Report of the meeting held on Tuesday 28th April 2015

Present: Board members: Mark Arthur, Caroline Richmond, Chanell Pritchard (secretary) Kit Sandford, David Webster, Sary Workman, Gary Narborough and 35 members. Apologies were received from Jose Drabwell (chairman), Andrew Symes and several members. The meeting was chaired by Kit Sandford.

Membership are recommended, and which are unsafe? This would be a useful topic for the

website.

Research: Mari described how important it is to involve patients in research design and implementation. For example, a recently-introduced treatment in children with serious genetic immunodeficiencies is to give them a new immune system by doing a stem cell transplant. This originally had a high death rate and was therefore offered only to the severely ill.

found it helpful in finalising the topic and prioritising what should be addressed. This improved the study design and made it more focused on patient need. It went so well that the team hope to run more focus groups in the future.

Individual consent to participating in research Sary Workman (researfr nrkmSary .75 Tg gaodiv XWKDV

have their data used, confidentially, in a range of research projects. Those who have already signed consent forms will be asked to sign again. As she is trying not to overload us with too many forms at once, she has asked Chanell to send the forms out to us a week before our clinic appointments. This will give patients time to read and consider

Dr David Webster reported that gene therapy is currently on trial at Great Ormond Street hospital and the Royal Free for Wiscott-