



St George Hospital Campus

Professor Dédée F Murrell MA(Cambridge), BMBCb(Oxford), FAAD(USA), MD(UNSW), FACD
Head of Department of Dermatology, St George Hospital
Conjoint Professor, University of New South Wales

DERMATOLOGY PRACTICE:
Private Consulting Rooms
17 Kensington Street
Kogarah, Sydney NSW 2217
AUSTRALIA
Ph: (61-2) 9598 5800
Fax: (61-2) 9598 5801
E: murrell.patients@ori.org.au

Dear _____,

You are invited to participate in a research study assessing an investigational topical treatment (ointment) for Epidermolysis Bullosa simplex (EBS), targeting the painful calluses and blisters on the soles of your feet.

The study is being conducted by Professor Dédée Murrell at her private practice – Premier Specialists in Kogarah, Sydney. Other doctors and nurses at the practice will assist her throughout the trial.

The purpose of the study is to investigate whether the investigational ointment will help reduce the calluses and blistering on the soles of the feet of people with EBS. Most people with EBS have blistering confined to soles of feet and palms of hands, this can be very painful and significantly impact on people's quality of life. No current treatment exists for this condition. Promising findings from the USA on the positive effects of this investigational ointment on a similar keratin disorder have lead us to think it may be beneficial in EBS too.

This study is expected to take approximately 46 weeks, split into four phases. Everyone will receive treatment with the study drug either during phase 1 or 3. There are a total of 12 study visits, all of which take place at Premier Specialists, at 2-4 weekly intervals with a physician phone-call 'check-in' half way through the trial and at the end.

If you are interested in being a participant in the trial we can will arrange an appointment at the clinic for you.

At this appointment, you will meet one of the doctors who is running the trial and will have a chance to discuss in detail what to expect during the trial, the risks and benefits, along with any other questions you may have. You will not be charged for this or any other appointment that you will attend during the trial.

Participation in this study is voluntary. It is entirely up to you whether or not you participate, and you can make that decision after you have received more information at your appointment. If you decide not to participate, it will not affect the treatment you receive now or in the future.

If you are interested, please contact Dr Charlotte Gollins at Premier Specialists on the above phone number to arrange an appointment,

Yours Sincerely,

Professor Dédée F. Murrell



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