

Staff

Senior HD Specialist

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HD Specialist

Julie Mann

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Admin / Resource Worker

Alison Shearer

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Specialist Youth Advisor

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Financial Wellbeing Officer

Melissa Higgins

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Office

Scottish Huntington's Association
Douglas Grant Rehabilitation Centre
Ayrshire Central Hospital
Kilwinning Road
Irvine
KA12 8SS

Contact

If you wish further information about
the Service please contact
Scottish Huntington's Association

Ayrshire Office- 01294 322305

Further information is also available from
our website www.hdscotland.org

National Office
Scottish Huntington's Association
Business First
Linwood Point
PAISLEY
PA1 2FB

Phone: 0141 848 0308

Email: sha-admin@hdscotland.org

Recognised by the Inland Revenue as a
Scottish Charity – No. SC010985



scottish
huntington's
association



Part of the HDA
Family Worldwide

Ayrshire
Service

Empowering ordinary people to
meet extraordinary challenges

What is Huntington's Disease?

- A genetic, hereditary, neurological, disorder of the central nervous system
- It is an autosomal dominant gene so if you have the faulty gene you will develop the illness at some point in your life
- It affects males and females equally
- Every child born to a parent with the faulty gene has a 50% chance of inheriting the gene
- Average age of onset of the illness is between 30-50 but this can vary widely
- It causes physical, emotional and cognitive impairment in varying degrees for each individual
- There is no known cure for this illness

Who are Scottish Huntington's Association?

- A registered charity
- Community based Huntington's Disease service provision since 1989
- Has community based services throughout Scotland
- Promotes needs led services and has a user led focus
- Commissioned by NHS Ayrshire, and local authorities

What service do we offer?

The Ayrshire Service has two HD Specialists and aims to significantly improve the quality of lives of those living with Huntington's Disease (HD) and their families through timely specialist assessment, condition management, information, advice, advocacy and emotional support. The Ayrshire Service also provides practical help for those with HD, carers and family members with benefit maximisation, adaptations, equipment, and access to services.

The service works cohesively with the multi disciplinary teams in Health and Social Care across the whole of Ayrshire that support our families by providing specialist information, educational sessions, and case management support.

Clinics

Enroll-HD Research Clinic:

Ayrshire is an active site for this worldwide observational study open to HD families; it will monitor how the disease appears and changes over time in different people. The database will eventually include more than 20,000 participants and is designed to accelerate the discovery and development of new therapeutics for HD.

For further information: www.enroll-hd.org

HD Management Clinic

Alternating , 1st Monday and the 1st and last Thursday of the month at the Douglas Grant Rehabilitation Centre
Ayrshire Central Hospital
Kilwinning Road
Irvine
KA12 8SS
Tel: 01294 323030

Youth Service

The Specialist Youth Advisor, Kirsten Walker, works with children and young people aged 8-25, living in families with HD, and provides one-to-one support, group work, advocacy and befriending. This service ensures accurate age appropriate information is given. The one-to-one support is essential to manage the daily challenges of living in a family with HD.

Financial Wellbeing

The Financial Wellbeing Officer, Melisa Higgins, provides specialist welfare rights advice including benefit checks, assistance with applications, disputes and appeals, money (debt) advice, and financial guidance on money matters such as planning for the future, power of attorney, pensions and life insurance. As well as responding to specific enquires, the aim is that all the clients of SHA will be offered a 'Financial Health Check'.

Where do we see people?

Where the person is most comfortable, either at the individual's home, or at another suitable venue.

Who can refer to the Ayrshire Service?

The service has an open referral system. Direct referrals can be made from those affected. A family member or other third party referrals with consent. Please get in touch by phoning, writing or emailing the Ayrshire Team.

Ayrshire Carers Group

This group was formed by family members to provide an opportunity to meet informally with others whose lives are affected by Huntington's Disease. Meetings are held monthly from 1pm - 2.30pm

Contact - Branch / Support Group Officer

Isobel Darroch
Tel: 0141 848 0308