



Application Information Package for the job
opportunity:

Chief Executive Officer

Reference Number: 001LEUK

Thank you for your interest in this position. This package contains the information you require to apply for the position, including:

- Overview about the Employer
- Job Description
- Position details
- Selection Criteria

Applications Close: COB (5pm) Mon 2nd November 2026

About the employer...

Our client is a small, national not-for-profit organisation dedicated to improving the lives of individuals and families affected by rare and complex health conditions.

The organisation provides information, advocacy, peer support and connections to specialist services, helping families navigate challenging circumstances and access the assistance they need.

Working closely with health professionals, researchers, community organisations and other stakeholders, they also play an important role in raising awareness and strengthening support for affected individuals and families.

The organisation is supported by a committed volunteer Management Committee and a small team of employees.

With an established foundation and opportunities for growth, the organisation is entering an important next chapter focused on strengthening its operations, increasing its profile, developing strategic partnerships and securing sustainable funding for its services.

The successful CEO will play a pivotal role in shaping this next chapter.

About the Services...

The organisation supports individuals and families navigating the challenges associated with rare and complex health conditions.

Its work includes providing information and guidance, connecting families with relevant health and community services, offering social work support, facilitating peer connections and advocating for the needs of affected individuals and families.

The organisation also provides assistance to families experiencing financial or practical challenges and works to increase awareness and understanding of the conditions affecting its community.

These services are supported through fundraising, donations and other funding sources, making financial sustainability and relationship development important priorities for the incoming CEO.

About the Opportunity...

Reporting to the Management Committee, this is an exciting opportunity to lead a small, purpose-driven organisation supporting individuals and families affected by rare and complex health conditions.

As CEO, you'll translate the Committee's strategic direction into practical plans and outcomes, while providing hands-on leadership across people, programs, operations, funding and stakeholder engagement.

Key responsibilities include:

- Leading and supporting employees and volunteers to deliver high-quality, responsive services
- Overseeing day-to-day operations, budgets, compliance and organisational performance
- Identifying, developing and securing grants, donations, fundraising and other funding opportunities to support ongoing services and organisational sustainability
- Building strategic relationships with medical professionals, researchers, health and disability services, government, corporate partners, donors and other stakeholders
- Strengthening the organisation's national profile, community awareness and referral pathways
- Identifying opportunities to expand services, partnerships and support for individuals and families
- Working closely with the Management Committee to implement strategic priorities, provide reporting and support effective governance

This is a hands-on and highly varied executive leadership role for someone who enjoys working within a small organisation, balancing strategic leadership with practical implementation, and building the relationships and resources needed to make a genuine difference.

The Strategic Plan

2026–2027 STRATEGIC PLAN

OUR DIRECTION

Strengthen the organisation as the national organisation supporting people and families— providing trusted support, connection and service linkages while building capacity, sustainability and reach.

WHAT WE WANT TO PROTECT & BUILD ON

Family advocacy • family events • financial assistance • emerging peer support • committed volunteers • strong community relationships • personal, practical and family-focused support.

OUR PRIORITIES FOR THE NEXT 12 MONTHS

1 PEOPLE, LEADERSHIP & STRUCTURE	2 FINANCIAL SUSTAINABILITY	3 SERVICES & PROGRAMS
PRIORITY / GOAL Appoint and embed the CEO, establish a clear organisational structure and strengthen support and supervision of the existing team.	PRIORITY / GOAL Strengthen the organisation's financial position and develop more sustainable sources of funding.	PRIORITY / GOAL Consolidate and strengthen existing family support and continue developing services that respond to the needs of people and families.
SUCCESS LOOKS LIKE • CEO appointed and established • Roles, reporting lines and delegations clear • Appropriate supervision and support in place • Less operational reliance on individual Committee members	SUCCESS LOOKS LIKE • Clearer funding strategy and financial outlook • Grants, fundraising and other opportunities actively pursued • Improved confidence in longer-term financial sustainability	SUCCESS LOOKS LIKE • Family advocacy embedded and consistently delivered • Peer support continues to develop • Information, referral and education opportunities progressed in line with family needs and capacity

ENABLERS ACROSS ALL PRIORITIES

GOVERNANCE & SYSTEMS Strengthen policies, procedures, delegations and organisational infrastructure to support sustainable growth.	REACH & AWARENESS Help more people affected know that support is available and how to access it.	PARTNERSHIPS & CONNECTIONS Strengthen relationships with medical teams, specialists, service providers, rare disease organisations and other stakeholders.
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OUR 3–5 YEAR PICTURE

Strong and sustainable family advocacy • A thriving peer support community • Accessible information and referral services • Strong connections with specialists and external organisations • A greater national voice
Remaining focused on the people the organisation exists to support, while increasing reach, influence and capacity.

Position Details...

Positions available:	There is 1 vacant position in total being advertised
Status:	Part Time
Term:	ongoing, dependent on funding
Hours per week:	22.8hrs per week in total
Days of work:	Negotiable
Award Coverage:	Salary and conditions of employment will be as described in the NSW SCHADS Award
Salary:	Salary classified at Level 8. Pay point to be determined with successful applicant based upon skills and experience.
Location:	Remote
Direct Reports:	2 employees + volunteers

Salary Packaging...

This employer is a charity registered with the ACNC. has been endorsed as a Public Benevolent Institute (PBI). As such, they can offer their employees access to salary packaging benefits. Salary packaging offers significant tax benefits which present an opportunity for you to increase your take home pay by allowing you to take part of your income as a tax-free benefit. Salary packaging is completely voluntary but if you choose to utilise this, it can decrease your taxable income and therefore tax paid, increasing the amount you take home each pay period.

Probationary Period...

A six-month probationary period applies to all positions at this employer from the date of appointment. A probationary review will be conducted prior to conclusion of this period.

Pre-employment checks required...

The successful applicant will be required to hold or obtain the following prior to commencement:

- National Police Check (within the last 12 months)
- Australian Citizenship or Permanent Residency

Why join this organisation?

- Lead a national not-for-profit organisation making a meaningful difference to individuals and families
- Opportunity to shape organisational growth, sustainability and future direction
- Build influential relationships across the health, disability, research and community sectors
- Work closely with a committed Management Committee and dedicated team
- Enjoy a varied, hands-on executive leadership role
- Remote working arrangement
- Purpose-driven work with genuine community impact

The Position Description...

Job Title	Chief Executive Officer
Reports To	Management Committee
Direct Reports	2
Location	Remote
Date	October 2026

Purpose of Role

The Chief Executive Officer (CEO) provides operational leadership to the organisation and is responsible for implementing the Committee's strategic direction into effective day-to-day operations, services and organisational outcomes.

Reporting to the Management Committee, the CEO will lead and support the organisation's employees and volunteers, oversee the delivery and development of programs and services, strengthen financial sustainability, and build relationships that increase the organisation's reach, profile and impact.

As the organisation's senior operational leader, the CEO will provide a clear link between the Committee and the team, ensuring operational matters are effectively managed while providing the Committee with the information, advice and recommendations required to fulfil its governance responsibilities.

This is a hands-on leadership role suited to someone who is comfortable working within a small, purpose-driven organisation and can move between strategic thinking and practical implementation.

Key Performance Responsibilities

The CEO will be accountable for achieving outcomes across the following key areas:

Leadership & Organisational Effectiveness

- Provide effective day-to-day leadership of the organisation
- Translate the Committee's strategic direction and priorities into practical plans, activities and organisational outcomes
- Monitor progress against agreed strategic priorities and report progress, emerging issues and opportunities to the Committee
- Establish clear roles, responsibilities, reporting relationships and ways of working
- Build a supported, connected and accountable team
- Reduce reliance on individual Committee members for routine operational management

Services & Family Impact

- Ensure programs and services remain responsive to the needs of people and families
- Strengthen the consistency, quality and effectiveness of existing services
- Monitor the reach and impact of services and identify unmet needs
- Progress agreed opportunities for service and program development

Financial Sustainability

- Actively contribute to improving the organisation's longer-term financial sustainability
- Identify and progress appropriate grants, fundraising, funding and other revenue opportunities

- Ensure organisational activities and programs operate within approved budgets and funding requirements
- Provide the Committee with clear information about financial performance, opportunities and emerging requirements

Organisational Growth, Profile & Relationships

- Strengthen the organisation's profile as a national organisation supporting people and families
- Develop productive relationships with medical professionals, researchers, service providers, funders, rare-disease organisations and other relevant stakeholders
- Increase awareness of the organisation and pathways for families to access support
- Identify opportunities for partnerships, advocacy and collaboration that further the organisation's purpose

Governance & Accountability

- Provide timely, meaningful reporting and recommendations to the Committee
- Implement Committee decisions and progress the organisation's strategic priorities
- Maintain appropriate operational systems, policies, processes and controls
- Ensure significant risks, issues and decisions requiring governance oversight are appropriately escalated

Specific Duties

People Leadership

- Provide direct leadership, management and supervision to employees
- Establish clear expectations, responsibilities and reporting arrangements
- Conduct regular one-to-one meetings, performance reviews and other appropriate employee check-ins
- Manage routine people matters including leave approvals, attendance, performance and employee concerns
- Coordinate appropriate coverage during employee absences
- Lead recruitment, onboarding and induction of new employees as required
- Facilitate regular team meetings and opportunities for collaboration and connection across the geographically dispersed team
- Promote a positive, supportive and accountable workplace culture
- Ensure employees undertaking complex family support work have appropriate internal leadership and access to relevant professional support
- Coordinate and support volunteers, including those involved in peer support and other organisational programs
- Identify future workforce and capability needs and make recommendations to the Committee where additional resources are required

Services & Programs

- Provide oversight of the organisation's services and programs, including family advocacy and peer support
- Monitor service quality, activity, reach and outcomes and report relevant information to the Committee
- Ensure meaningful support to families remains central to service delivery
- Identify gaps, emerging needs and opportunities to improve or expand services
- Support the continued development of the peer support program
- Progress agreed future initiatives, including development of the proposed Health Hub, working with employees, Committee members and external expertise as required
- Provide employees with high-level guidance and support in relation to complex client matters, while maintaining appropriate professional boundaries and responsibilities

- Develop systems and processes that support consistent and sustainable service delivery

Financial Sustainability & Funding

- Actively identify potential grants, fundraising initiatives and other funding opportunities
- Assess opportunities for relevance, feasibility and alignment before making recommendations to the Committee
- Prepare grant and funding submissions, drawing on Committee and subject-matter expertise where required
- Coordinate delivery, reporting and compliance requirements associated with successful funding
- Develop and maintain productive relationships with funders, donors and relevant partners
- Contribute to forward financial planning and budgeting
- Monitor operational expenditure against approved budgets and funding requirements
- Ensure employee timesheets, leave and other information required for payroll are appropriately authorised and provided to the Treasurer
- Work collaboratively with the Treasurer, Committee and any external financial specialists engaged by the organisation

Stakeholder Engagement, Partnerships & Profile

- Develop and maintain relationships with relevant medical professionals, researchers, health services, disability and community services, rare-disease organisations and other stakeholders
- Build familiarity with the rare disease landscape and the organisations, individuals and initiatives relevant to the organisation
- Represent and promote the organisation appropriately with external stakeholders.
- Strengthen referral pathways so families can more readily connect with the organisation
- Review research, clinical, partnership and other external opportunities and undertake appropriate initial due diligence
- Present relevant opportunities and recommendations to the Committee for consideration where approval is required
- Facilitate connections and collaboration between relevant stakeholders where this can benefit the organisation or the families it supports

Operations, Governance & Reporting

- Oversee the organisation's day-to-day operations and ensure routine operational matters are managed effectively
- Implement and maintain practical systems, procedures and processes that provide clarity and consistency
- Ensure approved organisational policies are implemented in day-to-day practice
- Identify operational risks and issues and take appropriate action or escalate them to the Committee
- Prepare a regular CEO report for Committee meetings covering agreed areas such as people, programs and services, finances and funding, stakeholder activity, emerging risks and matters requiring decision
- Review relevant employee/program reports before information is presented to the Committee
- Lead the operational implementation of the organisation's Strategic Plan and develop appropriate operational plans to support delivery
- Monitor organisational progress against agreed strategic priorities and provide regular progress reporting to the Committee
- Identify emerging opportunities, risks or changing circumstances that may affect the Strategic Plan and make recommendations to the Committee where appropriate
- Implement Committee decisions and monitor progress against the Strategic Plan
- Clearly distinguish matters within the CEO's delegated authority from matters requiring Committee consideration or approval

Selection Criteria

The successful candidate will demonstrate:

- Tertiary qualifications in business, management, finance, community services, social work or another relevant discipline and/or substantial relevant professional experience
- Demonstrated experience in a senior leadership or management role within the not-for-profit sector, with responsibility across multiple areas of organisational operations such as people, programs/services, finance, funding, stakeholder engagement and organisational development
- Demonstrated experience leading and managing employees, including setting expectations, supporting performance and building an effective team
- Experience overseeing programs or services and using information and feedback to evaluate performance, identify gaps and improve delivery
- Sound financial management capability, including the ability to understand budgets, financial reporting and working within available resources
- Experience contributing to organisational sustainability through identifying and progressing funding, grants, fundraising or other revenue opportunities
- Experience working closely with a Board or Management Committee, including preparing reports and recommendations to support informed decision-making
- Strong stakeholder engagement and relationship-building capability, with the confidence to represent an organisation externally
- Demonstrated ability to develop practical systems and processes and bring structure to a developing organisation
- Strong written and verbal communication skills, including the ability to prepare reports, recommendations and submissions for different audiences
- Sound judgement and the ability to determine when matters can be managed operationally and when they require governance oversight
- Ability to work both strategically and hands-on within a small organisation with limited resources
- Initiative, adaptability and a willingness to learn and develop knowledge of rare diseases and the needs of the people and families supported by the organisation

Desirable

- Experience within the health, disability or related not-for-profit sector
- Experience working with a Board, Committee or other governance body
- Experience working with or supporting people experiencing complex health, disability or family circumstances
- Experience working with funded programs and associated reporting or acquittal requirements
- Existing knowledge of relevant health, disability, government, research or community-sector systems and networks

Employment Checks & Requirements

Appointment will be subject to satisfactory completion of relevant pre-employment checks, which may include:

- National Police Check
- Verification of identity and right to work in Australia
- Employment history and reference checks
- Verification of qualifications where relevant to the successful candidate's application
- Working With Children Check, where required by the final scope of the role
- NDIS Worker Screening Check, where required by the organisation's activities or the final scope of the role

Recruitment process...

- You may be invited to initially participate in a brief telephone interview with us to discuss your application further and your suitability for the role
- Short listing of applicants for interview and notification is normally completed within a one to two-week period. Likewise, unsuccessful applications will be notified in this timeframe also
- It is standard practise to interview with a Selection Panel comprised by the employer themselves. The final decision of applicant suitability rests with them and is based on the Selection Criteria.

How to Apply...

To apply, please send us your resume including details of your previous work history as well as your educational achievements.

But don't leave it there – include a cover letter (either written or video) that tells us a little more about yourself and why you are applying for the position.

You will also be asked to answer some questions about the selection criteria mentioned in the advertisement and you can do that simply by filling out the questionnaire online (hint – if you have answers typed out in a Word document you can simply copy and paste them into the online form when you're ready).

Answering these questions doesn't to be a lengthy process, a few sentences to each is fine. It's all about allowing us a chance to get to know you a little deeper in things that might not be covered specifically in your just your resume.

When you've got these documents ready to go, head over to our website to fill out the online application form:

www.asterhr.com.au

Receipt of your application will be confirmed by email.

Still looking for more information?

If you have any questions or would like to talk a bit more about this job before applying, please call us on (02) 4555 4634 or email jobs@asterhr.com.au

Thank you for your expression of interest regarding this great opportunity.
Good Luck!