

## Living with RHD: Zafirah's Story

# Managing Pregnancy

Zafirah has striking dark features and a maturity beyond her young age of 20 years. She lives in the island nation of Fiji in the third largest city of Nadi. Nadi, on the island of Viti Levu, is a multicultural town with beautiful beaches that attract tourists from all over the world.



Zafirah was born and raised in rural Mulomulo, Nadi, where she attended primary school. Later her family moved to Nadi Town where she completed high school. Zafirah comes from a small family by Fijian standards – it's just herself, her parents and her elder brother – but she has a very large extended family.

Zafirah was diagnosed with RHD in 2010 while she was still in primary school. She says she had the usual signs and symptoms – sore throat, shortness of breath, swollen joints

– but there wasn't much awareness about RHD at the time, so the doctors at the local clinic didn't recognise what was wrong with her.

One afternoon, Zafirah's grandfather called her mother from Suva to ask about Zafirah's recent clinic visit. When he heard there were no answers and no treatment offered – that Zafirah wasn't getting any better – he suggested they come to the capital city of Suva to go to the Colonial War Memorial Hospital (CWM). Zafirah and her mother left home at 5 o'clock that

very afternoon, traveling more than four hours by bus to Suva, to her grandparents' house.

In the morning, they travelled to the CWM Clinic in her grandfather's car; arriving at the outpatient clinic without an appointment, they didn't know what to expect. Zafirah had a chest x-ray and was told to collect her results the next day.

"The doctors at CWM recognised right away that something big was wrong with me. They showed us my x-rays and we could see that my heart was enlarged. My valves were really damaged and I was admitted instantly." Zafirah was treated in hospital for six weeks.

A year later, in 2011, Zafirah received a call from the CWM Hospital telling her that her case had been assessed against the eligibility criteria and she had been nominated for surgery to repair her mitral valve by a visiting team of surgeons from Australia. Zafirah was 13 years old; she was scared, and wondered if she would make it through the surgery.

After weeks of waiting and preparing for surgery, the big day finally arrived. The procedure went perfectly, without complications. She had expected a long post-op stay and was very surprised and



happy to be discharged just four days later with what she calls her “new life”. As she recovered from the pain and soreness from the surgery, she started to experience the change – the very noticeable improvement in her strength and energy level!

Back at home after surgery, Zafirah finished secondary school and found a job at the airport. She met her “special guy”, got married and they started a family right away. Her daughter is now just over one year old. Zafirah had a normal easy pregnancy although labour and delivery were difficult; the doctors monitored her heart closely throughout the birth of her daughter. She feels she was well taken care of, and also credits her good experience to having been compliant to her \*Benza injections and other medications, and follow-up appointments.

Now Zafirah has a full-time sales and marketing job in the seafood industry; her husband works for

## ‘MY PARENTS NEVER GAVE UP ON ME.’

the same company. Because her work sometimes requires shift and weekend work, Zafirah’s auntie helps with child care. Zafirah has plans to complete her tertiary education. “Life is good!”

Zafirah has been active with the RHD patient advocacy group in the Western Health District in Lautoka since 2014. She attends workshops a couple of times a year to improve her advocacy and communication skills for increasing awareness about RHD in her community and taking part in World Heart Day celebrations each year.

Zafirah would like to tell other young women who have RHD not to hide their condition from their

partners and their communities. She knows there is discrimination and stigma. Zafirah also acknowledges that the *benza* injections are painful – although not as bad now that it’s mixed with Lignocaine, a local anaesthetic medicine. But Zafirah has seen young women who do not disclose their RHD diagnosis to their partners or healthcare providers, and then they become pregnant; their untreated RHD causes complications that could be avoided. Zafirah says that denial and not being compliant to *benza* secondary prophylaxis is dangerous.

Zafirah knows she is blessed to have good health, a lovely healthy child, and a strong marriage. She is thankful to her partner who has stood by her side in all situations and to her parents “who never gave up on me”. She shares her good fortune in life with her commitment to help other young women with RHD in her community by sharing messages of awareness and education so that they too can have the best possible outcomes.



*In collecting these stories of women with RHD and their pregnancies we have sought to honestly represent the reality of our patients’ lived experiences. RHD Action encourages all RHD patients to stay in care and follow their medical professionals’ advice, to achieve the healthiest and safest outcomes for themselves and their babies.*

\*“Benza” is Benzylpenicillin, benzathine g penicillin or BPG and is used as secondary prevention against the repeated streptococcal or “strep” infections that damage heart valves.