

EXPLORING THE EXPERIENCES OF ausEE MEMBERS LIVING WITH EOSINOPHILIC OESOPHAGITIS

INFORMATION FOR PARTICIPANTS

Introduction:

You are invited to participate in a focus group which aims to explore your and/or your child's experiences with Eosinophilic Oesophagitis (EoE). This study is being conducted by Dr Robert Loblay, Dr Anne Swain, Dr Velencia Soutter, Dr Louise Wienholt, Ms. Mary Agapides and Ms Annabel Clancy in the Department of Clinical Immunology at Royal Prince Alfred Hospital (RPAH).

Study procedures:

Before attending, you will be asked to complete a questionnaire covering symptoms, investigation, management and progress of your/your child's EoE. The questionnaire will be distributed in advance to all ausEE members by email and will take approximately 30 minutes to complete.

Focus group meetings will be held in the early evening at the RPAH Allergy Unit in Camperdown (<http://www.slhd.nsw.gov.au/rpa/allergy/services/location.html>). The groups will consist of 8-10 people and will run for 1½ to 2 hours. Allergen free, low chemical food will be provided.

During these sessions you will have the opportunity to discuss your experiences with diagnosis, medical treatment, and dietary management of EoE, and its impact on your/your child's quality of life. The focus group discussion will be audio recorded to allow us to analyse the discussions for our research, but you will not be identifiable when the results are collated.

Risks and voluntary participation:

Participation in this study is entirely voluntary. Apart from giving up your time to travel to and participate in the focus group, there are no foreseeable risks. If at any time during the discussion you become distressed or embarrassed, you will be free to leave without having to give a reason. Consent is implied on completion of the relevant instrument.

Confidentiality

All aspects of the study, including results, will be strictly confidential and only the investigators named above will have access to the information you provide. Although ausEE is involved in distributing information about the study, they will not be aware of which members have or have not participated.

A summary of the study findings will be provided to ausEE and may be posted on the website, but individual participants will not be identifiable. The study results may also be presented at a conference or in a scientific publication, but no identifying information will be included.

Further Information

If you would like to know more at any stage, please feel free to contact Annabel Clancy on 02 9515-3019 or 0448 230 279. This information sheet is for you to keep.

Ethics Approval and Complaints

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515-6766 and quote protocol number X15-0169.