



## ADVOCACY, EDUCATION & AWARENESS

We positively impact New Zealand via collaboration with clinicians and treatment manufacturers while also encouraging policy & legislative change to allow funded treatment drugs for suffering patients. A support network for patients and families.

New Zealand Amyloidosis Patients Association



### **ABOUT NZAPA**

### WE ARE BETTER TOGETHER

Starting in 2019, our patient association charity acts as the bridge between expert entities overseas and patients with the disease in New Zealand. We also identify and connect individuals 'in the same boat' to offer support to both diagnosed sufferers and their caregivers. By banding together using one voice, we are likely to be heard and push for accessibility to treatment drugs presently only available overseas.

More importantly, we want accurate and early diagnosis by doctors.











THE NZAPA TEAM Jaime comes from a Communication & Psychology background spending many years in not-for-profit counselling service. She also worked in the social media digital space before transitioning as a caregiver to her spouse that had HATTR amyloidosis.

Melinda comes from a Corporate Finance & Advisory background. Personally, she lost her dad and many family members to HATTR amyloidosis.

Aubrey had a variety of experience in the Information Technology & Management space. A sufferer of HATTR, he was pivotal to the conception of NZAPA and acted as the board trustee member as well as a strong advocate for patients & caregivers. He is remembered posthumously.

Lewis comes from a Medical background and served as a General Practitioner for many years before being diagnosed with TTR Wild Type. He is a strong proponent for palliative care & advises us on all things medical.

### **OUR SERVICE**



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Patient organization's advocacy on behalf of the afflicted is especially crucial for rare diseases since the nature of the unique conditions is not generally known to the broader community and because of the smaller number of those afflicted (compared to the other more well-known ones).



### **DIAGNOSIS & TREATMENT**

Ensuring provision of appropriate care and support within the HEALTH SYSTEM to sufferers particularly in the area of diagnosis & treatment.



### **EDUCATION**

Highlighting DISEASE FEATURE that are not common to doctors and nurses / \*HCP.



### **AWARENESS**

Help amplify the voices of sufferers so as to get the attention of the powers that may be to effect LEGISLATIVE & POLICY change for the better.



### **WELLBEING**

SUPPORT for patients & caregivers who otherwise would not know where to go or who to approach for help.



### **ADVOCACY**

Advocating for medical TREATMENT hampered by red tape and government laws.



\*Healthcare Practitioners









### **OUR JOURNEY**







WEBINAR 23rd Sept 2020, Wed, 20:00 hrs NZT

Amyloidosis; Introduction, Diagnosis & Treatment of Cardiac Amyloidosis



Adobe Spa

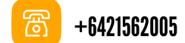


# THANK YOU FOR YOUR SUPPORT

"Our greatest social responsibility is to demonstrate to all others how to live in this world of hunger, sorrow, and injustice with generosity, dignity, and decency."

— Chris Ernest Nelson

NEW ZEALAND AMYLOIDOSIS PATIENTS ASSOCIATION





www.amyloidosis.co.nz

