

## **EB NURSE 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 specialist nursing care and EB dressings via the public health system on a State and National level. Each section is reported separately (*Refer to National EB Dressing Survey Report 2010 for results regarding access to EB Dressings*). The findings of the nurse survey will be utilised as base line data to evaluate new initiatives and lobby for further nursing services if gaps are identified.

At the time of the survey the following EB Clinics and EB Nurses were operating in Australia:

- Sydney Children's Hospital: EB Clinic held monthly; 1 x 0.5 FTE Specialised EB Nurse
- Royal Children's Hospital Melbourne: EB clinic held 3 monthly; Nurse Practitioner coordinates EB Clinic (1 day per fortnight)
- Brisbane Children's Hospital: EB clinic held 3 - 6 monthly; Genetic Counsellor coordinates EB Clinic, no specialised nurse
- St George Hospital Sydney: EB clinic held monthly for adults; Part time EB Nurse has been government funded in past, now from Prof Murrell's private practice

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

### **Methodology**

The survey tool was developed in conjunction with the DebRA Australia Committee, an 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 all written comments have been reported as described by the respondent.

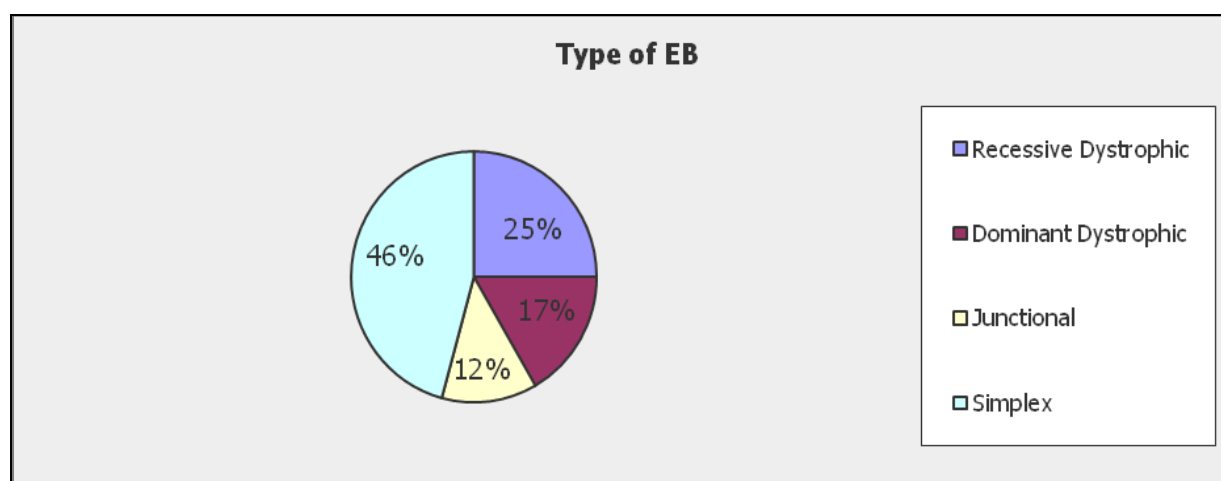
## Results

### **Respondents**

There was a very good response rate of 49 members, compared to 28 members in a 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%).

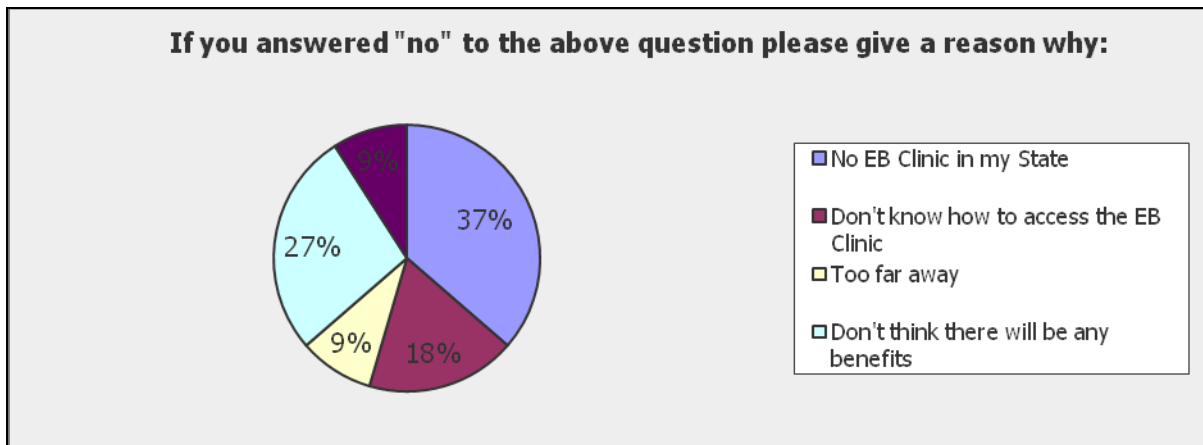
Figure 1: Distribution of EB types among the survey respondents



### **Access to Clinics and Specialised EB Nurses**

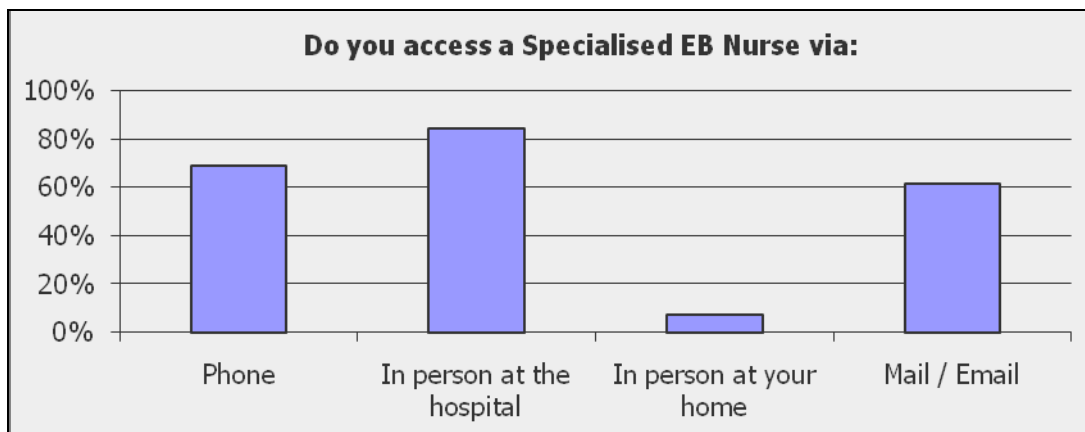
64% of families attended an EB Clinic in their State. The reasons given by the 36% who did not attend a clinic are shown in Figure 2. The largest group stated this was because there was no EB Clinic in their State (37%) or they did not know how to access the EB Clinic (18%) (*this may be due to the fact there is no EB Clinic in their State*). Further, 27% of the non-attendees thought there would be no benefit to attending (one commented that the severity of their condition was too minimal) and 9% were too far away.

Figure 2: Reasons for non-attendance at an EB clinic



45% of families stated they currently had access to a specialised EB Nurse. Families mainly accessed the EB Nurse in person via the hospital or by phone and Email (Figure 3). The majority of families have been accessing the EB Nurse in the last 2 years, with some families up to 23 years (*for example, some families have been accessing an EB Nurse via other States and the United Kingdom due to limited or nonexistent services available in their own State*).

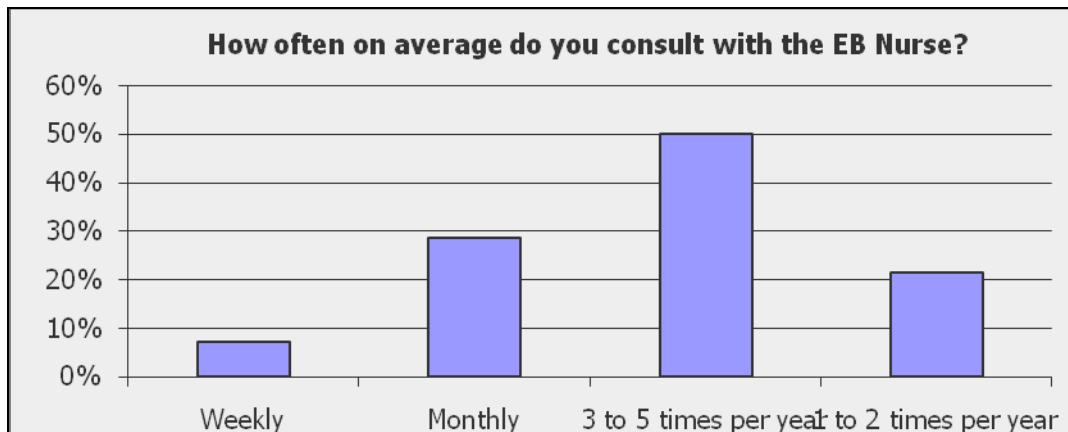
Figure 3: How families access the advice of an EB nurse



79% of families stated that the EB Nurse was located in their State with only 14% these families having access to an EB Nurse in their community. Families travelled a minimum of 10 km to see the EB Nurse and the average travel required was 103 km per family within their State (*if an EB Nurse was available*). However some travelled very large distances, up to 350 km or even further interstate.

50% of families consulted with the EB Nurse 3 to 5 times a year with 29% consulting on a monthly basis (Figure 4). Only 16% of families had access to a specialised EB Nurse when their baby was born.

Figure 4: Frequency of consultation with an EB nurse



### Feedback from Families Who Currently Have Access to a Specialised EB Nurse

100% of families that could access a specialised EB Nurse stated that it was helpful being able to access this service. 93% of families stated that the EB Nurse discussed further alternative dressings with them and 100% stated that the EB Nurse discussed the best way to use the dressings.

When asked to nominate the 3 main types of advice that should be obtained from the EB Nurse, in order of priority, the majority of families responded that dressings was the most important, followed by wound care as the second most important. Other items such as nutrition, integration into wider community, clothing, medications, bathing, specialist services, preventing injury, were just some of the additional priorities. Many very positive comments and no negative comments were made as to why it was helpful to have access to an EB Nurse.

The positive comments about the EB nurse's activities included:

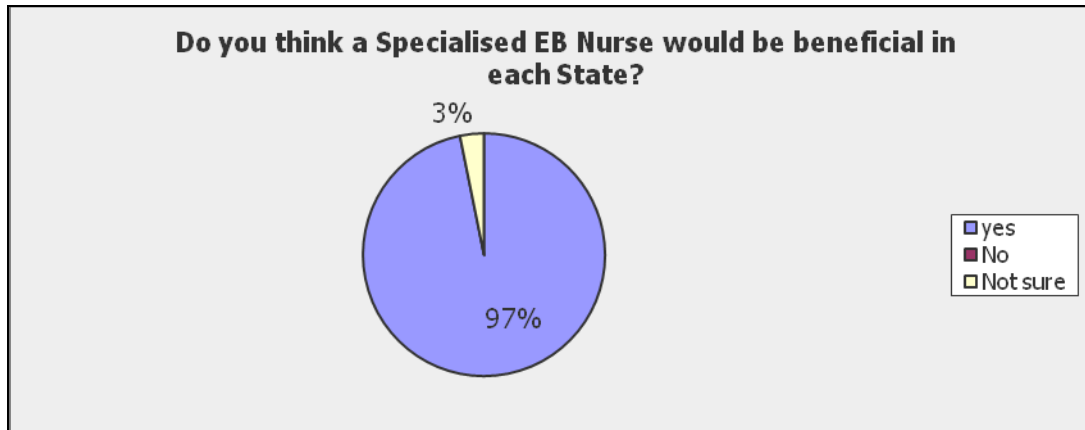
- \*Providing practical advice and information (easy to understand - day to day advice)
- \*Knowledge of EB Care and hospital system
- \*Knowing how to access dressings
- \*Liaising with health professionals
- \*Provided a support network
- \*Personal - sensitive service
- \*Updating on new products and how to use them
- \*Educating local health professionals
- \*Educating on preventative measures for EB Care

Of the small number of families who had access to a specialised EB Nurse when their baby was born, all thought that this service helped them to understand how best to care for their baby. Of the 84% of families who did not have access to an EB Nurse when their baby was born, 70% believed that this type of service would have changed their understanding of how to care for their baby with EB.

### Equity of Access to EB Nurses

100% of families surveyed thought that all EB families should have access to a specialised EB Nurse regardless of where they live. 97% of families thought the appointment of an EB Nurse would be beneficial in each State, with the remaining 3% unsure (Figure 5). 98% of families thought that a Specialised EB Nursing Service should be funded by the Federal Government or State Health Department, rather than a charitable organisation such as DebRA.

Figure 5: Opinion about EB nurse availability



*Report prepared by Sue McKenna  
(DebRA Australia)*