

Becoming the Expert

The ABCDs of Doing On-Line Research into Your Cancer,
or

How to Learn as Much as You Want to Know About Cancer And Treatment in Four Easy Steps, Which Can Lead to Better Communication with Your Doctor and Better Treatment for You or Your Child.

STEP ONE - Diagnosis Details

Unless you know what type of cancer you or your child has, you cannot find the most up-to-date standard and experimental treatments. The words are likely to be strange and easy to forget or confuse with other terms, so ask your doctor for the information in writing. You need to know

- **the general type of cancer**, for example *rhabdomyosarcoma* (also called Rhabdo or RMS),
- **the sub-type of cancer**, for example *alveolar rhabdomyosarcoma* (ARMS), and
- **the stage** (how advanced) the cancer is, for example *stage 3, clinical group III ARMS*.

STEP TWO - Type of Information You Are Looking for

Generally, people do research for two main reasons: to find doctors who specialize in a type of cancer, or to find different treatment options. Here are some of the uses of research.

Names of specialists These can be used for a second opinion or to add as a consultant to your treatment team.

Different treatments If treatment is going poorly or if you or your child has relapsed, you can look for different treatments or find out who might give you a second opinion.

Planning ahead Even if treatment is going well, you still might want to be prepared ahead of time in case the cancer returns.

STEP THREE – Where to Find It

This is the key to doing research, so we've spelled out in some detail how to go about doing it.

Finding Specialists

Ask your doctor Through journals and conferences, your doctor might know of specialists. Don't feel as though you are betraying your doctor in any way—any doctor concerned about you as a patient will encourage you to seek out second opinions.

Find established organizations that advocate for your type of cancer You can google these by typing in the type of cancer. In general, go for the most general type of cancer. For example, type in "sarcoma" and you will find the Sarcoma Foundation of America, the Kristen Ann Karr Foundation, and for that matter the Sarcoma Alliance. All of these organizations have a lot of useful information. Searching on specific cancer types will narrow the result—for example, search for "leiomyosarcoma" and you will find the LMSarcoma Foundation.

Join on-line lists specific to your type of cancer Take advantage of the “been there, done that” knowledge of others. You might start with the Association of Cancer On-line Resources (www.acor.org), which has many mailing lists for sarcomas, such as Sarcoma, Rhabdo-Kids or E-Sarcoma. If you prefer bulletin boards or chat rooms, many organizations such as our very own Sarcoma Alliance provide these.

Look for scientific articles about your type of cancer Many doctors who know the latest, greatest treatments are also researchers who write scientific articles. If you have access to a hospital library, you can look for articles in recent journals. If you don’t have access to a hospital library but have on-line access, go to PubMed, which is the National Library of Medicine site (www.ncbi.nlm.nih.gov/sites/entrez/).

- 1. Use keywords** These allow you to search for specific items, such as “translocation alveolar rhabdomyosarcoma.” Remember the keywords do not have to be a phrase or sentence, just individual words.
- 2. Try different combinations of keywords** to find what you are looking for, for example, just “rhabdomyosarcoma” or “outcome orbital rhabdomyosarcoma”.
- 3. Look for recent articles** You will pull up many articles unless your keywords are very specific. Start with the most recent and check to see what institutions the authors are affiliated with.
 - Are they in nearby geographic areas?
 - Do they give an email address to contact?
 - Don’t forget to look up the “related articles” links, too.
- 4. Find the right contact** Many articles have many authors. Sometimes one will be designated as the contact for reprints. If not, the FIRST or LAST author is probably the best one to contact.
 - Look for an author who has written at least several articles on this type of sarcoma. Some of these researchers are not clinicians—that is, they do not treat patients—but they will know others who do and they can point you in the right direction.
 - If that author’s contact information isn’t in your article, search for their name on PubMed or Google. PubMed is likely to give you other articles, some of which will probably have an email address. Google is likely to pull up the website of the institution they are associated with. You can often find their phone number there.

Finding Treatments

Ask specialists Contact the specialists you have found. They are likely to know the latest treatment alternatives.

Advocacy organizations Contact the sarcoma organization you have found for information about clinical trials of experimental treatments.

Ask others Use online mailing lists and bulletin boards what treatments others know about.

Finding treatment options yourself If you want to search for treatment options yourself, consider looking for clinical trials of new treatments. Although clinical trials may sound experimental, many include standard treatments. Children with cancer are often treated in clinical trials. Two good places to look for them are the National Cancer Institute site, www.cancer.gov/clinicaltrials and the National Institute of Health site, www.clinicaltrials.gov. Even though these are both U.S. sites, they list trials in many countries. Here’s how to search.

1. Go to one of these websites and choose the appropriate type of cancer and type of clinical trial you are looking for.
2. If location of the trial is important to you, fill in the appropriate information.
3. Consider whether you are willing to participate in a Phase I, II, III, or IV trial.
 - Phase III and IV trials compare different treatments that are known to work.
 - Phase II treatments are more experimental and investigate how well a new treatment works.
 - Phase I treatments are the most experimental. They investigate how safe a new treatment is. Phase I treatments are usually only available to people who have exhausted all other options.
4. Look at the requirements for enrollment to see whether the trial is open to you. Depending on how much detail you want, there are two versions you can look at—the Patient Version or the Health Professional Version. Both are available to anyone.

STEP FOUR – Judging Information Quality

Bad recommendations are worse than no recommendations at all. How can you tell whether the information you have found is reliable?

Where did you find it? In order of more to less reliability, here are some guidelines.

- *Peer-Reviewed Journals* The best quality information comes from scientific articles that have been published in journals (technical magazines) that are “peer reviewed.” Peer review is a process in which scientists who are knowledgeable about the topic—but who were not involved in the research being described—review the scientific article before it is published. The journals on PubMed are mostly peer reviewed.
- *Papers Presented at Scientific Meetings* These presentations are often preliminary information that eventually will be published. One good source is the American Society of Clinical Oncologists (ASCO), which has a searchable database of abstracts of all their meetings on line at www.asco.org/ASCO/Abstracts+%26+Virtual+Meeting/Abstracts
- *Articles in the Popular Press and Newsletter.* Often based on press releases, these may not tell the whole story and sometimes have an editorial bias.
- *“Anecdotal” Information* This is word-of-mouth information, such as “I took Vitamin X and it worked for me.” This is the least useful information because no one can really say for sure whether taking Vitamin X had any connection to success of treatment.

Unfortunately, much of the information that you will get from on-line sites will be anecdotal. It will be up to you, as the budding Expert, to be able to tease out what is reliable from what isn't. In particular, it seems as though supporting information for non-traditional treatments tends to be anecdotal. These types of treatment range from adding supplements to a standard treatment all the way to abandoning standard treatments and going with something completely different. One guideline that works for almost everything in life is, If it sounds too good to be true, it probably is.

Ask LOTS of questions No matter where you find the information, you can never ask too many questions before deciding on a new treatment. You will almost certainly be tempted to WANT the new treatment to be the answer, but if you are going to be the expert, you need to be a little skeptical. Ask the doctor lots of questions—and get definitive answers. Here are twenty questions to help you to judge the quality of the information you have found.

1. Why do you think this treatment would work for my type of sarcoma?
2. How many people with this sarcoma have you treated?
3. Did the other people have a similar subtype, stage, and location?
4. What were the results for those people?
5. Has this treatment been tested in clinical trials?
6. If there are results for this sarcoma or related cancers, what are the results?
7. Do the results of the clinical trials show this treatment is relatively safe?
8. Do the results of the trials show that the treatment is effective?
9. Are the results published in technical journals - NOT just the popular press?
10. How many people were in these studies?
11. Were the patients treated with any other treatments?
12. Can the doctor or clinic send me copies of the results?
13. How does the treatment work? (Make sure the explanation makes sense. You may have to do some homework here!)
14. What is the goal of the treatment and how is its efficacy measured (for example, is survival measured in weeks, months, or years)?
15. How do they measure success for treatments where, say, the goal of treatment might be to strengthen the immune system?
16. What are the risks of the treatment?
17. What are the side effects, short- and long-term?
18. Can they provide any information showing the percentage of patients who develop these side effects?
19. If the drugs are complementary medicines used during treatment, how will they interact with traditional treatment drugs? Are there studies that show there will not be adverse interactions?
20. Anything else you can think of. You will make the best choices if you have educated yourself thoroughly about each choice.

OTHER RESOURCES for Doing Research

Cancer.Net

This website is run by the American Society of Clinical Oncologists (ASCO) and is an excellent source of information for patients and families. It is mostly geared towards adults with cancer but there are also information pages for many types of childhood cancer.

www.cancer.net/portal/site/patient

CureSearch

This website is run by the two organizations: the Children's Oncology Group and the National Childhood Cancer Foundation.. CureSearch provides information on childhood cancer research and clinical trials.

www.curesearch.org

Liddy Shriver Sarcoma Initiative

This organization maintains a list of clinical trials specifically for sarcomas.

sarcomahelp.org/Clinical%20Trials/Clinical%20Trials.htm

Medscape

Medscape is an excellent source for the latest news in a variety of medical fields. You need to register, but registration is free.

www.medscape.com

Steve Dunn's Cancer Guide

This website is an excellent source of information for investigating different treatments, including how to do so, the pros and cons of doing so, how to make sense out of statistics, and many other pertinent bits of advice.

cancerguide.org

Other Sites You Might Find Useful

American Cancer Society, Making Treatment Decisions	www.cancer.org/docroot/ETO/ETO_0.asp
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Cancer411	www.cancer411.org
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The American Association for Cancer Research, Clinical Cancer Research	clincancerres.aacrjournals.org
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National Comprehensive Cancer Network	www.nccn.org
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CancerCare	www.cancercare.org
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CancerCompass	www.cancercompass.com
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CenterWatch, Clinical Trials Listing Service	www.centerwatch.com
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Children's Cause, Cancer Advocacy	www.childrenscause.org
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CureToday	www.curetoday.com
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Doctor's Guide	www.docguide.com
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HemOnc Today, Clinical News in Oncology and Hematology	www.hemonctoday.com
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PharmaLive, the Pulse of the Pharmaceutical Industry	www.pharmalive.com/News
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Medical News Today Newsletters	www.medicalnewstoday.com/newsletters.php
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MDLinx	www.mdlinx.com
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