



**Clan**

Caring & Living As Neighbours

Congenital Adrenal Hyperplasia

# **CAH Club Report**

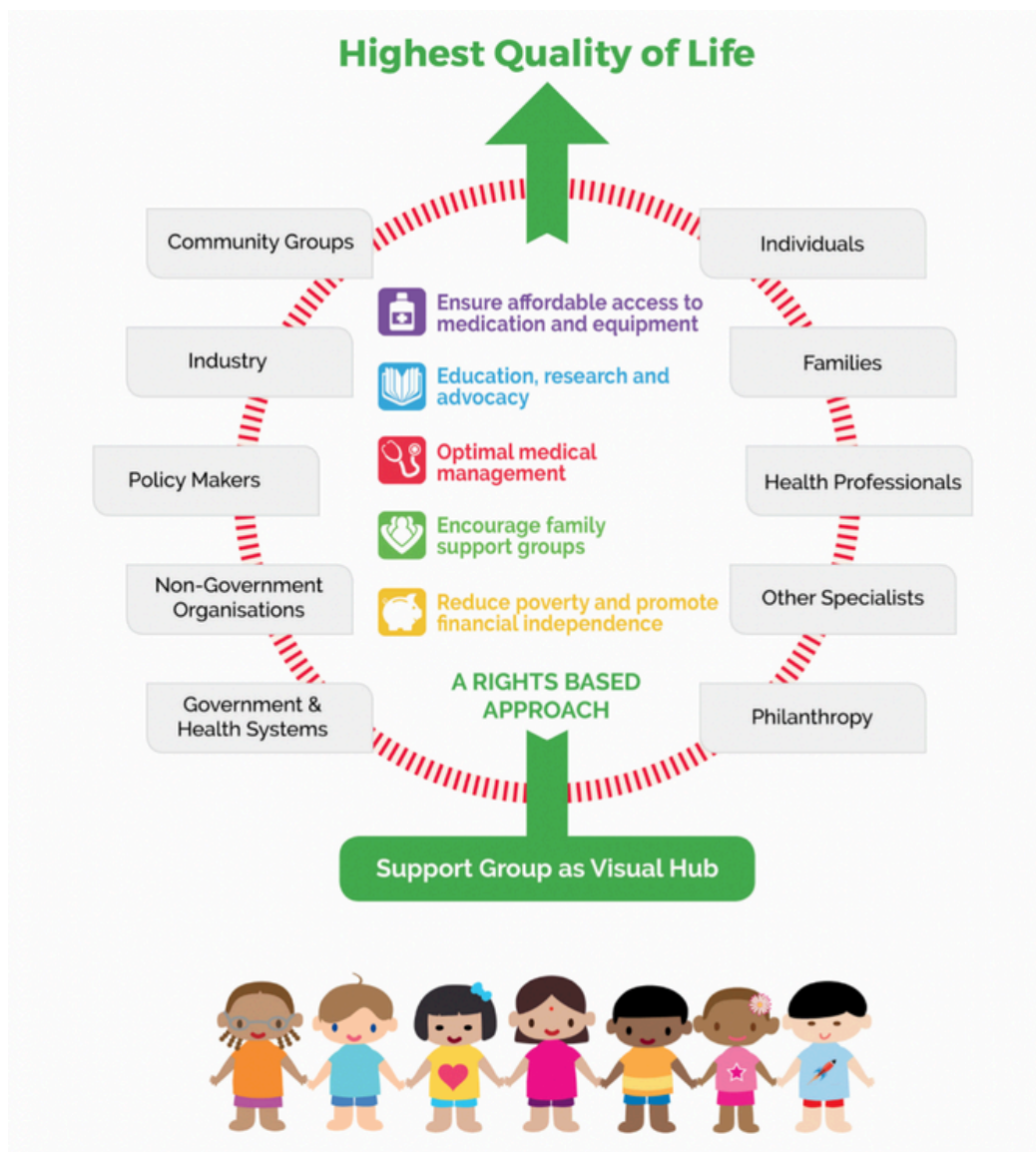
December  
**2023**



## Every child has the basic human right to health and life

Caring & Living as Neighbours (CLAN) is an Australian based Non-Governmental Organisation formally associated with United Nations Department of Global Communications (UNDGC) and in Special Consultative Status with United Nations Economic and Social Council (ECOSOC).

CLAN's mission is to maximise quality of life for children and their families who are living with chronic health conditions in resource-poor settings of the world. CLAN's five pillars and framework for action are foundational to meeting the needs of communities of children living with chronic health conditions.





# Congenital Adrenal Hyperplasia

## Introduction

On Friday 1st December 2023 Vietnam National Children's Hospital (VNCH) hosted its 19th Congenital Adrenal Hyperplasia (CAH) Club. Held in Lecture Theatre J of VNCH, the event brought together approximately 100 people for education, networking and support.

The event commenced at 9am and was hosted by Dr Thao (head of the Endocrinology and Diabetes Department of VNCH), with assistance from Dr Van to MC the event.

Due to large number of CAH patient at VNCH now (more than 1,000 children registered), the focus for this meeting was to invite families of children newly diagnosed with CAH to attend.



# Opening Address

Dr Vu Chi Dung (head of VNCH's Department of Paediatric Endocrinology and Metabolism) gave the opening address, and shared the history of the CAH Club. The first Club Meeting was held in 1998, 35 years ago, with only about 70 patients known to VNCH. In comparison, there are now more than 1300 CAH families registered at VNCH, and each year another 30-40 children with CAH attend VNCH for care.

Newborn Screening (NBS) for CAH is now available in Vietnam, enabling earlier diagnosis of CAH. In 2022, 20 children were diagnosed with CAH through NBS. Many children cared for at VNCH over the years have now transitioned to adult Endocrinologists for care and are living fulfilling lives. VNCH's older patients tend to keep in touch with the Endocrinology Department of VNCH. Some are now living in London, many have attended University, and some even work at VNCH! Young people living with CAH in Vietnam are now going into rewarding jobs, including teaching, business, hospitality. Some are now married and have children of their own, some even have more than one child.

Mortality associated with CAH in Vietnam is now very low. Families are attending hospital early during times of acute emergency and adrenal crisis, resulting in their survival.

Doctors and district level health professionals in Vietnam now have a better understanding of CAH. Furthermore, local management of crises has improved. This condition is now taught from first year medical school and included in ongoing medical education programs in hospitals. In fact, CAH is now also included as a question in medical students' exams.

All patients and families receive booklets on CAH, to help them learn how to manage CAH. There are two booklets available:

- A small cartoon style booklet on CAH by Garry Warne; and
- A book (by Hsu and Rivkees) that provides in-depth information on the management of CAH.

The role of parents in the optimal management of CAH is crucial; hospital staff can never replace parents. Parents care for children all the time, compared to the brief and intermittent involvement of health professionals. Parents must therefore learn all they can about CAH, how to look out for the symptoms of adrenal crises, and how to manage sick days. Parents are the ones who are responsible for deciding when to bring their child to hospital and ensuring they attend their regular visits to health centres.



For the last 20 years, VNCH has been partnering with Caring & Living as Neighbours (CLAN). CLAN has supported VNCH and the CAH Community with time and resources. Yesterday Kate Armstrong (President of CLAN) was awarded the People's Health Medal from the Ministry of Health for her contributions to Vietnam's health sector. Prof Maria Craig has also received the People's Health Medal from her work with VNCH over many years, including supporting Club meetings and health professional training. Congratulations Kate Armstrong and Prof. Maria Craig!

We are glad to welcome back Irene Mitchelhill, who has attended the VNCH Club meetings in 2012. Today she will be presenting on the importance of social support and sick day management for people living with CAH. These days families can access information on CAH from a range of different sources; a stark contrast to 15–30 years ago. The Support Group is an important source of information and connection. This Club meeting is a chance for attendees to share information and experiences while encouraging one another.

Thank you to the team from Australia for traveling and supporting this meeting and to the children and families for joining us here today.

The Australian visitors gave their presentations:

- Prof Maria Craig presented on CAH genetics;
- Irene Mitchelhill presented on CAH management and sick day care; and
- Kate Armstrong spoke from a mother's perspective on managing CAH and presented on the recent work of CLAN and @MATES4Kids.



# Q&A Session

Dr Thao facilitated an interactive question and answer session. Most families participating today were joining a CAH Club Meeting for the first time, although one family spoke about a meeting they had attended a Club meeting in 2019, and another in 2018. Some questions include skin discolouration, adominal pain, dermatitis, hypertrichosis, and having multiple children in the same family with CAH.

# CAH Club Executive

The CAH Club Executive introduced themselves to the CAH Community in the closing session, and encouraged families to get involved and connect with one another. Mr Kien, CAH Club President of 15 years, gave a speech where he shared his story and insights with CAH. He has a daughter who is 16 years old living with CAH, who is healthy and well. However, sometimes teenagers can have a difficult time, especially if they have not been compliant with taking medicine.



There are concerns about the cost of medicines (especially with medicines coming from Korea) and government support to approve access to medicine and care. Having firsthand experience living with and managing CAH, Mr Kien and his family are eager to develop support outside the hospital for other families with CAH.

Thank you to VNCH for bringing international guests to the meeting; to families and to doctors for caring for children with CAH; and to CLAN and KA for last 20 years. Having ongoing support and translating resources are instrumental for families with children living with CAH.



## Closing Address

The 19th CAH Club meeting was closed by Dr Dung, who shared the following messages:

- To join and connect through the CAH Club has a Facebook Community;
- VNCH will continue to support CAH Club meetings and aim to hold annual meetings.
- Hydrocortisone tablets are covered by insurance. Families can get a one month supply from VNCH and transfer documents last one year. It's possible to go to the previous hospital for medicine.
- Fludrocortisone remains a challenge. The cost to import is high and the price of fludrocortisone is expensive for families.
- Referral hospitals from provincial areas can be used for one year; families can then come to VNCH to get their medicines.
- Ten years ago the Ministry of Health tried to import fludrocortisone, but the price was cheaper on the black market. Families purchased the more affordable option and the medicines had to be thrown away.
- VNCH will work to assess drug price and quality to choose the best drugs for the hospital. There are many demands on the hospital for drugs and limited resources, so decisions must be made carefully to balance conflicting priorities and needs.

# Conclusion

It was an honour for CLAN's Team to attend the 19th CAH Club meeting at VNCH. Sincere thanks to VNCH for the very kind invitation to join. Health outcomes and quality of life for people living with CAH in Vietnam have improved markedly over the last twenty years. It was an especial pleasure for CLAN's team to meet with Mr Kien and Ms Giang (Club VP) at the end of the Club Meeting. Discussions focused on future priorities:

- Interested in Vietnamese version of teen book
- Important to emphasise to parents the necessity of taking medicines every day / not missing any doses
- Interested in school video in Vietnamese
- Interested in Jeff Cagandahan's story and request an introduction between Kien and Jeff

CLAN is grateful to VNCH for hosting this wonderful event, and commits to ongoing collaboration with VNCH and the CAH Community of Vietnam. Vietnam is showing that real change is possible within a short space of time – congratulations to all involved in driving such incredible advances.

