

UKNSCN POSITION STATEMENT ON STEM CELL TOURISM

The increasing incidence of patients from one nation seeking medical treatment based on stem cells in another has been termed “stem cell tourism”. This position statement concerns the actions of UK citizens in making decisions about medical treatments available to them in other countries.

Media sources and internet blogs are increasingly being used to publicise occasions when UK citizens have sought stem cell-based treatments outside the UK for currently untreatable, often chronic, conditions. Such individuals may have received advice from their GPs, but more than likely have sourced information from the internet and elected to risk treatment overseas with very little independent and objective advice. The UK National Stem Cell Network is well-positioned to provide such independent and objective advice, designed to help patients reach a carefully considered decision about treatments which may be available overseas.

The UKNSCN understands that there are many patients in the UK who currently suffer from incurable and painful degenerative diseases and who are prepared to take uncalculated risks to improve their quality of life, even if only for a short time. That, of course, is their right to choose, and it is certainly not the UKNSCN’s intention to prevent people from making, and being responsible for, their own decisions. It is the UKNSCN’s aim to help patients make better informed decisions.

Stem cell-based treatments currently available in other countries such as China, Mexico, and India are very likely to be unregulated and untested in the way that conventional medicines and stem cell-based treatments are controlled and tested in the UK and the West in general. That means that they may well have not undergone rigorous animal testing or properly phased clinical trials in man using placebo controls. As such, they may be at best ineffective, or at worst positively dangerous and potentially fatal, particularly if they are based on embryonic stem cells. If they appear to have worked in previous patients, we cannot be sure that any therapeutic effect is actually mediated by the stem cells themselves. Without access to data on placebo-controlled clinical trials, therapeutic effects may simply be a case of “mind over matter” and the long-term effects of the treatment completely unknown.

Many purported treatments available overseas are only available through private clinics at significant expense and it is clear that some providers are motivated by finance and may effectively be using patients as human guinea pigs. Not only may a patient lose significant sums of money on potentially ineffective treatments, but they may suffer a decrease in their quality of life and find themselves returning to the UK and seeking after-care within the UK healthcare system. It is therefore the UKNSCN’s considered view that UK patients seeking treatments abroad must avail themselves of all available clinical data concerning an advertised treatment before making a decision, and that they ought generally not to pay for expensive treatments overseas which may be improperly tested and dangerous. The UKNSCN wishes to see properly tested stem cell-based therapies available on the NHS in the earliest possible timeframe, and not prematurely in the private sector for the few who may feel they can afford to take what may well be an unknown risk.

The International Society for Stem Cell Research (ISSCR) has also prepared guidelines on the clinical translation of stem cells which UK patients are strongly encouraged to read. These are available on the ISSCR’s website at the link below. In particular, UK patients are encouraged to read the document at Annex 1 to the guidelines, titled *Patient Handbook on Stem Cell Therapies*.

http://www.isscr.org/clinical_trans/