

Mission Statement

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.

Contact List for Paediatric Centres of Expertise/Knowledge

VIC	National EB Dressing Scheme (Independence Australia)	Dayan Mashhour Program Lead	1300 290 400
	Royal Children's Hospital EB Clinic Melbourne	Emma King Dermatology Nurse Practitioner	(03) 9345 5522
NSW	Sydney Children's Hospital EB Clinic Randwick Sydney	Lauren Weston DEBRA EB Nurse Consultant	(03) 9345 4573 0427 937 699
		Rebecca Saad EB Clinical Nurse Consultant	(02) 9382 0389 Pager 46562 via Switch: (02) 9382 1111
QLD	Royal Children's Hospital EB Clinic (Burns outpatient Unit) Brisbane	Samantha Hay DEBRA EB Nurse	(07) 3636 9119 0458 937 000
SA	Women's & Children's Hospital, North Adelaide	Anna Malden Complex Care Clinical Practice Nurse Consultant	(08) 8161 7000
		Cassie Dujmovic Stoma/Wound/ Urology CPC	(08) 8161 6671
WA	Princess Margaret Hospital for Children, Perth	Jenny Irvine Dermatology Clinical Nurse Specialist Clinical Nurse Consultants	(08) 9340 8584 Page 7677
		Carmel Boylan Clinical Nurse Consultant Stomal/Wound Management	(08) 9340 8222 Page 8009
		Dr Anne Halbert	(08) 9340 8222