

CAH FORUM 2023



Written by Lulu Arraiza, November 2023
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Left to right: Alain Yap (CAHSAPI President), Dr Jedeane Aragonp, Lulu Arraiza and Isabelle Khamson (CLAN interns), Dr Lulu Castro-Malabayoc, Dr Regina Jacinto

INTRODUCTION ★

After a 3-year break, the PSPME and CAHSAPI communities have come together for another very successful CAH (Congenital Adrenal Hyperplasia) Forum!

The CAH Forum was held on 14th November 2023 and involved support from the Philippine Society of Pediatric Metabolism and Endocrinology (PSPME), and CAHSAPI (CAH family support group). PSPME and CAHSAPI usually try to organize a community gathering event like this once a year. However, the COVID-19 pandemic has put a hold on this event for the past few years. This year, they came back strong and collaborated with representatives from CLAN (Caring & Living as Neighbours) to support their mission. The representatives from CLAN are interns being sponsored by the Department of Foreign Affairs' New Colombo Plan Scholarship. The collaboration between these three groups resulted in a very informative and enjoyable event for all the attendees. Because of the pause on events since COVID, there were many new members with newborns and young children recently diagnosed with CAH. The event therefore aimed to provide both information on CAH and how to access support systems within the wider community.



Dr Regina Jacinto giving a lecture on CAH

IT'S LEARNING TIME!

The event was kickstarted by Dr Regina Jacinto, a current Fellow at PGH (Philippine General Hospital). Because there were several families attending with newly diagnosed infants and children, Dr Reg did a very important presentation on the basic medical explanation of CAH.

After Dr Reg's talk, the attendees were separated into two groups: infants and children, and adolescents (11 years and above), both being accompanied by their parents or other companions.



CLAN interns Isabelle Khamson (left) and Lulu Arraiza (right) in adolescent session

TEENS' SESSION

For the teenagers, they have already been living with CAH for more than a decade and might already be familiar with managing adrenal crises. Therefore, their session was focused on the psychosocial effects of living with CAH.

This session was facilitated by the two CLAN interns and encouraged the teenagers to open up about the challenges they face and share recommendations on how to manage these issues.

Despite the low number of teenage participants, it was an incredible sharing experience! The teenagers were at first hesitant to talk about themselves, but eventually became more comfortable and were able to have some really useful discussions.

They were even able to have a great game of Icebreaker BINGO, where the winner was rewarded with a packet of Tim Tams (which he shared with the group).



Dr Jedeane Aragonp facilitating the infant and children session

CHILDREN'S SESSION

In the infant and children's session, the families were given advice directly from the PSPME-member doctors about what an adrenal crisis is, and what to do if one occurs. This is critical information, especially for those families who have been given a very recent diagnosis.



PSPME members listening to participants in the open forum

OPEN FORUM

After the breakout sessions, everyone came back together. There was an open forum for any comments from participants to the whole community.

WRAPPING UP!

This ending was a great way to wrap up the event. There were parents who asked lingering questions they had from their sessions, and some who came up to the mic just to share their appreciation for the event.

Finally, everyone was able to just chat to each other over some lunch. Kids also came up to the little photo booth that was set up, and had some very fun pictures to remember the event by!



Group photo of all the families, companions, children, and organisers

★ SOME MORE FUN HIGHLIGHTS! ★



Children, organizers, and doctors all having fun with a homemade photo booth!



There were 2 lucky winners of a raffle for free medicines!

