RArEST
Rare Disease Awareness, Education, Support, and Training

A shared purpose - hearing from the rare disease community

“Even though our organisation is small in size, fairly new and runs completely with volunteering members, we have strived to access opportunities because we see a need and many gaps in many areas of our systems.”

Rare disease organisation leader

“Every vulnerable community gets tired of advocating and asking to be respected, but really, the responsibilities need to start to shift toward the sector to understand why that respect is not there in the first place.”

Person living with an undiagnosed disease

“As a clinician at the coalface and working closely with families, consumer organisations and the interdisciplinary team at SCHN, the priorities emerged from everyday practice and through careful listening to the needs of patients, families and clinical teams.”

Clinic lead and paediatric neurologist

“This multi-stakeholder approach might start to help shift patient organisations from thinking that they need to be the sole engine room of change. The reason I'm drawn to this approach is the philosophy that says multiple stakeholders have not only an interest, but a responsibility to be part of this.”

Rare disease organisation leader

The information in this factsheet includes authentic quotes from people within the rare disease community. Their permission has been granted to include these quotes for public display.

Scan the QR code for more information.

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