CANCER SUPPORT COMMUNITY®

A Global Network of Education and Hope

Uniting The Wellness Community and Gilda's Club Worldwide

Clinical Trials Information Needs of Black & African American Cancer Patients & Caregivers

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ICEC 2020
October 12-16, 2020
Virtual Conference

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Conflict of Interest Disclosure

I do not have any potential conflicts of interest to disclose.

This project was made possible with generous support from:

Pfizer

Bristol Myers Squibb

Novartis

Learning Objectives

- Understand the information needs about clinical trials among Black and African Americans.
- Identify perceptions, attitudes, and beliefs about clinical trials among Black and African Americans.
- Identify two barriers to participation in clinical trials among Black and African Americans.

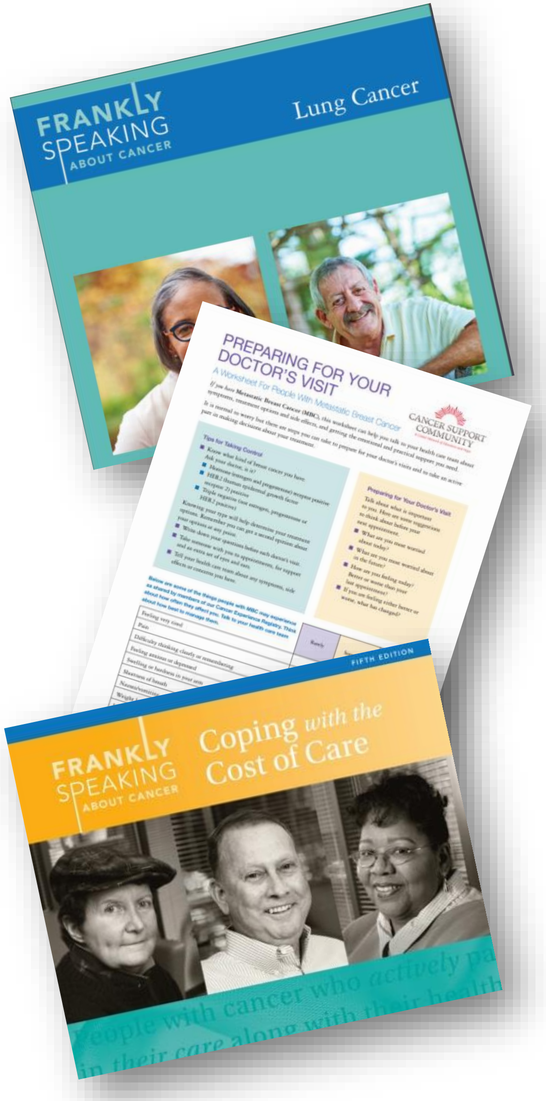
Cancer Support Community

OUR MISSION:

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

Frankly Speaking About Cancer®

- High quality, evidence-based educational programming for cancer patients, survivors, caregivers, and health care professionals
- Frankly Speaking About Cancer (FSAC)
  - Provide easy to understand in-depth coverage of topics relevant to those affected by cancer
  - To educate and to empower cancer patients, survivors, caregivers, and health care professionals
  - Topics are tumor type-specific (e.g. melanoma, lung, metastatic breast, liver, colorectal, multiple myeloma) or cross-tumors (e.g. immunotherapy, clinical trials, treatments and side effects)
  - Provide up-to-date content and reflect new advances in knowledge



FRANKLY SPEAKING ABOUT CANCER
Lung Cancer

PREPARING FOR YOUR DOCTOR'S VISIT
A Worksheet For People With Metastatic Breast Cancer
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FIFTH EDITION
FRANKLY SPEAKING ABOUT CANCER
Coping with the Cost of Care

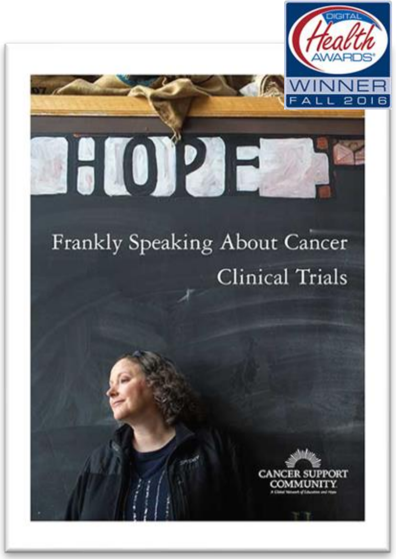
CSC’s Frankly Speaking About Cancer: Clinical Trials Educational Materials

Photo Narrative

- **innovative, award-winning publication that takes a photojournalistic approach** to refreshing the conversation about clinical trials
- features **real patients talking with their families and health care teams** about the issues they face when considering a clinical trial
- **debunks myths** about clinical trials in patients’ own words and **highlights the importance of becoming an active partner** with one’s health care team.
- after culturally adapting this for Spanish speakers in the US, CSC wanted to ensure that our materials were culturally-relevant for Blacks & African Americans in the US.

Clinical Trials booklet

- provides **deeper information** to learn about clinical trials as a treatment option and what participation in a clinical trial entails
- Both are available in print and downloadable PDF formats



DIGITAL Health AWARDS WINNER FALL 2016

HOPE

Frankly Speaking About Cancer
Clinical Trials

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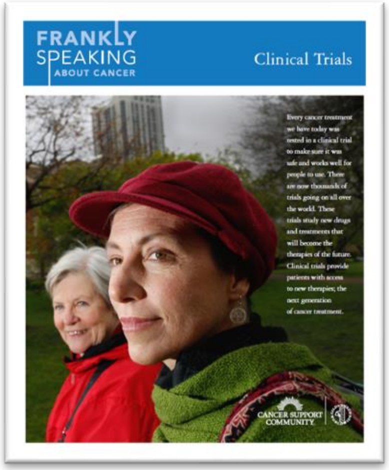

FRANKLY SPEAKING ABOUT CANCER

Clinical Trials

Every cancer treatment we have today was tested in a clinical trial to make sure it was safe and works well for people to use. There are now thousands of trials going on all over the world. These trials study new drugs and treatments that will become the therapies of the future. Clinical trials provide patients with access to new therapies; the next generation of cancer treatment.

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Participation of African Americans in Clinical Trials

- Fewer than 6% of cancer clinical trial enrollees are Black and African American, although they comprise 12% of the U.S. population

- Potential barriers to cancer clinical trials participation among Black and African Americans include, among others:
  - Fear, suspicion, and mistrust of researchers and medical research
  - Fear of possible side effects or procedures
  - Logistical concerns such as lack of transportation, family and work commitments, financial burdens
- Potential barriers to cancer clinical trials among the medical community include, among other:
  - Time to find clinical trials that patients are eligible to participate in
  - Researcher bias exist in their assumption related to the willingness of minorities to participate in research

Addressing Clinical Trials Participation Barriers among African Americans

- CSC is committed to increase and improve minority and underserved populations' access to comprehensive, culturally appropriate cancer education, information and services

- Use of culturally sensitive approaches to enhance ethnic minorities' participation is important for advancing cancer care and eliminating health disparities

- With the impact of low clinical trials participation among AAs in mind, CSC conducted community research to gain insights about the information needs of African Americans about clinical trials

CSC’s Community Research Purpose

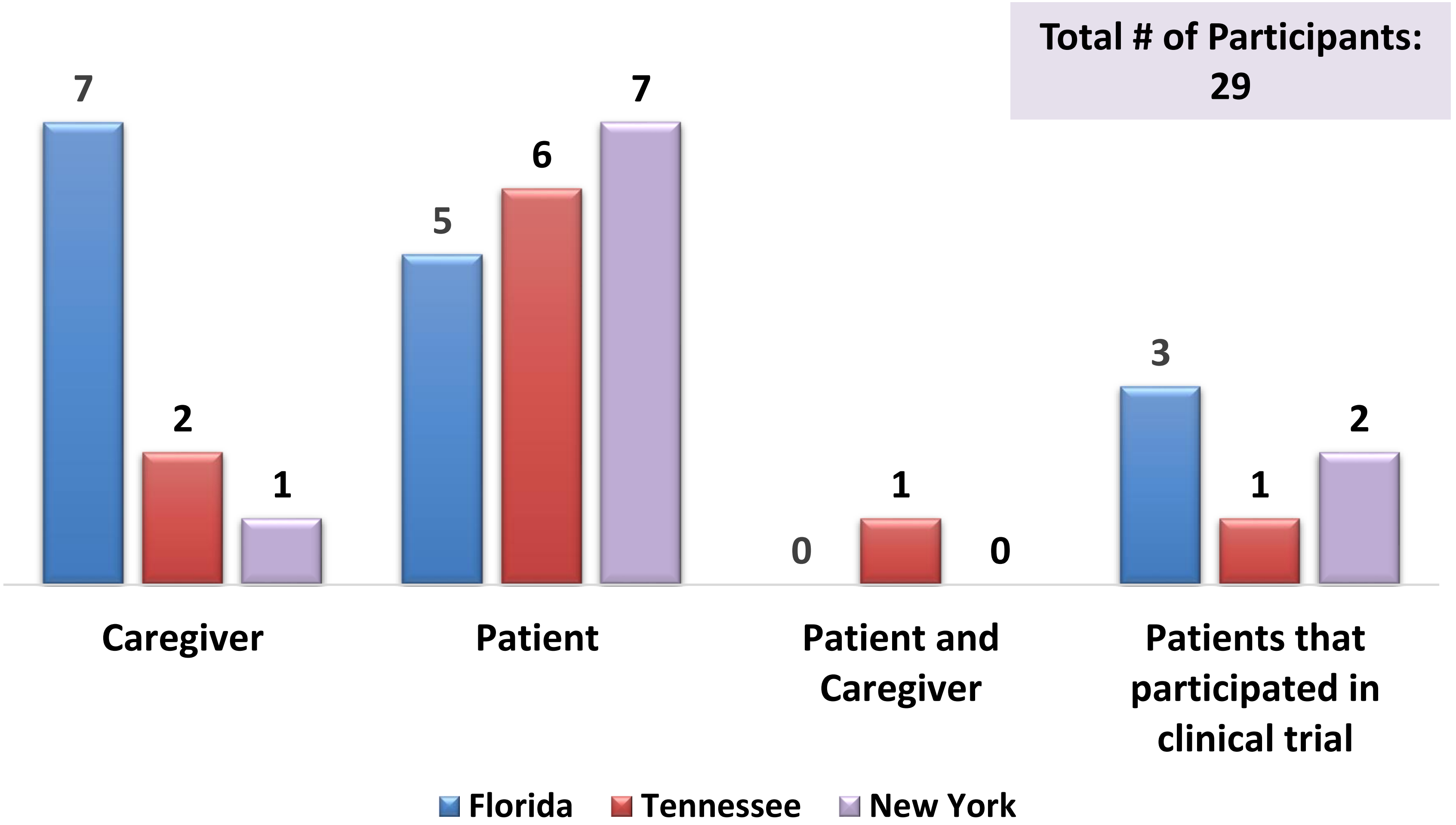
- Understand the information needs of Black and African American cancer patients and caregivers to support the development of culturally sensitive health education programs

- Increased understanding about effective ways to communicate with Blacks and African Americans to:
  - Raise awareness about clinical trials
  - Provide context about the importance of research and how clinical trials impact outcomes both on a personal and societal level, and
  - Provide tools to foster an open dialogue with their healthcare team

Methodology

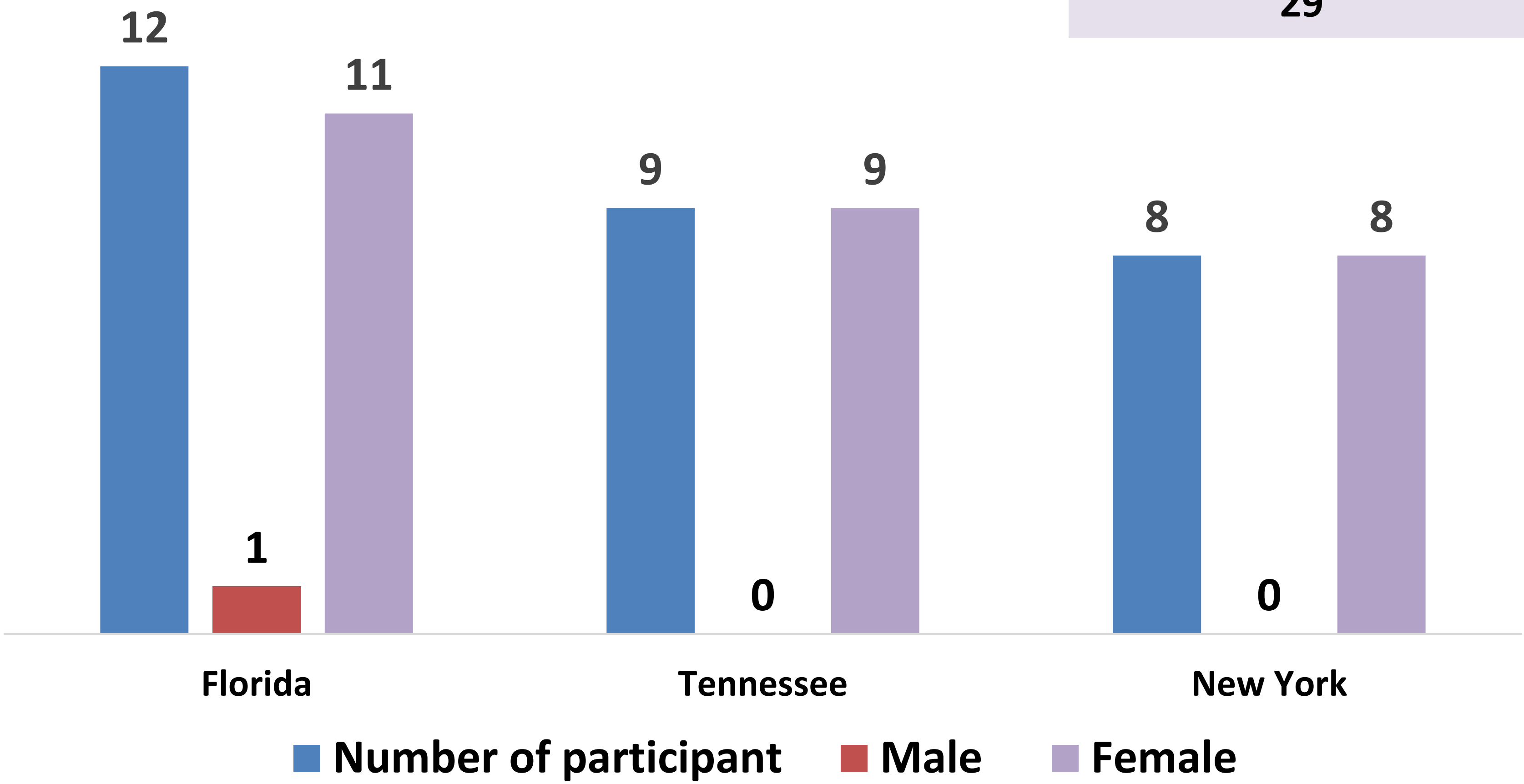
- In 2019, Cancer Support Community (CSC) facilitated three in-person focus groups with Black and African American cancer survivors and caregivers in Florida, New York and Tennessee
- Each group discussion was led by the same facilitator. The discussion guide explored participants' unmet educational needs about clinical trials
- The discussions were transcribed; thematic content was categorized and coded, and frequencies of categories were tabulated
- In total 29 patients and caregivers participated in the focus group. FL (N=12), NY (N=9), and TN (N=8). All participants self-identified as Black or African American with a few identifying as Caribbean American

Participants Characteristics



Participants Characteristics

Total # of Participants: 29



Main Themes: Important Topics for the African American Population

Being Black/African American

Medical Ethics/Mistrust

Spirituality

Support

Understanding Clinical Trials

Sub Themes for **Being Black/African American**

Trust/Experiences (ie testimonials)

Identity

Emotions (e.g., fear, anger, etc)

I would like to hear what other groups of Black folks think. Not only Afro-American, Caribbean, different Blacks, not only one different group within the Black community. (FL)

There's a lot of communities in which you say the word C, it is a death trap, it took me four-and-a-half years to realize why I was so upset and angry. And I had an epiphany; it's because everybody I knew that had cancer died, and I'm the only one surviving. (NY)

Sub Themes for **Medical Ethics/Mistrust**

Past Experiences

Transparency

Even though a lot of the younger generation doesn't know about it, the older generation knows about Tuskegee and what they did to those men and everything. So, that was a clinical trial. It wasn't termed as a clinical trial, but it was a clinical trial. That's why there is this fear amongst especially the African American community about clinical trials. (TN)

In the beginning of last year I was told, oh, you have to take this chemo, the liquid chemo, because six months you're gonna be cured. Turned out to be a lie. (NY)

Sub Themes for **Spirituality**

Religion/Church
Hope/Faith

I trust God more than I trust a lot of this medicine.(NY)

Everything with the hope is with white people, Black culture is nurturing. We have faith. (FL)

Sub Themes for **Support**

Family

Most times, specifically in the African American Community, it's a family decision. It's a family conversation, that conversation about what to do next. (FL)

I would have never joined the clinical trial without the support from my family. Well, I may have joined, but I would have dropped out after the first week if it wasn't for them. (NY)

Sub Themes for **Understanding Clinical Trials**

Process/Protocol

Purpose:

Well and sometimes, the doctor don't have – you want to know the process before you go. Sometimes you want to know what it's gonna encompass along the way. (TN)

I would consider it if I had more evidence, more factual evidence, and stuff in my face to show me what you trying to tell me would benefit me would be suffice.(NY)

Summary of Findings

When engaging African Americans/Blacks for the purpose of increasing participation in cancer clinical trials, the following should be addressed in oral and written form:

- Use terminology that validate emotions regarding the medical experiences of African Americans/Blacks and abuses from the past
- Trust is a relevant cultural value, inclusion of testimonials from Black and African Americans who have had positive experiences participating in clinical trials is imperative
- Information about participation rates, and outcomes (both positive and negatives) increases transparency and builds trust
- Inclusion of facts about clinical trials is important. Allowing individuals to assess personal risks increases transparency

Implications

Key findings suggest that educational materials about clinical trials should:

- Explain why is important for racial minorities to participate in clinical trials
- Address barriers to participation such as: mistrust of the medical community, fear of side effects, disparities in access to healthcare, and lower socio-economic status
- Provide information related to clinical trials that involved Black and African Americans and the outcomes of those studies on the lives of participants
- Provide a list of questions about clinical trials to ask the health care team, this should include questions about cost of participation, financial support, and how to find clinical trials

Conclusions

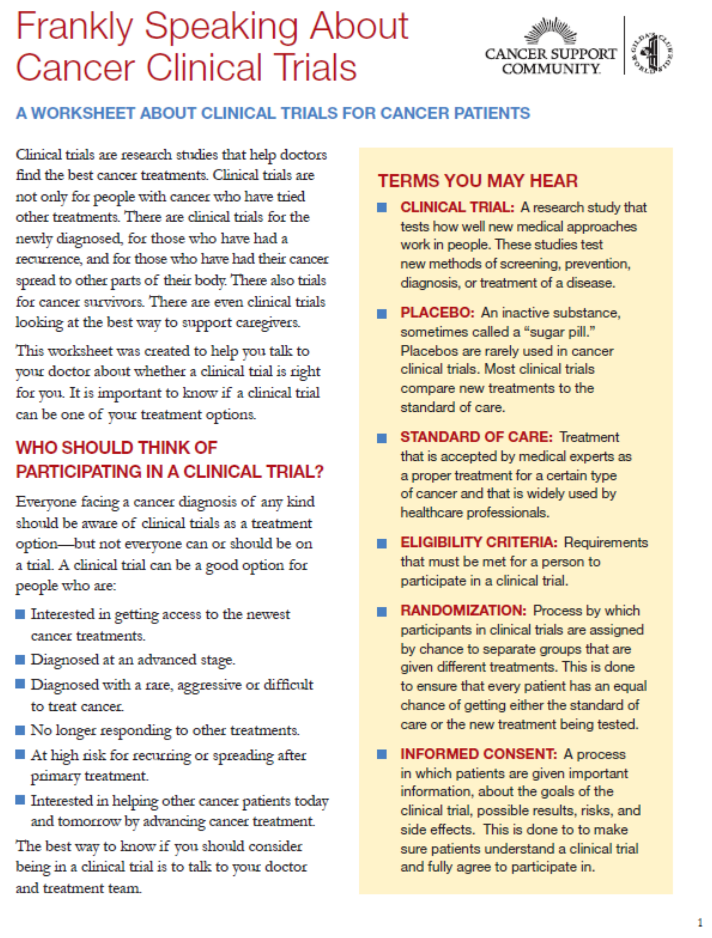
- These findings suggest the need to construct culturally tailored messaging around clinical trials for Black and African Americans
- Many participants were previously unaware of many of the topics discussed during the sessions but became more open to the idea of clinical trials after the discussion
- Additionally, there is a need to work towards clear concepts and terminology to talk to Black and African American patients about clinical research and its benefits

Next Steps

- Development of educational materials about clinical trials to ensure that Black and African American communities have access to cultural appropriate educational materials about clinical trials
- Ensure we test new materials with Black & African American men, since they were inadequately recruited for the focus groups.

Next Steps: Patient/Provider Discussion Tool

- Development of educational materials about clinical trials to ensure that African American communities have access to cultural appropriate educational materials about clinical trials
- Those include a patient/provider discussion tool and a factsheet for racial minorities
- Once finalized, materials will be printed, posted online, and offered to health care providers and partner organizations



Frankly Speaking About Cancer Clinical Trials

CANCER SUPPORT COMMUNITY

A WORKSHEET ABOUT CLINICAL TRIALS FOR CANCER PATIENTS

Clinical trials are research studies that help doctors find the best cancer treatments. Clinical trials are not only for people with cancer who have tried other treatments. There are clinical trials for the newly diagnosed, for those who have had a recurrence, and for those who have had their cancer spread to other parts of their body. There also trials for cancer survivors. There are even clinical trials looking at the best way to support caregivers.

This worksheet was created to help you talk to your doctor about whether a clinical trial is right for you. It is important to know if a clinical trial can be one of your treatment options.

WHO SHOULD THINK OF PARTICIPATING IN A CLINICAL TRIAL?

Everyone facing a cancer diagnosis of any kind should be aware of clinical trials as a treatment option—but not everyone can or should be on a trial. A clinical trial can be a good option for people who are:

- Interested in getting access to the newest cancer treatments.
- Diagnosed at an advanced stage.
- Diagnosed with a rare, aggressive or difficult to treat cancer.
- No longer responding to other treatments.
- At high risk for recurring or spreading after primary treatment.
- Interested in helping other cancer patients today and tomorrow by advancing cancer treatment.

The best way to know if you should consider being in a clinical trial is to talk to your doctor and treatment team.

TERMS YOU MAY HEAR

- **CLINICAL TRIAL:** A research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease.
- **PLACEBO:** An inactive substance, sometimes called a "sugar pill." Placebos are rarely used in cancer clinical trials. Most clinical trials compare new treatments to the standard of care.
- **STANDARD OF CARE:** Treatment that is accepted by medical experts as a proper treatment for a certain type of cancer and that is widely used by healthcare professionals.
- **ELIGIBILITY CRITERIA:** Requirements that must be met for a person to participate in a clinical trial.
- **RANDOMIZATION:** Process by which participants in clinical trials are assigned by chance to separate groups that are given different treatments. This is done to ensure that every patient has an equal chance of getting either the standard of care or the new treatment being tested.
- **INFORMED CONSENT:** A process in which patients are given important information, about the goals of the clinical trial, possible results, risks, and side effects. This is done to to make sure patients understand a clinical trial and fully agree to participate in.

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THANK YOU!

For More Information, contact Owen Renault at
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