SPECIAL ISSUE 05 / 2026 ISSN: 2036-9468

# CANCERWORLD












# 25th Anniversary of TKIs in CML

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**CANCERWORLD**
magazine is published
by OncoDaily (P53 Inc)

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**ISSN:** 2036-9468

NOT FOR SALE

## 25 Years of TKIs in CML: A Revolution and a Responsibility

*Twenty-five years ago, the arrival of imatinib changed the course of a disease and the lives of countless people diagnosed with it. Chronic myeloid leukemia (CML), once defined by uncertainty and limited time, became a condition many could live with, plan around, and, in some cases, even move beyond.*

*But breakthroughs do not reach patients on their own.*

*For many around the world, the promise of tyrosine kinase inhibitors (TKIs) arrived slowly, shaped by barriers that had nothing to do with biology, where they lived, what they could afford, and whether systems existed to support them. The story of CML is not only one of scientific triumph, but of the long, determined effort to turn discovery into real-world impact.*

*This Cancerworld special issue, developed in collaboration with The Max Foundation, brings together voices from across the global CML community—clinicians, researchers, patients, and advocates, who have lived this transformation in very different ways.*

*Their stories speak not just of survival, but of time regained: time to raise children, build careers, and imagine a future that once seemed out of reach. They also remind us that access has been as transformative as science itself. Because the TKI revolution did not unfold evenly, its true impact has depended on the partnerships and persistence required to reach those beyond the margins. Over the past two decades, The Max Foundation has been part of that journey, helping extend the reach of life-saving treatment to patients across the world.*

*A quarter century on, CML is more than a success story. It is a reminder of what medicine can achieve, and of the responsibility to ensure that such progress is shared by all.*

***Knarik Arakelyan, Managing Editor, CancerWorld***

**Pat Garcia-Gonzalez**
Cofounder & CEO
The Max Foundation

**Dear Friends,**

*Twenty-five years ago, we received a request through our helpline on behalf of a 22-year-old man named Raul from Honduras, who had been diagnosed with chronic myeloid leukemia (CML). The family had heard of a new compound being developed for CML, then called STI-571, and asked for our help accessing it.*

*This was 10 years to the date when my stepson, Max, had lost his battle with the same disease at the age of 17. Though we had searched for help for Max all over the world, we never found a matching donor. At the time, CML patients had a median survival of three to five years, with a bone marrow transplant being the only treatment option.*

*In my heart, since we lost Max, I had known that in my lifetime I would witness a treatment being developed that could have saved him. What I could not have imagined was that I would be at the center of one of the largest and most impactful global access programs for people diagnosed with CML and many other cancers.*

*After receiving the request for Raul, we learned that the company developing the treatment was Novartis and reached out to introduce ourselves and advocate on his behalf. That phone call changed history. It led to a landmark global partnership, providing access—for the first time—to a targeted therapy that, 25 years later, has enabled more than 110,000 people around the world to receive the medicines they need, adding more than 700,000 years of life.*

*The magic of the Glivec International Patient Assistance Program (GIPAP), and the subsequent Max Access Solutions, may never again have a parallel. The perfect trifecta—a medicine that changed the nature and course of the disease, the decision of the manufacturer to make it widely available, and the role of The Max Foundation, with Max's legacy at the center of the access program—sparked a worldwide human bond that, to this day, inspires hundreds of thousands of individuals to dedicate themselves to helping others in their communities, in whatever role is needed. It inspired medical students to become hematologists; it inspired entire communities, including first responders during the COVID-19 pandemic, to deliver medicines to patients' homes; and it inspired program beneficiaries to become patient leaders, form patient organizations, and dedicate themselves to helping others.*

*As we look back at the 25-year legacy since the approval of imatinib as the first tyrosine kinase inhibitor (TKI) to treat CML in May 2001, this issue is for them—to honor their daily contributions to a better world. As such, we feel it is critical to hear from the global community—advocates, innovators, researchers, clinicians, and patients—working together to transform the lives of people diagnosed with this once-deadly cancer, as well as their families and communities. The stories shared in these pages are ones of hope and progress. They demonstrate the power of people helping people. We are honored that Cancerworld has agreed to dedicate a special issue to commemorate this milestone. The diverse voices in these pages demonstrate that, through partnership and shared commitment, we can improve the lives of those in need, whatever the barriers, restoring dignity and hope in the face of cancer.*

*The progress achieved since 2001 spans treatment, diagnostics, advocacy, and access. Thanks to research-driven advances, we now live in a world with multiple lines of therapy that provide new options for people living with aggressive disease and help others successfully achieve treatment-free remission. Today, molecular monitoring can detect a single leukemia cell among hundreds of thousands—or even a million—normal cells, and a simple blood spot on paper can be used to diagnose the presence of disease. A global community of more than 100 patient organizations advocates, educates, and uplifts the lives of patients and their families. Accessibility to CML medicines is among the highest for cancer treatments globally. Today, CML patients are on treatment in every corner of the world, with median survival rates that compare favorably to those in resource-rich settings.*

*And yet, more work remains to be done. There are still patients across high- and low-income countries who cannot access treatment, diagnostics, or care. The chronic, long-term nature of treatment often forces patients to choose between their families and their health, as a bus fare or a day off work to visit the oncology clinic can mean sacrificing a family meal or school supplies—or because they cannot afford co-pays and other healthcare costs. Disease monitoring is not consistently available or affordable, creating unnecessary risks of disease progression and preventing eligible patients from considering treatment-free remission. Gleevec/Glivec and a few other TKIs have lost market exclusivity; however, the availability, cost, and quality of generic versions mean these medicines remain out of reach for too many, and CML is still not a priority for many governments.*

*As one community, we must not accept the status quo but instead step forward and drive change. Geography must not dictate one's destiny. All people living with CML should be able to face this critical illness with dignity and hope. We can prevent unnecessary suffering and premature death today—we have the tools. And because we can, we must, and we will. As humanitarians and leaders, we have a moral imperative to ensure access to treatment and care for all patients now. We urge you to join us as we expand our lifesaving work around the globe.*

**With gratitude and determination for a better future.**

## 1997 The Max Foundation is founded

A small group of volunteers joined forces with a mission to help families in Latin America with children diagnosed with leukemia gain access to resources and support. They named their grassroots organization, The Max Foundation, to honor Maximiliano "Max" Rivarola, who passed away from chronic myeloid leukemia (CML) in 1991 at age 17.

## 2001 A New Class of Treatment for Cancer

FDA approves imatinib for the treatment of CML.

## 2004 A Global Partnership for Access

The Max Foundation and Novartis partnered to develop and administer the Glivec® International Patient Assistance Program (GIPAP), a direct-to-patient international drug access program providing free-of-charge treatment for CML and other rare cancers to patients in more than 80 low- and middle-income countries.

GIPAP™

## 2004 First Evidence of Treatment-Free Remission (TFR)

The first TFR pilot study showed that 50% of CML patients who discontinued imatinib maintained undetectable BCR::ABL1 levels for over two years.

## 2006 Dasatinib

FDA approves dasatinib for patients with imatinib-resistant or intolerant CML.

## 2005 2007 A Global CML Community

In 2005, at the 4th International "New Horizons in Cancer" conference for CML and GIST patient advocacy groups in Dublin, the idea for the CML Advocates Network was first discussed. By 2007, this international patient group organization had launched its website.

CML ADVOCATES NETWORK

## 2007 Nilotinib

FDA approves nilotinib for patients with imatinib-resistant or intolerant CML.

## 2008 A Growing Divide

A majority of CML patients receiving imatinib and other targeted therapies continue to see positive results and experience extended lifespans. For those who develop resistance to imatinib, newer, more potent oral medications used as second- and third-line treatments have demonstrated success. While many patients in high-income countries have access to these highly effective therapies, most patients and healthcare providers in low-income settings lack access to these treatments and to vital diagnostic monitoring needed to detect treatment-resistant disease.

## 2012 Bosutinib

FDA approves bosutinib for CML patients with resistance or intolerance to prior therapy.

## 2012 Access to Diagnostic Testing

Cepheid and The Max Foundation sign an agreement to expand access to PCR testing across low-resource countries.

## 2012 Ponatinib

Ponatinib is first approved as the first therapy specifically designed to inhibit T315I, a mutation that confers resistance to all prior TKIs.

## 2012 First Generic Imatinib Approval

The European Medicines Agency approves the first generic imatinib in October.

## 2013 TFR Included in European LeukemiaNet (ELN) Guidelines

The guidelines recognize treatment discontinuation as a possible strategy in highly selected patients for the first time.

## 2015 Expanding Global Access Beyond CML

The Max Foundation launches Max Access Solutions, the first global oncology model of its kind, offering a portfolio of cancer therapies, diagnostic solutions, and patient services through diverse partnerships that further support patients in accessing quality treatment and care.

## 2015 2017 Bridging the Gap

Five multinational pharmaceutical companies join The Max Foundation to provide access to cancer treatment and quality care. Together, they form the Humanitarian Partnership for Access to Cancer Treatment (PACT)—a commitment to providing access for patients who have no other means of accessing treatment.

## 2017 A New Way to Diagnose Patients

The Fred Hutchinson Cancer Research Center, in partnership with The Max Foundation, launches Spot on CML, a groundbreaking collaboration to increase access to testing for chronic myeloid leukemia (CML) patients in under-resourced countries using blood spots on paper that can be easily shipped to the laboratory of Dr. Jerry Radich, the innovator behind the program.

## 2020 Health Equity Achieved in CML

Real-world survival analysis shows 89% five-year overall survival for CML patients in GIPAP, an outcome comparable to those reported in high-income countries (Umeh et al., 2018). *

## 2021 Asciminib

Asciminib, the first allosteric TKI targeting the ABL myristoyl pocket (STAMP inhibitor), is approved.

## 2022 Equity in Action

The Max Foundation announces a five-year strategic plan, Equity in Action, to expand its mission of accelerating health equity. The plan's visionary goals encompass doubling the number of partners, new patients reached, and diseases with access to treatment.

EQUITY IN ACTION

## 2022 TFR Is Possible in LMICs

Four patients in Paraguay successfully attempt treatment-free remission (TFR) through The Max Foundation TFR Support program. More than 100 patients follow.

## 2025 New Commitment to Double Our Impact

The Max Foundation announces a bold commitment at the Clinton Global Initiative Annual Meeting to deliver breakthrough cancer care to 100,000 patients annually within the next five years.


## 2025 Novartis and The Max Foundation Sign a Landmark Five-Year Agreement to Extend Their Collaboration

Access to CML therapies is an important component of the agreement to expand access to cancer and rare disease therapies and strengthen health systems.

## 2026 A New Generation of Treatments

Multiple new TKIs are in development to address the unmet needs of patients.

****EClinicalMedicine. 2020 Jan 26;19:100257. doi: 10.1016/j.eclinm.2020.100257. PMID: 32140674; PMCID: PMC7046500.*

# Pat Garcia-Gonzalez

## She Doesn't Speak About Challenges. She Speaks About Doing What Must be Done.

by Gevorg Tamamyan

***

Max, the stepson of Pat Garcia-Gonzalez, was 14 years old when he was diagnosed with chronic myeloid leukemia in 1988. At first, like many families, they believed it was something treatable. Then came the reality—this was a rare leukemia, and at the time, the only possible cure was a bone marrow transplant, if a matching donor could be found.


*Max's Day, October 19th, 2017*

They searched everywhere.

From Argentina to the United States, Max was treated at MD Anderson Cancer Center, under the care of Dr Moshe Talpaz, one of the pioneers of interferon therapy. But no donor was ever found.

In March 1991, Max died.

*"When the doctor says, 'It's over, go home,'"* Pat recalls, *"we couldn't accept that it was over. Go home to what?"* So they didn't.

They stayed engaged—first through fundraising, then through something that would become much bigger than they could have imagined—***the Max Foundation.*** The Max Foundation began, quietly, in 1996.

Someone had explained to them what a *"website"* was—a place where you could put information, and anyone in the world could access it at the same time.

Max had been diagnosed before the internet. But now, Pat and her family realized they had accumulated something powerful: knowledge.

They knew how to navigate donor registries, how to search internationally, and how to connect to institutions.

So they built a website.

And on day one, they opened an email address: ***help@themaxfoundation.org***

*"Every single day until this morning,"* Pat says, *"we receive desperate messages from people around the world."*

The Max Foundation

At the beginning, the message was simple:

There is a treatment. It's not in my country.

Today, it has changed:

There is a treatment. I just can't afford it.

But the need has never gone away.

## The Moment Everything Changed

In the year 2000, a message arrived.

A 22-year-old man from Honduras, Raul, had been diagnosed with CML. His family had heard about a promising new treatment in development and asked a simple question:

Can you help him access it?

The drug was being developed by Novartis. Pat and her team reached out.

At the same time, Novartis was facing a different problem. They knew the drug—later known as Gleevec—would not be commercially available in many countries, yet patients would still need it.

They were looking for a partner.

The Max Foundation became that partner.

What followed was the creation of one of the most impactful global access programs in oncology—the Gleevec International Patient Assistance Program (GPAP)—bringing life-saving treatment to patients across dozens of countries.

Twenty-five years later, Raul is still alive.

More than 100,000 patients have benefited.

## "We Don't Talk About Challenges"

When asked about the challenges of building such a system, Pat answers in a way that defines her leadership.

*"I don't allow my team to tell me anything about challenges,"* she says. *"Our work is challenging by design."*

Instead, she describes what needed to be built.

At the beginning, the obstacles were regulatory—how to deliver medicine across borders, to specific patients, in specific hospitals, within systems that had never done this before.

Then came something even more complex: continuity. *"We didn't know how long patients would need to be on treatment."*

Now we know: often for life.

So they built systems—tracking individual patients, prescriptions, supply chains—ensuring that a patient who had traveled for days would arrive at a hospital where the medicine was waiting.

## From Drug-Centered to Patient-Centered

By 2015, a new problem emerged.

New therapies for CML were being developed. Some patients needed second-line treatments. But access was inconsistent, fragmented across companies and systems.

That was the moment of reinvention.

*"We realized,"* Pat says, *"that you cannot have the treatment at the center of the program. The patient has to be at the center."*

The result was a new model: Max Access Solutions.

Instead of relying on one company's distribution, the Foundation built its own system—partnering with multiple pharmaceutical companies, managing logistics, and ensuring physicians could access the right treatment for each patient.

Today, The Max Foundation is a huge infrastructure: partnerships with multiple companies, access to 14–15 therapies, global distribution networks reaching the most remote settings.

*"If you live in a remote island of Papua New Guinea,"* she says, *"your chances of survival can compare to a patient in Europe or the U.S."*

That was the dream.

*Pat Garcia-Gonzalez was recognized and awarded by the President of Kenya, William Samoei Ruto, PhD, in honor of Mashujaa Day, 2023*

## The Real Barrier Is No Longer Geography

As Foundation expanded beyond CML, most notably into breast cancer, it encountered a different reality.

Access to drugs is no longer the only problem.

Diagnosis is.

*"You can have the treatment,"* Pat explains, *"but if you don't know which type of cancer the patient has, you cannot use it."*

So the work expanded again into diagnostics, systems, and infrastructure.

At the same time, a deeper insight emerged:

The world's traditional categories—low-income, middle-income, high-income—no longer define access. *"If you have money, you may access treatment almost anywhere,"* she says. *"If you don't, even in the U.S., you may not."*

The problem is no longer geography.

**It is affordability.**

## A New Model for a Changing World

Now, Pat is thinking about the next transformation.
A system that is geography-agnostic.

A platform that helps patients wherever they are, independent of borders, income classifications, or traditional structures.

*"We need to think differently,"* she says. *"AI is coming. The world is changing fast."*

Her vision is clear:

A global access system that adapts to reality, not the other way around.

## Leadership Without Ego

When asked about leadership, Pat returns to a simple principle: *"It's not about you."*

She speaks about empowering others, building teams that go beyond expectations—what she calls *"impact players."*

She recommends books. She reflects on pressure. She speaks about responsibility—not as a burden, but as something to be managed with discipline.

At one point, the weight became overwhelming.

Lives depended on decisions.

So she changed her mindset.

*"Every day, I wake up, I do my best, I make the best decisions I can. That's all I ask of myself."*

No fear.

No long-term anxiety.

Just daily commitment.

## Paul Farmer

Among those she admires, one name stands above all: Paul Farmer.

*"I try to be 10% of what he was,"* she says.

What she sees in him is not only intelligence or impact, but a moral compass, and the ability to bring people together around a cause.

## Advice to the Next Generation

Her message is simple, but hard-earned: *"Do your best—every day! Don't operate out of fear! Stay curious! And never stop learning!"*

Everything else, she believes, will follow.

Pat Garcia-Gonzalez

## Who Is Pat Garcia-Gonzalez?

She doesn't define herself through titles or achievements.

Instead, she speaks through action.

Through systems built where none existed.

Through patients reached where access was impossible.

Through a belief that doing good every day is enough to change the world.

*"I am very optimistic right now,"* she says.

In a world that feels unstable, unpredictable, and fast-changing, her orientation is simple: *"Do something good today."*

And if enough people do that the system, eventually, will follow.


BETA 58A
CML HORIZONS
20th INTERNATIONAL CONFERENCE
Bahija
Gouimi
Morocco

# From Survival to Empowerment

by Bahija Gouimi

"You have CML (chronic myeloid leukemia). It is blood cancer." I was pregnant with my third child in 2002 when I heard the words that would change my entire life.

At that moment, my world collapsed. I felt lost, powerless, and useless. But the diagnosis was only part of the shock. In my country at the time, there was no treatment available, no patient association, and no real support system to help a young mother facing such a diagnosis. No treatment. No support. And above all, no hope. Doctors told me I had only three years to live.

Three years. I kept asking myself: What am I supposed to do with these three years? Should I spend them preparing my husband for my death? Should I tell my children everything? Should I try to fulfill a few dreams before it is too late? Those three years felt like a sentence.

I was angry. I was in denial. I refused to accept this fate. Of course, there was deep sadness, but there was also a growing determination inside me: there had to be a solution. And sometimes, when there is no solution, you have to invent one.

## From Diagnosis to Determination

After four months of searching, I found a possibility: the treatment existed in Spain. If I could convince my health insurance and access it, maybe I could survive.

Bringing that first box of medicine to Morocco was a journey of determination. It took four days and more than 1,500 kilometers of travel. At the time, the healthcare system was highly centralized. I was living in Marrakech, but I had to travel to Casablanca to see my doctor, then to Rabat to complete administrative procedures, and finally to Tangier to cross to Spain and bring the medicine back.

When I finally held that first box in my hands, I felt proud. I thought to myself, *"I saved Bahija."*

I even wanted to show it to my doctor and say, *"Look, I did it."* But when I walked into the waiting room, I saw other patients receiving treatment. At that moment, my pride turned into something else: guilt.


The question *"Why me?"* suddenly became *"Why not me?"*

That moment changed my life. I realized I had a responsibility. Even with cancer, I had a role to play. I could not keep this treatment only for myself. I had to help other patients understand their disease, follow their treatment, and, most importantly, fight for access to treatment in my country. What helped me most was therapeutic writing; I wrote down all my struggles, thoughts, and dreams. Today, I am extremely proud to have published four books, sharing experiences and reflections that aim to inspire others.

So I began another battle: bringing the treatment to Morocco.

I launched petitions, spoke to the media, and advocated relentlessly to raise awareness about our vital need and secure access for patients with chronic myeloid leukemia. After 18 months of advocacy and persistence, we succeeded. The treatment became available in Morocco.

**For me, imatinib, the life-saving TKI, was not just a medicine or a targeted therapy. It was hope. It was proof that a life once counted in years could become a life with a future.**

## Building a Movement for Change

This experience helped me understand that my mission was bigger than my own survival. I had to work to improve cancer care and treatment access in my country and become a voice for patients.

I began educating myself. I attended conferences, joined discussions with experts, and worked to understand both my disease and the healthcare systems that shape access to treatment. I also joined other cancer patient organizations to learn from their experience. But I did not want to simply copy existing models; I wanted to create something strong and adapted to the specific needs of CML patients.

In 2011, I founded the AMAL Organization (Association des Malades Atteints de Leucémies). Today, AMAL has become a reference organization for cancer patients in Africa. Our work focuses on therapeutic education, psychological and moral support, advocacy, and empowering people with lived experience so they can become active participants in their care and advocates for change.

In 2022, we took another major step forward by opening Dar AMAL, a house created to host patients in need who travel long distances to receive treatment in Marrakech and

who otherwise would have nowhere to stay. Dar AMAL was designed to ensure that patients can follow their treatment and see their doctors while maintaining dignity during one of the most difficult moments of their lives.

The house provides free services, including transportation, accommodation, medical tests, medicines, meals, clothing, and social and psychological support. Everything is offered free of charge to help patients and their families face the challenges of cancer.

Dar AMAL was inaugurated on World CML Day 2022, and today it is much more than a house. It is a place of hope, solidarity, and dignity. And every day it reminds me of something powerful: a diagnosis that once felt like the end of my life became the beginning of a mission to change the lives of others.

## From Survival to System Change

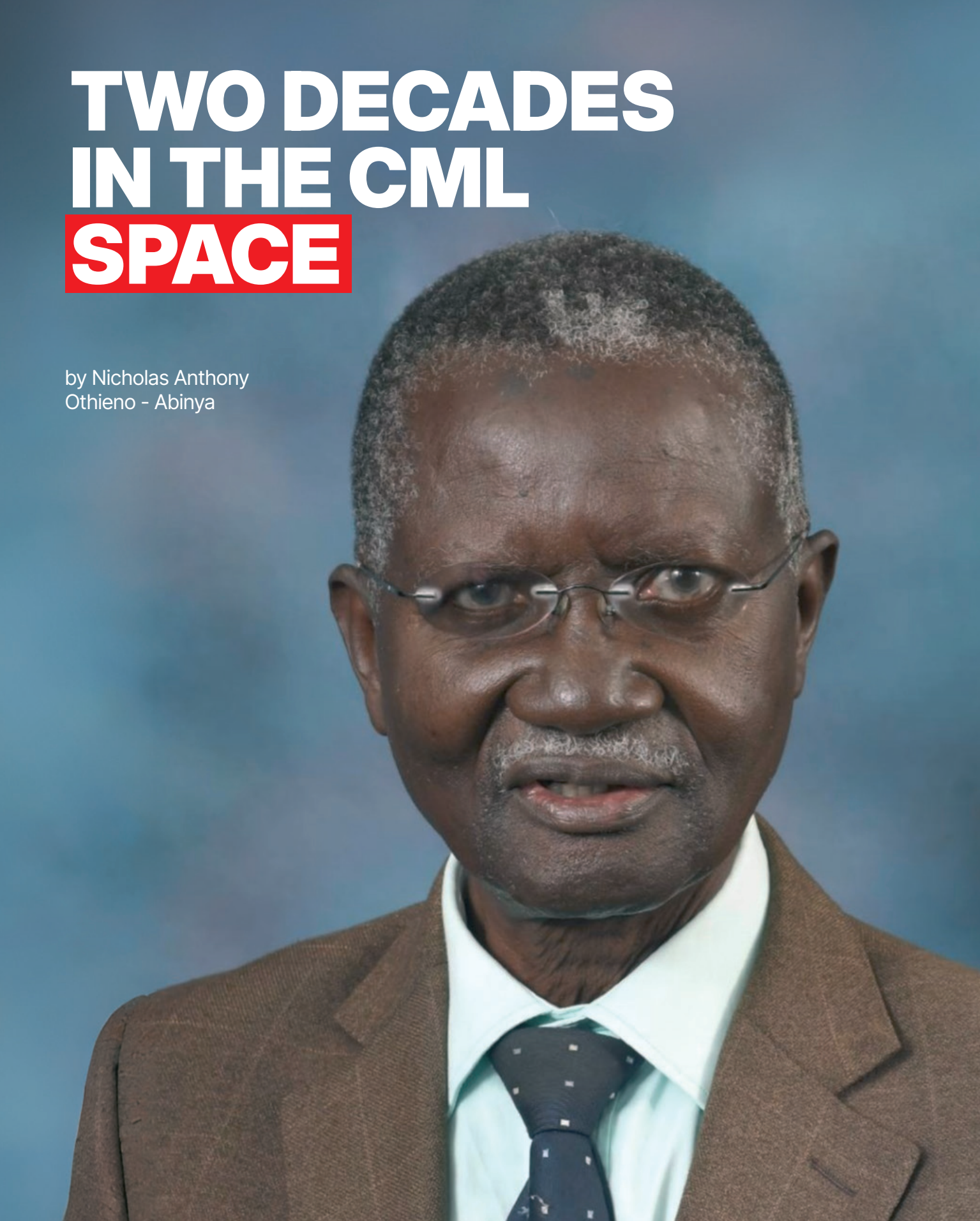
Above all, I remain profoundly grateful for the treatment that gave me a second chance at life. It allowed me to return to a normal life, to see my children grow up, and to witness their achievements—moments I once feared I would never experience. Today, I am proud of the journey that began with fear and uncertainty and evolved into a lifelong mission. I am proud to be a cancer advocate and patient expert, and a mentor.

I hold a degree as a Patient Partner in Cancerology from Mohammed VI University of Medicine and collaborate with several international organizations dedicated to improving access to treatment and increasing the visibility of patients' needs. Through this work, I contribute to mentoring, capacity building, and supporting the development of many cancer patient organizations in my country and across the region.

Looking back, the diagnosis that once felt like the end of my life became the beginning of a commitment: **to ensure that no patient feels alone, powerless, or without hope.**

# TWO DECADES IN THE CML SPACE

by Nicholas Anthony Othieno - Abinya



## A Calling Born from Compassion and Literature

My decision to become a cancer doctor was first inspired by reading a novel that I was given as a biology prize in 'A levels'. The book title was "Cancer Ward" by Alexandr Solzhenitsyn. It was through this novel that I saw doctors, nurses, and support staff toil day and night in a central Russian cancer clinic in the early 1940s to make the lives of cancer patients bearable and livable. I also saw the plight of cancer patients as some went through hope, and others gloom. It was clear that illness did not choose between the lowly and the mighty. *I not only decided I wanted to be a doctor, but a cancer doctor.*

Whereas medical education at the University of Nairobi had its challenges, some teachers were outstanding. Professor Thomas Arimba Ogoda, our haematology professor, literally guided me into the discipline of internal medicine, then medical oncology. My fellowship was undertaken at the Royal London Hospital, where Professor Tim Oliver greatly inspired me. Apart from the regular mentors, I also came across influential personalities with excellent grasps of the cancer space.

In the course of my search for knowledge in haematology/medical oncology, I have had the opportunity to visit world-renowned cancer centres, including St. Bartholomew's Hospital in London, the Christie and Holt Radium Institute in Manchester, Memorial Sloan-Kettering in New York City, Dana-Farber in Boston, and the University of Nebraska Medical Center in Omaha, among others. I have concentrated most effort in malignant haematology, though I also take care of patients with solid tumours, breast cancer in particular.

## Before the Breakthrough: Treating CML with Limited Options

Up to the year 2001, we treated chronic myeloid leukaemia (CML) with busulfan, hydroxyurea, and low-dose cytarabine. Interferon and allogeneic stem cell transplant were not available to us. With busulfan and hydroxyurea, median survival was about 3–4 years, but some patients survived much longer, and in good physical health. We were cognisant of the risk of prolonged cytopenias induced by busulfan and monitored blood counts very closely. However, not everyone could be lucky, and I remember two patients who developed severe myelosuppression and required red cell and platelet transfusions for in excess of six months. One died, and another gradually recovered marrow function.

In May 2001, Dr Brian Druker presented results, earlier published, on the outcome of CML patients treated with STI571, and that changed everything. From then on, CML has been treated differently.

A twenty-two-year-old patient I had treated from the age of sixteen with busulfan, then later hydroxyurea, had deteriorated to accelerated phase and secondary myelofibrosis and was in need of better therapy, yet she could not afford to be treated with interferon-alpha or allogeneic bone marrow transplant. Apart from massive splenomegaly, she had unhealing ulcers scattered all over both legs, was wasted, and her abdomen was grossly enlarged. After listening to Dr Brian Druker's talk at the New Orleans ASCO meeting, I returned home confident that I would offer help to this young woman who very badly needed the medicine.

It wasn't that simple, since I didn't know the manufacturer of this drug. I tried to find out how I could get hold of Dr Druker but didn't succeed. The young woman succumbed to her disease, but I didn't give up. I kept referring patients who were financially capable to the United States to access the magic cancer bullet. No luck for most, because even where it was available, the cost was intimidating.

## Building Access: A Lifeline Through Global Partnership

Fortunately, The Max Foundation, in partnership with Novartis Pharma, started the imatinib International Patient Assistance Program (GIPAP), administered by Axios International in Kenya in 2004. I got wind of the fact that the medicine was being administered free in a hospital where I had a practice.

*Can my patients also access?*
*No, thank you.*

*Clinic day: from left to right—N.A. Othieno-Abinya, Elo Mapelu (patients' group chairman), Dr Becky Mwakichako, Prof P.P. Piccaluga*

Early in 2004, I received a call from *Axios International in Kampala,* with the information that I should consider joining the program as a volunteer physician. I didn't hesitate and joined in 2005 after some hiccups. I registered my first patient in August 2005 after having met with Pat Garcia-Gonzalez and members of The Max Foundation in Orlando, Florida, during the 2005 ASCO Annual Conference.

We set up a GIPAP clinic at The Nairobi Hospital, where patients are registered and treated as long as they demonstrate BCR-ABL1-positive myeloproliferative neoplasm and meet other requirements for inclusion. Physicians are drawn from volunteer haematologists and medical oncologists from the University of Nairobi and Kenyatta National Hospital and are assisted by medical oncology fellows from the same university. The clinics are purely voluntary. Pharmacists, nurses, and counsellors employed by The Nairobi Hospital participate. We also get collaborating haematologists from abroad, particularly from Italy. Professor Pier Paolo Piccaluga from Bologna has been outstanding.

The clinics commence with talks by patient representatives. There are also counselling sessions, then consultation. So far, we have treated CML patients exceeding 1,500 in number, as we also take care of patients with several other cancers.

During the COVID-19 era, we had patients take blood tests from their residential areas, send them to us via

WhatsApp, then the team would review the results and prescribe medicines. The pharmacists would dispense the medicines and send them to patients by courier service.

The Government entered a partnership with The Max Foundation, paving the way for registration of Max Access Solutions. This enabled decentralization of services to four regional centres.

For this donation, Pat was given a Hero's honour by the President of Kenya in 2024. For my part as the lead physician, I was awarded the International CML Foundation prize in 2005 at Estoril, Portugal. For their participation, The Nairobi Hospital received an international award for humanitarian service in 2023, also in Portugal.

The journey has been long and tiring. The doctors and my office staff cannot enjoy two weekends in a month. It has also been satisfying when patients express their sincere appreciation for the lease of life they have been given following all the gloom that characterises the diagnosis of cancer. Ten percent CML-related deaths have so far been registered, while successful treatment rates stand at about 70%.

A challenge is that as patients live longer, numbers increase, yet devolved units have not proved attractive enough for many, since some still come back to us at the main administration centre. Concerning some of the drugs, the donors have capped the numbers, so we cannot register new patients for these medicines. Because our hospital is a high-cost facility, patients whose leukaemias have transformed to a blastic phase prefer to go elsewhere for care. This way, we lose vital contact with and information from these patients.

Many patients have otherwise benefitted, the government has benefitted, medical oncology fellows have benefitted, and the physicians have also broadened their capacity to handle CML.

**I am grateful to The Max Foundation, the physicians including medical oncology fellows, The Nairobi Hospital, the Government of Kenya, and Henzo Kenya.**

*Physicians running the virtual clinic*

# Celebrate Life Every Day

by Hilda Paz Rivera

My name is Hilda Paz. I am from Santa Cruz de la Sierra, Bolivia, and I am 70 years old. If I could summarize my life in one sentence today, it would be this: **"God allowed me to stay... to learn how to live, to love more, and to never give up."**

My story did not begin with illness. It began with a child.

## From Childhood Illness to a Lifetime of Survival and Purpose

I was a child of just 10 years old who did not understand why her body was different. While others played without worry, I watched my skin fill with bruises for no reason. My gums would bleed when I brushed my teeth. A small bump would leave large marks. Something was not right, but no one knew what it was.

My days became filled with hospitals, tests, and silence. Doctors searched for answers, but at that time medicine did not have what it has today. They spoke of anemia, low platelets, and blood disorders. I received treatments, but I did not improve. While the world continued moving forward, mine seemed to stop with every inconclusive diagnosis.

Then the pain came with greater force.

A deep pain on the left side of my body that would not let me walk. It was constant and heavy, as if my own body were asking for help. That is when a decision came that would mark my life: surgery.

I was just a child, but fear has no age.

I heard things no child should hear: that I might not survive, that it was a high-risk operation. And in the middle of all that, I also experienced one of the hardest trials: loneliness.

My parents did not always have the resources to stay with me. There were moments when I felt abandoned, but today I understand something I could not see then: I was never truly alone.

God placed people in my path—helping hands, an aunt, a cousin and an invisible strength that held me even when I could not hold myself.

The surgery was long, difficult, and painful. I lost a lot of blood. I received transfusions. My body fought, but so did I.

Until one day, my heart stopped. It happened during a transfusion. My body rejected it, and in an instant, everything changed.

I felt myself leaving. I saw a dark tunnel and at the end, a light. A light so strong, so beautiful, that it was not frightening. It was a peace that cannot be explained with words. It was a rest. It was silent. It was love. I felt no pain. I felt no fear. Only peace.

But I did not stay. Because it was not my time. I came back. And although I did not understand why at that moment, today I do: I returned because my story was not finished.

After that, my life continued with care, limitations, and fear, but also with a new opportunity.

At 22, I became a mother. And I understood something that changed everything within me: when you have a reason to live, you find strength where you did not know it existed. At 25, I became pregnant again. But my health worsened. Doctors told me I should terminate the pregnancy, that it was the safest option.

But some decisions are not made with the mind, they are made with the heart. And my heart chose to fight. I continued forward with fear, uncertainty, but also with faith.

And once again, after giving birth my heart stopped.

Again the silence. Again the darkness. Again the light. And once again I came back.

I opened my eyes and my daughter was alive.

Today, she is one of my greatest blessings. She is proof that even in the midst of pain life finds a way.

At 30, I had my third daughter. And for many years, my life was calm. I worked, raised my children, and moved forward. I thought the hardest part was behind me.

But life sometimes tests you again.

## "I Came Back Because My Story Was Not Finished"

In 2008, I began to feel a different kind of fatigue. It was

not only physical; it was deep, as if my soul were tired. I underwent tests. I remember that moment clearly: the lab called me back to repeat them. That is when I felt fear not for myself, but for my children. Because a mother does not fear for her life, she fears what she might leave behind.

After several tests in 2008, I received the diagnosis: chronic myeloid leukemia. I felt like my world was collapsing. I walked in tears. I did not know how to face something like that. I did not know where to begin. And for a time, I remained silent. I did not want my children to suffer. But I came to understand that silence does not heal. And giving up was never an option for me.

I began treatment. It was not easy. Long journeys, exhaustion, strong medications, side effects. There were days when I had no strength, days when my body seemed ready to give up. But my soul did not. Because there is something illness cannot touch: *the decision to continue.*

Over time, I gained access to a more specific treatment for chronic myeloid leukemia. Today, I continue my treatment with nilotinib, a therapy that has been fundamental for my condition.

Thanks to this treatment, little by little my life began to stabilize. What initially seemed like a path full of uncertainty began to transform into the possibility of continuing to live, of watching my children grow, and of continuing to build my story.

***These advances in medicine gave me something very valuable: time, hope, and the opportunity to keep going.***

Gradually, my body began to respond, my disease became manageable, and my life stabilized. What once seemed uncertain became a path forward. I understood something very important: the diagnosis was not the end. It was the beginning of a new stage of struggle and also of life.

Then I realized something that changed my story: *I did not want to only survive.* I wanted to serve.

I began helping other patients, accompanying them, calling them, reminding them of their check-ups, and being there when fear paralyzed them. Because I knew exactly how they felt. I knew what it meant to receive a diagnosis that breaks you. I knew what it felt like to believe the world was ending. And I also knew this: it does not end. Life continues. Pain passes. Hope can be rebuilt.

Since my diagnosis in 2008, I have been part of the association Celebrating Life, where we work like a family, supporting patients from diagnosis through treatment. We provide support for tests, medication, and transportation, which we receive thanks to *The Max Foundation.* Many patients come from remote areas, from departments such as Pando, Beni, Sucre, Tarija, or border towns like Roboré and Quijarro. We also provide emotional support, guidance, and follow-up to help them adhere to their treatment. Although we face challenges such as administrative barriers and limited resources, we continue to train and organize ourselves to provide comprehensive support to all patients.

Over the years, I have faced new challenges: diabetes, thrombosis, and a difficult surgery where amputation was even discussed. Was I afraid? Of course I was afraid. But I also had faith. And I learned something I want to share with you: fear is human... but faith is what sustains you.

Today, at 70 years old, I am still here. Not perfect. Not without scars. But standing.

**Grateful. Living. Loving.** Supporting others. Because I understood that life is not about never falling. It is about rising each time with greater meaning.

## Living Through CML: From Fear and Survival to Helping Others Live

If you are going through a difficult moment, if you have received a diagnosis, if you feel like you cannot go on I want you to hold on to this: *you can continue.* Maybe not as before. Maybe with changes. Maybe with fear. But it is possible.

Because as long as you have life you have an opportunity. An opportunity to love more, to forgive, to value, and to begin again.

Today, I thank God for every day, for every breath, and for every person placed in my path. And if there is something I can say with all my heart, it is this: life did not stop for me, life taught me how to live it better.

**I am still here.**

And as long as I am here I will continue to believe, to fight, and to celebrate life one day at a time.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# Forty Years Treating CML in Mozambique

## Between Death Sentence and Hope of Life

by M. Patrícia M da Silva

*Multidisciplinary meeting at the Oncology service to discuss implementation of the TKI donation program by the Max Foundation*

# From Busulfan to Breakthrough: Building Hemato-Oncology in Mozambique

I began to deal with chronic myeloid leukemia (CML) in 1986, when I was transferred from a primary care Health Unit to a Medicine service at Maputo Central Hospital (HCM), the most differentiated unit in the country, located in the capital of Mozambique.

By mere chance, I was assigned the beds of hemato-oncological pathology. At that time, patients with leukemias, lymphomas, and myelomas were admitted and followed up in the medical service, and I took over the care and follow-up of these patients. All my subsequent practice was determined at that time, and the training was focused on this area with the support of the senior internists and Service Directors. At the time, there was no specialist in Hematology in the whole country.

The diagnosis of CML was confirmed based on clinical observation and peripheral lamina (ESP) that revealed the hypergranulocytosis characteristic of CML, often accompanied by severe anemia and thrombocytosis. Bone marrow was rarely studied, since there was no resource for genetic study of the 9:22 translocation to confirm the BCR-ABL mutation.

The practice of interpretation of blood smear and bone marrow was also a central occupation, having spent a significant time in the Hematology and Pathology laboratory.

It should be remembered that Mozambique is a very low-income African country (currently with 35 million inhabitants), victim of frequent and periodic natural calamities (from drought to floods and cyclones). In addition to climate disasters, there are social conflicts, and, at that time, there was a cruel civil war that took place between 1980 and 1992 that caused more than a million deaths.

All this made it difficult for patients to access hospitals, leading to late diagnoses and already advanced stages, hindering therapeutic success.

In 1986, the CML therapeutic approach available in Mozambique was basically busulfan and sometimes hydroxyurea. These drugs were only available at HCM in Maputo. The risk of severe cytopenia, which was difficult to control, was frequent. Many patients, due to the obstacles and difficulties already mentioned, were not always able to attend appointments on the scheduled dates and kept taking busulfan, ending up being hospitalized with severe aplasia.

Hydroxyurea was reserved for cytoreduction in cases of hyperleukocytosis and leucostasis risk. Blast conversion was frequent, and mortality very high due to the difficulty and lack of means to treat acute leukemias.

The following years were a long period of continuous learning and training inside and outside Mozambique to complete the specialty in Haemato-Oncology. The final exam was carried out in 1994, and at that time a Haemato-Oncology unit was created.

It also increased the responsibility in the diagnosis, follow-up, and treatment of all hemato-oncology patients. In particular, the care provided to patients with CML, always in the anguish of a blast crisis and lack of treatment resources. However, until the second decade of the 2000s, little progress and improvement had been made in the diagnostic and therapeutic approach, despite the fact that the use of TKI was already widespread worldwide.

## Barriers Beyond Medicine: The Long Road to Access CML Therapy

Around 2003/2004, we were contacted by colleagues from Tanzania to join the GIPAP (Glivec International Patient Assistance Program). Despite all the enthusiasm to join this program and, after many hours of work filling out forms and meetings with the Hospital Board and the Ministry of Health of Mozambique, it was not possible due to the inability to carry out the Philadelphia Chromosome research.

However, a minority of patients with economic capacity or health insurance support were able to take tests in South Africa and started imatinib, doing clinical and hematological control in Maputo.

For many years, the difficulties and challenges already listed prevailed, with the population of patients

*First patient to receive imatinib, November 2019*

increasing, and very few with access to TKIs. Until, in 2018, a new possibility arose. Through Dr Ellen Baker, Oncologist at the MD Anderson Center, efforts were made to initiate contacts and meetings with The Max Foundation team headed by Pat Garcia-Gonzalez and the HCM Hematology team.

Throughout 2019, several online and live meetings made it possible to ascertain the laboratory, diagnostic, and treatment conditions of CML to start the imatinib donation program to Mozambique. The conditions for importation and customs clearance of medicines were also discussed with the government authorities, involving multidisciplinary teams with professionals from the MISAU (Ministry of Health), HCM, CMAM (Central de Medicamentos e Artigos Médicos), laboratory, and Hemato-Oncology service.

## A Turning Point: Access, Hope, and the Beginning of Change

All these efforts and hours of work paid off, and in November 2019, we received the first donation of imatinib.

At that time, GeneXpert tests for BCR-ABL were also started in order to confirm the diagnosis and monitor the effect of the treatment. The community of CML patients was grateful for the possibility of molecular diagnostic confirmation and access to this new drug that allows them to achieve molecular remission.

Currently, thanks to Max Foundation donation, more

than 100 CML patients are benefiting from this program, either by making available the GeneXpert tests to detect BCR-ABL or by providing TKIs: imatinib, Nilotinib, or Asciminib. This has been a victory and has ameliorated their lives so much.

However, the difficulties and obstacles persist and do not stop, namely:

- Donated tests and medicines are only available at HCM
- There are stockouts, making it impossible to continuously administer and perform tests regularly, as established by the protocols.
- Difficulty in patients' access to the hospital (various reasons such as economic, climatic, and social) that do not allow patients to have periodic and timely access to the hospital for clinical, laboratory, and medication collection
- Lack of laboratory resources for the study of genetic and molecular variants that lead to failure and therapeutic resistance.

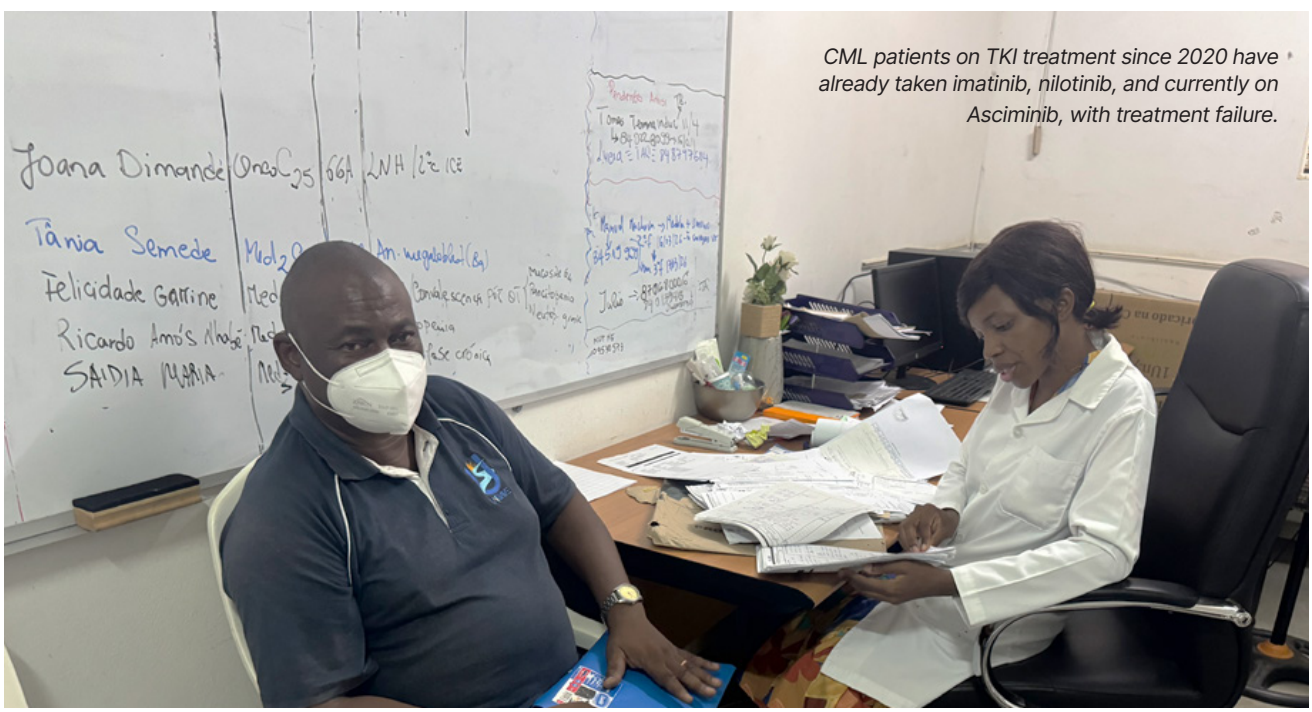
Despite everything, the hematology team is determined to overcome all the problems and difficulties previously pointed related to acquisition and access of medications and tests such as:

1. *Acceleration of import documentation,*
2. *Facilitation of customs clearance,*
3. *Guarantee of non-interruption of medication and test supply,*
4. *Outreach to other hospitals in other provinces with prior training of health providers,*
5. *Better conditions to attend and follow up of the patients (helping transport; apps for patients' cellphones),*
6. *Access to effective diagnosis and treatment for all the patients,*
7. *Getting genetic and molecular laboratory tests for diagnosis of causes of resistance and therapeutic failure,*
8. *Possibility of discontinuing TKI therapy (treatment-free remission).*

We know that we still have a long and arduous way to go for our CML patients, but we are determined to work, in the certainty of continued support from the Max Foundation and the expansion of the program to other provinces of Mozambique. In this way, we can reach more population and contribute to the improvement of the diagnosis and treatment of patients with CML throughout the country.

We reiterate all our gratitude to the Max Foundation and express our willingness to continue together in this battle to bring medication to all those who need it.

**There are no words to thank for actions that save human lives.**




*CML patients on TKI treatment since 2020 have already taken imatinib, nilotinib, and currently on Asciminib, with treatment failure.*

# Beyond the Breakthrough

## 25 Years of TKIs and the Global Pursuit of CML Equity

by Karen Meliksetyan

Twenty-five years ago, the oncology community witnessed a profound paradigm shift that would forever alter the trajectory of cancer treatment. The introduction of tyrosine kinase inhibitors (TKIs) for the treatment of chronic myeloid leukemia (CML) transformed a disease that was once considered uniformly fatal into a manageable, chronic condition.[1] Before the dawn of targeted therapy, the prognosis for a patient diagnosed with CML was grim, with limited options that often carried severe toxicities and marginal success rates. The arrival of the first-generation TKIs did not just add months to a patient's life; it offered the genuine prospect of a normal lifespan. However, the true measure of a medical revolution is not found solely in the elegance of its science, but in the reach of its impact. A breakthrough in a laboratory or regulatory approval in a high-income nation does not immediately translate into saved lives globally.

### Closing the Gap Between Innovation and Access: A Model for Equitable Cancer Treatment

This critical gap between scientific innovation and patient access is where the story of CML evolves from a strictly clinical triumph into a powerful testament to

global health advocacy and humanitarian partnership. For the past twenty-three years, The Max Foundation has stood at the forefront of this narrative. Operating on the fundamental belief that geography should not dictate destiny, this organization has fundamentally reshaped the landscape of cancer care in low- and middle-income countries. Over the last two decades, through relentless advocacy and logistical expertise, thousands of patients with CML worldwide have received life-saving medicines that would otherwise have been entirely out of reach.

The impact of this global health initiative becomes profoundly clear when examining specific regional partnerships. The experience of patients in Armenia serves as a powerful illustration of how consistent, long-term advocacy can build comprehensive care infrastructures even in resource-constrained settings. Since 2003, The Max Foundation has provided unwavering support to Armenian CML patients, ensuring that the country's healthcare providers can offer an evolving standard of care that mirrors the clinical progress seen in the world's most advanced oncology centers.[2]

## From Imatinib to Asciminib: Twenty-Three Years of Transforming CML Care in Armenia

The clinical evolution of CML treatment is marked by the continuous development of new therapies to outpace the disease's ability to mutate and resist treatment. In Armenia, The Max Foundation has ensured that patients have not been left behind during this rapid evolution. Over the years, the foundation has facilitated access to a vital succession of targeted therapies. This began with the pioneering first-generation TKI, imatinib, which initially turned the tide against the disease. As clinical understanding deepened and resistance patterns emerged, the partnership expanded to include the second-generation TKI, nilotinib, offering deeper and faster responses for those who needed a different approach. Recognizing the complex, mutating nature of leukemia, access was further expanded to include the third-generation TKI, ponatinib, a crucial lifeline for patients carrying specific, highly resistant genetic mutations.

Remarkably, this commitment to providing state-of-the-art care continues to the present day. Just this year, the partnership has introduced asciminib to Armenian patients. As a novel inhibitor that works through a completely different mechanism—targeting the disease by binding to a distinct site on the BCR-ABL protein—asciminib represents the very cutting edge of CML therapy.[3] Providing access to this innovative medicine ensures that even patients who have exhausted previous options still have a pathway to survival and stability. The fact that a health system in a developing nation can offer a sequence of four different, highly advanced targeted therapies is a monumental achievement in global health equity, made possible directly through humanitarian collaboration.

## References


1. *Hehlmann R. Long-term outcomes of tyrosine kinase inhibitors in chronic myeloid leukemia. Blood. 2025;145(9):910-924.*
2. *The Max Foundation. Accessing Innovative Solutions and Global Reach: Expanding Access Through our Supply Chain. The Max Foundation; 2024. Accessed March 29, 2026.*
3. *Rea D, Mauro MJ, Boquimpani C, et al. A phase 3, open-label, randomized study of asciminib, a STAMP inhibitor, vs bosutinib in CML after 2 or more prior TKIs. Blood. 2021;138(21):2031-2041.*
4. *National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Chronic Myeloid Leukemia (Version 1.2024). NCCN; 2024.*
5. *Sharf G, Marin C, Bradley JA, et al. Treatment-free remission in chronic myeloid leukemia: the patient perspective and areas of unmet needs. Leukemia. 2020;34(8):2102-2112.*

# The Evolution of BCR::ABL1 Testing in CML

by Jerald Radich

The unique success of tyrosine kinase inhibitors (TKIs) in revolutionizing CML care relates first to their ability to inhibit the biological function of the pathogenic BCR::ABL1 kinase. Equally important is the fact that, in CML, disease burden monitoring of BCR::ABL1 mRNA can be easily, accurately, and sensitively performed using peripheral blood. This has led to the establishment of therapeutic milestones that help physicians and patients determine when a TKI is working, when it needs to be changed due to resistance, and even when the drug may be safely discontinued.

The evolution of BCR::ABL1 monitoring has paved the way for other diseases as they seek to learn from and emulate the success of CML as the poster child of precision medicine.

## The Early Days of BCR::ABL1 Monitoring

Prior to the introduction of TKI therapy in the late 1990s, the only curative approach in CML was allogeneic stem cell transplantation. Indeed, for most transplant centers, CML was the most frequently transplanted leukemia, with survival rates for chronic phase patients exceeding 80%. It was in the transplant setting that qualitative monitoring of BCR::ABL1 (yes/no) was established as an important predictor of post-transplant relapse. This explains why PCR testing for BCR::ABL1 in early TKI therapy was largely performed in major transplant center laboratories, which had the most experience with the assay.

Indeed, the testing intervals established in the landmark IRIS randomized registration trial of imatinib (and subsequently in later TKI trials) were modeled on time points used in the allograft setting (every three months). In the late 1990s, several laboratories developed methods for quantitative RT-PCR of BCR::ABL1, generally by amplifying both the target BCR::ABL1 and comparing it to an internal control "housekeeping" gene. Different control genes were used, most commonly ABL1, BCR, or beta-2 microglobulin (B2M). Once again, transplantation served as the proving ground for quantification: the higher the post-transplant BCR::ABL1 level, the higher the subsequent relapse rate.

Samples were collected at predefined time points in the IRIS trial, and quantitative BCR::ABL1 analysis was retrospectively performed by three laboratories after trial completion. The results reported by Tim Hughes and colleagues in 2003 showed that a three-log reduction in BCR::ABL1 after 12 months of therapy strongly correlated with improved progression-free survival and lower relapse rates. This three-log reduction was defined as a "major molecular response" (MMR). While the biological basis of this threshold was not fully understood at the time (and, arguably, still is not), it was rapidly confirmed across multiple trials.

A key outcome of this finding was that MMR at 12 months became a major endpoint in subsequent clinical trials, accelerating drug development and regulatory approval. This would not have been possible without the foundational work of Sue Branford and others who established an "International Standard" for BCR::ABL1 testing, including WHO-sanctioned controls, enabling results from different laboratories to be directly compared. This standardization had a profound impact on the democratization of BCR::ABL1 monitoring, improving both clinical trial design and routine community-based CML care.

## From Lab Innovation to Global Standard: How Molecular Monitoring Became Routine in CML

BCR::ABL1 quantification is a powerful technique, but not a simple one. It was initially established in a limited number of laboratories with expertise in complex molecular diagnostics. The assay was therefore difficult to implement in many parts of the world where most CML patients live—namely low- and middle-income countries (LMICs).

Fortunately, Cepheid, which had developed experience with biodefense-related molecular assays and later expanded into infectious disease testing (HIV, TB, etc.), became interested in oncology diagnostics and collaborated with our Seattle group to develop a simple cartridge-based quantitative RT-PCR assay for BCR::ABL1. Coincidentally, this collaboration aligned with the WHO deployment of Cepheid platforms across LMICs for infectious disease testing. CML cartridges

could therefore be run on the same systems, and testing rapidly expanded, enabling patient access to TKIs through programs run by The Max Foundation.

Further technical advances followed quickly, driven by evolving clinical needs. It became clear that ABL1 mutations were important determinants of TKI resistance, and that traditional Sanger sequencing, with its limited sensitivity, often detected emerging resistance too late. Methods based on next-generation sequencing (NGS) therefore emerged, increasing sensitivity approximately tenfold compared to Sanger sequencing.

Further gains in sensitivity were achieved through digital PCR and ultra-sensitive NGS methods capable of detecting a single mutant allele among up to one million normal alleles. Digital PCR also proved important in the context of treatment-free remission (TFR), where patients discontinue TKI therapy after sustained deep molecular response. These methods appeared more sensitive than conventional RT-PCR by approximately five- to ten-fold and provided additional predictive value in identifying patients who could safely discontinue therapy without relapse.

## Spot on CML: A New Option for Low-Infrastructure Settings

BCR::ABL1 monitoring and mutation analysis are now widely available in Western, educated, industrialized, rich, and democratic (WEIRD) countries. However, access remains limited in many LMICs, even with successful platforms such as Cepheid. Shipping samples to referral laboratories is logistically and financially complex: blood must be shipped rapidly, on ice, often at high cost (a sample sent by air from Africa to Seattle can exceed $500 per shipment).

A cost-effective alternative has been the use of dried blood spots on specialized filter paper. We have found that this enables low-cost postal shipping, allowing samples to reach reference laboratories within weeks. This approach, known as Spot on CML, significantly reduces costs, as samples can also be batched and shipped together.
We have successfully extracted nucleic acids from dried blood spots for BCR::ABL1 testing, ABL1 mutation analysis, and broader somatic mutation profiling, with results comparable to those obtained from fresh blood samples.

The Max Foundation has recently demonstrated that TKI discontinuation under carefully monitored conditions can be as successful as in WEIRD settings. However, frequent BCR::ABL1 monitoring is essential during discontinuation trials to detect molecular recurrence early and restart TKI therapy before clinical relapse occurs. This requirement can limit eligibility, as patients must have reliable access to testing.

The success of spot-based testing may help broaden access to discontinuation strategies, as samples can be collected inexpensively and sent to centralized laboratories experienced with the method. The establishment of regional "Spot Centers" could therefore expand access to state-of-the-art molecular testing to large numbers of CML patients currently living in diagnostic "testing shadows."

## References


- *Radich JP, Kopecky KJ, Boldt DH, Head D, Slovak ML, Babu R, Kirk J, Lee A, Kessler P, Appelbaum F, Gehly G. Detection of bcr-abl fusion genes in adult acute lymphoblastic leukemia by the polymerase chain reaction. Leukemia 8: 1688-1695, 1994*
- *Radich JP, Gehly G, Gooley T, Bryant E, Clift RA, Collins S, Edmands S, Kirk J, Lee A, Kessler P, Schoch G, Buckner CD, Sullivan KM, Appelbaum FR, Thomas ED. PCR detection of the bcr-abl fusion transcript after allogeneic marrow transplantation for chronic myeloid leukemia: Results and implications in 346 patients. Blood 85: 2632-2638, 1995*
- *Radich JP, Gooley T, Bryant E, Chauncey T, Clift R, Edmands S, Flowers MED, Kerkof K, Nelson R, Wong L, Appelbaum FR. The significance of bcr-abl molecular detection in chronic myeloid leukemia patients "late," 18 months or more after transplant. Blood 98: 1701-1707, 2001*
- *Hughes TP, Kaeda J, Branford S, Rudzki Z, Hochaus A, Hensley ML, Gathmann I, Bolto AE, van Hoomissen IC, Goldman JM, Radich JP. Frequency of major molecular responses*

*to imatinib or interferon alfa plus cytarabine in newly diagnosed chronic myeloid leukemia. N Engl J Med 349: 1421-1430, 2003*

- *Hughes TP, Deininger MW, Hochhaus A, Branford S, Radich JP, Kaeda J, et al. Monitoring CML patients responding to treatment with tyrosine kinase inhibitors-Review and recommendations for "harmonizing" curing methodology for detecting BCR-ABL transcripts and kinase domain mutations and for expressing results. Blood 108: 28-37, 2006.*
- *Branford S, Cross NCP, Hochhaus A, Radich J, Saglio G, Kaeda J, Goldman J, Hughes T. Rationale for the proposed recommendations for harmonizing current methodology for detecting BCR-ABL transcripts and for expressing results on an International Scale. Leukemia 20:1925-1930, 2006.*
- *Winn-Deen ES, Helton B, Van Atta R, Radich JP. Development of an integrated assay for detection of Bcr-Abl RNA. Clinical Chemistry 53: 1593-1600, 2007*
- *Oehler V, Qin J, Ramakrishnan Facer RG, Ananthnarayan S, Cummings C, Deininger M, Shah N, McCormick F, Willis S, Daridon A, Unger M, Radich J. Absolute quantitative detection of ABL tyrosine kinase domain point mutations in chronic myeloid leukemia using a novel nanofluidic platform and mutation-specific PCR. Leukemia 23:396-369, 2008*
- *Hughes T, Saglio G, Branford S, Soverini S, Kim D-W, Müller MC, Martinelli G, Cortes J, Beppu L, Gottardi E, Kim D, Erben P, Shou Y, Haque A, Gallagher N, Radich JP, Hochhaus A. Impact of Baseline BCR-ABL Mutations on Response to Nilotinib in Chronic Myeloid Leukemia Patients in Chronic Phase (CML-CP). Journal Clin Oncol 27:2404-4210, 2009*
- *Martin C Müller, Jorge Cortes, Dong-Wook Kim, Brian J Druker, Philipp Erben, Ricardo Pasquini, Susan Branford, Timothy P Hughes, Jerald P Radich, Lynn Ploughman, Jaydip Mukhopadhyay, and Andreas Hochhaus. Dasatinib treatment of chronic phase chronic myeloid leukemia: analysis of responses according to preexisting BCR-ABL mutations. Blood 114:4944-4953, 2009*
- *Hughes TP, Hochhaus A, Branford S, ....Goldman JM, Radich JP. Long-term prognostic significance of early molecular response to imatinb in newly diagnosed chronic myeloid leukemia: an analysis for the international randomized study of interferon vs STI571 (IRIS). Blood, 116:3758-3765, 2010*
- *Schmitt MW, Fox EJ, Prindle MJ, Reid-Bayliss KS, True LD, Radich JP, Loeb LA. Sequencing of small genomic targets with high efficiency and extreme accuracy. Nature Methods 12: 423-425, 2015*
- *Schmitt MW, Pritchard JR, Leighow S, Aminov BI, Beppu L, Kim DS, Hodgson JG, Rivera VM, Loeb LA, Radich JP. Single-molecule sequencing reveals patterns of pre-existing drug resistance that suggest treatment strategies in Philadelphia-positive leukemias. Clinical Cancer Research, 24:1316-1331, 2018*
- *Attalah E, Schiffer C, Radich JP, et al. Assessment of outcomes after stopping tyrosine kinase inhibitors among patients with chronic myeloid leukemia. JAMA Oncol 7:42-50, 2020*
- *Shelton DN, Bhagavatula P, Sepulveda N, et al. Performance characteristics of the first Food and Drug Administration (FDA)-cleared digital droplet PCR (ddPCR) assay for BCR-ABL1 monitoring in chronic myelogenous leukemia. PLOS, https://doi.org/10.1371/journal.pone.0265278, 2022*
- *Sala-Torra O, Beppu L, Smith J, Welden L, Georgievski J, Gupta K, Yeung CCS, Paguirigan A, Gooley T, Branford S, Radich JP. Paper or plastic? BCR-ABL1 quantitation and mutation detection from dried spots. Blood 127: 2773-2774, 2016.*
- *Sala O, Reddy S, Hung LH, et al. Rapid detection of myeloid neoplasm fusions using single-molecule long-read sequencing. PLOS Global Public Health, 2023, 3:e0002267.doi: 10.137*
- *Oehler V, Sala Tora O, Beppu L, et al. Point-of-care BCR::ABL1 transcript monitoring using capillary dried blood in chronic myeloid leukemia patients. Leukemia, 2024, 38:1822–1824*
- *Oehler V, Sala Torra O, Gilterman N,...Radich J. Next generation sequencing from CML dried blood spots: insights and implications for global oncology. Leukemia, 2026, https://doi.org/10.1038/s41375-025-02852-8*
- *Annamalay A, García González I, Forsyth C, ... Radich J. Treatment-Free Remission in Chronic Myeloid Leukemia: Feasibility and Outcomes in Low- and Middle-Income Countries. NEJM, 2026, in press*

# Patient Advocacy in CML

## From Grassroots Movement to a Catalyst for Change in Cancer

By Jan Geissler

When I was diagnosed with chronic myeloid leukemia (CML) in 2001, the outlook looked grim. CML was, for most patients, a life-limiting disease. Treatment options were limited, often harsh, and rarely curative. Survival was uncertain, and hope was fragile.

Around that time, a new compound, STI571, later known as imatinib, was showing early results in clinical trials. For many of us, it felt like a distant lighthouse in a storm: visible, promising, but still far from certain. Would it work? Would resistance develop? Would we live long enough to find out?

In those early days, the internet was not what it is now. Digital infrastructure and social media such as Google, Facebook, and YouTube did not exist. Yet something remarkable began to happen. Patients and caregivers, scattered across the world, started to find each other online through email groups, Yahoo forums, and early websites. These were not formal organisations. They were lifelines.

We followed every piece of emerging research, shared updates from conferences, translated scientific findings into plain language, and supported each other through uncertainty. We were not trained advocates. We were patients trying to survive and to make sense of a rapidly evolving science that would determine our future.

In many ways, CML became a pioneer disease. It was one of the first cancers to transition from a largely fatal condition to a chronic disease with near-normal life expectancy, provided that patients could access effective treatment. Unfortunately, that last condition remains critical and unresolved for many patients around the world even today.

## From Connection to Collaboration

As these grassroots efforts grew, so did the need to connect them. In 2003, Novartis brought together leaders from emerging patient groups in CML and GIST in Switzerland. The meeting, known as *"New Horizons,"* was a turning point. For the first time, CML and GIST advocates from different countries could meet, exchange experiences, and learn from one another.

Two years later, in 2005, a small group of us—Giora Sharf, Jana Pelouchova, Sandy Craine, and myself felt that informal exchange was not enough. We wanted to build something more structured that bridged annual meetings and geographic distances. In 2007, we gathered in my home near Munich and spent several days laying the groundwork for what became the global network of CML patient organisations.

That was the beginning of the *CML Advocates Network.*

There was no grand strategy, no funding, no formal structure at the start. What we had was trust, shared urgency, and a belief that collaboration could amplify our impact. We began connecting patient organisations, sharing best practices, and creating resources such as lay summaries of clinical guidelines translated into more than 20 languages. We reported from major medical conferences like ASH and EHA, ensuring that patients worldwide could access and understand the latest developments.

What started as a small, informal initiative gradually

evolved into something much larger.

## Building a Global Voice

In 2010, together with Giora Sharf, Jana Pelouchova, and Erik Aerts, we established the Leukemia Patient Advocates Foundation in Switzerland. This provided a legal and organisational backbone to support the growing network and enabled us to host the annual *"CML Horizons"* conference as an independent, patient-led global meeting.

Today, the CML Advocates Network connects more than 130 member organisations across over 90 countries. It is one of the strongest global networks in rare cancer, led by a steering committee of CML patient advocates representing all world regions.

From early on, we believed that patient advocacy needed to evolve beyond storytelling alone. Personal experiences are powerful, but to influence research, policy, and clinical practice, they need to be complemented by robust evidence.

This led to a series of pioneering initiatives in evidence-based advocacy. The global CML Adherence Survey, involving more than 2,500 participants from 63 countries, provided critical insights into how patients take their medication and why adherence can be challenging, even when the drug keeps you alive. It was published in peer-reviewed journals and presented in an oral session at the European Hematology Association (EHA) congress, an unprecedented achievement for a patient organisation at the time.

We conducted surveys on treatment-free remission (TFR), explored the quality and consistency of generics including independent sample testing of imatinib generics and copy drugs for active ingredients and continuously gathered data to inform advocacy priorities.

At the same time, we strengthened collaboration with researchers, clinicians, and industry. The introduction of Community Advisory Boards (CABs), inspired by the HIV community, was a major step forward. Since 2016, the CML-CABs have brought together global panels of our most experienced patient advocates, collectively representing hundreds of years of lived experience, to connect community priorities on clinical trials, access to diagnostics and treatment, adherence, survivorship, and unmet needs with pharmaceutical companies and academic researchers.

More than 25 CML-CABs have been held to date, shaping research agendas and ensuring that patient perspectives are integrated from the outset.

In 2020 and 2023, we went a step further by organising academic CABs focused on curing CML beyond treatment-free remission. These meetings brought together leading scientific experts and patient advocates to challenge prevailing assumptions—that lifelong treatment with manageable side effects is "good enough" and to reassert the community's ambition for a cure for all patients.

## Beyond CML: A Model for Advocacy

While rooted in CML, the network has always looked beyond its own disease. It has contributed to cross-cancer collaboration, supported the development of patient advocacy tracks in major scientific congresses such as EHA, and shared its approaches with other rare cancer communities.

In many ways, the CML community has served as a testing ground for modern patient advocacy. It demonstrated that patients can be informed partners in research, that global collaboration is possible even with limited resources, and that structured engagement grounded in both lived experience and data can influence outcomes. But this progress was not driven by any single organisation or individual. It was, and continues to be, the result of a collective effort: a community of patients, caregivers, advocates, clinicians, researchers, and partners who share a common goal.

## A Quarter Century Later, We Still Cannot Rest

CML is often described as a success story, sometimes even as the *"lucky cancer."* And in many respects, it is. The development of tyrosine kinase inhibitors (TKIs) has transformed outcomes for patients who can access them.

But this success is not universal.

Access to diagnostics and treatment remains a major


challenge in many parts of the world. Even where medicines exist, diagnostics and monitoring can be the invisible barrier. And for those who do have access to therapy and monitoring, survivorship is not "easy mode." Living long-term on TKIs means living with chronic side effects, late toxicities, and the psychological burden of lifelong cancer therapy, while only a minority of CML patients can successfully pursue treatment discontinuation.

There is still no cure beyond bone marrow transplantation, which also carries a significant risk of mortality and morbidity and is only an option when TKIs fail for a patient.

For the CML advocacy community, this means there is no room for complacency. The same grassroots energy that emerged in the early 2000s continues to drive efforts today, whether advocating for equitable access, improving survivorship, or pushing for research into curative approaches.

## Scientific Innovation Needs Social Innovation Beside It

Looking back, what stands out is not a single milestone or achievement, but the journey itself over the past 25 years. A journey that began with patients searching for information and evolved into a global movement that has helped shape cancer advocacy more broadly. The CML community did not set out to become a model. It simply responded to a need: to survive, to understand, to support, to shape opinion, and to accelerate innovation. In doing so, it demonstrated what is possible when patients are empowered, connected, and heard.

If the last quarter century has taught us anything, it is that scientific innovation needs social innovation beside it. Patient advocacy is not an accessory to innovation; it is part of the machinery that makes progress reach people.

Yes, CML has been a pioneer. As we mark 25 years of TKIs in CML, it is important to celebrate scientific innovation. But it is equally important to recognise the parallel innovation in patient advocacy: the emergence of a global community that has not only adapted to change but actively shaped it. Many of us in CML advocacy carry a particular responsibility: we are alive long enough to learn. We are alive long enough to effect change. We are alive long enough to argue that equity is not optional, and that the real cure for everyone is still the horizon we need to walk toward.


REPUBLICA DEL PARAGUAY

# Time Life Purpose

## The Story of Pablo González

by Pablo González

My name is Pablo González. I am from Paraguay, and I was diagnosed with chronic myeloid leukemia at the age of 47, in June 2007. As happens to many people when they receive a cancer diagnosis, that moment was filled with questions, uncertainty, and fear. I clearly remember those days: the shock of the diagnosis, the conversations with doctors, and the need to understand what it truly meant to live with a condition like this.

Shortly afterward, in September of that same year, I began treatment with imatinib. From the very beginning, I had a very favorable response to the medication, which over time allowed me to achieve a complete molecular remission that, fortunately, continues to this day. At that time, I may not have fully understood what it meant to have access to a treatment that was already transforming the course of this disease for thousands of patients around the world.

### From Diagnosis to Long-Term Survival

Over the years, I came to understand that my personal experience was deeply connected to one of the most important advances in modern medicine. Tyrosine kinase inhibitors (TKIs), starting with imatinib, transformed the prognosis of chronic myeloid leukemia. What was once a disease with a very uncertain future can now, for many patients, become a manageable condition that allows for a long and active life.

Before my diagnosis, much of my life had been dedicated to my profession. I hold a degree in Business Administration and had the privilege of building a career of more than 45 years in the banking sector. Throughout those decades, I grew professionally within the bank facing challenges and learning at every stage and eventually reached the position of Vice President. It was a journey that brought me great personal and professional satisfaction.

When I received the diagnosis, I inevitably wondered how this disease would affect my life, my work, and my plans. However, over time, I understood that, thanks to treatment and the support of those around me, it was possible to move forward. In fact, I was fortunate to retire while still practicing the profession I had always loved, something for which I am deeply grateful.

## The Power of Support and Access

If there is one thing I have learned along this journey, it is that facing an illness is never an individual process. From the very beginning, I had the unconditional support of my wife, who has been by my side throughout this entire experience. Her presence, strength, and calm were essential in navigating the uncertainty that inevitably arises at the beginning of diagnosis and treatment.

At that time, our son was still very young. As a parent, one always wants to protect their children from life's worries, but over time he also grew alongside this story. Today, with great pride, I can say that he graduated from an American university and has built his own path. Watching him grow, study, and achieve his goals has undoubtedly been one of my greatest motivations to keep moving forward.

I often say that I had the best possible combination to face this disease. First, early detection, which allowed treatment to begin at the right time. Second, the opportunity to have a top-level hematologist like Dr. José Ferreira Niza, whose expertise and commitment were key from the beginning. And third, access to the right medication—imatinib—which has been fundamental in my treatment.

In the early years, I received my medication through *The Max Foundation,* an organization that has enabled thousands of patients in different countries to access treatments that would otherwise be very difficult to obtain. I will always be deeply grateful for that support, because it made it possible for me to start and continue my treatment from the very beginning.

Later, I continued receiving the medication through *the Social Security Institute* in my country, which allowed me to ensure continuity of treatment over the years. Continuity in this type of therapy is essential, and I greatly value that it was possible to maintain it.

## Giving Back: From Patient to Advocate

Over time, my personal experience with chronic myeloid leukemia also led me to become actively involved in supporting other patients. More than ten years ago, I joined FUNCA – *United Against Cancer Foundation, an organization that works alongside people facing different types of cancer.*

FUNCA provides support and accompaniment to people with cancer and their families, promoting education, prevention, and early detection. It also advocates for patients' rights, including participation in public hearings. Among the ongoing challenges are timely access to diagnosis, treatment, and information. At the same time, there is a strong opportunity to strengthen patient education and collaborative work with healthcare professionals and authorities. Within this organization, I had the honor and responsibility of serving as its president.

From that space, I work alongside others with the goal of ensuring that more patients can have the same opportunities that I had. We know that three factors are essential: early diagnosis, access to qualified professionals, and access to appropriate and timely treatment. Unfortunately, these conditions are still not guaranteed for all patients, which is why the work of patient organizations continues to be so important.

## More Than Medicine: The Value of Time

When I reflect on what tyrosine kinase inhibitors have meant for those of us living with chronic myeloid leukemia, I understand that it is not only a scientific advancement. It is something much more human: time. Time to live, to share with family, to watch children

grow, to continue working, and to keep building our life projects.

After all these years of treatment, I can say that the disease is under control and that I live with a complete molecular response. But beyond the medical results, what truly matters is what this means in everyday life: *the possibility of living normally, making plans, enjoying time with loved ones, and looking toward the future with hope.*

For me, TKIs are not just medications. They represent years of life gained, opportunities that once seemed impossible, and proof that scientific research can profoundly change patients' lives.

Today, I look back with a deep sense of gratitude: to God, to my family, and to all the people who have been part of this journey. To *Novartis,* for developing a treatment that marked a before and after in the history of this disease. To The Max Foundation, for making access to treatment possible when I needed it most. And to all the doctors who have supported me throughout these years from Dr Ferreira Niza to *Dr Carolina Barreto of the Social Security Institute,* who is my current treating physician.

**Behind every successful treatment, there is something much greater: lives that continue, families that remain together, and futures that can still be built.**

# A Journey on the Wheels of Hope

# Friends of Max

by Viji Venkatesh


It was a sweltering summer, the summer of 2002, but it will be remembered for something more than just how very hot it was. It was on one blazing May afternoon of that year that I was handed a file with some 20-odd names from different towns in India. These were the names of people enrolled in a Compassionate Use Program for a then-unnamed drug (known only as STI571) to treat their rare condition: a leukemia called chronic myeloid leukemia (CML).

The compound had been approved in record time by the FDA, and Novartis, the company behind the drug that came to be known as imatinib—the "magic bullet" had launched it at $2,000 for a month's supply. The single pill, which could convert a fatal leukemia into a chronic, manageable condition, had to be taken by patients for the rest of their lives. One pill, every day.

What followed was the creation of a patient assistance program like no other. It is now part of pharma folklore that when the then CEO, Dr Dan Vasella, was asked how people could afford such an expensive drug for lifelong use, he said that anyone without access to insurance, reimbursement, or the private means to purchase the drug should receive it at no cost.

And thus was born the *Glivec International Patient Assistance Program*—a program with no precedent.

And those 20-odd names in that file. They were the first beneficiaries of this program, put in place by Novartis and managed by The Max Foundation, named

after Max, the young, brave boy who had succumbed to CML within three years of his diagnosis.

## From 20 Patients to a Movement

Now we come to Friends of *Max (FOM)*, which today is the largest registered support group for CML patients in India and will soon turn 25. At that time, FOM was not even a dream or a fully charted plan. It grew organically from the needs of those facing a life-threatening diagnosis and their shell-shocked families. They were people set apart from their peers—schoolmates, colleagues, even family members. People who suddenly found themselves left by the roadside, their journey rudely interrupted, forced to find a new and unknown destination. All they were told was that they had cancer and would need lifelong treatment. Some were even told they had the "best possible cancer"—a "good cancer."

How could there be such a thing as good cancer?

And so began the fear, the isolation, and the uncertainty. All they saw was the sword of Damocles hanging over their heads. Gradually, they realized that in this new phase of life, in this no man's land, they were alone, while others continued forward. And then, one by one, they began to see others like themselves appear on the horizon—stragglers forced to step off the treadmill of life and find their footing again.

FOM is the story of how these individuals came together to chart and navigate their own journey toward what once seemed an unattainable destination.

## Building a Community of Strength

With the twin sails of *Novartis* and *The Max Foundation* propelling them forward, this unique group, one of its kind and soon the largest of its kind, began taking small but significant steps. Their destination was the same as everyone else's. All they needed was to discover a new "normal" and take a parallel path.

At a local FOM support group meeting in a northern Indian city some years later, more than 850 patients and their families turned up. They wanted to meet others like themselves, to share, and to learn. We had to abandon registration altogether. Perhaps this was inevitable. Perhaps there was no other direction this movement could have taken.

Just as these individuals evolved and grew over the years, so did Friends of Max.

In the beginning, I often felt like I was holding a baby doing everything for it. Slowly, I could put it down. It began to find its feet: to sit, crawl, stand, and then walk while holding my hand. Now, it no longer needs anyone to hold its hand. It walks confidently on its own. It has developed its own personality. It expresses its needs not by demanding attention, but by commanding it.

Through the use of the internet and technology, members first connected via email groups. Today, they are linked through WhatsApp groups across cities and towns in India, as well as through social media and their website.

It all began with the sharing of personal stories and testimonials that inspired and motivated others to keep going, hand in hand. People gathered in meetings across cities, towns, parks, and beaches throughout the country.

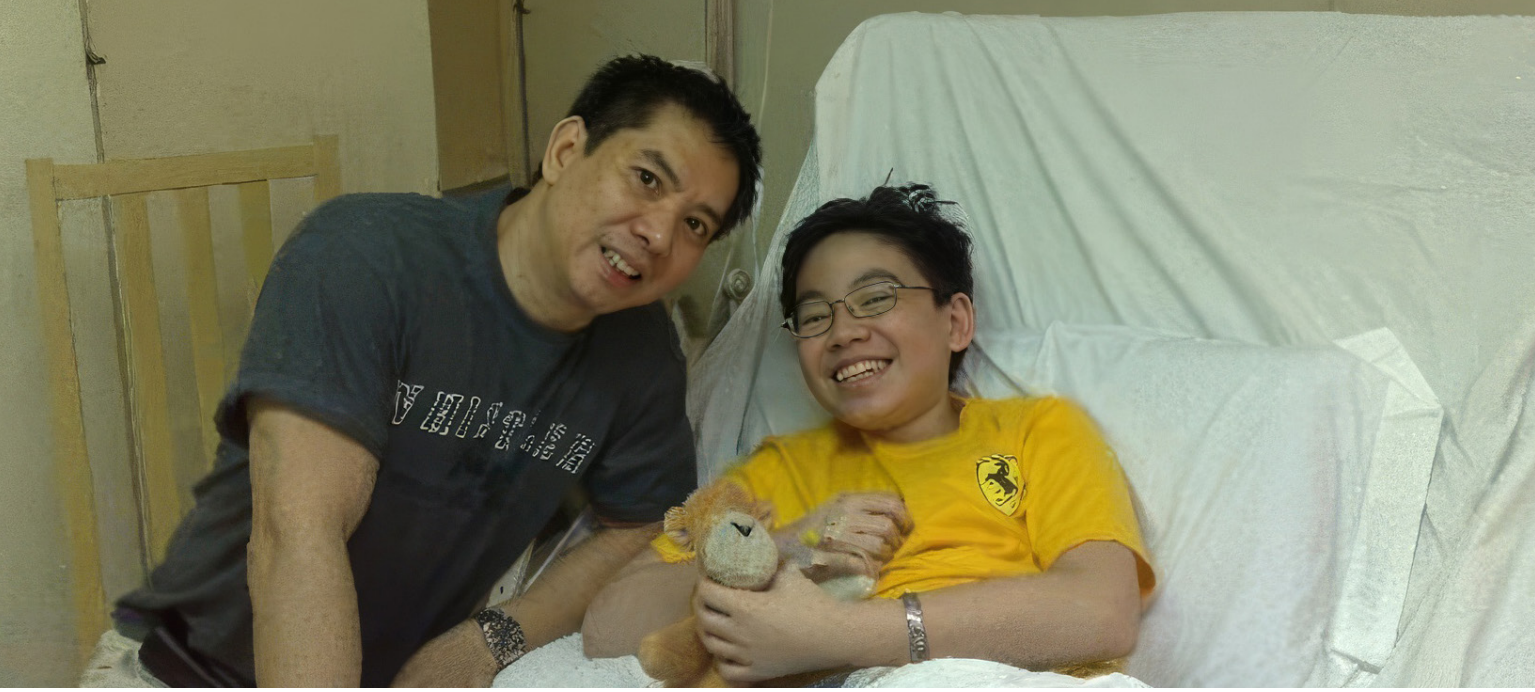
Their creativity found expression in artwork that became logos for banners, posters, and events. They trained to become exceptional volunteers, uncovering hidden talents along the way.

Friends of Max, now a registered trust with a clear mission and a powerful identity, began to make its presence felt. Campaigns were launched, and FOM became a vehicle not only for awareness but also for raising funds to support those from financially challenged backgrounds. *"Chai for Cancer"* was born.

With the support of physicians and partners from all walks of life, FOM grew in confidence and influence. City chapter leaders began promoting treatment adherence, one of the most critical factors in achieving positive outcomes in CML.

## Looking Ahead: A Journey Still Unfolding

This has been the story of Friends of Max, one that continues to unfold. We now look ahead, wondering what lies in store and how we can continue to give back to the community in the decades to come.



# An Email to Remember

by Rod Padua

**17 July 2006**

*My friend,*

*This is all too sudden. My eyesight is cloudy from the tears constantly flowing. It pains me deeply just to write this email...*

*My youngest son just turned 9 years old. Ominously, on the day of his birthday, his grandmother, who was cradling him, noticed that his stomach was far too big and taut. After tests were conducted the next day, we found out that his spleen was eight times the normal size. His doctor said that if, by accident, his spleen were punctured at school, he would not last three minutes. But as it turned out, this was only one more tragic piece of news to come...*

*The next few days were spent with several doctors—hematologists, they are called. Days when I wished to the heavens it had been me, not my son. He still has so much to live for. Soon, he was diagnosed with CML. It is a rare type of leukemia, usually not seen in children. There is no known cure yet, but there have been some very promising drugs. We are in the hospital right now, and he is to undergo bone marrow tests. The bottom line is this: he could die at any time in the future.*

*The costs of treatment are staggering. There is a group that provides aid, but his doctor says they have closed the window for additional applicants.*

*Please tell me anything you know about cures, herbal medicines, foundations, aid, miraculous saints, anything I can explore. Please help me and my son. I hope it is not too late...*

***Rod***

## The Email That Traveled the World

Eventually, this email circled the world through the internet in 2006. Soon, my inbox was flooded with blood donation offers from people I did not know, prayers from congregations I had never heard of, and messages that inspired me to cling to hope and faith.

But there was one email that stood above all the rest. One that changed everything. An email about a miracle drug called imatinib and about The Max Foundation.

And the rest is history.

## Twenty Years Later: A Life Reclaimed

Twenty years passed in what feels like a blur. From a white blood cell count of 296,000 (when normal is below 10,000) and FISH levels of 59% (when normal is 0%), my son Maverick is now on his way to complete remission.

Instead of being frail, he is energetic. Instead of having burnt skin from chemotherapy, he looks radiant. Instead of losing his hair, he styles it however he likes. He missed years of schooling because of bullying, because he was called "the leukemia kid." But today, he is living his life as an IT enthusiast, enjoying the world on his own terms.

Truly, God works in mysterious ways.

During those sleepless nights in the hospital through many life-threatening episodes, my family never stopped talking to the Almighty, seeking his loving and healing hand. I do not think I could ever thank God enough for allowing Maverick to live a normal life. But I can devote my time, in every way possible, to helping others.

And perhaps one day, when all of this settles in my son's heart and mind, he will write emails of gratitude to people he has never met, to congregations he barely knows.

Because in the end, one email saved my son's life.

## From Gratitude to Advocacy

**Epilogue:**

In that same year, 2006, when my son and I began this journey, I joined a newly formed CML patient advocacy group in the Philippines called Touched By Max Inc. (TBM).

TBM supports the well-being of patients with CML and gastrointestinal stromal tumors (GIST), as well as their caregivers. I became a board member the following year and have now served as President for the past 18 years.

Today, TBM has more than 2,800 members across the islands and conducts three major events each year. In partnership with local and international organizations. We have helped facilitate access to free or highly subsidized medicines and laboratory tests.

Our board includes 10 members from teachers to engineers to IT professionals—all united by a direct connection to this disease.


# Hope Beyond Economic Classification

by Silvana Torselli

As a hematologist practicing in Guatemala, every day I witness the challenging reality faced by our country's patients. I have worked for 20 years in one of the main reference hospitals in Guatemala's capital, where I see patients from across the country representing diverse backgrounds. The hematology unit at my hospital sees approximately 13,000 patients every year.

## A Growing Economy, Unequal Access to Care

On the surface, Guatemala seems to be a growing economy and is now classified by the World Bank as an upper-middle-income country. The largest economy in Central America, Guatemala has experienced steady economic growth averaging around 3–3.5% annually in recent years, supported by stable macroeconomic policies and remittances.[1]

However, despite this apparent stability, the country faces significant structural challenges. The benefits of Guatemala's economic growth have not been evenly distributed, reflected in its high Gini index score. More than half of the population lives below the poverty line, and around 70% of working people are obliged to seek income through the informal economy. Furthermore, public health expenditures represent only 2.4% of GDP, below regional averages.[1] Access to healthcare services poses a significant challenge for rural communities, especially for Indigenous peoples, who bear a disproportionate burden of disease and mortality.[2]

## The Long Road to Care

In the hospital where I work, these stark challenges are apparent. Difficult road conditions and limited

transportation options pose significant barriers for patients in rural communities who need specialized care. Many of our patients travel for hours from rural areas to access medical care in the capital. For some families, the cost of transportation alone represents a significant barrier to accessing treatment.

The story of one of my patients illustrates this reality. Only 16 years old, he lives in a village in the northeastern part of the country, near the border with Mexico, approximately 300 kilometers from Guatemala City. His mother works in domestic cleaning, which is why his grandmother accompanies him to his medical appointments. To help support his family financially, he had to leave school and now works as a carpentry assistant.

They leave a full day before each appointment to ensure they arrive on time. The first leg of their journey begins at 7:00 in the morning, and they arrive at the nearest municipal town around 1:00 in the afternoon, where they pay for a modest hotel to spend the night. The following day, they set out at dawn to reach the hospital on time. They repeat this process four times every year.

## Partnerships That Change Lives

When we consider diseases such as leukemia and other hematologic malignancies, access to timely diagnosis, specialized therapies, and long-term care remains extremely limited. For many patients with cancer, the difference between life and death is not determined by scientific advances, but by access to care.

This is why the support of organizations such as *The Max Foundation* is critically important. The Max Foundation has been working in Guatemala since 2002, when it administered the Glivec International Patient Assistance Program with Novartis to bring imatinib to people with chronic myeloid leukemia (CML). Since then, my institution has partnered with The Max Foundation. Initially, one of the main barriers we had to overcome was access to testing for the Philadelphia chromosome, which was prohibitively expensive for patients. We were able to secure free testing for patients from a nonprofit laboratory, the Institute for Research on Genetic and Metabolic Diseases, enabling patients to be monitored according to guidelines.

Today, 341 patients receive imatinib or other tyrosine kinase inhibitors (TKIs) through the program, mostly for CML. The results have been encouraging. Around two-thirds are 48 years old or younger, and half have achieved a major molecular response. In my daily practice, I have seen patients who presented with devastating diagnoses and, thanks to access to treatment, are now able to return to work, care for their families, complete a university degree, start their own businesses, and lead meaningful lives.

*The Max Foundation* continues to provide access to imatinib as well as newer TKIs (bosutinib and ponatinib), in addition to education and transportation support programs. These programs do more than provide medications; they offer hope, information, emotional support, and a tangible opportunity for patients not only to survive but also to thrive.

We still have more challenges to overcome, from improving outcomes in mutation management and molecular responses to securing access to additional TKIs, as well as treatments for chronic lymphocytic leukemia, paroxysmal nocturnal hemoglobinuria, and other rare hematological diseases.

While macroeconomic indicators may suggest progress, the reality is that more than half of the population continues to live in poverty, and the needs of our patients remain urgent and substantial. We are driven by the belief that no patient's care should be limited by geography or socioeconomic barriers.

**Behind every treatment, there is not only a patient, but a family, and a future that still deserves a chance.**

## References


1. World Bank 2026, "Guatemala". https://www.worldbank.org/ext/en/country/guatemala#tab-economy. Accessed on March 26, 2026.
2. World Bank 2024, "Improving Health and Nutrition for Indigenous Communities in Guatemala" https://www.worldbank.org/en/results/2024/10/21/improving-health-nutrition-indigenous-communities-guatemala. Accessed on March 26, 2026.

# How I Turned My Most Feared Word into My Strength

by Stutika Thapa Shrestha

It has been 11 years since my father was given a new life. In 2015, my dad (Mr. Suresh Thapa Shrestha) was diagnosed with chronic myeloid leukemia (CML), a type of blood cancer. This was the news that shocked my entire family. My dad was a caring son, a responsible brother, a devoted husband, and, most importantly, a loving father. Ever since 2015, he has also become a fighter—a warrior battling cancer.

Throughout this journey, my family has supported my dad and given him the strength to face this disease. From diagnosis to treatment, he always had his family by his side. We gave him hope and believed that one day he would be okay. Not only did he have his family, but he also had great doctors and an incredible medical team supporting his treatment. The Max Foundation and its compassionate team played a vital role in his journey by organizing support groups for CML patients, where he found not only guidance but also emotional strength and encouragement to keep fighting.

## When My Father's Secret Became My Calling

I was in sixth grade at the time of his diagnosis, and I had no idea that my father was fighting cancer. He was still playing with me, teaching me literature, and preparing me to take care of myself if he were not around. He looked tired and unwell, but I could not imagine how difficult things truly were for him.

It was two years later when I learned that my dad had CML. I vividly remember the night he told me. He was crying. I stayed quiet. I felt a heavy weight on my chest, and tears filled my eyes—tears of guilt for not knowing sooner. My throat tightened, and I could not even ask him how he was doing, nor could I hug him and tell him I was there for him.

"Chronic myeloid leukemia" was the scariest phrase I had ever heard, and I could not stop thinking about it. That same night, I also heard about *The Max Foundation,* how they were saving the lives of people like my dad. My dad sighed in relief and told me, *"They are not just giving us medicines, but also hope, the hope that I will see the future my children will have."*

**As much as the word "cancer" suffocated me, the words "The Max Foundation" allowed me to breathe.**

## A Daughter's Promise to Fight What She Fears Most

My story began that night, with a dream of becoming a cancer researcher and helping people like my dad. I began researching cancer, no matter how much it scared me. I wanted to excel in my studies, so I worked hard. I worried that I might not have a normal life with my father, because he was sick, but that did not happen.

My father was still a young man working in vegetable gardens, managing the logistics of our small business, playing with our dog, singing songs, and cracking jokes from time to time. He says this is his second life, and he wants to make the most of it. In the midst of everything, he was still afraid because he was battling cancer. But what he did not realize was that he was not alone—his daughter was there too, ready to fight alongside him as a future researcher.

I often accompanied my father to Patan Hospital for his doctor's appointments. At the hospital, he became quieter, and I could see fear in his expressions. I stayed beside him and listened as the doctor discussed his reports. During one visit, Dr Gyan Kayastha, a physician at Patan Hospital, explained CML to me and how a mutation involving chromosomes 9 and 22 leads to this disease. He became an inspiration to me, and I knew I wanted to become someone like him.

I started searching for more information online and learned that studying molecular biology could be the foundation for becoming a cancer researcher. From that moment, I began looking for places to pursue this field for my undergraduate studies. My father and my entire family were incredibly supportive of my decision. We shared a dream, and little did I know that I would travel 8,000 miles from home to pursue it.

In August 2023, I began my undergraduate degree at Jacksonville State University in Alabama, USA, on a full scholarship. I am majoring in Biology (Cellular and Molecular Biology) with a minor in Chemistry, and I am currently in my junior year.

## From a Diagnosis at Home to a Future in the Lab

Every time my professors discuss cancer, it feels less frightening. When I study tyrosine kinases during cell signaling lectures, I pay even closer attention, knowing how closely this relates to CML. I have learned more about how tyrosine kinase inhibitors


work against this disease and about the risks of mutations and relapse. This has strengthened my determination to study cancer more deeply and contribute to finding a cure.

I reached out to biology professors at my university, and they welcomed me into their labs as an undergraduate researcher. I contributed to research on osteosarcoma, a type of bone cancer, in Dr Hensley's lab. Currently, I am researching acute myeloid leukemia (AML), a fast-growing blood cancer, and studying the effects of cannabinoids on this disease in Dr Barth's lab. With each step, my passion for cancer research continues to grow.

As I pursue my dream, I continue to receive support from many people. My family has been incredibly encouraging. Mr Bishnu Prasad Paudel, a CML patient and my father's friend, treats me like his own daughter and motivates me along this journey. Ms Sweta Agrawal, Program Coordinator for Nepal at *The Max Foundation,* has also provided unwavering support, along with the entire Max Foundation team, who *believe in the big dream of a little girl.*

**Because of them, I have been able to transform the word I once feared the most into my greatest source of strength.**

# From Distance to Access

## How a "Wonder Pill" Changed the Story of CML in Rural Tanzania

by Oliver Henke

When I began working at the Kilimanjaro Christian Medical Centre (KCMC) in Moshi, Tanzania, in 2016, I quickly learned a central reality of oncology in sub-Saharan Africa: most patients arrive too late.

Disease is advanced, treatment options are limited, and outcomes are often poor. In many cases, our role is not to cure, but to relieve suffering. This makes every exception deeply meaningful.

Chronic myeloid leukemia (CML) should be one of those exceptions. Globally, it has become a model disease transformed by tyrosine kinase inhibitors (TKIs) from a fatal condition into a chronic, manageable one. But at that time in northern Tanzania, this transformation had not yet reached our patients.

## When Treatment Exists, But Patients Cannot Reach It

We were able to diagnose CML with reasonable confidence. Many patients presented with massive splenomegaly and characteristic blood count abnormalities. *The clinical picture was often clear. What was missing was not knowledge, it was access.*

TKIs were not available in our hospital. Occasionally, they could be found in private pharmacies, but at a cost far beyond what most patients could afford. *We were diagnosing a disease, we knew how to treat it, but with no means to do so.*

Through a colleague in Berlin, I learned about The Max Foundation and its access programs, which provided imatinib free of charge to eligible patients. At that time, however, there was only one partnering institution *in Tanzania: the Ocean Road Cancer Institute in Dar es Salaam.*

For our patients, this meant traveling an entire day one way just to receive their medication. And this was not a one-time journey, but a monthly requirement. For many, even the cost of transportation was a barrier. Some patients made the journey once or twice, then stopped coming. Others never attempted it at all.

*Access existed, but it was out of reach for most patients, especially from rural areas.*

As more patients presented to our clinic, this situation became increasingly difficult to accept. The idea that a simple oral therapy could transform their prognosis, yet remain out of reach due to geography and cost, was deeply frustrating.

## Bringing Treatment Closer to Patients

We decided to act.

After persistent communication and preparation, KCMC became a partnering site of The Max Foundation. We were the first such centre outside a capital city in Africa. This marked the beginning of a different approach—*bringing treatment closer to patients, rather than expecting patients to travel to treatment.*

At the same time, we worked to improve diagnostic capacity. With support, we established RT-PCR testing for BCR-ABL within our own laboratory, making both diagnosis and monitoring more affordable and locally available.

The impact was immediate. Today, more than 200 patients have been enrolled in the program at KCMC. Many are in deep molecular remission. For a disease that once carried a poor prognosis in this setting, this represents a fundamental shift.

What has changed most, however, is not only the clinical outcome. It is the nature of care. In a context, where many cancers remain incurable, CML has become something different. We see patients regularly over years. We follow their progress. The disease becomes part of a long-term relationship, rather than a short and often terminal encounter.

**For us - clinicians, this is powerful. It provides a sense of continuity and purpose that is often missing in oncology in low-resource settings.**

## From Late Diagnosis to Earlier Action

At the same time, significant challenges remain. One of the most striking is how late many patients are still present. We continue to see complications that should be avoidable, including permanent visual and hearing impairment caused by extreme and longstanding


*Cytology Course for Primary Health Care Workers, left side: Mr Priscus Mapendo, Head of Laboratory Cancer Care Centre at KCMC*

leukocytosis.

What is particularly frustrating is that many of these patients had already sought care earlier, often at primary healthcare facilities. The issue is not a lack of contact with the health system, but a gap in recognition and referral.

To address this, we launched the *Online Outreach Cancer Clinic* in 2025. The goal was to strengthen early detection at the primary care level using simple, low-cost tools. Healthcare workers were trained to prepare and interpret manual blood smears, and weekly online case discussions were established with specialists at KCMC.

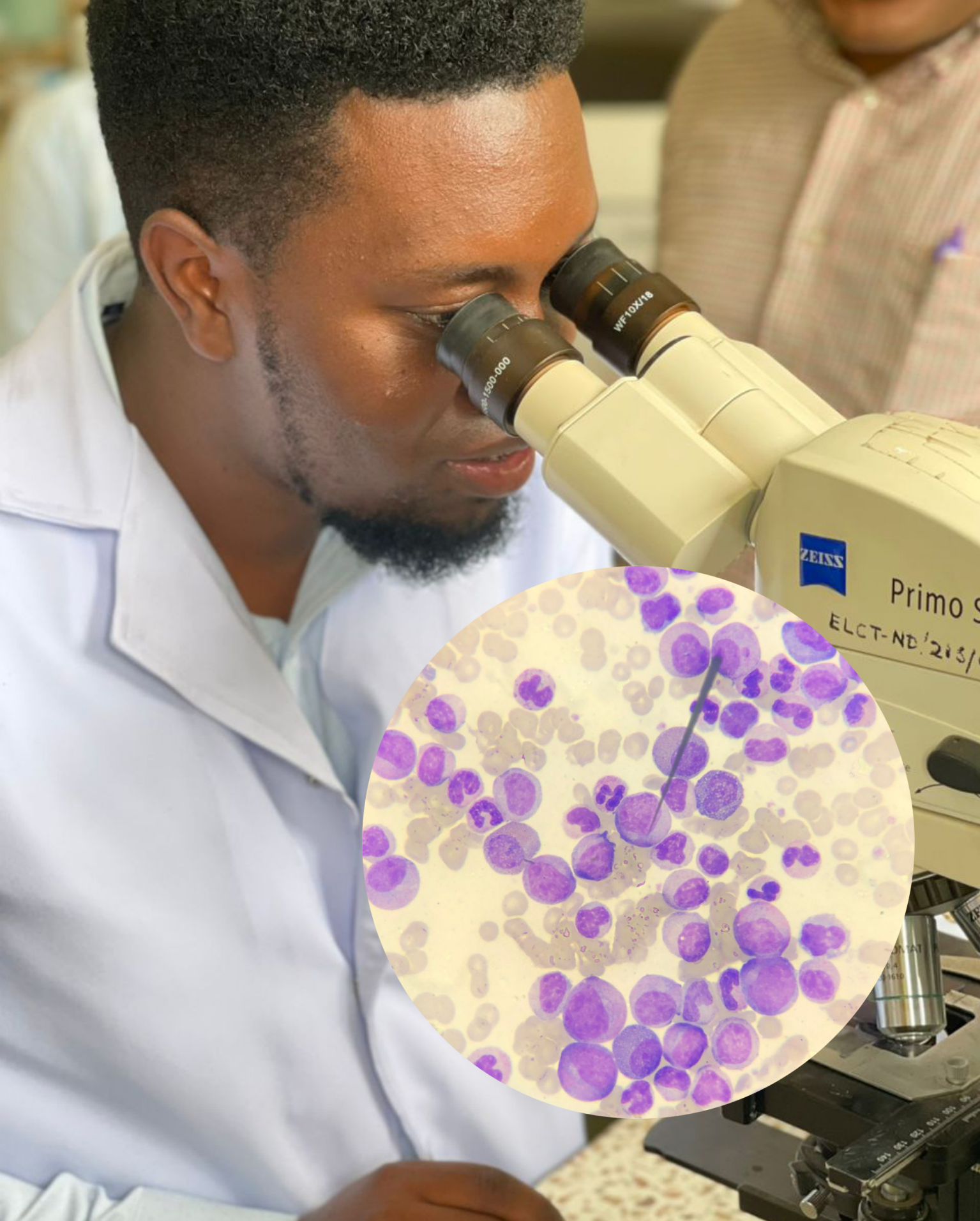
*This approach does not rely on advanced technology. It builds on existing structures and focuses on practical skills. Since its introduction, we have already identified three patients with suspected CML in rural settings and initiated treatment within one to two weeks.*

This is a remarkable achievement. It demonstrates that timely diagnosis and treatment are possible even in resource-limited environments when systems are adapted to local realities.

Looking back, the story of CML in this setting is not only about a drug. It is about access, infrastructure, and persistence. Imatinib is often described as a *"wonder drug,"* and in many ways it is. But its true impact depends on the systems that deliver it to patients.

*What we have learned is that access is not fixed. It can be expanded beyond major cities. It can be adapted to local needs. And it can be improved through collaboration between clinicians, organizations, and communities.*

There is still much work to be done. Patients continue to present late, and infrastructure remains fragile. But the progress achieved over the past years shows what is possible.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25 years
of TKIs
iCMLf

# From Revolution to Reality

## The Work of Transforming a Medical Milestone into Global Progress

By Nicola Evans

Twenty-five years ago, a CML diagnosis carried a five-year survival rate of around 30%. Patients faced limited treatment options and the knowledge that their time was likely measured in years. Then came imatinib, a drug designed to target the precise genetic driver of cancer and switch it off. The results were extraordinary. *Dr Brian Druker,* the scientist who drove that discovery, recalls the day in the clinic when the promise became undeniable:

*"Three patients came in on the same day. Just months earlier, they had been told to put their affairs in order. They shared tears, and I shared tears. Now, some of those patients are still with me 25 years later."*

Beginning with imatinib, tyrosine kinase inhibitor (TKI) therapy has transformed outcomes in CML, with most patients in chronic phase now achieving near-normal and in some cases normal life expectancy[1]. The diagnosis that once carried a median survival measured in years has become, for many, a chronic condition compatible with a full life.

But the word "many" carries weight. For a significant proportion of the world's CML patients, especially those in low- and middle-income countries, the revolution of TKIs has arrived unevenly, delayed by barriers to drug access, diagnostic infrastructure, and specialist knowledge that geography and income continue to impose. *Closing that gap has defined the mission of the International CML Foundation (iCMLf) since its founding in 2009.*

## From Breakthrough to Global Mission

The iCMLf was established by leading hematologists who understood that a medical breakthrough alone is not enough. Professor John Goldman, co-founder and first Chairman, stated in 2010: *"These new agents must be made available to the greatest possible number of eligible patients as rapidly as possible throughout the whole world."*

Professor Jorge Cortes, co-founder and current iCMLf Chairman, reflects: *"I still follow many of the patients who were enrolled in those early trials, many years later. I remain in awe every time I see them and think of how different their lives are. What began as a radical idea is now a global standard, and it was out of this extraordinary success that the iCMLf was formed."*

That founding conviction shapes everything the iCMLf

*Founders of the iCMLf in 2009: from left to right Professors Michele Baccarani, John Goldman, Brian Druker, Jorge Cortes, and Tim Hughes*

does, from its education programs in lower-resource settings to its global research agenda oriented toward a cure.

## Building Capacity, Changing Outcomes

The iCMLf's education programs translate scientific advances into better clinical practice on the ground, with a particular focus on clinicians in settings where access to diagnostic tools, molecular monitoring, and specialist knowledge is limited. The impact of this work multiplies far beyond the individuals directly reached.

*Dr Gebremedhin* from Ethiopia is one example. Through an iCMLf-supported preceptorship with *Professor Tim Hughes,* along with sustained access to expert guidance and clinical networks, he reshaped CML management in his country establishing one of its first dedicated CML clinics, now serving more than 2,500 patients, introducing molecular monitoring, and training the next generation of hematologists.

*"Our patients are living longer, healthier lives," he has said, "and the iCMLf has walked with us every step of the way."*

The iCMLf sustains this learning through ongoing initiatives connecting healthcare professionals worldwide. Professor Zeba Aziz, from Pakistan, has observed the cumulative effect:

*"In every way, the iCMLf has improved physician*

*education around the world. But the biggest impact is the benefit to patients. The iCMLf has shown that just a few people who are committed to the disease can impact the world."*

That commitment is shared. Organisations including the CML Advocates Network and The Max Foundation bring their own distinct expertise to the same mission, ensuring that progress in CML reaches as many patients as possible.

## Patients at the Centre

Darshana Ramesh was 39 and relocating for a new job when a routine blood test returned alarming results. In a clinic where she did not speak the language, she understood only one word: cancer. She spent nine months on a first-generation TKI that caused crippling fatigue and swelling before being switched to a second-generation agent that finally brought relief.

*"What I want doctors to know is that information is just as important as medicine. Patients need to understand their options, what their treatment journey might look like, and how to manage side effects."*

For others, the aspiration extends further still. Yunus has lived with CML for over a decade and become an active advocate. He is direct about where the community's ambitions must lead:

*"I've become more and more involved in advocacy work. My dream is to be cured one day."*

His mother Conny is equally clear: *"CML has changed from a fatal to a chronic disease. This is a great achievement. But this is not enough. Our children need healing therapy."*

Their voices articulate something the iCMLf has always understood: closing the gap in CML outcomes requires better-informed clinicians, stronger patient communities, and ultimately a scientific answer to the question that remains unresolved 25 years on.

## The Next Frontier: From Control to Cure

TKIs have transformed survival, but effective treatment does not remove the burden of disease entirely. Many patients remain on therapy for life, facing chronic side effects, financial and emotional burdens, and the constant risk of relapse. With CML cases potentially rising to over ten million globally by 2050[2], finding treatments that fully eradicate the disease is a global health imperative.

Today, only 20–25% of patients achieve the deep molecular responses needed to attempt stopping treatment, and only half remain in remission once therapy is withdrawn. The barrier to cure is now clearly identified: leukemic stem cells that survive despite long-term therapy and can reignite disease when treatment stops. If these cells can be eliminated, cure becomes possible.

The iCMLf's response is the iCMLf Cure Consortium. Its aim is to elucidate and eradicate the mechanisms of leukemic stem cell persistence, enabling durable treatment-free remission and, ultimately, a cure for CML. Uniting the world's leading experts across leukemic stem cell biology, immunology, genomics, data science, and clinical trial design in one integrated mission, it will uncover the biological basis of CML persistence, develop biomarkers predictive of sustained remission, and design new therapeutic strategies targeting leukemic stem cells.

Critically, the Consortium is built on global collaboration, bringing together leading research centres and scientific expertise from across the world to ensure that the pursuit of a cure draws on the full breadth of international knowledge.

## A Revolution Continued

*Dr Druker,* reflecting on where the field now stands, is clear about what remains to be done: "We know that around 20% of patients can stop treatment altogether. But we don't yet know why only some can stop, or how to get more patients there. That's the next step: moving from well-controlled disease to cure."

## References


1. *Hochhaus A, Baccarani M, Silver RT, et al. European LeukemiaNet 2020 recommendations for treating chronic myeloid leukaemia. Leukemia. 2020;34:966–984.*
2. *Jabbour E, Kantarjian H. Chronic myeloid leukemia: 2025 update on diagnosis, therapy, and monitoring. Am J Hematol 2024 Nov; 99(11): 2191-2212.*

# Closing the Monitoring Gap

## in CML Care for Equitable Outcomes Globally

by Alicia Annamalay

For more than two decades, global oncology has rallied around a clear and urgent goal: expanding access to life-saving cancer medicines. Through partnerships between pharmaceutical and biotechnology companies, global health organizations, local healthcare institutions, and governments, certain treatments that were once out of reach in low- and middle-income countries (LMICs) are now accessible to patients. While this progress is far from adequate for most cancers, it is most clearly demonstrated in chronic myeloid leukemia (CML), where outcomes have been transformed. Once associated with poor survival, CML is now a manageable condition for many patients in LMICs. This is reflected in real-world outcomes, with one evaluation of CML patients supported through The Max Foundation and Novartis Pharma AG's Glivec International Patient Assistance Program (GIPAP) reporting five-year survival rates of around 89%, comparable to those reported in high-income countries (Umeh et al., 2018).

## CML Survival in LMICs Now Comparable to High-Income Countries With Sustained Treatment Access

As access to treatment has expanded, a less visible gap has become increasingly clear: the need to monitor molecular response. In CML, treatment decisions depend on reliable molecular monitoring over time. BCR-ABL PCR testing allows clinicians to assess treatment response, detect resistance early, and guide decisions about changing treatment or whether patients may safely discontinue therapy through treatment-free remission (TFR). Without consistent monitoring, clinicians are left making decisions with incomplete information, and patients may remain on ineffective therapies longer than they should or miss opportunities to adjust treatment at the right time. In this context, molecular monitoring is not an optional layer of care but a central part of achieving optimal outcomes.

Despite this, access to PCR testing remains inconsistent across many LMICs. A recent global analysis by The Max Foundation found that in 2025, of approximately 31,900 CML patients across 77 countries supported through treatment access programs, an estimated 45% were not receiving annual molecular monitoring. The implications are significant. Without routine testing, treatment decisions may be delayed, resistance may go undetected, and patients may not fully benefit from the therapies now available.

## Nearly Half of Patients Still Lack Annual Molecular Monitoring Despite Treatment Gains

These gaps reflect broader differences across health systems. In Africa, an estimated 68% of patients did not receive an annual molecular test in 2025, with the largest unmet need concentrated in high-population countries. In Asia, the gap is 66%, with wide variation between countries and continued reliance in some settings on out-of-country testing. Even in regions such as Latin America and Eastern Europe, where health systems may be stronger, access remains uneven, with estimated gaps of 33% and 31%, respectively. India, which represents the largest CML patient cohort within The Max Foundation's programs, highlights both progress and persistent barriers. Testing is largely delivered through private laboratories, often requiring out-of-pocket payment, and an estimated 405% of patients in India are not receiving annual monitoring. Together, these patterns show that the issue is not only whether testing is available, but whether it is integrated into routine care and consistently accessible.

Financing plays a central role in determining access. In 11 countries, PCR testing for CML is included in national health systems and provided at no cost to patients, showing that high coverage is achievable when diagnostics and monitoring are prioritized. In others, access depends on a mix of approaches, including donations, co-financing arrangements with hospitals or governments, and preferential pricing agreements with diagnostics manufacturers or local laboratories. The Max Foundation supports a range of these models, adapting to local contexts to expand access. Despite these efforts, many patients still face out-of-pocket costs that are unaffordable, and in 12 countries, patients still rely on sending samples to laboratories in other countries. This introduces delays, increases costs, and reduces the likelihood that testing will happen consistently.

The scale of the gap is both significant and solvable. Earlier analyses estimated that closing the PCR monitoring gap for CML patients supported through The Max Foundation's access programs would require

approximately $30 million over five years, covering around 30,000 patients across 60 LMICs and enabling regular monitoring of approximately three PCR tests per patient per year, in line with clinical guidance (Rowley et al., 2021). This estimate was based on optimal monitoring frequency. More recent analyses take a more pragmatic approach, focusing on whether patients receive at least one test annually as a minimum standard of care and a measurable first step toward routine monitoring. Based on this definition, a 2025 gap analysis conducted by The Max Foundation estimates that approximately 14,000 CML patients are still not receiving even one annual PCR test, indicating that progress has been made but that a substantial gap remains.

## Expanding Access to PCR Testing Is the Next Critical Step in Closing the CML Equity Gap

Partnerships are helping to address this challenge. Since 2012, The Max Foundation has partnered with Cepheid to expand access to BCR-ABL PCR testing through the GeneXpert platform. This collaboration has enabled preferential pricing for cartridges and equipment across more than 60 LMICs, while a novel approach from Fred Hutchinson Cancer Center facilitates testing through Spot On CML, a program designed to lower the cost of shipping blood samples by extracting RNA from dried blood spots on paper. Several other organizations, including the American Society of Hematology (ASH), have provided grants to support the provision of tests in certain countries. A few patient organizations and hospitals have contributed by developing sustainable funds and taking advantage of preferential funding agreements, including those with local labs. The Max Foundation's Solidarity Fund supports the provision of tests in 40 countries. Together, these efforts show that the tools and delivery models needed to expand access to diagnostics are already in place in most countries. The challenge now is ensuring they are implemented consistently and at scale. This requires sustainable financing for reagents and equipment, reliable supply chains, clear regulatory pathways, and alignment within health systems so that molecular monitoring becomes part of routine care.

Stronger data systems are also essential. Not only is testing limited, but it is also not always captured in a consistent way. Without reliable data, it is difficult to understand where gaps exist or to track progress over time. In 2024, The Max Foundation strengthened its digital Patient Access Tracking System (PATS) to enable recording of PCR test results for each patient. This is an important step toward improving visibility of molecular monitoring, supporting more informed clinical decision-making, and enabling more accurate tracking of patient outcomes over time. Improving data capture and use will also help identify gaps more precisely, guide resource allocation, and strengthen the case for sustained investment in diagnostics.

Closing the monitoring gap will require action across stakeholders. Governments must prioritize diagnostics within national cancer strategies and ensure they are funded. Industry can help make diagnostic technologies more accessible and affordable. Global health organizations can support coordination and implementation across settings. Clinicians and patient advocates can continue to highlight the importance of molecular monitoring in achieving better outcomes and ensuring that progress in access translates into real impact for patients.

The progress made in expanding access to treatment shows what is possible when partners align around a shared goal. That same level of focus is now needed for diagnostics. At The Max Foundation, there is a shared vision to ensure that all patients supported through its treatment access programs have at least one PCR test recorded each year. This reflects a broader vision of equitable cancer care, where patients not only receive treatment but also have the tools to benefit fully from it. The question is no longer whether treatment can reach patients in LMICs, but whether those patients can achieve the same outcomes as patients elsewhere. Closing the monitoring gap is essential to making that possible.

# YVONNE AWARD 2026

# From Fatal to Chronic
## Witnessing the Transformation of CML Care in India

### A clinician's perspective on 25 years of science, access, and advocacy

by Neeraj Sidharthan

## The Moment Medicine Changed Before Our Eyes

At a recent patient meeting organized by The Max Foundation, I found myself saying something I had never quite articulated before. As I looked around the room, at individuals who had been living with chronic myeloid leukemia (CML) for two decades or more, I realized that I had been a witness to one of the most profound transformations in modern medicine.

When I entered medical school in 1994 at Government Medical College, Trivandrum, CML was a very different disease. During my internship, the few patients I encountered were treated with Busulfan, a drug that offered limited control. Some were referred to Christian Medical College, Vellore, for bone marrow transplantation—the only potentially curative option, but one that was expensive, toxic, and inaccessible to most. Survival was uncertain, and hope was measured in narrow margins.

## The Arrival of the "Magic Bullet"

In 2002, as a first-year resident in internal medicine, I had my first glimpse of something new. On my very first day, my mentor, Professor Mathew Thomas, asked me a question I could not answer: *"What is STI571?"* I had no idea. That evening, I went back, read, and returned to rounds with the answer—STI571 was imatinib. It was my first encounter with what would soon be called a *"magic bullet."*

It was only in 2005, when I joined Christian Medical College, Vellore, that I finally saw the magic bullet. Patients with CML were no longer being prepared for transplant, they were receiving a tablet. Imatinib had already begun to change the course of the disease. Yet what struck me even more was not just the science, but the system around it.

Each patient file carried an orange sticker. That sticker meant access. It meant that the drug, otherwise costing nearly ₹1 lakh a month, was being provided free of cost through the GIPAP program, supported by The Max Foundation. As trainees, our responsibility was simple but profound: to ensure that patients were enrolled, followed up, and continued therapy.

And then we began to see something remarkable. Within weeks, blood counts normalized. Within months, patients returned to their lives. A disease that once required hospitalization and heroic interventions had been transformed into something closer to a chronic condition—*manageable, predictable, and, for*

*many, compatible with a normal life.*

Over the years, as I returned to Amrita Hospital and continued my practice, this transformation became even more tangible. The GIPAP program allowed this revolution to extend far beyond a few centres. Patients who would otherwise never have accessed such therapy were now living full lives.

I remember a patient who was a photographer, traveling across countries with his medication packed as routinely as a passport. Another spent long periods abroad but continued treatment seamlessly. For many, a diagnosis of CML no longer meant the end of ambition—it simply meant adapting to a new routine.

*What changed was not just survival, but the very meaning of the disease.*

## From Survival to Freedom: Redefining the Future of CML

For us as physicians, the conversation shifted from *"How long?"* to *"How well?"* and increasingly, even to *"How much less treatment?"* In recent years, the concept of treatment-free remission has emerged as another milestone. Some patients, after years of sustained deep molecular response, are now able to discontinue therapy under careful supervision—something that would have seemed inconceivable in the early years of my training.

At the same time, we have learned to manage CML as part of a broader clinical reality. Patients age, develop comorbidities, and live with other chronic conditions—diabetes, hypertension, renal, or cardiac disease. Treating CML is no longer an isolated task; it is integrated into long-term, holistic care. This, too, is a sign of success.

*Yet, as much as this story is about science, it is equally about access.*

The GIPAP program remains, in my experience, one of the most impactful patient access initiatives in oncology. It ensured not only availability of a life-saving drug, but also continuity, structure, and accountability. Patients were not simply given medication—they were brought into a system of care.

Even today, many of the earliest beneficiaries continue on therapy. At that same patient meeting, we met individuals who had been on treatment for 25 years. To see them healthy, active, and engaged with life is perhaps the most powerful validation of what this journey has achieved.

Equally important has been the emergence of a patient community. Such programs have brought patients together, creating networks of support, awareness, and advocacy. In India, groups like Friends of Max have amplified patient voices and helped ensure that access to care remains a priority.

And yet, challenges remain. Access is still not uniform. Molecular monitoring is not universally available. Newer therapies, while promising, come with their own cost and accessibility barriers. Ensuring adherence over decades is not trivial. The next phase of the CML journey will require not only continued scientific innovation, but also a sustained commitment to equity.

Looking back, the past 25 years have not only changed how we treat CML, they have changed how we think about cancer itself. What was once a fatal disease has become a model for precision medicine, long-term survivorship, and the power of combining science with access.

Standing in that room, surrounded by patients, who had lived through this transformation, I realized that the story of CML is not just about a drug. It is about what becomes possible when innovation, access, and sustained care come together.

For me, the GIPAP program represents something even deeper. It reflects what can emerge when personal loss is transformed into collective good. Born from the experience of a family that faced the reality of not having access to life-saving treatment, *it evolved into a program that has enabled thousands of patients to live full and meaningful lives over the past 25 years.*

That arc—*from loss to impact, from one life to many*—captures not just the story of CML, but something larger about medicine itself. It reminds us that progress is driven not only by scientific discovery, but also by empathy, advocacy, and the will to ensure that no patient is left behind.

**In the end, the legacy of CML is not just that we learned how to treat it, but that we learned how to make treatment matter.**

# ONCODAILY MEDICAL JOURNAL

Peer-reviewed
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Scientific journal

doi.org/10.69690/odmj
oncodailyjournal.com
ISSN: 3067-6444

September
2026

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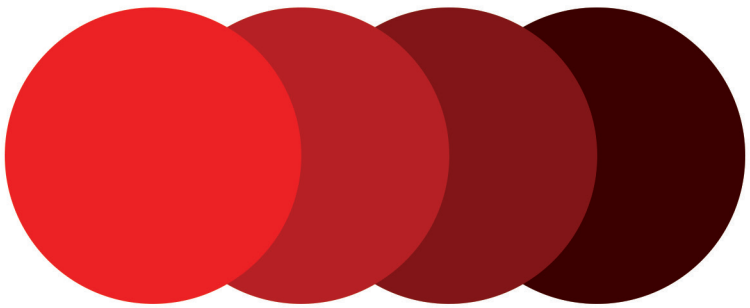

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SPECIAL ISSUE 05 / 2026 ISSN: 2036-9468