

Rules of Conduct for the EBF Patient/Survivor Forum

We are glad that you are here, and we hope that you find this to be a pleasant and safe place to be. We want you to feel comfortable in sharing your thoughts and emotions here. We have created this Forum with the intention of helping the patient find the support that is needed while you strive for a cancer-free life.

However, we are serious about the peaceful and positive aspects of this Forum. So, we have strict rules about behavior in this place. PLEASE NOTE: FAILURE TO ADHERE TO THESE WILL CAUSE YOU TO BE DENIED ACCESS TO THE FORUM.

Use of this Forum is a privilege, not a right. We would like The EBF Patient/Survivor Forum to be a place where people are free to express their concerns, and share information and support. But we also want the lists to be SPAM-FREE, to stay within the bounds of the law, and to be civil. We also want to protect your privacy to the degree we can. So we do need a few rules. If you have any doubt about whether a posting would break the rules, please write to us at EBF before you post!

- Commercial Postings are STRICTLY PROHIBITED
- The lists are for Patients and their supporters
- Respect Copyright
- Don't Post Chain Letters, Virus Warnings, or Other Off Topic Material
- Be Positive and Civil
- Respect Religious and Political Diversity
- Do not advocate for other cancer cures or treatments
- You may NOT put a link in your signature block.

Two Important Rules

We put these two up front so you cannot miss them - please read!

RULE #1: Commercial postings are STRICTLY PROHIBITED

If you have something to sell, you are very definitely in the wrong place. Anyone posting advertisements to this list will be deleted immediately and without warning. In addition, we may request that your ISP terminate your account for willful abuse. We are very serious about this.

RULE #2: The EBF Forum is for patients and their supporters

The forum is primarily for cancer patients, their supporters and loved ones who wish to lend their support and knowledge. If you are posting to the forum for any other purpose, please contact the Foundation PRIOR TO POSTING ANY MESSAGE.

This includes people who want to post a survey or questionnaire of any sort, who want to post an announcement for a charity, or who wish to archive or redistribute the contents of any posting on the message board.

We also request that anyone observing our list for research purposes contact us. Attorneys researching cases, or looking for clients are not permitted on the EBF forum. Anyone else who is not a cancer patient or supporter should contact us at annie@ElkaBest.org or rebecca@ElkaBest.org. Requests will be considered on a case-by-case basis.

Things which are always OK to post include:

- Anything you write yourself, including a summary of another's copyrighted work.
- The URL of a page on the Internet array(post the URL, not the content of the page!), after checking with EBF. AGAIN - Please check with EBF prior to this. We wish to protect our readers by reviewing other sites that you may wish to refer people to.
- A reference to any paper in the medical literature.
- Quoting a message someone else posted to the list.
- Anything which you have permission of the copyright holder to post.
- Medline abstracts
- Other alternative cancer cures or treatments. However, if you are a proponent of these ideas and places -DO NOT BRING THEM UP ON THIS MESSAGE BOARD. EBF is dedicated to the discussion of IPT, effective treatment modalities, and adjunctive array therapies that support and enhance the IPT treatment.

Things which MAY be OK to post array(and to which EBF usually won't object) include:

- Short quotations from copyrighted material to illustrate a point.
- Press releases or other material clearly intended to be distributed - but remember advertising is not allowed! Only post PR material if you have absolutely no interest or involvement, and are completely sure it's relevant! For the most part news releases should be posted to the EBF/IPT/cancer in the news section. Please forward these types of things to EBF at Rebecca@ElkaBest.org for our review and inclusion in the news section.

Things which are NOT OK to post without permission include:

- News articles and other copyrighted material from web sites, newspapers, and the like, except for small CREDITED EXCERPTS.
- Private correspondence

Rule #3

If you are unsure of your facts say so. If it is an opinion say so. If it is your personal experience say so. There are few absolutes in the world of cancer. Do not post anything that might be considered such. Try to qualify your statements and opinions.

Do not speak in absolutes unless you are completely certain that the information is correct. Following wrong advice or misinformation can hurt people. You have a responsibility to those who read your posts, and you must be careful to do no harm, even in your attempt to assist others. Speak from your own personal experience, and identify it

as such. This way others realize that what worked for you may or may not work for them. If you are a doctor please do not identify yourself as such on the boards. We do not wish to have any reader construe your comments to constitute medical advice. Clearly without personal examination and the revelation of all the facts, none of us can, without reasonable doubt, tell another what is best for them over the Internet, regardless of our knowledge, or expertise in any given subject matter.

RULE #4:

Don't Post Chain Letters, Virus Warnings, or Other Off Topic Material

By a chain letter we refer to any message which asks you to forward it on to others. Internet messages like this acquire a life of their own even though it turns out they are usually hoaxes or scams. Typical examples include warnings about computer viruses, or claims that you can help a charity by going to a certain web site. Even in the rare case where one of these letters is actually accurate, they are off topic. So before you forward a chain letter on to the list, stop and think:

1. Is this on topic?
2. Have I checked to be sure it's accurate?

Some places where you can check on the status of various hoaxes and virus warnings are:

- Computer Virus Hoax Page from Symantec Corporation. Symantec is one of the major anti-virus companies, and if there is a real virus, you will certainly find information on it in their Virus Encyclopedia.
- Snopes.com is a comprehensive site which covers myths, chain letters, fake virus warnings, and much more.
- Urbanlegends.com - covers various other stories you might find floating around on the net.
- Finally you can always go to a high quality search engine such as Google, and type in a key phrase from the chain letter you got. You'll almost always get telling results.

RULE #5: Be Civil

Disagreements and occasional friction are inevitable. It's perfectly OK to disagree with someone, but it's important to keep the tone civil. No verbal wars! If you writing an angry post, stop and ask yourself if you could make your point in a calm way before you press "send". If you think that someone has criticized you, keep in mind that our words don't always come out exactly the way we meant them to, and occasional misunderstandings are possible even when no criticism is intended. This is especially true on the Internet where you can't see the person's face, look in their eyes, and hear their tone of voice. We reserve the right to delete posts at any time that EBF unilaterally finds offensive or inappropriate.

RULE #6: Respect Religious and Political Diversity

While EBF espouses a spiritual connection to aid in healing and in Quality-of-Life, religion is a delicate topic. Faith is very important to many, especially during a life crisis

like cancer. No matter how strong your personal faith, it's important to realize we have a great diversity of religious beliefs among our posters, and that not everyone shares your faith, whatever that might be. Many people will be offended by posts which preach to them, or which assume that they believe in the same God you do. Anything which might be considered proselytizing should be avoided or it will be deleted. At the same time asking people to pray for you, or expressing how your faith has helped you should be fine. Sometimes it's a very fine line - use your best judgment. If disagreement occurs on the forum regarding this topic, we ask that those involved in the disagreement take their discussions off the board and, if they desire, conduct their discussions by email or private messaging. EBF may edit religious references out of any post or delete it altogether.

Politics is generally off topic and not an appropriate subject for the forum unless related to IPT and cancer activism. Occasionally a legislative bill touches directly on cancer, and in this case, careful discussion in your own words would be appropriate. Again, please use your best judgment. Forwarding calls to action relating to political causes that you're passionate about falls under Rule #4 above on chain letters. Please don't.

This doesn't cover every possible issue with posting on a public board, but it is a good starting point as you begin to participate in EBF's online support forum. If you have a problem with a particular posting and wish to bring it to the attention of the board administrator, you may copy the postings URL and email it to any of the admin moderators whose names appear on the board.

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The Elka Best Foundation