

# **Home Care Program Improves the Life Quality of Patients with Epidermolysis Bullosa: a Taiwanese Perspective**

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EB ?















understand

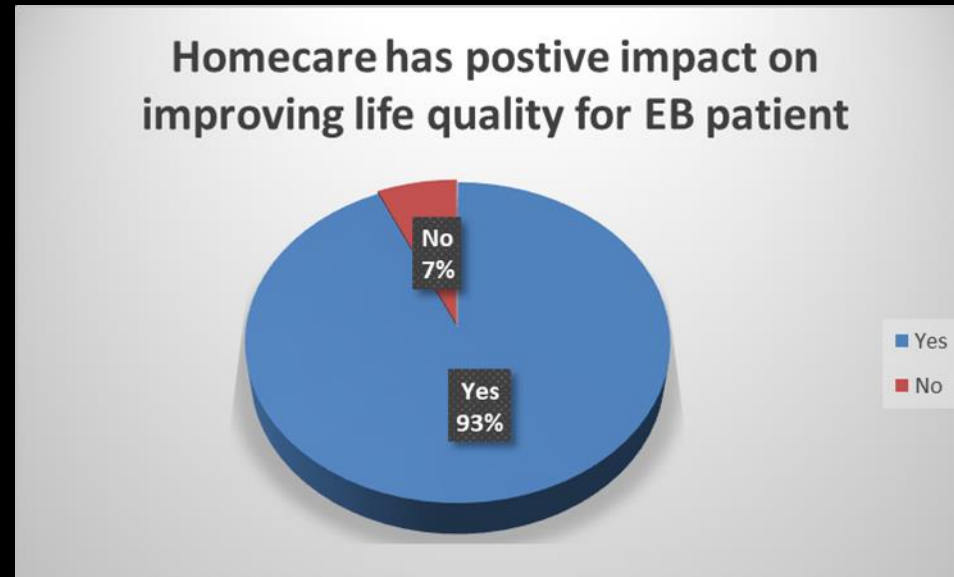
# Home Care Program Improves the Life Quality of Patients with Epidermolysis Bullosa: a Taiwanese Perspective

Documented literature, the needs of caregivers and the current reality of wound treatment indicates that the best results are achieved by treating patients in the familiar environment of the home, followed up with regular hospital visits to monitor wound-dressing and skin changes.

The aim of this project is to develop, perform and evaluate a home care nursing program to provide assistance to families with EB patients in Taiwan .

## Patients and Methods

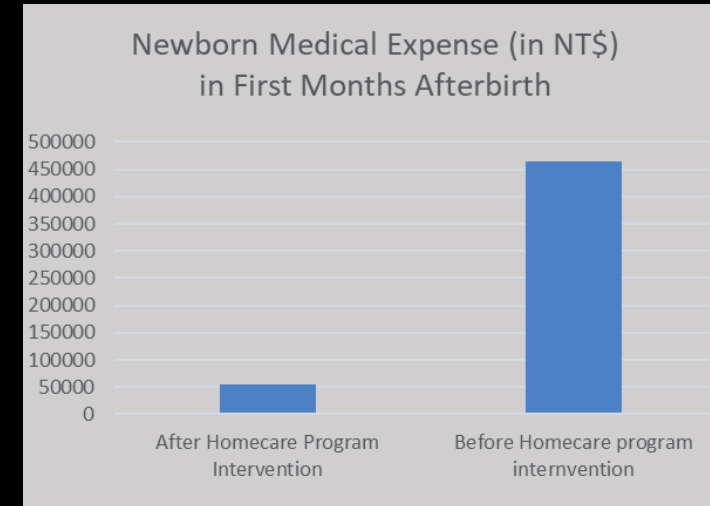
Nursing care includes dressing changes and consultation with the family in their home. This study collects records of visits and questionnaires from a total of 15 patients who voluntarily received homecare care program and calculates their satisfaction and the care needs they wish to acquired. Both family members and patients were surveyed periodically using a questionnaire to assess the benefits of this home care program and its assistance for the patients and their families.





## How home care program improve the life quality of patients

- An effective reduction in medical expenses
- Effect of stable family environment on butterfly babies
- The effective reduction of economic burden on the family
- The health education from home care providers helps break the traditional ties to superstitious ideas that permeate society
- By learning to accept the challenge, parents can emerge from the valley of darkness to help their fragile butterfly babies.



# Home care program



# Documentation

申請日期: 2023年11月17日		家庭日期: 2023年11月17日 (第 1 次)		協會編號:	
個案姓名: 陳					
診斷: Epidermolysis bullosa, junctional type					
醫院名稱: 馬德紀念醫院 新山分院		性別: 男	女	出生年月日: 10/5/23	
出生體重:				出生地: 馬來西亞	
家屬姓名: 父親: 陳	母親: 林			住院日期: 10/9/23	
其他: 身體字號: K22226			出院日期: 10/10/23		
家長戶籍地址: 新加坡 100 禧街大馬路			電話: 091-1111111		
家長現址: 同上			電話: 091-1111111		
臨床詳情: 全身性水泡, 平日就是靠一人換藥, 換藥耗時, 每天換藥時間需耗費 2 小時, 若能提供換藥協助, 減輕父母壓力。					
(個案需求: 查詢視察團): (請詳述):					
申請狀況:	1. 護理師	人	金額: 6200 元	2. 4000 元	
護理師意見:	<p>今次視察發現該群份有大範圍水泡, 予協助水泡清涼, 果用表示昨天帶個來返診, 果文及色果, 果中果缺溫度上升, 水泡也跟著出現; 現個果伴係 16yoga, 進食奶量 15ml/103.4g, 每次餵食時間 30-40min, 期望果王果能跟上同年齡層進度; 果與果建成失敗, 每週一、四至家中探訪, 協助換藥及給予護理評估, 依評估結果擬訂照顧計劃, 建議果獲得安寧三級家屬護理師簽名: 陳</p>				
主要防範: 家屬護理師姓名: 曾	醫院: 馬德紀念醫院	家屬簽名: 林	協理		

# Publication in April 2017







**2016.3**：生產前一週，背部傷口已癒合



**2016.4**：生產前一天  
飲食及胎兒發育正常

“Find a way of life”  
writed by a member who suffered from RDEB



**為生命找到出路**

文：姜宥慈  
病友  
RDEB

# Thank you for your attention!

## Acknowledgements :

Member of Debra Taiwan are very grateful for Director of Debra New Zealand, Anna Kemble Welch, as her encouragement two years ago in London thus make the home care program in Taiwan could be initiated and achieved.



Teamwork approach to help our patients enjoy their most possible high quality of life