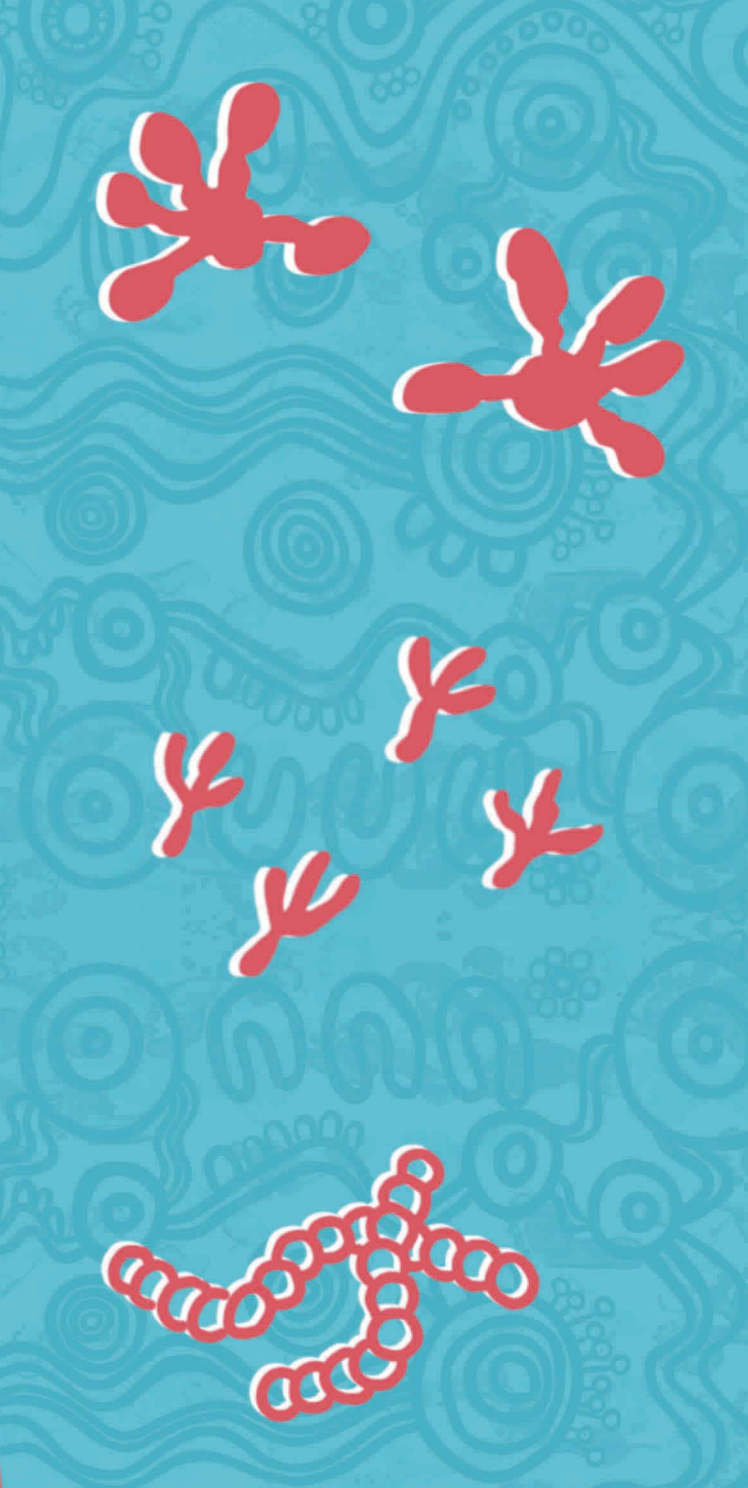


Blobby's Big Brave Journey

The START Study Story





Cover Artwork - Walking Together, Holding Their Hearts in Our Hands

This artwork illustrates the ongoing partnerships through co-design and community-led research between The Kids Rheumatic Heart Disease Network teams and support staff, walking and working alongside Aboriginal families and communities with the shared objective of eliminating Rheumatic Heart Disease in Australia. It also symbolises the engagement with Aboriginal communities, Indigenous leaders, families, and communities, who help direct our efforts across clinical trials, treatment development, policy, and advocacy aimed at preventing diseases caused by Streptococcus A— including skin sores, sore throats, invasive infections, Acute Rheumatic Fever, and Rheumatic Heart Disease.

The footprints in the background, symbolise the collective contributions of the five RHD Network teams, whose work encompasses a wide spectrum from fundamental research to translational projects, embodying a comprehensive approach from "bush to bench to bedside and beyond".

Central to our methodology are principles of Aboriginal leadership, cultural guidance, and governance, with a focus on building strong relationships and meaningful community connections, which are depicted by the yellow and white small circles and the flowing of the rivers throughout the artwork. The interconnected circles and lines represent vital relationships within communities highlighting the importance of yarning and listening to lived experiences, understanding community priorities and the sharing of cultural knowledge in urban, regional and remote communities. This creates a culturally safe and responsive environment that fosters mutual two-way learning and empowers Aboriginal and Torres Strait Islander children, families, and communities impacted by RHD.

At the base of the artwork is the Derbarl Yerrigan (Swan River), Boorloo (Perth), symbolising our shared Boodja (country/land) and the foundation of our work. The Derbarl Yerrigan sustains and supports our capacity to make meaningful contributions to research on Strep A, Acute Rheumatic Fever and RHD, and the resilience of Aboriginal and Torres Strait Islander communities across this Boodja (country/land).

Our primary focus is to foster positive changes and promote ongoing improvements in health outcomes for Aboriginal and Torres Strait Islander children, families, and communities. We are committed to supporting community-driven, culturally respectful research that contributes to enhanced health equity for children, families, and communities.

We acknowledge and pay respect to all Aboriginal communities we collaborate with and walk alongside in this important work.

Artist - Gillian Woods

Gillian is a Noongar woman living on Whadjuk country. Gillian grew up on Goreng and Mineng country, in the upper and lower great southern region of Western Australia. Gillian had a strong cultural upbringing in a small rural community surrounded by nature, paddocks, trees, and a simple family lifestyle back in the day. Gillian grew up with family members who were very artistic, they were known for their intricate and colourful landscape paintings, didgeridoo making, emu egg carvings, and burnt wood art. These inspired her to create her own style as an urban and contemporary visual artist. Gillian uses Aboriginal symbols in her artwork, and these symbols tell the story in an impactful way. Gillian creates her artwork based on commissioned themes, and personal stories of her travels and connections to country.

This book was co-written with the START Study team and:

Noeletta Young– First Nations Community Leader and Advocate

Noeletta Young is a proud Luritja and Yamatji woman, born in Darwin and now living in Maningrida, Arnhem Land. She is deeply committed to social justice, cultural strength, and community empowerment. A strong voice for her people, Noeletta is known for her fearless advocacy for Aboriginal youth and families, and her dedication to truth-telling and systemic change.

Currently studying a Bachelor of Social Work through the NIKERI Institute at Deakin University, Noeletta brings both lived experience and professional insight to her work. She is passionate about supporting young people to rise strong, walk proud, and connect deeply to culture and Country.

As a mother of six and a natural leader, Noeletta is guided by love for her community and a fierce belief in the power of self-determination. Her journey is grounded in healing, resilience, and the knowledge that real change starts from the grassroots.

RayRay McKenzie - First Nations & Lived Experience Advocate.

Raychelle (RayRay) McKenzie is an Anbarra, Nakara young person with ties to Luritja and Yamatji mobs, passionate about grassroots initiatives and community empowerment. Ray Ray is passionate about addressing Rheumatic Heart Disease and Streptococcus A, sharing insights from their lived experience and the effects it has on families and their community.

Will Bessen of Tuna Blue provided creative support for the book.

We want to acknowledge the START Study Aboriginal Governance Council (AGC) contributions to the START Study Book. We thank Heather Ann D'Antoine, Mark Mayo, Glenn Pearson and Rachel Burgess for their wisdom, knowledge and cultural guidance in developing and shaping this resource to share the study's findings with its participants and wider community.

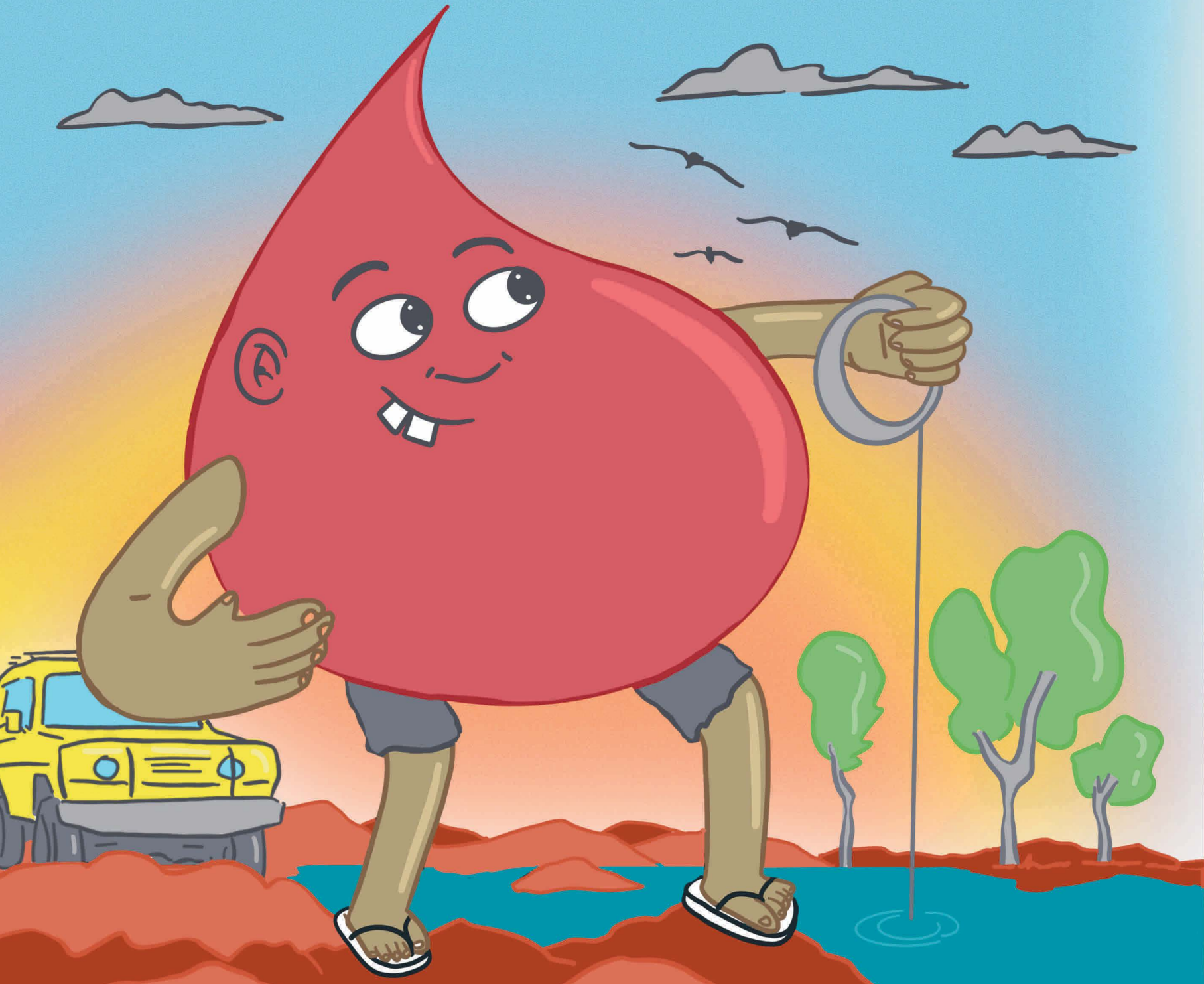


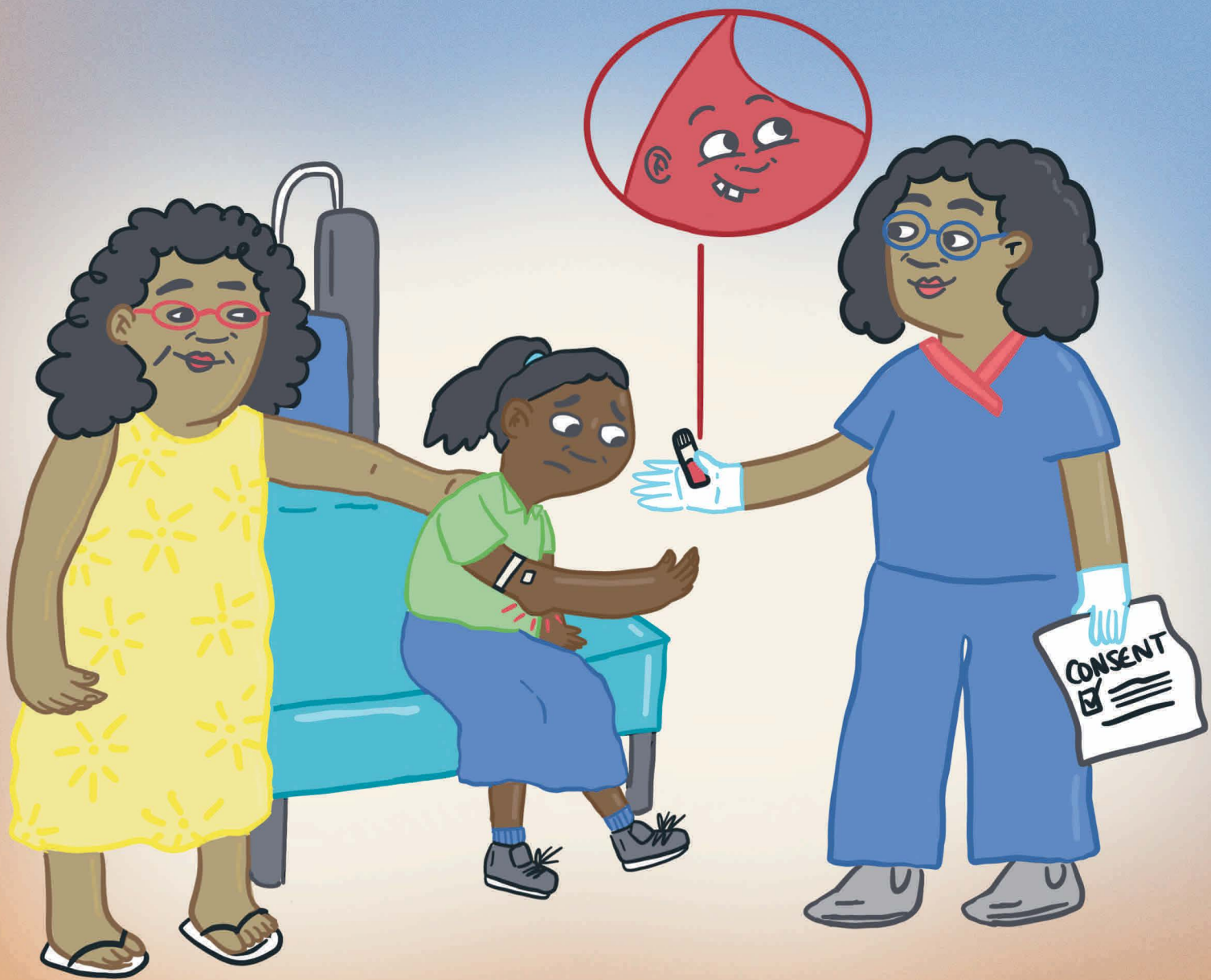
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The story in this book is a simplified version of the START Study research project and is intended for educational purposes only.

This is Blobby the blood sample

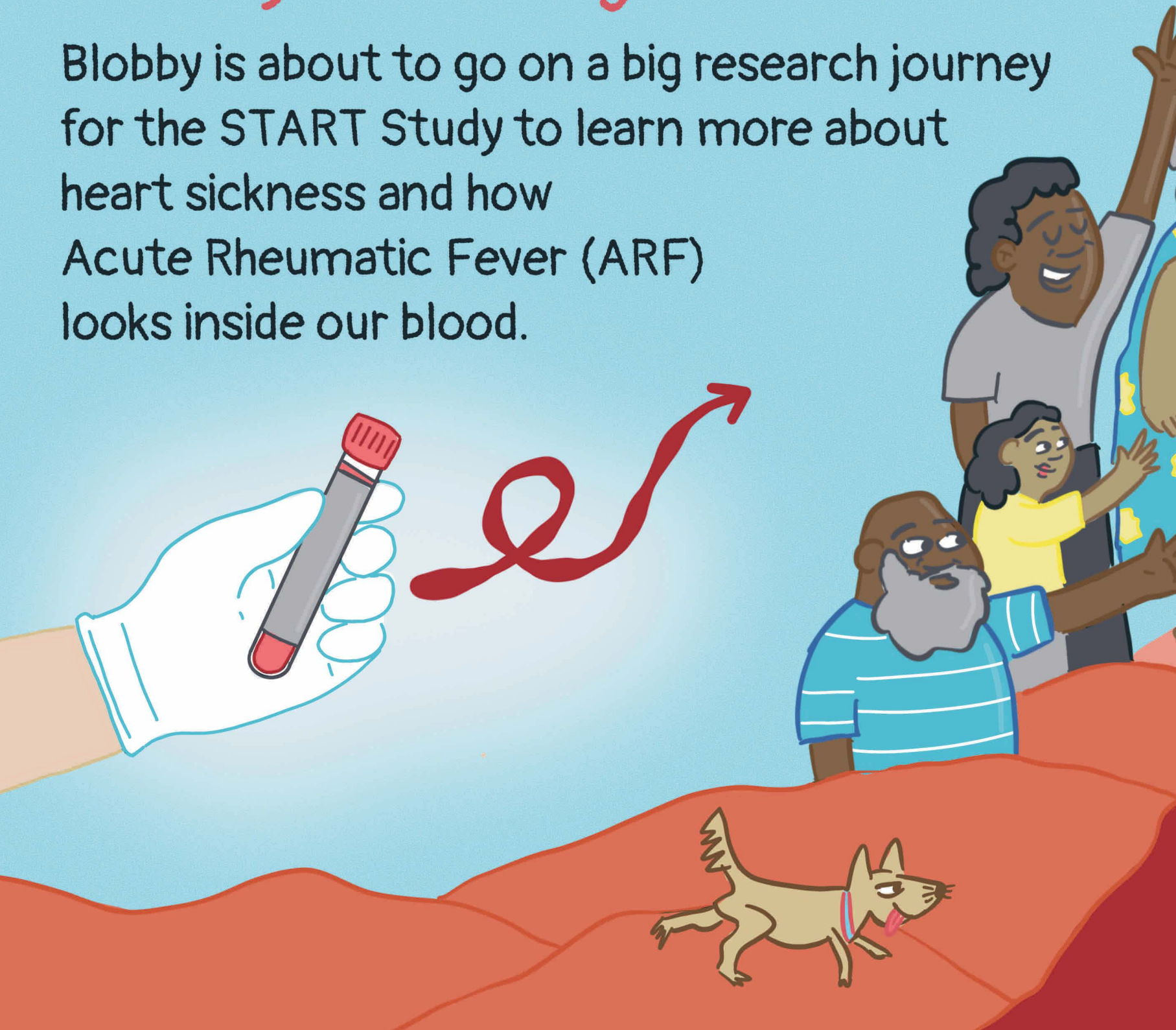


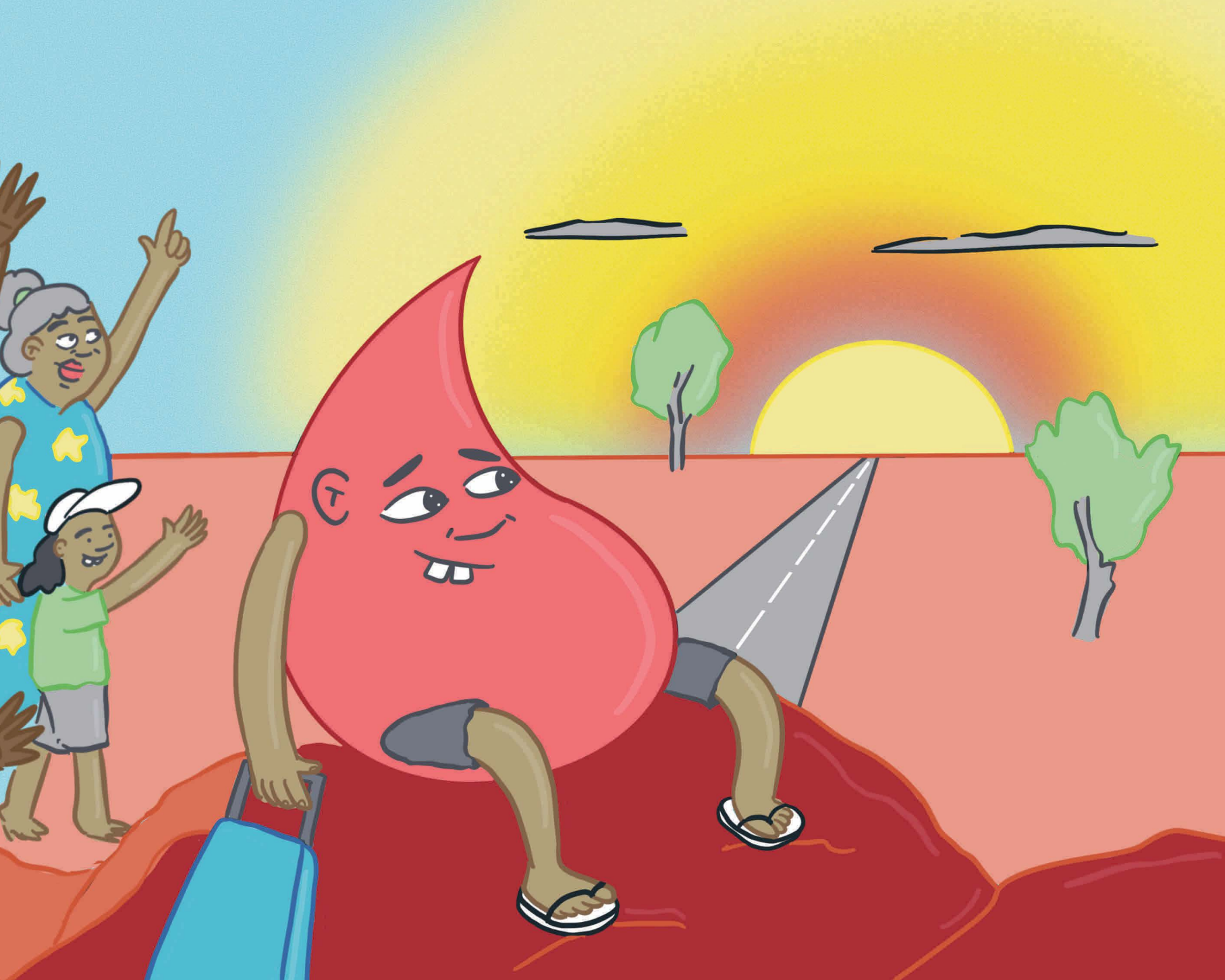


Blobby came from a young Aboriginal or Torres Strait Islander kid at Royal Darwin Hospital who was feeling sick with heart sickness like a fever, sore throat or pain in the joints.

Blobby is feeling a bit worried

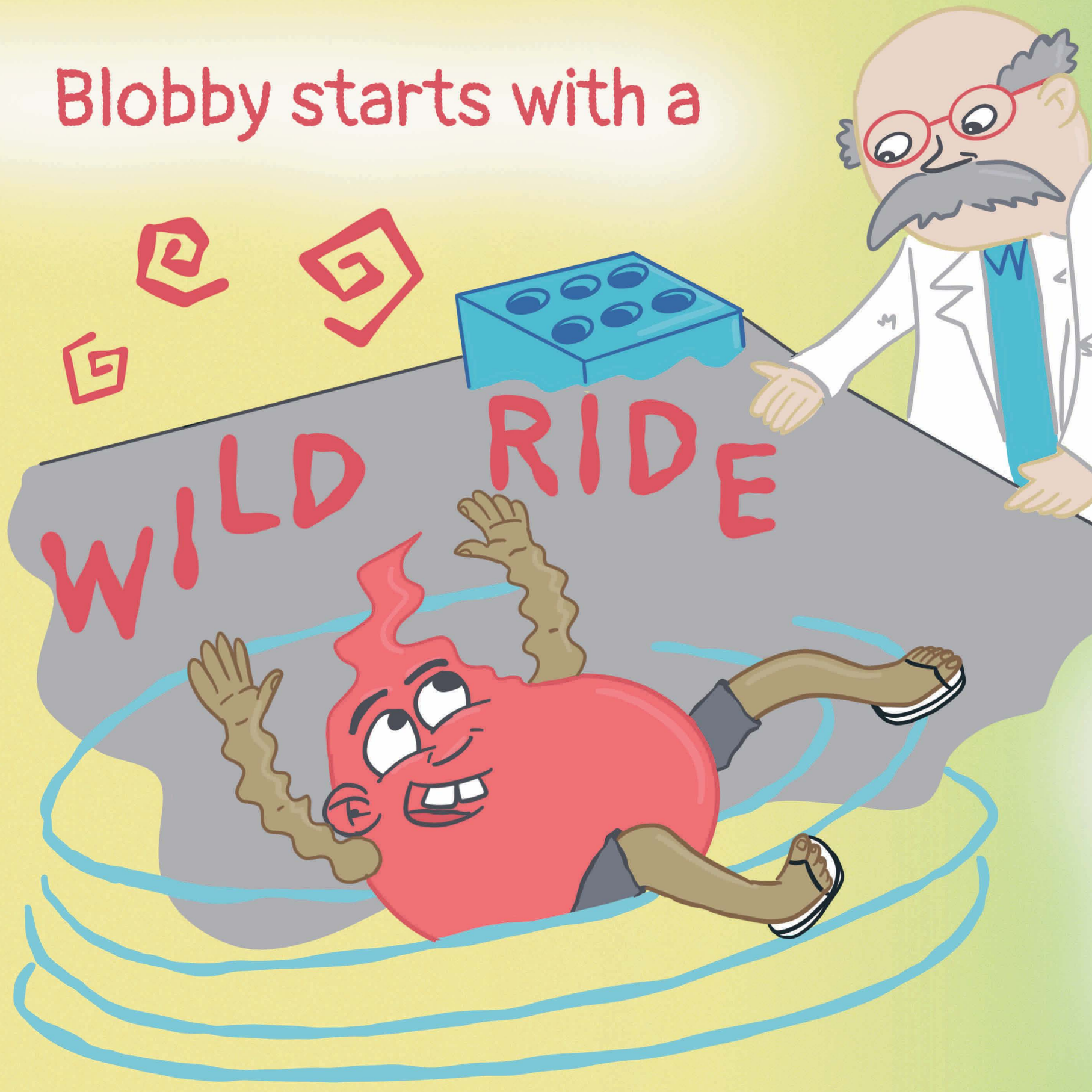
Blobby is about to go on a big research journey for the START Study to learn more about heart sickness and how Acute Rheumatic Fever (ARF) looks inside our blood.



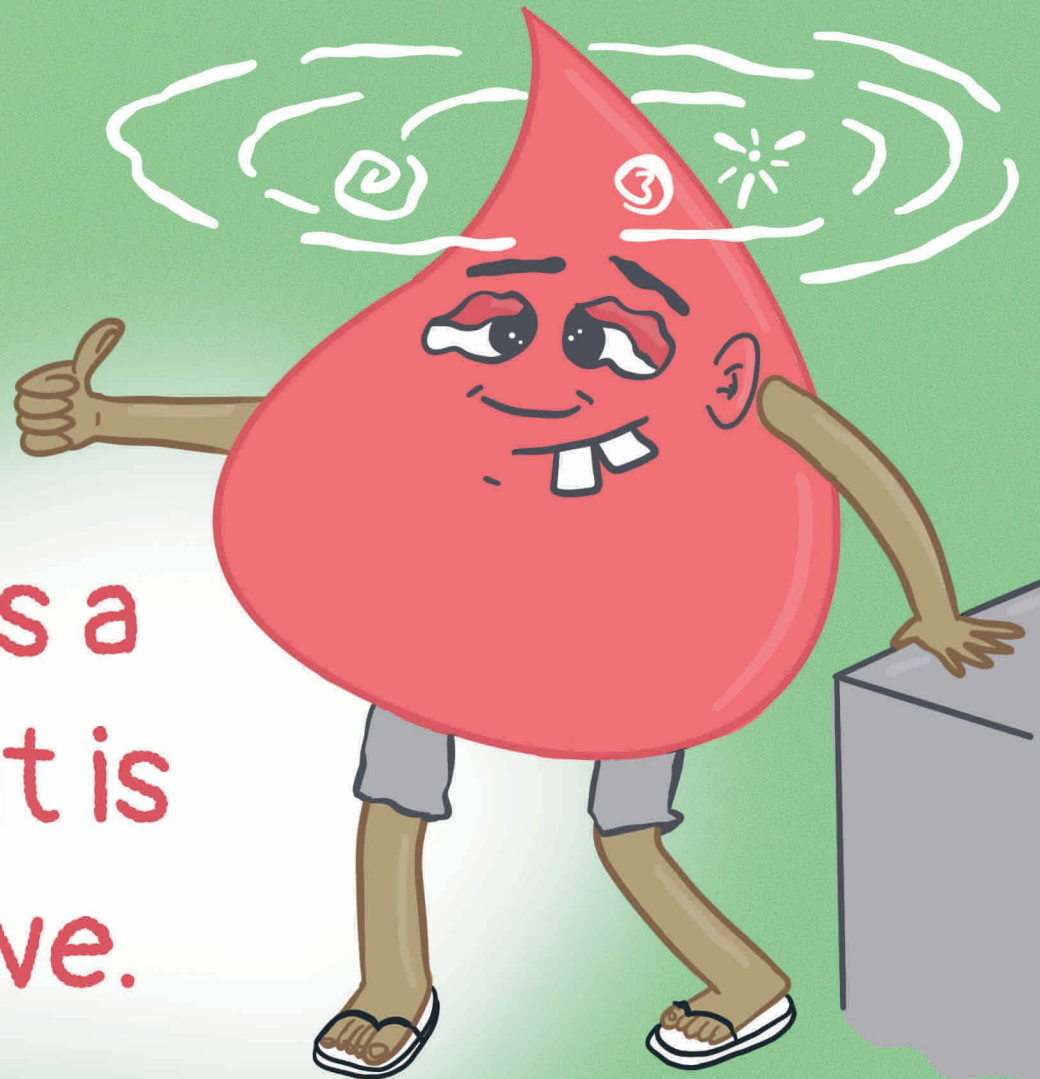


But Blobby is being
brave for our mob

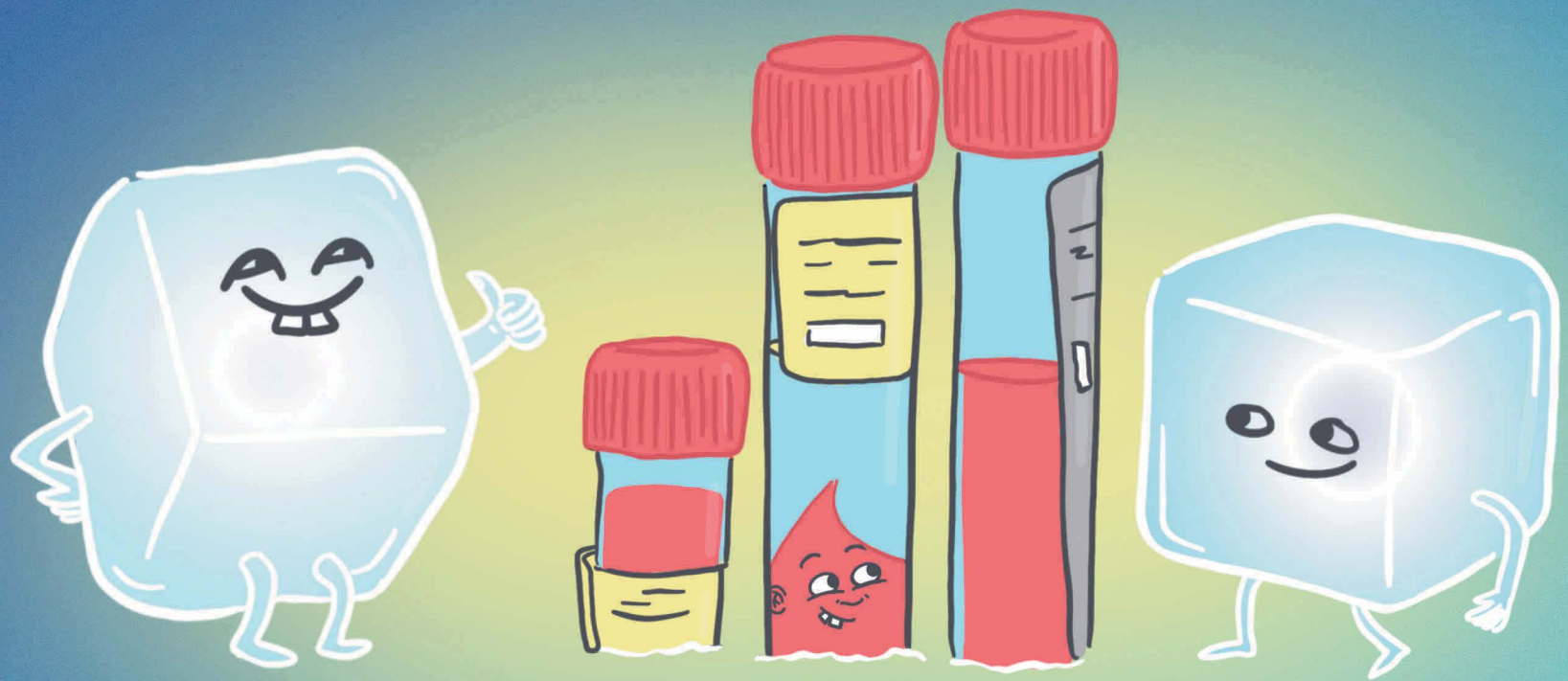
Blobby starts with a



Blobby goes across the road from Darwin Hospital to the Menzies Lab for processing in the centrifuge machines that spin the blood samples around, ready for testing.



Blobby feels a bit dizzy but is staying brave.



Then Blobby goes into the freezer to stay cool in the Darwin heat

The cold helps Blobby and the other blood samples to stay fresh, so that they can be part of the START Study for longer.

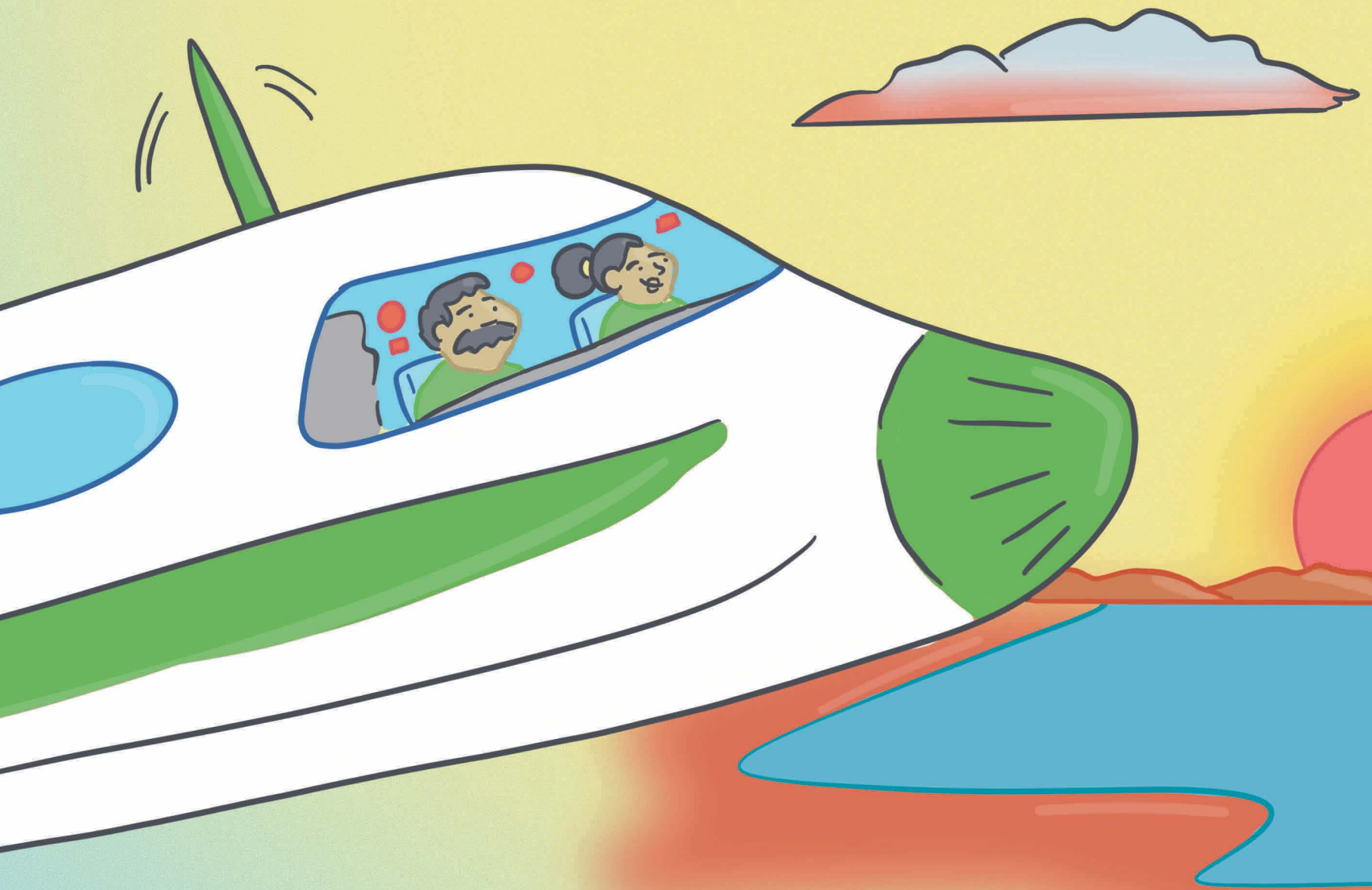
Blobby is
feeling very
cold but is
still being
brave



After that Blobby takes off
on a big airplane trip



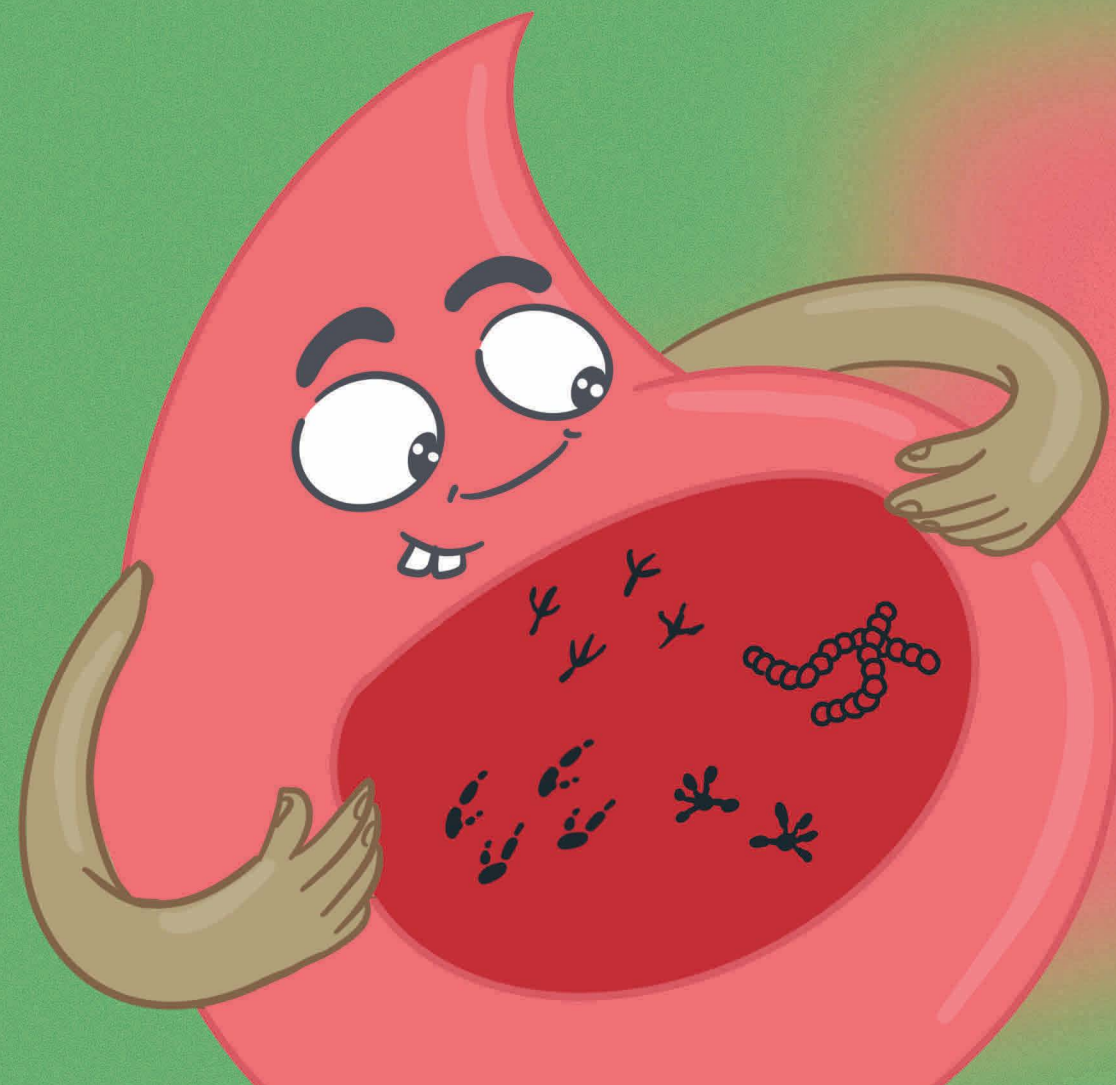
Blobby is going to different labs around the world so that Blobby can work with research mob with all the best skills and ideas.



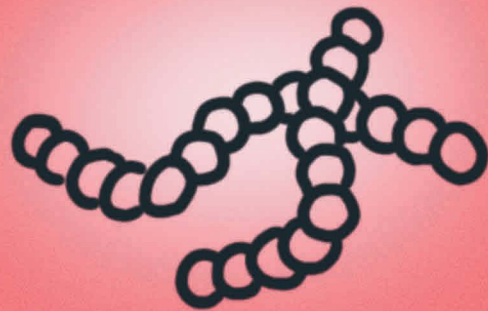
This was Blobby's first time
outside of the Territory!

The research mob look for the footprints inside of Blobby

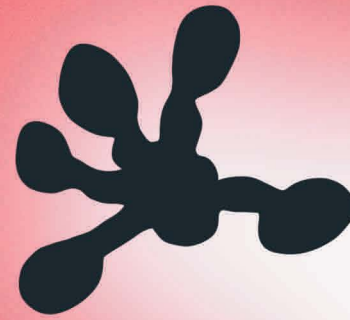
Everyone has footprints inside their blood (genes, chemicals and proteins) that tell a story about that person



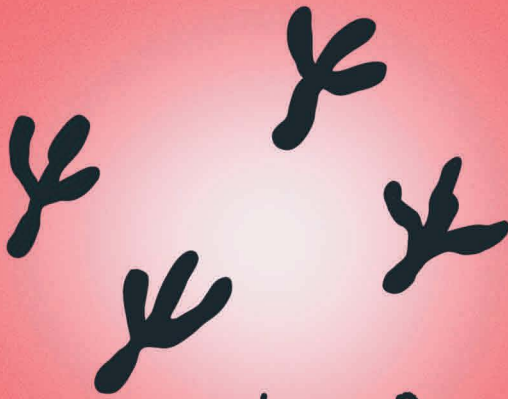
COVID?



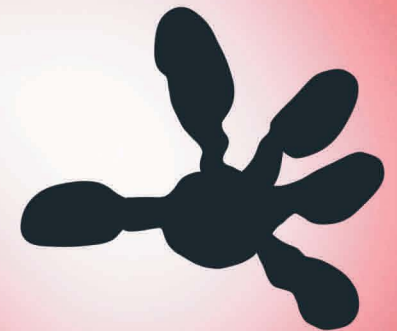
ARF?



RHD?



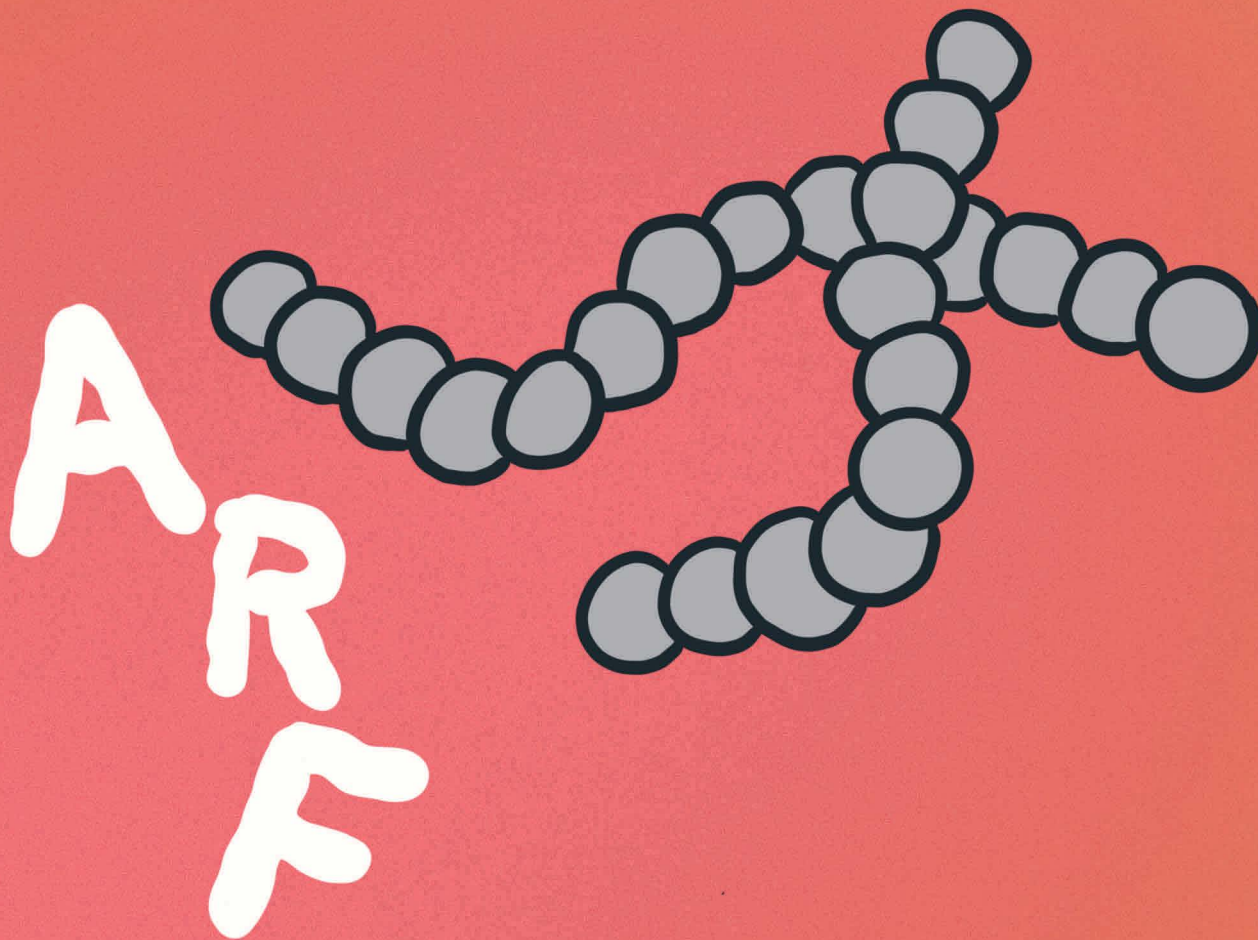
Iron?

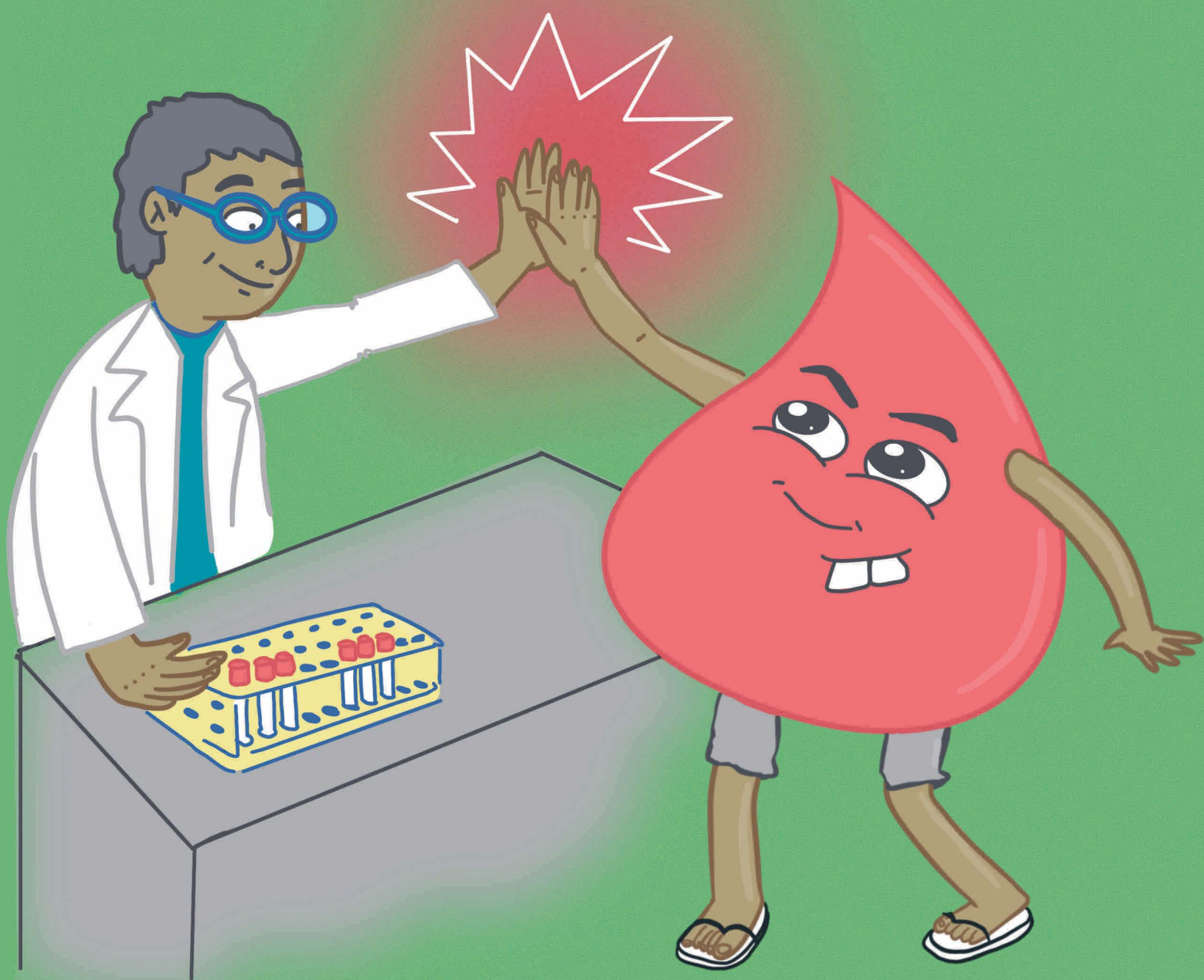


The research mob thinks that Blobby might hold a special footprint inside...

The ARF Footprint

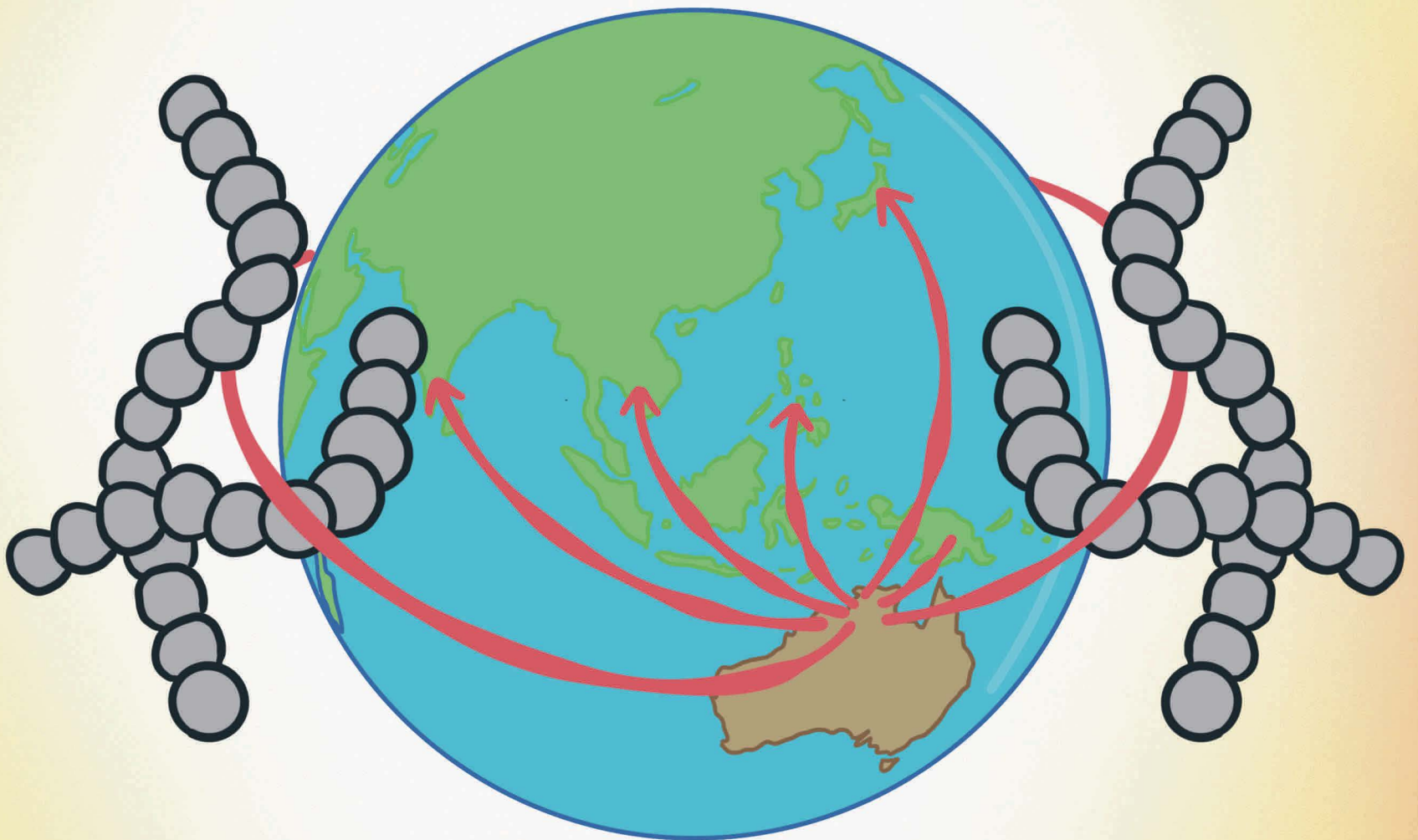
The research mob are looking inside Blobby for an Acute Rheumatic Fever (ARF) footprint that could help to see early if kids are getting heart sickness.





They haven't found that ARF Footprint yet but they're still working hard with Blobby to learn more about the heart sickness story

Blobby's big brave journey
could help millions of kids
around the world with Acute
Rheumatic Fever





and then...

And Blobby is proud to be
a brave blood sample!

Thank you to the brave Territory kids
who gave their blood samples!

What is Acute Rheumatic Fever (ARF)?

Acute Rheumatic Fever (ARF) is an illness that can develop after a throat infection caused by Streptococcus bacteria. In some children, the immune system reacts too strongly, mistakenly attacking the body's own tissues. This can cause painful joints, fever, and swelling, and can damage the heart. If ARF is not properly diagnosed and treated, it can lead to Rheumatic Heart Disease (RHD). Aboriginal and Torres Strait Islander peoples are affected at much higher rates than other Australians, making this an urgent health priority.

Why is this important?

Right now, there is no single test to diagnose ARF. Doctors must rely on a combination of symptoms, medical history, and test results, which can be uncertain and stressful for families. A clear, reliable test would help children get the right treatment more quickly and prevent unnecessary treatments for those who do not have ARF.

What did the START study do?

The Searching for a Technology-Driven Acute Rheumatic Fever Test (START) study began in 2018 and involved three hospitals:

- Royal Darwin Hospital (Australia)
- Starship Children's Hospital (New Zealand)
- Middlemore Hospital (New Zealand)

A total of 331 children and young people took part. Some had ARF, while others had conditions that looked similar or were healthy volunteers. Blood samples were collected and studied using advanced laboratory techniques that look at proteins, immune signals, and other markers in the blood. Researchers then used powerful computer tools (machine learning) to search for patterns — known as biomarkers — that might reliably show whether a person has ARF.

What have we found so far?

The research has identified promising groups of biomarkers that can help distinguish ARF from other conditions. These early findings were first tested using participants from Australia and then checked again in participants from New Zealand to make sure the results were consistent. While more work is still needed, these results bring us closer to developing a test that could be used in clinics in the next few years.

What could this mean for families and communities?

Earlier and more accurate diagnosis of ARF. Reduced risk of ARF progressing to RHD.

Next steps

The START study has provided new knowledge about ARF and a strong foundation for developing a future diagnostic test. Researchers are now working with global partners to test these findings in other communities where RHD is common. We are also committed to sharing results back with participating families and communities in clear and accessible ways.

