



MYRTLE ELLIS FUND

supporting rare dementia

Founded in 2007 by the family of Myrtle Ellis following her diagnosis of Posterior Cortical Atrophy, the Fund exists to provide support, information and advice to individuals with rare forms of dementia and their carers.

The *Myrtle Ellis Fund* provides regular support group meetings, newsletters, telephone contact networks, websites and access to information and advice for people affected by four conditions:

- Posterior Cortical Atrophy (PCA) – a progressive disorder of vision which affects skills such as reading, driving and seeing what and where things are. PCA involves damage to the brain not the eyes and is most commonly caused by Alzheimer's Disease
- Primary Progressive Aphasia (PPA) – a degenerative condition associated with the gradual loss of the ability to understand and/or produce speech
- Familial Alzheimer's Disease (FAD) – the rare, directly genetically inherited form of Alzheimer's disease which runs in families and

typically affects people in their 30s, 40s and 50s.

- Familial Frontotemporal Dementia (fFTD) – the rare autosomal dominantly inherited frontotemporal dementia which runs in families and is caused by mutations in the tau, progranulin or C9ORF72 genes.

If you or someone you know might benefit from the services provided through these support groups, please contact our nurse coordinator Jill Walton (jill.walton@ftdsg.org / 07592 540 555) or visit our website: www.pcasupport.ucl.ac.uk

The Myrtle Ellis Fund is part of *The National Brain Appeal* (charity number 290173). Formerly known as The National Hospital Development Foundation, it is dedicated to raising vital funds for *The National Hospital for Neurology and Neurosurgery*, Queen Square, London.

For more information on the work of the Fund or to make a contribution, please contact *The National Brain Appeal* on 020 3448 4724 or go to: www.justgiving.com/Myrtle-Ellis-Fund



familial frontotemporal dementia



[fFTD] SUPPORT GROUP

www.ftdsupport.org

Being at risk of a disease which causes any kind of cognitive impairment raises all sorts of issues and concerns. There is often a sense of isolation when faced with these issues and few facilities are appropriate to this group's specific need.

The *familial frontotemporal dementia support group* is for families affected by familial frontotemporal dementia (fFTD) – the rare autosomal dominantly inherited frontotemporal dementia which runs in families and is caused by mutations in the **tau**, **progranulin** or **C9ORF72** genes. The group is run through the National Hospital for Neurology and Neurosurgery.

It currently holds a national meeting once a year in London.

At this meeting, the group offers information, advice and social opportunities for people with fFTD and their families. A newsletter is also published and circulated to members between meetings.

For more information please visit: www.ftdsupport.org
or contact our nurse coordinator Jill Walton;
jill.walton@ftdsg.org / 07592 540 555