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**Job Description**

**Alström Syndrome Care Coordinator  
(Highly Specialised Service)**

**Purpose of the role**

To support the aims and objectives of the Charity and demonstrate the values of Alström Syndrome UK (ASUK). In particular, to provide support to children, young people, adults and families affected by Alström Syndrome.

**Responsible for:**

* Supporting individuals and families throughout their life journey.
* Liaising with the clinical and administration teams at Birmingham Women’s & Children’s Hospital and The Queen Elizabeth Hospital, Birmingham to help coordinate the Alström Syndrome multi-disciplinary clinics.
* Liaising with professionals and supporting external organisations and agencies to ensure they have an awareness of Alström Syndrome and a good understanding of the impact of living with a dual sensory loss and complex health condition.
* Ensuring the confidentiality, safety and welfare of children, young people, adults and families is maintained at all times.
* Supporting individuals who are affected by Alström Syndrome to empower, enrich and enable them to live the life they choose.

**Responsible to:**

The Chief Executive

**Location**

The registered office of Alström Syndrome UK is 4 St Kitts Close, Torquay, Devon TQ2 7GD. ASUK work as a geographically dispersed and virtual team. All team members work from home.

The post holder will be required to work from home. Living within a close proximity to Birmingham will be an advantage but is not essential. Travel to various locations throughout the UK will be required to visit families, attend clinics, take part in activities, liaise with professionals and attend various meetings, training events and conferences on the charity's instructions.

**Contract - Permanent**

##### Terms and Conditions of Service

* This is a 0.6 post, 24 hours per week, over 3 days. Specific days will be discussed with the successful applicant.
* Salary £25,233 - £28,605 (FTE)  
  Actual salary for 0.6 role is £15,140 - £17,163 (depending on knowledge and experience).
* Evening and weekend work may be required alongside some overnight stays. Time off in lieu and relevant and agreed expenses can be claimed.
* The post holder is expected to participate in team meetings, family support meetings and to attend relevant training to their specific roles and responsibilities.
* There is a three-month probationary period.

**Main areas of work**

* Achieve a working knowledge of Alström Syndrome and provide a support service (by telephone and face to face) in collaboration with the ASUK team.
* Liaise with the clinical teams and administrators to support the coordination of the Alström Syndrome multi-disciplinary clinics. Manage the administration to ensure patients attend, support people at clinic, gather feedback and attend pre and post clinic meetings.
* Provide support to all those who are part of our diverse Alström Syndrome community, and to those who are awaiting confirmation of a diagnosis.
* Develop and implement person centred plans and involve children, young people and adults throughout the process. Ensure that all statutory duties are carried out and are person centred and people are aware of the benefits and social care to which they are entitled.
* Support young people who are affected by Alström Syndrome to increase their confidence and independence and prepare for adulthood.
* Support children, young people, adults and their families to develop the appropriate exercise/diet regimes. Promoting a healthy lifestyle.
* Support individuals and their families to cope with living with progressive sight and hearing loss. Identify and signpost to professionals and organisations who can support families in their local area.
* To be responsible for ensuring that children, young people and adults are safeguarded.
* Liaise with professionals and supporting organisations for integrated working and support. Work closely in partnership with other relevant agencies, including Health, Education, Social Care, Specialist Services and other relevant agencies, to enable effective cross-disciplinary working.
* Maintain accurate case records and up-to-date case files in line with ASUK policies and procedures. Understand the importance and significance of Data Protection and Confidentiality. Ensure information is well organised and up to date and reports are submitted promptly through the IT system.
* Manage a caseload with competing priorities.
* Contribute to the development of resources for publication, including but not exclusively the ASUK website and newsletters.
* Understand and comply with ASUK’s policies and procedures and promote equity within your work and in the provision of services.
* Contribute to a positive working culture with colleagues, working as part of a team.
* Attend relevant meetings/conferences as directed.

**General Areas of Responsibility**

* Further the aims and objectives of ASUK and co-operate fully with all policies and procedures.
* Assist with any reasonable duty at the request of the Chief Executive.
* Work flexibly and be willing to travel throughout the UK.
* The responsibilities above form the core of the role, however the employee may be asked to undertake additional activities from time to time.

**Confidentiality**

1. The confidential nature of the work means that employees working for ASUK must maintain the strictest security in relation to documentation and ensure that confidentiality is maintained, in accordance with relevant Data Protection and associated legislation.
2. This role will require an enhanced DBS check.

**Health & Safety**

1. Comply with ASUK’s Health & Safety Policy.

This role profile is designed to identify principal responsibilities. The post holder is required to be flexible in developing the role in accordance with changes within ASUK’s management agenda and priorities.