

National Neonatal Epidermolysis Bullosa (EB) Boxes – Mission Statement

The National Neonatal Epidermolysis Bullosa (EB) boxes are an initiative between Mölnlycke Health Care, BrightSky 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.

BrightSky Australia is a not-for-profit organisation which provides health care products to consumers Australia-wide. BrightSky Australia is the administrator of the National EB Dressings Scheme on behalf of the Australian Government. A Clinical Nurse Consultant is employed to educate in best practice of wound care and dressing application. www.ebdressings.com.au or email eb@brightsky.com.au.

DEBRA Australia offers advocacy, 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.

BrightSky Australia

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HOW TO TAKE A BIOSPY

Please refer to the following website: <http://blisters.org.au/>

CONTACT LIST FOR PAEDIATRIC CENTRES OF EXPERTISE/KNOWLEDGE

Queensland	Royal Children's Hospital, EB Clinic (Burns outpatient Unit), Brisbane	DEBRA Nurse, Samantha Hay	(07) 3636 9119 Mobile: 0458 937 000
NSW	Sydney Children's Hospital, EB Clinic, Randwick Sydney, NSW.	EB Clinical Nurse Consultant, Sarah Hill	(02) 9382 0389 Pager 46562 via Switch: (02) 9382 1111).
		Dermatology Fellow	via Switch (02) 9382 1111
	The National EB Dressing Scheme, BrightSky Australia, Sydney, NSW	EB Dressing Scheme Clinical Nurse Consultant, Louise Stevens	(02) 8741 5721
Victoria	Royal Children's Hospital, EB Clinic, Melbourne	Dermatology Nurse Practitioner	(03) 9345 4803
		DEBRA EB Nurse Consultant	0427 937 699 or via Switchboard: (03) 9345 5522
South Australia	Women's & Children's Hospital, North Adelaide	Lisa Naeher – Stoma/Wound/ Urology Clinical Practice Consultant	(08) 8161 7000
		Head of Dermatology, Dr Lachlan Warren	
Western Australia	Princess Margaret Hospital for Children, Perth	Narissa Wieland / Carmel Boylan – Clinical Nurse Consultants	(08) 9340 8584
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