

Important information for patients considering experimental stem cell therapy

This briefing seeks to flag up important issues that anyone considering stem cell therapy should be aware of before making decisions about treatment, including:

- Different financial schemes in how stem cell therapy is offered to patients
- Marketing techniques used by stem cell therapy providers
- Hidden costs of stem cell therapy outside of formal clinical trials

What are the different forms in which patients access experimental stem cell therapies?:

Many doctors and regulators recommend that stem cell therapy should only be provided through formal clinical trials. Yet, many commercial stem cell providers also refer to their services as part of clinical research or trials in order to lend scientific legitimacy to the treatments they provide. Some of the different ways in which experimental stem cell therapy is advertised and administered include:

- Formal clinical trials in which stem cell therapy is provided as part of clinical research which conforms to specific safety and ethical conditions such as requiring informed consent for patients, undergo approval from an Institutional Review Board and require specific eligibility criteria for inclusion. All expenses are covered by the sponsoring institution;
- Pay-to-participate clinical trials in which patients make a financial contribution towards treatment procedures (the degree to which these trials are conducted on a systematic basis as part of wider scientific research studies can vary widely);
- 'Patient-sponsored research' in which patients are asked to donate lump sum donations to sponsor research. These differ from pay-to-participate trials in that those patients contributing to the trials need not be the same ones that are receiving treatment;
- Commercial stem cell therapy where treatment is provided outside the context of clinical research or systematic study and the cost is entirely born by the patient;
- Cosmetic stem cell therapy where treatment is for cosmetic, rather than medical, purposes only (for example, anti-aging treatment, breast augmentation, etc.). In many such cases, the term 'stem cell' is used as a marketing buzzword rather than as a precise technical term, often by small clinics marketing non-therapeutic products and services which are at best only loosely regulated;
- Support therapy where stem cell therapy is used alongside other forms of treatment (e.g., rehabilitation or other alternative/complementary therapies).

What are the different ways in which experimental stem cell therapy is marketed to patients?

Patients often approach research institutes or stem cell providers directly about enrollment in clinical trials or are recruited through official channels (doctor referrals, etc.). In some cases, more indirect means are used to recruit patients for both research as well as commercial treatment.

Different patient recruitment strategies may include:

The **Internet** is one of the primary ways in which patients learn about stem cell therapy:

- Websites of individual practitioners/clinics;
- Medical tourism websites which act as umbrella websites for clinics around the world offering various forms of treatment;
- Online forums which host discussions between patients, caregivers, doctors and other people interested in treatment and advice for specific conditions;
- Social network sites such as Facebook, Twitter, YouTube, Myspace or group/personal blogspheres.

Other forms of **media**, such as articles and advertisements in newspapers or magazines (oftentimes, articles which appear as legitimate news items but which have been paid for by a particular clinic/hospital to promote their practice).

Through different **organisations** or individuals involved in the medical industry:

- Patient organisations;
- Word-of-mouth recommendations from other patients, specialised stem cell tourism agents or 'patient-recruiters' (former stem cell patients or people pretending to have been received successful treatment who are in fact commissioned or paid by a particular provider).

Possible hidden costs of stem cell therapy

These can vary considerably to include a number of 'hidden costs' beyond the treatment itself, such as:

- Hospital fees (does the treatment require in-patient or outpatient services, or both);
- Charges incurred from clinical and laboratory services;
- International and local transport to the city where the clinic is located as well as during the treatment period (airport pick-up, transport to and from the hotel and clinic, visa fees);
- Accommodation/hotel costs, for example in a nearby hotel or overnight hospital charges;
- Medical examinations and tests;
- Cost of follow-up tests and rehabilitation;
- Translation services (if the treatment takes place in a country where the doctors and clinicians speak a language other than that of the patient)
- Expenses incurred for the transport, accommodation and stay for caregiver.

Note: This briefing is informational in its aim; we do not take a position on wider questions of ethics or effectiveness in the provision of experimental stem cell therapy. The information contained here is based on social science research conducted by members of the Centre for Bionetworking, University of Sussex.

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