

## **SRHMRA Submission 4 — Phillip Whiley**

Recently, while doing my research I stumbled across an online forum dedicated to patients who have an inherited alteration in their genes but it was unknown how pathogenic that alteration is. Patients and other family members were sharing information they have learned from their own research or learned from their physician. As I read through the entries, I was alarmed at some of the dramatic decisions people were making based on very limited information but on reflection, I realized that many people want to take their own lives and welfare into their own hands and be pro-active.

My research aims to classify these genetic alterations as either pathogenic or not significant and without our research many of these families would be still guessing and making life changing decisions based on very little evidence. I hope that the level of commitment to medical research in Australia continues and even increases over time. I can see in my work that medical research has a direct impact on people's health and their lives overall. The benefits for the country in economic and social terms will be long lasting.