

## Support Group for Bladder Cancer

Last Updated Sunday, 30 November 2008

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May,2007: Research published on the usefulness of ACOR's cancer mailing lists, "How Cancer Survivors Provide Support on Cancer-Related Internet Mailing Lists": <http://www.jmir.org/2007/2/e12>

Survivor stories

{/niftybox}email discussion list

I am very grateful to all who so graciously responded to help a stranger understand this mysterious journey he will shortly undertake. As they say, "the devil is in the details," and that has certainly been true for me. The more I know about what to expect and the choices I face, the better I can deal with this situation. This list is an absolutely marvelous medium for people to help people, and I can think of no higher favor each of us can do for our fellow sufferers than to offer them the information so painfully gathered through our experiences with fighting and enduring bladder cancer.

Paul R.

Join the list

Leave the list

Bladder Cancer Cafe, WebCafe's affiliated support/discussion email list hosted by the Association of Cancer Online Resources, is a place to meet kindred spirits, at least if you agree with the premise that knowledge is power.

ACOR

ACOR offers free access to over a hundred mailing lists that provide support, information, and community to everyone affected by cancer and related disorders. ACOR's complete directions for subscriptions and using the archives can be followed for any ACOR list. Guidelines may differ from list to list.

Our discussion group is for patients with bladder cancer, their family and friends. Health professionals with an interest in this area are encouraged to join. As of June, 2005 we have 500members.

You can familiarize yourself with many list members via this site's survivors stories at "Tales from the Trenches."

The knowledge that you are not alone can help relieve some of the fear and anxiety the diagnosis can bring. E-mail lists are a wonderful way to make contact with others on a similar journey, to exchange information, provide support and much more.

The goal of any ACOR list is the sharing of information, support and first hand experiences regarding cancer's treatments, drugs, side effects and the impact it has on our lives. Feel free to ask any questions.

The information shared on Bladder Cancer Cafe is not intended to replace medical advice. If you have symptoms or need medical advice, see your medical professional.

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Basics - There are several types of lists on ACOR:

**Moderated** - On a moderated list all posts are sent to the moderator (usually the list owner) to be approved before forwarding to the whole list. The moderator/listowner will determine which posts are suitable.

**Unmoderated** - With an unmoderated list the exchanges are not censored in any way before reaching the group. This doesn't necessarily mean that no one is monitoring the list. Experienced, knowledgeable volunteers monitor ACOR lists.

**Open** - An open list is one where any interested person can join. Open groups welcome caregivers, patients and interested professionals.

**Closed** - Anyone wishing to join a closed group must apply for membership by the list owner. This is a useful approach for private and sensitive topics. There are many cancer groups that segregate patients and medical professionals or patients from caregivers so that each may vent without worry of upsetting the other.

**List Owner** - The list owner is responsible for keeping the list running smoothly, both technically and on a human level. The list owners monitor the daily posts, provides guidelines and have the right to add or remove members. Other ways of referring to the list owner are list monitor, list admin or list manager. After subscribing you'll receive a welcome message including the e-mail address for posting to the group. Bookmark this address.

Bladder Cancer Cafe is an open, unmoderated list.

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The goal of any ACOR list is the sharing of information, support and first hand experiences regarding cancer's

treatments, drugs, side effects and the impact it has on our lives. Feel free to ask any questions.

When writing for the first time, please tell us about yourself; it may be helpful to mention age, any details you wish to share about past or current treatments, and place of residence/treatment.

Some feel more comfortable reading the posts for a while before joining in, and you may want to browse the archives to acquaint yourself with the group. This is best done by starting with the most recent messages and working backwards. The Internet is international. Out of respect for the wide range of beliefs and opinions in the world, religion and politics are not appropriate topics for a cancer list.

There is a Christian cancer forum also hosted by ACOR,

Cancer Patients Christian Online Support Group at:

<http://listserv.acor.org/archives/cpcos.html>

and Jewish Parents Network:

<http://listserv.acor.org/archives/jp-net.html>

a more general list,

FAITH,

<http://listserv.acor.org/archives/faith.html>

Please do not send message that consists solely of a URL; it is helpful to provide a summary. To ensure privacy and safety, please do not post private addresses or phone numbers to the list. Do not post the phone numbers or e-mail addresses of physicians. Posting the phone numbers and addresses of institutions is fine.

If you are sending a congratulatory or sympathetic message to one person, do not automatically post your reply to the whole list. Chit-chat is best done off the list. Please keep the topic in mind when posting the whole list.

No insulting or annoying messages.

Forwarding copyrighted material to the list is illegal; we ask that you send the link with an excerpt or summary rather than the whole article, which is a breach of copyright laws.

If you are a researcher who wishes to recruit members willing to provide information, please get permission from the list owners. List mining, for addresses and/or spamming members privately is strictly forbidden and will result in being served off of all ACOR lists.

Advertising, or commercial postings are not allowed and could lead to the removal of your subscription. This is defined as: "To proclaim the qualities or advantages of a product or business so as to increase sales." Sending web sites that proclaim undocumented and unscientific evidence of cures for the same purpose, advertising, are included in this ban.

Editing messages

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When replying to a message it's important to edit the previous message to include only the most relevant parts. This saves bandwidth and downloading time. Also, copies of previous messages in one post make reading the mail cumbersome, especially for the digest subscribers. To edit a message, include only the parts of the previous message that you are answering. Deleting the superfluous parts can do this. Another option is to highlight the most relevant parts

of the message, then cut and paste those into a new e-mail. Address it to the list and put a suitable subject on the message.

Please note the subject line and adjust it as the topic being discussed evolves or changes.

Please write your answer on the top part of the body of the e-mail, above the post you're replying to.

For the sake of people using the digest mode, which is a daily compilation of posts in one long message, we also suggest that you use the plain text option of your e-mail program and not MIME (the default for many email programs) when posting the list.

Accessing the archives for the first time

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You can access the pages of Bladder Cancer Cafe's archive pages online from here  
<http://listserv.acor.org/archives/bladder-cancer-cafe.html>

When you reach this 'archives and subscription options' page, bookmark it. Here you will find links to various options plus a monthly log of all messages under 'browse the archives'.

Before being able to read the archives for the first time-

You must be a member

You will need to get a password and

You also have to register, but just once.

Click on a month to browse the archives, which will bring you to a Login Required page. Click on the words, get a new LISTSERV password first, which is a link that turns red when the mouse runs over it (the e-mail address you give must be the exact address with which you subscribed) and select a password that's easy to remember.

If you request the server to save your login settings in a "cookie", you won't have to type your e-mail address and password to look at the archive on future visits. This option should present itself without any effort on your part.

In summary:

Sign in with your e-mail address

Give yourself a password you can remember

Check the box that says remember my password

Accept the cookie the site wants to put on your computer

Go to your e-mail inbox and find the confirmation email which is sent automatically after you sign in for the first time

Click on the URL contained in the e-mail (or paste it into your browser window) and your password will be confirmed You are now able to use your list's archives and subscription options.

Contact your list owner about how to avoid signing on and off the list, or try using the 'mail disabled temporarily-no mail' mode described below. If you sign off the list and re-join, you'll need to get a new password before again having access.

## Tips on Using the Archives

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The Browse Mode option featured on the main page allows you to view all messages from the list for a given month. Once you get the list of subject titles you can have it arranged in different ways by using the buttons at the top of the page, i.e.: chronologically, by author, by thread, etc. When you open a message more buttons will appear at the top of the page that help to make browsing easier. There's a button for replying via a web interface page. In this way it is possible to post to the list without using e-mail. This interactive page is accessible from the main archive page as well ("Post to the List").

The Search Option page is accessible by each list's main archives page ("Search the Archives"), or you can use the search button found at the top of each opened message while browsing. When searching for specific information the search option may be quicker. There is a link to a help page at the bottom of the search form - spend a minute to check it out before searching. When giving a date in the "since" and "until" fields on the form, there are certain requirements about how to give the date. Dates should be written like this: 2 April 2000 (day, month year, no commas).

When using the search for recent messages, use the "since" field.

## Subscription options

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The subscription options available to you can be viewed by clicking on the link: Join or leave the list (or change settings), which is found on the main archive page of a list. The link will bring you to an interactive area; choose the option: Alternatively, you can login with your LISTSERV password (if you have one) and update your subscription interactively.

After signing in with your e-mail address and password, you will have access to your account and may individualize your subscription options. The form contains the following options:

### Subscription Type

Regular-receive messages as they are posted, the default setting

Digest-one daily long message of all the postings

Index-receive one message with the only subjects of the day's postings.

### Mail Header Styles:

Normal LISTSERV-style header -Full" mail headers containing Internet routing information, MIME headers, and so forth.

Listserv-style- with list name in the subject, the default setting

Listserv-style, short -These headers are similar to the normal LISTSERV-style header except that Internet routing information and MIME headers are removed.

Dual- second header in mail body- shows what list the message is coming from ('Sender:'), the name and address of the person who posted the message ('Poster:'), the poster's organization, if present, and the message subject

Send mail -style (advanced option) - This option selects send mail-style headers, i.e. an exact copy of the original, incoming mail header with the addition of a 'Received:' line and of a 'Sender:' field.

## Acknowledgements

No acknowledgements- You will not receive any acknowledgement when you post to the list.

Short message confirming receipt- You'll receive a short message confirming the distribution of your message.

Receive copy of own postings- You will receive a copy of your own postings, so that you can see exactly how it appeared on the list. This is the default setting.

## Miscellaneous

Mail delivery disabled temporarily- This option stops your incoming mail. You may want to disable mail delivery if you will be away. You'll be able to access the archives from another computer after signing in with your e-mail address and password.

Address concealed from REVIEW listing- This option conceals you from the list of subscribers. Note that the list owner and the LISTSERV administrator can always get the complete list of subscribers, regardless of this setting. Most lists are configured so that only the list owner can use the REVIEW command, but some lists allow subscribers to get a listing of all the other participants.

Topics- For lists with topics enabled (if the 'Topics' section of the form is not visible, topics are not enabled), this section allows you to subscribe or unsubscribe to all, some, or none of the available topics. Bladder Cancer Cafe enables topics, but since nobody uses these subject titles in the posts, it's more or less a moot point.

For a more, detailed explanation of the options available, point your mouse to the link 'Subscription Types'. This takes you to a separate page explaining all the different options in more detail.

If you experience difficulties or have questions please feel free to contact the list owners for assistance:

[bladder-cancer-cafe-request@listserv.acor.org](mailto:bladder-cancer-cafe-request@listserv.acor.org)

## How To Unsubscribe

Do not send a message asking to be removed from the list to the whole group. There are two ways to get off the list; manually and interactively by using the list's archive page.

To leave manually, send an e-mail to [listserv@listserv.acor.org](mailto:listserv@listserv.acor.org). Leave the subject line blank and on the first line of the message type: `unsubscribe bladder-cancer-cafe` (including hyphens)

To unsubscribe automatically using the list's archive page, simply click on the link, 'Join or leave the list (or change settings)'. Fill in your name and e-mail address and click on 'leave the list'. Both methods are simple as long as you use the exact name and e-mail address of your original subscription.

Alternatives to signing off could be changing your subscription options to suit your needs, such as 'No Mail' mode or 'digest'.

If you still experience difficulties please contact your list owners for assistance.

If You are Changing E-Mail Addresses: Unsubscribe from your current address and re-subscribe from your new address. You'll need to register again in order to use the archives and subscription options.

Note on some closed lists the owner must make these changes for you

Privacy

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Yours - The copyrights of all posts belong to the sender and are protected by copyright laws. It is forbidden for others to forward or otherwise distribute your message without permission. Anything written to the list can be found in the archives (the data base of posts made to the list). All list members may access the archives of the group to which they belong.

If you receive unwanted messages from someone who has taken your e-mail address from the list, please notify the list owner immediately. Spamming is strictly forbidden and illegal. E-mail addresses are visible when you post to the list. Doing so implies an agreement to be contacted privately by other members.

Privacy of fellow members - Forwarding messages from the group to third parties is an invasion of privacy. Always ask permission before forwarding a message; you'll find that most people are happy to help and share. Respecting each other in this way enhances the atmosphere of trust and camaraderie.

ACOR lists do not allow anonymous memberships. For more info on ACOR's privacy policies see this page:  
<http://www.acor.org/about/privacy.html>

With special thanks to acor, Granny Barb and Steve Dunn