On a scorching Saturday in Kabarore Sector, Gatsibo District, Vestine Uwimana noticed her 8-year-old Claude Uwiyigiremana, was unusually tired. She assumed it was fatigue from fetching water.

Three days later, Claude developed fever, abdominal pain, and blood in his urine. Alarmed, Vestine rushed him to the nearest health center, where tests revealed he had Billizahia (Schistosommiasis), a disease caused by parasitic worms found in contaminated water.

“I thought he was just tired, and did want to go to school,” Vestine said. “I didn’t know that water itself could make him sick.”

In Rubavu District, Alice Nshimiyimana faced a similar ordeal when her daughter had persistent abdominal pain. After multiple hospital visits to Rabavu Main Hospital, she too was diagnosed with Bilharzia.

For years, Neglected Tropical Diseases (NTD’s) have silently undermined communities, reducing school attendance, productivity and health.

According to Dr. Jean Bosco Mbonigaba from Rwanda Biomedical Center (RBC), Bilharzia is among the world’s most persistent NTD. “Limited awareness and access to unhygienic water in vulnerable communities continue to fuel its spread,”

The World Health Organization (WHO) estimates that more than 251 million people are affected each year, with Sub-Saharan Africa carrying nearly half the global burden, and 280,000 deaths linked to the disease each year.

In Rwanda, a 2025 national mapping survey found that 2.4 percent of the population tested positive for Bilharzia, with 13 hotspots showing infection rates from 10.4 to 38.3%, mostly among school-aged children.

A map of Rwanda showing prevalence rates across the regions

Source: Mapping survey

Burera and Gisagara Districts show the highest rate of prevalence with over 50 people (60 per cent) testing positive, other areas include Rusizi District near Lake Kivu, Gatsibo, Nyagatare, and Rutsiro.

“Children often play in swamps and ponds,” says Esther Mutesi, a trained Community Health Worker (CHW) in Gatsibo District. “These infections hinder growth and health, and women and girls are most affected.”

Farmers working in marshlands are also vulnerable. “The rice field is our source of income,” Alphonse Mutuyimana, a farmer from Ntende cooperative notes. “But we spend long hours in stagnant water without realizing the danger.”

Life cycle of Schistosomiasis, from contaminated water to human infections

Source: Wikimedia Commons.

“The parasite depends on fresh water as an intermediate host,” Dr. Mbonigaba says, “Behavioral factors such as bathing in contaminated water, while unhygienic sanitation and hygiene continues to fuel the spread of Bilharzia.”

The NTD affects people of all ages alike. Communities that depend on marshlands for farming, particularly those engaged in rice growing, face high risks due to repeated contact with contaminated water

“Defecting near lakes, and streams, makes it easier for the parasites to return to water bodies,” he added, “In many cases , people may not realize they are infected because symptoms such as fever, blood in urine or stool, and skin irritation do not appear immediately.

He stressed that maintaining basic hygiene remains one of the most effective ways to prevent Bilharzia. “Providing access to clean water, improving sanitation, and ending open defecation near water bodies are vital preventative measures,” he said.

WHO recognizes 21 Neglected Tropical Diseases (NTDs) globally, affecting about 1.65 billion people, 40 percent of them in Africa. In Rwanda, over five million people live with one or more NTDs, though seven of the 21 are no longer considered a public health concern, according to the Rwanda Biomedical Center (RBC).

To tackle this, Rwanda is integrating Water, Sanitation and Hygiene (WASH) with NTD elimination. One of the innovative ways is the Bilharzia Storytelling Lab, launched between 28 November and 22 December.

The project uses comic notebooks to teach children, parents, and communities about causes of Bilharzia, symptoms and prevention.

“Our goal is to educate through creativity and participation,” explains Betrand Byishimo, the project founder.

“Before starting our awareness activities, we first visit schools to collect baseline data,” explained Yvonne Ninyembabazi, Project Coordinator of the Storytelling Lab. “We assess what students and communities already know about Bilharzia, their attitudes and behaviour’s, by asking questions such as whether they go to swamps barefoot, if they have heard about the disease, or recognize its symptoms,”

“After distributing notebooks containing health messages, we return later to measure the change in knowledge and behaviour. It takes time to build understanding, but using music, games, and storytelling helps make the lessons stick for sustainability,” she noted.

Students participate in competitions, storytelling, and art activities, reinforcing learning at school and at home. Top performers receive prizes, school materials, and one year coverage of school feeding fees.

Each student also receives a homework notebook filled with Bilharzia health messages written in local languages serving as an educational resource and a reminder to share information at home.

Best students receive gifts: Courtesy photo

“Many rural communities lack computers or smartphones, so the notebooks directly communicate public health messages,” Byishimo added.

Interactive workshops, skits further encourage children to share prevention messages with their families.

The project initially introduced in three schools in Bugesera District, has reached

25,000 students in Bilzarhia clubs, led by students, now guide awareness efforts within schools. To ensure sustainability, the Lab Project partners with the END Fund, Rwanda NGO Forum, and RBC.

Building on its early success in Bugesera, the project expanded to Gatsibo and Ruhango Districts, reaching four secondary schools. The team distributed more than 10,000 notebooks containing Bilharzia prevention messages.

“We’re already active in these districts,” said Ninyembabazi, “we our baseline data collection and final assessment will take place in March 2026 to measure how much knowledge, attitudes, and behaviors have changed.

“We’ve seen encouraging results where children now act as health messengers in their communities. Our aim is to keep building this network of young ambassadors, so that awareness about Bilharzia becomes part of everyday life, not just a classroom lesson.”

The project received a US$10,000 grant (roughly RWF 14.4million) at launch by Merck KGaA, Darmstadt, Germany.

“It is changing community perceptions,” said Dr. Mbonigaba. “Through engagements and health promotions, we believe the disease can be eradicated.

Ladislas Nshimiyimana, Senior NTD Research Director at the RBC and also an expert trainer with Lab Project praised the project approach, “We had realized that it is not possible to fight Bilharzia in this sector, due to high prevalence,” he said. “However, through greater community engagement and health promotion, we believe that the disease can be eradicated.”

Dr. Mbonigaba explained that partnership between Merck KGaA, and the END Fund have provided Rwanda with eight million praziquantel tablets each year to treat adults at risk of infection. Since 2001, Merck has donated 15 million tablets to Rwanda. This Bilharzia storytelling lab looks promising; it is changing community perceptions,”

Belén Garijo, Deputy CEO of Merck described the partnership as “another important step toward a schisto-free world.”

At Groupe Scolaire Nyiragiseke, the impact is already visible. Marie Goretti Kamanzi, Director of school, said the project has raised awareness among both pupils and their parents.

“It has been very important because children now understand the harmful effects of bilharzia,” she explained. “You can see the change in their daily behavior, when it rains; they avoid playing in stagnant water. They’ve learned that bilharzia can infect them through such contact.”

Kamanzi added that educational materials provided through the program have reinforced this understanding. “The books have been a constant reminder,” she said. “The only challenge is that many of the books have become worn out and now need to be replaced.”

Parents have also noticed changes too. Innocent Karanganwa, a parent in Rweru Sector, said my children explain how Bilharzia spreads and how to prevent it. Now we boil water and avoid sending children to fetch water from the lake.”

Teachers have also reinforced safety: “Students are taught not to fish or cultivate near contaminated water bodies without protective boots,” said Anaclet Ndatimana, teacher at Nyiragiseke.

Students like Charisse Ishimwe, in Primary Five, have altered daily habits. “We avoid dirty water, no longer wash clothes in wetlands, and always use the toilet,” she said.

Government-Led Measures Driving NTD Elimination

Rwanda’s fight against NTDs is spearheaded by the government under a One Health approach led by the Technical Working Group (TWG) that integrates WASH interventions into the National NTD Strategic Plan (2019–2024).

According to Dr. Mbonigaba, deworming and Bilharzia treatments, alongside awareness campaigns through radio and television, are being combined by WASH awareness, education, and behavioral change.

MDA campaigns have delivered over 68.8 million deworming treatments and 3.2 million Bilharzia treatments, significantly reducing intestinal worm infections among

school-aged children.

“Involving teachers in distributing medicines during lessons saves time and resources instead of relying on community drug distributors. Integrating into their teaching routine saves time and resources,” Dr. Mbonigaba explained.

Village meetings and parent’s forums further extended awareness campaigns and treatments to adults without extra financial costs. Rwanda integrated approach also included vector control, with staff conducting snail monitoring and surveillance.

So far, 89 percent of administrative zones meet Bilharzia elimination criteria. Since 2017, scorecards have tracked NTD progress, guiding resource allocation and interventions. More than 42,000 CHW’S have been trained to identify and manage NTD’s.

To prevent resurgence, new surveillance systems have been introduced. The Ministry of Health promotes cross section collaboration, linking health, malaria, WASH, agriculture, and veterinary services and malaria programs under a shared vision.

The digital tracking system tracks WASH –related NTD hotspots, and monitors interventions outcomes in real time.

The Ministry of Health through RBC is compiling data to support a formal request WHO officially validate Rwanda elimination seven NTDs as public health problems.

In Ruhango and Bugesera, local communities are on the frontlines of the fight against soil-transmitted helminths and Bilharzia. The projects are combining mass drug treatments with hands-on education and behavior-change campaigns, while improving access to clean water and better sanitation. The result is a full-scale, community-driven effort to stop these diseases before they take hold.

From the community perspective, Mutesi emphasizes that washing hands with soap removes germs from hands. It helps prevent infections like Bilharzia, and other NTD’s.”

Despite progress, challenges remain. “One of our main challenges is limited resources,” said Ninyembabazi. “Each notebook costs between RWF 800 and RWF 1,000 from suppliers, which makes it difficult to reach every school we plan to cover. But every book matters, it’s a small tool that can make a lasting difference.”

Also, many rural communities still lack reliable water sources. Limited data on infection rates and hygiene practices make it difficult to measure the impact of initiatives like Storytelling Lab.

“Scarcity disrupts hygiene practices, and some people resist new behaviors if they don’t see immediate benefits,” said Karaganwa.

Analysts have warned that limited data on infection rates, hygiene practices, and project outcomes makes it hard to measure the impact of Storytelling Lab Project and adjust interventions.

“In Bugesera, water scarcity disrupts hygiene practices, and some people resist to adapting to new behaviors if they don’t see immediate benefits. They still rely on traditional methods of directly fetching affordable and polluted water from the lake. Which makes it difficult to implement such projects against diseases like Bilharzia,” Karanganwa added.

To Mutesi the CHW, toilets and proper sanitation facilities are often insufficient. Some households have no or poor unhygienic lavatories.

“Remote schools, and communities face logistical challenges in receiving hygiene and educational resources, while conducting workshops, at times CHW and teachers often have limited training or are overburdened, this affects the quality as well as consistency of awareness campaigns,” she pointed out adding, “Some communities still lack the understanding of how Bilharzia spreads, and how to prevent it.”

To ensure sustainability, strong local government commitment and resource mobilizations are needed. UNICEF estimated that Rwanda requires Rwf.249 billion annually to meet the national WASH targets and Rwf.400 billion to achieve the 2030 Structural Adjustment Goals (SDG’s) of universal access to clean water, leaving a gap of up to Rwf.204 billion.

Esther Mukantwali of Rwangara Village, Bugesera, used to wake at 3 a.m. to walk an hour for swamp water. The African Development Bank funded a project to bring water closer to residents.

WASH and NTD projects like Storytelling still rely heavily on international funding, highlighting the need for stronger local government commitment and resource

mobilization.

“Climate change has worsened the challenges,” Daddy Rubangura, Executive Director of the Rwanda Journalists Association noted

“Floods and pollution force communities to rely on contaminated water sources, increasing exposure to Bilharzia and other diseases,” he added.

Still, the combination of education, behavior change, and government led interventions is showing results. Children, families, and communities are becoming the frontline fighters against Bilharzia in Rwanda, spreading awareness using one story, one sketch, and one clean drop of water at a time.