

Acknowledgement

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A story from our homes for our homes and others

We are mums, dads and children. We live with hepatitis B ourselves, some of our family members, too. We come from very different cultures but share the same dilemma of talking about hepatitis B with our children.

While hepatitis B is considered "family business" due to the requirement for life-long management and the involvement of possible mother-to-child transmission, it has never been part of our family conversation.

One of us noticed the value of reading time in our children's bedtime routine and wanted to introduce the hepatitis conversation during the most ordinary moment of our lives. We came together with Hepatitis Victoria to shape the conversation by considering our children's interest, the information we want to convey and our cultural norms.

Our core principles for this book are "bright, colourful, positive and silly".

This book is the result of our journey from January 2017 to February 2018 with much laughter, tears and emotional moments, with meetings and catch-ups at Hepatitis Victoria's Board room, cafes, parks and our homes. It was also a journey from being acquaintances to becoming friends.

In our lives and through this book, we make our children our Little Hep B Heroes, and would like to send the same wisdom to yours.

From our homes with love,

Nafisa Yussf, Zoe Hannon, Dang Van Thao, Manuela Udriste and little Tavi, Olivia Zheng, Yith Chhun, Linh Nguyen and her little one, and Lien Tran.



Mum and I are going next door to visit Rosa.



Sam says, 'Can I come too?'

Dad says, 'I hope she's been cooking, again.'



'Cooking makes me happy,' says Rosa. 'Even when I'm not feeling well.'

'What's the matter?' I ask her.

She stirs a delicious-smelling pot. 'Do you really want to know?' she says. 'Sure I do,' I say. I love chatting with Rosa. She takes a long, slow breath. 'Well... part of me is playing up...' 'What part?' I say. 'It's called my **liver**.'

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When Rosa frowns I think maybe I shouldn't have asked. 'What are you making?' I say.



'It's my famous tomato sauce,' Rosa replies.'The one your dad loves so much. Do you want to help?' She hands me a big sieve.

'We have to take the seeds out,' she says, 'otherwise it will taste bitter.'

Rosa pours the cooked tomatoes through the sieve. The pips glisten like little red pearls.

'This is like one of the jobs my liver should do. When our livers are working properly, they take out the things in our blood that aren't so good.'

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Rosa's sauce looks smooth and silky. It smells so good I could eat it by the spoonful. She smiles when she smells it, but it's not the **big**, **BIG** smile she sometimes smiles.

It's the other one. The one she smiles when she's not feeling well.



'Your liver is next to your stomach on the right side of your body, just under your ribs. It's the biggest organ inside your body and in grownups it weighs one and a half kilograms.'

The liver can fight diseases...

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...process and clean blood...

...and store energy.

'Hep B can harm your liver and make it harder to do these things.'





...bumpy-skinned lemons...



Back in Rosa's kitchen we cut the lemons for fresh lemonade. Mum comes in with Sam.



Mum frowns.

'It's OK,' says Rosa.

'Hep B is carried in some people's bodies...

...It's in blood. If one person's blood has hep B they can pass on the disease if even a little bit gets into someone else's blood.'

> 'That's why doctors use new needles every time they give someone an injection.'

'How did you get it?' I ask her.

'You sure ask a lot of questions,' she says.

'I don't know how...



... There are lots of ways people catch hep B.'

That's when Mum chimes in,

'Its not just blood in needles or from cuts and things. Infection can happen any time blood with hep B contacts another person's blood...



'Wow, Mum,' I say.'How do you know so much about hep B?''I've told you before,' she says.'Grown-ups know everything.'

'Well... almost everything.'



'That looks like enough juice?' says Rosa. She carefully wipes the knife we used to cut the lemons. 'Hep B,' I say, 'can doctors fix it?''My hep B is chronic,' says Rosa.'That means it doesn't go away. But my doctor helps me stay healthy.

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I have regular check-ups and tests to find out how I'm going. We test my blood and my liver. We have a plan so I don't feel sick so much.

I eat good fresh food and I keep myself busy with my garden and my cooking.'

'That's how I live with hep B,' she says.'A lot of the time I feel fine. But sometimes, like now, my hep B makes me feel unwell.'

Rosa mixes syrup into the lemon juice, but not too much. She pours a glass for me to try.

YUM... DELICIOUS!

'I think you're pretty brave,' I say, sprinkling mint leaves into the jug.

'I suppose,' she says. 'Nowadays doctors can stop other people getting hep B. They use a **vaccine** to fight the virus that causes the disease.'



Sam goes suddenly quiet. He doesn't like needles.

'I wish you'd had them,' I say to Rosa.

'I do too,' she says, with a bit of a sad face.

But then she tastes her lemonade and her smile starts to grow.

And this time it goes all the way to that **big**, **BIG** Rosa smile I love.

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'It's been really good talking to you about hep B. Sometimes all you need to be a hero is to listen to someone talk', says Rosa.

'I was feeling sorry for myself. Talking was just what I needed. You're my hero,' says Rosa.

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Sam frowns.





Draw your own Little Hep B Hero here.

Glossary

Hepatitis is inflammation of the liver.

Hepatitis B is a type of liver inflammation caused by the hepatitis B virus.

The liver is the largest internal organ of the human body weighing up to 1.5 kilos in an adult.

Acute hepatitis B is if it lasts less than 6 months. Chronic hepatitis B is if it lasts more than 6 months. Most people living with chronic hepatitis B live with it their whole lives.

A vaccine is a product administered to a person (mostly via injection) to protect the person from getting a particular infection.

Hepatitis B vaccine is a vaccine against hepatitis B.

Questions to think about and discuss:

Why is Rosa feeling unwell?

Where is your liver and what does it do?

Who is the Little Hep B Hero in the story?

Information for parents

Overview of hepatitis B

Hepatitis is an inflammation of the liver. Hepatitis viruses are the most common cause of hepatitis in the world but other infections, toxic substances (e.g. alcohol, certain drugs), and autoimmune diseases can also cause hepatitis.

Hepatitis B is caused by hepatitis B virus and people with chronic hepatitis B (CHB) live with it for life. People can live for decades without showing any symptoms but without treatment this condition can lead to cirrhosis, liver cancer and liver failure. Early diagnosis and sufficient management can prevent onset complications and reverse that trend. People living with CHB are recommended to have a check-up every 6 to 12 months.Hepatitis B is transmitted through blood or other body fluids contact, unprotected sex with people living with hepatitis B, and from mother to child at birth.

There is no cure for hepatitis B but it can be prevented by currently available safe and effective vaccines. The adult schedule consists of 3 shots at 0, 1, and 6 months interval. Mother-to-child transmission can be prevented by monitoring the mother and treating where necessary during pregnancy and providing birth dose immunoglobulin and vaccine for the child, followed by the normal infant hepatitis B schedule.



'This fascinating book was composed of stories from the local community, providing a peoplecentered resource for telling children about living with hepatitis. The book concept was submitted to the 2017 World Hepatitis Summit innovation track and selected for oral presentation based on innovation, clarity, and public health impact. This book can help to amplify community awareness of hepatitis and spark family discussions. I highly recommend it for families, children, and communities talking about hepatitis.'

> **Joseph Tucker**, MD, PhD, Associate Professor of Medicine, Chair of Innovation Subgroup at the 2017 World Hepatitis Summit.

'Be part of the solution.' Nafisa Youssef, community advocate

Nothing is more important than family. When we say hepatitis B is family business, we acknowledge the need to support people living with hepatitis B within their family context, and not in isolation. This wonderful little book does just that, by helping out with what is for some people a very difficult thing - the talk about hep B with their loved ones. I look forward to sharing this resource with my patients, so together we can create as many Little Hep B Heroes as possible!

Associate Professor Benjamin Cowie Director, WHO Collaborating Centre for Viral Hepatitis

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