The background of the slide features several large, semi-transparent pink butterflies with detailed wing patterns. There are also smaller pink butterflies and abstract, flowing pink and orange shapes that create a soft, ethereal atmosphere. The overall color palette is dominated by various shades of pink and light orange.

邁向卓越：遺傳性分解水泡症的 全人照護與長遠目標

成大皮膚罕病團隊|National Cheng Kung University Hospital

泡泡龍個管師林芝羽

2025.02.12

成大皮膚罕病照護團隊



成大皮膚罕病照護團隊



Dermatologist



Dermatologist



Dermatologist



Dermatologist



Pediatrician



Geneticist



Dentist



General physician



Pediatric neurologist



Ophthalmologist



Nutritionist



Pharmacist



Nurse



Nurse



Otolaryngologist



Nurse

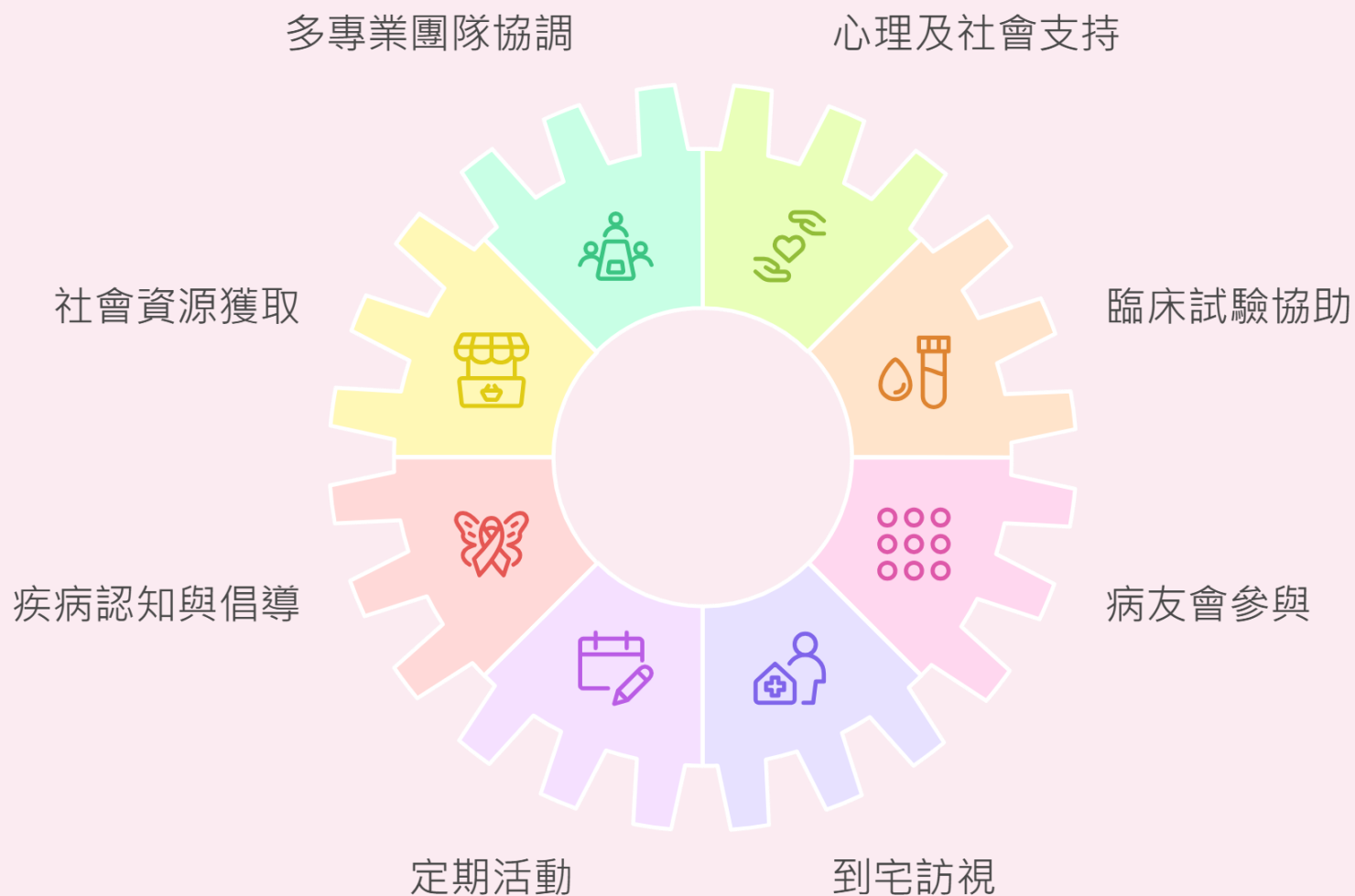


Coordinator



Genetic
Counselor

泡泡龍個管師職責



個案整體性評估

(Comprehensive Nursing Health Assessment)

生理

- 認識疾病
- 對日常起居、飲食、就學、就業等影響

心理

- 增進自我認同
- 接納自身疾病
- 病友團體支持
- 心理輔導
- 陪伴

生育 關懷

- 遺傳基因檢測
- 生育諮詢

社會 福利

- 協助罕病通報
- 身障手冊申請
- 加入病友團體
- 連結長照資源

參與病友團體活動



跨院、跨團隊協同合作 (interprofessional collaborative practice)



全人照護-到宅醫聊 (Home Visit)



因初生新生兒至中部醫院進行切片，跟轉介醫院照護團隊、家屬說明



初生新生兒家庭訪視提供照護並介紹泡泡龍協會提供支持

全人照護-到宅醫聊 (Home Visit)



成大皮膚

SNQ國家品質標章認證

- 成大皮膚罕病團隊榮獲SNQ認證
- 以卓越的病患照護模式與研究獲得肯定
- 多專業團隊合作提供高品質照護

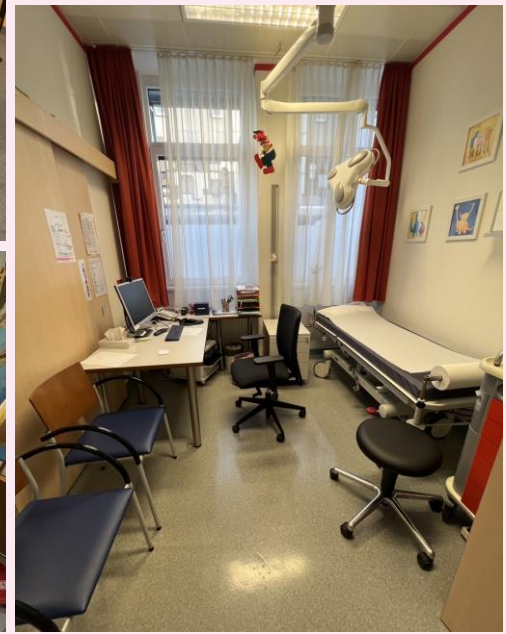
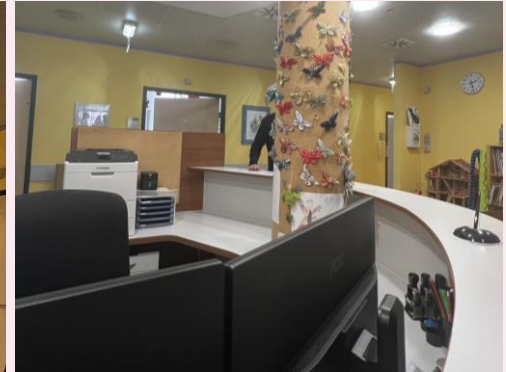
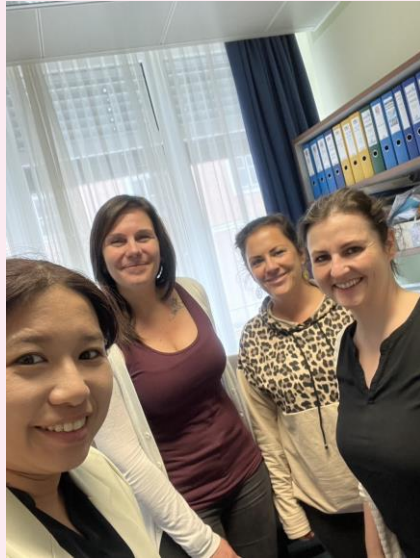


國際合作與經驗交流



EB HOUSE

- 2005年成立
- 分成臨床門診、臨床試驗、學術教育、研究
- 位於奧地利Salzburg





醫藥會

25 NHQA
National Healthcare Quality Award

國家醫療品質獎頒獎典禮

National Healthcare Quality Award

品質領先 國家榮耀 Committed to Excellence



參與國際性臨床試驗



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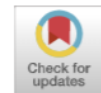
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FULL-LENGTH ARTICLE

Clinical Research

ABCB5⁺ mesenchymal stromal cells facilitate complete and durable wound closure in recessive dystrophic epidermolysis bullosa



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結論

致力於改善泡泡龍病患的全人照護

透過國際合作持續學習與精進

在照護與研究中追求卓越，邁向未來

