CANCERWORLD



A Global Initiative to Tackle Inequities in Pediatric Cancer

ARNAUD LALLOUETTE



OncoDaily

THE VOICE OF ONCOLOGY

#Largest #Fastest #MostInnovative #24/7 #Global #EveryoneHasASpace

oncodaily.com

The Fight Against Cancer Is Global — But Progress Still Isn't

Prof. Adriana Albini Prof. Lidia Schapira

Co-Editors-in-Chief

What does it take to change the odds in cancer care? Innovation? Yes. But also: persistence. Collaboration. The refusal to accept that some lives matter less because of where they're born.

In this issue of CancerWorld, we focus not just on what's new in oncology — but on what's necessary.

Our dual cover stories frame that promise.

On one side: A call to action. Arnaud Lallouette of Servier lays out the case for ACT for Children — a bold initiative confronting the global inequities in childhood cancer care. In a world where 80% of children with cancer live in low- and middle-income countries, but less than 30% survive, ACT is proving that access is not a dream. It's a strategy.

Managing Editor

Yeva Margaryan

One that's already working.

Turn the magazine over, and you'll meet a man who moved mountains in silence. Dr. Samvel Danielyan, who built Armenia's pediatric cancer system from nothing, reminds us that real progress rarely starts with a budget. It starts with belief — and someone unwilling to walk away when the world says "no."

News Editor

Janet Fricker

These are the poles of this issue: a global vision, and a deeply personal fight.

Between them, we dive into stories that challenge assumptions and push for change.

Illustrations

Liana Gogyan

A woman who has shaped modern oncology more than most: Professor Martine Piccart. In an unflinching profile, we trace her path from a small clinic in Belgium to global influence — founding BIG, fighting for scientific integrity, and refusing to compromise on what truly matters in cancer research. Her story is not just one of leadership, but of moral clarity.

We explore patient-reported outcomes, and ask why, in 2025, they still haven't become central to drug development. What does it say when the patient's voice is still an "optional endpoint"?

We bring forward hopeful evidence that SGLT2 inhibitors — once just diabetes drugs — may become powerful tools in protecting cancer patients' hearts during treatment.

We explore a hidden crisis in Africa: the deadly intersection of albinism and skin cancer, where sunlight becomes a slow killer and sunscreen can mean survival. From open-source formulas to local production, this is prevention reimagined.

And we tell the story of survival — twice removed. Once from cancer. And then, from the long shadow it leaves behind. A major simulation study shows survivors of childhood cancer face accelerated aging and early-onset chronic illness. The data is sobering. The implication is clear: survivorship must come with surveillance. We must rethink when

CANCERWORLD

magazine is published by OncoDaily (P53 Inc)

Alongside this, we hear from two global voices in action.

screening starts — and who gets left out.

Email: info@cancerworld.net Tel: +1 978 7174884 Adrian Gottschalk, the CEO of Foghorn Therapeutics, reflects on building a company at the frontiers of gene regulation. His story is one of humility, systems thinking, and what it means to lead through service.

ISSN: 2036-9468

And Zainab Shinkafi-Bagudu, soon to become the first African president of the Union for International Cancer Control, shares how a paediatrician became a force in global health diplomacy. Her insight: policy is personal — and political courage is its own kind of medicine.

NOT FOR SALE

This issue isn't just a reflection. It's a reckoning. With what we know, and what we still fail to do.

Thank you to the readers who return to these pages with each issue — physicians, researchers, advocates, patients, policymakers, and changemakers. You are part of this. Your voices, your work, your questions — are what keep this conversation alive.

We'll see you in the next issue.

Yeva Margaryan, Managing Editor, CancerWorld



Arnaud Lallouette

Executive Vice President, Servier Global Medical and Patient affairs

ACT FOR CHILDREN

A Global Initiative to Tackle Inequities in Pediatric Cancer

The disparity in childhood cancer outcomes is one of the world's most pressing health inequities. While over 80% of children with cancer are cured in high-income countries (HICs), survival drops to less than 30% in low- and middle-income countries (LMICs). This gap is not due to a lack of curative potential, but rather to unequal access to the essential resources, treatments, and care that determine survival.

These inequities affect more than just the children living in LMICs — they also hinder global progress in pediatric oncology research and development (R&D). Without including the 80% of children who live in LMICs, we limit our ability to develop better, less toxic, and more effective treatments. Closing the health equity gap is not only a moral imperative, but also essential for scientific advancement.

Drivers of Disparity

Healthcare providers in LMICs often open their medicine cabinets to find them empty. This lack of access to essential medicines creates a domino effect: limited diagnostic capabilities, substandard treatment, inadequate patient support, undertrained and scarce data to guide policy and investment. Specialized childhood cancer centers are rare in LMICs, and children are often treated in general wards — or not at all. These systemic issues compound long-standing challenges in delivering quality cancer care in resource-limited settings.

A Global Opportunity

The pharmaceutical industry has a critical role to play in reversing these trends. Over the past three decades, we've

learned that innovative medicines do not naturally reach children in LMICs. In fact, the absence of curative therapies — and the awareness that they exist — has fueled the spread of counterfeit and substandard drugs.

These products undermine trust, compromise treatment, and pose a danger to children everywhere. To address this, the industry must create access pathways that remove financial barriers and ensure safe, effective use of quality-assured medicines.

The Global Platform for Access to Childhood Cancer Medicines, led by World Health Organization (WHO) and supported by St. Jude Children's Research Hospital, offers a historic opportunity.

By removing the financial burden of medicine procurement, the platform provides a global framework for equitable access to life-saving pediatric oncology treatments.

We applaud the fact that blinatumomab — a treatment for pediatric acute lymphoblastic leukemia — has been recently submitted for consideration for addition to the WHO Essential Medicines List for Children.

We look forward to seeing this medicine, alongside pegylated asparaginase owned by Servier — a global, independent pharmaceutical group governed by a non-profit foundation — recognized as essential therapies and, most importantly, placed in the hands of capable medical teams in LMICs.

Turning Solutions into Action

To address this entrenched disparity, Servier joined a dedicated group of partners to launch the Access Cancer Treatment (ACT) for Children initiative. ACT for Children is a multi-stakeholder effort that brings together industry, clinicians, and patient advocates to build the full ecosystem needed to cure a child with cancer.

The initiative expands access to innovative medicines — previously inaccessible in LMICs due

to regulatory and cost barriers — within a hospitalbased quality improvement model.

ACT for Children supports the full continuum of care: timely diagnosis, skilled providers, adapted treatment protocols, nutrition and psychosocial support, and comprehensive training.

Rather than imposing a one-size-fits-all approach, ACT for Children works directly with hospitals to co-develop locally appropriate solutions. The model ensures every intervention is integrated, measurable, and sustainable.

ACT for Children also generates clinical guidance, monitors real-world outcomes, and informs national policy and investment — paving a bridge to long-term access through the WHO platform.

In just seven months, ACT for Children has made measurable progress. Five hospitals across Guatemala, El Salvador, Honduras, Armenia, and Indonesia have received \$2.8 million worth of high-quality medicines at no cost. More than 300 healthcare providers have completed in-person training.

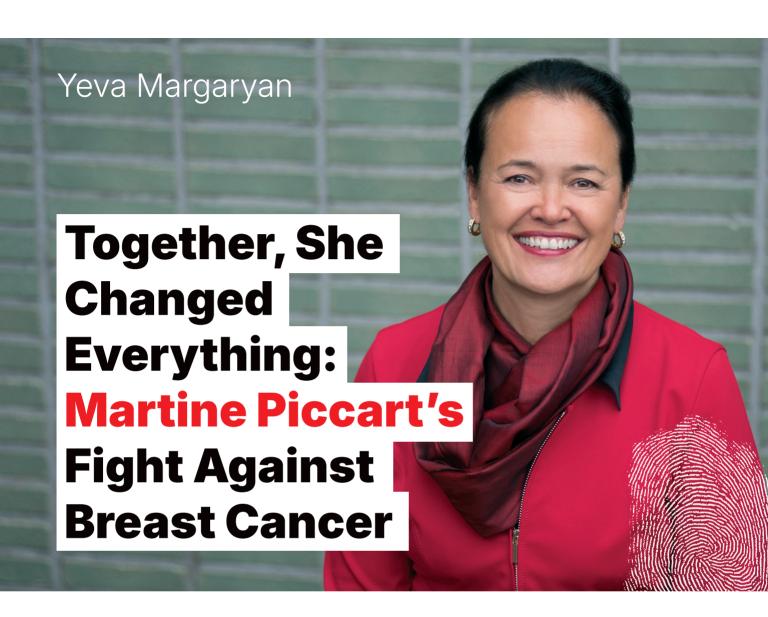
These results highlight the transformative power of partnership. No single actor can close this gap alone, but together, change becomes inevitable.

We are proud to collaborate with Childhood Cancer International (CCI), IDA Foundation, the International Society of Paediatric Oncology (SIOP), Resonance, World Child Cancer, and the Union for International Cancer Control (UICC)-led Access to Oncology Medicines (ATOM) Coalition.

The Road Ahead

ACT for Children is proof that coordinated global efforts can create lasting change. By striving for health equity, we can ensure that no child is left behind, and every child has a fair chance of survival and recovery.

With sustained commitment, we can turn this moment into a movement — and ensure no child is left behind.



Prof. Martine Piccart grew up in a house where medicine was part of the air. Her father, a gynecologist, treated patients at home. "I admired him deeply," she says. "He helped people. I saw that up close. It left a mark."

She considered pediatrics, but feared missing a diagnosis in a baby who couldn't speak. Oncology felt clearer, More certain.

She went to the Institut Bordet for her training where she met a doctor who would shape the arc of her life.

"Dr. Marcel Rosenzweig," she says. "He had just come back from the National Cancer Institute

in the U.S., where he'd spent four years learning how to develop cancer drugs. He was charismatic. Generous. He taught me how to think about trials, about molecules."

He later returned to the U.S. and became a pivotal figure in oncology drug development, playing a leading role in bringing Paclitaxel — Taxol — to the world. But before that, he gave Professor Piccart a piece of advice that would change her life: go to the United States for further training.

"I cannot imagine what would have been my career if I had not had the chance to meet him."

She did what he said. She landed at New York



University Hospital. Two years later, she returned home. And made a decision. "I chose breast cancer."

What BIG Was Built For

Back in Europe, Piccart was struck by how different things felt. The scale was smaller. The rhythm slower. In the U.S., she'd seen vast networks of collaboration. In Belgium, it was pockets of progress, each one working alone. That didn't sit well with her.

"Clinical trials in Europe were national. Fragmented. Underpowered. They couldn't answer big questions."

Once again, life placed the right person in her path. She met Aron Goldhirsch — a colleague who would become a close friend, a confidant.

"We met over dinner. I shared my frustration, this idea that we needed something like what existed in the U.S. And he just got it. Immediately. He became a big brother to me."

That dinner sparked the birth of the Breast International Group — BIG.

It wasn't smooth. The first meeting was tense. "We invited the chairs of the European groups. French, German, Dutch, British. They were suspicious," she remembers. "They thought Aron and I wanted to take over. To control. To destroy them."

But suspicion gave way to substance. Slowly. The plan wasn't to centralize everything. It was to join forces when it mattered most — especially for small populations, rare subtypes.

Science, Not Sales: The HERA Stand-Off

Then came trastuzumab. HER2-positive breast cancer represents just 15% of cases. Roche wanted a European trial. Piccart made the case: BIG was the right partner. "You run that trial nationally, it takes six years, even if it's a big country like France." she says. "We could do it in two."

But BIG had rules. The data would stay with an academic institution. The trial would be led by science, not sales. After months of negotiations, Roche walked away.

"I think they were probably afraid of losing control—and I understand that. Drug development is risky. These large registration trials cost a fortune. If they fail, it's a disaster. But then something remarkable happened—something I don't think could happen in today's world."

Piccart and Goldhirsch called a meeting — 40 research group leaders on the line. "We all agreed: we won't participate unless they respect the model." Ten of them flew to Basel. They met Roche's leadership. They pushed.

"There was so much pressure," she says. "We had to make this work."



They did. The HERA trial recruited 5,000 patients in two and a half years. The results were presented at ASCO. "Three trials: HERA and 2 American trials. One packed room. There was an emotional atmosphere in the room. That ASCO changed everything."

Trust in BIG was sealed.

Then came Affinity — adding pertuzumab to trastuzumab. More cures. A step closer to beating the disease. But even success demands difficult choices.

The Toughest Decision Of Her Career

One decision stayed with her — not because it was public, but because it tested her principles.

"There was a group in BIG," she says. "Brilliant, active, contributing real value — but they were forprofit. And for me, that mattered."

"Making money through research? That's for pharma. That's their job," she says. "But academic research — it must stay clean. If you cross that line, you lose the point."

She didn't want researchers thinking about patient numbers as revenue. She didn't want trial recruitment to become a transaction.

"There's already pressure in academia," she adds. "For a successful academic career you need to publish. That's one layer. But I didn't want to add a second layer, which is that the more patients you enter in a trial, the more money you make. If your income depends on how many patients you enroll — it changes everything."

So she drew a line. BIG would no longer work with them. "We had to protect our integrity. Our focus is the patient. That's it."

The principle stood firm. "We had to protect what made BIG trustworthy. We had to keep the mission clear."

And it came with cost. "We lost strength. We lost reach. Maybe younger oncologists wouldn't have



made the same call. This was one of the most difficult decisions in my career."

Later, they found a compromise. The group could collaborate with BIG, but not under its name. They also reviewed every member organization. "A few others were for-profit, but their profits went back into research. That was different. That we accepted."

Leadership Is Also a Psychology: Orchestrating Science

According to Prof. Piccart, a great scientist could live inside a single discipline. But a scientific leader? They had to live among many. That's where her experience at EORTC helped. "I learned how to work across disciplines — radiotherapy, surgery, pathology. If you want to lead, you have to listen. You have to speak the language of the people around you."

At EORTC, she joined the gynecological group. Then breast. She became secretary. Then chair. Eventually, she oversaw the treatment division — the whole thing. "That taught me what different teams needed. How they think. How they move. That helped me in BIG more than any single piece of knowledge."

Leadership, she said, was about psychology too. Spotting egos before they collided. Listening. Preventing.

ISSUE 103 05 / 2025

"There are big egos," she says. "Always. In every organization. And the important thing is that you need to pay constant attention to these conflicts. You better identify them at the beginning, when they start. Because if you ignore and you say, well, it's not important, it can destroy the organization."

She offers a clear example of conflict prevention in academia: authorship. It mattered — sometimes too much. "Everyone wants to be first or last," she says.

"That's how careers are built. But it's wrong. Science is a team sport. Like sending a rocket to the moon — no one gets there alone."

In BIG, she brought in structure. Rules.

"We planned authorship before trials even started. Paper one, paper two, primary endpoint, secondary endpoint. Everyone had a chance to contribute and be seen."

Because Survival Isn't Enough

At the center of it all is a deep sense of justice. But it isn't theoretical. It's lived. It began in the hospital corridors, yes — but it was forged at home.

"I always had one driving goal," she says. "To radically improve how we treat breast cancer."

Her mission took root at 28, when her mother was diagnosed with locally advanced breast cancer. "It was a disaster," she says. "I was terrified. I didn't think a cure was possible."

The odds were against them. But her mother survived.

"Twenty years later, she had a second cancer. Different time. Different treatment. But still — there were questions. And not just about survival. About what matters in care. About side effects mitigation. About optimal duration of care."

Piccart saw it clearly: pharma was not going to answer those questions. Not when shorter treatment meant smaller profits. "It's absolutely clear that it's not the role of pharma. They very often will choose a duration that brings more money back to them. There's no profit in reducing dosage."

She didn't want to waste time. "I knew I had limited years. I didn't want to spend them on noise. I wanted to bring people together and get the work done. So many essential questions were unanswered. We had new drugs — but didn't know how long to give them. Or how much."

And she knew one thing above all: "You cannot do great things alone. Never."

That belief led to MINDACT.

When Less Is More: Avoiding Unnecessary Chemotherapy

MINDACT, A pure academic trial. Massive in scale. The study asked: can we use gene signatures — genetic fingerprints of tumors — to avoid chemotherapy in some breast cancer patients?

At the time, chemotherapy was given broadly. Too broadly. "You only get one shot to cure cancer," she says. "So we treated aggressively. But we overtreated. We knew that."

The trial was massive. Collaborative. The EU gave €7 million. It needed €45 million. "We knocked on every door," she says. "Every country. Every foundation. And we got there."

It took 15 years. But they proved it: in women over 50, if the gene signature showed low risk, chemotherapy added no benefit. Endocrine therapy was enough. Lives were saved. And others were spared the burden of unnecessary chemo.

But younger women? The answer wasn't the same. "That's the next trial," she says. "We still don't know why they respond differently. But we'll find out."

She pauses. "If I had known it would take fifteen years? I'm not sure I would've started. That's why it's good we don't know everything in the beginning."



Too Many Drugs, Too Few Answers

Despite decades of progress, Piccart is frustrated by the imbalance.

"So much money goes to drugs," she says, "so little to biomarkers. In 40 years, what have we really added? Hormone receptors, HER2, cell proliferation, a gene signature — that's it."

She sees promise in AI, especially in reading pathology slides. But AI needs data. Lots of it.

"And that's the wall we're hitting," she says. "Too much trial data is locked away — owned, protected, inaccessible."

She's clear: science can't move forward unless data is shared. "It has to belong to the community — not companies. Otherwise, we'll drown in expensive drugs and fragile evidence."

Governments, she warns, won't be able to sustain the rising costs.

"We need to refine. We need to target. And for that, we need data."

Built For Impact. Not For Applause

When asked what impact means to her, she doesn't hesitate.

"For an oncologist, impact is simple," she says. "You either prolong life, or you improve its quality. That's it. That's the line."

She carries that clarity with her everywhere. Into meetings. Into debates. Into systems that need fixing.

And one of those fixes came in the shape of a scale. The ESMO Magnitude of Clinical Benefit Scale. It

ranks new cancer drugs not by price or popularity, but by what they actually do — how many lives they save, how much better they make patients feel.

"It started during my presidency at ESMO," she says. "I was visiting oncologists in Eastern Europe. They were angry. They couldn't access trastuzumab — the same drug that changed everything in the HERA trial. And we call this one continent?"

That frustration turned into a plan. "We needed to separate real breakthroughs from small steps," she says. "To say clearly: this drug is worth it. This one — not so much."

She wasn't alone. Dr. Nathan Cherny in Israel had been thinking the same way. They joined forces. . Like everything else — it wasn't solo work.

Nothing important ever is.

"It took years," she says. "Meetings, debates, drafts, rewrites. But we built it. We gave countries a tool to make hard choices. We gave patients something to point to. We gave students a better way to read the literature. I'm proud of that," she says. "Not because my name is on it. But because it's useful."

I'm a Work Addict

And what's her personal philosophy?



She smiles.

"My husband would say: her philosophy is discipline. And he's right. I'm a work addict."

Even on holidays, she works. On weekends, too.

Music first, then love, then a life

Outside the clinic, there is music.

She plays the piano. Her husband plays the violin. That's how it started — chamber music.

Music runs in their blood. "All three of our daughters are musicians," she says. "The youngest is a singer — an opera singer now — carving out something truly beautiful."

"Playing music at home was something that we did every Sunday. Sometimes we took a teacher because if there was no teacher, we started to fight when things were not very good and we needed someone from outside to say, this is the person who is responsible."

Now, she plays less. "I miss it," she admits. "But I follow my daughter. That's the joy now."

Read to Understand. Travel to See

There's reading, too. She gravitates toward two kinds of books. First: history. "To understand how conflict begins," she says. "It helps. Or should help. The history repeats itself. The tragedy is how little we learn from it."

And then there's fiction. Stories about the soul. She mentions two names — Melissa da Costa, Valérie Perrin. "They write about people. Deeply. And when I start one of their books, I can't stop."

She travels. Always has. But now, the trips are for teaching too. She brings her grandchildren.

"Travel shows them what books can't," she says. "That people live differently. Think differently. And you must understand that. You must respect it."

The Words She Needed Then

If she could speak to her 30-year-old self? She would keep it simple.

"Work hard. Build a team. Respect your team. Don't give up too early. Ignore the noise. If your idea is right — go ahead."

But she'd also whisper what no one says out loud.

"You will be doubted. Often. You will lose time defending ideas when you should be building them. You will want to quit. Don't. Keep going."

Because, in the end, it wasn't just knowledge that moved the field. It was persistence. And patience. And people who didn't stop.

A Life Built Not Alone — But Together

And what does she hope the world to say about her?

That she believed in something simple. And hard. Collaboration.

"That when people work together, really work, discoveries don't just happen faster — they go deeper."

She thinks maybe she was lucky. She came of age in a world still rebuilding.

"After the war, there was a hunger to create. To cooperate. People wanted to build."

BIG was born from that spirit. So was the EU. So was a lot of what still stands.

"If I were 30 today, I'm not sure it would be the same," she says. "The atmosphere now is different. More fractured."

But even in this climate, she sees flashes of what could be

"I hope young oncologists will stay focused on what matters. The unanswered questions. The

ones that don't make money. The ones that take time "

She doesn't romanticize the road.

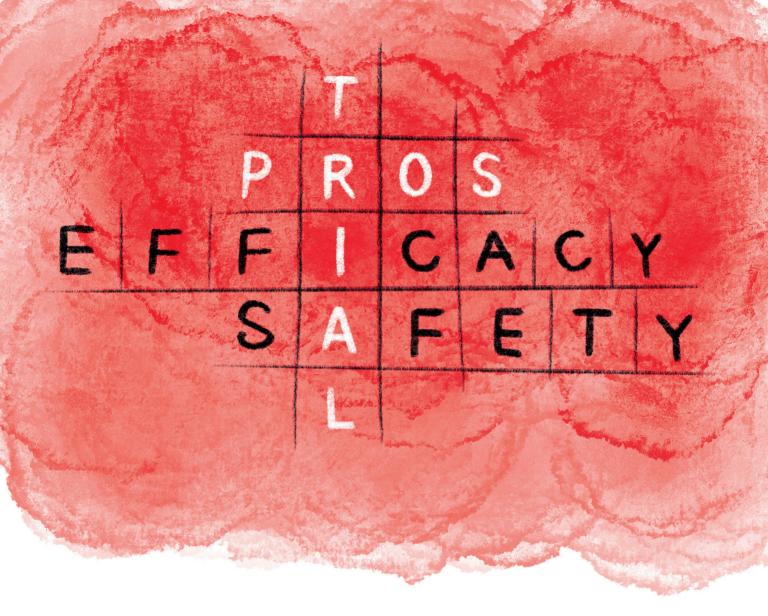
"Being a principal investigator in pharma trials gives you prestige. Recognition. Fast-track career. But it's not enough. Not if you want to look back and feel peace."

She looks ahead, not back.

"The real satisfaction comes from changing something. Not publishing a paper. Not getting applause. Changing the way we treat. Even if it takes years. Even if no one notices right away."

That's the legacy she wants. A life spent answering the hard questions. A life built not alone — but together.





Manuela Maria Campanelli

Why Patient Reported Outcomes Are Rarely Used In Trials, And How We Change That

If drug developers design trials to measure how well their drug addresses the issues most important to the target patient community, we could expect to end up with better drugs. Integrating patient reported outcomes into clinical trials is the way to do that. Manuela Campanelli asks why that isn't happening, and what has to change.

It's more than 15 years since the concept of 'patient reported outcomes' gained widespread recognition within the medical community as the gold standard for measuring the impact of new treatments on different aspects of patients' quality of life. Yet gathering information from patients is still not a routine part of new drug development and approval.

It remains more of an add-on, if it happens at all – something done after a new drug has already been approved, as part of the health technology assessment (HTA) process, or within the academic community to help inform clinical decision making.

Integrating patient reported outcomes (PRO) measures into clinical trials protocols, alongside safety and efficacy metrics, could ensure a stronger focus on outcomes that matter most to patients at every stage of the clinical drug development, regulatory approval and health technology assessment (HTA) processes. It would also speed up patient access to new treatments. So why is it not happening?

To address that question, last year the European regulators, the EMA, and Europe's largest not-for-profit independent cancer clinical research organisation, the EORTC, brought together pharma, advocates, clinical researchers, and statisticians at a workshop to exchange perspectives on problems and solutions.

Too Many Questions

Issues around getting agreement among stakeholders on what questions to ask, and how and when to ask them, were recognised as one of the key challenges hampering more effective use of PROs in drug development. "What matters to patients is not exactly what matters to clinicians or regulators...

and what matters to HTA is what matters to payers," is how Bettina Ryll, founder of the melanoma patient advocate group MPNE, summarised the problem.

If every stakeholder wants patients in trials to report back on their own set of questions, asked in their preferred format, it would put an intolerable burden on patients and those tasked with collecting the information; it would take forever; and the resulting data would be fragmentary, confusing and impossible to analyse.

"The first step would be to standardise all types of PROs used in the first place by stakeholders," suggested Silene Ten Seldam, from Myeloma Patients Europe. Madeline Pe, who has been leading the EORTC's work on quality-of-life and PRO tools, argued that this could be done by identifying overlapping quality-of-life concepts to work out, "which domains need to be collected across all stakeholders."

Joseph Cappelleri, Executive Director of Biostatistics at Pfizer, highlighted the extent to which stakeholders would need to maximise opportunities to talk together and actively collaborate, adding that it would be quite a challenge, because each of the actors tends to work within their own space, generating different questions to ask, and using different kinds of PRO tools for their assessment.

As he pointed out, developing a new drug is a dynamic process that requires "flexibility and versatility."

The question would be how to extend that to embrace an interdisciplinary perspective.

"Every time we should consider going back to the drawing board, involving patients in the discussion, and asking what they want to measure"

The importance of talking with regulatory and HTA decision makers at an early stage about the scope of the study, and which PROs would be measured, is certainly one way to facilitate interpretable and clinically meaningful results, noted Francesco Pignatti, Scientific Adviser for Oncology at the EMA.

He argued that trialists need to be more systematic in thinking about quality-of-life aspects and in designing clinical trials that can provide the relevant data.

"There is sometimes the feeling of a copy-and-paste approach to clinical protocols," he commented. "Every time we should consider going back to the drawing board, involving patients in the discussion and asking their views on what outcomes we should measure."

Poor Relevance

Lack of appropriate measuring tools was seen as another factor behind the very slow adoption of PRO measurement in clinical trials. Over the past 40 years, significant efforts have been made to develop robust and validated questionnaires to measure quality of life and the impact of different types of toxicities and symptoms.

These include EuroQol EQ-5D-3L/5L, the EORTC's QLQ-C30, and the PRO-CTCAE, developed by the National Cancer Institute in the US, as well as additional tools developed for use in specific diseases.

However, while they have many uses, they have proven to be blunt instruments for exploring very specific issues for patients that may be associated with particular types of medication, or particular priorities for a specific patient population.

The limited relevance of the data elicited by these 'off-the-peg' questionnaires was highlighted as one important reason why quality-of-life data are so rarely mentioned in the Summary of Product Characteristics that the EMA publishes for new drugs it has approved.

The limited relevance of data elicited by these 'off-the-peg' questionnaires was highlighted as one important reason why quality-of-life data are so rarely mentioned Speaking to a current issue for the myeloma patient community, Ten Seldam said, "We don't have any tools that have specifically been developed or adapted for use among myeloma patients receiving some of the newer immunotherapies, such as CAR-T therapy or bispecific antibody treatments, that have a very different side effect profile to other therapies."

The option of developing and validating a new tool designed specifically to capture that data could take a very long time, she explained, so Myeloma Patients Europe is now focusing on research to try to understand how to improve the consistency of data currently collected for these newer therapies using existing PRO tools.

Poor Methodology

The issues with consistency that Ten Seldam and colleagues are trying to tackle are part of a wider problem around lack of standardisation and poor methodology of many PRO tools, which undermine efforts to promote them as scientifically robust endpoints.

Myeloma Patients Europe is one of a group of European patient advocacy organisations that have been involved in SISAQOL (Setting International Standards in Analysing PRO and Quality Of Life endpoints data) – a five-year project funded by the EU Innovative Medicines Initiative that aims to improve the design and handling of PRO data, with an emphasis on robust methodology, with calls for clearer guidelines, greater transparency, and proper training for all.

The hope is that the SISAQOL recommendations and framework can be used "as a common language across stakeholders to facilitate communication and standardisation of PROs in cancer clinical trials," giving PRO data the scientific credibility to be routinely reported alongside other efficacy and safety data.

Paul Kluetz, Deputy Director, Oncology Center

of Excellence, at the US regulatory body, the FDA, cautioned against trying to use PRO data to show statistically comparative benefit, in the way that is done for instance with survival endpoints. He suggested they should be seen more as a "supplementary piece of information on safety and tolerability".

The hope is that the SISAQOL recommendations and framework can be used 'as a common language across stakeholders'

Pignatti went further, questioning the traditional approach of evaluating impact on quality of life as something separate from – and invariably secondary to – survival.

"Dichotomising survival and quality of life, as if they are two separated things, or discussing these endpoints in isolation, doesn't provide the complete picture," he commented, adding that, "Life in a good or poor health state is valued very differently."

He argued that drug development should be systematically informed by asking patients what endpoints are most relevant for them, using patient preference studies if appropriate.

That information needs to be available before the trial begins, he stressed, so that the trial design can be informed accordingly.

Too Time-Consuming

Gathering and processing PRO data is labourintensive work. "Someone has to report these PROs, and someone has to collect the reports, and neither patients nor clinicians tend to be keen on either," noted Ryll, adding that this reluctance often results in high rates of missing data, which may be an additional factor deterring triallists from making wider use of PROs.

More attention should be paid to giving patients an incentive to provide the information requested of them, rather than expecting them to collaborate through a sense of altruism, or a moral obligation to support research efforts, she said.

Patients in trials have an immediate interest in hearing about others' experiences, so one incentive might be simply to ensure that the overall results of the PRO responses that the patients contribute to are fed back to them as quickly as possible.

"More attention should be paid to giving patients an incentive to provide the information requested of them"

"If you want value for you, if you provide value for those who are completing the forms, then you can learn as much as you want on the backside. This is how Facebook makes money, this is how point schemes work in supermarkets. Everyone else does it that way. Why shouldn't it work for PROs?" she asked.

Next Steps

Summing up the discussion, Pignatti concluded, "We are all realising that there is often no perfect solution when there are multiple objectives... We need to sit together and say: What are our key objectives and requirements here?

What do we achieve by prioritising one or other endpoint? How should we do this in a way that will as best as possible fulfil the requirements of the regulators, the objectives of patients, clinicians, and health policy makers?"

Teasing out exactly who needs what kind of data, and finding common ground, will be high on the stakeholders' wish list, which is set to be published in a paper in Lancet Oncology, summarising the insights from EMA-EORTC workshop.

Reaching agreement on the need to do this was an important first step. The next step will be to make it happen.





I grew up around a lot of physicians," begins Adrian Gottschalk, President and CEO of Foghorn Therapeutics, a biotech company redefining how we understand and treat complex diseases by targeting the chromatin regulatory system. "My late father was a professor of orthopedic surgery at the medical school in Dallas, Texas. Science and medicine were always around me. I even studied biochemistry as an undergrad and was accepted to medical school."

But life, as it often does, nudged him down an unexpected path.

"I turned down med school in the 90s. I was

concerned about the future of medicine in the U.S. at the time, thinking it might become too regulated. Instead, I went into IT consulting with Price Waterhouse — and that's where I met my wife. So, I'd say it worked out."

Even in software, he found echoes of biology. "Programming felt similar to biochemistry. Both are about systems, feedback loops, regulation. It's all design and logic."

But the work — mainly in upstream oil and gas — left him unfulfilled.

"It didn't feel like I was helping people. I needed

purpose. So I applied to graduate school in New England and did a dual degree in business and science. That decision was about reconnecting with what I loved: science that serves humanity."

The Biogen Years: Where **Principles** Were Forged

That journey led him to Biogen, where he would spend the next 13 years, rising through leadership roles and absorbing lessons that would shape the rest of his career.

"I interned at Biogen in 2002 while in business school. I remember asking Bill Anderson — who's now the CEO of Bayer — if there was a formal training program. He said no. 'This place is more like choose-your-own-adventure,' he told me. That resonated."

At Biogen, Gottschalk says, he didn't just build a career — he found a platform for growth.

"It was big enough to have resources, but small enough to carve your own path. I worked with great people and learned some critical lessons." He pauses, then counts them off.

"One: It takes a long time to build something great — but a poor culture or bad leadership can destroy it fast. Two: Your people are your only sustainable advantage. Science matters, but people make it work. Three: Follow the data — always. Biotech companies must be relentlessly data-driven. Four: Plan clinical trials properly. Don't cut corners. Define your patient population clearly. Five: Plan for obsolescence, even when you're winning. I remember prepping for the post-patent future of Tecfidera while we were still launching it. Six: Stay humble. The moment you become arrogant in this business, you lose sight of what matters. Seven: It's not a solo mission. Success in biotech always takes a team."

A New Chapter: Building Foghorn from the Ground Up

Leaving Biogen wasn't easy — but necessary.

"I could see the company struggling, mostly due

to cultural shifts. I wanted to be part of building something better, from the ground up. That's when I came across Foghorn Therapeutics."

It was the science that caught his attention first.

"I remember reading about chromatin regulation and thinking, 'If this holds true, it could transform not just oncology, but other disease areas too.' We're talking about fundamental biology — gene expression, timing, sequencing. It's like cellular air traffic control."

He lights up, drawing a metaphor.

"Imagine planes needing exact timing and coordination to land safely. Now imagine your genome needing the same coordination to express the right genes at the right time. If that system fails, you get disease. What we're doing at Foghorn is restoring that coordination."

At the time, Foghorn was a 12-person startup.

"I wanted a place where I could help build the culture from day one. You can't reshape culture at a 5,000-person company. But here, we could set the tone. That was exciting."



Chromatin Regulation: Cracking Biology's Toughest Code

What makes Foghorn's work so revolutionary is its focus on the chromatin regulatory system — a field both fundamental and previously untouchable.

"These protein complexes we work on — like SWI/SNF — are enormous. The BAF complex, for instance, is over 1.5 megadaltons. That's like trying to drug a battleship."

So why now?

ISSUE 103 05 / 2025

"Historically, no one had the tools to study these complexes in context. Many of the proteins are 90% similar to their family members — paralogues — which makes selective targeting hard."

Foghorn changed that.

"Our scientific founders industrialized how to produce, purify, and assay these massive complexes. That gave us an edge. We built the capabilities from scratch — recombinant protein production, functional assays, structural biology. It's a platform built on rigor."

He emphasizes one word: context.

"Context is everything. You can't understand gene regulation in fragments. You need to study it in its native form — its real biological context. That's how we've made breakthroughs."

Protein degradation has also been a key part of their strategy.

"Once we mastered studying the system, we could design therapeutics that degrade malfunctioning proteins. That's opened up a whole new world."

Leading Through Service: A Philosophy Rooted in Humility

Gottschalk's leadership style is grounded in a concept he learned early: noblesse oblige.

"In college, I had to write an essay about it — this idea that those in power have a duty to serve. That shaped how I lead: servant leadership. My role isn't to be the most important person. It's to enable the team."

He outlines four core principles:

"Integrity. Trust. Accountability. Responsibility. The last two are different — accountability is your job; responsibility is helping others even when it's not."

When asked how he balances short-term execution with long-term strategy, he rejects the idea of a trade-off.

"They're inextricably linked. Strategy drives tactics.

But tactics teach you if the strategy still makes sense. It's a constant feedback loop."

Managing Risk, Sustaining Ambition

In a volatile biotech landscape, Gottschalk is acutely aware of the need for balance.

"Ambition will always outpace resources — especially in small biotech. So we focus hard on what actually creates value, and we stop what doesn't. You have to be disciplined."

Foghorn is financially sound with runway into 2027, but he still sees partnerships as key.

"We share risk. It means sharing upside too. But that's how you survive and scale. Strategic alliances are critical."

Culture of Innovation: Making Failure Safe

So how do you build a culture where scientists dare to fail?

"By creating psychological safety," he says firmly. "We've worked hard on that here. Anyone can challenge anyone else. It's not hierarchical. It's about ideas."

Failure isn't just tolerated — it's essential.

"When you work on cutting-edge science, most things won't work. But you can't punish people for failing on bold ideas. That's how innovation dies."

He mentions the book No Rules Rules: Netflix and the Culture of Reinvention.

"If you hire the right people, you don't need a lot of rules. But structure still matters. It's about balance."

Academic Foundations: The **DNA** of Innovation

Gottschalk's educational journey shaped his worldview.

"Texas A&M gave me technical rigor — my foundation in biochemistry. Then I did the dual degree at MIT Sloan and the Harvard-MIT Biomedical Enterprise Program. That's where everything clicked."

The program's focus on integration — science, medicine, and business — was formative.

"Biotech needs all three. Great science that doesn't reach patients is wasted. Great business with no scientific rigor is meaningless. That program gave me a common language across all disciplines."

He credits MIT's culture of innovation for sharpening his entrepreneurial instincts.

"I studied entrepreneurship and thought I'd go to a small company. But a professor, Stanley Lapidus — the founder of Exact Sciences — told me, 'Go to a big company first. Learn what works and what doesn't.' That's why I joined Biogen."

If I Could Tell My Younger Self...

Looking back, what advice would he give his younger self?

"Take time to enjoy the journey. I'm very actionoriented. I hit a milestone and immediately move to the next thing. I'd tell myself to stop and smell the roses. Celebrate more."

On Mentors and Role Models

"My father was my first mentor," Gottschalk says, emotion flickering behind his words. "I learned so much from him."

He also names Faheem Hasnain, a former Biogen leader, as a key influence.

"I learned how to lead with compassion from Faheem. He showed me that leadership is about lifting people up."

Two retired U.S. Marine Corps Top Gun pilots — David Robinson and Patrick Guinee — also shaped his leadership approach.

"People assume the military is rigid. These guys

are the opposite: creative, team-first, deeply reflective. They deeply influenced how I think about leadership."

Another mentor is Dan Mangelsdorf, a leadership coach and friend.

"All the good in me, they helped shape. The rest? That's on me."

Books That Changed His Thinking

He shares four titles that left a lasting impression:

- The Fearless Organization by Amy Edmondson – "Psychological safety in action."
- The Culture Code by Daniel Coyle "A blueprint for great organizational cultures."
- Extreme Ownership by Jocko Willink and Leif Babin – "Before blaming others, look in the mirror."
- Creativity, Inc. by Ed Catmull "How Pixar built a culture of fearless innovation."

And Who Should We Interview Next?

Gottschalk pauses, then smiles.

"This might be a long shot, but I'd be curious to hear from Vivek Ramaswamy. Say what you will about his politics — he's built multiple biotech companies. That could be a fascinating story."

A One-Sentence Bio

Finally, how would he describe himself?

"Caring, committed, focused," he says. "Adrian Gottschalk is an experienced biotech leader who puts people first and mission before self in an attempt to make a difference for his fellow human beings."

After spending time with him, it's hard to argue with that

Janet Fricker

Strategies Needed to Prioritise Screening in Survivors of Childhood Cancer



Survivors of childhood cancers experience accelerated onset of ageing-related diseases, regardless of prior radiation exposure. The simulation modelling study, published in Jama Oncology, online March 20, found that chronic health conditions developed 10 to 20 years earlier than expected and risks were up to three times higher than found in the general population.

"Our findings underscore the importance of prioritising cancer and CVD [cardiovascular disease] prevention and screening for survivors decades earlier than for the general population, regardless of diagnosis or prior radiation exposure," write the authors, led by Jennifer Yeh, from Boston Children's Hospital, Harvard Medical School. The study, they add, is the first to provide an overview of the risk of multiple conditions linked to childhood cancer treatment (previous studies have focused on single outcomes, such as heart failure).

In the US alone, approximately half a million individuals have survived childhood cancer, and consequently carry a substantial burden of morbidity related to chemotherapy and/or radiation. The consequence can be premature death, resulting in a significant gap in life expectancy compared with the general population. Hypotheses suggest exposure to chemotherapy and radiotherapy may induce biologic/ genetic changes that contribute towards accelerated ageing, including chromosomal aberrations, mutations, clonal haematopoiesis, telomere shortening, epigenetic alterations, and mitochondrial dysfunction.

While cohort studies have estimated risks for individual chronic health conditions in early adulthood, the 'trajectory' into middle and late adulthood remains largely unknown as only a small per centage of participants are now older than 40. For the current study, Yeh and colleagues estimate

the lifetime risk of eight treatment-related chronic health conditions – subsequent neoplasms (breast, colorectal, glial tumours, and sarcoma) and cardiovascular conditions (heart failure, myocardial infarction, stroke, and valvular disease) in survivors of childhood cancer and compared them to the general population.

The team did this by developing the COMPASS model which stimulates the clinical course of survivorship, including late recurrence of childhood cancers, chronic health condition risks and treatment-related excess mortality. Treatmentrelated risks were based on data from the Childhood Cancer Survivor Study (CCSS), a multiinstitutional, prospectively followed-up cohort study of five-year survivors diagnosed at 31 North America institutions which included approximately 20% of US childhood cancer survivors. The analysis, which projected lifelong outcomes beyond the CCSS follow-up period, included data from 22,585 participants diagnosed with cancer before the age of 21 years who were treated between January 1970 and December 1999 and survived five or more vears post diagnosis. All-cause and cause-specific mortality data from the US National Death Index was used from 25 institutions, with data from a further five sites reserved for validation.

Results showed that while 20% of individuals in the general population developed at least one health condition by age 65, among survivors of childhood cancers this threshold was reached by age 47.3 years (representing a 17.7 year acceleration of disease onset).

By the time survivors reached the age of 65, 54.5% were projected to develop at least one condition, indicating a 2.7 fold higher relative risk and a 34.2% higher absolute excess risk than the general population.

Furthermore, 45.6% of survivors of childhood cancers were projected to die by age 65, versus 15% of the general population (three times higher). Compared with the general population, survivors reaching age 40 had a 6.2 fold higher risk of developing a new condition within 10 years.

Risks for those treated with radiation therapy were higher (22 years earlier onset, 37.3% excess risk); but still elevated for those without radiation

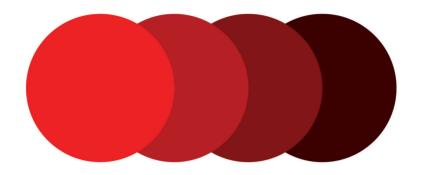
exposure (13.5 years earlier onset, 31% excess risk).

"By stimulating the clinical course of multiple CHCs [chronic health conditions], we captured the complex nature of frailty or snowballing of risks, which was prominent among survivors of all diagnoses. Consequently, survivors will have considerably greater health care needs as middleaged adults, increasing further as they age," conclude the authors.

In future studies the team plan to examine how chemotherapy modifications, including dose variations in alkylating agents, anthracyclines, and platinum-based compounds, affect long-term outcomes. They are also using simulation modelling to look at potential costs and benefits of prevention strategies, including studying the impact of breast cancer prevention and colon cancer screening interventions.

In an accompanying editorial Smita Bhatia (University of Alabama at Birmingham) and F. Lennie Wong (City of Hope in Duarte, California), write, "The studydemonstrated evidence for premature occurrence and higher risk of a select group of chronic health conditions in survivors of childhood cancer diagnosed before 1970 and 1999, reinforcing the need for preventive strategies such as screening for the diseases at an earlier age, to ensure early detection and appropriate management."

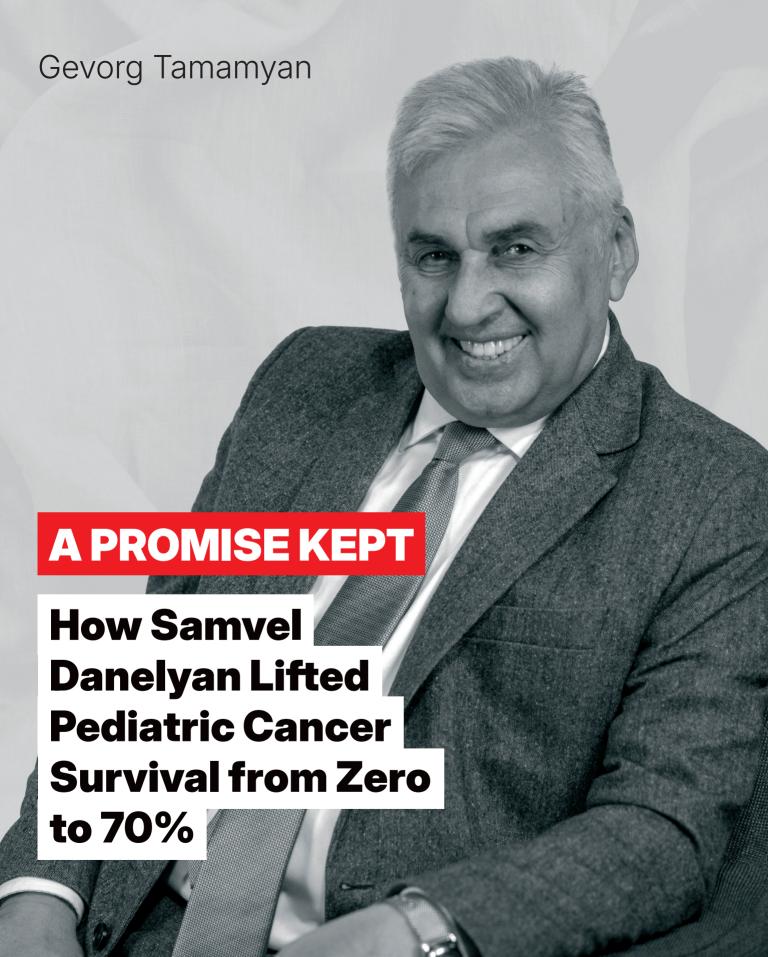
Although lumping eight conditions together and simulating lifetime risk provides an overview of the magnitude of the problem, they add, it does little to guide clinicians as to when they should start the screening, for what conditions, and in which subgroups of patients. It is unclear, they write, why these particular eight chronic health conditions were selected, and why other conditions (such as cognitive impairment, cardiac dysrhythmia, pulmonary compromise, gonadal dysfunction, diabetes, hypertension, dyslipidaemia, and frailty) were excluded. Other limitations identified by the editorialists include the cohort only extending to 1999 (leading to nearly 25 years of contemporary treatments not accounted for) and no consideration of modifiable risk factors (smoking, alcohol, and physical activity) or cardiovascular risk factors (diabetes, hypertension, and dyslipidaemia).



HEMOSTASIS TODAY

Your Daily Updates on Hemostasis and Thrombosis

https://hemostasistoday.com



In a country bruised by war, in a hospital crumbling under the weight of poverty and silence, one man made an impossible promise — and kept it.

Samvel Danelyan's story is not the story of easy heroes. It is a story of grit without applause, of stubborn hope carved into stone. A priest's son, raised on banned books and whispered prayers in Soviet Union, Dr. Danelyan fought not for fame or fortune but for the lives of children most of the world had already counted out.

Against broken walls, against rats, against the soft cruelty of bureaucracy and the brutal cold of neglect, he built a new future — one transfusion, one bone marrow transplant, one saved child at a time.

Born of Faith, Shaped by Books, Driven by Purpose

Samvel Danelyan was born in Tbilisi, a wonderful, warm city that remains dear to him to this day. "I grew up in a spiritual household; my father was a priest. Being raised in that environment naturally had a profound influence on me, especially considering that at the time, in the Soviet Union, the church was not welcomed — guite the opposite."

His decision to become a doctor was shaped by the books he read. "I loved Remarque's works — 'Arch of Triumph' was my table book. Bulgakov and Paruyr Sevak also played key roles in shaping my path. Medicine, after all, is about engaging with people, about healing fellow human beings."

After finishing school in Tbilisi, he moved to Yerevan to attend medical university. After graduating, he went to work in the regions. "Three years in Charentsavan, a small town" he said, "while striving for further training in larger, more developed centers. At that time, Moscow was considered the best in the region."

He moved to Moscow and lived there for six years. "Life was difficult," he said, "but I was surrounded

by brilliant people and mentors who left an indelible mark on my life. As I rotated through different departments, I realized that pediatric hematology and oncology were my true callings. My mentors in Moscow played a crucial role in welcoming me like family."

He returned to Armenia in 1994. "At that time, there was virtually nothing here. Doctors were trying to treat children, but there were no medications."

Everyone said: This man is crazy

He began his own search.

"I quickly realized that to establish real treatment programs, first and foremost, you needed funding. Chemotherapy was extremely expensive. Everyone said, 'This man is crazy.' After all, chemotherapy doesn't cost five dollars — or even five hundred. Each course of treatment costs thousands of dollars."

"At night, lying awake, I often thought maybe they were right — where could I possibly get that kind of money? But I was young, ambitious, and a maximalist."

He recalled the fathers who stayed with their children at the hospital because of the wartime conditions and cold. "The hospital, at least, was a little warm. In the mornings, the men would go shave without shirts on. I would reprimand them, saying, 'It's shameful—put on a shirt. There are young women here.' And they would reply, 'Why don't you solve the rat and cockroach problem first?' And they were right."

He started looking for help. "I went to all the provincial governors, asking each to renovate just one hospital room for the children from their regions. It would only cost six or seven hundred dollars to properly equip a room. We had about forty children with leukemia a year. But every single governor refused."

"I didn't give up. I thought, 'Fine, I'll turn to the oligarchs.' I spent hours in their offices, waiting, thinking, 'What am I doing here?' But then I'd remind



myself, 'I'm not doing this for me. I'm doing it for the children.' If it didn't work, I'd just get a one-way ticket back to Moscow and find work again. " But that, too, led nowhere.

"I started writing letters to various people."

His next target was the ambassadors. One of the first was the German ambassador to Armenia — Norbert Heinze.

"He changed the course of my life. I owe him a debt of gratitude I can never repay. A strong, remarkable man. When I approached him, he said he would try to help. He visited our ward, saw the grim conditions, and promised his support."

Years later, Heinze admitted that initially, he thought he would simply donate a small portion of his salary. "But Friedrichs — a German medical attaché in Moscow — warned him that it would involve large sums of money. They were concerned: given the unsanitary conditions, would it even be possible to implement the BFM protocol? And could the funds be used properly?"

"When I realized my chance was about to collapse again, I wrote to my mentor and former department head in Moscow — the world-known Alexander Rumyantsev — asking him for just one thing: 'Please tell Friedrichs that I am a trustworthy person. Nothing else "

Again, he thought about buying a one-way ticket to Moscow

The ambassador sent a hygienist to inspect the hospital. "Unfortunately, the hygienist— concluded that it was impossible to conduct any proper treatment under those conditions. Another devastating blow."

"I confronted him, saying, 'You've destroyed months of my work. These conditions are repairable — repairs depend on funding. If there's money, there'll be renovations, and I promise we can organize proper treatment.' I was only thirty-two."

The hygienist replied: "Germans don't tolerate deceit. I recorded what I saw. If you renovate, I'll return and reassess. Until then, everything remains theoretical." "And he was right," Samvel admitted.

Again, he thought about buying a ticket to Moscow. "My children were small, winter was brutal. What was I to do?"

He went back to the ambassador. Heinze said, "I'm a diplomat, not a philanthropist. I'm here on a diplomatic mission, not humanitarian aid. There are plenty of people in Armenia driving expensive cars — ask them."

He had realized things were heading into a dead end.

One Child Saved, Thousands to Follow

Fortunately, the ambassador had a brilliant aide — Levon Sargsyan.

"A phenomenal man. Next to him, I felt barely literate. Levon helped me immensely, advising me on how to communicate more effectively. At that time, I had no money in my pocket. My monthly salary was five dollars. We were barely surviving."

Levon spoke to the ambassador again. The ambassador returned to the hospital and said, "I will speak to only one person — you. I don't need an audience. We'll send a bone marrow sample to see if your diagnostics are accurate."

"I was thrilled," Dr. Danelyan said. "We had a fouryear-old patient with acute myeloblastic leukemia essentially a death sentence. I managed to cure him, sourcing medicines myself."

Around that time, he saw in the newspaper that Klaus Kinkel, a prominent German figure, would visit Yerevan. "I seized the opportunity," he said.

The media attention exploded. "Young doctors in Armenia cure myeloblastic leukemia!" The story was everywhere. Journalists came, visited our patient's home, and witnessed the abysmal living conditions firsthand.

"Kinkel invited the child and his mother to Berlin. That was a turning point."

His position solidified. He passed the test — and he had saved a child.

"Now it was time for the next stages of my plan."

A team of journalists from Schwäbische Zeitung visited.

"Their editor-in-chief, Hanns Funk — a legendary

journalist — later became the namesake of an award we now give annually. He wrote an article about us."

At that time, the paper had a circulation of half a million — read by two million people daily. "We needed that kind of exposure," Dr. Danelyan said.

The plan that WORKED

In 2005, he designed a plan: how the aid would be delivered and used.

"If money arrived here, it would be seized; I was defenseless. But if the medications arrived directly? That could work."

He instinctively found solutions to all logistical issues.

"We managed to raise one million German marks — a staggering sum back then. Heinze was thrilled, saying, 'This will last you until retirement.' Little did he know, those funds are still in use today."

They agreed: medicines would arrive at the embassy. Dr. Danelyan would collect them, distribute them, record everything by patient name, and reorder as needed. Everything operated like clockwork.

"We provided 100% of the necessary medications — all European-made. I submitted biannual reports."

He refused to attend conferences at first. "I'd say, 'Better to buy more vincristine for the children than spend on travel."

But then a famous German oncologist told him: "Without attending international conferences, without hearing new research findings, you'd remain a village doctor."

"I needed to 'waste' that money for the sake of quality."

They sent all their doctors for further training. Pediatric cancer survival rose from one or two cases to seventy percent.

"Later, my students — wonderful doctors — came along. Amazing people. They would do any country proud. This is my greatest achievement — something I am truly proud of."

He owes a tremendous debt to the entire staff — nurses and doctors alike.

The Job Is Temporary. The Mission Is Forever

Later, he left Hematology Center. "It became impossible to work with the new director. He offered me an administrative role — paperwork. But I am a doctor, not a bureaucrat."

Yet the Germans insisted they would continue working with him. He kept collecting medications from the Embassy to ensure children never lacked treatment.

He spent two years unemployed. "It was devastating. Not just financially — I felt rejected. My father said, 'You just can't find common ground with people."

But luck had always been on his side. "If a hailstorm came, somehow my car would always be spared."

He went to Gohar Kyalyan, back then the Rector of Yerevan State Medical University. She supported him. He became an associate professor at Muratsan Hospital's Pediatrics department.

"But by then, I had outgrown it — it felt too small for me."

One day, the Rector called him in and said, "I've decided to appoint you as the chairman of the department."

He thought it would be pediatrics or hematology. She said, "Neither — oncology."

"I told her, it's going to be difficult for me, because

I was practicing only the hematologic part of oncology, but given all the support she has given to me I will accept that role."

But she said: "This is not charity — it's part of a series of good deeds. Otherwise, you'd remain an associate professor forever."

He agreed. He gathered a phenomenal team. Their department became one of the leading ones in the university.

In 2011 the Rector changed, and again a few years later he left. "I couldn't find common ground with the new leadership."

He moved to the United States.

Leading the

Change

In 2018, he returned. There was a revolution in Armenia. "I thought, finally, I can do my real work. Salaries would rise. Corruption would end."

The new leadership called him, asking him to stay. They offered him to be the director of the Hematology Center.

He went to the Hematology Center and he changed a lot. They established the Pediatric Cancer and Blood Disorders Center of Armenia, merging all the existing facilities in the country. They expanded— new partnerships, training programs, staff, facilities. They now perform allogeneic bone marrow transplants.

Creating Teams That Win

When asked how he builds successful teams, he answered:

"First, work must be paramount. A person should be valued for their work ethic, dedication, intelligence, and curiosity — not for their clothes or watch brands."

"When hiring a new doctor or nurse, I always asked, 'What are you currently reading — professional or literary?' If they hesitated too long, likely they weren't reading anything — a red flag for me."

"I'd ask, 'When was the last time you went to the theater? What city have you visited recently? What did you enjoy? What film did you watch?' These little things tell you a lot."

"Second, nothing shapes a child like a parent's example. I always tried to set an example for the young doctors. I never left a young on-call doctor alone with a critically ill patient. I was always by their side — at 5 AM, at 2 AM.

"I also called on weekends. My wife would ask, 'Why do you call them? Good or bad, you'll go anyway.' And I always went. And when I'd arrive at the hospital and see my staff waiting for me — that was the greatest reward."

And finally, when asked the key to his success, Samvel Danielyan gave one word: "Work."

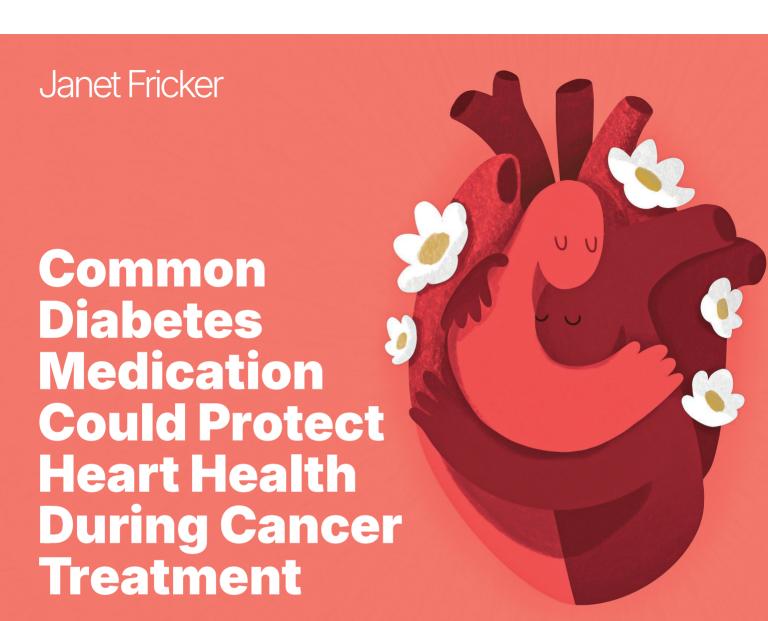
The story of Samvel Danielyan is not one of gold medals or grand speeches. It is the story of a man who simply refused to give up.

And because he did not give up, thousands of children lived.

Dr. Samvel Danelyan is the recipient of the Elfrieda-Albert-Foundation Lifetime Achievement Award. "With this prestigious award, the foundation wants to honor 34 years of professional work dedicated to the children and adolescents with cancer in Armenia"

Prof. Dr. Paul-Gerhardt Schlegel, from University Children's Hospital of Wuerzburg, states in his invitation for the ceremony. "Dr. Danielyan's vision and dedication has not only established a center of excellence for pediatric oncology in Yerevan, but most notably has trained and formed a wonderful team of professionals who will carry this vision into the future."





Sodium-glucose cotransporter 2 (SGLT2) inhibitors, a common type of diabetes medication, may protect the heart during and after cancer treatment. The systematic review and meta-analysis, published in European Journal of Preventive Cardiology, 6 March, shows that SGLT2 inhibitors halve the risk of hospitalisation due to heart failure and reduce the number of new heart failure cases by more than two thirds.

"While multiple large-scale trials have established SGLT2 inhibitors' cardioprotective effects in heart

failure populations, our analysis uniquely quantifies their efficacy specifically within oncology cohorts exposed to cardiotoxic therapy," Vassilios Vassiliou, the joint senior author, tells Cancerworld.

"There was a particularly robust statistical signal in anthracycline-treated breast cancer populations, indicating that these patients are likely to benefit the most."

The hope, adds Vassiliou, is that SGLT2 inhibitors will in future be prescribed routinely for cancer

patients receiving cardio-metabolic toxic chemotherapeutic agents.

Although chemotherapy indisputably improves cancer patient outcomes, some protocols are cardiotoxic, increasing cardiovascular related mortality and morbidity. Studies suggest that up to 20% of cancer patients who have had chemotherapy go on to develop heart problems, with up to 10% suffering heart failure. In addition to anthracycline chemotherapy regimens, high-dose cyclophosphamides, trastuzumab, and tyrosine kinase inhibitors also cause cardiac dysfunction. Such agents induce cancer therapy-related cardiac dysfunction through mechanisms such as cellular hypertrophy, extracellular matrix restructuring, impaired cardiac muscle contraction and hyperinflammation.

Recently, several publications have suggested that SGLT2 inhibitors (used for type 2 diabetes, heart failure, and chronic kidney disease) significantly reduce heart failure hospitalisation and all-cause mortality across a diverse group of patients, including those without diabetes.

For the current meta-analysis, Vasiliki Tsampasian and Vassilios Vassiliou, from Norwich Medical School, University of East Anglia, UK, and colleagues, set out to determine the impact of SGLT2 inhibitors on cardiovascular outcomes in cancer patients treated with known cardiometabolic toxic chemotherapeutic agents.

Altogether, the team screened 1,889 records from PubMed, Embase, MEDLINE & Cochrane Library, identifying 13 studies (including 88,273 patients) for the final analysis.

"Patients in these observational cohorts were predominantly receiving SGLT2 inhibitors for established indications – primarily type 2 diabetes mellitus and, less frequently, chronic kidney disease or existing heart failure – rather than being prospectively prescribed for primary cardioprotection," explains Vassiliou.

The study encompassed heterogenous treatment

patterns, including patients who had been taking SGLT2 inhibitors before cancer diagnosis, as well as those who started taking them during or after active cancer treatment, . The SGLT2 inhibitors used by patients in the study included (but were not limited to) canagliflozin, dapagliflozin, empagliflozin, and ertugliflozin.

"This heterogeneity was deliberately included in our eligibility criteria to comprehensively capture all available evidence on potential cardioprotection," says Vassiliou.

Results during a 29.8-month duration of follow-up showed:

- SGLT2 inhibitor treatment was associated with a significant reduction in heart failure hospitalisation risk (RR=0.49, 95%CI 0.36–0.66). The number needed to treat (NTT) to prevent one heart failure hospitalisation was 39. Notably, the cardioprotective effects of SGLT2 inhibitor treatment were most pronounced in breast cancer patients receiving anthracyclines (≥50% of patients), with a 99% reduction in heart failure hospitalisation risk (RR=0.0085, 95%CI 0.0001–0.2645, P=0.0081).
- SGLT2 inhibitor treatment was associated with a significant reduction in new heart failure risk (RR=0.29, 95%CI 0.10-0.87). The NNT to prevent one new heart failure event was 15.
- SGLT2 inhibitor treatment was associated with a significant reduction in all-cause mortality (RR=0.45, 95%Cl 0.35-0.59). The NNT to prevent one death was 4.
- SGLT2 inhibitor treatment was associated with a significant reduction in atrial fibrillation/ flutter (RR=0.38, 95%CI 0.26-0.56). The NNT to prevent one event was 26.
- No significant difference was found in the risk of acute myocardial infarction between patients treated with an SGLT2 inhibitor and controls.

 Regarding adverse events, sepsis rates, urinary tract infections and neutropenic fever were less frequent in the SGLT2 inhibitor group than the control group.

"This meta-analysis represents the first largescale evidence synthesis demonstrating a significant association between a pharmacological intervention and reduction in clinically meaningful heart failure endpoints across a diverse oncology population," says Vassiliou.

"While previous trials have examined older drug classes (ACE inhibitors, ARBs, beta-blockers), they predominantly focused on surrogate endpoints like left ventricular ejection fraction decline rather than clinical heart failure events and their effects were neutral or only applicable for a small subset of patients."

By off-setting cardiotoxic effects, he adds, SGLT2 inhibitors not only offer the potential to improve cardiovascular outcomes but also enable sustained administration of optimal cancer therapy.

The model for integrating SGLT2 inhibitors into cancer treatment, Vassiliou suggests, could be for patients to start taking the inhibitors 7–14 days prior to commencing treatment.

SGLT2 inhibitors are particularly important for patients receiving anthracycline-based chemotherapy (especially at cumulative doxorubicin-equivalent doses >250mg/m2); sequential or concurrent anthracycline/trastuzumab regimens; or combination regimens with additive cardiotoxic potential.

The approach would be "relatively cheap", Vassiliou adds, as SGLT2 inhibitors are already off-patent in many countries.

In an accompanying editorial, Jennifer Cautela (Aix-Marseille University, France) and Joachim Alexandre (Caen-Normandy University Hospital, France) comment on limitations of the study, including use of observational data (no randomised controlled trials); significant heterogeneity in cancer types, treatment regimens, follow-up

durations, and cardiotoxicity definitions; and reliance on surrogate markers. "Despite these limitations, SGLT2i [inhibitors] appear to be the first really promising pharmacological candidate for cardio protection in cancer patient," write Cautela and Alexandre.

"Moreover, these findings are even more striking, given that the risk reduction was observed despite patients on SGLT2i likely being at high risk of cardiotoxicity, due to conditions for which they were prescribed these drugs, most often diabetes or chronic kidney disease.

This suggests that SGLT2i are not only effective but also particularly beneficial in a high-risk population, reinforcing their potential as a cardioprotective strategy in oncology."

Currently two ongoing trials – PROTECT and SCARA-B – are looking to provide insights into the cardioprotective effects of SGLT2 inhibitors in cancer patients.

The PROTECT trial (NCT06341842) is a randomised controlled evaluation of the SGLT2 inhibitor dapagliflozin versus placebo for preventing chemotherapy-induced cardiotoxicity in breast cancer patients treated with anthracycline-based chemotherapy (with or without trastuzumab).

"PROTECT will provide Level 1 evidence regarding efficacy, optimal timing, and safety profile of SGLT2 inhibition specifically for cardioprotection in oncology," explains Vassiliou.

Complementarily, SCARA-B (NCT06443645) will elucidate underlying mechanisms through prospective evaluation of SGLT2 expression, inflammatory biomarkers, oxidative stress parameters, and cardiomyocyte energetics in breast cancer patients receiving anthracyclines.

"This mechanistic insight will strengthen the biological plausibility of our meta-analysis findings and potentially identify predictive biomarkers for SGLT2 inhibitor response," says Vassiliou.

Esther Nakkazi

Albinism and Skin Cancer in Africa: Tackling the Prevention Needs of a Stigmatised Population



Across Africa, people with albinism face many obstacles including the need to keep their skin healthy. Esther Nakkazi explores some of the problems, and what is being done to overcome them.

People with albinism face a disproportionate risk of skin cancer, as they lack the protection that melanin confers against the sun's ultraviolet rays. In Africa, the risk levels are particularly high, due to the continent's intense sunlight.

Incidence rates are up to four times higher in this population than among people with albinism living in other parts of the world, with cancers often developing at a relatively early age.

"This is a silent killer. Many PWA [people with albinism] in Africa die from cancer, but this is probably one of the least talked about issues," says Béatrice Garrette, the chief executive officer of the Fondation Pierre Fabre – a French public interest

foundation that is promoting efforts to highlight the unmet needs of this population, and working with governments and agencies to address them.

A recently published meta-analysis by Panawé Kassang, head of dermatology at the Regional Hospital of Kara, in Togo, and the deputy general secretary of the Togolese Dermatology Society, analysed available data to provide insights into the extent of the problem.

"Of all skin cancers reported worldwide in PWA, over 80% have been reported in people with albinism living on the African continent," Kassang told.

The study funded by the Fondation Pierre Fabre – a majority shareholder in the French pharmaceutical and cosmetics company Laboratoires Pierre Fabre – found that, of the 1,143 skin cancer cases identified in the review, 87% were reported in Africa. The most common type was squamous cell carcinoma

at 56.7%, followed by basal cell carcinoma at 37.4% and melanoma at 3.4%. The high frequency of squamous cell carcinoma in Africa contrasts with Europe and America, where basal cell carcinoma is more prevalent.

"Squamous cell carcinomas, which are the most dangerous, are the most common in people with albinism worldwide, and cutaneous melanoma – a type of cancer quite rare in Black Africans – is also rare in people with albinism in Africa. Further studies are needed to confirm this finding and understand its causes," says Kassang.

The study also found that the average age at which a skin cancer is diagnosed in people with albinism is only 40 years, which is much younger than for the general population. "To our knowledge, our study is the first in the world to provide global data by continent on skin cancers in people with albinism," says Kassang, who adds that getting access to unpublished data for the meta-analysis had been a major challenge.

"We believe that there are associations or nongovernment organisations that have interesting data but which are not published," he says.

Gathering the Data

Accurate data is always crucial for advocacy and policy change. While some figures exist, they are

often outdated and incomplete, making it difficult to fully understand the scale of the problem.

Garrette says that no comprehensive epidemiological study has been done in any country to accurately determine the number of people living with albinism. "Most available data come from albinism associations, which only provide estimates based on their registered members."

One possibility would be to include specific questions on albinism in national censuses, to find out how many people are affected, where they are located, and what resources they need, says Garrette.

In Rwanda, the 2022 national census recorded 1,860 people with albinism over the age of five. However, the rates of skin cancer remain unknown, since it's not routinely detected at district hospitals, says Nikodeme Hakizimana, Founder and Executive Director of the Organization for Integration and Promotion of People with Albinism in Rwanda.

Promoting Access to Protection

It is through the dermatology research carried out by Laboratoires Pierre Fabre that the Fondation Pierre Fabre – which aims to promote better access





to medicines and care in the Global South – got interested into the situation of people with albinism.

In 2015 the foundation started a programme for providing PWAs with dermatological care – access to early detection and management of skin cancers – through close collaboration with local associations, communities, and clinicians.

It is now working with some African governments to facilitate local production of sunscreen, as well as empowering local associations to advocate for imported sunscreen to be made available free of tax.

Garrette argues that production should be decentralised, with each country having several production units. The Fondation Pierre Fabre has worked with Laboratoires Pierre Fabre to develop an open-source formula, publicly available for anyone to use or modify.

"This formula is proven to be highly protective, as we have tested its effectiveness. Additionally, we can assist research departments in pharmacies to develop their own formulas while ensuring a high level of quality control," says Garrette.

A crucial aspect of this initiative is involving faculties of pharmacy in the production process. This ensures proper quality control, which can be overseen by trained professionals, university faculties, or governmental agencies responsible for medicine regulation. Garrette emphasises how important maintaining high standards is to quarantee the level of protection needed.

In Togo the foundation has implemented and

financed the Albitogo project, where the creams are produced locally by the Association of People with Albinism, and made available free of charge. "Since it was implemented, we have noticed a clear reduction in the number of skin cancers over the years," says Kassang.

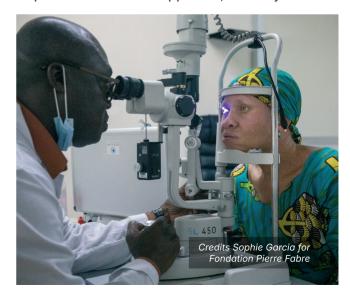
Other countries taking action include Malawi, where the government distributes free sunscreen to PWAs and in Rwanda it is provided through public insurance.

In Tanzania, a project led by the charity Under the Same Sun, partnering with local organisations, is focusing on access to high-quality education. Part of the charity's work is to make sure all the students they support are fully aware of the dangers of exposure to the sun as well as proper ways to keep themselves protected.

"We work with the schools that they are attending as well as a partner organisation in Tanzania to ensure they receive skin and vision check-ups every year," says Francis Tiangson, Fundraising Manager at Under The Same Sun.

The vision check-ups are very important, he adds, as people with albinism commonly suffer from problems with their eyesight, including short-sightedness. These can be so severe as to meet the legal qualification for blindness.

Garrette agrees on the importance of addressing barriers to accessing education. "Their needs require a more holistic approach," she says.





Cancer is a word no parent ever wants to hear. But when that word comes with no access to treatment, it doesn't just hurt — it destroys hope.

A year ago, I was walking through a coastal town in Africa. It was a beautiful day — blue skies, warm wind, the smell of cloves and cardamom in the air. Tourists passed by in sandals, drinks in hand, smiling. Then I saw something painted on the wall of a small building: "X-RAY NOW AVAILABLE."

Just that. Big letters. An announcement.

I stopped walking. I read it again. In many countries, an X-ray machine is ordinary. It's not even worth a sign. But here...

Behind the beauty of the island, I saw the gap. I

thought of the children — those with persistent fevers, unexplained pain, or swelling that their parents can't explain. Children who might have leukemia or a brain tumor. Children who don't just need X-rays, but scans, biopsies, blood work, and most of all — medicines.

Every year, more than 400,000 children are diagnosed with cancer. The vast majority live in low-and middle-income countries. And most of them will die. Not because their cancer is too advanced. Not because we lack the tools to treat them. But because the medicine doesn't reach them. And it's worse than it looks: according to a global simulation study published in The Lancet Oncology, estimates that 43% of childhood cancer cases — about 172,000 children each year — go undiagnosed. The

burden is overwhelmingly concentrated in low- and middle-income regions.

In some high-income countries, progress has been made. Certain childhood cancers now have survival rates over 95percent. But even there, life-saving medicines are missing from national essential medicine lists. Hospitals may not stock them. Insurance may not cover them. Access is still uneven.

That's why, on April 15, OncoDaily brought together voices from across the globe for a forum called "Essential Medicines for Children with Cancer: From Access to Action." It was a call to action. A collective voice rising to say enough is enough. Cancer doesn't wait. Neither can we.

Right now, the World Health Organization is preparing to decide whether two powerful cancer drugs — Blinatumomab and Temozolomide — will be added to its Model List of Essential Medicines for Children.

These drugs are already saving lives in countries where they're available. Blinatumomab is critical for survival in relapsed or refractory pediatric acute lymphoblastic leukemia, and its use is expanding in frontline settings due to its high efficacy and reduced toxicity.

Temozolomide is a standard component in global treatment protocols for high-grade gliomas (e.g., adapted Stuppregimens) and salvage regimens for neuroblastoma and sarcomas. It is included in COG, SIOP Europe, and HIT-HGG protocols and recommended in the WHO GAP-f formulary.

Getting these drugs on the list means more than recognition. It means that the ministries of health will take notice. It means countries will be more likely to include them in budgets and hospitals. It means these drugs could finally reach the children who need them most. In many places, that list is the first step toward access.

It's a decision that could change the future. And it's just days away.

But meanwhile, what is being done?

The ACT4Children initiative by Servier, World Child Cancer, Childhood Cancer International (CCI), IDA Foundation, the International Society of Paediatric

Oncology (SIOP) and Resonance, is pushing to close access gaps, in just six months delivering over \$2.8 million worth of innovative cancer medicines to childhood cancer centers in Asia and Central America - all at no cost to the families. More than 300 healthcare workers have been trained, as part of a model that brings medicine not in isolation, but with systems, protocols, and human support. Amgen, which makes **Blinatumomab**, has expanded its access programs, working in close partnership with St. Jude and the WHO to bring the drug to children in India, Pakistan, Vietnam, and beyond. And above all, the Global Platform for Access to Childhood Cancer Medicines — launched by St. Jude and WHO — is quietly rewriting the rules. It is not a donation program. It is a commitment. To ensure that 120,000 children across 50 countries receive a steady, quality-assured supply of lifesaving medicines. These are hopeful signs. But they cannot stand alone. They must become the norm, not the exception.

Governments must act. Pediatric cancer must be part of national health strategies. Donors must step in — not just to fund research, but to fund access. And WHO must recognize the urgency of this moment.

Because every day that passes without action is another day when a child somewhere is told, "There is nothing more we can do," not because that's true, but because the medicine isn't there. And in those moments, I've realized something painful: for too many kids, it's not biology that decides who survives cancer. It's geography.

This should not be our legacy.

We're not asking for miracles. We're not demanding the impossible.

This is not just a medical choice. It's a moral one.

Let's change that. Let's make essential medicines truly accessible. Let's move from talk to action, from policies to patients, from signatures to shipments.

Because every child deserves a chance, not just in theory, not just in speeches, but in real treatment that reaches their bedside.

The Time is Now.



Experience gained over decades of tackling cancer and supporting patients in Africa's most populous country gives Zainab Shinkafi-Bagudu unique insights and influence to help bring about progress in similar settings across the globe. She talked to Diana Mwango about her journey into advocacy, and her priorities as the next UICC President.

The election of Zainab Shinkafi-Bagudu to take over the next presidency of the UICC has been widely welcomed as a significant milestone for the global cancer community. When she assumes the leadership role in October 2026, she will become the first African to lead the world's oldest and largest global cancer organisation since it was founded in 1933.

That is important at the level of representation – as a role model and recognition of the progress that sub-Saharan Africa has made in building its cancer advocacy. More significant, perhaps, are the personal skills and experience Bagudu brings from years of navigating Nigeria's under-resourced healthcare system.

She did this not by following a pre-written plan, but by responding to real-world gaps with practical solutions – blending her medical training from the UK with on-the-ground realities in Nigeria. She mobilised civic, corporate, and international support, and used her platform as First Lady of Kebbi State (2015–2023) to rally other First Ladies in pushing for equitable cancer care across Nigeria.

The Road to Cancer Advocacy

When Bagudu returned to Nigeria after her Master's in Tropical Paediatrics from the London School of Hygiene and Tropical Medicine, she intended to treat children. But she quickly saw an urgent gap in cancer care.

"Cancer awareness was low, and so was diagnostic capacity. The elaborate tests available in the UK weren't there," she recalls. She set up a diagnostic centre, and one of the tests they offered was mammograms, which exposed the extent of latestage breast cancer diagnoses.



Realising that most patients lacked awareness, she started informal gatherings, small coffee evening meet-ups for women, to teach them how to self-examine. These efforts grew into the Medicaid Cancer Foundation, which supports patients and caregivers across Nigeria.

"It began with chats: 'If there's a breast lump, touch here, feel that.' Then, we'd advise screening: 'Go for a mammogram or ultrasound'," she says.

As her work on awareness and early detection began to bear fruit, another issue emerged: patients didn't know where to go next. There were no clear pathways. Funding treatment for those without means was another hurdle. Bagudu responded by organising annual cancer walks to raise funds.

"We'd raise about US\$26,000 (40 million naira) annually, but that could be exhausted by treating just 10 cancer patients. So, what next?"



This led to deeper advocacy. She began looking beyond donations, turning to the government – not for direct financial aid, but to push for sustainable mechanisms to fund cancer care.

"That's how we worked tirelessly to establish the National Fund for Cancer Care [a government-backed fund to support patients]," she says, "But many don't even know this fund exists. That's why advocacy is crucial." Over the years, she became a public figure strongly associated with cancer work. "As soon as people see me, the conversation turns to cancer. It has become my mission, my identity."

Under her leadership, the Medicaid Cancer Foundation has expanded its scope – from awareness to policy. Prevention, especially HPV vaccination, is a priority. With support from Gavi, over 13 million girls in Nigeria are now protected against cervical cancer.

The Experience to Lead

Nigeria's cancer challenges are mirrored in many low- and lower-middle-income countries. Bagudu's 30 years as a doctor, 16 years running a foundation, and nearly two decades managing diagnostics

equip her with experience to help in similar contexts as the next UICC president.

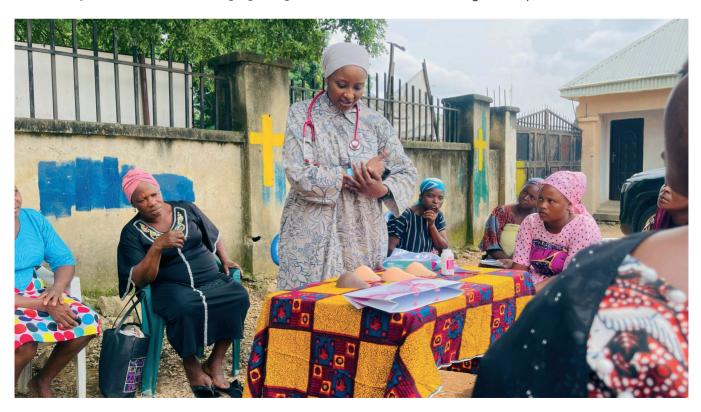
"There's so much work to be done," she says, "but I understand both worlds – wealthy and poor nations. I know where to focus "

Her focus: push for stronger national cancer policies, improve prevention, reduce late diagnoses, and increase access to treatment. "Whether it's getting women to examine their breasts, ensuring our girls are vaccinated against HPV, or making drugs more affordable, there are critical issues."

She lists tough questions: "How do we ensure someone in a rural area can access chemotherapy? How do we improve cancer awareness at the grassroots? Can we negotiate better service contracts for our radiotherapy machines?"

Success, she says, also hinges on human resources. "We have too few doctors. Yet, lecturers, doctors, nurses, physicists, and lab scientists are migrating to high-income countries. We must offer opportunities to keep them."

She believes digital tools, exchange programmes, and better training can help stem the brain drain. She





also wants more clinical trials in underrepresented regions and partnerships with organisations like AORTIC and the African Medicines Agency.

Mobilising the UICC to Get National Action

Bagudu is mindful of the opportunity her UICC presidency brings. "This is the first time we have an African at the helm. What can Africa bring to the table?"

In countries where health budgets are already stretched across malaria, HIV, and TB, cancer must fight for attention.

"Getting cancer on political agendas requires strategy and persistence," she says. Her UICC platform includes over 1,100 member organisations in 170+ countries.





"I understand how governments work. This is an opportunity to ensure global advocacy translates into national action."

With global progress on cutting mortality from noncommunicable diseases currently falling well short of the sustainable development goal of a reduction by a third by 2030, and with cancer incidence in countries with the lowest human development index predicted to almost double by 2040, the expertise and experience that Bagudu is set to bring to the Presidency of the UICC offers some welcome good news.

She is optimistic: "The UICC has already had an enormous global impact. World Cancer Day, for instance, has raised awareness worldwide." Over the last six years as a UICC board member, she's seen both the scale of the problem and the progress being made. Now, she says, is the time to build on that progress.



Second Global

ONCOTHON

OncoDaily & International Society of Paediatric Oncology (SIOP)

Support Global Pediatric Cancer Research



