

Translation of a Psychosocial Education Program Congenital Adrenal Hyperplasia in DVD Format

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Introduction

Congenital Adrenal Hyperplasia (CAH) is an inherited disorder resulting in glucocorticoid and mineralocorticoid deficiency and androgen excess. Patients are at risk of salt losing adrenal crisis and the effects of virilisation with out adequate treatment.

Management of CAH requires good parental and/or patient knowledge and understanding of the disorder, and understanding of what action to take when clinical problems arise.

Effective education initiatives are of vital importance in helping families to manage the condition. Access to good quality health care and education in a language that is understood is a basic human right. Culture and language may be different, but the effect and impact of a chronic health condition is the same for any child I the world.

Aim

Translate the Psychosocial Education Program (PEP) title "The CAH Family Workshop" for families (patients, parents and carers) with a child with CAH.

Method

Patient interviews, health professional focus groups, literature review, questionnaire design and validation, informed the DVD content.

Program content centred around what was necessary for families to understand and manage the condition, child to adulthood, with consideration regarding literacy levels and lay understanding. The content was clear, concise and culturally relevant.

Format: didactic slide presentations, with key points and graphic overlay.

Presented and evaluated 4 times amongst the Children's Hospital Network in NSW Australia.

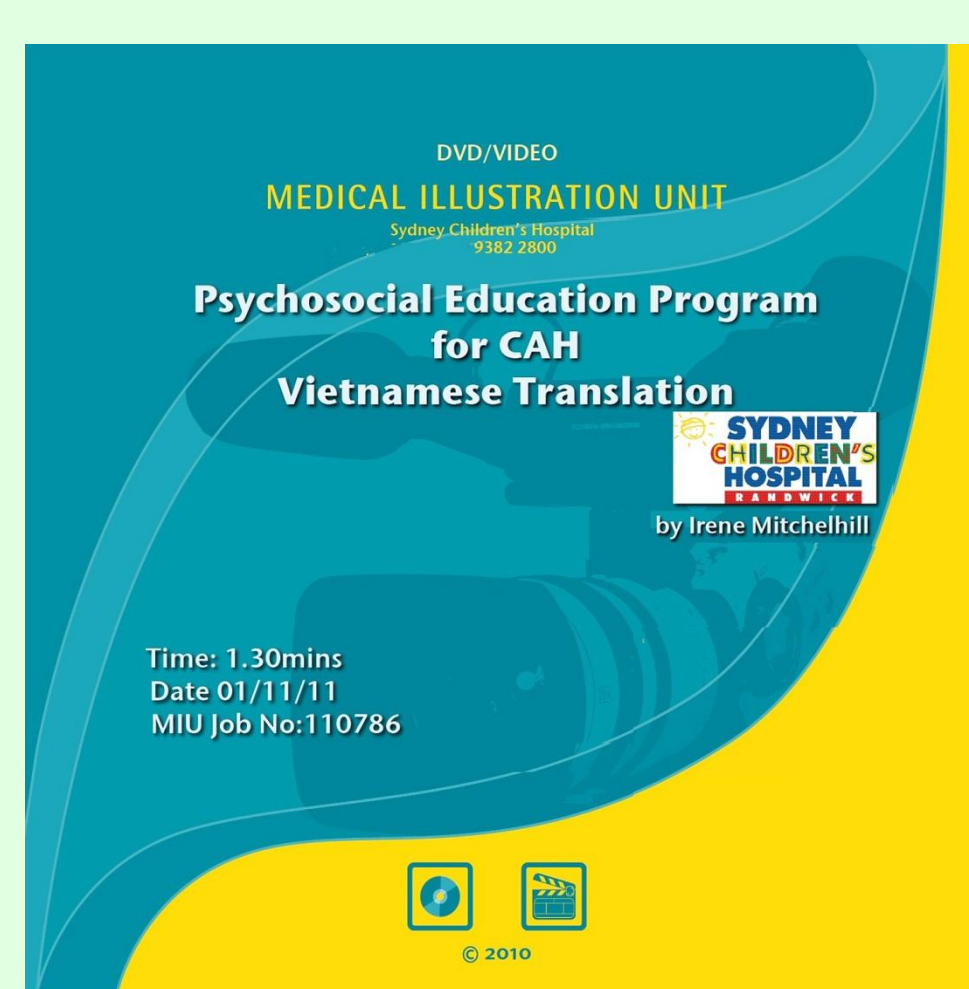
Translation

The transcript of each presentation was typed verbatim, with timing of slide transition for ease of placing voice overlay.

The translation of the transcript was word for word by 2 medical practitioners with graphic design of the PowerPoint slides.

Editing for lay understanding and recording of the narration of the script by a health service interpreter.

The final DVD development process included movie editing in sequence with the verbal translation and translated slides..

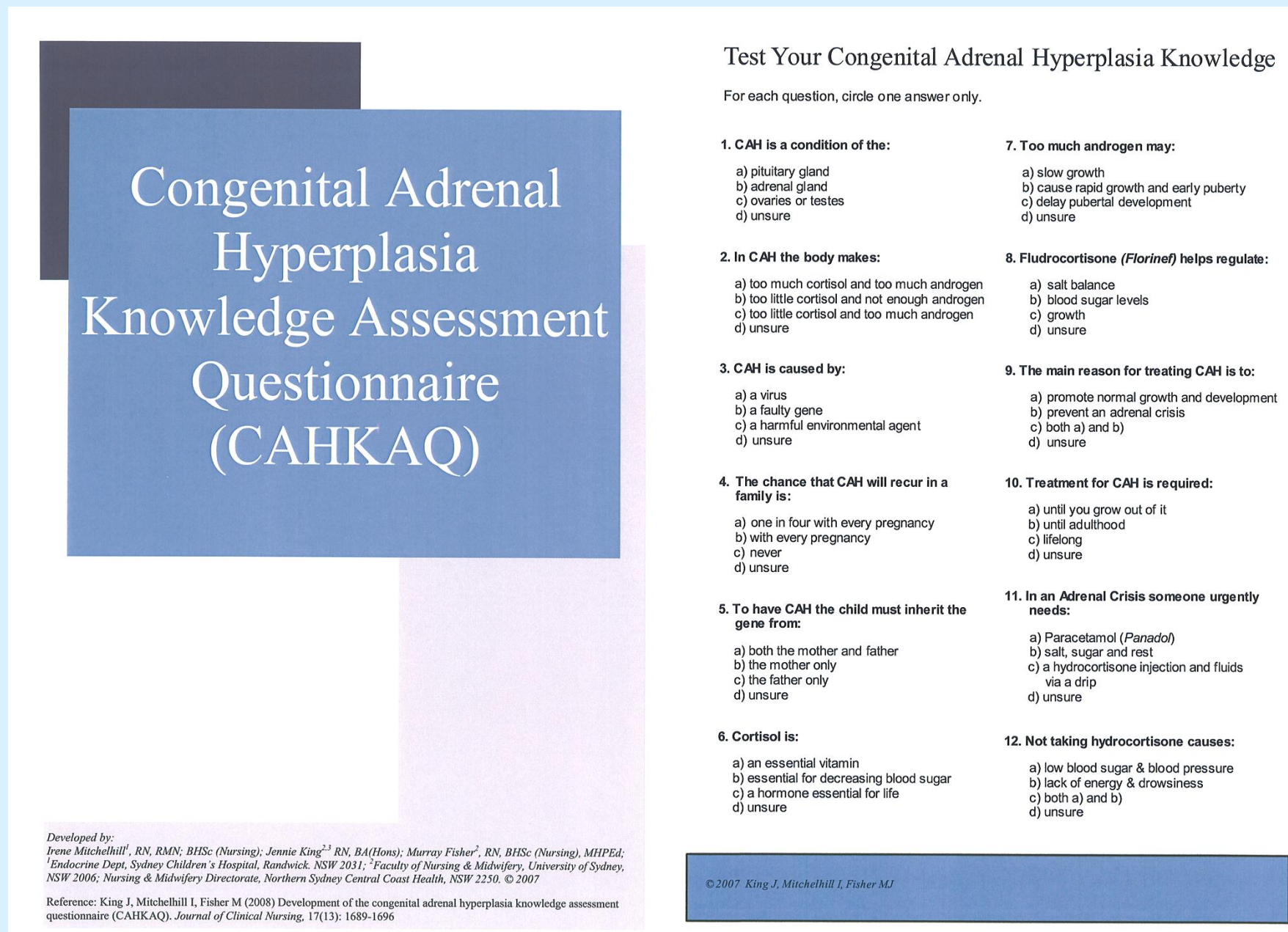


Vietnamese translation: PEP



- The total program takes approximately 1.5 hours to play
 - Toàn bộ chương trình kéo dài khoảng 1 giờ rưỡi.
 - You may choose to view any one of the 5 chapters individually by clicking on the chapter number from the main menu
 - Bạn có thể chọn xem bất kỳ phần nào trong 5 phần bằng cách nhấn vào số hiệu của phần đó từ bảng nội dung chính.
- If you have any questions about the information presented in this program, please discuss this with your health professional
- Nếu bạn có bất kỳ câu hỏi nào về những thông tin được trình bày trong chương trình này, xin vui lòng thảo luận với chuyên gia y tế của bạn.

Evaluation CAHKAQ: Available translated



Conclusion

Developing educational material for patients and families is an important part of the health professional role. Tools to support and evaluate the education process are included with the program.

Ensuring that families of all non - English speaking background, receive the necessary and appropriate information to enable them to manage their child's condition is the responsibility of all health professionals.

Developing this comprehensive education program was seen as a necessary step when considering the needs of families in caring for their child with CAH.

Translating the "PEP" into Vietnamese and Indonesian was considered a necessary step, given the limited educational resources available to families in these developing countries. The **CAH Family Workshop**, is a comprehensive Psychosocial Education Program, which can be presented individually or in a group setting, and is able to be facilitated by one health professional.

Indonesian translation: PEP



- Welcome to the CAH Family Workshop, an education program developed for families with Congenital Adrenal Hyperplasia.
- Selamat datang di Lokakarya Keluarga CAH, sebuah program edukasi yang dikembangkan untuk keluarga dengan Hiperplasia Adrenal Kongenital

Program chapters Program Acara

- Chapter 1: Bab 1: What is Congenital Adrenal Hyperplasia, diagnosis & management:** Apakah yang dimaksud dengan Hiperplasia Adrenal Kongenital, diagnosis, dan terapi. Presented by Dr Charles Verge Paediatric Endocrinologist, Sydney Children's Hospital. Dipresentasikan oleh Dr Charles Verge, AHI Endokrin Anak.
- Chapter 2: Bab 2: Adolescent and Adult issues:** Masalah yang timbul pada masa remaja dan dewasa. Presented by Professor Kate Steinbeck Consultant Adolescent and Adult Endocrinologist Sydney Children's Hospital. Dipresentasikan oleh Professor Kate Steinbeck, Konsultan Endokrin Remaja dan Dewasa.
- Chapter 3: Bab 3: Psychological Issues:** Masalah Psikologis Presented by Ms Julie Kozyk, Consultant Clinical Psychologist, Sydney Children's Hospital. Dipresentasikan oleh Julie Kozyk, Konsultan Psikolog Klinis.
- Chapter 4: Bab 4: Sick Day Care:** Perawatan pada hari sakit! Presented by Ms Irene Mitchellhill Clinical Nurse Consultant Sydney Children's Hospital. Dipresentasikan oleh Irene Mitchellhill, Konsultan Perawat Klinis.
- Chapter 5: Bab 5: Emergency Injection of Hydrocortisone** Penyuntikan Hidrokortison pada kondisi gawat darurat. Presented by Ms Irene Mitchellhill Clinical Nurse Consultant Sydney Children's Hospital. Dipresentasikan oleh Irene Mitchellhill, Konsultan Perawat Klinis.

References

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Acknowledgements:

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