# Staff

# Senior HD Specialist

Gordon Bogan

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Mob: 07788 923776

# Admin / Resource Worker

**Christine Malhan** 

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# **Specialist Youth Advisor**

**David Drain** 

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# Financial Wellbeing Officer

Katrina Lovie

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Mob: 07496 865342

# Office

Scottish Huntington's Association Highland HD Service Recreation Hall Building Raigmore Hospital Inverness IV2 3UJ

## **Contact**

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

Highland Office- 01463 729958

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



PA1 2FB
Phone: 0141 848 0308
Email: sha-admin@hdscotland.org

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









# Highland 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 Highland, and local authorities

#### What service do we offer?

The Highland Service has one HD Specialist 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 Highland 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 Highland that support our families by providing specialist information, educational sessions, and case management support.

#### Clinics

## **HD Management Clinic**

Facilitated every two to three months managed by Dr. Zosia Miedzybrodzka Clinical Genetics Dept. Ground Floor Foresterhill Aberdeen AB25 2ZA Tel: 01224 438154

For further information: www.enroll-hd.org

#### **Youth Service**

The Specialist Youth Advisor, David Drain, 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, Katrina Lovie, 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 or at another suitable venue.

## Who can refer to the Highland 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 Highland Team.

# Contact - Branch / Support Group Officer

# **Family Support Groups**

This group was formed by family members to provide an opportunity to meet informally with others whose lives are affected by Huntington's Disease. The group meets four times a year

Isobel Darroch Tel: 0141 848 0308