REGULATION OF AUTOLOGOUS STEM CELL THERAPIES;

DISCUSSION PAPER FOR CONSULTATION.

Introduction.

I am a member of the public, who also happens to be a retired Registered Nurse, Health Visitor, Primary Health Care Facilitator Residential Social Worker and Health Educator, who has been on the receiving end of stem cell therapy for osteoarthritis of hips. I have also been working for 4 years as a volunteer Research & Patient Liaison Officer following the osteoarthritis patients treated by Dr Ralph Bright, Macquarie Stem Cells, Sydney.

My background for research was in the Coronary Heart & Stroke Prevention Programme in the UK, where we proved that with General Practitioner intervention & the introduction of Practice Nurses to undertake regular screening, we cut the risks of heart and stroke dramatically. Thus cutting the costs of the health service in nursing those patients.

The same could apply to stem cell treatment, treat the disease, cut the costs long term.

The reason I volunteered for this role was the fact that we needed to know the long term outcome of SCT, as well as possible side effects.

MY COMMENTS:-

I would like to say that I am writing this objectively as a patient who was a non-responder to Autologous Stem Cell Therapy. I found that I only had a 50% improvement in the Osteoarthritis in my hips and consequently I did have bilateral hip replacements. I was one of the very early stem cell recipients and the treatment has changed a great deal as we have learnt more from the patients treated. I must say I do not regret having SCT as it may have worked, as many, many other patients have since had very real improvement in their conditions.

Out of the 360 patients that I have been following over the last 4 years, I found that 75% have had improvement which has given them a better quality of life. Those improvements have continued for up to 2,3, & 4 years, and in one case 5 years, I am afraid that is the longest we have been able to follow up at the moment.

Out of the 25% of those who failed to respond, very few have regretted having stem cell therapy, their comments are, "if we had not tried we may have lived to regret it."

Personally, I believe that all patients should have a choice of treatments if they can afford it, if it were to be taken on by Medicare many more patients would be able to have that choice. The patients are all informed of the figures regarding failure, so they are able to make an informed decision regarding the prospective treatment.

There have been no side effects except for swelling or bruising after liposuction and due to the fact that their own cells are used there have been no other problems.

As a member of the public and a person who is aware of the changes that SCT can make to the quality of life of patients, I feel the more we spend on clinical trials which take so many years and cost so much money, the more disabled people we will have in our communities. If they had insisted on clinical trials when they discovered Penicillin, there would have been many lives lost needlessly. The longer it takes for stem cell therapy to be accepted by the Government the more it is going to cost them in hospital and home care of those disabled with arthritis. It must be remembered that most of these patients have no medical problems so they could live very long lives with their disabilities, costing the Government a great deal of money.

I am aware that many people gain financially from these patients, i.e. by patients attending surgeries and specialists, plus taking analgesics produced by pharmaceutical companies at considerable cost. It has to be noted though that this is at the cost of the Government and the tax payer.

So the sooner the Government recognises and accepts autologous stem cell therapies the better off the patients and the country will be.

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