



To all Associations for Neuromuscular Diseases

Re.: myoblast transfer treatment

Dear Sir/Madam,

In an increasing number of countries clinics were established for the application of myoblast transfer treatment for people who have a muscular dystrophy. These clinics charge between 125.000 and 150.000 US\$\$ per treatment and claim “all patients transplanted have either seen great improvement and/or considerable decrease in muscle degeneration”. (see [www.celltherapy.com](http://www.celltherapy.com))

We have in our possession various reports from families of which a member with a muscular dystrophy received this treatment. These reports are very negative. We also have reports stating that diagnosis of patients was not checked and that there were no examinations prior to acceptance for this treatment.

Experimental trials with myoblast transplantation performed by several recognized scientific groups have proven to be of some scientific interest but have no therapeutic effect for people with Duchenne or other forms of muscular dystrophy. Despite these negative results, it seems that 40 or more people have received this treatment for which several paid by selling of their houses, cashing in pensions, draining money from family and friends, regional TV campaigns etc.

We mention as an example, out of reports from various other countries, information from Brazil where at least 20 people with a muscular dystrophy were treated in the Brazilian Centre for Myoblast Transfer Treatment. This treatment is now prohibited. This will prevent new patients from being deceived by false promises of a cure. This prohibition is the result of a Brazilian journalist's story that faked to be the godmother of a boy with Duchenne Dystrophy and requested treatment. In addition to the attached report we could provide copies of various other documents (letters, statements, publications).

We refer to a statement of the Mediterranean Society of Myology, MSM (see [www.cardiomiologia.it](http://www.cardiomiologia.it), click on MSM) against the practice of myoblast transfer as a potential therapy for Duchenne muscular dystrophy. *“Such therapy has been clearly shown to be ineffective while its high cost and potential risks cause unnecessary strain to the patients' families. The MSM takes a strong position in criticizing or condemning unproven therapies which are not only ineffective but have also the potential to cause harm while exploiting desperate patients and their families”.*

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We draw your attention to this matter and suggest that you publish an article on this subject in your journal or newsletter. This could be of great importance and will hopefully prevent a lot of suffering to people who have muscular dystrophy and their families who in despair agree to be submitted to this treatment.

The World Alliance of Neuromuscular Disorder Associations (WANDA) is committed to represent fairly the interests of families involved in neuromuscular diseases. Receiving information and being asked about this treatment from a variety of sources from all over the world we felt obliged to disseminate this warning.

We would appreciate receiving additional reports/experiences in relation to this subject.

Thank you for your attention to this subject

Andy Esworthy,  
Acting president and Secretary General

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