

ICPPA 2024

The Magazine of the International Conference on PEN-Plus in Africa

Premier Issue



CLOSE TO HOME

Despite his severe and worsening symptoms, João Mindo lacked even a diagnosis. Then a PEN-Plus clinic opened near his village in rural Mozambique.

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Cover photo: Fourteen-year-old João Mindo received his diagnosis—and learned what lifesaving treatment he needed—within weeks of a PEN-Plus clinic opening nearby.

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SEIZE THE MOMENT

An inaugural conference offers an unprecedented opportunity.



HEALTH FOR ALL:
A nurse tends to a patient
in Zanzibar, Tanzania.

“PEN-Plus” was coined only five years ago, but already the healthcare-delivery model is receiving a spotlight on the global stage, with the launch of the first International Conference on PEN-Plus in Africa (ICPPA 2024), hosted in Dar es Salaam, Tanzania, in April by the World Health Organization’s Regional Office for Africa.

PEN-Plus trains nurses and clinical officers to provide care to people living with severe noncommunicable diseases—such as type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease—in the rural areas of low-income countries.

“PEN-Plus addresses a critical gap in healthcare for the world’s poorest billion, bringing lifesaving chronic care for severe noncommunicable diseases to first-level rural hospitals for the first time,” said Dr. Ana Mocumbi, a co-chair of the NCDI Poverty Network. “It also bridges major gaps in health systems for training, mentorship, and referral pathways.”

The NCDI Poverty Network serves as one of the organizing partners of ICPPA 2024, along with The Leona M. and Harry B. Helmsley Charitable Trust—the principal funder of the conference—and the United Republic of Tanzania.

“PEN-Plus showcases the lifesaving impact of collaborating with local health leaders and designing health systems around people,” said Dr. Gina Agiostratidou, type 1 diabetes program director for The Helmsley Charitable Trust. “Now, children with noncommunicable diseases in rural areas can receive the care they need to lead full, vibrant lives.” ■

PHOTO: MAMUENA / WORLD HEALTH ORGANIZATION COMMUNICATIONS

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MIND THE GAP

No disease should be treatable in one country and yet a death sentence in another.



BRINGING IT HOME: During a home visit, PEN-Plus nurse Euna Museva takes a blood sample from Ruvarashe Chikombe, a three-year-old living with sickle cell disease in the Masvingo Province of Zimbabwe.

Where a person lives should never determine *whether* a person lives. Yet without access to treatment, half of the nearly one thousand children born with sickle cell disease in sub-Saharan Africa each day will die before their fifth birthday.

Each year, severe noncommunicable diseases kill more than a half million children, adolescents, and adults in Africa alone. Just four conditions—type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease—account for as many as 100,000 of those annual deaths. And these tragedies persist even though proven, cost-effective treatments have long been routinely available in high-income countries, sometimes for decades or, in the case of insulin, for more than a century.

Noncommunicable diseases, which now represent the biggest gap in universal health coverage for the poorest billion, have been identified as global health priorities. Yet policies and funding devoted to these diseases still focus almost entirely on those often linked to lifestyle-associated risk factors. This agenda effectively excludes the world’s poorest people, who suffer a heavy burden of noncommunicable diseases without preventable causes.

These avoidable deaths occur mostly in rural areas of sub-Saharan Africa, where healthcare for these and other severe diseases often remains unavailable. As a result, beautiful young lives are lost, often before their diseases are even recognized. With PEN-Plus, an innovative healthcare-delivery model, this reality is as unnecessary as it is unjust. ■

PHOTO: © TAFADZWA UFUMELI / WORLD HEALTH ORGANIZATION



IMMEDIATE IMPACT: Within weeks of the opening of a PEN-Plus clinic in Nhamatanda, Mozambique, João Mindo, seated in the red chair near his mother and baby sister, received a lifesaving diagnosis.

CLOSE TO HOME

Despite his severe and worsening symptoms, João Mindo lacked even a diagnosis. Then a PEN-Plus clinic opened near his village in rural Mozambique.

When Dr. Ana Mocumbi, a cardiologist who co-chairs the NCDI Poverty Network, met João Mindo for the first time, his heart was weak, his breathing labored, and his face gaunt. Fortunately, he was right where he needed to be: Mozambique's newly launched PEN-Plus clinic.

João's acute health problems began in 2020. For three long years, he struggled to walk, eat, and even breathe. It wasn't until February 2023, when the PEN-Plus clinic opened at Nhamatanda Rural Hospital, 20 kilometers from his home, that João finally received a diagnosis: rheumatic heart disease.

Paper Trail

João, now 14, lives with his widowed mother and three siblings in a home without electricity or plumbing in a rural area of central Mozambique. The family's only means of support is his mother's small-scale farming.

"We were told he needed surgery for his heart condition," said João's older brother, Lazaro. "My mother was heartbroken João had received such a serious diagnosis, and she had difficulty accepting that he needed surgery. I told her we had to pursue treatment for him."

The severity of his condition meant João would need to undergo surgery to repair his mitral and tricuspid valves at ICOR (the Heart Institute) in Maputo, 800 kilometers to the south. First, though, a complication required resolution. João's family had lost their identification papers in 2019, when

"The lack of resources in the area often means we have to solve one problem before we can confront the next."

Cyclone Idai devastated the area. Without those papers, João could not fly to the capital.

"The lack of resources in the area often means we have to solve one problem before we can confront the next," said Dr. Mocumbi, who is also an associate professor of cardiology at Universidade Eduardo Mondlane in Maputo. "João



THE PATH TO HEALTH: Top left: João Mindo undertakes laboratory testing in preparation for his heart surgery. Above: João and his brother, Lazaro, spend time together at ICOR (the Heart Institute) in Maputo. Left: Dr. Ana Mocumbi, a co-chair of the NCDI Poverty Network, and Dr. Raoul Bermejo, a healthcare specialist for UNICEF, talk with João during a visit of PEN-Plus Partnership members to the newly opened PEN-Plus clinic in Nhamatanda in March 2023.



LONG-TERM INVESTMENT: After the surgical repair of his mitral and tricuspid valves, João Mindo receives his chronic care close to home at the PEN-Plus clinic that diagnosed his rheumatic heart disease. Here, Dr. Lindolfo dos Santos measures João's arm circumference during a routine visit.

didn't have the identification papers required to fly within Mozambique, so we had to make him exist on paper before he could travel for his surgery."

Under Dr. Mocumbi's leadership, the Maputo co-secretariat of the NCDI Poverty Network provided all the necessary support for João to undergo surgery, which included securing identification papers, arranging a free roundtrip flight for João and Lazaro, and even negotiating an agreement with Lazaro's school to ensure he could continue his studies while accompanying his brother.

João and Lazaro stayed in the capital for three months. There João's recovery went as well as his surgery. The brothers are now back in their hometown with their mother.

"I will forever be grateful that everything went well," Lazaro said, "and I expect João to have a healthy life."

Free to Run

In rural Mozambique, where severe noncommunicable diseases often go undiagnosed and untreated, João's story highlights the importance of access to lifesaving treatment and financial support to help young people like him defy the odds.

"Access to essential medicines is often a significant health barrier in rural Mozambique," said Dr. Mocumbi. "The PEN-Plus program ensures that João has free and consistent access to lifesaving care—including medicines and specialized treatment. This has not only improved his health but also alleviated his family's financial pressures."

"Before I got sick, I would run and run," João said. "But later, when I tried to run, I fell. My heart would beat so fast, and I couldn't even play anymore. Since my heart surgery, though, I am fine, and I can play and run." ■

PHOTO: © IVAN SIMONE CONGOLO / WORLD HEALTH ORGANIZATION

DESIGN FOR LIFE

PEN-Plus has proved to be effective in delivering both healthcare and hope.

As an infant, Tawonashe Mugura was always in and out of the hospital. Sometimes he had difficulty breathing; other times, his tiny body was jaundiced. His pain was so severe he cried constantly. The provincial hospital in nearby Masvingo, Zimbabwe, treated his symptoms, but he still lacked a diagnosis.

Then, when he was nine months old, an aunt provided a critical clue: Three of her grandfather's siblings had died of sickle cell disease. A test confirmed Tawonashe's diagnosis. After he received treatment for sickle cell, both his crying bouts and hospitalizations decreased. Yet his parents still faced a terrible dilemma—pay for his treatment or feed the family.

To stretch the medicine for a few more days, Tawonashe's parents occasionally missed a dose or underdosed their son. Several times a year he would be hospitalized with severe joint pain, difficulty breathing, and abdominal and chest pain. Those visits usually corresponded with the times he lacked adequate dosing.

In 2022, after presenting to the hospital with diabetic ketoacidosis, a potentially fatal condition, Tawonashe received a second diagnosis: type 1 diabetes. Fortunately, with insulin treatment, he was able to stabilize.

YOUNG WARRIOR: Tawonashe Mugura, an 11-year-old with both sickle cell disease and type 1 diabetes, receives his care at the PEN-Plus clinic at Masvingo General Hospital in southeastern Zimbabwe.



“The PEN-Plus clinic has been a silver lining in our lives. I feel we got another chance to breathe.”

In June 2023, when he was ten, Tawonashe enrolled in the PEN-Plus clinic at Masvingo Provincial Hospital. The clinic now provides him with continuous pharmaceutical support, including hydroxyurea for his sickle cell disease, insulin for his diabetes, and pain medications. The nurses educate him about his illnesses, and he receives free routine laboratory and radiology tests.

“With this treatment, we hope to reduce both his sickle cell complications and his hospitalizations in general,” said Dr. Alvern Mutengerere, project manager for noncommunicable diseases at SolidarMed, the implementing partner for the PEN-Plus clinic in Masvingo. “Tawonashe is exactly the kind of patient for whom PEN-Plus was designed.”



STAYING STRONG: Tawonashe Mugura poses with his parents, Stella and Tranos Mugura, for a portrait at their home in Masvingo, Zimbabwe.

System Integration

PEN-Plus, an integrated healthcare delivery model, was originally developed in Rwanda to provide lifesaving care to children and young adults living with severe, chronic noncommunicable diseases in extreme poverty. More than a dozen countries—including 11 in Africa—are now implementing the model, and the World Health Organization’s Regional Office for Africa is undertaking a major expansion of PEN-Plus on the continent.

PEN-Plus complements the WHO Package of Essential Noncommunicable (PEN) Disease Interventions for Primary Health Care by focusing on first-level hospitals and care for severe, chronic conditions such as type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease.

The PEN-Plus strategy seeks to increase coverage of these less common but more severe conditions by decentralizing services normally available in many low- and low-

middle-income countries only at tertiary referral centers. By providing training, mentorship, and supervision, PEN-Plus also strengthens WHO PEN services at mid-level facilities, such as district hospitals.

Disease Integration

The PEN-Plus approach is as simple as it is effective: In aiming for an optimal configuration of scarce healthcare resources, PEN-Plus trains mid-level providers such as nurses and clinical officers to deliver crucial, integrated services—including diagnosis, symptom management, and psychosocial support—across a range of severe, chronic noncommunicable diseases.

The innovation is in the design. PEN-Plus clinics optimize infrastructure and human resources by clustering conditions and interventions that take advantage of shared space, training, workflow patterns, and competencies, including the management of medications with narrow therapeutic

windows, such as insulin, anticoagulants, and heart failure medications.

Patient-Centered Approach

“The PEN-Plus clinic has been a silver lining in our lives,” said Tawonashe’s mother, Stella Mugura. “I feel we got another chance to breathe. And I am thankful for our education about sickle cell; I thought it was a death sentence, but now we have hope.”

The clinic has also relieved their financial pressures.

“PEN-Plus has lifted a huge burden from us,” Stella Mugura said. “The extended help from SolidarMed and the clinic reminds me of the meaning of my son’s name. In English, *tawonashe* means ‘we have seen God.’ Indeed, we have seen God in our lives.”

Tawonashe—now a robust fifth grader—has found inspiration in his journey. “When I grow up I want to be a doctor so I can treat myself and others,” he said. “And now my dream will succeed because of PEN-Plus.” ■

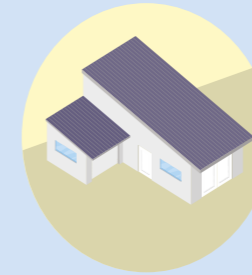
BETTER BY DESIGN

PEN-Plus bridges gaps across health systems, treatment protocols, and solidarity movements to save precious lives.



REFERRAL HOSPITALS

Specialists in referral hospitals provide PEN-Plus clinicians with training and mentorship. In turn, PEN-Plus clinicians send patients to referral hospitals for surgery when needed and provide essential chronic care services following acute specialty interventions, such as anticoagulation treatment for people with heart valve surgery.



FIRST-LEVEL HOSPITALS

PEN-Plus trains nurses, clinical officers, and other mid-level providers to treat severe chronic conditions, secures lifesaving medicines and supplies, and brings care closer to home for the millions of people living in rural and near-urban areas of sub-Saharan Africa.



HEALTH CENTERS

WHO PEN provides outpatient primary care for common noncommunicable diseases that frontline clinicians can manage, often in tandem with other conditions, such as HIV and tuberculosis.

HEALTH SYSTEMS

The WHO Package of Essential Noncommunicable (PEN) Disease Interventions provides protocols and tools that help countries integrate and scale up care of more common and less severe noncommunicable diseases—such as hypertension and type 2 diabetes—at the primary or **health-center level**. PEN-Plus complements WHO PEN by focusing on care for people with less common and more severe noncommunicable diseases at **first-level hospitals**, also known as district hospitals. PEN-Plus providers receive training and mentorship from specialists at **referral hospitals**, refer patients for acute specialty interventions such as surgery, and provide chronic-care services following those interventions.

TREATMENT PROTOCOLS

PEN-Plus brings the needed expertise to treat severe, chronic noncommunicable diseases to first-level referral hospitals by training health workers to provide **essential endocrine, hemoglobinopathy, and cardiac services** through a single point of care. Nurses and clinical officers with this advanced training can offer such services as **echocardiography** for patients with rheumatic and congenital heart disease and **management of medications with narrow therapeutic windows**, such as insulin, anticoagulants, heart failure medications, and morphine for pain control.



Type 1 Diabetes

Sickle Cell Disease

Rheumatic Heart Disease

Congenital Heart Disease

SOLIDARITY MOVEMENTS

The **PEN-Plus Partnership** seeks to enable millions of children, adolescents, and adults living with severe noncommunicable diseases in rural areas of low- and lower-middle-income countries to receive lifesaving care previously available only at referral hospitals in large cities. This collaboration of advocacy, policy, funding, and technical partners from around the world works with ministries of health to implement PEN-Plus wherever it is needed. By joining advocates across diseases—particularly type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease—the PEN-Plus Partnership works to create synergies across efforts and to advocate for funding—from individuals, organizations, legislatures, and parliaments—for PEN-Plus internationally.





FEELING NO PAIN:

Fourteen-year-old Sara shares a lighthearted moment with her six-year-old sister, Linda, after their visit to the PEN-Plus clinic in Nhamatanda, Mozambique, where they receive treatment for their sickle cell disease.

The **FACES** of **PEN-PLUS**

Clinicians pioneered PEN-Plus by devising a series of technical solutions, yet it's the people—the patients, the providers, and the partners—who are at the core of the model's success.

When sisters Sara and Linda return home with their mother after a visit to the PEN-Plus clinic in Nhamatanda, Mozambique, they carry more than the supply of the hydroxyurea pills they will need until their next appointment. They also carry the lessons that clinic staff members taught them about managing their sickle cell disease.

“A people-centered approach to health delivery is organized around the health needs and expectations of people rather than diseases,” said Dr. Ana Mocumbi, a cardiologist based in Maputo, Mozambique, and a co-chair of the NCDI Poverty Network. “The PEN-Plus model views patients, their families, and their communities as participants as well as beneficiaries of their care. As part of this holistic care, patients and their families receive the education and support they need to make decisions and participate in their own care.”

Championing this approach is the PEN-Plus Partnership, an international collaboration of the World Health Organization's Regional Office for Africa and leading organizations that support work in the sentinel diseases of PEN-Plus—type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease. Partnership members work across diseases and across borders to build a global solidarity movement aimed at ensuring that people living with severe noncommunicable diseases everywhere have access to the lifesaving care they need and deserve.

That work has already transformed Sara's and Linda's lives. Before the PEN-Plus clinic opened just 20 kilometres from their home, the sisters were often in too much pain to attend school or play with their friends.

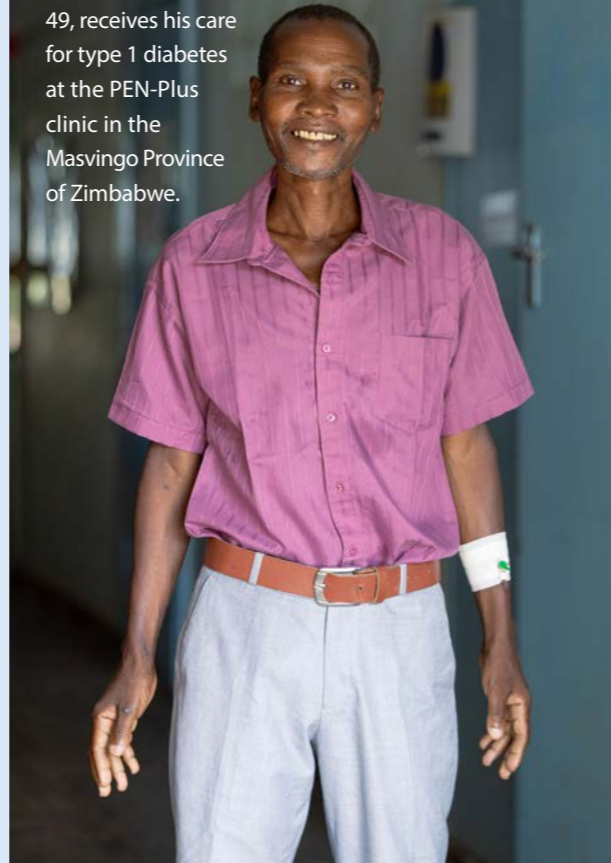
Now that Sara is getting the care she needs, her clinicians report, her light cannot be dimmed. “I was born this way, but I'm happy anyway,” she said. “I want to show the world I am feeling good.” ■

PHOTO: © IVAN SIMONE CONGOLO / WORLD HEALTH ORGANIZATION

NEW PROMISE: Elisa Edson, an eight-year-old with type 1 diabetes, awaits her appointment at the PEN-Plus clinic in Nhamatanda, Mozambique. "I thought my daughter had fallen victim to witchcraft for being born with a health condition and doubted she would have any chance to live," Elisa's mother said. "The PEN-Plus clinic changed our knowledge about her disease."



HAPPY IN HEALTH: Michael Mandebvu, 49, receives his care for type 1 diabetes at the PEN-Plus clinic in the Masvingo Province of Zimbabwe.



FAMILY READY

Left: Ategei Safia poses for a portrait in front of her home with her son, 14-year-old Emong Abdul Shakur, and 11-year-old Anyait Stella, both of whom receive treatment for sickle cell disease at the PEN-Plus clinic in Atutur, Uganda. Safia and her husband informally adopted Stella, whose family could not care for her. "I adopted Stella," Safia said, "because I was sure she was going to die if I did not do something." Above: Agnes Mangenge, 46, receives treatment at the PEN-Plus clinic in the Masvingo Province of Zimbabwe for congestive heart failure and chronic liver failure. "At first it was like a dream that this program exists only to help people like me," she said. "Our lives have become better. I wish God to intervene and make sure that this program extends."

PHOTO: © BADRU KATUMBA / WORLD HEALTH ORGANIZATION (LEFT)

PHOTO: © BADRU KATUMBA / WORLD HEALTH ORGANIZATION

BRIGHT FUTURES: Eighteen-year-old Farida Aguti (left), and her 22-year-old sister, Rukia Aumo, smile broadly outside the PEN-Plus clinic in Atutur, Uganda, where they receive care for their sickle cell disease.

The PATIENTS



LEARNING CURVES

Left: Nurse Lillian Phillie leads a daily health discussion at the PEN-Plus clinic in Kono, Sierra Leone. Above: PEN-Plus master trainer Naasson Nduwamungu teaches Laetitia Twizerimana to use point-of-care echocardiography in Rwinkwavu, Rwanda. Below: Patients and caregivers at the PEN-Plus clinic in Nhamatanda, Mozambique, listen to a talk by Dr. Lindolfo dos Santos on nutritional considerations for people living with sickle cell disease. PEN-Plus clinic staff initiated this series of one-hour peer support sessions to enable patients with the same conditions to find community, receive psychological support, and learn additional guidance on managing their condition.



CLINICIANS WITH HEART

Above: Emmanuel Joseph Fofanah, a clinical officer at the PEN-Plus clinic in Kono, Sierra Leone, has undertaken comprehensive training in diagnosing and treating acute noncommunicable diseases. Right: Akuyo Regina, a nursing officer, talks with a patient's mother inside the reception area at the PEN-Plus clinic at Atatur General Hospital in Uganda.



The PROVIDERS



CHALLENGE ACCEPTED

A. Eunice Owino, a sickle cell warrior from Kenya, serves as an advocate for Voices for PEN-Plus, a program of the NCDI Poverty Network. **B.** David Panzirer (left), a trustee of The Leona M. and Harry B. Helmsley Charitable Trust, and Dr. Aaron Kowalski, chief executive officer of JDRF International, visited the PEN-Plus clinic in Nhamatanda, Mozambique, in March 2023. **C.** Moses Echodu, a childhood cancer survivor from Uganda, lends his expertise to both Voices for PEN-Plus and the Uganda Child Cancer Foundation. **D.** The High-Level Advisory Group of the PEN-Plus Partnership—including representatives from the American Heart Association, The Helmsley Charitable Trust, JDRF International, UNICEF, and the World Health Organization’s Regional Office for Africa—gathered at Universidade Eduardo Mondlane, the Maputo co-secretariat of the NCDI Poverty Network, in March 2023. **E.** Kenyan-born Ruth Ngwaro, who serves as a Voices for PEN-Plus advocate, lives with congenital heart disease. **F.** Voices for PEN-Plus advocate Tinotenda Dzikiti, who lives with type 1 diabetes in Zimbabwe, is a certified diabetes educator and a global advocate for T1International.

The **PARTNERS**



HEALING CIRCLE: Medson Boti, a clinical officer at the PEN-Plus clinic in Lisungwi, Malawi, talks with seven-year-old Kevini Jamu, who receives free, specialized care for his sickle cell disease.

Felix Maniriho was a shy eight-year-old with large, soulful eyes and a weakened heart when he became an early patient of a new model of care.

It was 2007, and Felix appeared at the Mulindi Health Centre in eastern Rwanda struggling to breathe. After the nurses ruled out tuberculosis, they began suspecting a heart ailment.

Using a portable ultrasound machine—a point-of-care technology then relatively new to the rural, remote area—a cardiologist could see that Felix’s heart mitral valve had been destroyed. That damage, coupled with a loud heart murmur, led to the diagnosis: rheumatic heart disease.

The World Health Organization estimates that rheumatic heart disease, the most commonly acquired heart disease in people under age 25, claims nearly 300,000 lives each year, mostly in low- and lower-middle-income countries. The condition—attributed to an autoimmune reaction to strep throat—was once the leading cause of heart disease in the United States. Over the course of the 20th century, though, with improved living conditions and the development of antibiotics, the disease had largely disappeared in the United States and other high-income countries.

PHOTO: KARIN SCHERBRUCKER/SLINGSHOT MEDIA FOR PARTNERS IN HEALTH

the UNFOLDING PROMISE

PEN-Plus, which originated in Rwanda nearly two decades ago, now provides care for people living with severe noncommunicable diseases across Africa—and beyond.



EARLY DAYS: Gedeon Ngoga, one of the first clinicians to be trained in the advanced noncommunicable disease care that would eventually become PEN-Plus, always wanted to be a nurse. “As a child, I didn’t know the difference between nurses and doctors,” he said. “All I knew is that the people in white coats had the power to help sick patients become healthy, and that is what I, too, wanted to do.”

At the time of Felix’s diagnosis, Rwanda had only one pediatric cardiologist for a country of nearly 10 million people: Dr. Joseph Mucumbitsi, who had recently returned to his home country from Belgium to practice at the King Faisal Hospital in the capital city of Kigali. The few patients sent outside of the country for cardiac surgery were those identified in the capital city; cardiac diagnoses and care were largely inaccessible in rural areas, where most of the population lived.

The cardiologist who had diagnosed Felix’s disease—Dr. Gene Bukhman, a Brigham and Women’s Hospital physician then based in Rwanda—worked with Dr. Mucumbitsi to send Felix to a cardiac

surgery center in Sudan that provided free heart surgeries.

“The surgeons had two options for Felix: a biological valve, which carried the risk of wearing out quickly, and a more durable mechanical valve, which would require Felix to be on a blood thinner and be monitored clinically for the rest of his life,” said Dr. Bukhman, a Harvard Medical School faculty member who also worked with Partners In Health. “The clinic didn’t have the capacity for long-term follow-up, so the surgeons chose the biological valve.”

Felix’s valve did wear out. By that time, though, the Rwanda Ministry of Health and a team of clinicians at Inshuti Mu Buzima (Partners In Health–Rwanda)—including Dr. Bukhman—had made significant

strides in developing strategies for treating severe, chronic noncommunicable diseases. When he returned to Sudan for a second replacement surgery, Felix was able to receive a mechanical valve.

Integration Within the System

Fortunately for Felix, the team of collaborators had begun designing an integrated care-delivery model for noncommunicable diseases at two rural district hospitals two years earlier.

“At the time clinics had guidance for treating less severe, more common diseases such as hypertension,” said Dr. Bukhman. “Yet they lacked integrated strategies for caring for more complex chronic diseases. That was the gap we were seeing in the

“Our healthcare delivery model aims to serve all Rwandans, especially the most vulnerable.”

health system. We realized the district hospitals had a crucial role to play.”

Dr. Agnes Binagwaho, then minister of health for Rwanda, was eager to collaborate with Inshuti Mu Buzima on integrating treatment of severe noncommunicable diseases into the district hospitals.

“The Government of Rwanda views healthcare as a basic human right and, as such, our healthcare delivery model aims to serve all Rwandans, especially the most vulnerable,” she wrote in a foreword to a Partners In Health guide on chronic care integration for endemic noncommunicable diseases in 2011. “This rights-based approach is at the root of Rwanda’s health strategy.”

Integration Across Diseases

Type 1 diabetes, sickle cell disease, and childhood heart diseases customarily fall into disparate clinical specialties. Even so, those conditions share certain disheartening characteristics. They’re all severe, chronic noncommunicable diseases that cannot be prevented. Their treatment protocols are

complex. And, when left untreated, they kill children, adolescents, and young adults living in rural areas of sub-Saharan Africa at devastating rates.

Fortunately, these diseases also share a clinical cadence, and it was in that pattern of services that the clinicians in Rwanda found another solution of integration.

“These diseases all require a diagnosis, symptom management, psychosocial support, palliative care, referral for surgical and other specialty care when necessary, and long-term monitoring,” said a member of the team, Dr. Charlotte Bavuma, now an endocrinologist at Centre Hospitalier Universitaire de Kigali. “So we organized the clinics to optimize both infrastructure and human resources.”

The team clustered conditions and interventions to take advantage of shared space, training, workflow patterns, and competencies. These included managing medications with narrow therapeutic windows such as insulin, heart failure medications, and anticoagulants.

Each clinic was staffed by two or three advanced nurses who saw 10 to 20 patients a day. Physicians supervised initial consultations and consulted on complex cases, and specialists visited the clinics every month or two to confirm diagnoses and consult on complex cases. The clinics also became training sites for a three-month course designed to prepare advanced NCD nurses nationally.

Delivery of Hope

Gedeon Ngoga, one of the first nurses to be trained in the new model, had recently joined Inshuti Mu Buzima.

“My biggest challenge as a nurse is working with limited resources,” said Ngoga, who now serves as the training director for the NCDI Poverty Network. “It breaks my heart to see the devastating levels of poverty that many of our patients face, and it is difficult to provide comprehensive care to these vulnerable people. But nothing is better than seeing a patient smile after many years of critical sicknesses and hopelessness.”

PEN-Plus Milestones

What began as an innovation born of necessity has grown into a proven, evidence-based worldwide clinical strategy for delivering healthcare to people living in rural areas far from high-level care facilities.

2006

Rwanda’s Ministry of Health, with support from clinicians at Inshuti Mu Buzima (Partners In Health–Rwanda) and Harvard Medical School, begins designing a new care-delivery model for severe, chronic noncommunicable diseases such as type 1 diabetes and rheumatic heart disease.



2016

The Rwanda Ministry of Health has scaled this model to all 42 district hospitals in the country, with progressively decentralized services for more common noncommunicable diseases—such as hypertension, type 2 diabetes, and asthma—to the health center and community levels. Based on that success, Partners In Health begins working with additional Ministries of Health to introduce the model in Malawi, Liberia, and Haiti.

2017

Brigham and Women’s Hospital and Harvard Medical School host a meeting in Boston with the World Health Organization’s Regional Office for Africa to explore approaches for treating less common and yet more severe noncommunicable diseases, such as type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease.



2019

In advance of a regional consultation in Kigali, Rwanda, the World Health Organization adopts “PEN-Plus” as the official name of the model, acknowledging its role as a complement to WHO PEN.

2020

Led by co-chairs Gene Bukhman and Ana Mocumbi, the Lancet Commission on Reframing Noncommunicable Disease and Injuries for the Poorest Billion—which began in 2015—publishes a report detailing gaps in access to treatment for severe noncommunicable diseases. In addition to presenting many findings, the Commission calls for significant new resources to end the needless death and suffering caused by these diseases among the world’s poorest people.

Drs. Bukhman and Mocumbi go on to launch the NCDI Poverty Network in collaboration with the national NCDI Poverty Commissions of 15 low- and lower-middle-income countries with large populations of people living in extreme poverty.



One of his most memorable experiences as a nurse, Ngoga added, was when he encountered a young man with type 1 diabetes who was on the brink of death. “I felt so drawn to him; I couldn’t bear to see another patient die at a young age of a manageable disease,” Ngoga said. “He eventually recovered fully from his clinical crisis. Seeing him healthy and happy again was incredibly rewarding.”

A Complement to WHO PEN

By 2016, the Rwanda Ministry of Health had scaled the model to all 42 district hospitals in the country and progressively decentralized services for more common NCDs—such as hypertension, type 2 diabetes, and asthma—to the health center and community levels. Based on that success, Partners In Health began working with additional Ministries of Health to introduce the model in Malawi, Liberia, and Haiti.

By then, Dr. Bukhman had joined with Dr. Ana Mocumbi, a cardiology professor at Universidade Eduardo Mondlane in Maputo, Mozambique, in co-chairing the Lancet Commission on Reframing Noncommunicable Disease and Injuries for the Poorest Billion Commission, a panel of 23 global health experts. Also, by then, the World Health Organization had launched the WHO Package of Essential Noncommunicable

Disease Interventions for Primary Health Care (WHO PEN), a prioritized set of cost-effective interventions that could be delivered at an acceptable quality of care, even in resource-poor settings.

In 2019, the World Health Organization recognized the Rwanda-developed model of healthcare delivery as “PEN-Plus” in reference to its capacity to complement and strengthen WHO

“Nothing is better than seeing a patient smile after many years of critical sickness and hopelessness.”

PEN by focusing on lifesaving care for people with relatively complex, less common diseases that require specialized skills and cannot be managed effectively with simple, standardized protocols at health centers and in the community. PEN-Plus nurses and clinical officers with advanced NCD training provide training, supervision, and mentorship to staff who deliver WHO PEN services

at health centers and in the community. This training enables health center staff to improve the quality of care for more common, less severe NCDs and to recognize and refer patients with severe conditions to the PEN-Plus clinic.

A year later, the Lancet Commission published a landmark report that found that the annual burden of death and disability caused by NCDs among the world’s poorest billion amounted to 93.8 million avoidable disability-adjusted life-years. More than half of that burden accrued in people younger than 40 and more than a third in children and adolescents.

The Lancet Commission also found that without integrated care delivery strategies that make chronic care services for severe NCDs available in resource-limited rural areas, hundreds of thousands of the world’s most vulnerable children, adolescents, and young adults go without lifesaving care for severe conditions that almost always lead to premature death if left untreated.

Commission members recognized that these deaths were not inevitable. The Lancet Commission report concluded with a call for global solidarity and plans to launch a global network to catalyze financing and technical partnerships to support the implementation of PEN-Plus. Later that year, representatives of National NCDI Poverty Commissions from 15

PHOTO: © BADRU KATUMBA / WORLD HEALTH ORGANIZATION



TAKING CARE: Namazzi Mercy, a medical intern, takes the blood pressure of 11-year-old Lubwama Jackson, who receives treatment for his sickle cell disease at the PEN-Plus clinic in Nakaseke, Uganda.

lower-income countries joined with the Lancet Commission co-chairs to form the NCDI Poverty Network.

Regional Strategy

In August 2022, all 47 member states of the African Region of WHO voted to adopt the PEN-Plus strategy to address severe NCDs at first-level referral health facilities. WHO Africa has since set a series of ambitious goals: to have 50 percent of member states rolling out

PEN-Plus services to district hospitals by 2025, 65 percent by 2028, and 70 percent by 2030.

In 2023, with support from The Helmsley Charitable Trust, WHO Africa began leading the continent-wide implementation of PEN-Plus. The grant supports WHO Africa efforts to strengthen and expand PEN-Plus in 20 additional countries. WHO AFRO will begin this expansion with Lesotho, Niger, and the Republic of the Congo.

“PEN-Plus has proven its value for expanding lifesaving care in resource-limited areas,” said Dr. Mocumbi. “In Rwanda, we watched the model’s impact grow exponentially when the Ministry of Health integrated PEN-Plus into its national strategy for caring for people living with severe noncommunicable diseases. Now, under WHO Africa’s leadership, we cannot wait to see the model create new pathways to critical care for communities across the continent.” ■

PEN-Plus Milestones

continued

2021

The Leona M. and Harry B. Helmsley Charitable Trust and JDRF award a three-year grant to support the NCDI Poverty Network. Later that year, the Network and collaborators launch the PEN-Plus Partnership with the ambition of reaching significant annual funding for PEN-Plus implementation by 2030. The following year, UNICEF hosts the partnership’s official launch in New York City.

2022

All 47 member states of the WHO African Region adopt PEN-Plus as their official strategy for providing care to people living with severe noncommunicable diseases.

In 2022 and 2023, ten additional countries worldwide—including Ethiopia, Kenya, Mozambique, Sierra Leone, Tanzania, Uganda, Zambia, and Zimbabwe—launch their first PEN-Plus clinics. Eight other countries—including Benin, Burkina Faso, Cameroon, the



Democratic Republic of Congo, Ghana, and Nigeria—establish National NCDI Poverty Commissions and begin planning PEN-Plus implementation.

2023

WHO Africa sets the ambitious goal of having 50 percent of member states roll out PEN-Plus services to district hospitals by 2025, 65 percent by 2028, and 70 percent by 2030.

The Helmsley Charitable Trust awards a three-year grant to WHO Africa to support efforts to expand PEN-Plus to 20 additional countries. In announcing the grant, Dr. Gina Agiostratidou, program director for type 1 diabetes at The Helmsley Charitable Trust, says,

“WHO Africa’s diverse NCD programming and regional expertise make them an ideal partner in our mission to ensure that everyone with a severe NCD has access to quality care and support—no matter where they call home.”



2024

The World Health Organization Regional Office for Africa hosts the first International Conference on PEN-Plus in Africa. The event—whose theme is “Prioritizing Person-Centered Approach to Chronic and Severe NCDs—Type 1 Diabetes, Sickle Cell Disease, and Childhood Heart Diseases”—attracts the interest and support of countries across the continent and beyond.



2030

By 2030, the World Health Organization Regional Office for Africa, the NCDI Poverty Network, and their partners aim to achieve a tenfold increase in the number of people receiving treatment for severe noncommunicable diseases such as type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease in rural sub-Saharan Africa.

PHOTO: WORLD HEALTH ORGANIZATION

ANATOMY OF A CLINIC

The PEN-Plus clinic in eastern Uganda began as a gathering under a tree and blossomed from there.



PHOTOS: ASIO SARAH (TOP LEFT); WUBAYE DAGNAW (MIDDLE LEFT); © BADRU KATUMBWA / WORLD HEALTH ORGANIZATION (ALL OTHERS)

FOR YEARS, THE LEAFY CANOPY OF A MAJESTIC acacia has provided Atatur General Hospital in eastern Uganda with more than a respite from the hot sun; it has also sheltered an open-air clinic for people living with sickle cell disease.

“A critical lack of funding meant the hospital couldn’t expand to accommodate all the people who needed care,” said Dr. Wubaye Dagnaw, the East Africa regional advisor for the NCDI Poverty Network. “On clinic days, hundreds of children with sickle cell disease would gather under the tree for their treatment. To call these circumstances less than ideal for providing care would be a dramatic understatement.”

Fortunately, this PEN-Plus clinic now has a home in a newly built structure adjacent to the hospital. The clinic held its groundbreaking in May 2023 and its official opening six months later.

Funded through the NCDI Poverty Network in collaboration with the Uganda Ministry of Health, the 325-square-meter structure houses a training center that can accommodate more than 80 participants, three consultation rooms, a treatment room, a laboratory, a counseling room, a pharmacy, a data center, an office, and a tea room for staff. The reception area can hold several dozen people at a time.

The Uganda Initiative for Integrated Management of Noncommunicable Disease works with the Ministry of Health to support both the PEN-Plus clinic in Atatur and one housed at Nakaseke General Hospital in central Uganda.

“After years of carrying the extra burden of clinic days under a tree,” said Dr. Dagnaw, “patients now receive their treatment in the setting they deserve.” ■

BREAKING NEW GROUND: Clockwise from top left: Before the PEN-Plus clinic was built at Atatur General Hospital, people with sickle cell disease would gather under a tree to receive their treatment; Joyce Apolot, a senior nursing officer, prepares medical supplies and equipment at the PEN-Plus clinic on a Tuesday, the designated clinic day for people living with sickle cell disease; medical interns gather outside the newly constructed clinic; Dr. Siprian Achau examines a child inside his office; Dr. Asio Sarah, medical superintendent at Atatur General Hospital, and Daniel Aкои cannot contain their excitement as they tour the clinic under construction.



LEAVE NO ONE BEHIND

Estrela Anselmo is one of the fortunate ones; she can access specialized care in the capital. Even so, her challenges underscore the urgent need for PEN-Plus to be scaled up nationally.



THE POWER OF HOPE: Above: Enjoying time together are, from left, Dr. Apoorva Gomber, associate director of advocacy for the NCDI Poverty Network; Artemisa and Estrela Anselmo; and Dr. Aaron Kowalski, chief executive officer of JDRF International. Below: Dr. Gomber teaches Estrela how to use a glucometer while her mother watches and Ivanilson Abilio, membership and engagement manager for the Maputo Co-Secretariat of the NCDI Poverty Network, translates. Left: Artemisa retrieves the container holding Estrela's insulin from its storage place in the cool dirt.



IN THE FALL OF 2022, ESTRELA Anselmo, a 12-year-old living in rural Mozambique, developed painful ulcers on her feet that wouldn't heal. She stopped attending school because she could no longer walk. Workers at the local health clinic said her feet needed to be amputated.

Fortunately, Estrela's mother, Artemisa, managed to get her daughter to a district hospital in the capital city of Maputo. After several delays, Estrela was diagnosed with type 1 diabetes. By then, though, she had lost consciousness. She was rushed to a referral hospital in Maputo, where she recovered after five days in a coma.

Although Estrela's feet—and her life—were saved, her challenges did not end there. The home she shares with her widowed mother, her three siblings, her grandparents, and four other members of her extended family lacks refrigeration. So her family keeps her insulin cool by storing it in a small container buried in the ground near the water pump.

A refrigerator was not the only advantage that Estrela's family lacked.

Without a glucometer, Artemisa would try to estimate her daughter's glucose levels by monitoring her moods and the color of her blood. "We needed to control her diabetes with a machine we did not have," she said.

In March 2023, when members of the PEN-Plus Partnership visited Estrela, they brought her a glucometer and arguably something as valuable: hope.

Among those visiting were Dr. Aaron Kowalski, chief executive officer of JDRF, and Dr. Apoorva Gomber, associate director of advocacy for the NCDI Poverty Network, both of whom live with type 1 diabetes. Dr. Gomber sat down with Estrela, pulled out her own glucometer, and showed Estrela how to check her glucose level.

Until then, Estrela had never met anyone else with type 1 diabetes. She was shocked to learn that people with the disease could live into adulthood; she had just been waiting to die.

After convincing her that death was not imminent, Dr. Gomber said, "I felt the warmth of her fingers around mine. A spark seemed to light within her, and I

could see her lips twitching." For the first time since her diagnosis, Estrela smiled.

For all the radiance of that moment, Estrela's grim assumption was not entirely misplaced; in sub-Saharan Africa, children living with type 1 diabetes in extreme poverty often die within a year of diagnosis.

Estrela does not have access to PEN-Plus services, given that the country's only PEN-Plus clinic is more than 800 kilometers to the north. Geography has been kind, though; she lives just 15 kilometers from the hospital that saved her life. Many living in rural areas far from the capital are not as fortunate.

"Estrela's story reminded us of the urgent need for more resources to allow a faster national scale-up of PEN-Plus in many countries in sub-Saharan Africa," Dr. Gomber said. "I will keep fighting for her and everyone else living with type 1 diabetes. I remember when I was diagnosed at the age of 13 in India; the feeling of being alone can be overwhelming. Yet hope and community can be powerful healers." ■

PHOTOS: IVANILSON ABILIO (TOP); APOORVA GOMBER (NEAR RIGHT); JUCELINA ROSA NOVELE (FAR RIGHT)

PEN-Plus at a Glance

Where a person lives should never determine whether a person lives. Yet many people with severe noncommunicable diseases in rural areas of sub-Saharan Africa are at high risk of chronic suffering—and even death—simply because they lack access to the specialized care they need.

The Problem



In many parts of sub-Saharan Africa, treatment for people with **severe noncommunicable diseases**—such as **type 1 diabetes, sickle cell disease, and rheumatic or congenital heart disease**—is available only at referral hospitals in major cities, leaving rural communities without vital access to care.



Many families face devastating costs or forgo care altogether, risking disability and even death.



Deaths that noncommunicable diseases cause among children, adolescents, and young adults in the African region each year: **> 540,000**

The Solution: PEN-Plus

PEN-Plus—a proven, integrated, decentralized, community-focused, and person-centered healthcare delivery model—bridges the service gap for people living with severe noncommunicable diseases by bringing lifesaving care closer to home.



PEN-Plus brings high-level expertise in the chronic care of severe noncommunicable diseases to district hospitals for the first time.



To optimize scarce healthcare resources, PEN-Plus trains and equips nurses and clinical officers to deliver crucial services—including diagnosis, symptom management, and psychosocial support—across a range of severe noncommunicable diseases.



The PEN-Plus Partnership convenes advocacy organizations supporting type 1 diabetes, sickle cell disease, and childhood heart diseases to raise voices and increase opportunities for support.

PEN-Plus Across Africa

Twenty countries in sub-Saharan Africa are in various stages of initiating, implementing, or scaling up PEN-Plus.

More than 10,000 people are receiving treatment for severe noncommunicable diseases in PEN-Plus clinics across 11 sub-Saharan African countries.



- Phase 4: National Scale-Up
- Phase 3: Initial Implementation
- Phase 2: Delivery Model Design
- Phase 1: Situation Analysis and Priority Setting
- Additional First-Wave Countries



Scan to view the magazine of the International Conference on PEN-Plus in Africa.

By 2030, the World Health Organization's goal is for 70 percent of the African Region Member States to have national plans for integrated care, NCD training for health workers, and essential medicines in district hospitals.

Severe NCDs in Africa: A Snapshot

< 1 year

The average life expectancy for a child newly diagnosed with type 1 diabetes in rural sub-Saharan Africa.¹

> 50%

The odds that babies born with sickle cell disease will die before their fifth birthday.²

> 70%

The odds that a nine-year-old with rheumatic heart disease in a low-income country will die before the age of 25.³

These tragedies are avoidable. Political leaders, donors, and partners must seize the occasion of the International Conference on PEN-Plus in Africa and commit to PEN-Plus as the proven system for delivering lifesaving care to people living with severe noncommunicable diseases in rural sub-Saharan Africa.

Sources: World Health Organization Regional Office for Africa; Lancet Commission on Reframing Noncommunicable Diseases and Injuries for the Poorest. Billion

¹ Beran D and Yudkin JS. Diabetes care in sub-Saharan Africa. *The Lancet* 2006;368:689-95.

² Modell B and Darison M. Global epidemiology of haemoglobin disorders and derived service indicators. *Bull World Health Organ* 2008;86(6):480-487.

³ Hewitson J and Zilla P. Children's heart disease in sub-Saharan Africa. *SA Heart J* 2010;7(1): 18-29.

PEN-Plus Timeline

2006

Clinicians in Rwanda begin designing a new model for delivering healthcare to people in rural sub-Saharan Africa.

2015

This new model enables the number of people receiving care for type 1 diabetes to increase by a factor of 10, from around 200 to 2000.

2019

Together, the World Health Organization Regional Office for Africa and the NCDI Poverty Network adopt "PEN-Plus" as the official name of the model, in acknowledgement of the role it serves as a complement to WHO PEN.

2020

The NCDI Poverty Network launches shortly after the publication of the Lancet Commission on Reframing Noncommunicable Diseases and Injuries for the Poorest. Billion report, which identified the gap in access to treatment for severe noncommunicable diseases.

2022

All 47 members of the WHO African Region adopt PEN-Plus as their official strategy for providing care to people living with severe noncommunicable diseases.

2024

The WHO African Region hosts the first International Conference on PEN-Plus in Africa.

2030

The PEN-Plus Partnership continues to work with global partners to reach significant annual funding by 2030 to help save countless lives, transform noncommunicable disease care, and accelerate progress toward universal health coverage.

THE POWER OF UNITY

Together, we can combat injustice and complacency.

BY ANA MOCUMBI, MD, PHD

Throughout the history of global health efforts, policymakers have argued that limited health-care resources in low-income countries are best spent on prevention, leaving many of the world's poorest people to die of treatable diseases. More than two decades ago, though, Partners In Health proved that notion wrong, by showing that novel, community-based treatment strategies could deliver high-quality healthcare even in the poorest settings.

In so doing, Partners In Health inspired a paradigmatic shift in global health, one that replaced complacency and pessimism with audacious humanity. In that same tradition, the PEN-Plus Partnership responds to the moral imperative of providing high-quality healthcare to those who need it most with an undaunted optimism and the determination, political will, and collaborative ingenuity required to achieve the seemingly impossible.

The PEN-Plus Partnership—a collaboration of advocacy, policy, funding, and technical partners from around the world—works to expand PEN-Plus services for people living with severe, chronic noncommunicable diseases within currently participating countries as well as to set the stage for introducing PEN-Plus to additional countries. Hundreds of thousands of children and young adults with type 1 diabetes, sickle cell disease, childhood heart diseases, and other severe chronic noncommunicable diseases are relying on us to end a great injustice. These people live and die in rural areas of lower-income countries. And because of cruel historical circumstances, they lack access to the health



professionals, supplies, and social protection they need to survive. PEN-Plus aims to bridge this shocking gap.

To ensure the best possible outcomes for patients and health systems, the PEN-Plus model was founded on principles of science-based evidence. Data from micro-costing studies in Rwanda have found, for example, that the initial start-up costs for PEN-Plus clinics—including new construction, equipment, and initial training—amount to around \$50,000 per facility serving 250,000 people. The ongoing operational costs of these clinics to manage 500 to 1,000 patients are an estimated \$70,000 per year, which represents around \$100 per patient, or about 30 cents a person on a population basis. Through our Lancet Commission research, though, we found that low-income countries will simply be unable to finance their most basic services without external support for at least the next decade.

But we are optimistic that there is a solution. And together, we are that solution. If we can marshal the voices, energy, and passion of even just the type 1 diabetes, sickle cell, and childhood heart disease communities, we believe we can find the resources to right a cruel injustice. ■

Ana Olga Mocumbi, MD, PhD, is a co-chair of the NCDI Poverty Network and an associate professor of cardiology at Universidade Eduardo Mondlane in Maputo, Mozambique. She also heads the Division of Non-Communicable Diseases at the National Public Health Institute in Mozambique's Ministry of Health. She served as a co-chair of the 1996–2020 Lancet Commission on Reframing NCDs and Injuries for the Poorest Billion, which led to the creation of the NCDI Poverty Network.

RETURN TO HEALTH: Ten-year-old John Blessing Sesay had visited the hospital often for his mysterious swelling and pain, only to return home each time with misdiagnoses and ineffective medications. After several years of frustration for his family, John was referred to the PEN-Plus clinic in Kono, Sierra Leone. There he finally received a definitive diagnosis: nephrotic syndrome. "I don't pay anything for this treatment," his mother, Sarah, said. "If this clinic were not here it would be a big problem for me. I couldn't afford these medicines."



ILLUSTRATION: ISTOCK
PHOTOS, THIS PAGE AND BACK COVER: © MICHAEL DUFF / WORLD HEALTH ORGANIZATION



BACK IN PLAY: Fatmata Fofanah, a six-year-old with congenital heart disease, lives in Kono, Sierra Leone. With support from the nearby PEN-Plus clinic, which Partners In Health runs, her symptoms have eased enough for her to be able to play with her friends again.



International Conference on PEN-Plus in Africa
World Health Organization—Regional Office for Africa
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ORGANIZING PARTNERS

