

Trial & Error?

I am sometimes asked whether people with arachnoiditis should participate in clinical trials. Given the damage the condition does to people, generally they are prepared to try anything in a bid to get better and as there is not a known cure for arachnoiditis nor indeed a well established treatment, most treatment protocols will be on a trial basis.

I'd like to sound a warning note: drugs (including those approved by FDA ,CSM or other regulatory bodies), taken singly or especially in combination, can have untoward effects, both immediately and more long term. Although trial drugs will have already been tested on animals initially and then on healthy volunteers, the effects on ill people can still be unpredictable. Many people with Arachnoiditis are particularly sensitive to drugs which doctors might anticipate would help the condition, including drugs like steroids.

For those offered the chance to participate in a drug trial: first you should ascertain the credentials of the team undertaking the research. Have they published previous studies in reputable peer reviewed journals ?

Second, what exactly will the proposed treatment entail and especially, what route of administration will it involve (any invasive procedures carry additional risks for people with arachnoiditis)?

Thirdly, what risks (immediate and more long term) does the treatment carry? Who will be responsible for treating any complications (this is particularly important if the trial is carried out in a different area/country from where you live)?

Finally, are the results of the study going to be made available to the public? If it is an effective treatment, others can access it, if it is too risky to be beneficial, others can be warned.

Answers to these questions are essential in order to give informed consent which is an absolute must (a legal requirement).

See <http://clinicaltrials.gov/ct2/info/understand#Q05> for further information.