

Clinical study of natural wound healing in Dystrophic Epidermolysis Bullosa

Professor Dedee Murrell from Sydney, has secured a spot as a study site in Australia for a clinical study of wound healing in Dystrophic Epidermolysis Bullosa.

This new observational study is funded by the biopharmaceuticals company, Shire, which makes medications for rare disabling genetic conditions similar to Epidermolysis Bullosa. The aims of the study are to monitor how wounds in patients with Dystrophic Epidermolysis Bullosa change over time by using both 2D and 3D photography and to test which scoring methods are best for wound healing studies in EB. This is an observational study, and no investigational drug is being used in this study.

This new study will take place at Professor Dedee Murrell's private practice in Sydney, Australia. Each participant is asked to present for three visits, two weeks apart over a month period and participate in a follow up phone call one week after the last visit. The visits will be held on Wednesday mornings and are expected to take about three to four hours from 8.30am onwards, and do not require any new blood tests or biopsies. Copies of historical test results and medical records are needed for this study.

The study includes participants with either Recessive Dystrophic Epidermolysis Bullosa or Dominant Dystrophic Epidermolysis Bullosa of any age. There are strict criteria that the participant has to have at least five active wounds and NO current evidence of squamous cell cancers. Reasonable travel expenses will be provided for the travel required for the study for the participant and care giver.

Please contact Professor Dedee Murrell's fellow, Dr Adam Harris, if interested, on adamgeorgeharris@gmail.com or nurse, Charmaine, on 02-9598-5800.