CISCRP

AWARE for All
LONG ISLAND

# FREE COMMUNITY HEALTH EVENT

## HOFSTRA UNIVERSITY'S STUDENT CENTER
## THURSDAY, NOVEMBER 7, 2019

### 5:00PM – 8:00PM
**Free Health Screenings & Information Alley**
Alcohol Screenings, Blood Pressure, Chlamydia, Dental Screenings, Flu Vaccines, Gonorrhea, Hep C, HIV, Oral Cancer Screening, Stroke Assesment, and Substance Abuse

### 6:00PM – 6:10PM
**Opening Remarks**
**Ellyn Getz**, Associate Director, Development & Community Engagement

### 6:10PM – 6:45PM
**Overview Presentation**
*"What Clinical Research Means to You"*
**John A. Boockvar,** MD, Vice Chair, Dept. of Neurosurgery
Director, Brain Tumor & Pituitary/Neroendocrine Centers Lenox Hill Hospital/Manhattan Eye, Ear and Throat Hospital

### 6:45PM – 7:45PM
**Panel Discussion**
*A chance to hear from local research professionals and study participants about their experiences in clinical research*

### 7:45PM – 8:00PM
**Medical Heroes Ceremony & Raffle**
**Closing Remarks**

**Complete two onsite surveys to be entered into the raffle**
***Must be present to win***

WIN PRIZES!

# **Clinical trials:** Be a part of the discovery

**Clinical trials are research studies that explore whether a medical strategy, treatment or device is safe and effective for humans. These studies also determine which medical approaches work best for certain illnesses or groups of people. The purpose of clinical trials is to find ways to more effectively prevent, diagnose or treat diseases. There are strict scientific standards that protect patients and help produce reliable results.**

At Northwell Health, we have more than 400 clinical investigators enrolling in clinical trials with the support of more than 270 research coordinators, nurses and assistants.

## Why should you enroll in clinical trials?

1. **You can help advance medicine.** Clinical trials are at the heart of all medical advances and provide the most accurate information for individuals to make healthcare decisions. Every medicine available today was initially passed through a clinical trial. Being a part of the trial gives you the chance to make a difference.
2. **You'll have access to new treatments.** New drugs and devices take many years to make it to the market; first, they must go through a rigorous approval process by the FDA. By participating in a clinical trial, you could have the opportunity to benefit from these treatments much sooner.
3. **You can monitor your disease closely.** Studies have shown that clinical trial participants receive careful attention and monitoring of their conditions. You are under the constant care of the research team.
4. **You trust your physician.** If your physician believes the clinical trial is a valid option, it is beneficial to follow their guidance.
5. **You can pay it forward.** Clinical trials offer hope for many people, including you, your family and community. Long term, they can help others with the same condition you might have.

**Interested in learning more?** Contact us at **(516) 881-7067** or **clinicaltrials@northwell.edu**. You can also visit us at **northwell.edu/clinical-trials**.

Feinstein Institutes for Medical Research
Northwell Health®

**Office of Clinical Research**
1981 Marcus Avenue
Suite E110
Lake Success, NY 11042

November 7, 2019

Dear *AWARE for All* attendees, supporters and friends:

It is with great pride and excitement that we welcome you to *AWARE for All – Long Island*. Today serves as an important milestone in building awareness about both clinical research participation and the crucial role that clinical research volunteers play in advancing new medicines.

We would like to thank all the members of the Planning Committee for their assistance in bringing *AWARE* to Long Island for the first time and in developing this educational, outreach program. We are very grateful for the support from our Host Sponsor Northwell Health, National Sponsors Lupus Research Alliance and EMD Serono, Patron Sponsors Backpack Health and BRANY, and Outreach Supporters Alzheimer's Association, Allergy & Asthma Network, Project Safety Net and Susan G. Komen.

The terrific response *AWARE for All* has received from this community has been heartwarming and convinces us even more of the important need this program fills. With the assistance of over 350 community partners, brochures were distributed, posters were displayed, and announcements and articles were included in newsletters and on websites throughout the state.

Special thanks to Northwell Health, Project Safety Net, St. John Episcopal Hospital—Department of Surgery, and Walgreens for providing and staffing today's health screenings. It is a great service to the community to be providing screenings for Alcohol Screenings, Blood Pressure, Chlamydia, Dental Screenings, Flu Vaccines, Gonorrhea, Hepatitis C, HIV, Oral Cancer Screening, Stroke Assessment, and Substance Abuse. Please be sure to visit the health screenings today from 5:00pm – 8:00pm.

We are also very grateful to today's researchers for sharing their knowledge and expertise with *AWARE for All* attendees. In addition, we would like to thank our study participant panelists whose personal stories are captivating, powerful, and inspirational.

Please remember to fill out the evaluations before and at the conclusion of the overview presentation. We value your input and appreciate your participation in *AWARE for All – Long Island*! To continue the conversation and learn about other helpful resources, we encourage you to visit www.ciscrp.org.

Kind regards,

Ken Getz
Founder & Board Chair
CISCRP

Ellyn Getz,
Associate Director, Development & Community Engagement
CISCRP

Hope Ventricelli
Senior Events Coordinator
CISCRP

Johanna Walsh
Events Marketing Coordinator
CISCRP

# Planning Committee

*CISCRP wishes to thank the AWARE—Long Island planning committee for all their hard work and dedication to bring this program to fruition!*

## Alzheimer's Association Long Island Chapter

Kate Anastasia, Director of Programs

## Biomedical Research Alliance of New York (BRANY)

Kim Irvine, Executive Vice President & Chief Operating Officer

## The Center for Information & Study on Clinical Research Participation (CISCRP)

Joan Chambers, Senior Director, Marketing & Outreach
Ellyn Getz, Associate Director, Development & Community Engagement
Katherine Marriott, Marketing and Communications Coordinator
Leslie Perez, Marketing and Communications Coordinator
Hope Ventricelli, Senior Events Coordinator
Johanna Walsh, Community Engagement and Events Marketing Coordinator

## Lupus Research Alliance

Diane Gross, National Director, Advocacy and Programs

## Northwell Health

Christina Brennan, MD, MBA, VP, Clinical Research
Janine Sandy, Senior Executive Assistant to VP of Clinical Research
Giovanna DeLeon, Administrative Support Associate
Yihenew Abetu, CCRC, ACRP-PM, Manager, Research Education
Christine Hannigan, Senior Administrative Director
Anita Haridat, Manager, Investigator Support
Hallie Kassan, CIP, Director, Office of the HRPP
Michelle Kong-Rosario, Clinical Research Supervisor
Raquel Lima, Admin Manager
Kristine McGowan, Manager, Clinical Research
Asha Mellor, Admin Manager, Research
Betsy Moclair, RN, BSN, CCRC, Director, Clinical Research Programs
Natasha Phrsai, Director, Investigator Support
Ramona Ramdeo, Director, Clinical Research Programs

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## Key Community Supporters

*Thank you to the many individuals and organizations who helped to engage the community about this educational initiative. A big thanks to the following teams who extensively promoted this program and provided us with educational and health resources.*

ACRP
Adelphi University
Adelphi NY Statewide Breast Cancer Hotline &
American Cancer Society
The American Foundation for Suicide Prevention
American Red Cross
Apicha Community Health Center
Support Program
ALS Association—Greater New York
Alzheimer's Association—Long Island Chapter
American Diabetes Association
American Heart Association
American Lung Association
Apicha Community Health Center
Association for Mental Health and Wellness
Arthritus Foundation
Asthma & Allergy Network
AWCA NJ
Backpack Health
Bens Crab
Big Brothers Big Sisters
Bio IVT
Biomedical Research Alliance of New York (BRANY)
Boots on the Ground NY
Boston Market
Brain Aneurysm Foundation
Brain Injury Association of New York State
Breast Cancer Hotline Adelphi
Bronx Veterans Medical Research Foundation
Bryant Park Library
CancerCare
Catholic Charities Diocese of Rockville Centre
Catholic Health Services of Long Island
The Center for Translational and Basic Research
(CTBR) Hunter College
CENTRO SALVADORENO, INC.
The Cerebral Palsy Association of Nassau County
Children Care Council of Nassau
Childhood Cancer Society
Chipotle Mexican Grill
Christs First Presbytarian Church
Círculo de la Hispanidad
Colette Coyne Melanoma Awareness Camaign
Cross Island YMCA
Diabetes Research Institute Foundation
Diabetes Resource Coalition of Long Island
Dunkin Donuts
EAC Network
East Meadow Library
EMD Serono
Empire Justice
The Ethical Humanist Society of Long Island
Family & Childrens Association
Family Dollar
Fountain of Life Church
Five Towns Neuroscience Research
Friends of Bridge
Garden City Library
Gilda's Club NYC
Grace Cathedral International
Grace Lutheran Church
H Mart
Healthy Latino Community
Healthix
HealthyVibe
Health and Welfare Council of Long Island
Health and Wellness Farmacia Inc
Hempstead Library
Hempstead Park Nursing Home
Hicksville Library
The Hispanic Counseling Center
Hofstra University School of Medicine - Office of
Diversity & Inclusion
Hofstra Counseling and Mental Health Professions
Clinic
Hudson River Health Care

*To receive a complete list of community supporters, please email awareforall@ciscrp.org.*

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Human First
Iglesia Cristiana Bet-EL
The INN
Interfail Nutrition Network
Island Harvest
Jersey Mikes Subs
Key Food
King Kullen
Korean American Association of Greater New York
The Korean American Community Foundation
La Sevillana Bakery Inc
Life Center
Long Island Advocacy Center
Long Island Cares
Long Island Community Hospital
Long Island Crisis Center
Long Island Health Collaborative
Long Island Progressive Coalition
Long Island TRIO
Long Island Volunteer Center
LI Community Hospital
Lupus Research Alliance
Lustgarten Foundation
Manhasset Public Library
Maurer Foundation for Breast Health Education
Mental Health Association of Nassau County
Mental Health and Wellness
MercyFirst
Mineola Library
Nassau County Dental Society
Nassau County Office of Minority Health and Health
Nassau Rehabilitation & Nursing Center
Nassau University Medical Center
Neuroscience Research at Stony Brook
New York College of Health Professions
New York Health Plan Association
New York Life Insurance
New York Presbyterian
NYS Association of Health Care Providers
National Association of Hispanic Nurses - Long Island Chapter
NAMI
NAMI Queens/Nassau
Disparities Prevention
Nassau-Suffolk Hospital Council
National MS Society
North Shore University Hospital
Northern Westchester Hospital
Northwell Health
Northwest Uniondale Neighborhood Association
NYU The Bluestone Center for Clinical Research
NYU Winthrop Hospital
NYU Langone
Options for Community Living
Our Lady of Fatima RC Church
Parallax Clinical Research, LLC
Pitter Patter Day Care
Popeyes Louisiana Kitchen
Port Washington Public Library
Project Safety Net
Propper Manufacturing Company
Pulse Center
The Rebecca Center
The SASS Foundation
Sarcoidosis of Long Island
Saltzman Center
Salvation Army
Shelter Rock Library
Sarcoidosis of Long Island
St. Josephs College--Nursing
St. John Episcopal Hospital-Department of Surgery
St. Vladimir's Ukrainian Parish Center
Stop & Shop
STRONG Youth
Suffolk Cooperative Library System
Suffolk County Office of Women's Services

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Super Laundry Tajc LLC
Susan G. Komen
TKO Strong
Tonys Pizza
Uniondale Community Center
United Cerebral Palsy Association of Nassau
Uniondale Library
United Healthcare
Veterans Health Alliance of Long Island (VHALI)
Viscardi Center
Visiting Nurse Service and Hospice of Suffolk
Walgreens
Weill Cornell Medical Center
Westbury Library
White Plains Hospital
Williston Park Library
Yes We Can Community Center
100 Black Men
7-11
99 Cents Mall

## Health Screenings (from 5:00PM—8:00PM)

Our health screenings are provided around the Multi-Purpose Room and in Rooms SC0141 and 0145

*Alcohol Screenings, provided by Northwell Health*
*Blood Pressure, provided by Northwell Health*
*Chlamydia, provided by Project Safety Net*
*Dental Screenings, provided by St. John Episcopal Hospital—Department of Surgery*
*Flu Vaccines, provided by Walgreens*
*Gonorrhea, provided by Project Safety Net*
*Hepatitis C, provided by Project Safety Net*
*HIV, provided by Project Safety Net*
*Oral Cancer Screening, provided by Northwell Health*
*Stroke Assessment provided by Northwell Health*
*Substance Abuse, provided by Northwell Health*

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# Agenda

**5:00PM—8:00PM: Health Screenings & Information Alley**
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**6:00PM—6:10PM: Opening Remarks**
Ellyn Getz, Associate Director, Development & Community Engagement, CISCRP

**6:10PM—6:45PM: Overview Presentation—*What Clinical Research Means to You***
John A. Boockvar, MD, Vice Chair, Department of Neurosurgery
Director, Brain Tumor & Pituitary/Neuroendocrine Centers Lenox Hill Hospital/Manhattan Eye, Ear and Throat Hospital

**6:45PM—7:45PM: Panel Discussion about Clinical Research in Long Island**

Christina Brennan, MD, MBA, VP, Clinical Research, Northwell Health

Christele Felix, Study Volunteer

Raffaella Hart, MA, CIP, VP, IRB and IBC, Biomedical Research Alliance of New York (BRANY)

Lisa Heller, Study Volunteer

Hallie Kassan, MS, CIP, Director, Office of the HRPP
The Feinstein Institutes for Medical Research, Northwell Health

Mark J. Sinnett, PharmD, FASHP Chair of IRB, BRANY
Assistant Director, Clinical and Educational Pharmacy Services
Division of Pharmacotherapy, Montefiore Medical Center

Jeannine Villella, D.O., FACOG, FACS
Vice Chair, Gynecology, Chief, Gynecologic Oncology, Lenox Hill Hospital

**7:45PM—8:00PM: Ceremony to Honor Study Volunteers (Medical Heroes)**
**Raffle & Closing Remarks**


Welcome to AWARE for All—Clinical Research Education Day. We're thrilled that so many of you are joining us to learn more about clinical research.

This program is brought to you by CISCRP, the Center for Information and Study on Clinical Research Participation.

Our goal is to help you understand the clinical research process – including the risks and benefits of participating.


Have you ever taken an allergy medicine? Have you ever given your child a pain reliever? Perhaps you have a friend or a family member who is a cancer survivor.

If so, you can thank a clinical research volunteer.

Around the world people are living longer, healthier lives because someone they never met took part in a clinical research study. And that research helped find a way to prevent, treat or cure a certain medical condition.

That's why we like to call these volunteers "Medical Heroes."


Most people don't understand what clinical research is all about. Some people are afraid. They may think clinical research volunteers are treated like "guinea pigs." Or they've heard news stories about clinical trials that have gone wrong. Or they still remember past abuses when there were no protections in place for clinical research volunteers.

That's why, at CISCRP, we believe in 'Education before Participation.' We think the more people understand about research, the more they'll appreciate those who are research volunteers. And the more likely they'll be to think about volunteering.

## What do we learn from studies?

- How does a disease progress and how can it be prevented?
- How well does a new drug work or not work?
- Is there a better way to treat a disease?
- How are genes connected to illnesses?

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What we learn from clinical research studies improves public health.

And it all starts with these questions.

Researchers can only answer these questions with the help of clinical research volunteers.

## What is a clinical trial?

- Scientific study that answers a medical question.
  - Is a treatment safe?
  - Does it improve a certain medical condition?
  - Does it have side effects?
  - How should people take it?
  - Is it any better than medicines that are already on the market?

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So what is a clinical trial? It is a carefully designed study where researchers ask volunteers to do something -- like take a new drug or take several medicines at once – so they can answer a specific medical question.

Is a treatment safe? Does it improve a certain medical condition? Does it have side effects? How much should people take? Is it any better than medicines that are already on the market?

Because researchers don't have the answers to all these questions, there are risks to participating in a clinical trial. But in all cases, something was learned from the clinical research study that helped improve public health.

## A clinical trial is NOT the same as standard of care

- Standard of Care
  - Routine care
  - Has been tested and approved
  - Works for most people
- Clinical Trial
  - Looks for answers to a scientific question
  - Still learning how it works

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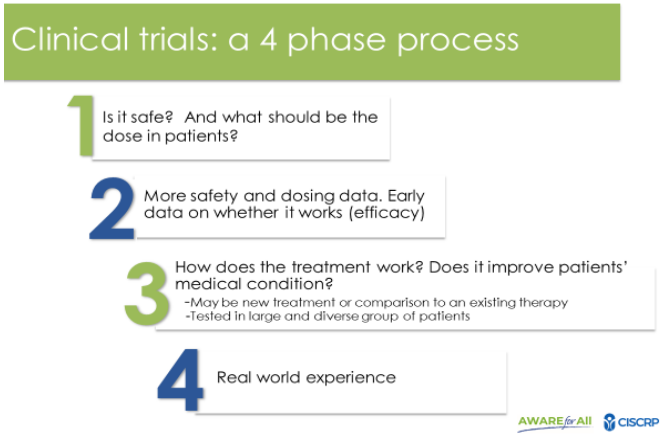
It's important to understand that being in a clinical trial is not the same as going to your doctor for care. When you go to your doctor, she will give you a treatment that has already been tested and approved by the government. This is called "routine" or "standard of care." This is the care we know works for most people. This is the care you would get if you go to the doctor for regular check ups or if you had a health problem.

An example of usual care is a person breaks a bone and the doctor applies a cast. We know how it works for most people. An example of a clinical trial is: checking whether a new drug keeps breast cancer from coming back.


You cannot fully understand something by studying just one group of people.

We know that things like being male or female, age, race and ethnic background – affect the way people respond to diseases and treatments. For example, Alzheimer's disease happens twice as often in women than men. Type-2 diabetes and asthma are more common in African Americans. Hispanics, Asian and White women are more likely to develop osteoporosis. Children respond to drugs differently than adults.

That's why scientists need all different types of people to volunteer for research.



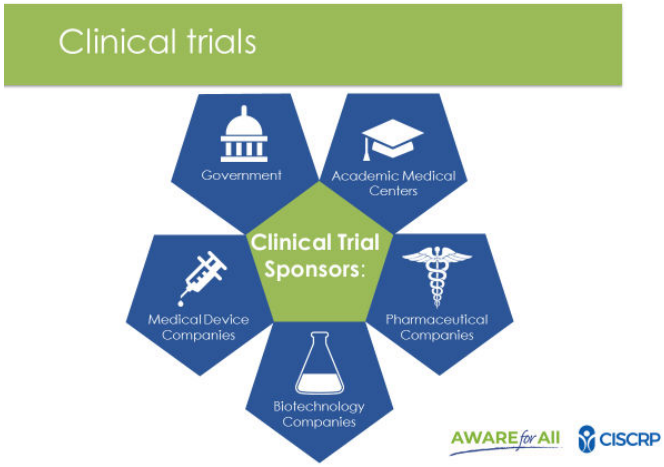

During phase 1 studies, a drug is tested for the first time with a very small number of volunteers. And often these are healthy volunteers. The goal of these trials is to learn what is a safe dose. And how does it work in the body? Is it harmful?

In phase 2 studies, researchers begin to understand how well a drug works. And if it is safe for patients who have a specific disease or condition. Like phase 1, safety is still the main goal. Phase 2 studies look to answer such basic questions as: how much should people take? And what are the usual side effects?

Only about one-third of drugs that enter clinical testing ever successfully complete phase 2 and progress to larger, phase 3 studies. This stage provides hard facts about a drug from a large group of patients. At this stage, researchers may check the drug's safety and how well it works in different groups of patients. Or the trial may compare the new drug with an already approved drug.

Phase 4 studies happen after a treatment has been approved by the Food and Drug Administration. They usually involve large numbers of patients who are regularly taking a medicine. Phase 4 studies look at real world experience and check to see if the drug works well over a long time.

This whole process of all phases could take over ten years!




Clinical trials can be sponsored by the government, academic medical centers, pharmaceutical companies, biotechnology companies or medical device companies.


Research involves a lot people who do different things. Like members of a sports team, clinical trials have coaches, players, and officials and each person has an important role to play.


The Principal Investigator (PI) is like the head coach of a team. He or she is responsible for organizing and leading the study as well as recording and studying the data. The PI also directs the team.

Like a head coach, the principal investigator follows a play book, which is called the study "protocol." The protocol is a set of instructions that everyone in the game must follow. It is the plan for how the study will be carried out.


The research staff members are like assistant coaches who help the Principal Investigator. The Clinical Research Coordinator handles the day-to-day activity at the research site. He or she has easy access to the principle investigator and is the main contact for volunteers.

If you have questions about the trial or your health, ask the coordinator.

## Volunteer Protections

### Like the referees

- Review the study before it starts
- Make sure the team follows the rules
- Keep you safe and informed

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Referees help protect the safety of volunteers by making sure teams follow the rules. The referees review the study before it starts. The referees keep you safe and give you all the information. The number and type of referees involved in a trial depends on the research being conducted.

## Volunteer Protections

### Institutional Review Boards (IRB)

- Make sure a trial is ethical and fair
- Make sure a trial is not too risky for volunteers
- Receive continuous updates on trial status
  - Serious side effects from study drugs
  - Change in study plan
- Can end a trial if it feels volunteers are not safe

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Every clinical trial is reviewed, approved and watched over by an independent local committee called an Institutional Review Board or IRB. It's the law. The IRB makes sure a trial is ethical and fair and that there is not too much risk for volunteers. During the trial, researchers must let the IRB know if there are any changes in the study plan. Or if volunteers experience serious injuries or side effects. The IRB can end a trial if it feels volunteers are not safe.


## Volunteer Protections

### Food and Drug Administration

- Reviews studies
- Inspects research centers
- Monitors research groups
- Has the final say as to whether or not a treatment is approved

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Referees from the federal government are also involved.

The Food and Drug Administration reviews studies, inspects research centers and monitors research groups. The FDA has the final say in whether or not a treatment is approved.


Now let's talk about the most important members of the team: The research volunteers. Volunteers are like the players on the field. Without them, research can't happen.

We need all different types of people to participate in clinical research. You do not even need to be sick. A lot of research involves healthy volunteers.


Your friends and family may provide you a support system while you are taking part in a study. It is good to talk to your friends and family about the clinical study. They can help you come up with questions to ask your doctor about the study. They can also support you while you participate. In the end it is your job to make the final decision if you will participate in the study.


Everyone has the chance to participate in research - you just have to find the study that is right for you.

Just like a football game there are rules and not everyone can be on the field at the same time.

The research team has a list of requirements for the participants just like the coaching staff draft players. Both the coaches and the players have to know the game and agree to work together.

Let's talk about eligibility first. A 10-year-old would never be allowed to play on a pro football team, right? Why? Because it would be too dangerous.

Just like in sports, clinical trials have "eligibility criteria." These are guidelines that say who can or can't be in a study. Eligibility criteria protect people if a trial might be too risky for them. This helps researchers get results that are correct and mean something.

If you're considering a trial, you must be honest with researchers about your health. Lying or hiding information to get into a trial could endanger your safety and ruin the study.


OK, let's assume the coaches say you're eligible to play. The next question you have to ask yourself is: Do I choose to play? Well, that depends, right? You cannot say whether or not you want to participate without understanding the rules of the game.
What are your responsibilities as a player?
How long will the game last?
What are the risks and benefits of playing?
What are you going to get in exchange for playing?

The "informed consent" process is designed to answer all these questions and is required by the FDA and IRB. This is one of the most important parts of research and it's a term you're going to hear a lot. Before any volunteer can participate in a trial, he or she must read, understand and sign the informed consent form. This is a long form that lists your rights as a volunteer. It includes detailed facts about the trial. It describes your job as a volunteer and any procedures or tests you'll need to have. It will warn you about any known or unknown side effects of the study drug. It describes the benefits of participating in the trial. By signing the form you're saying that you understand the trial and are agreeing to do what the study asks.

The informed consent form is a complex document. The study staff should go through it carefully with you and answer all your questions. You should never feel rushed or pressured to sign the form.

It is important to note that the IRB can ask the researcher to translate the informed consent form to a language the volunteer speaks.

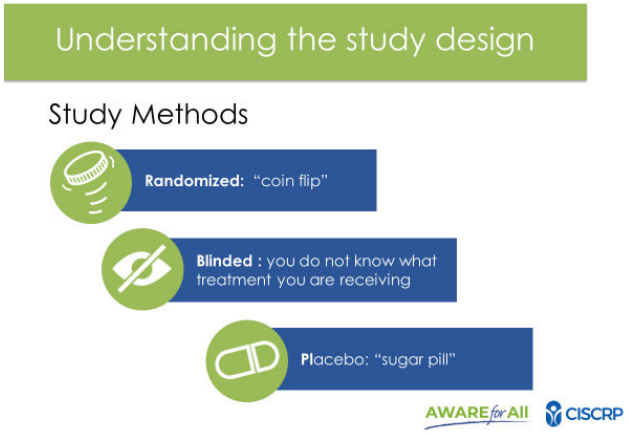

As a research volunteer you have rights. You have the right to understand the purpose, benefits, risks and side effects of the clinical trial.

You have the right to ask any questions and discuss any concerns with the research staff at any time during the trial. And you have the right to full, complete and clear answers.

Most importantly, you have the right to quit the trial at any time for any reason. You are a volunteer and are free to leave the trial if you choose to. The research staff will help you do this safely!


You've heard a lot about clinical trials and your rights and responsibilities as a volunteer. But I'm sure a lot of you are still struggling with the most basic question: "Should I participate or not?"

Deciding to take part in a clinical trial is a personal decision. What's right for the person sitting next to you may not be right for you.

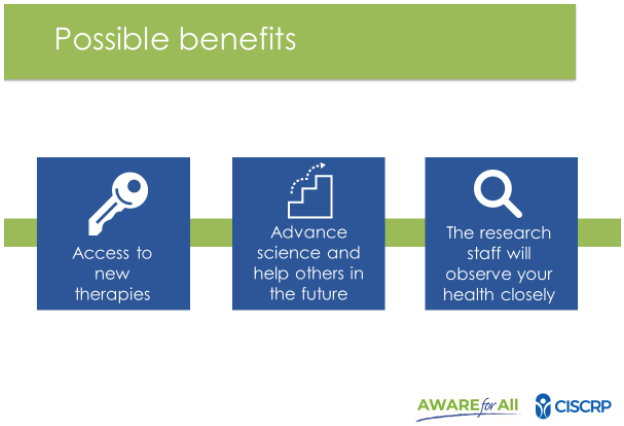



Scientists set up their studies so that their research will be fair. They also want their research to be accurate and unbiased. In other words, they don't want their own ideas about what they think should happen in a trial to influence the results.

To set up fair studies, scientists will often split volunteers into groups by chance. This is like a coin toss. The researcher and the volunteer do NOT get to decide which group the volunteer will be in. This is called a "randomized" study.

Sometimes researchers will go a step further and "blind" a study. This means that the volunteer and the researcher both do NOT know which treatment the volunteer is receiving.

In some trials, researchers will use a "placebo". A placebo looks like medicine but has no medicine in it. Sometimes the placebo is referred to as a "sugar pill" or "dummy drug." What's interesting is that even though the placebo has no medicine in it, there are times when people who are taking a placebo improve or feel better during a trial. This is called the "placebo effect". As a clinical research volunteer, even if you are on a placebo, you will be closely monitored.




Deciding whether or not to participate in a clinical research trial is an important, personal decision. Here are some of the reasons why people say they get involved in research trials.

- √ Get access to brand new therapies that are not yet available on the market;
- √ Advance science and help others with their condition
- √ The research staff will observe your health closely

SOME, but NOT ALL trials will pay for volunteers' travel costs and pay you for your time and commitment. The amounts vary widely. Getting paid should never be your only reason for volunteering.

## Possible risks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All research involves risk – because we are asking a question and do not know what will happen. Researchers do their best to ensure that you are safe, but there are no guarantees. You need to be comfortable with the risks that you might experience.

There can be physical risks. You may not get better. You may even get worse or you may be uncomfortable.

Emotional risk - Most clinical trials ask you to take a quality of life survey to see how you are doing – some of these questions can be upsetting or cause distress.

Financial risk – there could be out of pocket expenses such as parking, child care and missing work. Some insurance companies do not cover research so be sure to check with your insurance provider.

Privacy and confidentiality – usually your health information is private, when you agree to participate in research, you are giving permission for researchers to collect information about you. Researchers must follow rules that protect your privacy and your information.

## Things to consider…


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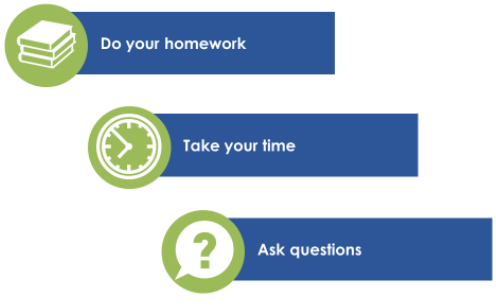
Be sure to let all your doctors know you are in a research trial and have a contact number for the research staff with you in case of an emergency.

Volunteering takes time and effort, be sure you have the time to participate and if you don't just let the study staff know that this is not a good time. You can always stop your participation and volunteer in other ways or in future research.

Even if you want to continue to participate, your doctor, the referees, or the company making the drug could stop the study – be sure to ask these questions when you sign the consent form.

## Education before participation

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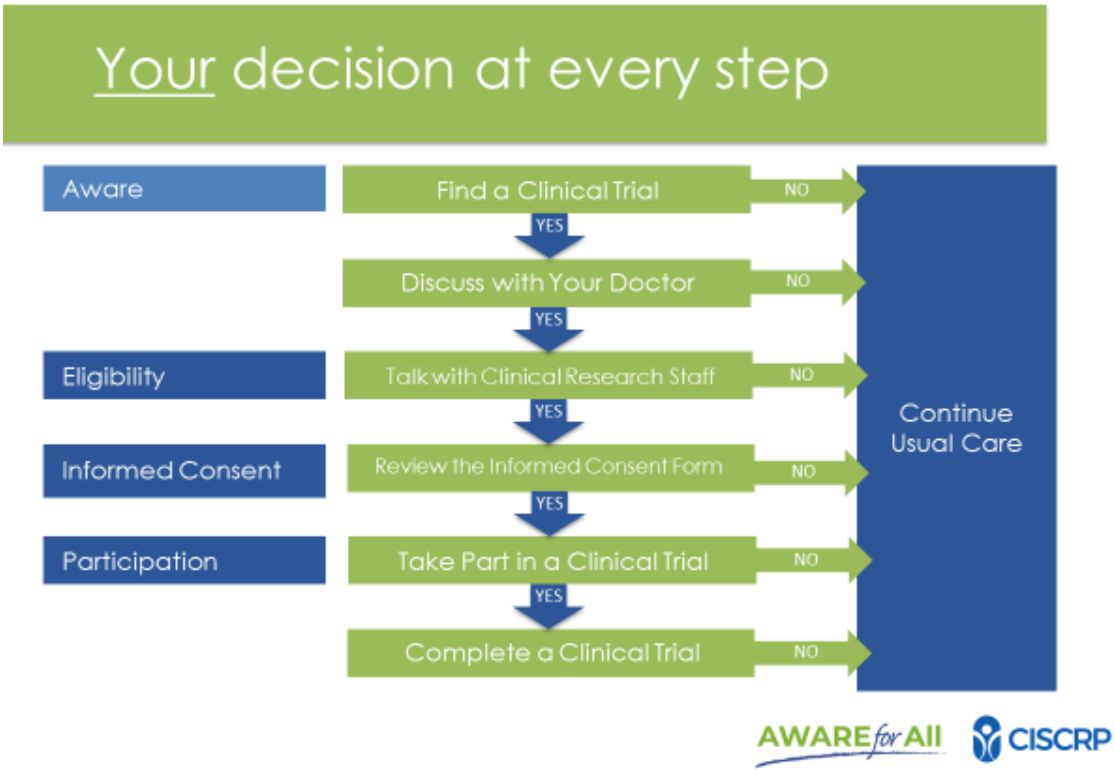
Many volunteers drop out of studies because they didn't fully understand what they were signing up for. Both the volunteers and the research suffer when this happens.

√ Do your homework. Learn about the trial and ask questions. Read all the information provided by the study staff. You may even go on-line to research the treatment being studied.

√ Take your time. There is absolutely nothing wrong with asking a researcher to slow down or explain something using simpler words.

√ Ask questions. Talk about your concerns with the study staff, your doctor and your friends and family. Bring a friend or family member to study visits so they can ask questions too. Try tape recording your visits or take notes so you can refer to the information later and follow up with questions as needed.

If you decide to join a study, you should feel confident that you have made an informed choice. You should feel comfortable that the trial staff will support you and answer all your questions.




Here's a handy way to think about it, at every step.

You start by becoming aware of a certain study. You think you're interested so you discuss it with your doctor. If you're still interested, you need to know all the details. So you talk to the research staff and find out whether you're eligible. If it sounds like something that's right for you, you can choose to sign the informed consent.

But even while you're taking part in the study, continue to ask questions and decide whether you choose to complete the study or not. Informed consent is an on-going process – not a one shot deal.


Remember, today's presentation is an important first step. Now it's up to you to learn more about clinical trials.

The best place to start is with your doctor. You can also get information from your local research center, disease advocacy groups, medical journals and conferences.

There are also a number of web sites devoted to clinical trials. ClinicalTrials.gov is a site maintained by the National Institutes of Health (NIH) that includes trial and enrollment information. CenterWatch.com lists trials that are enrolling volunteers. You may also check ResearchMatch.org to join a matching service for clinical trials. In addition, many pharmaceutical and biotechnology companies list active trials on their web sites.


Research volunteers truly are Medical Heroes without whom medical science cannot move forward. I'd like to sincerely thank you for taking time today to learn about the clinical research process. And I strongly encourage you to share what you've heard with your friends, family and people throughout your community.

On behalf of all of us, I'd like to say "thanks to the millions of people who give the gift of participation in clinical trials each year; and to the rest of us who admire them for doing so."

## For More Information Visit:
www.ciscrp.org

CISCRP provides a free search service designed to help patients find trials that might be right for them.

Call 1-877-MED-HERO or visit
www.searchclinicaltrials.org

# Debunking Common Myths About Clinical Trials

**MYTH:** ***Clinical trial volunteers are merely human guinea pigs.***

**FACT:** Strict guidelines are in place to ensure that all clinical trial volunteers are treated fairly and ethically. Before an investigational drug can be given to people who participate in clinical trials, scientists must do thorough tests of the drug in the lab. Additionally, every clinical trial has an informed consent process to help participants understand their rights, including the right to leave the trial at any time.

**MYTH:** ***Informed consent is just reading and signing a piece of paper.***

**FACT:** Informed consent is more than just signing a document—it is a process. The informed consent document contains information to help volunteers make a decision about taking part in a clinical trial. This includes all the known information about the safety of the investigational drug and how it might work. The informed consent document describes the purpose of the trial and explains what will happen during the trial. It also includes the possible risks and benefits of participating. The informed consent process, however, is an ongoing one. It involves conversations with the trial doctor and staff and the chance to ask questions. It is a continuing, interactive discussion, rather than a one-time informational session.

**MYTH:** ***Clinical trials are dangerous because they use new practices and medicines.***

**FACT:** Clinical trials are designed for research purposes, and as a result, some level of risk is involved. However, an investigational drug is given to clinical trial participants only after the drug has been tested in a lab and the FDA has decided the drug may be tested in humans. The safety of trial participants is a top priority for those involved in running the trial. All clinical trials are reviewed before they start by an Institutional Review Board (IRB). This is a committee made up of doctors, scientists and community members who have the responsibility to protect clinical trial participants. The purpose of the IRB review is to make sure that appropriate steps are taken to protect participants' safety and rights both before and during the trial. During the trial, researchers assess and monitor participants' safety.

**MYTH:** ***Once I decide to participate in a clinical trial, I will not be able to change my mind.***

**FACT:** Clinical trials rely on voluntary participation. You are free to leave a clinical trial at any time, even after you have signed an informed consent document and received the investigational drug. However, you should always let the trial doctor or staff know before you decide to leave the trial. This way, they can help you stop safely.

**MYTH:** ***All clinical trials include painful or unpleasant parts.***

**FACT:** While all trials involve some risk and many involve some discomfort or pain, each trial is different. The procedures may also be different. The trial doctor will talk to you about what to expect, and the procedures and risks will be listed in the informed consent document. The IRB will ensure that the risks and benefits are carefully weighed and that the trial is reviewed for unnecessary harm or discomfort before it starts.

**MYTH:** ***Some people who want to volunteer for a clinical trial are told they cannot participate, for no reason.***

**FACT:** Every clinical trial has a protocol, which is a plan that describes how the trial will be conducted. The protocol also includes "eligibility criteria" for who can and cannot take part in the trial. These are guidelines that include the details of the population to be studied in the trial. This includes age range and gender, health condition, and other important details. These eligibility criteria are used to make sure that the researchers can answer the questions about the investigational drug that they plan to study. The criteria can also help identify the population believed to be most likely to benefit from the clinical trial.

**MYTH:** ***I have nothing to gain from being in a clinical trial.***

**FACT:** Before you decide to participate in a clinical trial, you should speak with the trial doctor or staff about the possible risks and benefits of participating. In some trials, participating may mean that you have the opportunity to receive an investigational drug that is not available to people outside the trial. You may also get additional tests and lab work that might not be part of your usual care. While you may not get a health benefit from being in a trial, you may find it helpful in other ways. According to CISCRP's 2013 Perceptions and Insights study, some trial volunteers felt great personal satisfaction in the fact that they played a key role in helping to advance medical science.

**MYTH:** ***Being in a clinical trial is expensive and isn't covered by medical insurance.***

**FACT:** Clinical trial volunteers are rarely responsible for the costs related to participating in the trial. There are two types of costs associated with a clinical trial: research costs and patient care costs. Research costs are those associated with conducting the trial. They include costs for data collection and management, research physician and nurse time, and tests performed purely for research purposes. These costs are usually covered by the sponsoring organization, such as a biopharmaceutical company. Patient care costs are those that are not covered by the research sponsor doing the clinical trial. These include costs for routine care such as visits to a primary care doctor, and clinical trial-related activities that would be done even if a participant was not in the trial. Many health insurance carriers will cover patient care costs, but you should ask the trial doctor or staff which costs will be your responsibility. You should also check with your health insurance carrier about the coverage they provide for clinical trial participants before deciding whether to participate in a clinical trial.

**MYTH:** ***If there is a clinical trial that might help me, my doctor will tell me about it.***

**FACT:** The best place to start is with your doctor, but your doctor may not know about all available clinical trials that might benefit you. You can get information from local research centers, friends and family to help find resources for you. Here are a few websites that might help:

- www.clinicaltrials.gov is a site maintained by the National Institutes of Health (NIH) that includes trials and enrollment information.
- www.searchclinicaltrials.org is a free search service, organized by CISCRP that's designed to help people find trials that may be right for them. You can also call 617-725-2750 to speak with a CISCRP team member who can manually search for you and connect you with a study team.
- www.centerwatch.com lists trials that are enrolling volunteers.

You might also contact a patient advocacy organization by phone or email to help you navigate the process. Many of them have tailored services that can help you with your search and help you understand the options.

## Should I, or Shouldn't I?

### *How to Weigh the Benefits and the Risks*

Participating in a clinical trial is an intensely personal decision, and the stakes differ for each person.

Each individual should consider the risks and benefits, and how trial participation might affect his or her life.

**Potential Benefits—** there are several reasons that people may choose to participate:

√ **To gain access to new investigational drugs**

Depending on the trial, there may be an opportunity to get an investigational drug that is not available to others.

√ **To advance science and help others who have the illness**

Helping researchers learn about new drugs or potential treatments that could aid patients and advance science is a powerful motivation. Many participants are willing to assume some risk because they feel they are helping to make a valuable contribution to research.

√ **To receive compensation for time and commitment**

Along with complimentary medical care, sometimes study volunteers receive compensation for the time and commitment that they must give complying with the study protocol.

√ **To receive free medical care**

The investigational drug or treatment is usually free to the participant. The participant also has their health and medical condition monitored by the trial doctor or staff during the trial.

*I know what I went through with chemotherapy treatment. If I can in any way help someone else not go through that, it can't be anything but good. The trial I'm in is for a possible new treatment for breast cancer and could help millions of people down the road. That in itself outweighs any possible chances of major side effects [for me].*

- Jennie, a participant in a breast cancer relapse prevention trial

**Potential Risks—**there are many things to consider:

√ **Getting a placebo (a pill or treatment that has no effect) instead of the study drug**
Some trials include a control group that gets a placebo so that comparisons can be made between the placebo and the investigational drug. A participant might be randomly chosen to get the placebo and not to receive the investigational drug.

√ **Exposure to harmful side effects**
There are potential risks with any experimental drug or treatment. It's important to know what potential medical problems are associated with the drug or treatment being studied.

√ **The investigational drug or treatment may not help more than the standard treatment**
A participant might stop taking their current treatment and find that the investigational treatment does not help their disease or condition.

√ **Inconvenience**
The trial procedures and visits may interfere with a participant's daily life. There will often be a disruption to the participant's normal schedule.

√ **Unexpected costs**
Although the costs for the investigational drug or treatment and procedures are usually covered, there could be other expenses. These might include travel or hotel costs that may not be covered by the sponsor.

**How to Decide—** two key questions can help you make this important decision:

√ **Do I have all the information that I need to make an informed choice?**
It's important to know as much as possible about the experimental drug or treatment and the clinical trial requirements. This way, you can weigh all the factors. Get information about the trial purpose, the potential risks, and what the protocol requires of you.

Start by getting information from the research center that will be conducting the clinical trial but use other information sources as well.

Get a second opinion about the clinical trial you're interested in; ask your doctor, other health professionals, family, and friends.

√ **Are the risks and impact to my daily life 'worth it'?**
Only you can answer the question of how hard you're willing to push yourself to get the information you need and to be willing to comply with the clinical trial requirements.

*This article was originally published in the June/July 2009 issue of CISCRP's Medical Heroes newsletter.*

# FREQUENTLY ASKED QUESTIONS ABOUT CLINICAL STUDIES

*Choosing to participate in a clinical study is an important personal decision. These frequently asked questions will give you some basic information about what clinical research is and what it means to be a participant. If you have more questions about clinical research in general or about specific studies, talk to your doctor, research staff, family, and friends, Also, please take advantage of the resources in this handbook.*

## What Is a Clinical Research Study?

A clinical research study involves research with human volunteers (also called participants) that is intended to add to medical knowledge. There are two main types of clinical studies: interventional studies (clinical trials) and observational studies.

### Clinical Trials

In a clinical trial (also called an interventional study), participants receive specific interventions according to the research plan (protocol) created by the sponsor of the study. An intervention may be a drug or device, a procedure, or a change in behavior. Clinical trials may compare a new medical approach to a standard one that is already available. They may compare a new drug to a placebo that contains no active ingredients.

When a new product or approach is being studied, it is not usually known whether it will be helpful, harmful, or no different than alternatives that are already available. Researchers try to determine if an intervention is safe and if it works by measuring certain outcomes in the participants. For example, researchers studying a new blood pressure drug might want to find out if participants have lower blood pressure after taking the drug.

### Observational Studies

Participants do not receive a specific intervention as part of an observational study. Researchers assess health outcomes in groups of participants according to a protocol or research plan, but the participants get only their routine medical care. For example, researchers may observe a group of older adults to learn more about the effects of different lifestyles on cardiac health.

## Who Conducts Clinical Research Studies?

Every clinical study is led by an investigator, who is usually a medical doctor. Clinical studies also have a research team that may include doctors, nurses, social workers, and other health care professionals.

Clinical studies can be sponsored (funded) by pharmaceutical companies, academic medical centers, and other organizations. They can also be sponsored by federal agencies such as the National Institutes of Health, U.S. Department of Defense, and U.S. Department of Veterans Affairs. Physicians, health care providers, and other individuals can also sponsor clinical research.

## Where Are Clinical Research Studies Conducted?

Clinical studies can take place in hospitals, universities, doctors' offices, and community clinics. They may also take place at other locations. The location depends on who is conducting the study.

## How Long Do Clinical Research Studies Last?

The length of a clinical research study varies, depending on what is being studied. Participants are told how long the study will last before they join.

## Why Are Clinical Research Studies Conducted?

In general, clinical studies are designed to increase medical knowledge about the treatment, diagnosis, and prevention of diseases or conditions. Some common reasons for conducting clinical studies include:

- Evaluating one or more interventions for treating a disease, syndrome, or condition
- Finding ways to prevent the initial development of a disease or condition, or its recurrence
- Evaluating one or more interventions aimed at identifying or diagnosing a particular disease or condition
- Examining methods for identifying a condition or risk factors for that condition
- Exploring and measuring ways to improve the comfort and quality of life for people with a chronic illness through supportive care

## How Are Clinical Research Studies Conducted?

A clinical study is conducted according to a research plan known as the protocol. The protocol is designed to answer specific research questions, as well as to safeguard the health of participants. It contains the following information:

- The reason for conducting the study
- Who may participate in the study (the eligibility criteria)
- The number of participants needed
- The schedule of tests and procedures
- How often the investigational drug or treatment will be given and its dose
- The length of the study
- What information will be gathered about the participants

## Who Can Participate in a Clinical Research Study?

Clinical research studies have guidelines that describe who can participate. These are called eligibility criteria, and they are listed in the protocol. Some studies seek participants who have specific illnesses or conditions that will be researched. Other studies invite healthy participants to join. And some studies are limited to a select group of people who are asked by researchers to enroll.

The eligibility criteria include factors that allow someone to participate in a clinical study, as well as factors that would disqualify someone from participating. These are based on characteristics such as age, gender, disease type and stage, and treatment history.

## How Are Participants Protected?

One way that participants are protected is through the Informed consent process. During this process, researchers provide potential and enrolled participants with information about a clinical study. This information helps people decide whether they want to join the study and continue to be in the study. The informed consent process should provide enough information for a person to understand the risks and potential benefits of the study. It should also provide information about possible alternatives to being in the study. In addition to the informed consent document, the consent process may include recruitment materials, verbal instructions, question-and-answer sessions, and activities to measure participant understanding.

In most cases, a person must sign an informed consent document before entering a study. The signature confirms that he or she was given information on risks, potential benefits, and alternatives, and that he or she understands this information. Signing the document and providing consent does not create a contract. A participant may withdraw from a study at any time, even if the study is not over. See below “Questions to Ask” for ideas about what to discuss with a health care provider or researcher about participating in a clinical study.

## Institutional Review Boards

Each federally supported or conducted clinical study and each study of a drug, biological product, or medical device regulated by FDA must be reviewed, approved, and monitored by an institutional review board (IRB). An IRB is made up of physicians, researchers, and members of the community. Its role is to make sure that the study is ethical and that the rights and welfare of participants are protected. This includes, among other things, making sure that research risks are minimized and that they are reasonable in relation to any potential benefits. The IRB also reviews the informed consent document before it is provided to potential participants.

Some clinical studies are also monitored by data monitoring committees (also called data safety and monitoring boards). These committees look at safety results during the study and help make decisions about how the study should be conducted to minimize risks to the participants.

Various federal agencies, including the Office of Human Subjects Research Protection (OHRP) and FDA, have the authority to determine whether sponsors of certain clinical studies are adequately protecting research participants.

## Does Participating in a Study Affect Usual Health Care?

Typically, participants continue to see their usual health care providers while enrolled in a clinical study. While most clinical studies provide participants with medical products or interventions related to the illness or condition being studied, they do not provide extended or complete health care. If the participant's usual health care provider communicates with the research team, the participant can make sure that the study requirements don't conflict with their usual care.

## What Are Some Considerations for Participation?

Even when there is no direct personal benefit to being in a study, participation contributes to medical knowledge. What is learned in clinical studies can make a difference in the care of future patients. Study results provide information about the benefits and known risks of new or existing interventions. Clinical trials provide the basis for the development and marketing of new drugs, biological products, and medical devices.

Some other important considerations:

- The safety and the effectiveness of the experimental approach or use may not be fully known at the time of the study.
- Some studies may provide participants with the prospect of receiving direct medical benefits, while others do not.
- Most studies involve some risk of harm or injury to the participant. (For trials approved by IRBs, the IRB has decided that the risks of participation are balanced in relation to anticipated benefits.)
- Many studies require participants to undergo additional procedures, tests, and assessments based on the study protocol. These will be described in the informed consent document for a particular study.
- A potential participant should discuss the informed consent document and study protocol with members of the research team and with his or her usual health care provider.

## Questions to Ask

Anyone interested in participating in a clinical research study should find out as much as possible about the study and feel comfortable asking the research team questions about the study. The following questions might be helpful during such a discussion. Answers to some of these questions would be provided in the informed consent document. Most of these questions are specific to interventional studies, but some also apply to observational studies.

- What is the purpose of the study?
- What are the possible interventions that I might receive during the study?
- Why do researchers believe the intervention being tested might be effective? Why might it not be effective?
- Has the intervention been tested before?
- How will it be determined which interventions I receive (for example, by chance)?
- Who will know which intervention I receive during the study? Will I know? Will members of the research team know?
- How do the possible risks, side effects, and benefits of this study compare with those of my current treatment?
- What will I have to do if I participate? What tests and procedures are involved? How often will I have to visit the hospital or clinic? Will hospitalization be required?
- How long will the study last, and how long will I be in the study?
- Who will pay for my participation?
- Will I be reimbursed for expenses?
- What type of long-term follow-up care is part of this study?
- If I benefit from the intervention, will I be allowed to continue receiving it after the study ends?
- Will results of the study be provided to me?
- Who will oversee my medical care while I am in the study?
- What are my options if I am injured during the study?

*Information adapted from resources provided by ClinicalTrials.gov, a service of the National Institutes of Health.*

# KEEP THE CONVERSATION ALIVE

Your participation at AWARE for All – Clinical Research Education Days played an important role in advancing the future of clinical research. Thank you for building awareness about participating in clinical research and helping fuel the discussion about advancing medical science.

We hope you share your experience at AWARE for All with others, and encourage them to learn more about clinical research.


*"Thank you to the millions that participate in clinical trials each year. Your selfless act is admired and respected."*

*– Center for Information and Study on Clinical Research Participation*

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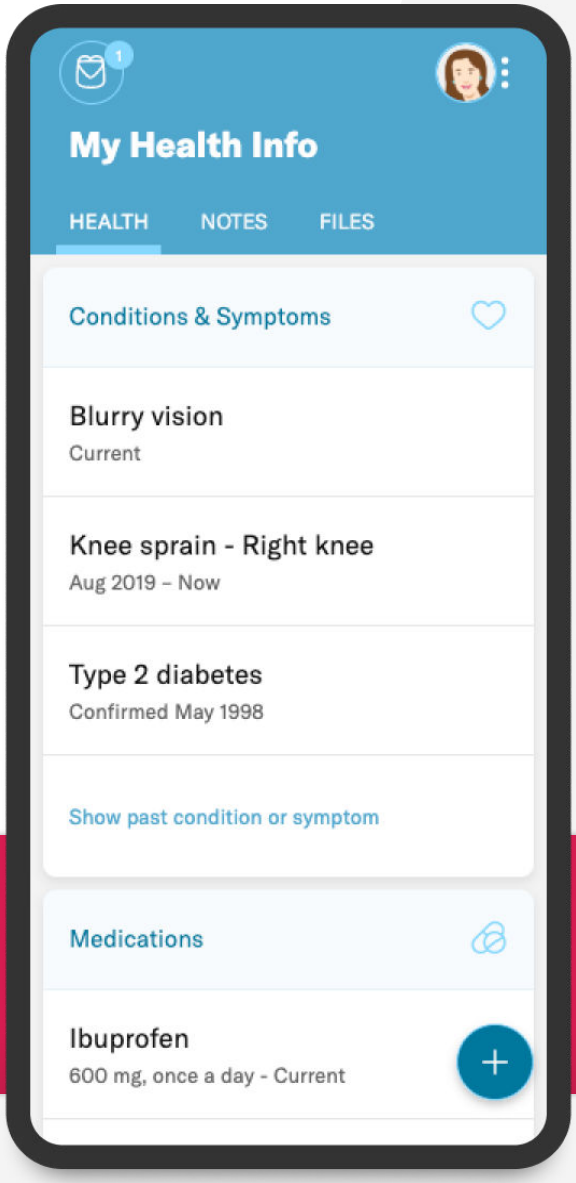


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Interested in More Ways to Stay Involved with CISCRP?

# Participate in One of Our Editorial Panels!

## About This Opportunity

CISCRP's Communicating Trial Results program provides study volunteers with the results of their clinical trials written in plain language. To develop these summaries, we call upon medical professionals, patient advocates and members of the public to form Editorial Panels that review plain language summaries before they are sent to study volunteers.

## Who Can Participate?

✓ General member of the public with no health or research background

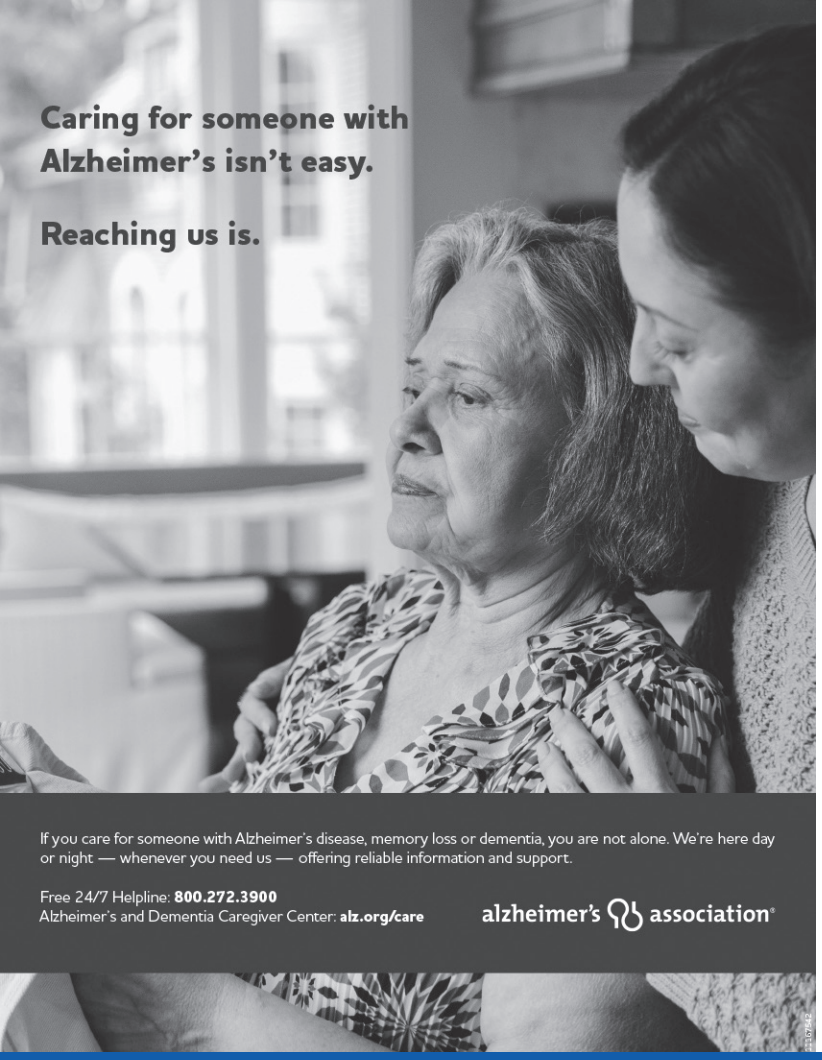
✓ Patient or patient advocate with a disease or condition

✓ Healthcare professional who does not currently work in the clinical trial enterprise

If you are interested in participating or would like to learn more about this opportunity, please contact **Lauren Menna**, our Quality and Compliance Associate.

**Email:** lmenna@ciscrp.org

**Phone:** 617-725-2750 x116

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## CISCRP Offers Opportunities for All Members of the Community to Get Involved

Join our Volunteer Network to help enrich the study volunteer experience, shift public perception around clinical trial participation, and improve public awareness and engagement.

The Medical Hero Alumni Community: Are you a clinical trial participant, friend or caregiver? Join our Alumni Community to share your personal experience and insight. Alumni can contribute in a variety of ways:

- Join a Patient Advisory Board to help review study protocol design
- Participate in an Editorial Panel and review lay language summaries
- Enroll in a Patient Clinical Trial
- Journey Workshop
- Host a booth at local fairs, libraries, schools, etc.
- Attend or speak at CISCRP's upcoming events
- Share your story to be featured in our quarterly newsletter

Ambassador Program – Are you an industry professional? Join our Ambassador Program to share your expertise about clinical studies and advocate for study participants. Ambassadors can contribute by:

- Joining a CISCRP Speakers Bureau
- Speak at CISCRP's Upcoming events
- Host a booth at CISCRP's upcoming events
- Host a booth at local fairs, libraries, schools, etc.
- Share our educational resources
- Serve on our event planning teams

Visit **www.ciscrp.org** | Call **617.725.2750** | Email **info@ciscrp.org**

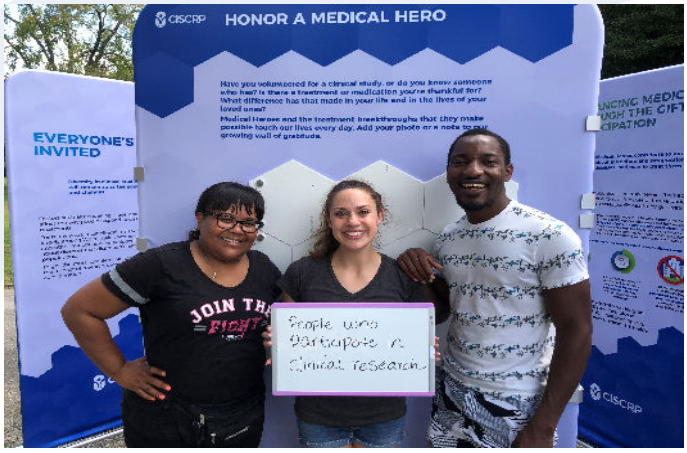
# Journey to Better Health – Educational Exhibit

**There are significant disparities in clinical research literacy among minority and underserved communities. We believe that the way to reach these communities is to meet them where they live, with local ambassadors to guide them to appropriate educational resources.**

CISCRP and Janssen Research & Development, LLC - part of the pharmaceutical companies of Johnson & Johnson have developed an educational exhibit that is journeyed to Atlanta, Chicago, and NYC this summer and fall. Our goal is to bring clinical research education to diverse communities by hosting our exhibit at local health fairs, expos, advocacy and support group meetings, faith-based lunch-and-learns, and community events.


Our exhibit contains the following interactive stations:

- Clinical research navigators to answer questions, address concerns, and serve as personal guides through the exhibit
- Overview of the clinical research process
- Why diversity is important in clinical trials
- Timeline of advancement in public health
- Spotlight on a group study volunteers and their experiences
- Resources & take-aways for individuals interested in clinical research participation




**Check Out Our Interactive Booth!**

On the last leg of this year's Journey to Better Health tour, CISCRP has brought our pop-up to *AWARE for All - Long Island!* The pop-up is located in the exhibitor hall at the entrance to the Student Center. Stop by for an interactive experience. Our final stop on the tour will be at Seniors Health and Wellness Resource Fair in Brooklyn. Please contact Hope Ventricelli with any questions about attending or volunteering at the booth!


Hope Ventricelli · hventricelli@ciscrp.org · 617.725.2750 x 323 · www.ciscrp.org

# WHAT DOES IT FEEL LIKE TO MAKE A DIFFERENCE?

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