galiwin’ku researchers’ alaska trip highlights global hepatitis problem

It took a trip almost halfway around the world for three Indigenous researchers from Galiwin’ku to be reminded of a sobering, yet comforting truth: all Indigenous peoples are faced with the challenge of viral hepatitis.

Three Menzies School of Health Research community-based researchers – Sarah Bukulatjpi, George Gurruwiwi and Roslyn Dhurrkay – travelled almost 40 hours each way to attend the World Indigenous Peoples’ Conference on Viral Hepatitis in Anchorage in August.

“We realised it’s not just our people in Arnhem Land that have hepatitis health concerns; it’s all over the world. We’re not alone,” said Sarah.

“In Galiwin’ku, people feel shame about hepatitis B. Now I can tell them it’s not just them; people all over the world have this problem and people all over the world are working on it.”

Hepatitis B virus infection can lead to liver failure and liver cancer. Up to 20 per cent of the Indigenous population of the Northern Territory are infected with hepatitis B.

The conference saw Indigenous community representation from around 13 countries coming together to share their stories of how they diagnose, treat and raise community awareness of viral hepatitis.

For Roslyn, the sharing of stories provided the most insight into how other communities lived and worked to prevent and treat viral hepatitis.

“We felt proud sharing what we do in our community; other countries were impressed by how Yolngu people helped each other,” she said.

“We talked about the Hep B story app” (an app developed by Menzies and the Galiwin’ku community that uses graphics and explanations in language to educate people on hepatitis B and its effects) and how we go to peoples’ homes to talk to them about hep B.”

Paula Binks, hepatitis B program coordinator at Menzies, who was part of the Menzies contingent to Alaska, said attending the conference reinforced the importance of the community-based researchers’ work.

“It reinforced that the work we are doing is right and necessary,” said Paula. “When you work in communities, it is a long process, but you need to build trust and consult with them, and use their language to pass on the knowledge to them.”

All three researchers presented at the conference. Roslyn’s presentation was in the form of a video, of her speaking in Yolngu matha about the women’s business aspect and obtaining truly informed consent for research, while George presented on his work going from house-to-house to obtain samples and deliver education.

Meanwhile, Sarah talked about the ‘Liver one-stop shop’ project running in the community. Through this initiative, people with hepatitis B receive regular and specialised care from a visiting liver specialist, as well as ultrasounds and a scan to assess the stiffness of the liver.

“We hope to have the one-stop shop in more communities near Galiwin’ku,” said Sarah. “Hepatitis B is a big problem in a lot of communities, and we want to help.”

Roslyn’s video can be viewed here: https://vimeo.com/235684414