CLINICAL TRIAL LITERACY: EMPOWERING NURSES TO EDUCATE HISPANIC PATIENTS

Recorded on May 1, 2025

Provided by The Leukemia & Lymphoma Society (LLS) in collaboration with the National Association of Hispanic Nurses (NAHN) and The Oncology Nursing Society (ONS).

WELCOME AND INTRODUCTIONS

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Clinical Trial Support Center
The Leukemia & Lymphoma Society
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LEARNING OBJECTIVES

After completing this activity, the participant should be better able to:

- Summarize the brief evolution of research in the United States and its impact on current clinical practice
- Describe the phases of a clinical trial and explain their significance in advancing medical treatments and benefiting the broader population
- Identify key barriers to clinical trial participation, particularly among Hispanic Patients
- Demonstrate effective communication techniques for educating patients about clinical trials
- Apply culturally sensitive strategies to address misconceptions and build patient trust
- Explain how LLS Clinical Trial Support Center can help you and your patients

CE INFORMATION

Registered Nursing Credit Designation
Approval for nurses has been obtained by the National Office of The Leukemia & Lymphoma Society under provider number CEP 5832 to award 1.0 continuing education contact hour through the California Board of Registered Nursing.

- **Method of Participation**
  Learners must participate in the entire activity, complete the post-assessment with a score of 70% or higher, and complete and submit the evaluation form to earn credit. Once completed, the certificate will be generated. If you have questions regarding the receipt of your certificate, please contact us via email at ProfEducation@LLS.org.

  There are no fees for participating in or receiving credits for this activity.
- **Supporters**
  There is no commercial support associated with this activity.

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SPEAKERS

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DISCLOSURE INFORMATION

The Leukemia & Lymphoma Society requires all faculty to fully disclose current and recent financial relationships with commercial interests. A conflict of interest may be considered to exist if such a person has financial relationships with the grantor or any non-eligible entities (commercial interests) that may have a direct impact on the content of the program. Financial relationship is defined as being a shareholder, consultant, grant recipient, research participant, employee, and/or recipient of other financial or material support. Recent is defined as within the past 24 months.

- Jessica MacIntyre, DNP, MBA, APRN, AOCNP, has no relevant financial relationships with ineligible companies to disclose for this educational activity.
- Christopher Otero, BSc, MSN AGNP-C, has no relevant financial relationships with ineligible companies to disclose for this educational activity.
- Leah Szumita, MS, RN, CCRN, ACNS-BC, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

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IN PURSUIT OF *YOUR CURE.*®

Clinical Trial Literacy: Empowering Nurses to Educate Hispanic Patients

Jessica MacIntyre, DNP, MBA, APRN, NP-C, AOCNP®, FAANP

Christopher Otero, BSc, MSN, APRN, AGNP-C

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Designated
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Poll Questions

Poll Question 1

Provide one word that describes what research means to you?

Poll Question 2

Have you been involved in speaking to a patient about participating in a research study or clinical trial?

A. Yes
B. No

Poll Question 3

Do you feel comfortable speaking to a patient about the importance of being part of a research study or clinical trial?

A. Yes
B. No

Poll Question 4

What would help you feel more comfortable being involved in research?

Images taken from Google images

Basics and Background

Research and Common Terms

- **Study**: a **systematic investigation**, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge (Protection of Human Subjects, 2017).
  - Term clinical trial related but not the same as a research study.

- According to the U.S. Food and Drug Administration (FDA): an individual who is or becomes a **participant** in research, either as a recipient of the test article or control.
  - May be referred as a study participant or human subject.

- **PI:** Principal Investigator
- **Sub PI:** Substitute Principal Investigator

- **Informed Consent:** Communication between you and your health care provider that often leads to agreement or permission for care, treatment, or services.

Importance of Hispanics & Clinical Research

- According to the United States (U.S.) Census Bureau (2022), there are 63.6 million Hispanics/Latin (of any race), living in the United States, representing 19.1% of the total U.S. Population.

- Hispanics/Latinos are the nation's second-largest racial or ethnic group after non-Hispanic whites.

- Only 11% participate in clinical trials.

- The underrepresentation of ethnic and racial minorities in clinical trials is a persistent issue in the U.S. despite the National Institutes of Health (NIH) Revitalization Act of 1993.

- Nurses have a unique opportunity to increase accrual of minority patients to clinical trials.

Consequences of poor clinical trial participation

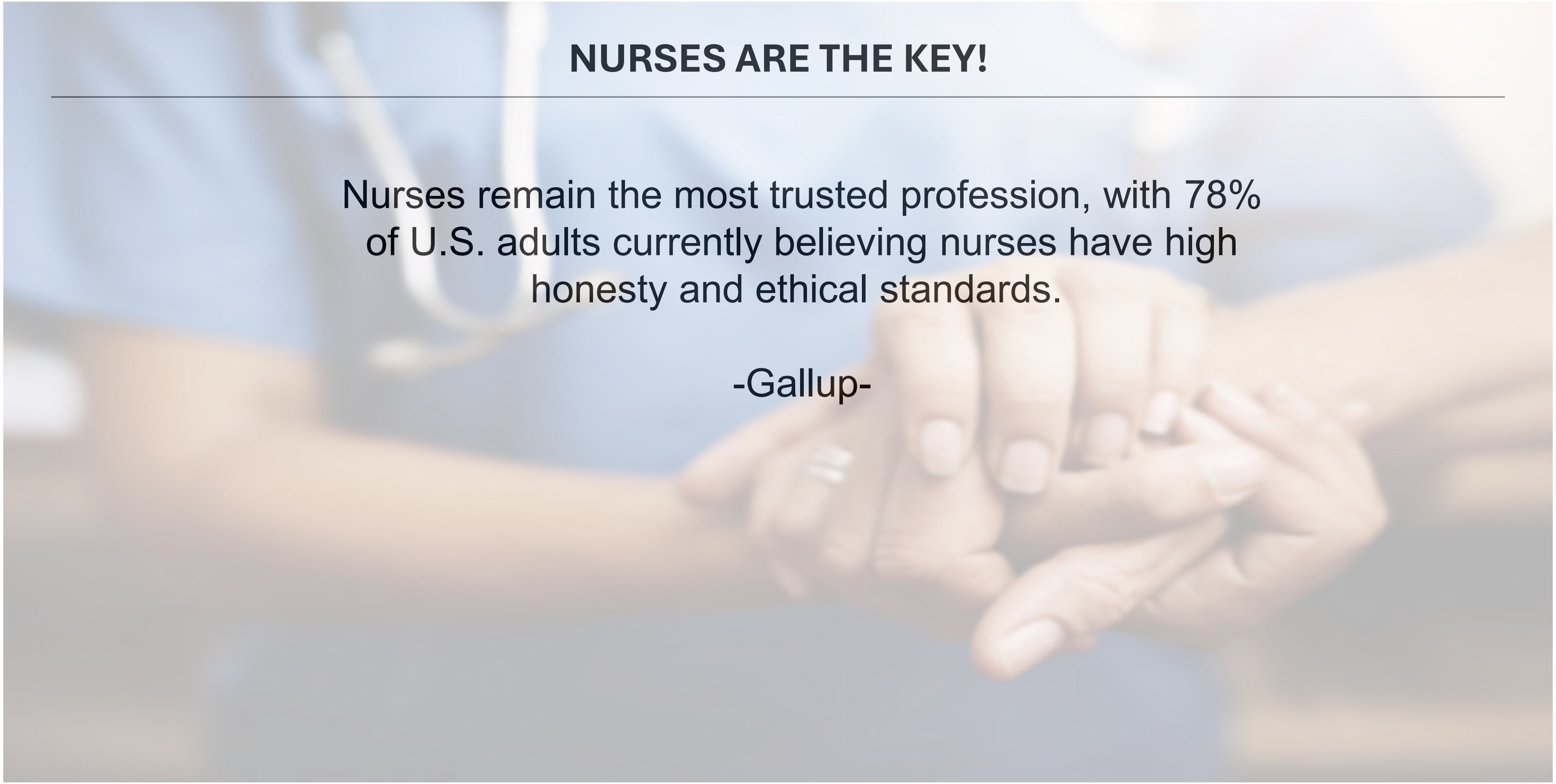
- Lack of access to **quality/optimal care**.
- Trial participants may receive more **comprehensive follow-up.**
- Lost opportunity to evaluate drug responses in a specific **population-differences in drug metabolism exist**.
- Poorer survival observed in minority population may be explained by **genetic factors that interact with effects of drugs**.
- Example: BiDil approved in CHF-combines isosorbide dinitrate and hydralazine hydrochloride was more effective in African Americans.
- Example: Erlotinib more effective in Asian women lung cancer patients who are non-smokers.

History Informs Participation

- Achieving high participant involvement in research can be challenging, especially in communities that have been historically underrepresented in research and where mistrust of researchers is common
- The privilege of conducting clinical research, and of earning and maintaining trust of those who agree to participate in that research, comes with great responsibility.

Image from: University of Miami
https://news.miami.edu/stories/2020/11/research-shows-covid-19-has-hit-hispanic-communities-hard.html

NURSES ARE THE KEY!



Nurses remain the most trusted profession, with 78% of U.S. adults currently believing nurses have high honesty and ethical standards.

-Gallup-

Evolution of Research

Evolution of Clinical Research

562 BC

- In the Book of Daniel: King Nebuchadnezzar wanted everyone to eat a meat and wine diet.
- Nutritional experimentation (meat vs vegetarian)

1747

- Dr. James Lind conducted the first randomized clinical trial (1:1)
- Tested different approaches to the management of scurvy

1863

- First placebo clinical study by Dr. Austin Flint
- Small trial of 13 patients with rheumatism (herbal vs placebo)

1943

- First double-blind controlled study (physicians and patient were both blinded to each treatment arm and only nurses knew what each group received.
- Performed in the UK with over 1K British factory workers looking at the common cold.

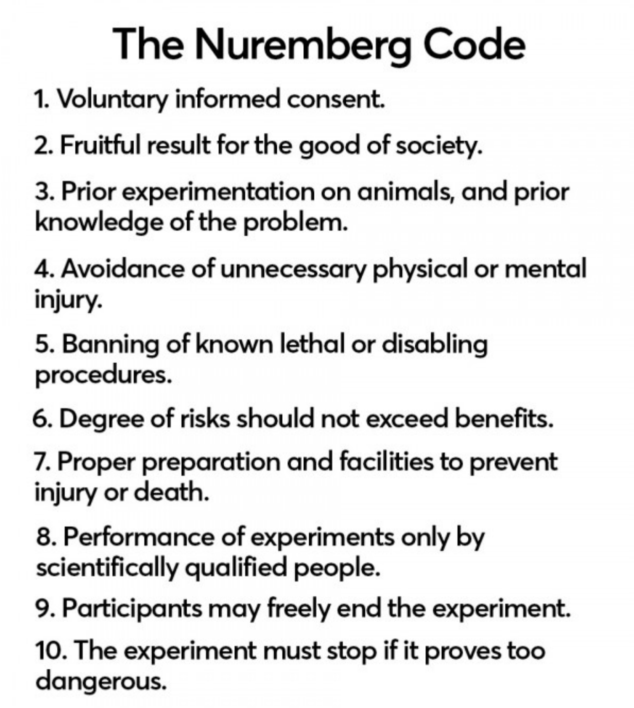
1946

- First curative randomized control trial of streptomycin in the treatment of pulmonary fibrosis.
- Process was similar to what we use today (clear criteria, schedules, data collection, etc.)

Herzog-LeBoeuf C & Willenberg KM. The History of Clinical Trials Research: Implications for Oncology Nurses. Semin Oncol Nurs. 2020 Apr;36(2):150997. doi: 10.1016/j.soncn.2020.150997. Epub 2020 Mar 19. PMID: 32201023.

Importance of Ethics

- Nuremberg Code of 1947
  - Considered the first code of modern research ethics.
  - Written by American judges overseeing trials of doctors who performed "experiments” on prisoners in Nazi Germany.
  - Defined fundamental points necessary for the conduct of research to be ethical.



The Nuremberg Code

1. Voluntary informed consent.
2. Fruitful result for the good of society.
3. Prior experimentation on animals, and prior knowledge of the problem.
4. Avoidance of unnecessary physical or mental injury.
5. Banning of known lethal or disabling procedures.
6. Degree of risks should not exceed benefits.
7. Proper preparation and facilities to prevent injury or death.
8. Performance of experiments only by scientifically qualified people.
9. Participants may freely end the experiment.
10. The experiment must stop if it proves too dangerous.

Image from: https://www.renews.co.nz/

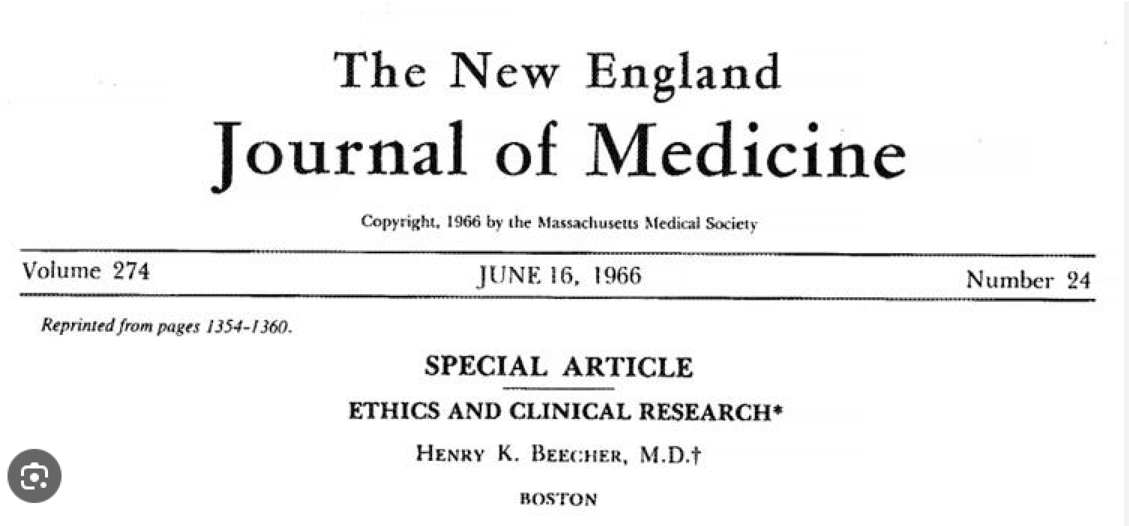
Importance of Ethics

- Declaration of Helsinki
  - Drafted and adopted in 1964 by the World Medical Association.
  - Ethical guidelines for physicians.
  - Added from components of the Nuremberg Code
    - Discontinue treatment if harm to patient and withdrawal language.
    - Legal guardian consent

Image from: https://humanexperimentandethics.wordpress.com/2017/12/06/declaration-of-helsinki/

Ethics in Research

There was a belief that unethical and "bad" research was conducted by bad and unethical people and well-trained physicians who were acting for the good of humanity performed only good, ethically appropriate research.



The New England
Journal of Medicine

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Volume 274 JUNE 16, 1966 Number 24

Reprinted from pages 1354-1360.

SPECIAL ARTICLE

ETHICS AND CLINICAL RESEARCH*

HENRY K. BEECHER, M.D.†

BOSTON

Examples of Unethical Research

Willowbrook school picture
Taken from the College of Staten Island website

Figure 3. Dr. Walter Edmondson of the PHS drawing a blood sample from a study participant during an annual roundup in Milstead, Macon County, 1953. Reproduced from National Archives (in public domain). PHS = Public Health Service.

Picture taken from article :
Tobin, M.J. (2022).

Tobin, M.J. (2022). The Fiftieth Anniversary of Uncovering the Tuskegee Syphilis Study: The Story of Timeless Lessons, American Journal of Respiratory Critical Care Medicine, (10), 1145-1158.

Importance of Ethics

- 1974 creation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.
  - Charged with establishing a code of research ethics.
- Ethics of conducting and being part of a research is an important principle
  - *Belmont report*: Release in 1979.
  - Has remained the primary code underlying the conduct of ethical clinical research in the United States.
  - Provides an ethical framework for the federal regulations designed to protect human research subjects.
  - Three principles:
    1) Respect for Persons (i.e., informed consent & privacy)
    2) Beneficence (i.e., minimize harms and maximize benefits)
    3) Justice (i.e., fair selection)

Additional Safeguards

- Pure Food and Drug Act of 1906
  - Prohibited interstate commerce of contaminated and misbranded drugs.
  - Did not require investigators to demonstrate safety or efficacy of the drug.
- Federal Food Drug Cosmetic Act (FFDCA)of 1938
  - Required that drugs are to be proven safe before manufacturers are permitted to sell them in the interstate commerce.
- Kefauver-Harris Drug Amendment to FFDCA of 1962
  - Increased safety provision requiring that drug manufacturers must prove safety and efficacy.

Image from: Google Images

Phases of Clinical Trials

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Clinical Trial Research

- Clinical Trials are highly controlled clinical experiments used to investigate the systemic effects of specific medications or regimens or methods of administration to determine efficacy, safety, and toxicity.

Phase 0	Examine if a drug produces a desired outcome	Pharmacodynamics, Pharmacokinetic, dosage for future studies
Phase I	Establish maximum tolerated dose by evaluating a drug's pharmacokinetics and corresponding toxicities.	Example: Drug 123GHT in all solid tumors
Phase II	Establish effectiveness in specific tumor types and validate drug properties and toxicities	Example: Drug 123GHT in colorectal cancer
Phase III	Compare agent to standard of care. Validate efficacy and quality of life	Example: Drug 123GHT in colorectal cancer in comparison to FOLFOX
Phase IV	Add to current information about risks and side effects of the new agent or regimen	Example: Drug 123GHT is now showing cardiac toxicity post trial

MAY 28, 2001 www.time.com AOL Keyword: TIME

TIME

THERE IS NEW AMMUNITION IN THE WAR AGAINST

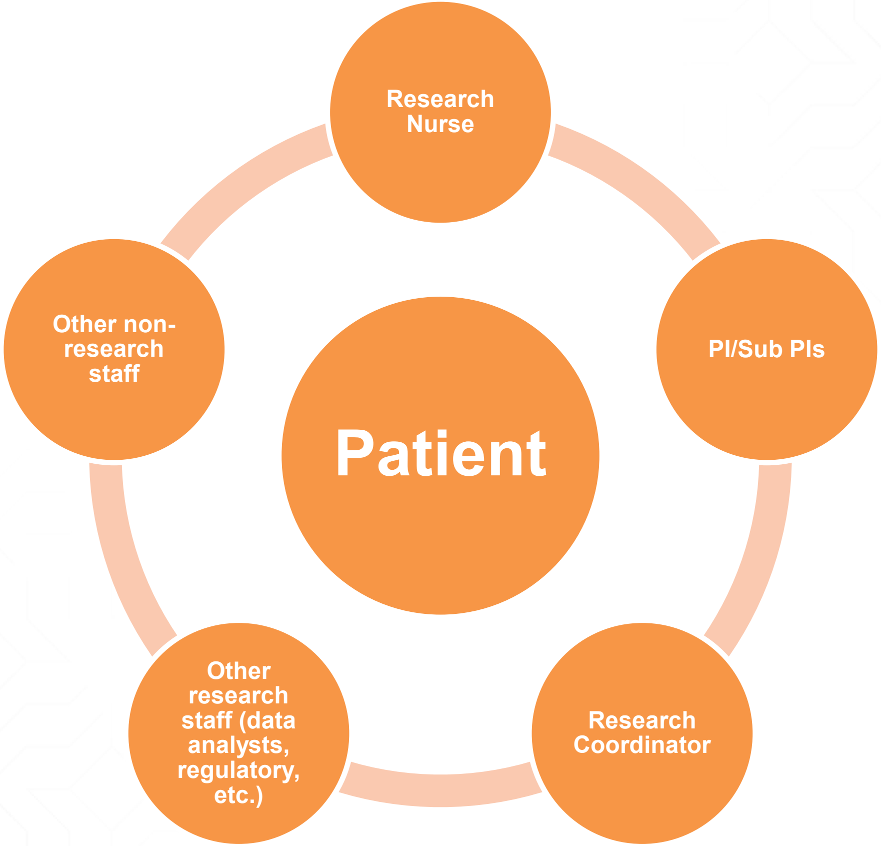
CANCER.

THESE ARE THE BULLETS.

Revolutionary new pills like GLEEVEC combat cancer by targeting only the diseased cells. Is this the breakthrough we've been waiting for?

Image obtained from Google Images

Research is a Team Approach



Patient

Research Nurse

PI/Sub PIs

Research Coordinator

Other research staff (data analysts, regulatory, etc.)

Other non-research staff

Barriers to Clinical Trial Participation in Hispanic Communities

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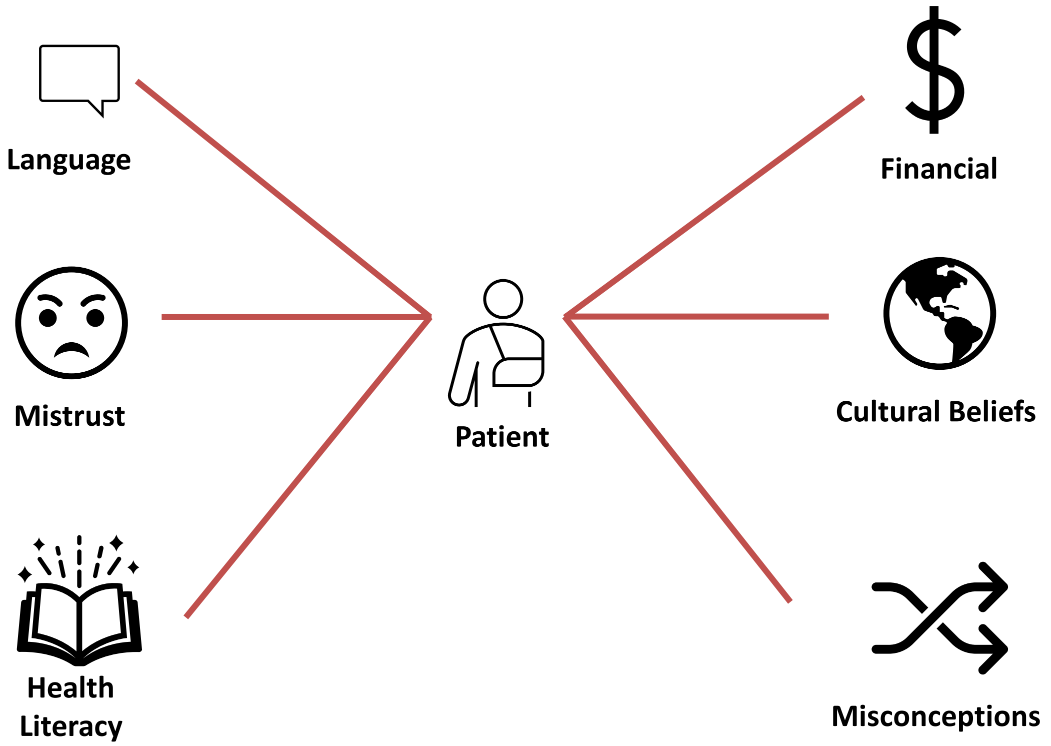
Barriers to Clinical Trial Participation in Hispanic Communities



Language

Mistrust

Health Literacy

Patient

Financial

Cultural Beliefs

Misconceptions

Nearly half of Hispanic adults **(46%)** have a close friend or family member who requires a Spanish-speaking health care provider or translator, highlighting substantial language barriers in health care settings.

Patients with Limited English Proficiency are about **70%** less likely to engage in clinical trials compared to English-proficient individuals.

Hispanic Americans are more likely than other racial and ethnic groups to be uninsured, with **20%** lacking health insurance as of 2019.

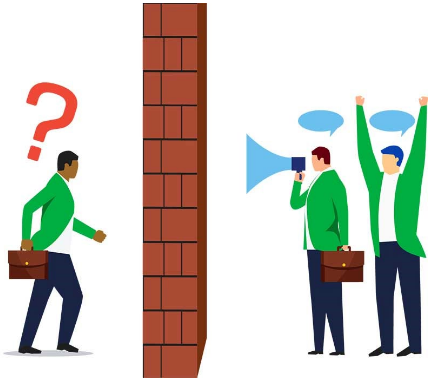
In a 2013 survey of U.S. Latinx cancer patients, only **48%** were aware of clinical trials, despite **65%** expressing willingness to participate

What are some areas of mistrust in healthcare?

- Experiences of discrimination and bias
- Exploitation on research with poor explanation
- Immigration status concerns
- Lack of Hispanic representation among healthcare providers and research teams

Dreyfus et al. (2023). Understanding Hispanic/Latino Participation in Clinical Trials and Observational Studies, and Strategies to Increase Participation. *Project MUSE*. Retrieved from https://muse.jhu.edu/article/882042

Misconceptions and Language Barriers



- Misconceptions: Research for terminal patients.
- Fear of losing autonomy.
- Language barriers hinder understanding.
- Poorly translated materials frustrate.
- Non-inclusive language disconnects culturally.

Arevalo et al. (2016). Mexican-American perspectives on participation in clinical trials: A qualitative study. *Contemp Clin Trials Commun*, 4, 52-57. doi: 10.1016/j.conctc.2016.06.009.

Why is health literacy confusing within clinical research?

Comprehension of Clinical Complexity

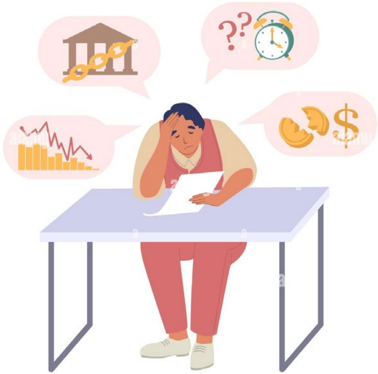
Confusion between Care Types

Uncertainty about Risks and Benefits

Limited Understanding without culturally tailored communication

Evans KR, Lewis MJ, Hudson SV. The role of health literacy on African American and Hispanic/Latino perspectives on cancer clinical trials. J Cancer Educ. 2012 Jun;27(2):299-305. doi: 10.1007/s13187-011-0300-5. PMID: 22203466; PMCID: PMC3712748.

Financial Concerns



Limited insurance, wary of costs.

Lost wages concern hourly workers.

Extra costs deter participation.

Mistrust due to **unclear compensation**.

Garza et al. (2025). Bridging the gap: Understanding Latino willingness to participate in public health and clinical trials research across diverse subgroups. *Contemp Clin Trials Commun*, 44, 101440. doi: 10.1016/j.conctc.2025.101440.

What do nurses have to do with this?

Patient advocacy

Build trusting relationships

Bridge between research & patient care

Language concordant care

Patient navigation

Protocol review boards

What do nurses have to do with this?

Communication

Strategies for Effective Communication?

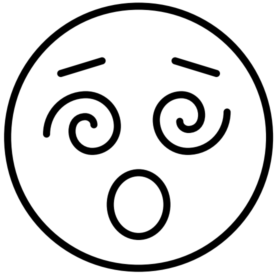
Understanding Cultural and Health Beliefs → Providing Empathy and Respect → Engaging in Family Member Inclusivity → Use of Non-Technical Language → Acknowledgement of concerns and patience to review with family → Teach Back Methods

Ledesma Vicioso et al. (2022). Implementation Strategies to Increase Clinical Trial Enrollment in a Community-Academic Partnership and Impact on Hispanic Representation. *JCO Oncol Pract*, 18(5), e780-e785. doi: 10.1200/OP.22.00037

Case Study #1

Patient Background:

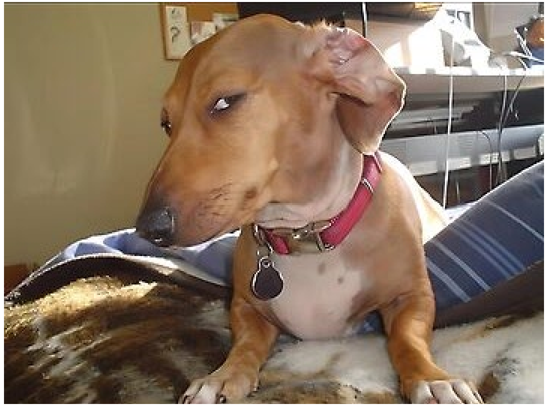
- Maria Doe, a 60-year-old female with a recent diagnosis of Renal Cell Carcinoma (RCC), 6 months ago.
- She was referred to the Oncology Research Clinic after her oncologist identified her as a candidate for a clinical trial.
- She presented to the clinic with her adult daughter, who speaks English fluently and often acts as her interpreter. Maria appeared anxious and hesitant, asking, “¿Van a experimentar conmigo?” (“Are they going to experiment on me?”).
- Referral Reason: Eligible for a Phase II clinical trial evaluating a novel immunotherapy agent.



Case Study #1

What barriers were identified initially with Maria Doe?

A. Language barrier with consent process
B. Financial Risks and understanding
C. Lack of Understanding Clinical Research
D. Family Member support



Case Study #1

Visit Details

Maria **struggled to understand** the consent form, even when translated into Spanish.

She was **unclear** about trial procedures, randomization, and the difference between standard care and investigational treatment.

Maria depended heavily on her **daughter for translation**, which complicated sensitive health conversations.

The research coordinator was not fluent in Spanish, and interpreter services were not readily available during the visit.

Nursing Intervention

Scheduled a follow-up visit with a Research Staff Translator.

Used **visual aids and the teach-back method** to explain the purpose of the trial, safety protocols, and patient rights.

Addressed Maria's fears that could be an indication of a previous experience on a clinical research study. Review previous experience and clarify any misunderstanding.

Worked with the research team to provide **Spanish-language materials** and **adapt communication** to Maria's cultural preferences.

Case Study #2

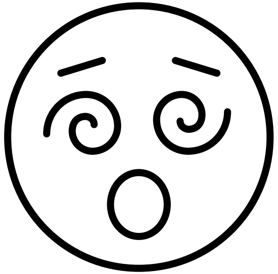
Patient Background:

- Jorge Doe, a 63-year-old male with a recent diagnosis of Metastatic Colorectal Cancer, 12 months ago.

- He was referred to the Oncology Research Clinic by his primary Oncologist for a Phase 1 KRAS Targeting immunotherapy.

- During the initial intake, Jorge appeared reserved. Although he understood English, he continuously deferred to his wife—who spoke only Spanish—and asked to receive all information in Spanish. He voiced concerns about "research" and his unfamiliarity with it. He stated that he knows very little of clinical research from back home in Colombia. He was confused by the complex wording that was used by the clinical research coordinator.

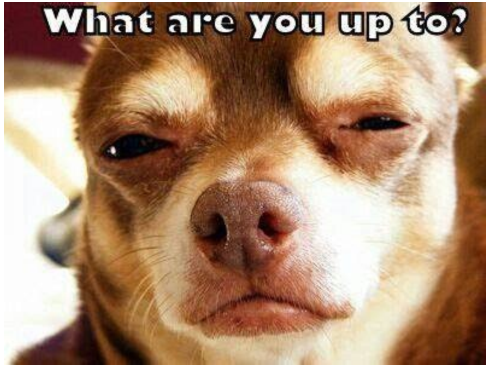
- He stated that he would like to call his brother and sister while this study was explained.



Case Study #2

What barriers were identified initially with Jorge Doe?

A. Language barrier with consent process
B. Financial Risks and understanding
C. Mistrust of Clinical Research and the process of it
D. Family Member support
E. Complex Clinical Research Literacy
F. Both D&E



Case Study #2

Visit Details

He was unfamiliar with **targeted therapy**, assuming all cancer treatments involved chemotherapy.

Jorge **relied heavily** on his **wife** and **siblings** to help make healthcare decisions. He felt conflicted when the clinical team spoke mostly to him without addressing his family directly.

Although Jorge was bilingual, he **preferred Spanish** for medical conversations to feel confident and respected. The research staff was not culturally attuned to Hispanic norms of communication and family involvement.

Nursing Intervention

Schedule a dedicated **family consultation** with a professional interpreter present, giving space for questions from Jorge's wife and siblings.

Described the trial in terms of "**personalized treatment**" rather than "experimentation," which helped reduce fear.

Explained the process of informed consent in a **group format**, honoring Jorge's desire for family consensus.

Ensured every encounter included verbal summaries and **repeat-back techniques** in Spanish.

Common Tips to Connect with Hispanic Patients

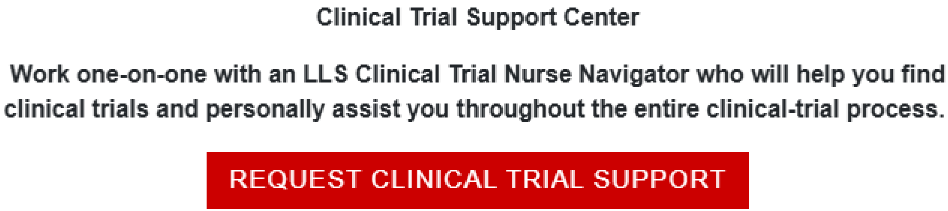
Build	**Build Personalismo (Personal Connection)** Take time for warm, respectful small talk before diving into medical discussions. Davis et al, 2019)
Respect	**Respect Familismo (Family Involvement**) Encourage Family participation if patient desires, invite family members into clinical and research conversations. (Joachim-Celestin et al, 2024)
Engage in	**Engage in Cultural Humility** Treat each patient as a cultural expert and ask open-ended questions about their care beliefs and preferences.
Recognize and Address	**Recognize and Address Mistrust** Recognize experiences that may cause mistrust and be clear about procedures, risks, and benefits.

Why is Clinical Research important?

- May improve patient's quality and quantity of life
- Advance medical knowledge and practice
- Development of tailored medicine
- Early access to innovative therapies
- Contributions to Public Health
- Patient empowerment
- Optimizes current and potential practice
- Further expand on the "Known"

Resources

Non-profit Organizations

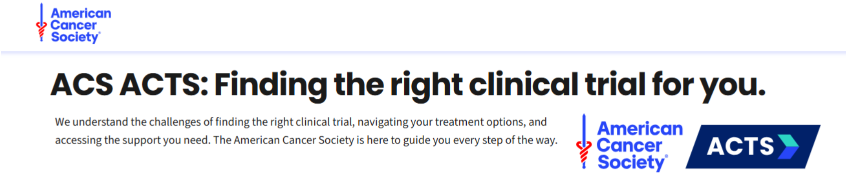


Clinical Trial Support Center

Work one-on-one with an LLS Clinical Trial Nurse Navigator who will help you find clinical trials and personally assist you throughout the entire clinical-trial process.

REQUEST CLINICAL TRIAL SUPPORT

For more information, please visit: www.LLS.org/CTSC



American Cancer Society

ACS ACTS: Finding the right clinical trial for you.

We understand the challenges of finding the right clinical trial, navigating your treatment options, and accessing the support you need. The American Cancer Society is here to guide you every step of the way.

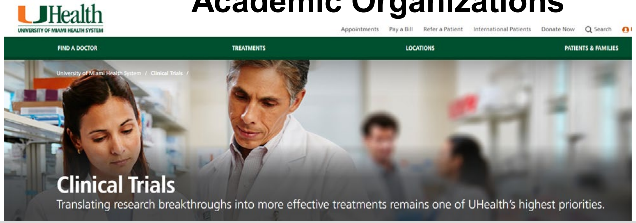
NIH National Library of Medicine
National Center for Biotechnology Information

ClinicalTrials.gov

World Health Organization

International Clinical Trials Registry Platform (ICTRP)

Academic Organizations



Clinical Trials

Translating research breakthroughs into more effective treatments remains one of UHealth's highest priorities.

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Special Thanks!

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SOCIETY®

NAHN
National Association
of Hispanic Nurses

ONS™
Oncology Nursing
Society

Gracias!

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FREE LLS RESOURCES FOR HEALTHCARE PROVIDERS

- ☐ CME & CE courses: www.LLS.org/CE
- ☐ Fact Sheets for HCPs: www.LLS.org/HCPbooklets
- ☐ Videos for HCPs: www.LLS.org/HCPvideos
- ☐ Podcast series for HCPs: www.LLS.org/HCPpodcast
- ☐ LLS Research Grant Programs: www.LLS.org/Research or email researchprograms@LLS.org

LEUKEMIA & LYMPHOMA SOCIETY®

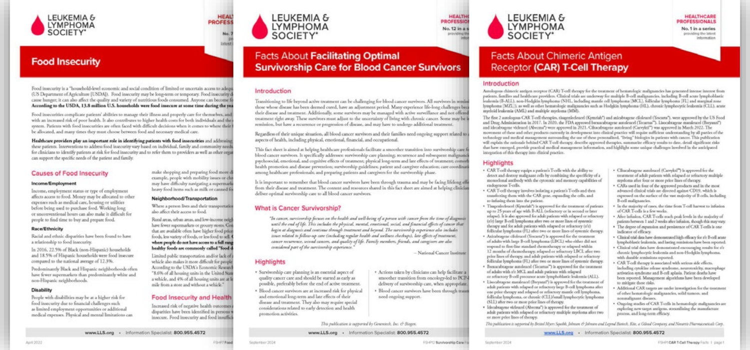
LLS PODCAST SERIES FOR HEALTHCARE PROFESSIONALS

TREATING BLOOD CANCERS

Each month, tune in as experts discuss the latest developments in blood cancers, new and emerging treatment options, side effects management, survivorship issues and more!

To subscribe, visit: www.LLS.org/HCPpodcast

For continuing medical education activities, visit: www.LLS.org/CE



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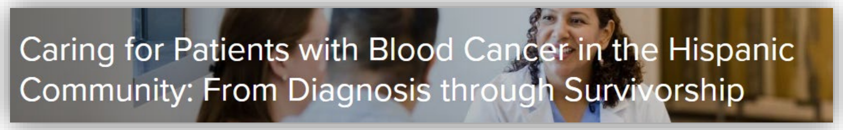
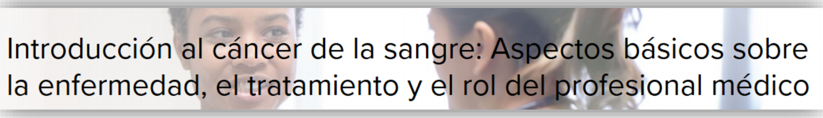
Food Insecurity

Facts About Facilitating Optimal Survivorship Care for Blood Cancer Survivors

Facts About Chimeric Antigen Receptor (CAR) T-Cell Therapy



Caring for Patients with Blood Cancer in the Hispanic Community: From Diagnosis through Survivorship



Introducción al cáncer de la sangre: Aspectos básicos sobre la enfermedad, el tratamiento y el rol del profesional médico

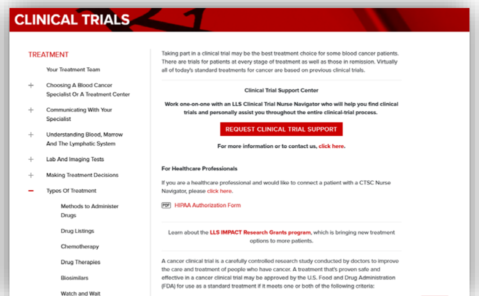
CE Webinar – Blood Cancer 101

Now available in English and Spanish

LEUKEMIA & LYMPHOMA SOCIETY®

FREE LLS RESOURCES FOR PATIENTS AND CAREGIVERS

- ☐ **Webcasts, Videos, Podcasts, booklets**:
  - ○ www.LLS.org/Webcasts
  - ○ www.LLS.org/EducationVideos
  - ○ www.LLS.org/Podcast
  - ○ www.LLS.org/Booklets
- ☐ **www.LLS.org/clinicaltrials**
- ☐ **Support Resources**
  - ○ Financial Assistance: www.LLS.org/Finances
    - Urgent Need
    - Patient Aid
    - Travel Assistance
  - ○ Other Support: www.LLS.org/Support
    - LLS Regions
    - Online Weekly Chats Facilitated by Oncology SW
    - LLS Community Social Media Platform
    - First Connection Peer to Peer Program



Taking part in a clinical trial may be the best treatment choice for some blood cancer patients. There are trials for patients at every stage of treatment as well as those in remission. Virtually all of today's standard treatments for cancer are based on previous clinical trials.

Clinical Trial Support Center

Work one-on-one with an LLS Clinical Trial Nurse Navigator who will help you find clinical trials and personally assist you throughout the entire clinical-trial process.

For more information or to contact us, click here.

For Healthcare Professionals

If you are a healthcare professional and would like to connect a patient with a CTSC Nurse Navigator, please click here.

HIPAA Authorization Form

Learn about the **LLS IMPACT Research Grants program**, which is bringing new treatment options to more patients.

A cancer clinical trial is a carefully controlled research study conducted by doctors to improve the care and treatment of people who have cancer. A treatment that's proven safe and effective in a cancer clinical trial may be approved by the U.S. Food and Drug Administration (FDA) for use as a standard treatment if it meets one or both of the following criteria:

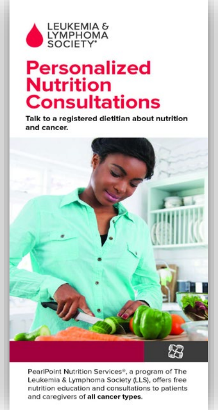
LEUKEMIA & LYMPHOMA SOCIETY®

FREE LLS RESOURCES FOR PATIENTS

- ❑ **Nutrition Education Services Center (NESC)** – one-on-one **free** nutrition education and consultations to patients of all cancer types with RDs who have expertise in oncology nutrition www.LLS.org/Nutrition

- ❑ **Information Specialists** (IRC) – Personalized assistance for managing treatment decisions, side effects, and dealing with financial and psychosocial challenges.

- ❑ **Reach out Monday–Friday, 9 am to 9 pm ET**
  - ○ Phone: 800.955.4572
  - ○ Live chat: www.LLS.org/IRC
  - ○ Email: LLS.org/ContactUs
  - ○ HCP Patient Referral Form: www.LLS.org/HCPreferral



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Personalized Nutrition Consultations

Talk to a registered dietitian about nutrition and cancer.

PearlPoint Nutrition Services®, a program of The Leukemia & Lymphoma Society (LLS), offers free nutrition education and consultations to patients and caregivers of **all cancer types.**

LEUKEMIA & LYMPHOMA SOCIETY®

CLINICAL TRIAL SUPPORT CENTER (CTSC)

CTSC PROCESS FOR SUPPORTING PATIENTS

- Learn about patient & treatment goals
- Educate about clinical trials
- Conduct a clinical assessment
- Search for appropriate clinical trials
- Patient & HCP discuss results
- Connect with trial sites
- Address barriers to enrollment
- Patient enrollment

THE CLINICAL TRIAL SUPPORT CENTER TEAM

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Senior Director, CTSC

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CPNP, MSN, RN,
CPHON
Director, CTSC

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MSN, RN, CPNP
Senior Clinical Trial
Nurse Navigator

Ashley Giacobbi
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AOCNS, OCN
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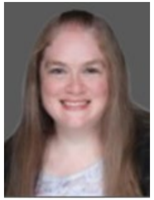
Nurse Navigator



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FAACM
Clinical Trial Nurse
Navigator

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RN, BSN, BMT-CN
Clinical Trial Nurse
Navigator

Kelly Stackhouse
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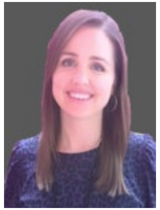
Clinical Trial Nurse
Navigator



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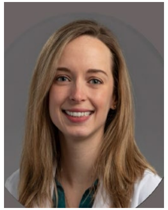
Clinical Trial Nurse
Navigator

Sloane Cammock
MSN, RN, CPNP
Clinical Trial
Nurse Navigator

Elise Curry
BA, BSN, RN, OCN
Clinical Trial Nurse
Navigator



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MSN, RN, AGACNP-BC
Clinical Trial Nurse
Navigator

Melanie Fyfe
MSN, APRN, AGCNS-BC,
OCN, BMTCN
Clinical Trial Nurse
Navigator

Michelle Bibo
CTSC Operations
Specialist

HOW TO ACCESS THE CLINICAL TRIAL SUPPORT CENTER (CTSC)

Information Resource Center (IRC) 1-800-955-4572

Patient, Caregivers, or Healthcare Providers can complete an online referral form to refer themselves, a loved one, or a patient:

https://www.lls.org/support-resources/clinical-trial-support-center-ctsc

Email: CTSC@lls.org

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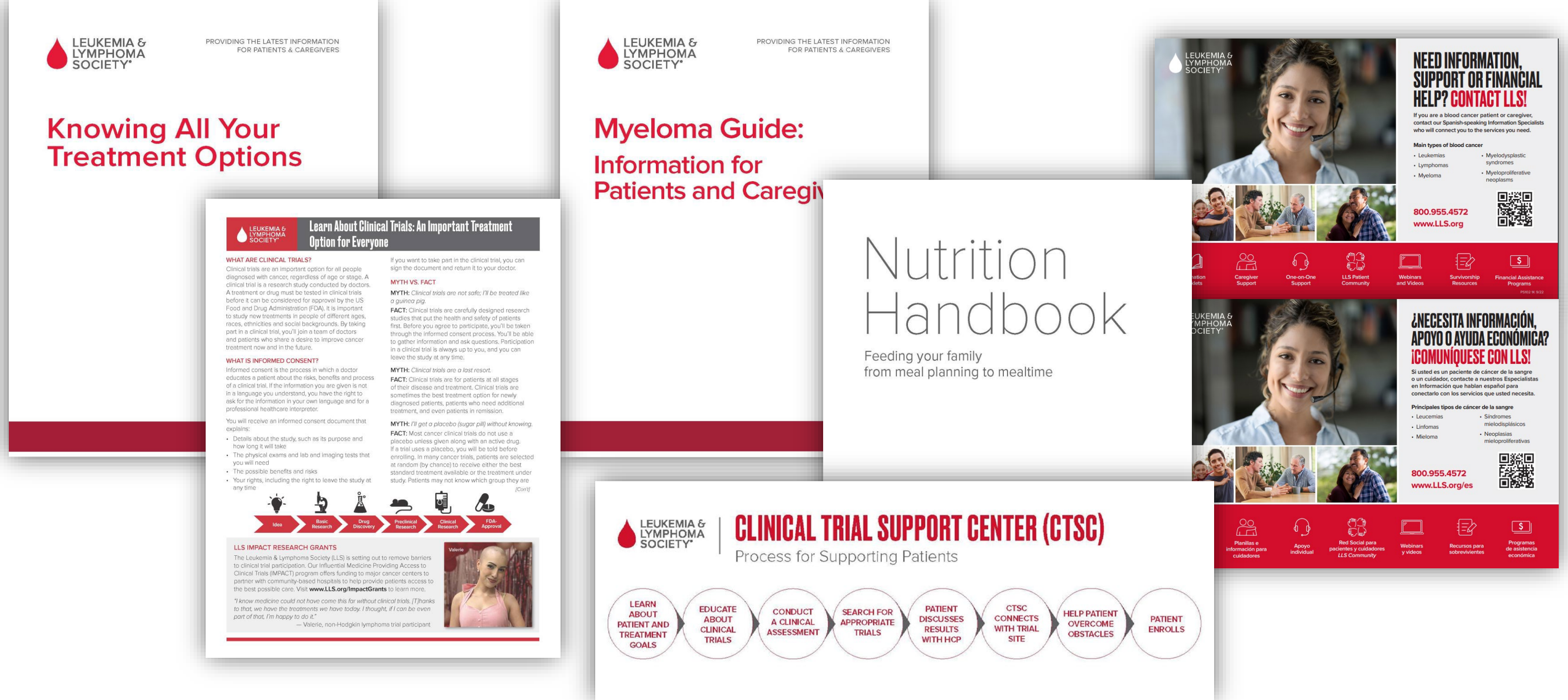
FREE LLS RESOURCES FOR YOUR PATIENTS



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PROVIDING THE LATEST INFORMATION FOR PATIENTS & CAREGIVERS

Knowing All Your Treatment Options

LEUKEMIA & LYMPHOMA SOCIETY®

PROVIDING THE LATEST INFORMATION FOR PATIENTS & CAREGIVERS

Myeloma Guide:

Information for Patients and Caregi

LEUKEMIA & LYMPHOMA SOCIETY®

Learn About Clinical Trials: An Important Treatment Option for Everyone

WHAT ARE CLINICAL TRIALS?

Clinical trials are an important option for all people diagnosed with cancer, regardless of age or stage. A clinical trial is a research study conducted by doctors. A treatment or drug must be tested in clinical trials before it can be considered for approval by the US Food and Drug Administration (FDA). It is important to study new treatments in people of different ages, races, ethnicities and social backgrounds. By taking part in a clinical trial, you'll join a team of doctors and patients who share a desire to improve cancer treatment now and in the future.

WHAT IS INFORMED CONSENT?

Informed consent is the process in which a doctor educates a patient about the risks, benefits and process of a clinical trial. If the information you are given is not in a language you understand, you have the right to ask for the information in your own language and for a professional healthcare interpreter.

You will receive an informed consent document that explains:

- Details about the study, such as its purpose and how long it will take
- The physical exams and lab and imaging tests that you will need
- The possible benefits and risks
- Your rights, including the right to leave the study at any time

If you want to take part in the clinical trial, you can sign the document and return it to your doctor.

MYTH VS. FACT

MYTH: *Clinical trials are not safe; I'll be treated like a guinea pig.*

FACT: Clinical trials are carefully designed research studies that put the health and safety of patients first. Before you agree to participate, you'll be taken through the informed consent process. You'll be able to gather information and ask questions. Participation in a clinical trial is always up to you, and you can leave the study at any time.

MYTH: *Clinical trials are a last resort.*

FACT: Clinical trials are for patients at all stages of their disease and treatment. Clinical trials are sometimes the best treatment option for newly diagnosed patients, patients who need additional treatment, and even patients in remission.

MYTH: *I'll get a placebo (sugar pill) without knowing.*

FACT: Most cancer clinical trials do not use a placebo unless given along with an active drug. If a trial uses a placebo, you will be told before enrolling. In many cancer trials, patients are selected at random (by chance) to receive either the best standard treatment available or the treatment under study. Patients may not know which group they are

[Con't]

Idea → Basic Research → Drug Discovery → Preclinical Research → Clinical Research → FDA-Approval

LLS IMPACT RESEARCH GRANTS

The Leukemia & Lymphoma Society (LLS) is setting out to remove barriers to clinical trial participation. Our Influential Medicine Providing Access to Clinical Trials (IMPACT) program offers funding to major cancer centers to partner with community-based hospitals to help provide patients access to the best possible care. Visit **www.LLS.org/ImpactGrants** to learn more.

"I know medicine could not have come this far without clinical trials. [T]hanks to that, we have the treatments we have today. I thought, if I can be even part of that, I'm happy to do it."

— Valerie, non-Hodgkin lymphoma trial participant

Nutrition Handbook

Feeding your family
from meal planning to mealtime

LEUKEMIA & LYMPHOMA SOCIETY®

NEED INFORMATION, SUPPORT OR FINANCIAL HELP? CONTACT LLS!

If you are a blood cancer patient or caregiver, contact our Spanish-speaking Information Specialists who will connect you to the services you need.

Main types of blood cancer

- Leukemias
- Lymphomas
- Myeloma
- Myelodysplastic syndromes
- Myeloproliferative neoplasms

800.955.4572
www.LLS.org

Caregiver Support · One-on-One Support · LLS Patient Community · Webinars and Videos · Survivorship Resources · Financial Assistance Programs

PS102 1K 9/22

¿NECESITA INFORMACIÓN, APOYO O AYUDA ECONÓMICA? ¡COMUNÍQUESE CON LLS!

Si usted es un paciente de cáncer de la sangre o un cuidador, contacte a nuestros Especialistas en Información que hablan español para conectarlo con los servicios que usted necesita.

Principales tipos de cáncer de la sangre

- Leucemias
- Linfomas
- Mieloma
- Síndromes mielodisplásicos
- Neoplasias mieloproliferativas

800.955.4572
www.LLS.org/es

Planillas e información para cuidadores · Apoyo individual · Red Social para pacientes y cuidadores *LLS Community* · Webinars y videos · Recursos para sobrevivientes · Programas de asistencia económica

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CLINICAL TRIAL SUPPORT CENTER (CTSC)

Process for Supporting Patients

LEARN ABOUT PATIENT AND TREATMENT GOALS → EDUCATE ABOUT CLINICAL TRIALS → CONDUCT A CLINICAL ASSESSMENT → SEARCH FOR APPROPRIATE TRIALS → PATIENT DISCUSSES RESULTS WITH HCP → CTSC CONNECTS WITH TRIAL SITE → HELP PATIENT OVERCOME OBSTACLES → PATIENT ENROLLS

BOOKLETS AND FACT SHEETS

English – www.LLS.org/Booklets
Spanish – www.LLS.org/Materiales

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QUESTIONS?

Thank you for participating!

Please complete the post-assessment and program evaluation.

For a list of our CME and CE activities, podcasts and fact sheets, please visit: www.LLS.org/CE.

Questions or concerns, please contact ProfEducation@LLS.org

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