

THE PARTICIPANT

THE PATIENTS' PERSPECTIVE

Personalized search helps patients in need

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Finding an appropriate clinical trial can pose problems for many potential volunteers. Many patients lack the computer savvy needed to search for trials. When patients do reach a registry site that lists clinical trials, the listings typically use scientific or complex terms that can be hard to understand.

Add the fact that people struggling with a disease are often stressed and anxious, which makes it even harder for them to think clearly enough to decide whether a particular clinical trial is right for them.

When they do find a trial, many potential volunteers don't know the key questions to gain the information they'd need to make an informed decision about the trial.

To overcome these stumbling blocks, CISCRP launched its Search Clinical Trials expanded service earlier this year. (www.SearchClinicalTrials.org).

As part of this service, CISCRP staff members help patients find appropriate clinical trials. Volunteers can phone or send an e-mail to request a personal search when searching on their own seems difficult.

Some of the requests are anguished and heart-wrenching. They illustrate the emotional state of the volunteers and their need to find a clinical trial.

One person wrote in his e-mail subject line: "Desperate for Treatment." He was struggling with terrible pain from a torn meniscus cartilage and was looking for a test treatment that might help him.

Another e-mail came from a husband whose wife had stage IV breast cancer that had spread to her brain and lung. She was given about two months to live. He was hoping that getting into a trial immediately could help prolong his wife's life.

Still another person wrote in for his grandfather who had stage IV adenocarcinoma spreading throughout his stomach to his other organs, and was looking for any kind of experimental treatment.

Volunteers get help in finding trials

Response has been enthusiastic. "We've handled hundreds of requests since the program launched in January 2009," says Meaghan Dunn, Manager of Outreach & Customer Service at CISCRP.

"Many of the people who contact us don't know how to conduct an effective search over the internet or don't have much access to a computer. Our service is really helpful for them. They find it more useful to communicate directly with someone who can do the searching."

CISCRP staff members review each request, and within a day or two will conduct a search and send the requestor a packet of information listing trials available to them.

"I try to make each communication individual by including a personal note," says Dunn. "Users don't feel that they are simply receiving a print-out of a computer-generated list."

The CISCRP staff tries hard to find an appropriate trial, although it's not always possible. "It depends how rare their disease is, where they live, and how much they're willing to travel," says Dunn. All volunteers who contact CISCRP receive an educational brochure.

CISCRP is not involved in recruiting patients for clinical trials and is not involved in conducting trials. CISCRP neither recommends nor endorses any of the trials it finds through the Search Clinical Trials service. The organization's goal is to connect prospective clinical trials volunteers with the professionals who run the trials so the public can ask questions about their specific trial and their eligibility for a specific trial.