

# TALKING ABOUT BIOMARKER TESTING

## A Guide for Discussing Precision Medicine and Biomarker Testing

Precision medicine is a newer way to find the right treatment for each patient, based on cancer subtype. Before, the only option was to treat all cancers of one type (such as lung or breast cancer) with the same treatment. With precision medicine, doctors use biomarker testing to find your subtype of cancer.

Cancer subtypes are smaller groups that cancer can be divided into, based on certain traits of the cancer cell. Biomarker test results show which treatment is likely to work best for you. Precision medicine is only available for certain types and stages of cancer. It is important to know the subtype of a cancer in order to plan treatment and determine possible outcomes. Biomarker tests can find your specific subtype of cancer.

This guide provides a quick overview on precision medicine and biomarker testing. It is designed to help you talk with your health care team about this type of testing and decide if it is right for you. You will find helpful questions to ask your health care team, a worksheet to help you set your own goals, and resources for information and support.



### WHAT IS A BIOMARKER?

Biomarkers tell your doctor about the subtype of cancer in your body. A biomarker can be a sign of disease or abnormal function. It can be measured in your blood, tissue, or bodily fluid. Biomarkers can be proteins, genes, or gene mutations. For cancer, biomarkers are often used to help choose the best treatment for you. They are often referred to by a 3- or 4-letter abbreviation. Examples of biomarkers include HER2 in breast cancer and EGFR in lung cancer.

## WHAT IS BIOMARKER TESTING?

Biomarker testing can help your doctor better match the right treatment or drug to the specific subtype of cancer you have. The type of treatment may be a targeted therapy or an immunotherapy.

In biomarker testing, a sample of your cancer is collected from your blood, bodily fluids, or tissue taken during surgery or biopsy.

Your sample is then sent to a lab, for further testing. The test looks for biomarkers in your cancer sample. The test results can be used to help guide your treatment options. There are many kinds of biomarker tests. Ask your doctor what kind of biomarker testing is right for your type and stage of cancer.

## WHAT ARE TARGETED THERAPY DRUGS?

Targeted therapy uses drugs to target specific changes in cancer cells that help them grow,

divide, and spread. Targeted therapy drugs keep cancer from growing and spreading with less harm to cells that are not cancer. They may have fewer side effects than other treatments because they are better able to attack your cancer cells and leave healthy cells alone. These drugs “target” specific cancer subtypes. They are only likely to work on those specific subtypes.

Targeted therapy drugs can work in several ways:

- They can find cancer cells.
- They can destroy cancer cells directly.
- They can stop cancer cells from growing uncontrollably.
- They can cut off the blood supply that tumors need to grow and survive.

## BUILD YOUR HEALTH CARE TEAM

Cancer treatment is complicated and changes all the time with new discoveries. You need a health care team you can trust to take the best care of you. The team can include doctors, nurses, and other health care professionals who work together. This is often called “multidisciplinary care”.

Here are some questions to ask your health care to decide if the team is right for you and your needs:

1. Do you have experience working with my cancer type or subtype?
2. Do you accept my insurance? Are there any out-of-pocket costs for me?
3. Do you work with a team of health care professionals that can help me with different aspects of my care?
4. What tests or treatments would you suggest for my cancer type?

## TIPS FOR TAKING CONTROL

- Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, take notes and/or record your conversation with your doctor. Be sure to ask your doctor if it is OK to record.
- Be proactive. Talk to your health care team or financial navigator about ways to manage treatment costs before you start treatment.
- Write down your questions before each doctor's visit. Keep a journal to take notes or use this worksheet to track your progress over time. This can include information about tests, lab work, and the symptoms and side effects you may be experiencing.
- Be your own advocate. If you don't feel your health care team is addressing your concerns, consider getting a second opinion.
- Learn the words that doctors use to talk about your type of cancer. This can help you better understand your test results and treatment options.

## TALKING TO YOUR HEALTH CARE TEAM

Biomarker testing can help your care team find the right treatment for you. For some cancer types and stages, your doctor may suggest that you get tested right away. Even if your doctor does not bring this up first, you can always ask if biomarker testing is right for your cancer type and stage. For some cancer types, biomarker testing may not be available. If you are told that testing is not an option, you can consider getting a second opinion. Many people with cancer get a second or even third opinion to confirm their diagnosis and review treatment options. Talking with another doctor may help you better understand your cancer and how to treat it. It may also help you feel more confident that you are making the right choices.



## QUESTIONS TO ASK YOUR HEALTH CARE TEAM ABOUT GETTING BIOMARKER TESTING

### QUESTIONS TO ASK

Is biomarker testing an option for me?

Can you do biomarker testing in this office?

If you cannot do biomarker testing here, can you send my samples out to another lab that offers these services?

How long will it take for the results to come back?

How will you use the results to recommend a treatment plan?

Will my insurance pay for biomarker testing? If not, are there any financial assistance resources available to help pay for testing?

Does your office have a social worker or financial counselor that can help me determine if my insurance covers biomarker testing or help me figure out how to cover costs?

I am interested in getting a second opinion about biomarker testing to make sure I am making the best decision for me. How do I access my medical records so that I may share them?

### NOTES


## QUESTIONS FOR YOUR HEALTH CARE TEAM ABOUT YOUR BIOMARKER TEST RESULTS

If you and your doctor decide to move forward with biomarker testing, it may take some time before your test results come back. In some cases, it may take two to four weeks for the test results to return from the lab.

You may feel nervous, scared, or anxious about waiting to start treatment. Talk to your health care team about your concerns. They are here to support you.

Here are some suggested questions and discussion points to keep in mind, once your test results are back:

- Did any of the biomarkers come back positive after the biomarker test? If so, which ones?
- Are the test results clear or should I get tested again?
- Are there any targeted therapies, immunotherapies, or other treatments for this biomarker? If yes, what is the treatment called, and do you recommend it?
- Can I start any of the recommended treatments now?
- Is this treatment different from the treatments you would have recommended before testing?
- Does this recommended treatment have any major side effects?
- How long will I need to take this treatment? What will happen if it stops working?
- Will my insurance cover the cost of the recommended treatment? Does your office have a financial counselor that can help me determine if my insurance covers the cost of treatment or help me figure out how to cover costs?
- Are there other biomarker tests that should be done?

Notes or additional questions:

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## WHAT BIOMARKERS SHOULD YOU LOOK FOR?

Use this table to keep track of your biomarker test results and whether your doctor recommends a treatment option for any positive biomarker test results.

Biomarker Name	Did the doctor test for this biomarker? (Yes/No)	Did you receive a positive test result? (Yes/No)	Are there treatments available for this biomarker?	Did your doctor recommend this treatment option? Why or Why Not?





## WHERE TO GO NEXT

If your test results are positive for biomarkers, talk to your doctor about targeted therapy drugs, immunotherapy, or other treatment options. If your doctor performs biomarker testing, and there are no biomarkers found or no treatment options available based on your test results, ask your doctor if a clinical trial may be right for you.

Clinical trials are research studies to test new treatments or learn how to use existing treatments better. For more information about clinical trials, visit [www.CancerSupportCommunity.org/Clinical-Trials](http://www.CancerSupportCommunity.org/Clinical-Trials) or call CSC's toll-free Cancer Support Helpline® at 888-793-9355.

## QUESTIONS FOR YOUR HEALTH CARE TEAM ABOUT CLINICAL TRIALS

- Am I a good candidate for a clinical trial?
- Are there any clinical trials you would recommend for me based on my test results?
- How can I sign up for a clinical trial?
- Where can I learn more about clinical trials?

Notes or additional questions:

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## THINK ABOUT TREATMENT AND YOUR PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of the treatment and how each treatment might affect the goals that you have for your life. Possible goals may be to: live as long and as well as possible, contribute to progress by taking part in research, make it to a special event/milestone, or find cutting edge treatments. Let your health care team know about your treatment and personal goals. Remember that your goals may change over time.



## SETTING YOUR PERSONAL GOALS FOR TREATMENT

### Physical Health and Mental Well-Being

*What is most important for you to be able to do and feel?*

### Family and Social Relationships

*What is going on in the lives of others that are important to you?*

### Work/School

*Do you want or need to continue working? Can you adjust your schedule or responsibilities?*

### Social Support/Community Involvement

*Are you getting the support you need from your loved ones and community?  
Are you able to stay active/involved in your community?*

### Other:

*What else is important to you?*



## GETTING SUPPORT

Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers).

- Make a list of things you need help with (childcare, meal prep, laundry, etc.) and who can help with each task. Consider using **MyLifeLine.org** to help you stay organized and let friends know what you need.
- Ask your health care team about resources for social, emotional, and practical support.
- You can also ask for a mentor or to be matched with another person with your specific cancer type.
- If you search for information online, make sure that you are using trusted websites.
- Turn to the back page of this guide to see a listing of trusted organizations. CSC and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have cancer.

## FINANCIAL RESOURCES

Even with a health care plan, treatment can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

- Talk with your health care team and your pharmacist about the cost of your treatment.
- Ask your doctor to refer you to an oncology social worker, financial counselor, or to a nonprofit organization for help managing financial issues and costs.
- Reach out to your health care plan to find out what resources they have that could help you.
- Ask about pharmaceutical assistance programs and what the eligibility requirements are.
- If your treatment center is far away, ask if there are assistance programs that can help cover your travel costs.

The more you learn, the more you can help to reduce unexpected costs.

To learn more about ways to manage the cost of treatment, visit:

**[www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment](http://www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment)**





## COPING WITH EMOTIONS

As with any other aspect of the cancer journey, going through biomarker testing can lead to a range of emotions.

1. You may start off confused about biomarker testing and how it can help your diagnosis. It is important to be prepared for your doctor's visits and come ready to ask any questions and express your needs. Remember you also have the right to get a second opinion.
2. After you get your biomarker test results you may feel sad, disappointed, or scared to learn that there were no biomarkers found. Talk to your doctor about your options for what comes next. Be sure to ask about clinical trials.

3. If your test results find that there may be targeted therapy drug options available for you, then you may feel excited, nervous, or still scared. You may feel concerned or upset to learn that you have a mutation. Remember, finding mutations may help you find more treatment options.

No matter what, your feelings during this process are valid. It may help to find support and talk with others who have experienced biomarker testing. You may find a support group that fits your needs at your local CSC or Gilda's Club location. Visit, [www.CancerSupportCommunity.org/Find-Location-Near-You](http://www.CancerSupportCommunity.org/Find-Location-Near-You) to learn more.



## **CANCER SUPPORT COMMUNITY'S BIOMARKER TESTING TOOL**

Check out Cancer Support Community's Biomarker Testing Online Tool to learn more about known biomarkers in lung cancer. Answer a few questions about the kind and stage of lung cancer you have and then our online tool will tell you what biomarkers matter for you and why. The tool will also highlight which biomarkers have approved targeted therapy drugs and which have therapies being tested in clinical trials. You can access the tool by visiting: [www.CancerSupportCommunity.org/Biomarker-Testing-Tool](http://www.CancerSupportCommunity.org/Biomarker-Testing-Tool).

## **PRECISION MEDICINE INFORMATION & SUPPORT**

Cancer Support Community · 1-888-793-9355  
[www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

American Cancer Society · 800-227-2345  
[www.Cancer.org](http://www.Cancer.org)

CancerCare · 800-813-4673  
[www.CancerCare.org](http://www.CancerCare.org)

Cancer.net · 888-651-3038  
[www.Cancer.net](http://www.Cancer.net)

Fight Colorectal Cancer · 877-427-2111  
[www.FightColorectalCancer.org/biomarkers](http://www.FightColorectalCancer.org/biomarkers)

GO2 Foundation for Lung Cancer · 888-298-2436  
[www.go2foundation.org](http://www.go2foundation.org)

LUNGeVity Foundation · 321-407-6100  
[www.LUNGeVity.org](http://www.LUNGeVity.org)

National Cancer Institute (NCI) · 800-422-6237  
[www.Cancer.gov](http://www.Cancer.gov)

Patient Advocate Foundation · 1-800-532-5274  
[www.PatientAdvocate.org](http://www.PatientAdvocate.org)

# CANCER SUPPORT COMMUNITY RESOURCES

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking About Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**Services at Local CSCs and Gilda's Clubs** — With the help of 190 locations, CSC and Gilda's Club network partners provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/Find-Location-Near-You](http://www.CancerSupportCommunity.org/Find-Location-Near-You).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine®** — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/Become-Advocate](http://www.CancerSupportCommunity.org/Become-Advocate).

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.





All photos are stock images posed by models.

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Exact Sciences Genetech Lilly Oncology NeoGenomics**

This booklet is available to download and print yourself at  
**[www.CancerSupportCommunity.org/Precision-Medicine](http://www.CancerSupportCommunity.org/Precision-Medicine)**.

For print copies of this publication or other information about coping  
with cancer, visit **[Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org)**.

