

## Living with RHD: Livini's Story

# Managing Pregnancy

Livini is a young woman in her mid-twenties with a shy smile, that quickly warms into an openness to share and engage others with her personal story about living with Rheumatic Heart Disease and her journey through diagnosis, sickness and health, pregnancy and life.



Livini is from Fiji and lives on the big island of Viti Levu in the city of Lautoka. Lautoka, on the western coast, is the second largest city in Fiji and is known for its shipping and fishing industries, as well as being situated in a vast area of sugar cane production. Most people in Fiji live in cities and towns along the coast. Its mountainous interior is less populated, and development is limited by poor roads, steep terrain and dense vegetation.

Livini's family is originally from Malolo Island, about 30-minutes by boat from Lautoka. Livini is a twin and one of seven children. The family lived for a while in coastal Ra Province (Rakiraki Town) where

Livini went to primary school before the family settled permanently in Lautoka. There, she completed secondary school and took some classes afterward but has not yet finished her tertiary education.

While growing up, Livini remembers feeling weak, and having shortness of breath and joint pain. She remembers her joints aching as she was traveling to and from school, but she pushed it out of her mind, thinking she was just tired and hurting from running and playing. When she did go to the clinic, she was told she just had fever or a headache and was sent home with medication. She also remembers, when she was 21 years old, going

to the hospital in the middle of the night with pain and shortness of breath. "They gave me an injection and told me to go home. That's it." There was no follow-up or further investigations offered.

At 24 years old, Livini was diagnosed with heart failure. Her shortness of breath was getting worse and one night it became so bad that her parents took her to the local hospital. The doctors told her that water had accumulated in her lungs because her heart wasn't functioning properly. She also found out she was pregnant at that time. She stayed in hospital for an entire month around the Christmas holidays; doctors drained fluid from her lungs two separate times.

Livini did get to go home for a few days over Christmas, but then she went right back to hospital after the New Year. Doctors told Livini that her pregnancy was unsafe - that her heart was not strong enough to handle pregnancy, and the labour and delivery to follow. The doctors advised Livini not to continue with her pregnancy to protect her own life. They also told her there was no guarantee her newborn baby would be healthy and normal.

Livini consulted with her parents for support and guidance for



this very difficult decision. After discussing all the aspects of the situation as a family, they all agreed to support Livini's decision to see the pregnancy through despite the risk. Livini says she and her family just kept hoping and praying. She followed doctors' orders, made sure she got her *benza* injections on time, and kept all her follow-up appointments for the rest of her pregnancy.

During one of the follow-up visits late in her pregnancy, Livini learnt that she had RHD - that her heart valves were damaged and causing her heart failure. This diagnosis came after an echocardiogram of her heart during a consultant appointment at the hospital. It all began to make sense but there was hardly time to think through this information because just three weeks later, Livini's baby girl was born; the delivery was normal with no complications. Her baby girl was perfect! Livini, her family and the hospital staff felt it was a miracle.

Livini lives at home with her daughter, her parents, a brother, and a sister. Her baby girl is now 18 months old - healthy, normal, growing fast - keeping everyone in the household very busy. Livini is feeling well but admits to still getting tired at times. There are no immediate plans for the surgical repair of her heart valves. She is managing with medication, keeping her follow-up appointments and taking her monthly *benza*.

Livini admits that she did default on the *benza* for a while, exclaiming "It's such a painful injection!" But she started to feel sick and worried, so she decided to make her way back to the hospital for her injections. A phone call from the clinic nurse, Nurse Ana, added to her motivation to get back into her

## 'DON'T' GIVE UP... KEEP ON HOPING. BE STRONG FOR YOURSELF!'

*benza* routine. Now Livini feels it's her role to encourage other RHD patients to take care of themselves and to stick to the monthly injections - despite the pain.

Not yet working, Livini is feeling discouraged, having been turned down for a job because the employers were worried about her health after she told them about her RHD. She hasn't given up, and in the meantime, she has joined a newly-formed RHD patient group in the Western District in Lautoka. She just completed a training session with 25 other PLWRHD, attending a 2-day workshop for communications training to prepare for promoting RHD Awareness during Heart Month in Fiji.

Livini feels that RHD is a problem in Fiji mainly because of a lack of

awareness in the community as well as among the health workers in the clinics. She feels the problem is worse in the interior of the country where health services and the infrastructure for communications and transport are not well developed. They are the people in her mind that need to be targeted for outreach and awareness about RHD treatment and prevention.

Livini knows she is extremely fortunate to have such a happy outcome to a very serious situation and is very thankful for her loving and supportive family. Her message to her fellow RHD patients around the world, especially young women, is simply "Don't" give up... Keep on hoping. Cooperate with your doctors. Get your *benza* on time... And stay positive! Don't ever lose hope! ... Be strong for yourself!"



*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.