

Resources

How to Find Reliable Information



Video transcript –

Victoria Pemberton, RNC: I would encourage parents to get as informed as they can, to talk with friends and family, to perhaps talk with other families who have experienced the same thing that they have, locate educational materials, call your primary care physician. There are Internet resources. You do have to be careful about what is out there on the Internet.

Renee Jenkins, MD: When they go to a website, try to identify where the people are located, if it's run by health professionals, or if it's run by lay people. There are sources that can be useful that are run by lay people. But you have to really check out that information.

Victoria Pemberton, RNC: In many cases, there are legitimate sites that can help you find information about clinical studies, and educate yourself about what it means to be in a clinical trial. **Jose:** I did a lot of research on her condition, so when she was born, I pretty much knew what to expect.

Dawn: Really you just had to find out on your own. And people are willing to help, but they don't realize what you need to know. And I'll write down questions. And I'll have the boys write down questions that they have. I'll say, "What are we going to ask?" The doctors can tell you something, but then that's it. They've done their part. "We've diagnosed it." And they're wonderful-and nurses and case workers. But I would suggest using any kind of sources that you have. If you don't have the Internet, then giving out your phone numbers to some of those people, and eventually maybe they'll give them to some of these parents or families that are dealing with the same disease.

Information is knowledge. And knowledge is power.

Getting educated about your child's condition and how studies work is often the first step toward making a decision.

There are lots of resources out there to help you get the facts you need to make a good decision; the Internet, families with similar concerns, medical experts, support groups, patient advocates, friends and family members as well as others.

The Internet is a powerful tool, but use it wisely. You want to be sure the information you're getting is trustworthy and true.

- Look for who publishes the site. Is it reliable? Is it balanced? Focus on sites that end in .gov, .org or .edu as a place to start. Government sites like the National Institutes of Health (www.NIH.gov) and health organization sites like the American Academy of Pediatrics (www.aap.org) are sites that you can trust for good information.
- Find the date when it was last updated. Is the information current?
- If it is a personal site make sure the information is credible. Is it a blog or opinion? Does it have references?

"...parents should research it first, go on the Internet, do a lot of research, weigh out the pros and the cons and then pick and see if the pros outweigh the cons..."

Bianca, child in kidney disease study

Remember, you're not alone.

There are people out there who can help too. You can ask your own physician, or a friend of the family who may have more knowledge about the condition.

"Many large studies have a study coordinator who's usually a nurse. People often find that it's easier to approach a nurse than a physician."

Dr. Gail Pearson, Pediatric Cardiologist

You can even ask the study team to put you in touch with other families who have faced the same decision. Connecting with families who have dealt with the same disease or who have been in a study can often help you.

"Then I did find some families that already had formed a support group...there were people. And so we got to actually meet some of the families and spend a week together. We'd see each other at the immune conferences."

Dawn, mother of child in chronic granulomatous disease study

And ask questions of your medical team - your primary care doctor, nurse, specialist or others involved in your child's care.

"I will ask the question first, 'Who is your primary care pediatrician' and get that individual involved. This is hopefully someone...who can provide both information to the [study] practitioner but also provide some level of comfort for the family as information is being given to them."

Dr. Joe Wright, Pediatrician

Finding a Clinical Trial

Parents most often find out about clinical studies from a healthcare provider who is conducting a study and sometimes your doctor or nurse may recommend a study to you. If you are seeking a clinical study, there are a few ways to search.

ClinicalTrials.gov is a database of trials in many different diseases for different age groups. Here are a few tips to help you get started:

1. In the search box (upper right corner), enter the medical condition, disease or term you are interested in searching like “asthma”. This might turn up many studies.
2. To help narrow your search, click the tab ‘**Refine Search**’ at the top of the page. The most important fields to complete might be:
 - a. ‘**Location**’: You may pick up to three locations.
 - b. ‘**Age Group**’: Trials for children will fall into the ‘Children’ category.
3. Once the form is complete, click the ‘**Search**’ box at the bottom of the page.
4. The next page presents a full list of the trials. The trials are listed based by best match first.

Recruiting means the trial is looking for volunteers

Unknown means that the search system is not sure if the trial is open.

Completed means the trial has closed and no new participants are being taken

ResearchMatch.org is a tool to match patients with appropriate studies. You must register to receive notifications about relevant clinical studies. The site will walk you through the process to register you or your child. Once registration is complete, any matches will be emailed to you with further instructions about how you can get more information about participation.

The National Institutes of Health Clinical Center, America's research hospital, is located on the NIH campus in Bethesda, Maryland. About a thousand clinical research studies are currently under way at the Clinical Center on diseases such as cancer, AIDS, heart trouble, eye problems, dental problems, depression, and nerve diseases, to name just a few. You may visit the database of studies (<http://clinicalstudies.info.nih.gov/>) to search for details on those studies. Or you may contact someone at 1-800-411-1222 or by email at prpl@mail.cc.nih.gov to get more information.

Related Materials

There are more ways to learn about children and clinical studies. Read the press, see the awards, and view online videos! Find resources that may be helpful to you if you work with children in research. To order any items, please send an email to Researchandkids@nhlbi.nih.gov

Resources

- **Facebook**

- Visit our Facebook Page and become a friend.
(<http://www.facebook.com/pages/Children-and-Clinical-Studies-Campaign/144563897770?ref=ts>)

- **Online Videos**

Videos for families interested in learning more about clinical trials

- Video 1 – (<http://www.youtube.com/watch?v=sAaF9VTvmI4>)
- Video 2 – (<http://www.youtube.com/watch?v=IP4r7w0FHJs>)

- **DVDs**



DVD for Clinics: This looped DVD features the 10 minute documentary film and selected features, designed to be used in waiting rooms, with Spanish and English captions.



DVD Video Segments: This DVD includes all video segments as seen on the website, organized into individual chapters, for use in presentations or discussions.

- **Postcards**



Postcard for the Children and Clinical Studies Web Site

- English Version –
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/documents/CACS_Postcard_English.pdf)
- Spanish Version –
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/documents/CACS_Postcard_Spanish.pdf)

- **Posters(16 x 22 with post-it note tear-offs)**



- Poster 1 English Version –
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/downloads/english/Poster_3-8yo_eng_final.pdf)

- Poster 1 Spanish Version –
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/downloads/spanish/Poster_3-8yo_span_final.pdf)
- Poster 2 English Version –
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/downloads/english/Poster_9-16yo_eng_final.pdf)
- Poster 2 Spanish Version –
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/downloads/spanish/Poster_9-16yo_span_final.pdf)

- **Awards**

The Children and Clinical Studies site has won numerous awards, including a Telly Award, CINE Golden Eagle, Aesculapius Award, National Health Information Award, and Videographer Award.

View Award Information –

(http://www.nhlbi.nih.gov/childrenandclinicalstudies/documents/ChildrenAndClinicalStudies_Awards.pdf)

News and Press Releases

- **Articles**

- Children and Clinical Studies: The National Heart, Lung, and Blood Institute's New Multimedia Resource for Pediatric Research
Journal of the American College of Cardiology (2009)
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/documents/Article_JACC.pdf)
- Children & Clinical Studies - New NIH Website For Parents Helps Answer Questions
National Marfan Foundation Newsletter (2008)
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/documents/Article_NAPS.pdf)
- Pediatric Research Gets Boost From Web
JAMA (2008)
(http://www.nhlbi.nih.gov/childrenandclinicalstudies/documents/Article_JAMA.pdf)

- **Press Releases**

- NIH Launches New Web Site for Parents on Medical Research Studies for Children (<http://multivu.prnewswire.com/mnr/nhlbiclinicalstudies/35258/>)

- **Radio Segments**
 - NIH Research Radio Clip: Hear about the Children and Clinical Studies Website (<http://ocplmedia.od.nih.gov/nihradio/20090109NHLBIClincialstudies.mp3>)