Make a Plan for Progress Against Ph+ CML

TEST. TRACK. TAKE CONTROL.
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This brochure also includes:

- A Test Tracker and graph to record your PCR test results
- A list of questions you can ask your health care team during your appointments
Blood is made up of 3 parts: white blood cells, red blood cells, and platelets. When you have leukemia [loo-key-me-ah], the white blood cells in your body have disease that makes them grow in a strange way. As leukemia spreads, cells with disease take over the healthy ones. This can make you feel very sick.

Chronic myeloid leukemia (CML), also known as “Philadelphia chromosome positive CML,” is a cancer of the blood and bone marrow.

### What is Philadelphia chromosome-positive chronic myeloid leukemia (Ph+ CML)?

**You may have symptoms including:**

<table>
<thead>
<tr>
<th>Weakness</th>
<th>Fever</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tiredness</td>
<td>Bone pain</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>Weight loss</td>
</tr>
<tr>
<td>Night sweats</td>
<td></td>
</tr>
</tbody>
</table>

Over time, leukemia cells can spread to the rest of your blood and other organs. When this happens, other cells in your body may stop working the way they should.

A main goal of treating Ph+ CML is to reduce the number of leukemia cells in your body. Medicines used to treat CML can help you lower the number of leukemia cells in your body as much as possible.

It’s important to take an active role in your care. You can do this by taking your medicine the way your doctor tells you. You should also get regular tests to check how the medicine is working.

**Understand your disease so you can take an active role in your care.**
Your doctor has given you medicine to treat your Ph+ CML.

**The 2 main goals of taking your medicine are to:**
- Lower the number of leukemia cells in your body as soon as possible
- Keep your leukemia from getting worse

How is Ph+ CML treated?

How can I track the progress of my treatment?

The best way to work toward these goals with your doctor is to know if your medicine is working.

There is an easy blood test that can keep track of how well your treatment is working for you. This blood test is often called polymerase chain reaction (or PCR for short). It is also called a BCR-ABL test.

The test checks for the amount of BCR-ABL in your blood. BCR-ABL is a gene that causes leukemia cells to grow out of control and crowd out healthy cells.

How do PCR tests work?

PCR testing is an accurate way for doctors to measure how much BCR-ABL is in your body. PCR blood testing can find very small amounts of BCR-ABL that other tests cannot find.

PCR is a simple blood test, so it is much less painful than bone marrow testing. However, doctors still must do bone marrow testing to diagnose Ph+ CML.

Guidelines recommend that your doctor give you a PCR blood test when you first learn you have Ph+ CML, then every 3 months during your treatment to check your progress.
The PCR test helps your doctor track your treatment by:

- Measuring the amount of BCR-ABL levels that cause leukemia in your blood or bone marrow before and during treatment
- Testing how much your leukemia has decreased

Ask your doctor to get tested every 3 months to track your progress as recommended by guidelines. If the levels start to get high again, your doctor needs to know right away.

As you stay on treatment you will hopefully have fewer leukemia cells in your body. This means the tests used to track your progress must be able to find low numbers of leukemia cells.

PCR is the ONLY test shown to be able to find a single cancer cell among 1 million normal cells.

How do polymerase chain reaction (PCR) tests help track the progress of my treatment?
Throughout your treatment, you may see your numbers drop by levels of 10. This is called a log reduction.

The log reductions of BCR-ABL levels found on your report are another way to show the decrease of leukemia in your body.

**What does my PCR number mean?**

It may be helpful for you to understand the results of your PCR report. To make sure your test is done the same way each time, ask if your doctor is using a lab that does your PCR test based on the International Scale.

**Know Your Numbers**

**At Diagnosis**

- **A Log Reduction** means that the levels of leukemia cells are 10 times lower than when you were diagnosed.

**A 2-Log Reduction** means your levels are 100 times lower than when you first started treatment.

**A 3-Log Reduction** means your levels are 1000 times lower than when you first started treatment.
How long does it take to know if my treatment is working?

Your doctor should regularly track your progress with PCR blood tests. Your test results will show your doctor several signs that your treatment is working. You can ask your doctor to chart your numbers—they should get lower over time.

**Test Tracker**

**THE BEGINNING OF YOUR TREATMENT**

A PCR test can tell how many leukemia cells are in your body by measuring levels of BCR-ABL.

<table>
<thead>
<tr>
<th>12 MONTHS</th>
<th>9 MONTHS</th>
<th>6 MONTHS</th>
<th>3 MONTHS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>12 months</strong></td>
<td><strong>9 months</strong></td>
<td><strong>6 months</strong></td>
<td><strong>3 months</strong></td>
</tr>
</tbody>
</table>

**WITHIN THE FIRST 3 MONTHS OF TREATMENT**

The first sign that your treatment is working is when your blood cell levels return to normal. This is called a complete hematologic response (CHR).

**6 MONTHS AFTER STARTING TREATMENT**

If no leukemia cells are found in your blood or bone marrow, you have reached a complete cytogenetic response (CCyR).

**IDEALLY, WITHIN 12 MONTHS OF STARTING TREATMENT**

If there are very few BCR-ABL genes in your blood or bone marrow cells, this is known as a major molecular response (MMR). Reaching MMR means the amount of BCR-ABL in your body has been reduced 1000 times from the level at the beginning of your treatment.

A PCR test is the ONLY test powerful and accurate enough to measure MMR.

To take control of your treatment:

- Take your medicine exactly as your doctor tells you
- Keep your appointments with your doctor
- Talk to your doctor about getting PCR blood tests every 3 months as recommended by guidelines
- Ask your doctor any questions you have about your leukemia or your treatment

See signs of progress during your treatment journey.
These tests include:

• A fluorescence in situ hybridization (FISH) – This test shows how many leukemia cells are in your body – It is the second-most powerful way to measure how much leukemia has been removed

• A complete blood count – This is a simple blood test that counts the number of white blood cells, red blood cells, and platelets – It is the least powerful way to measure how much leukemia you still have in your body

Everyone is different and each patient is on their own journey. If you feel that your treatment plan isn’t working as well as you had hoped, it may be time to talk to your doctor about other options.

Remember, the goal of your treatment is to lower the number of leukemia cells in your body as soon as possible.

Talk to your doctor about getting PCR tests every 3 months to help track your progress as recommended by guidelines. Remember to make sure your doctor is using a lab that does your PCR test based on the International Scale.

What if my treatment isn’t working as I had hoped?

Track your progress by getting regular tests.

What are other ways to track how well my treatment is working?

There are other tests doctors can use to understand how your treatment is working. However, these tests are not powerful enough to measure very low amounts of leukemia cells like a PCR test is.

These tests include:

• A fluorescence in situ hybridization (FISH)
  – This test shows how many leukemia cells are in your body
  – It is the second-most powerful way to measure how much leukemia has been removed

• A complete blood count
  – This is a simple blood test that counts the number of white blood cells, red blood cells, and platelets
  – It is the least powerful way to measure how much leukemia you still have in your body
Here are some tips to help you make the most of your next visit with your doctor:

- **Come prepared**
  Make a list of questions you’d like to ask your doctor. This will help you make sure all your questions and concerns are answered. If you don’t understand something your doctor says, ask for more information or tell your doctor to explain it again

- **Take notes**
  Bring a pen and paper to write down what you and your doctor talk about during your visit. This can help you remember the information when you return home and may help you think of other questions to ask at your next appointment

- **Bring a friend or family member**
  You don’t have to go through this journey alone. Bring a friend or family member with you to your next appointment for support. This person can also help you take notes or ask questions. This person can also help remind you when you are due for your next PCR test

- **Talk about your test results**
  Be sure to talk to your doctor about your results and make sure you understand what they mean. Being more aware of how your treatment is working will help you better manage your health condition

- **Keep all your doctors informed**
  You’re probably seeing several doctors as part of your treatment plan. Speak with your doctor or nurse to make sure that all your doctors are aware of your progress and are sharing your test results amongst themselves
Summary

Tracking your progress can help you and your doctor treat your Ph+ CML.

Be sure to talk to your doctor about your treatment plan and get scheduled for regular PCR blood tests.

Guidelines recommend that you get tested every 3 months.

Getting regular PCR blood tests is the best way to know how well your treatment is working for you.

PCR (or BCR-ABL) blood testing is very useful. This type of test:

- Shows the amount of disease in your body that other tests cannot show
- Is a simple blood test, so it is much less painful than bone marrow testing
- Helps your doctor know when to change your treatment if you are not meeting your goals

Helpful Resources

The MAX Foundation
110 W Dayton Street
Suite 205
Edmonds, WA 98020
www.themaxfoundation.org

The National CML Society
130 Inverness Plaza #307
Birmingham, AL 35242
www.nationalcmlsociety.org

Leukemia Research Foundation
3520 Lake Avenue
Suite 202
Wilmette, IL 60091
www.allbloodcancers.org

The Leukemia & Lymphoma Society
1311 Mamaroneck Avenue
Suite 310
White Plains, NY 10605
www.lls.org

American Cancer Society
250 Williams Street NW
Atlanta, GA 30303
www.cancer.org

Remember—guidelines recommend getting tested every 3 months.
Keep track of your tests

To take control of your Ph+ CML, it’s very important to get PCR blood tests every 3 months. Keep track of your test results and be sure to talk about them with your doctor.

BEGINNING OF TREATMENT

<table>
<thead>
<tr>
<th>DATE</th>
<th>PCR TEST RESULTS</th>
<th>CHANGE FROM YOUR LAST VISIT</th>
<th>NEXT STEPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 MONTHS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DATE</td>
<td>PCR TEST RESULTS</td>
<td>CHANGE FROM YOUR LAST VISIT</td>
<td>NEXT STEPS</td>
</tr>
<tr>
<td>6 MONTHS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DATE</td>
<td>PCR TEST RESULTS</td>
<td>CHANGE FROM YOUR LAST VISIT</td>
<td>NEXT STEPS</td>
</tr>
<tr>
<td>9 MONTHS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DATE</td>
<td>PCR TEST RESULTS</td>
<td>CHANGE FROM YOUR LAST VISIT</td>
<td>NEXT STEPS</td>
</tr>
<tr>
<td>12 MONTHS</td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>DATE</td>
<td>PCR TEST RESULTS</td>
<td>CHANGE FROM YOUR LAST VISIT</td>
<td>NEXT STEPS</td>
</tr>
</tbody>
</table>

Track your PCR test results

Use the graph to track your progress.

- **Diagnosis**
- **3 Months**
- **6 Months**
- **9 Months**
- **12 Months**
Questions for my doctor

Use this checklist to help you remember questions to ask your health care team or topics you want to talk about with them. You can record the answers here, too.

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>DOCTOR'S OR HEALTH CARE TEAM MEMBER'S RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does a Ph+ CML diagnosis require me to change my lifestyle? What I eat? My exercise habits? My work or occupation? My hobbies?</td>
<td></td>
</tr>
<tr>
<td>How often will I need to visit my doctor?</td>
<td></td>
</tr>
<tr>
<td>What is the Ph+ CML test that is being performed?</td>
<td></td>
</tr>
<tr>
<td>What do the results of these tests mean?</td>
<td></td>
</tr>
<tr>
<td>Do I need to do anything before I come for testing?</td>
<td></td>
</tr>
<tr>
<td>When will the test results be available?</td>
<td></td>
</tr>
<tr>
<td>When will we talk about the results?</td>
<td></td>
</tr>
<tr>
<td>What are the treatment options available for me?</td>
<td></td>
</tr>
</tbody>
</table>

| Why do you offer this treatment over another?                          |                                               |
| When do I begin the treatment?                                        |                                               |
| What are the goals of the treatment?                                  |                                               |
| Are there any risks or potential side effects with this treatment?   |                                               |
| Are there ways to manage the potential side effects?                 |                                               |
| How do I know if a side effect is severe enough that I should contact you? |                                               |

Next appointment:

Notes
For more information on your disease, visit www.CMLEarth.com now.