

Mission Statement and Contact List

for National Neonatal Epidermolysis Bullosa (EB) Boxes

The National Neonatal Epidermolysis Bullosa (EB) boxes are an initiative between Mölnlycke Health Care, Independence Australia and DEBRA Australia (Dystrophic Epidermolysis Bullosa Research Association). The aim of this initiative is to provide best practice information, education and resources to those clinicians who are looking after a newborn baby with suspected EB. Early information, education and early use of best practice dressings, is imperative for better health outcomes for the baby. Supply of these EB boxes ensures appropriate care is provided therefore reducing trauma that may be experienced from inappropriate dressings use. They also provide a consistent approach to newborn management of EB cases around Australia.

Transfer of a baby with moderate/severe EB to a centre of expertise will often be the choice of the neonatologist or paediatrician. However, immediate transfer is not always possible, and movement/transfer can cause further trauma. The information and materials in this box will help to provide safe, best practice care in the interim.

Independence Australia is a not-for-profit organisation which provides health care products to consumers Australia-wide. Independence Australia is the administrator of the National EB Dressings Scheme on behalf of the Australian Government.

DEBRA Australia offers advocacy, education, financial support, emotional support and networking opportunities to individuals, families and professionals who are living and working with EB. Ensuring all research and best practice treatments are investigated leading to improved quality of life for all. DEBRA Australia also uses donations to fund local and international research into a cure for EB and provide much needed services. Their aim is to work for a life free of pain. If you would like to know more about DEBRA please visit the website www.debra.org.au or contact secretary@debra.org.au.