



**AWARE** *for* **ALL**  
PHOENIX

CLINICAL  
RESEARCH  
EDUCATION  
EVENT

DÍA PARA  
LA EDUCACIÓN  
DE ESTUDIOS  
CLÍNICOS

UNIVERSITY OF ARIZONA COLLEGE OF MEDICINE  
THURSDAY, DECEMBER 5, 2019

**5:00PM – 8:00PM**

Free Health Screenings & Information Alley  
*Flu vaccines, dental screenings, blood pressure,  
chest-compression-only CPR training, and more!*

**6:00PM – 6:10PM**

Opening Remarks

**6:10PM – 6:45PM**

Overview Presentation  
*"What Clinical Research Means to You"*

**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*

¡Por favor complete las encuestas #1 y #2 para participar en el sorteo!

*Es necesario que esté presente para ganar*

**WIN  
PRIZES!**



**Our mission is clear.  
We are pioneers  
in neuroscience.**

Biogen  
is proud to  
support  
**AWARE for All**  
Phoenix

**Caring Deeply. Working Fearlessly. Changing Lives.™**

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

December 5, 2019

It is with great pride and excitement that we welcome you to *AWARE for All – Phoenix*. 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 Phoenix for the first time and in developing this educational, outreach program. We are very grateful for our national collaboration with Biogen, patron sponsorship from Life Line Screening, and in-kind outreach support from All of Us Research Program, Alzheimer’s Association, Allergy & Asthma Network, Cancer Support Community Arizona, IGNITE, The Society of St. Vincent de Paul, the University of Arizona College of Nursing, and Valle del Sol.

The warm response *AWARE for All* has received from this community has been encouraging 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 Arizona Department of Health Services—Maricopa County, The Society of St. Vincent de Paul, The Southwest Center for HIV / AIDS, University of Arizona Sarver Heart Center, and Walgreens for providing and staffing today’s health screenings. It is a great service to the community to be providing blood pressure and dental screenings, flu vaccines, chest-compression CPR training, and clinic cards for free HIV and STD testing. 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 – Phoenix*! To continue the conversation and learn about other helpful resources, we encourage you to visit [www.ciscrp.org](http://www.ciscrp.org).

Kind regards,

Handwritten signature of Ken Getz in black ink.

Ken Getz  
Founder & Board Chair  
CISCRP

Handwritten signature of Ellyn Getz in black ink.

Ellyn Getz,  
Associate Director, Development &  
Community Engagement  
CISCRP

Handwritten signature of Hope Ventricelli in black ink.

Hope Ventricelli  
Senior Events Coordinator  
CISCRP

[www.ciscrp.org](http://www.ciscrp.org) . One Liberty Square, Suite 1100 . Boston, MA 02109 . [awareforall@ciscrp.org](mailto:awareforall@ciscrp.org)

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## **Planning Committee**

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

### **All of Us Research Program**

Luz Jimenez, Engagement Manager

### **Alzheimer's Association—Desert Southwest Chapter**

James Fitzpatrick, MAS, Director of Public Policy & Advocacy

Katie Skvarce, Communications Director

### **Biogen**

Narinder Chopra, Director Feasibility, Enrolment & Retention Optimisation

Kate Wilson, Associate Director, Feasibility, Enrollment & Retention Optimization (FERO) Global Clinical Operations

Wanda Castro-Borrero, Director, US Medical MS Franchise & Interferons

Yusuf Ghadiali, Senior Director of Global Clinical Operations

Jamie Torrington, Clinical Country Lead

Julie Kennedy, PA-C

Charity Roddy, Senior Manager, Feasibility, Enrollment, Retention, Optimization

Jennifer Sacks, Sr. Manager, Clinical Operations Lead

Liz Thelander, RN, MSN, Associate Director: Global Clinical Operations Sr. Clinical Country Lead: US Central/West Region  
Clinical Country Management

Lisa Wilson, Regional Account Manager, Multiple Sclerosis/Spinal Muscular Atrophy

### **Cancer Support Community Arizona (CSCAZ)**

Viridiana Zendejas, LCSW, Program Director

### **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

# AWARE *for* ALL

## 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.*

100 Club of Arizona	Arizona Alliance for Community Health Centers
2-1-1 Arizona	Arizona Behavioral Health Corporation
About Care	Arizona Care Network
Abrazo Health	Arizona Children Association—Phoenix
Abrazo Health's Paradise Valley Hospital	Arizona Department of Economic Security
Access Administration	Arizona Department of Health Services
ACRP	Arizona Department of Health Services—Maricopa County
Adelante Healthcare	Arizona Health Care Cost Containment System (AHCCCS)
Adult Friendly Arizona	Arizona Hospital and Healthcare Association
Against Abuse, Inc.	Arizona Lung Association
Aid to Adoption of Special Kids (AASK)	Arthritis Foundation
Aetna	Arizona Health Education Center
Aetna Medicaid / Mercy Care Plan	Arizona Hispanic Chamber of Commerce
Aetna Better Health	Arizona Palliative Home Care
Alea Research	Arizona Partnership for Healthy Communities
Alice's Place, an Empowerment Center	Arizona Public Health Association
Allergy & Asthma Network	Arizona State University
All of Us	Arizona State University—College of Nursing and Health
Alma Healthcare	Arizona State University—Center for Health Promotion & Disease Prevention
Alport Syndrome Foundation	Arizona State University—Center for Innovation in Health and Resilient Aging
ALS Association— Arizona Chapter	Arizona State University—Sleep Study
Always Best Care Home Health	Association of Arizona Food Banks
Alzheimer's Association—Desert	AZ Housing Coalition
American Cancer Society	AZOI
The American Foundation for Suicide Prevention	Banner Alzheimer's Institute
American Diabetes Association	Banner Boswell Medical Center
American Heart Association	Banner Health-Bariatric Center Support Group
American Lung Association	Banner Olive Branch Senior Center
American Liver Foundation	Banner University Medical Center Tucson
A New Leaf	Barrow Neurological Institute
Animals (and Humans) in Disaster	Benevilla
Area Agency on Aging	
Arizona Arthritis & Rheumatology	
Arizona Asthma and Allergy Institute	
Arizona Association for Home Care / Arizona Hospice and Palliative Care	

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Benson Hospital	Edson College of Nursing and Health Innovation
Biogen	El Rio Community Health Center
Blue Cross Blue Shield Advantage	El Rio Health
Border, Transborder, and Binational Public Health	Ensign Services
Collaborative Research	Equality Health
Brain Injury Alliance of Arizona	Family Tree Healthcare International
Brighter Way Institute	First Things First
Build Healthy Places Network	Ford Consulting
Bx3 Management Solutions, LLC	Freedom Plaza
CancerCare	Fresh Start Women's Foundation
Cancer Support Community Arizona	FSL
Cenpatico Integrated Care	Glendale Fire Dept. Crisis Response
Central Arizona Health Education Center	Gorden C. James Public Relations
CHEERS Recovery Center	Grand Canyon University
Chicanos por la Causa	Griswold Home Care
Child and Family Resources	Habitat for Humanity Central Arizona
Circle the City	Healthcare Rising
Citadel Post Acute	Health Current
City of Mesa Fire and Medical Department	Health Improvement Partnership of Maricopa County
City of Peoria	HealthSouth Rehabilitation Hospital
City of Phoenix Birth to Five Program	Healthwaves
The Cholangiocarcinoma Foundation	Home Assist Health
ClownTown Healing Fest	HonorHealth Desert Mission
CMG	Hope Lives—Viva la Esperanza
Cochise Health and Social Services	HOPE Network
Cochino County Public Health Services District	HSAG
Consortium with Academic Medicine	Humana
Crisis Preparation & Recovery, Inc.	International Rescue Committee
Crisis Response Network	KC's Home Health Care
Cronkite News	KCC Community Consulting
Cronkite News Community Hospital	Keogh Health Connection
Cystic Fibrosis Foundation	King Dee Tee Kay Enterprises
DaVita	Kingman Regional Medical Center Foundation
Dependable Home Health	The Leukemia & Lymphoma Society
Dignity Health	LFSAZ
Dignity Health Medical Group—St. Joseph's Hospital	Life Choices Women's Clinical AZ
Easterseals Blake Foundation	Lifewell Behavioral Wellness

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LVM Systems	Phoenix Area Indian Health Service (PAIHS)
Maggie's Place	Phoenix Clinical Research
Maldonado Care1st Health Plan AZ	Phoenix Health Systems
Manhellan Complete Care	Phoenix Rescue Mission
Maricopa County Department of Public Health	Pinal County Public Health Services District
Maricopa County Food System Coalition	The Primary Care Association
Maricopa County Human Services Community Development	PV Health Solutions
Maricopa Integrated Health System	Rare Action Network
Maricopa Medical Center	RI International
Maricopa Healthcare Services	Rightcare Foundation
Mayo Clinic Hospital	Rising Stars, LLC
Medix	Sanctuary Hospice
Mercy Care Plan	SandRose
Mercy Maricopa Integrated Care	Shot in the Dark
MIHS	Sonoran Prevention Works
Mission of Mercy	Sound Physicians
Mobile Meals of Southern Arizona	South Mountain Post Acute
Mountain Park Health Center	Southland Home Health
Mountain Vista Medical Center	Special Olympics Arizona
Mt. Graham Regional Medical Center	STAR
NAMI Valley of the Sun	A Stepping Stone Foundation
National Kidney Foundation	St. Luke's Medical Center
The National MS Society	St. Mary's Food Bank Alliance
Native Health	St. Vincent de Paul Family Wellness Program
The Neighborhood Christian Clinic	Steward Health Choice
Neighborhood Outreach Access to Health	Sun Life Family Health Center
Neighbors Who Care	Surprise Fire-Medical Department
Neurologic Music Therapy Services of Arizona	The Society of St. Vincent de Paul
Neurological Physicians of Arizona	Southwest Center for HIV/AIDS
Northern Cochise Community Hospital	St. Luke's Behavioral Health
Palliative Home Care	Survivelt
Patient Advocates AZ	T Gen
Peoria Fire-Medical Department	Tanner Community Development Corporation
Phoenix Allies for Community Health	Team Select Home Care
	Terros Health

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The Bob and Renee Parsons Foundation  
Tucson Medical Center  
United Health Care  
University of Arizona Cancer Center  
University of Arizona Health Plans  
University of Arizona Sarver Heart Center  
University of Arizona Office of Diversity & Inclusion  
Valle del Sol  
Valley of the Sun United Way  
Valleywise Community Health Center  
Vasquez Maricopa County Department of Public Health  
Veterans Justice Outreach Coordinator  
Victory Home Care Agency

Vitalyst Health Foundation  
Walgreens  
Wellsprings of Gilbert  
Wesley Community Health Centers  
Wildfire (formerly AZ Community Action Association)  
Winslow Indian Health Care Center  
Women Veterans Program Manager  
Yavapai Regional Medical Center  
YMCA of Southern Arizona  
YOPAS & Homewatch Caregivers  
Your Patients Advocate  
Yuma County Public Health Services District

*To receive a complete list of community supporters, please email [awareforall@ciscrp.org](mailto:awareforall@ciscrp.org).*

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

Our health screenings are provided around the Health Science Education Building Lobby

*Blood Pressure, provided by Walgreens*

*Dental Screenings, provided by The Society of St. Vincent's de Paul*

*Flu Vaccines, provided by Walgreens*

*HIV and STD Testing Cards, provided by the Arizona Health Department of Maricopa County and the Southwest Center for HIV/ AIDS*





*Spanish interpretation services are available—please ask a volunteer in a blue shirt for a headset.  
Hay servicios de interpretación—por favor, pida ayuda a un voluntario con camisa azul.*

## **Agenda**

### **5:00PM—8:00PM: Health Screenings & Information Alley**

Blood Pressure and Dental Screenings, Flu Vaccines & Clinic Cards for Free HIV and STD Screenings  
Chest-Compression CPR Training

### **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***

Danny Viramontes Apodaca, Clinical Research Coordinator, Banner Alzheimer's Institute

### **6:45PM—7:45PM: Panel Discussion about Clinical Research in Phoenix**

*Moderated by Hope Ventricelli, Senior Events Coordinator, CISCRP*

Wanda Castro-Borrero, US Medical MS Franchise & Interferons, Biogen

Christina Sosa, Research Coordinator, University of Arizona Cancer Center—UAHS

Michael Carrel, Study Volunteer

Andrea Parrella, Patient Advocate and Study Volunteer

Sachin Pandya, Clinical Research Program Manager  
Banner Alzheimer's Institute

Tonya Winders, President and CEO, Allergy & Asthma Network

### **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?



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?



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



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.

## Clinical trials: a 4 phase process

- 1 Is it safe? And what should be the dose in patients?
- 2 More safety and dosing data. Early data on whether it works (efficacy)
- 3 How does the treatment work? Does it improve patients’ medical condition?  
 -May be new treatment or comparison to an existing therapy  
 -Tested in large and diverse group of patients
- 4 Real world experience

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 of 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.



## Principal Investigator (PI)

### Like the head coach

- Organizes the study
- Records and studies the data
- Directs the study staff
- Follows a protocol (play book)

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.



## Clinical Research Coordinator (CRC)

### Like the assistant coach

- Handles day-to-day activities
- Works with principal investigator (PI)
- Main contact for volunteers

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 principal 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



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



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



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.



## Volunteers

### Like the players

- The MOST important team member
- Wide range of studies available (clinicaltrials.gov)
- Healthy volunteers needed too!



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.



## Friends, family and your supporters

### Like the fans

- People to talk to about the study
- Help you ask questions about the study
- Support you during the study



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.



## Eligibility Criteria

Who is the right player for the game?

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.

## Informed Consent

A process to make sure you understand and agree to be in the study



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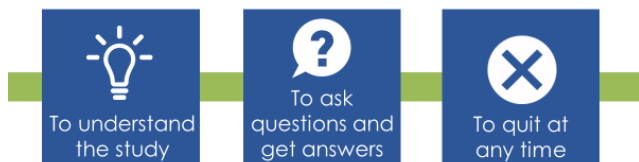
OK, let's assume the coaches say you're eligible to play. The next question you have to ask yourself is: Do I choose to play? Well, that depends, right? You cannot say whether or not you want to participate without understanding the rules of the game. What are your responsibilities as a player? How long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

## You have rights and responsibilities



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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.

## Understanding the study design

### Study Methods



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.

## Possible benefits



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...



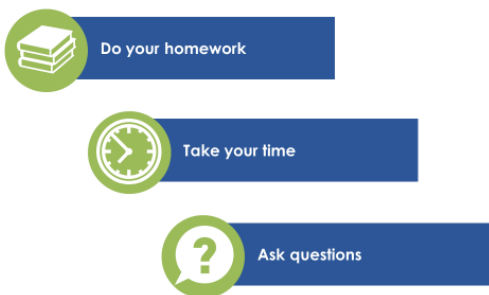
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Be sure to let all your doctors know you are in a research trial and have a contact number for the research staff with you in case of an emergency.

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.

## Your decision at every step



AWARE for All CISCRP

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.

Where should you go to learn more?



- [www.searchclinicaltrials.org](http://www.searchclinicaltrials.org)
- [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- [www.centerwatch.com](http://www.centerwatch.com)
- [www.cisr.org](http://www.cisr.org)

AWARE for All CISCRP

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 websites 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](http://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](http://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](http://www.clinicaltrials.gov) is a site maintained by the National Institutes of Health (NIH) that includes trials and enrollment information.
- [www.searchclinicaltrials.org](http://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](http://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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# Medical Hero Spotlight

## Jeanne Cronin



Alzheimer's is a disease that affects more than 5 million Americans. Jeanne Cronin has an intimate experience, due to her family history. She recalls stories shared by family members about her grandmother, whose behavior resulted in her being moved from nursing home to nursing home. Thinking back Jeanne explains that, although Alzheimer's was not part of the public conversation at the time, her behavior could very well have been symptoms of the disease. Many years later Jeanne noticed her own mother having trouble understanding things and conversing with her while out to dinner for her 60th birthday. It was at this time that she encouraged her mother to visit Massachusetts General Hospital (MGH) where she was later diagnosed with a mild case of Alzheimer's.

Despite these experiences, Jeanne maintained a distance from the topic of Alzheimer's. The disease, on the other hand, continued to take its toll on her family. In 2008 Jeanne's sister was diagnosed with a mild cognitive impairment. Ultimately her sister passed away at the age of 76. Having expressed a desire to donate her brain to science, Jeanne's family was made aware that her sister did indeed have Alzheimer's, along with Lewy body disease. Upon reflection, she shared how grateful she was to have this diagnosis. "I felt like I was able to look back on her behavior, which I previously judged, in a new way." It was at this time that Jeanne expressed her willingness to get involved in Alzheimer's research to Dr. John Growdon, a neurologist at MGH who worked with her sister.

In 2015 Jeanne became involved in an Alzheimer's study at Brigham and Women's Hospital in Boston. The study is testing an anti-amyloid treatment to evaluate its effectiveness in preventing memory loss due to Alzheimer's. In order to be eligible to participate, individuals must have elevated levels of amyloid-beta plaque and not be exhibiting any clinical signs of cognitive impairment or dementia. Confident that she would not display signs of plaque, Jeanne completed all necessary screenings. Unfortunately her tests came back positive. The research staff explained to Jeanne that, although the plaque can lead to Alzheimer's, it is not definitive. Jeanne shared her complete shock and hesitance to continue in the study. "I didn't want to be reminded of the disease with each visit." It was her conversation with another patient, already involved in the study, which helped her decide to continue. Both have a family history of Alzheimer's and were able to speak candidly about their experiences and participation.

Jeanne is currently still enrolled with one year left of the five-year study. Despite being aware that she may be receiving a placebo, Jeanne shares that in her experience, whether she is receiving the drug or not is the least significant part of her participation. She explains that her monthly visits, not only contribute to research, but also help track any possible decline in her memory. Jeanne notes that her visits also serve as a regular reminder of the disease which helps minimize denial, something she often noticed within her family. She emphasizes, "Our minds are so precious that people don't want to deal with it."

For anyone considering participating in a study, Jeanne notes, "You will benefit no matter what the outcome. Ultimately all you need is a willing heart to participate." In fact, she shares that her experience has also changed her perception of the disease. "I'm not as afraid of Alzheimer's as I used to be."

**To share your story and be featured in a CISCRP newsletter contact us at [info@ciscrp.org](mailto:info@ciscrp.org).**



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## Become Our Partner

### What is Precision Medicine?

Precision medicine is health care that is based on you as an individual. It takes into account factors like where you live, what you do, and your family health history. Precision medicine's goal is to be able to tell people the best ways to stay healthy.

### What is the *All of Us* Research Program?

*All of Us* is part of the Precision Medicine Initiative. It will gather information from many people to help researchers learn how to fit the right treatments to the right people. We hope that one million or more people will join the *All of Us* Research Program. We are asking people from all over the United States to join *All of Us* so that our research reflects the diversity of our country. People who join will give us information about their health, habits, and what it's like where they live. By looking for patterns, researchers may learn more about what affects people's health.



### How to Join

1 3 health surveys

2 Physical measurements

3 Blood & urine collection

4 **\$25**  
After completion of basic requirements

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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](mailto:lmenna@ciscrp.org)

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



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