

## **STEM CELL THERAPY – POSITION STATEMENT**

We believe that stem cell therapy offers significant hope for future treatment for the ataxias. Ataxia UK fully supports ethical research into stem cells in the UK and has actively sought to encourage researchers in this field. We have awarded a number of grants to study their potential as future treatments for the ataxias; the first step in bringing stem cell-based therapies for the ataxias to clinical trials.

We believe that any treatment should be offered on the basis of the results of rigorous trials in patients that assess both the risks and benefits of the intervention. Currently, clinical work with stem cells is at a very early stage. While possible benefits have been highly publicised in the press, there have been no clinical trials proving the effectiveness of stem cell therapy for Friedreich's ataxia or any of the other ataxias. Nor have any of the potential risks been fully evaluated. Many countries are now tightening their regulations to prevent unproven stem cell products from being offered as therapies in clinics.

Anyone thinking of having stem cell therapy might like to consider as a first step consulting with their neurologist to discuss the following:

- Whether it is possible to obtain a fuller assessment of their condition
- The source of the stem cells being used, whether adult or embryo, and how this source is monitored for quality and purity
- The possibility of mid- to longer term effects of treatment which, while not formally studied, may include an increased risk of cancers and serious infections
- The possible risk of contamination, including possible infection with HIV, hepatitis or other diseases associated with the transfer of bodily fluids
- The treatment of any donors from whom the stem cells are harvested ie whether donors are receiving payment and whether donors are treated fairly.

We would strongly advise anyone deciding to pursue stem cell therapy to get a full clinical assessment from a specialist neurologist with an interest in ataxia before, during and after any treatment so that any potential improvements and/or safety concerns can be accurately measured and the outcomes recorded to allow others to benefit from their experiences.

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