

Staff

Senior HD Specialist

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HD Specialist

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Specialist Youth Advisor

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Financial Wellbeing Officer

Joanne Baldock

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Office

Scottish Huntington's Association

Fife Service

Whyteman's Brae Hospital

Kirkcaldy

KY1 2ND

Contact

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

Fife Office- 01592 647993

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

Fife
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 Fife and local authorities

What service do we offer?

The Fife 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 Fife 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 Fife that support our families by providing specialist information, educational sessions, and case management support.

Clinics

Enroll-HD Research Clinic:

Fife 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.

Clinics are held on Tuesday afternoons between 1pm and 3pm at Whyteman's Brae Hospital
Whyteman's Brae, Klrkaldy
KY1 2ND

For further information: www.enroll-hd.org

Cognitive Clinics:

This Psychologist led clinic commenced in January 2016. Clients who are experiencing executive functioning difficulties can be referred.

Youth Service

The Specialist Youth Advisor, Peter Carruthers, 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, Jo Baldock, 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?

Wherever the person is most comfortable, either at the individual's home, at Whyteman's Brae Hospital or at another suitable venue.

Who can refer to the Fife 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 Fife Team.

Family Branch 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 on the 2nd Monday of each month at 7.30-9.30pm. Further information about the Fife Family Branch Support Group, social activities and/or fundraising is available from the Fife office.

Contact - Branch / Support Group Officer

Isobel Darroch
Tel: 0141 848 0308

Information is also available on Fife's Carers' Group which meets on the last Monday of the month, and Symptomatic Group is held on the 3rd Thursday of the month.