

Narcolepsy UK

Narcolepsy UK is the sole national charity for the 30,000 people with narcolepsy in the UK. According to the NHS, less than 20% have been correctly diagnosed; the average time for diagnosis is ten years. Narcolepsy is an auto-immune disease that causes an area of the brain to stop producing a hormone called hypocretin. Hypocretin manages the sleep/wake cycle, body temperature, feelings of hunger as well as blood pressure. 90% of people with narcolepsy suffer from cataplexy – an involuntary loss of muscle control. More people in the UK have narcolepsy than Huntingdon's.

In 2008 the charity were beneficiaries of two significant legacies. This created a one off income of over £200,000. The trustees employed an interim manager to work with them to construct a three year plan that they then put into action. This plan is now almost complete and the trustees are involving the members in the next delivery plan; due to be agreed by March 2012.

In 2010 the vaccine for H1N1 Avian Flu, Pandemrix, was shown to have caused narcolepsy in genetically vulnerable children between the ages of 4 and 16. While a tragedy for those individual families involved, for the charity it has significantly raised awareness of the disease.

Narcolepsy UK has gone through a period of profound change. It now has one full time and two part time employees. Over the last two years they have changed name, become incorporated, applied for Scottish charity status, introduced free membership and created a good working relationship with the key clinical centres in the UK. In addition they “merged” with Narcolepsy Connections a second support service for people with narcolepsy. The website (www.narcolepsy.org.uk) is the most viewed narcolepsy site in the world, attracting over 2,500 unique visitors every month. A quarterly newsletter Catnap is sent to more than 700 individuals and sleep centres and neurological units.

The trustees employed a (part-time) fundraiser in 2011 and will have a better indication of the long term financial prospects for the charity by the first quarter of 2012. In addition work is continuing to improve income from members, not just in terms of legacies, but regular donations.

The board of Narcolepsy UK, under its new constitution can have a trustee body of 12; seven of that body (including the Chair) must always be narcoleptic. At the moment the board stands at 10, with seven narcoleptics on the board and the remaining three related to narcoleptics. Each trustee is expected to attend at least four board meetings per year, the AGM, national conference and chair or sit on at least one sub-committee.

All trustees of Narcolepsy UK are also Directors of Narcolepsy UK Limited. The liability is set at £10. All trustees must complete an enhanced CRB check, confirm they are legally able to become a trustee of the charity and commit to the Nolan

seven principles of public life: selflessness, integrity, objectivity, accountability, openness, honesty and leadership

The successful Trustee will be able to give evidence of:

1. Experience of board or committee membership, in a charitable, public sector or commercial organisation.
2. Understanding and acceptance of the legal duties, responsibilities and liabilities of trusteeship and an understanding of the respective roles of the Chair, Trustees and Chief Executive
3. Knowledge of the health service and how it works
4. Proven experience of helping an organisation through strategic and structural change during a time of significant change externally
5. Having good connections with a number of potential donors both corporate and individual and a willingness to approach them to support and further develop Narcolepsy UK
6. Experience of finances, risk and reserves management, audit and other corporate governance responsibilities
7. A proven track record of being able to process detail and get to the heart of an issue
8. Able to devote at least 2 days per month to the charity, which will include a quarterly board meeting (held on a Saturday) and chairing a Sub-Committee