

HCU

Classical Homocystinuria (HCU) is a rare genetic disorder present from birth. In HCU, the body is unable to break down an amino acid called methionine. This causes a build up of methionine and another amino acid called homocysteine which affects the eyes, brain, bones and blood vessels and can cause serious health problems when untreated.



HCU Network Australia is a charitable organisation established in 2014 with a vision “to be a driving force in the journey to a cure, improving quality of life along the way”.

Our aim is to improve individual outcomes through **education, research** and **support**. Our priorities are to:

- Connect and support people impacted by homocystinuria;
- Improve the diagnosis path to enable appropriate treatment;
- Provide education and information to people impacted by homocystinuria;
- Encourage and support clinical research, research for novel therapies and ultimately a cure; and
- Raise funds to achieve our objectives.



For more information please visit **HCUNetworkAustralia.org.au**
to subscribe to our **eNews**

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HCU Network Australia is registered with the Australian Taxation Office as a Health Promotion Charity. We are endorsed as a Deductible Gift Recipient (DGR). All donations over \$2 are tax deductible.



COMMUNITY

Providing support by in-person and virtual events and online communities:

International Patient - Expert Meetings held in different international locations annually

Virtual Patient Meetings to provide peer support and reduce isolation

Online Patient Forum to foster discussion and information sharing

Contact Register to build stakeholder engagement

Facebook page keeps stakeholders updated with latest information



EDUCATION

Educating persons impacted by homocystinuria:

Repository of **Meeting Reports**, **Presentation Slides** and **Video Recordings** to build resources for the community

Interactive Disease Checklist to reduce barriers to accurate diagnosis

Q & A Interviews with leading experts to inform on topics of interest

Webinars with leading experts on topics of interest

eNews to inform stakeholders of latest developments in the community



PATIENT SERVICES

Providing support and knowledge of available resources:

Diagnosis Packs for newly diagnosed individuals

Smartphone App for dietary management

Infographics to bring awareness and provide information

Interactive Disease Checklist to reduce barriers to accurate diagnosis

Video **patient testimonials** and online **patient stories** to enhance the community



RESEARCH

Encourage and support research in the field:

International **Scientific Advisory Board** to advise on strategy and key research priorities

Research Map to inform all stakeholders about clinical and preclinical stage technologies in development for treatment

Research Strategy to illustrate overall principles and criteria for prioritisation of the research focus