PRINCIPAL SPONSOR
Ecclesiastical
PLANNING SERVICES

NAFD
ANNUAL CONFERENCE & AGM
GUILDFORD 2019

NAFD CONFERENCE 2019 SUPPORTS THE HUNTINGTON'S DISEASE ASSOCIATION

NAFD President Abi Pattenden has chosen Huntington's Disease Association (HDA) as her nominated charity for 2018-2019 and funds raised during Conference 2019 will go towards supporting the charity, which supports people suffering from this rare, genetic condition which causes changes in the brain affecting movement, feelings, thinking, eating and speech.

The Huntington's Disease Association is the national charity supporting people affected by Huntington's Disease across England and Wales. Huntington's affects the central nervous system and is caused by a faulty gene passed down through families, with each child of a parent with Huntington's having a 50% chance of inheriting it. It changes the whole person – body, mind and behaviour.

Around 8,000 people in the UK are living with a diagnosis of Huntington's, and around 32,000 are at risk of developing it.

Imagine living with the symptoms of Motor Neurone Disease, autism, schizophrenia, Parkinson's and Alzheimer's disease all rolled into one, and you've just imagined Huntington's Disease.

HDA believes a better understanding of Huntington's by people with the disease in their families, the professionals involved in their care and service commissioners will lead to significant improvements in the quality of Huntington's care and support services in England and Wales. The charity knows that people prefer to access information about Huntington's in different ways and offers advice and support in various ways, including a face-to-face visit service, a presence at specialist Huntington's Disease clinics around the country, a telephone and email helpline, specialist publications and dedicated advice and support sections of its website.

Information and Advice

In 2017-18, the charity's dedicated helpline responded to over 24,000 calls and 37,000 emails from family members and professionals, and its specialist Huntington's Disease advisers carried out 2,467 home visits, providing advice and support to over 4,000 family members.

Financial Support

In the same year, it provided over £8,000 in small welfare grants to families affected by Huntington's Disease.

Activities

The Huntington's Disease Association offers a range of activities to families and people affected by Huntington's, including the Juvenile Huntington's Disease Weekend (an activity weekend for families affected by JHD), the Young Adults Weekend (a series of workshops relevant to young people directly or indirectly affected by Huntington's), family days organised locally by its advisers and the HDA's flagship Family Weekend (a national conference featuring keynote speakers, workshops and social activities). For young people living in families affected by Huntington's, childhood and adolescence can be particularly challenging. Often they witness a loved one steadily decline. They can be the main carer for a relative and may be at risk themselves – all whilst tackling the day-to-day challenges faced by all young people.

> **"Around 8,000 people in the UK are living with a diagnosis of Huntington's, and around 32,000 are at risk of developing it."**

Branches

The Huntington's Disease Association has almost 60 local branches and support groups to provide general support, including support for carers of people with Huntington's Disease. For people living in remote areas, where there are no local branches or support groups, a number of its advisers held pop-up cafes throughout the year to help bring people together for peer support in hard-to-reach areas.

Professional Training

Just under 3,000 professionals attended training events run by HDA's specialist advisers, or events at which its advisers were guest speakers. It ran two in depth Huntington's Disease certificated courses during 2017-18, covering topics such as genetic testing, managing behaviour, physiotherapy and diet.

Research

Following a robust process, HDA awarded two research grants - the first to the University of Cambridge for a study into Huntington's Disease economics, and the second to Cardiff University for a study on physiotherapy at Huntington's clinics.

The work of HDA is only made possible through the generosity of supporters. For more details please contact HDA at **info@hda.org.uk** or call **0151 331 5444.**

Huntington's Disease Association