


*A Guide to  
Participating in  
Clinical Trials*

# Iowa Cancer Resources

 Iowa Cancer  
Consortium





This guide is intended to help Iowans find resources to participate in clinical trials. The guide is meant to accompany the National Cancer Institute's brochure, 'Taking Part in Cancer Treatment Research Studies' and the DVD, 'Understanding Cancer Clinical Trials.' The brochure and DVD explain in more detail what are clinical trials. To order a FREE copy of the NCI brochure and/or DVD call the National Cancer Institute at 1-800-4-CANCER (1-800-422-6237).

# What does this guide cover?

## Resources for finding out if a trial is right for you:

**Medical** pg. 2  
*Questions to ask your cancer doctor*

**Understanding Clinical Trial Information** pg. 4  
*Resources to help understand information about clinical trials*

**Searching for Clinical Trials** pg. 6  
*Resources for finding clinical trials*

**Social Support** pg. 8  
*Resources for making the decision to participate in a trial*

## Resources for participating in a trial:

**Insurance** pg. 9  
*Questions to ask your insurance company*

**Money** pg. 10  
*Questions to ask the clinical trials team*  
*Financial resources for taking part in clinical trials*

**Travel** pg. 11  
*Questions to ask the clinical trials team*  
*Resources to help with travel for clinical trials*

**Work** pg. 12  
*Questions to ask your employer*  
*Resources to help with work related questions*

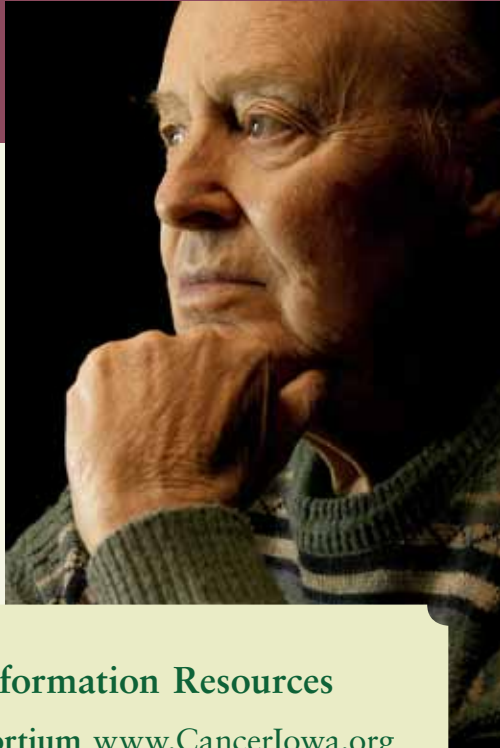
# Medical



## Questions to ask your cancer doctor

### Helpful Tips:

- Bring a list of questions with you to your appointments.
  - Bring a trusted family member or friend to your appointments to help you understand and remember what your doctor is telling you.
  - Bring a tape recorder or paper and pencil to record what the doctor is telling you.
1. What type of cancer do I have? What is the stage?  
Ask the doctor for written or audio visual information about your cancer.
  2. What are my treatment choices, including opportunities to participate in clinical trials?
  3. What are the pros and cons of each treatment?
  4. What are the known possible side effects of each treatment and how will they be controlled?
  5. Will I be able to work throughout treatment?



## **Other Cancer Information Resources**

**Iowa Cancer Consortium** [www.CancerIowa.org](http://www.CancerIowa.org)  
1-800-237-1225

**National Cancer Institute** [www.cancer.gov](http://www.cancer.gov)  
1-800-4-CANCER (1-800-422-6237)

**American Cancer Society** [www.cancer.org](http://www.cancer.org)  
1-800-ACS-2345 (1-800-227-2345)

**American Society of Clinical Oncology**  
[www.cancer.net](http://www.cancer.net) 1-888-651-3038

# Understanding Clinical Trial Information

*A clinical trial is a type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Also called a clinical study.*

## **Resources to help you understand information about clinical trials**

The guide is meant to accompany the National Cancer Institute's brochure, "Taking Part in Cancer Treatment Research Studies" and the DVD, "Understanding Cancer Clinical Trials." These materials talk in basic terms about what clinical trials are. To order a FREE copy of the brochure and/or DVD call the National Cancer Institute at 1-800-4-CANCER (1-800-422-6237) or 1-800-237-1225 or visit [www.CancerIowa.org](http://www.CancerIowa.org) for electronic copies.



If you have questions about clinical trials the following resources might help:

- Your doctor or nurse
- Clinical trials team
- Social workers
- Patient advocates
- Patient navigators
- Medical interpreters
- Iowa Cancer Consortium [www.CancerIowa.org](http://www.CancerIowa.org)  
1-800-237-1225
- National Cancer Institute [www.cancer.gov](http://www.cancer.gov)  
1-800-4-CANCER (1-800-422-6237)  
TTY: 1-800-332-8615
- American Cancer Society [www.cancer.org](http://www.cancer.org)  
1-800-ACS-2345 (1-800-227-2345)
- American Society of Clinical Oncology [www.cancer.net](http://www.cancer.net)  
1-888-651-3038
- CancerCare [www.Cancercare.org](http://www.Cancercare.org) 1-800-813-HOPE
- Coalition of Cancer Cooperative Groups  
[www.cancertrialshelp.org](http://www.cancertrialshelp.org) 1-877-227-8451

### Resources in Spanish

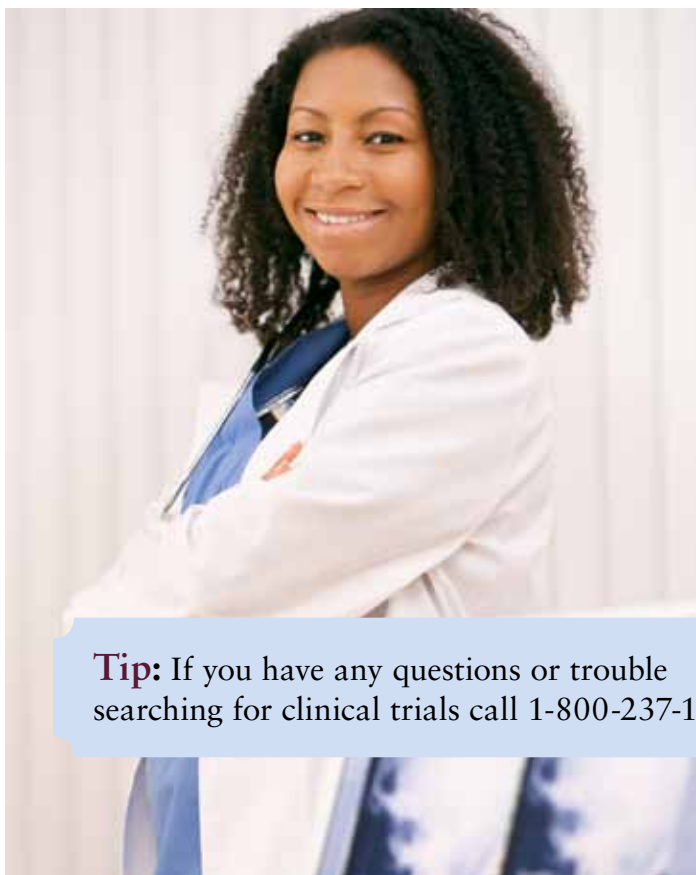
- [www.cancer.gov/espanol](http://www.cancer.gov/espanol)
- ¿Preguntas sobre el cáncer? 1-800-422-6237
- Llame de lunes a viernes de 9:00 a.m. a 4:30 p.m., hora local en Estados Unidos y sus territorios



# Searching for Clinical Trials



Resources on the next page have lists of trials available and basic information about participating in a clinical trial. At this time there is no resource that lists all trials.



**Tip:** If you have any questions or trouble searching for clinical trials call 1-800-237-1225.



## Resources for finding clinical trials

- Your cancer doctor
- Clinical trials team at your treatment center
- Individual cancer treatment centers,  
**[www.CancerIowa.org](http://www.CancerIowa.org)**
- Iowa Cancer Consortium **[www.CancerIowa.org](http://www.CancerIowa.org)**  
1-800-237-1225
- National Cancer Institute **[www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)**  
1-800-4-CANCER (1-800-422-6237)
- American Cancer Society **[www.cancer.org](http://www.cancer.org)**  
1-800-ACS-2345 (1-800-227-2345)
- EmergingMed **[www.emergingmed.com](http://www.emergingmed.com)**  
1-877-601-8601
- Lance Armstrong Foundation **[www.livestrong.org](http://www.livestrong.org)**  
1-866-673-7205
- Centerwatch **[www.centerwatch.com](http://www.centerwatch.com)**  
1-866-219-3440
- Leukemia & Lymphoma Society (LLS)  
1-800-955-4572  
The LLS Information Resources Center will assist  
blood cancer patients in searching for clinical trials.
- Coalition of Cancer Cooperative Groups  
**[www.cancertrials-help.org](http://www.cancertrials-help.org)** 1-877-227-8451



# Decision Making Support

## Resources for making the decision to participate in a trial

Everyone has different support systems, please think about who has helped you make important decisions in the past.

- Your cancer doctor
- Primary care provider
- Family members
- Friends
- Cancer survivors
- Social worker
- Pharmacist
- Mental health provider
- Local pastor
- Mentor
- Cancer center support group
- Iowa Cancer Mentors Assisting and Preparing Survivors [www.iowacancermaps.org](http://www.iowacancermaps.org)  
1-888-994-6277
- Leukemia & Lymphoma Society Iowa Chapter  
1-800-347-1074  
*First Connections, peer mentoring program*
- Lance Armstrong Foundation [www.livestrong.org](http://www.livestrong.org)  
1-866-673-7205

# Insurance

## Knowledge Points:

1. Check with your individual insurance company to see if they cover routine costs of clinical trials.
2. Medicare covers the routine costs of treatment for patients participating in clinical trials. Check with Medicare to make sure your specific trial is covered.
3. The VA Medical Administration covers routine costs of treatment for patients participating in National Cancer Institute clinical trials.
4. **If you are told that your insurance does not cover a clinical trial ask your provider to write to the Medical Director of the insurance company for a review.**

## Resources to help with your insurance questions

- Your insurance company/agent
- National Cancer Institute [www.cancer.gov](http://www.cancer.gov)  
1-800-4-CANCER (1-800-422-6237)
- Iowa Veterans Affairs [www.iowava.org](http://www.iowava.org) 1-800-838-4692
- Medicare and Medicaid [www.cms.hhs.gov/contactcms/](http://www.cms.hhs.gov/contactcms/)  
1-800-633-4227

## Helpful Tips: Know before you call...

### ASK YOUR CLINICAL TRIALS TEAM:

What parts of the trial are routine care versus trial related care?

### QUESTIONS TO ASK YOUR INSURANCE COMPANY:

Is prior authorization required?

What does my insurance cover?

- Routine care
- New drugs or tests
- Additional blood work, scans, etc.
- Investigational therapies

Does the insurance company classify this therapy an FDA-approved therapy or investigational?

Do I have disability insurance and will I qualify to use it?

A photograph of a black blood pressure cuff and its gauge. The gauge is circular with a white face and black markings, showing a reading of approximately 120 mmHg. The cuff is connected to the gauge by a black tube. The background is a light beige color with a dark red horizontal band across the middle.

# Money

## Questions to ask the clinical trials team

1. What tests and treatments does this trial pay for that are free to me?
2. What tests or treatments must be paid for by me or my insurance company?
3. What if I don't have insurance?
4. What resources are available to help me meet the costs of clinical trials?

## Financial resources for taking part in clinical trials

- County Human Services
- Social workers
- Financial counselors at cancer treatment facility
- Churches
- Iowa Comprehensive Health Association  
[www.hipiowa.org](http://www.hipiowa.org) 1-877-793-6880
- NeedyMeds [www.needymeds.org](http://www.needymeds.org) Calls should be directed to the pharmaceutical company that makes the medicine you need
- Leukemia & Lymphoma Society Iowa Chapter  
1-800-347-1074

# Travel

## Tips:

- If you have a health care spending account check for health-care travel reimbursement or coverage.
- Check with your tax preparer to see if any of your medical expenses, including travel, can be considered as deductions.

## Questions to ask the clinical trials team

1. How many trips are required for standard treatment?  
Will additional trips be required to participate in this trial?
2. How far is it to the treatment center?
3. Can I do any of the tests/treatments in my home community?
4. Are overnight stays required?
5. Will my travel be paid for?
6. Will I need to bring a driver/caregiver with me?

## Resources to help with travel for clinical trials

- Social workers or nurses at treatment facility
- Churches
- County Department of Human Services
- Local motels with hospital rates
- Leukemia & Lymphoma Society Iowa Chapter  
1-800-347-1074
- Iowa United Way <http://www3.irissoft.com/iowa>
- American Cancer Society 1-800-227-2345  
Road to Recovery  
Hope Lodge and other lodging

# Work

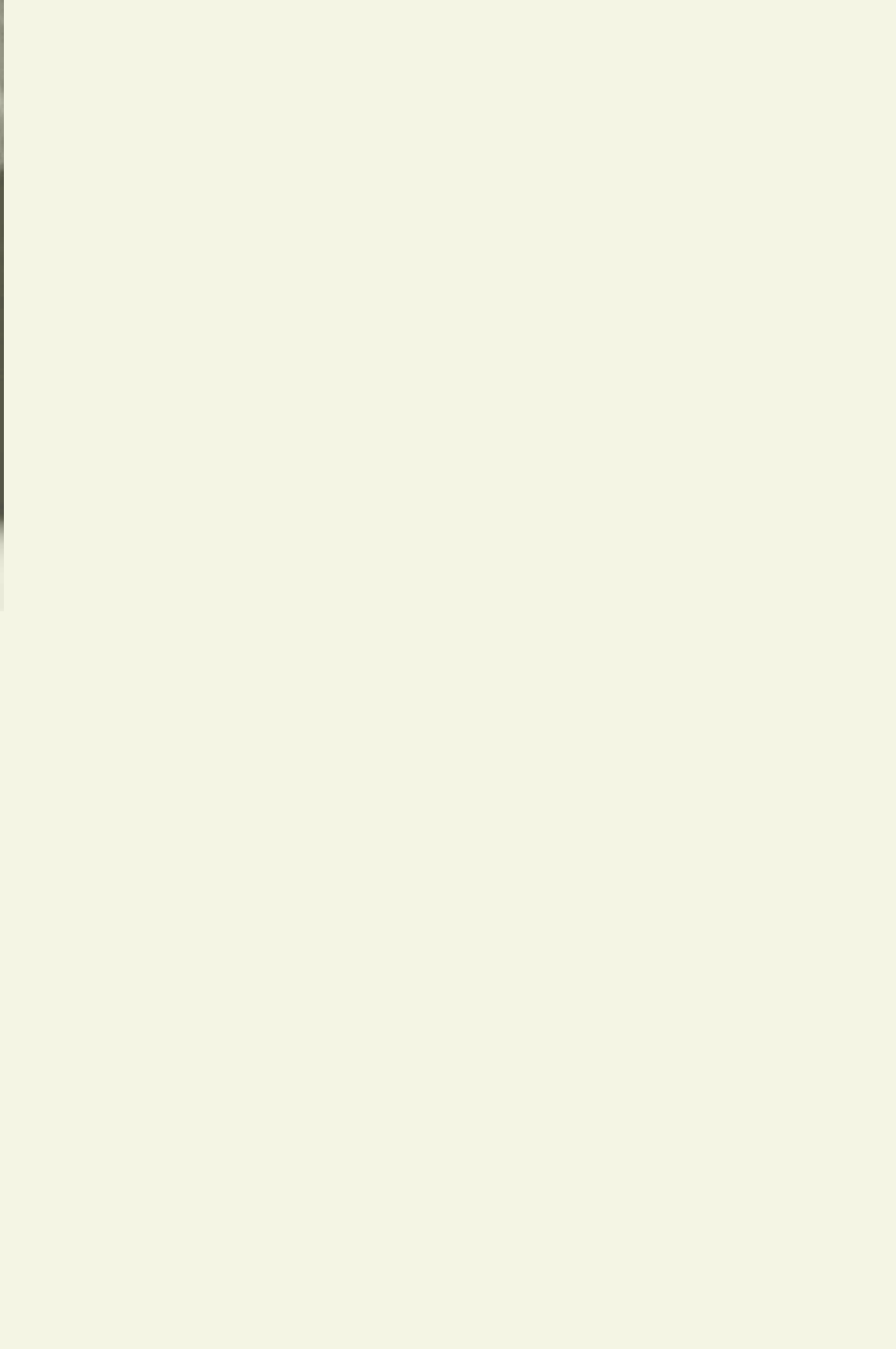


## Questions to ask your employer

1. Will I be able to continue to work during treatment?
2. Is my company required to follow the Family and Medical Leave Act?
3. How many sick and vacation days do I have?
4. Will I have to take a leave of absence ?  
If I do, will I still have insurance coverage?
5. Do I have disability insurance?
6. Will I qualify to use disability insurance?
7. How are going to tell your employer? Your co-workers?

## Resources to help with work related questions

- Human resources at your place of employment
- American Cancer Society [www.cancer.org](http://www.cancer.org)  
1-800-ACS-2345 (1-800-227-2345)
- Working Women with Cancer  
[www.cancerandcareers.org](http://www.cancerandcareers.org)
- Family and Medical Leave Act  
<http://www.dol.gov/esa/whd/fmla>  
1-866-4USWAGE (1-866-487-9243)  
TTY:1-877-889-5627
- Drake University Legal Clinic 1-515-271-3851
- University of Iowa College of Law Legal Clinic  
1-319-335-9023
- Iowa Legal Aid [www.iowalegalaid.org](http://www.iowalegalaid.org) 1-800-532-1275





[www.CancerIowa.org](http://www.CancerIowa.org)  
1-800-237-1225

For more information or to order this guide,  
contact 1-800-237-1225 or [staff@CancerIowa.org](mailto:staff@CancerIowa.org)