

## **NATIONAL EB DRESSING SURVEY REPORT 2010**

(Condensed Version)

### **Introduction**

Epidermolysis Bullosa (EB) is a rare genetic skin condition where the skin blisters externally and internally. DebRA Australia is a non for profit organisation which supports families in Australia with EB.

A combined survey of DebRA members was initiated in December 2009 to determine their level of accessibility to EB dressings and EB specialist nursing care via the public health system on a State and National level. Each section is reported separately (*Refer to EB Nurse Survey Report 2010 for results regarding access to EB Nursing Services*).

The findings will be utilised as base line data to lobby for further services and to evaluate the national EB Dressing Scheme being implemented in January 2010.

This report gives an overview of the key findings for the dressing survey.

### **Methodology**

The survey tool was developed in conjunction with the DebRA Australia Committee, EB specialist nurse and independent advisors. The survey link was distributed nationally via email and the national DebRA website over a one month period (17th December 2009 - 17th January 2010). The survey was open to families with any type of EB of any severity.

Results were collated by the DebRA secretariat. Please note that interpretation of dressing names and all written comments have been reported as described by the respondent.

### **Results**

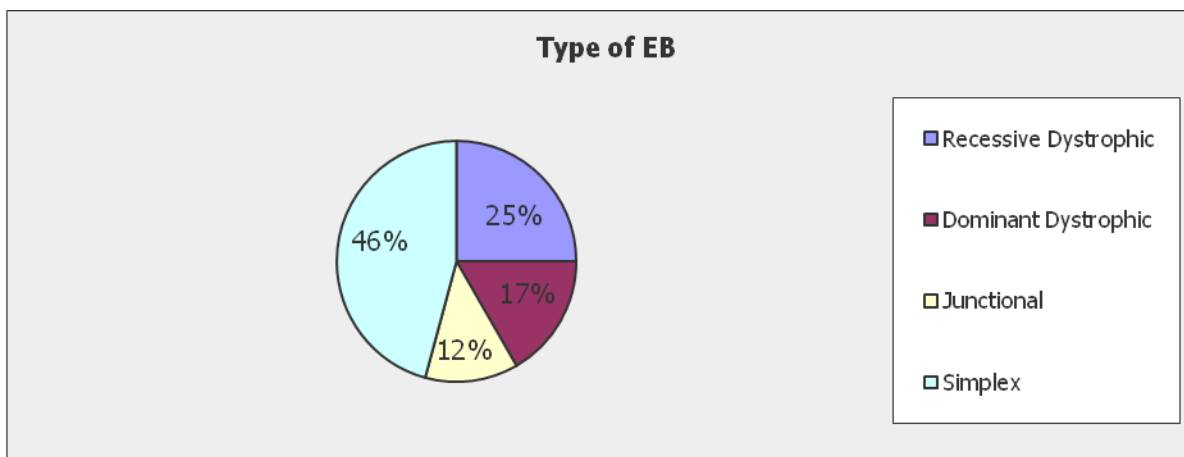
#### **Respondents**

There was a very good response rate of 49 members, compared to 28 members in the previous survey conducted in 2005. One response was excluded due to inappropriate answers. The majority of families completing the survey were from Queensland and New South Wales followed by Victoria, with half of the families living in metropolitan areas.

The majority of families were involved with the care of patients with Simplex EB (46%) followed by Recessive Dystrophic EB (25%), and then Dominant Dystrophic EB (17%) and Junctional EB (12%) (Figure 1).

Ages of participants ranged from newborns up to 74 years of age, with the average age being 19 years. Surveys were completed by adults with EB (46%) or parents of children with EB (54%).

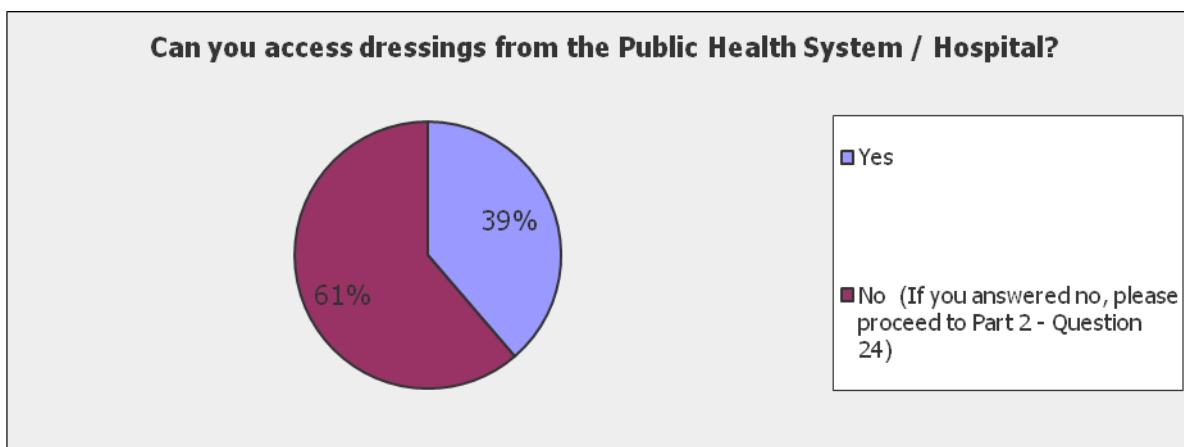
Figure 1: Distribution of EB types among the survey respondents



### Access to Dressings

Members reported that they acquired dressings from more than one source, with 50% being accessed via the public health system. Other means of securing dressings were via DebRA organisations (39%) and members purchasing their own dressings (31%). Only 39% of members were able to access dressings via the public health system (Figure 2).

Figure 2: Distribution of respondents who were able to access dressings from the public health system



### Experiences with the Public Health System

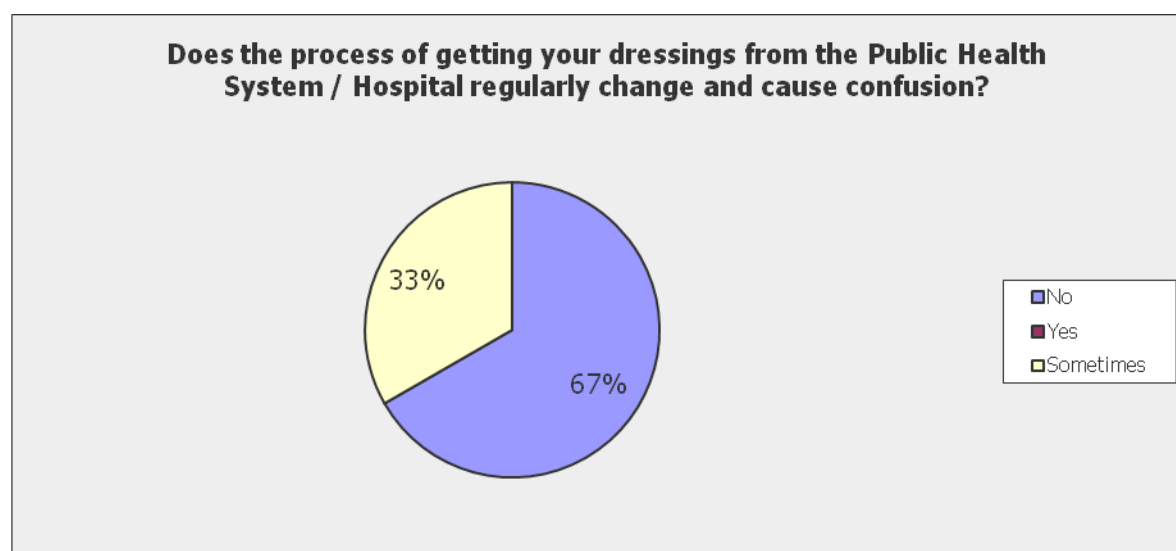
Families who were able to access dressings via the public health system obtained them in various ways, with the majority receiving them via courier (47%), followed by collecting them from the hospital (39%) and by post (30%).

92% of families obtained their dressings on a monthly basis and reported they might spend up to 6 hours per month organising dressing orders (average time taken 2 hours per month).

50% of families always received enough dressings, but 17% of families reported that usually not enough dressings were supplied. Another 33% reported that while they mostly received enough dressings, sometimes the quantity was limited. 59% of families were always able to get access to the type of dressings they needed. The rest mostly, but not always, were able to access the type of dressings they needed. 17% of families have had stock on back order 6 or more times in one year. 25% have experienced out of stock situations 2 to 3 times a year and 17% once a year.

17% of families stated that they were made to feel guilty that they were accessing dressings via the public health system on an ongoing basis, and 33% were sometimes made to feel guilty. 33% of families stated that the process of getting their dressings from the public health system regularly changed and caused confusion (Figure 3).

Figure 3: Level of confusion associated with access to the public health system



### Types of Dressings Commonly Used

The commonly used dressings are summarised in Table 1. 36 different types of dressings were listed as being commonly used by members. It was also noted that some members could not access the dressings that they would like to use, so this list only reflects what was obtainable at the time of the survey. Mepilex (68%) was the most popular dressing used, followed by Mepilex Lite (35%), Tubifast (32%), Mepitel (29%), Mepilex Transfer (23%) and then Polymem, Mepitac and Melolin (19%).

Answers included multiple dressings, therefore the list in Table 1 has been formatted in order of the most popular dressings in order of usage.

Table 1: Types of dressings commonly used by the respondents

DRESSING TYPE	PERCENTAGE OF MEMBERS USING THE DRESSING
Mepilex	68%
Mepilex Lite	35%
Tubifast	32%
Mepitel	29%
Mepilex Transfer	23%
Polymem Mepitac Melolin	19%
Bandages - Crepe Mepilex Border Lite	16%
Micropore Tape	13%
Bandage - Handy Band Mepilex Ag Vas Gauze Webril Telfa	10%
Gauze Jelonet Needles	6%
Activon Tulle Aquasell Bactroban Bandage - Cohesive Bandaids Cotton Tips Cotton Wool Cica Care Silicone Gel Sheeting Lyafoam Polymem Max Polymem Silver Nexcare Tape Sterilised Sheets Surgifix Tubigrip Tubing Urgotul	3%

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