



**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 can not 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).
- **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:** either 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 relapsed, you can look for different treatments or find out who might give you a second opinion.
- **Plan ahead:** even if treatment 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, or the Kristen Ann Karr Foundation, or for that matter the Sarcoma Alliance, all of which will have a lot of useful information. Type in "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](http://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, but have on-line access, go to PubMed, which is the National Library of Medicine site (<http://www.ncbi.nlm.nih.gov/sites/entrez/>)
  - **Use key words** that allow you to search for specific items, such as "translocation alveolar rhabdomyosarcoma". Remember the key words do not have to be a phrase or sentence, just individual words.
  - **Try different combinations of key words** to find what you are looking for, for example, just "rhabdomyosarcoma", or "outcome orbital rhabdomyosarcoma".
  - **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.
  - **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 the specialists** if you have found them. They are most likely to know the latest treatment alternatives.
  - **Advocacy organizations** for sarcomas may have links to clinical trials of experimental treatments.
  - **Ask others** what treatments they know about if you have joined an on-line mailing list or bulletin board.
    - 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 and many children with cancer are treated on clinical trials. Two good places to look for them are the National Cancer Institute site, [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials) and the National Institute of Health site, [www.clinicaltrials.gov](http://www.clinicaltrials.gov). Even though these are both U.S. sites, they list trials in many countries. Here's how to search:
      - Go to one of these websites and choose the appropriate type of cancer and type of clinical trial you are looking for

- If location of the trial is important to you, fill in the appropriate information.
- Consider if you are looking for a Phase I, II, or III, or IV trial. Very simply put, 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, and see how safe a new treatment is. Phase I treatments are usually only available to people who have exhausted all other options.
- Look at the requirements for enrollment to see if 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 if 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 <http://www.asco.org/ASCO/Abstracts+%26+Virtual+Meeting/Abstracts>
  - **Articles in the popular press and newsletters.** Often based on press releases, these may not tell 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 if 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:

- Why do you think this treatment would work for my type of sarcoma?
- How many people with this sarcoma have you treated?
- Did the other people have a similar subtype, stage, location?
- What were the results for those people?
- Has this treatment been tested in clinical trials?
- If there are results for this sarcoma or related cancers, what are the results?
- Do the results of the clinical trials show this treatment is relatively safe?
- Do the results of the trials show that the treatment is effective?
- Are the results published in technical journals - NOT just the popular press?
- How many people were in these studies?
- Were the patients treated with any other treatments?
- Can the doctor or clinic send me copies of the results?
- How does the treatment work? (Make sure the explanation makes sense - you may have to do some homework here!)
- What is the goal of the treatment, and how is its efficacy measured (for example, is survival measured in weeks, months, years)?
- How do they measure success for treatments where, say, the goal of treatment might be to strengthen the immune system?
- What are the risks of the treatment?
- What are the side effects, short- and long-term?
- Can they provide any information showing the percentage of patients who develop these side effects?
- If the drugs are complementary medicines used during treatment, how will they interact with traditional treatment drugs, and are there studies that show there will not be adverse interactions?
- 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 cancers.

<http://www.cancer.net/portal/site/patient>

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

<http://www.curesearch.org>

Liddy Shriver Sarcoma Initiative. This organization maintains a list of clinical trials specifically for sarcomas.

<http://sarcomahelp.org/Clinical%20Trials/Clinical%20Trials.htm>

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

[www.medscape.com/](http://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.

<http://cancerguide.org/>

Other sites you might find useful:

[http://www.cancer.org/docroot/ETO/ETO\\_0.asp](http://www.cancer.org/docroot/ETO/ETO_0.asp)

<http://www.cancer411.org/>

<http://clincancerres.aacrjournals.org/>

<http://www.nccn.org/>

<http://www.cancercares.org/>

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

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

<http://www.childrenscause.org>

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

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

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

<http://www.pharmalive.com/News/>

<http://www.medicalnewstoday.com/newsletters.php>

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