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Welcome to the second edition of Living Sphere NEWS, we hope you find it useful and enjoyable, and please remember your feedback on any topic is always welcome.

Special Announcement

The 'official launch' date for the Living Sphere website is November 4, 2005.

We'd like to invite you all to come along and celebrate this auspicious occasion with us at Hevent 2005 in Sydney - please drop by for a glass of champagne if you can!

For those of you who have been with us from near the beginning and have been privileged to watch the Living Sphere concept and site slowly evolve as we have developed it, this is a long-awaited moment! For us it is a very exciting time - to finally see our dream realised and to be able to begin actively spreading the word and inviting everyone to come and check out the completed site!

The journey from initial idea to completed project has been challenging, stimulating and very

rewarding. We have shared and learnt a lot along the way, and that's what it's really all about.

We are currently in the process of making some major changes to the Living Sphere website in response to feedback received regarding issues of confidentiality. Some areas of the site will only be accessible to members who are logged in and the same goes for the forum; we hope this will make people feel more comfortable about using the forum and our site in general.

The **Sphere Personals Service** will also be open for registrations from November 4. You will be able to join Sphere Personals and post your profile without charge during our initial free trial period. In the near future a fee will be introduced to help cover our costs, (details in a future newsletter), so get in early to take advantage of this opportunity.

Looking forward to seeing you at Hevent or on the forums!

Best wishes to you all from

Jeannie and Damion

National Herpes Day

October 13 is National Herpes Day. Raising awareness of genital herpes is fundamental to the AHMF's awareness campaign, they will again be providing an opportunity to ask questions of their Online Doctor.

This year's Online Doctor is Andrew Gowers, a GP based in inner Sydney. Andrew has a special interest in genital herpes and other sexually transmitted infections, and is a member of the AHMF General Practice Working Party.

To contact Dr Gowers with your question for International Herpes Week this year, visit the AHMF website.



Australian Herpes
Management Forum
www.ahmf.com.au



Dr Andrew Gowers



Know herpes

International Herpes Week
31 st October - 6th November 2005

The International Herpes Alliance have made available a variety of resources on their website for International Herpes Week.

Visit their site to download their Media Release, 'Fact and Fiction' info sheet (highly recommended) and to read about previous years activities.

> www.herpesalliance.org



Support Groups

With the 'international' nature of the internet there is no need to limit yourself to joining just the local online support groups. You can explore a wide variety of groups around the world.

International groups often have a larger membership base and some have been in existence for many years. The support, advice, encouragement and assistance provided by others who share the same virus is an inspiration to us all.

Check out the small selection listed below, and please feel free to recommend other groups for future editions of our Newsletter.

Picking Up The Pieces

- support and encouragement

> <http://health.groups.yahoo.com/group/PickingUpThePieces/>

HclubUK

- herpes support and discussion

> <http://uk.groups.yahoo.com/group/HclubUK/>

Positive People With HSV

- sharing positive experiences (HSV & HPV)

> <http://health.groups.yahoo.com/group/PositivePeopleWithHSV/>

Common Denominator

- HSV & HPV group

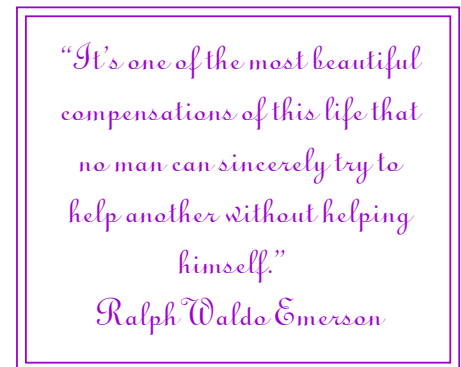
> <http://health.groups.yahoo.com/group/common-denominator/>

Shut Up and Post!

STD Message Board

- herpes and STD info and support

> <http://yoshi2me.com/ipw-web/bulletin/bb/index.php>



Hevent 2005 ~ Celebrating life after herpes

The Australian 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.

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

Hevent 2005 is a non-profit function planned and organised by a team of dedicated volunteers. Registration fees are \$30 AU per person and payable in advance by cheque, postal order or secure online payment with PayPal or Paymate.

To register, please send your contact information by mail or email ASAP to:

Hevent 2005
PO Box 674
Helensvale Q 4212

> hevent2005@yahoo.com.au

For more info, see the website:

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

Interview

Terri Warren is a nurse practitioner and the owner of the Westover Heights Clinic in Portland, Oregon. She has 23 years experience running a private STD clinic, has been an investigator on over 80 clinical trials, primarily involving genital herpes infections and has a Masters Degree in both nursing and counselling.

Terri is the author of the well-known 'Herpes Handbook', an invaluable guide for patients and medical professionals alike.

The following 'online interview' took place in 2005 and is republished from the Living Sphere website.

LS: *What do you think is the most challenging aspect for a person with herpes?*

Terri: Infectiousness to others and asymptomatic shedding. People don't know exactly when they are infectious to others, which makes sexuality difficult.

LS: *Do you have any thoughts on reducing the negative social stigma associated with herpes?*

Terri: If more people knew that they were infected (one in four adults has HSV 2, but 90% don't know it), there would be far less stigma. Right now, people with herpes think that they are highly unusual, that they are abnormal, that their problem is uncommon, so they feel isolated and different. But if all the people who were infected knew it, there would be far less stigma. People from all walks of life would be identified as positive and it would lose the 'unusual' aspect that it currently has.

LS: *Do you believe that current sex education resources and practices are adequate?*

Terri: No, I don't. I think that the abstinence only agenda, under

which we are currently working (in the US), doesn't help teens know about STDs in the way that they should. There is little talk about oral sex, for example, but 70% of new genital herpes in college students is HSV 1, most often transmitted through oral sex. We need to be more honest with our teens who are starting to have sex, to protect them.

LS: *Are there any other measures which you believe could be implemented to help reduce the transmission of herpes?*

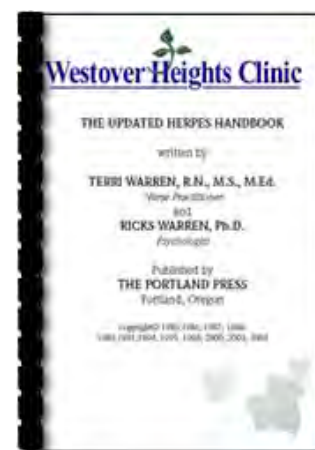
Terri: Greater use of testing and appropriate use of suppressive (daily) therapy. We can reduce transmission by half in relationships where one is infected with herpes and the other is not, if only we would put the infected person on daily medication. Of course, more testing is also important to identify those who are infected but don't know it.

LS: *Do you believe that an effective vaccine or cure will be developed in the near future?*

Terri: I don't believe there will be a cure for herpes in the near future, nor do I believe that there will be a completely effective vaccine for many years to come. The one vaccine we have now that is somewhat effective, only works in women and certainly doesn't provide the kind of protection against infection that say, the HPV vaccines, will.

LS: *When, how and why did you come to write 'The Herpes Handbook'?*

Terri: I wrote the Herpes Handbook more than 20 years ago as a patient education tool. The Updated Herpes Handbook is far more recent, and gets updated at least every six months. I felt that patients needed something concrete to take home in their hands when diagnosed or tested,



that gave accurate information about herpes. Big books can be too long and drug pamphlets can be too biased. I think the handbook is just right!

LS: *What has been the general response from the public to this book?*

Terri: Its been good. People like it because it is small enough to read at one sitting, but answers a lot of questions. Patients like to have it at home so they can refer back to it, and also have it there for partners to read, if necessary.

LS: *What has been the general response from the medical profession to this book?*

Terri: I think clinicians like the book because they can give it to patients when they are tested (either swabs from symptoms or blood testing), and then, when they have to give a positive result, patients are more educated about their condition and less blown away. If they wait until the patient is diagnosed to give them the book, the patient is still pretty upset and less educated about herpes.

LS: *Do you have any plans for developing any other herpes related publications or resources?*

Terri: Not at the moment. I think the 'big book' category is well filled with the Ebel/Wald book, the Steve Sacks book, and Larry Stanberry's book. I have recently

made a DVD for GlaxoSmithKline on patient counselling that is to be handed out to patients diagnosed with herpes, for them to watch at home and keep. I think this will fill a gap in the counselling that currently happens around herpes. Clinicians have difficulty finding the time and the right words to do herpes counselling on their own. This will help fill that gap.

LS: *What can you tell us about your involvement with the WebMD site?*

Terri: I think I've been answering questions on WebMD for about four years now. It is a great opportunity for patients to ask questions if their clinician is unhelpful or doesn't know the right answers or they just feel uncomfortable asking about herpes. I do wonder how many people go to this website and just read but never post anything. That's fine of course, I'm just curious about it. Given that WebMD is the largest medical website online, I have a feeling that we touch a lot of people. I am amazed by how many people post who simply will not believe that they don't have herpes, even when they repeatedly test negative for antibody. They are so fixated. I'm not quite sure what's up with that, but it is fascinating. One would suppose the opposite.

LS: *The Herpes Handbook incorporates a section by psychologist Ricks Warren PhD talking about the life adjustments having herpes involves. How important do you believe the psychological aspects of having herpes is when it comes to dealing with this life-long virus?*

Terri: I think they are huge! Most people who have herpes will tell you that the physical aspects of the infection are not severe, but that the emotional stuff is very hard. People decide that they are somehow less desirable as people and partners because they have herpes, and that can be

reinforced by someone rejecting them as a partner because they have herpes. But how stupid is that??

So lets say that you decide to reject someone as a partner because they have lesions on their genitals 5 times a year and can be infectious in between those outbreaks. What kind of criteria is that to base a life on? Aren't there so many things that can ruin relationships besides this, things that are much more important? When people can get past the reputation of herpes, and get to the nitty gritty of what the disease is really like, I think they do OK, but too often they get stuck on how the rest of the world feels about herpes, instead of looking at it honestly and thoughtfully and deciding that this infection should not define them in any way and be moving on. Herpes is but one small aspect of who people are, with all of the qualities that they bring to the world.

LS: *Are there any other comments you would like to make, or a message you wish to pass on to people living with the herpes virus?*

Terri: This does not define you! Let the other aspects of who you are shine through, live lives that are generous and loving and kind and honest, treat people as you would like to be treated, and herpes will take it's rightful place as a minor annoyance and a manageable health concern.

Visit Terri Warren's Website to read the her book online, or to download a PDF version of the Herpes Handbook.


Westover Heights Clinic

> <http://www.westoverheights.com>

Sphere Personals

Because Living Sphere is a very personal project, our dating service will also benefit from that 'personal' touch.

We don't want people to sign up, tick a few boxes and hope for the best; and nor do we wish to use an automated service which 'matches' people by age, sex and location!

We want to encourage people to explore the possibilities of online dating. . . to put some genuine effort into creating an interesting and effective profile.

We have made the free eBook 'Looking For Love Online' available on our LS downloads page and encourage members to make use of the advice and tips it provides.



We are also more than happy to assist individuals with writing their profiles and will be providing an opportunity for members to have their profile featured in future editions of the newsletter.*

If you wish to be considered as a 'Featured Single' please get in touch for more info and conditions (contact info on page 5).

Don't forget, Sphere Personals will be open for registrations in November!

Note to Hevent attendees - make sure to check your Hevent 2005 souvenir/info bag for a special offer from Sphere Personals!

(*Note: no names, contact details or identifying information will be published; in order for anyone to get in touch with one of our 'Featured Singles' they will need to become a member of Sphere Personals.)

Group News

The Sydney Group

The Sydney Group have set up an email notification service. To stay informed of any social activities in the Sydney area, email: sydneydt@yahoo.com



New Perth Social Group

The new Perth Herpes Social group have chosen a name for themselves - **the Perth Friendship Club**. All enquiries may be made to Rochelle on 0438 751 249, or email: painhelp@iprimus.com.au



LS Newsflash

We are very excited to present our first marketing tool - **Living Sphere Business Cards**.



We have deliberately chosen to use business cards because of their size and convenience. They are small enough to be carried anywhere, and they can be easily and discreetly passed on to others.

We are quite happy to make them available to anyone who wishes to make use of them at support group meetings and group social functions. The cards will also be made available for distribution through sexual health clinics, medical and health centres; and we have a special offer available for group owners who would like to develop something similar to promote their own groups.

Feedback

"Congratulations on such a wonderful site and providing a much-needed service for people like us."

Jenny

"What a great newsletter."

Andrew

"A great effort from your team, congrats to all for a long-missing service."

Falcon

"I think the dating site is a great idea, I compliment everyone who is involved with it."

Rob



"Wearing 'the ring' makes me feel like I am a part of something bigger. It's a very positive experience for me, and, let's face it, there are precious few positives in having herpes."

Rebecca

"It makes me feel good about myself, which is a big change because I have been feeling bad about myself ever since I got herpes."

Graham

"I am wearing a pinkie ring too! I hope to meet someone one day who is also wearing one and knows what it's all about, and that he's my type too!"

A girl's gotta have a dream!"

Juls

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

Living Sphere NEWS is a bi-monthly production, published every even-numbered month. To submit an article, news item, calendar date, review, comment or letter to the editor for publication in the next or subsequent edition/s of Living Sphere News, please send via email or mail to the address below.

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Contact

Living Sphere
PO Box 674
Helensvale Q 4212
Australia

E: info@livingsphere.com
W: www.livingsphere.com