness or itching is the first sign of an outbreak for some people, and the skin overlying the area often looks normal. A group of small, painful blisters then appears on the skin, and the surrounding skin will often become red. The blisters often join up and burst, leaving an ulcer or sore. These ulcers become crusted over with a scab. When the crust falls away from the skin, there is often a patch of redness which fades over a few days.

During recurrences, some people may experience pain around the site. Sometimes the skin might feel numb or prickly (like when you get 'pins and needles'). Occasionally, there may be more unusual symptoms, such as back pain, or flu-like symptoms.

When herpes presents with the 'classic' symptoms described above, the diagnosis is usually straightforward. However, we now know that only one out of every five people who have the genital herpes virus will experience these classic symptoms. Another twenty percent will have absolutely no symptoms at all! For the remaining sixty percent, recurrences will be 'atypical'. These atypical symptoms can vary widely. They can include itch, pain passing urine, painless ulcers, splits in the skin, patches of redness, numbness or tingling. These are symptoms that can be very easily confused with other skin conditions.

In other words, the majority of people who have herpes virus on their genitals will have either no symptoms or very minor symptoms. It is not surprising that most people who have the virus that causes genital herpes don't realise that they have it.

In general, the first episode of herpes is the most severe. During this time, a person may experience fevers, chills, muscle or joint aches, headache, or tiredness. These 'flu-like symptoms are common to many other infections. The blisters and ulcers of the first episode are sometimes severe, and passing urine can be quite painful, especially for women.

Recurrences of herpes tend to get milder, shorter and less frequent over time. While most people will get virus shedding from the skin at different times, not everyone will get obvious recurrent episodes of herpes. Flu-like symptoms and severe ulcers are not usually seen in recurrences of herpes.

How common is genital herpes?

About 80 percent of Australian adults acquire HSV-1. Some of those people will know that they have the virus because they come out with 'cold sores' around the lips or nose. For the rest of those who have the virus, there is little or no hint that the virus is there. It is safe to say that acquiring HSV-1 is pretty much a normal part of being a human being!

About twelve percent or about one in eight Australian adults have HSV-2. Most people who have herpes virus on their genitals are unaware that they have the virus. Most studies tend to agree that of all those who have evidence of exposure to genital herpes, only about one in five will know that they have the virus.

How is it transmitted?

Herpes simplex viruses are transmitted from one person to another during skin to skin contact. These viruses are very fragile, so they don't survive in the environment for significant periods of time. Consequently, herpes is unlikely to be transmitted through clothing, bedclothes, toilet seats, and so on. If you have been infected with one type of herpes simplex virus, your body's immune reaction prevents you from getting that same virus again. In other words, if you get cold sores around your lips from HSV-1, you are extremely unlikely to get HSV-1 on any other part of your body, including the genitals. You may, however, still be susceptible to acquiring the other herpes simplex virus, HSV-2.

While the virus is definitely present at the time of recurrences, it can be shed from the skin at other times too, even if the skin looks and feels completely normal. This shedding of virus is called 'asymptomatic shedding'.

As the majority of people who have HSV don't actually know that they carry the virus, and the virus can be spread from skin which looks and feels normal, it can be very difficult to know exactly where a person has acquired their infection. It is not surprising that most people who pass the virus on to a partner don't know that they have herpes themselves. This can be difficult to accept for partners in a relationship, and it is important to avoid blaming one another.

Knowing how to decrease the risk of transmission to partners is important for people with genital herpes.

There are several ways of decreasing transmission, but none of them is one hundred per cent effective:

- Avoiding all sexual contact during outbreaks

☛ Using condoms each time there is sexual contact, even if there are no symptoms

☛ Taking suppressive treatment with valaciclovir (the role of the other drugs in preventing transmission has not yet been fully evaluated).

How is herpes diagnosed?

Herpes is best diagnosed by identifying the virus in the laboratory with a swab test. This is a fairly simple test, and involves your doctor or sexual health nurse rubbing a suspicious area of skin with a swab (like a cotton bud). This method of diagnosis makes it possible to match up the virus with changes that are happening in the skin. A positive test tells you and your doctor

☛ Which virus is responsible for the lesions (HSV-1 or HSV-2)

☛ Which part of your body the virus is affecting

☛ Confirm what sort of symptoms your herpes is causing

Blood tests for herpes are available, but they need to be used with caution. Routine blood testing for herpes is not recommended, as interpretation of the tests can be complex, and in some circumstances these tests are not particularly accurate. Furthermore, positive blood test results do not give any information about which part of the body is affected, or whether or not the symptoms a person is experiencing are definitely due to the virus rather than another cause. In Australia, a positive blood test without swab confirmation is not sufficient evidence to access subsidised treatments through the Pharmaceutical Benefits Scheme.

However, the blood tests are of use in some special situations. Probably the most important situation is when a woman is pregnant, and her partner has genital herpes. Great care should be taken to avoid acquiring herpes in the later stages of pregnancy, as the chances of transmitting herpes to the baby are higher in this situation.

The implications of a positive test require some careful thought. If a positive test would make a person feel bad about themselves, but not change their sex lives or make them eligible for treatment, one wonders if there is a point to doing the test at all. It is always worthwhile taking the time to seriously think about the consequences before agreeing to a test. For some people, taking the plunge and getting the blood test is the right thing to do, but for others it might do more harm than good.

Are there any serious complications of herpes?

Fortunately, serious complications of genital herpes are rare. In fact, most people with genital herpes will either get no symptoms, or only very minor symptoms.

Perhaps the most serious consequence of genital herpes is transmission of herpes from pregnant mother to the newborn baby. As newborn infants only have weak immune systems, herpes infections can be severe or even life-threatening. Fortunately, this is a very rare occurrence in Australia, and seems to be restricted to women who acquire herpes in the last part (the third trimester) of pregnancy. For women with a longer history of herpes, there will be transfer of antibodies which provide immunity from the mother's blood stream to the baby through the placenta, and the baby will thus be protected. For women with herpes who are pregnant, or intend to fall pregnant, it is worthwhile talking to your health care provider about your management.

For pregnant women with genital herpes, or who have a partner with genital herpes, letting your health care provider know this so they can give you the best advice about managing your pregnancy.

For adults with herpes, serious consequences are rare. Sometimes severe initial herpes can affect the nerves which supply the bladder. When this happens, the bladder does not function properly and cannot empty. If the bladder becomes over-stretched there may be long term damage, so prompt medical attention should be sought.

There are a few other potentially serious problems that are almost always related to the first episode of herpes, but they are very uncommon.

How is genital herpes managed?

The most effective tool for managing herpes is knowledge. Most experts agree that the psychological consequences of genital herpes present a much greater problem than the physical consequences for most people. In strictly biomedical terms, genital herpes is usually a minor, recurrent skin condition that just happens to affect the genitals. Psychological reactions to a diagnosis of genital herpes can include feelings of guilt or shame, anger, fear and sadness. Many people go through a period of low self-esteem after the diagnosis. These feelings usually improve with time, and are helped by gaining information about herpes and being able to talk about the condition and what it means for you. People often find that their feelings about having herpes change with time as they

start to develop a different perspective on herpes. Sometimes the help of a counsellor can assist with the psychological part of the healing process, especially if there is a severe psychological reaction to the diagnosis, or if the negative feelings last for a long time and aren't improving. Your general practitioner or sexual health clinic can provide information about options for counselling.

There are three medications available in Australia for the treatment of genital herpes: aciclovir, valaciclovir and famciclovir. These medications all work in the same way: they stop HSV from reproducing itself. Medications are particularly useful in the first episode of herpes, when symptoms are most severe. For people with many recurrences, the medications can be taken regularly to prevent outbreaks (suppressive therapy). For those with infrequent or mild recurrences, the medications can be used during the outbreak (episodic therapy). Not all people with herpes require treatment with medication. Your doctor can provide you with advice about medication that is tailored to your individual circumstances.

During outbreaks, the affected areas can be quite sore. Some useful tips for managing symptoms are listed below:

☛ Simple pain-relieving medications, like paracetamol, can be quite effective, especially for people with their first episode who are getting lots of aches and pains or fevers.

☛ Some people experience pain when passing urine: this can be lessened by passing urine in the bath or shower. A water bottle squeezed over the area while urinating can be an effective alternative if it is impractical to have a shower or bath. Avoiding dehydration helps to keep urine dilute, and less likely to cause pain on broken skin.

☛ Gently cleansing the affected area with some warm, salty water (one teaspoonful in a litre of tap water) twice a day can help to keep the area clean.

☛ After showering, avoid vigorous towelling of the area. Many find that using a hair-dryer on the cool setting is a gentle alternative for drying the skin. Carefully blotting the area with a soft towel or tissue is another strategy.

☛ Local anaesthetic creams or gels can also be effective at decreasing pain from ulcers.

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Friendship Rings Show Support

One of Living Sphere's aims is to help provide support and encouragement for people living with the herpes virus.

Our first herpes support project is called the 'Living Sphere Circle of Friends' program.

This initiative is intended to help people with herpes feel less isolated and more optimistic about their future. It will be promoted in tandem with Hevent, International Herpes Week and on the Living Sphere website.



Living with the herpes virus can be an emotionally isolating experience. Gradually accepting it, coming to terms with it, and feeling positive about the future can be difficult for some people. The value of peer support should not be underestimated - just knowing that others are in the same position and feeling similar emotions can be very beneficial.

A program has been developed to help people overcome the feelings of isolation sometimes associated with having herpes - allowing those 'in the know' to recognise each other as they go about their daily lives.

Introducing *The Living Sphere Circle of Friends* - a supportive program for people with herpes which aims to raise self-esteem and provide opportunities to build new friendships and show your support for others.

Background

In early 2005 a suggestion was made that we needed a unifying symbol for people with herpes. By wearing or displaying this optional symbol, people could locate others who also have herpes.

The basic idea involves the wearing of a ring (of any description and to suit the taste of the wearer) on the little finger of the right hand (the traditional greeting hand). Although some people, with and without

herpes, may already wear a ring on their little finger, this should not create any unnecessary confusion as it is only a symbol of support and friendship, not a blatant statement.

The Predicament

Most people with herpes will agree that whilst the physical symptoms of herpes are indeed unwelcome, the psychological and emotional factors are a much bigger issue. Negative feelings can fluctuate from mild to severe, impacting on self-confidence and social skills which can affect all areas of a person's life.

People with herpes often find themselves in awkward situations when forming relationships and usually become good at avoiding social settings where they may end up in such situations. Side-stepping social functions becomes the norm for many people with herpes, with social isolation and depression a common result.

The Friendship Ring Idea

Medical science has so far been able to relieve and repress the physical symptoms of herpes. It is hoped that the psychological pain and emotional distress mentioned above, and indeed expressed in stories such as those posted on the Living Sphere website, can be partly relieved by simply being able to recognise others during normal

day to day activities. This can be done inconspicuously by wearing a ring that suits you, when it suits you, on the little finger of the right hand. It may take a year before you shake hands with someone who also supports this concept, but until then, you can stay positive and feel good about showing your support for others with herpes.

The founders of the Living Sphere website were approached to help promote and develop the concept of a supportive symbol for people living with herpes. Obviously such a simple, subtle, positive, life-affirming concept fitted in beautifully with Living Sphere's Mission, so there was never a question about our willingness to support the idea. The initial 'ring idea' has evolved into the *Living Sphere Circle of Friends program*.

Participating in the 'The Living Sphere Circle of Friends' by wearing a ring on your little finger is one simple way that you can show your support for people with herpes; seek out like minded people who also support the concept; and, feel good about doing something positive for yourself while you are showing your support for others.

It's also a great excuse to splurge on something nice for yourself... and a little retail therapy never hurt anyone!

Real Life Stories

The 'My Story' section is arguably one of the most important sections of the Living Sphere site.

Being able to read about other people's real life experiences dealing with having herpes, their fears, hope and dreams, can be of invaluable assistance when coming to terms with it yourself.

Writing your own story, getting it all down on paper, remembering and reliving the experience, can be particularly beneficial too. Many people comment that it was a cathartic experience which made them realise just how far they have come, and also gave them a sense of satisfaction knowing that their own story may one day help someone else through this often difficult emotional period.

If you haven't already considered it, you might like to give it a go yourself. Submissions can be made anonymously or using a 'pen name' and editorial assistance is available if required.

To submit your story, visit the 'My Story' section and click on the 'Submit My Story' link and follow the instructions. Alternatively, you can email your story direct to Living Sphere: info@livingsphere.com

Looking For Love Online

With the fast-paced, high-pressure lifestyle many of us lead today we no longer have the luxury of time to seek out new friends and develop relationships gradually. The internet offers the opportunity to check out and chat to an endless stream of people easily and almost instantaneously.



'Looking' for love online is easy - there are a multitude of sites which offer a range of services. However, 'finding' love online is not always that simple!

Finding the right site, one which can best meet your needs, assessing whether it provides good value for money, writing an effective profile that gets responses, following up once contact has been initiated... are all things which you need to consider in order to make your search effective and successful.

All too often people join a dating service, take the free option, tick a few boxes and expect offers of interest to come flooding in. Should it really be a surprise when this does not happen?

Your online profile is an opportunity for you to 'sell yourself' (in advertising terms) to other single people. In order to do this effectively you have to tell them enough about yourself to pique their interest and to make them want to find out more.

Your online profile isn't something which you should toss together on the spur of the moment. You need to take the time write a good profile which features your qualities and outlines your interests. Many people are not used to writing about themselves and find this quite difficult. Often people do not realise that what you write about yourself is far more important than all those boxes you ticked outlining your vital statistics. Whilst these details are necessary, people don't fall in love with your age, your height, or the colour of your hair and eyes... they fall for 'who you are'; and the best way to give them an indication of who you are is to write an interesting profile which gives them an insight into 'who' you are.

The eBook 'Looking for Love Online' is a basic guide to online dating. Topics include: finding the right service for you, tips on writing a great profile, using photos to your advantage, common sense safety issues, and commonly used online lingo. Worksheets are included for you to explore your qualities, create an appropriate screen/nickname and headline, and to draft your own unique profile.

Download your copy of this free eBook from the Living Sphere website.

Sphere Personals

The Living Sphere exclusive custom designed herpes personals service will be open for registrations soon. Features will include an exclusive message service and the ability to display up to six photos (viewable only by other members).

Visit the Living Sphere site to register your interest - you will be notified when it is open. A yearly fee will be introduced in the near future so don't miss out on your chance to trial if for free.

Support Groups

Support - to hold up, to encourage, cheer on, be there for, champion, assist, and strengthen. All this and a whole lot more is provided by the countless volunteer support groups throughout the world.

Whilst doctors can test, diagnose, provide information and prescribe medications, and even refer a patient for counselling if necessary, learning to accept and manage a condition like herpes often requires more support than can be provided solely by the medical profession.

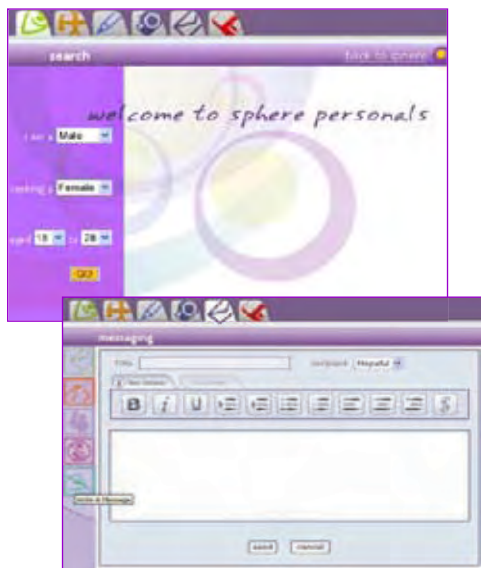
Having the opportunity to share your feelings and experiences with someone who has been through the same process can be immeasurably beneficial to someone newly diagnosed and struggling to come to terms with the virus, the associated stigma and the impact it can have on relationships.

The range of support provided varies from group to group, depending on needs, numbers and available resources. Some groups hold regular meetings, share educational

resources, and organise group social functions. Some groups are encompassed totally online utilising forums or message boards. Some produce newsletters, pamphlets, flyers and actively promote the groups in order to continually reach out to new people in need, yet others continue to sustain themselves by word of mouth alone.

Below are listed a selection of herpes groups based in Australia. In the next issue of Living Sphere News we will we will feature some international herpes support groups.

Living Sphere is currently developing a number of resources for support group owner / managers, the first one being an eBook outlining how to set up a support group. Topics will include: basic 'how to' info; forum options; marketing tips; financial concerns; group owner responsibilities; goals and strategies. If you would like to contribute your own experiences to this forthcoming eBook, either with setting up and running a support group or participating in one, please feel free to get in touch.



Australian Herpes Social, Support and Self-Help Groups

Gold Coast H Friends

> <http://au.geocities.com/gchfriends>

Herpes Hangout

> <http://au.groups.yahoo.com/group/herpeshangout/>

Herpes in Brisbane

> <http://groups.msn.com/HerpesinBrisbane>

HSingles

> <http://au.groups.yahoo.com/group/hsingles/>

Melbourne Herpes Self Help Group

> <http://home.vicnet.net.au/~mhshg/>

Perth Herpes Support Group

> <http://geocities.com/perthgroup/>

South Australian Herpes Support Group

> <http://groups.yahoo.com/group/saherpes/>

Tasmanian Herpes Social Support Group

> <http://groups.msn.com/THSSG>

The Sydney Group

> <http://www.geocities.com/sydneygroup/>

News

There's a brand new herpes social group in **Perth** - in fact it's so new they haven't even got a name yet! If you'd like to hear more about it, contact Rochelle:

Phone - 0438 751 249

Email - painhelp@iprimus.com.au

As we mentioned earlier, we do have a few other projects on the Living Sphere drawing board.

We now have a **Downloads page** where you can access and save a variety of resources. This section will continue to expand with several PDF eBooks currently being developed, including an instruction manual on how to set up and run a support group.

Sphere Watch is a project loosely based on the concept developed for the well-known Stigma Busters and Stigma Watch programs. The various forms of media will be 'watched' for mention of herpes and 'safer sex'. Positive, informative representations will be recognised and congratulated; authors and publications who present negative, biased or inaccurate information which reinforces the stigma will be contacted and politely informed of their errors. Suggestions for improvements, and / or a request for an apology or retraction may also be made.

Living Sphere will be seeking volunteers to review herpes websites and resources. You don't have to be an expert on herpes or the net to become a **Sphere Reviewer**. All that's required is that you check out herpes related websites and resources and write your honest opinion of

the professionalism, accuracy and relevance of the material. Guidelines will be provided and you can even choose to use a 'pen name' or pseudonym for your reviews if you wish.

A **Sphere Blog** (online journal) is also on the drawing board. This will be an opportunity for someone to explore and share their personal journey towards acceptance - their 'coming to terms' with herpes - candidly exploring their feelings about the various issues associated with having herpes.

Feedback

The concept of the Living Sphere website was to specifically design a site to meet the needs of the herpes community. Ongoing feedback is essential if we are to continue to meet those needs effectively.

The feedback received so far has been very positive and extremely encouraging, but that's not to say we only want to hear good things about our site! Genuine constructive criticism is welcome too, so please get in touch and tell us what you think.

You can either contact us directly via mail or email, or you can post your comments and suggestions directly on the Sphere Forum - we've even included a few quick polls on various aspects of the site to make it easier for you.

If you have found this newsletter interesting, feel free to recommend it to others, and don't forget to subscribe to Sphere Alerts to keep up with the latest news in the herpes community.

Living Sphere Mission Statement

Living Sphere is devoted to promoting and supporting herpes self-help, social and support groups; providing practical advice and lifestyle tips for people living with the Herpes virus; increasing public awareness of the virus through marketing campaigns and publications; providing opportunities to share experiences and connect with people who are in a similar situation; offering one-on-one peer support through the Aussie H-Mate program; and, most important of all, reassuring people that they are not alone.

Submissions

To submit an article, story, comment, website, event or meeting calendar listing for publication in the next issue of Living Sphere News, email or write to the editor at the address below.

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