



LIVING WITH RHD

Valder's Story

Valder Dormilus was born and raised in Haiti, a low-income island country of about 10 million people located in the Caribbean. He grew up with his father and three older sisters on a rural farm, where the family lived and worked.



Valder was officially diagnosed with rheumatic heart disease (RHD) at 14 years old, when he visited a clinic run by Partners In Health in the mountains of central Haiti. It is likely that Valder had been living with RHD for several years already, but without appropriate health care, he had been unable to receive an accurate diagnosis, let alone treatment.

Rheumatic heart disease (RHD) is a preventable and treatable disease of the heart. It most commonly affects children and young people living in conditions of poverty and overcrowding. RHD can be prevented and treated using one of the world's most basic medicines, penicillin, but if caught too late or left untreated, RHD can be fatal: it kills 275,000 people every year.¹

In Valder's case, his rheumatic heart disease was already severe by the time help arrived. His untreated condition had affected his growth, leaving Valder significantly smaller than his father. By the time Partners In Health was able to connect Valder with a newly-founded organization called Haiti Cardiac Alliance, it was clear that Valder required urgent surgery to repair his heart.

Despite the urgency of Valder's condition, locating a hospital and surgeons willing to donate the heart surgery, and subsequently navigating the Haitian bureaucracy to obtain a passport, took two years. As Valder waited, he was given prophylactic penicillin and had regular cardiac check-ups to keep him as healthy as possible. In early 2015, he boarded his first ever aeroplane, and made a journey of over 1,500 miles to the US donor hospital in New York state.

The surgery itself went well: one of Valder's damaged valves was repaired, and the second damaged valve was replaced with a mechanical valve.

But shortly after returning home, it became clear that Valder's heart was still pumping almost as weakly as it had been before the surgery. His heart had been damaged for so long during his wait for treatment that even the new heart valves could not support him.

Valder was hospitalized several times in Haiti, where he was able to access medicines to prevent his heart from failing completely. Medical staff remember his bravery and optimism

during these visits. However, it soon became clear to his doctors that Valder would not recover from his end-stage heart failure.

Valder Dormilus died at home on 18 April 2016, surrounded by his family. His father, who had sold almost all the family's farm animals to pay for his son's care, was about to sell his last cow to pay for a dignified funeral. The Haiti Cardiac Alliance stepped in and fundraised for the costs to be met, so that the family would not be left destitute from the cost of Valder's RHD.

Valder's story could have ended very differently. Had he been able to access timely diagnosis and the correct medicines, he might not have needed surgery at all. If the systems and services were in place for Haitians to access primary health care for RHD, Valder would still be with us today. There is much to be done in Haiti and other countries with a high burden of RHD. Governments, NGOs, academia and individuals all have a role to play. Find out what you can do at: www.rhdaction.org. To learn more about the Haiti Cardiac Alliance, visit: www.haiticardiac.org.

Valder's story has been shared with the kind permission of the Dormilus family and the Haiti Cardiac Alliance. By honouring Valder and other people who have lived with RHD, we hope to strengthen support for RHD prevention and control across the world.



Photos courtesy of Cristina Baussan



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Wesly's Story

Wesly Marcena is a 19-year-old young man who lives near Port-au-Prince, Haiti. When Wesly was 13, he fell ill from rheumatic fever which severely damaged his heart.



Before his rheumatic fever, Wesly was a healthy, active boy; afterwards, he became fatigued and lost weight. Wesly's symptoms grew worse: within 3 years he could no longer attend school. Doctors in Haiti recognized that he had now developed rheumatic heart disease (RHD), but none could offer basic medical treatment or surgery to manage this preventable disease.

In 2015, when Wesly was 18, his aunt brought him to be examined by Haiti Cardiac Alliance (HCA), an organization that helps young Haitians access heart surgery. The volunteer cardiologist was concerned that Wesly's rheumatic heart disease might be too advanced to withstand treatment. Nevertheless, HCA started Wesly on heart failure medication and penicillin prophylaxis, and began sharing his story in the hope of finding a hospital willing to donate his surgery.

After several months, a hospital in the USA agreed to accept Wesly for valve surgery, free of charge. It took several more months to complete Wesly's paperwork, but in January 2016 he arrived in the USA for his procedure.

However, when Wesly went to the hospital for his pre-operative examination, his disease had deteriorated during the long wait, and he was now in end-stage heart failure. In this state, the surgical team felt that surgery was too risky, and that Wesly may only have a few weeks to live.

This created a difficult dilemma. Wesly could either remain in the United States hoping to find a different hospital able to offer surgery; or return to Haiti without treatment to be with his family. Wesly, his family and the HCA discussed this decision, and decided that Wesly would remain in the USA for two weeks. If no solution came he would fly back to Haiti for end-of-life care at home.

Wesly was incredibly courageous and mature about this approach and the fact that he might not have long to live.

Meanwhile, HCA sent Wesly's medical information to several hospitals, including Health City Cayman Islands. After multiple reviews, their cardiac team felt that Wesly might still have a window of opportunity for surgery – although with a very high risk of death during or just after the operation. Ultimately, the choice was left in Wesly's hands whether to undergo risky

surgery in Cayman, or spend his remaining weeks with his family in Haiti. After many conversations and prayers, he decided to have the surgery.

Health City Cayman Islands spent over a week administering powerful cardiac medications to prepare Wesley's heart for the surgery. Then, after a last phone conversation with his family in Haiti, Wesley was wheeled in to the operating room where a world-class cardiac team spent the entire day labouring over the incredibly difficult task of replacing Wesley's heart valves.

Wesly survived the operation. The entire cardiac team watched apprehensively as he struggled to recover in the intensive care unit. Slowly but surely, he made progress and was soon giving a 'thumbs up' from behind his oxygen mask to the hospital team, and to his family in Haiti over video link.

Without life-saving surgery, Wesly would not have survived. But it need not have come to this. If Wesly had been given health care and simple medication to prevent his RHD from worsening, this could have saved him and his family much heartache.

Wesly is now back in Haiti, and is enjoying being a healthy teenager. He will need daily medication and regular blood tests to manage his artificial heart valves for life. But otherwise Wesly lives his life with no limitations or cardiac symptoms. He is preparing to return to school for the first time in three years, and has incredible energy and optimism for the future.



There is much to be done in Haiti and other countries with a high burden of RHD. Find out what you can do at: www.rhdaction.org. To learn more about the Haiti Cardiac Alliance, visit: www.haiticardiac.org.

Wesly has shared his story in the hope that it will inspire more work on prevention and control of rheumatic heart disease across the world. Find out how you can play a part at: www.rhdaction.org