CAH Global View

A publication of CAH International
voices of congenital adrenal hyperplasia

FALL 2025 | VOL. 3

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Dear Friends of CAH International,

As we welcome you to this new edition of the CAH International Newsletter, we are once again reminded of the strength and value of our global community. Across countries and organizations, important steps are being taken — and when we bring these efforts together, they truly begin to count.

In this issue, you'll find information about upcoming events hosted by our associated organizations, offering opportunities to learn, connect, and contribute. As always, we also share updates from our member countries, showing the inspiring ways local initiatives are making a difference.

We are pleased to provide news on our joint advocacy regarding the surgery topic and our continued engagement with the UN Human Rights Council — a reminder that our united voices can help shape change at the international level. Finally, we share important information about a new drug that has recently entered the market, offering fresh perspectives for treatment and care.

Each of these developments reflects a piece of the larger picture: steady progress made possible by collaboration and commitment. Together, step by step, we are making a difference for everyone living with CAH.

With gratitude and hope,

The CAH International Org-Team

Human Rights Council Update

In our last newsletter (06/2024), we reported on the discussions in the UN Human Rights Council on the topic of intersex ("Combating discrimination, violence, and harmful practices against intersex persons"). In Fall 2024, we contacted you with a request for statements for a report to be compiled by the UN Human Rights Council. As CAH International, we wrote a statement. Several AGS Groups from different countries submitted their own statements. Individual statements from people with CAH regarding the intersex issue and the repeatedly questioned issue of surgery were also submitted to this committee.

With regard to human rights, any form of discrimination must of course be rejected – however, the question of the definitions of intersex/DSD and the question of surgery for girls with CAH must be considered in a very nuanced way. Surgery is repeatedly portrayed as a "harmful practice against intersex persons." We are, of course, aware that people with CAH have had painful experiences in connection with surgery. But there are also many other perspectives and positive experiences. These must also be heard and taken into account in order to obtain a balanced picture of this issue. We at CAH International are committed to this, and we are very pleased that we have been able to work together on this through our networking efforts, which began in 2022.

Thank you to all the groups and individuals who submitted statements in November 2024!

Our statements have been received by the Office of the High Commissioners of Human Rights (OHCHR), and this week (August 2025) we received confirmation of this in the form of a request asking whether our submissions may also be published.

The report on this topic will be presented and discussed at the upcoming UNHRC session. The report will be published in advance on the UNHRC website. We are curious to see how our statements will be taken into account and mentioned in this report. If necessary, we will respond in advance.

The report will be available at OHCHR | 60th regular session of the Human Rights Council.

Spain Conference

On August 29th and 30th, the **AEHSC (Spanish Congenital Adrenal Hyperplasia Association)** and the **Germans Trias i Pujol Hospital** in Barcelona hosted a two-day conference featuring Dr. Peter Hindmarsh, a renowned expert from the niversity College of London. The event brought together endocrinologists, researchers, and patient advocates to explore advancements in CAH management.

Dr. Hindmarsh's keynote focused on the critical role of cortisol measurement in optimizing hydrocortisone dosing for CAH patients. His work underscores how precise cortisol levels can guide personalized treatment, reducing long-term complications. Over the two days, he addressed endocrinologists first and then members of the Spanish patient association, emphasizing the importance of patient-centered care.

Following his presentations, the hospital's team shared their work. Silvia Martínez outlined new techniques for analyzing blood samples, improving diagnostic accuracy. Dr. Ignacio Blanco, an expert in genetics, discussed how CAH is inherited and the role of genetic counseling. He emphasized that counseling should be a supportive process, helping patients make informed decisions—particularly regarding family planning. Marta de Diego, president of the Spanish Pediatric Surgery Society, explained current techniques for separating the urethra and vagina in CAH patients. Psychologist Pilar Mundo highlighted the emotional stages families often experience when a child is diagnosed with a rare condition.

After lunch, Dr. Hindmarsh engaged in an informal Q&A with AEHSC members. Both he and the hospital's professionals demonstrated a strong commitment to improving CAH care, going beyond their roles to improve the lives of patients with CAH.

The Voice of CAH for 25 Years | www.caresfoundation.org

CARES Foundation 25

Co-host

Riley

Riley Children's Health
Indiana University Health

●REC RECORDINGS OF SESSIONS

ANNUAL PATIENT EDUCATION CONFERENCE

Riley Hospital for Children | Indianapolis, Indiana


Sign-up here! (Free to sign-up for CAH International)

To request the link to view these recordings, please email: john@caresfoundation.org.

www.caresfoundation.org



This year's conference has been sponsored by

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PANTHER RAREX

QUALITY OF LIFE STUDY

Living with Congenital Adrenal Hyperplasia: Global Insights on Health Outcomes, Quality of Life, and Adrenal Crisis Experiences

A collaboration between CARES Foundation and the University of Virginia

Thank you for your willingness to participate in this study. This survey is intended for caregivers/parents/guardians of children between the ages of birth-17 years of age and adults (18 years or older) with classic (salt-wasting) congenital adrenal hyperplasia (CAH). Your insights are valuable in helping us better understand the diverse perspectives and experiences within the Congenital Adrenal Hyperplasia (CAH) community.

This survey is designed to explore health-related and quality of life information; differences between U.S. and international participants; and patient experiences with adrenal crisis events and CAH treatment/ management. Please answer the questions to the best of your knowledge and remember that the answers to this survey are confidential.

If you don't feel like you qualify to participate in this study, please contact me (lfleming@virginia.edu) before continuing the survey. This survey should take approximately 20-30 minutes to complete.

To access this survey, please scan the QR code or visit:

https://virginia.az1.qualtrics.com/jfe/form/SV_396wIpuCrbNrTkW

***PLEASE COMPLETE BY NO LATER THAN OCTOBER 31, 2025**

If after completing the survey, you have questions regarding your care or feel you need additional support, please contact your healthcare provider or CARES Foundation (www.caresfoundation.org).

Thank you.

SAVE THE DATE!

Our Next **CAH International Community Update Meeting** will take place on November 8, 2025 at 11:00 UTC.

Here are a few local times to help you plan:

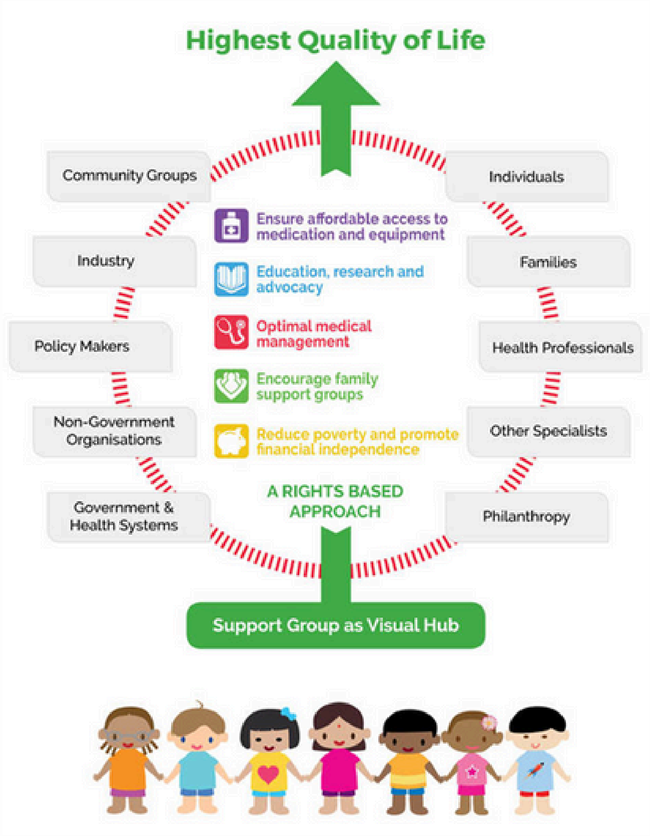
- New York: 6:00 AM
- São Paulo: 8:00 AM
- Berlin: 12:00 PM
- Sydney: 10:00 PM

More information, including the invitation and login details, will follow shortly.

Updates from CLAN (Caring & Living As Neighbours)

Founded in 2004, CLAN is an Australian Non-Government Organisation committed to equity for children living with CAH in lower income countries around the world. CLAN takes a rights-based, community development approach to driving sustainable change, and commits to collaborative action on five key pillars to maximise quality of life for children living with CAH in the most vulnerable circumstances:

1) Affordable access to essential medicines and equipment
2) Education, research and advocacy
3) Optimal medical management
4) Encouragement of family support groups and
5) Reducing financial burdens on families



Some key updates to share include:

1) @MATES4Kids side event at UNGA80 Science Summit

In 2021 CLAN started work as founding Secretariat of @MATES4Kids (Maximising Access To Essential Supplies for Children), an international movement committed to reducing the preventable mortality associated with CAH by 30% by 2030. This bold aim aligns with delivery of the United Nations Sustainable Development Goals – particularly SDGs 3.2.1, 3.2.2 and 3.4.

On 10 September members of the @MATES4Kids Network came together for a side event at the Science Summit on the sides of the 80th UN General Assembly, to celebrate some of the latest advances in research and science to reduce mortality and improve health outcomes for children living with CAH and other chronic conditions. A video recording of the event is available online – we would welcome you to take a look and hear some of the inspirational work CAH Communities and caring health professionals are leading around the world!

2) Round 7 @MATES4Kids Community Development Grants available!

CLAN and @MATES4Kids are supporting grants for CAH Communities in lower-income countries, to help them drive local change to benefit their community members. At the UN Science Summit event @MATES4Kids were proud to award Round 6 grants to Brazil and Colombia, and we are thrilled about all they will achieve!

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Round 7 Grants have now opened and will close on **28 November 2025**. If you know of a CAH Community in a lower-income country that has exciting ideas on how to help children living with CAH, please encourage them to apply! The next grants will be awarded at the **next @MATES4Kids Community of Practice Meeting on 10 December** – we will be awarding 40 grants by 2030, so please reach out to communities you know who may be interested!

3) Huge thank you to the Austrian CAH Community!

CLAN is delighted to be working with the CAH Community of Zimbabwe, to facilitate a donation of life-saving medicines (hydrocortisone and fludrocortisone tablets) and we could not have achieved this without generous financial support from the CAH Community of Austria!!! Thank you so much to everyone who has donated… The medicines have now been purchased, and we are awaiting clearance from the Ministry of Health in Zimbabwe to courier them over… stay tuned for more updates!

If you would like to learn more about the work of CLAN – or even get more involved – please reach out to the CAH International Team for more information, or email CLAN at info@clanchildhealth.org… Together, we can create a world where #EVERYchild with CAH enjoys their rights to health and life!

Research

Important Information for the CAH Community

Crinetics
Pharmaceuticals

Building a premier, endocrine-focused global biopharmaceutical company to improve the lives of patients

Atumelnant
in development for
Congenital Adrenal Hyperplasia
Scan the QR code for Phase 2 Topline Results Release

Initiating global clinical studies this year:
Phase 3 Calm-CAH in **adults** and
Phase 2/3 Balance CAH in **pediatrics**

Calm-CAH

Balance-CAH

Stay connected to your physician and CARES for the latest information!

NP-PAT-0054-1 8/2025

CARES Foundation's Podcast...

CAH Pulse

Season 2 | Episode 9
Kristina: "We're going to call your baby...'Baby'" - Removing the Stigma from CAH

In this touching episode, Stephanie and Dina speak to Kristina, a young mom to 2 little girls who's younger daughter lives with salt wasting CAH. Kristina recalls her journey from giving birth to Franny through her now fifteen months of life, including feeding routines, hospital visits, medication and explaining her condition to family, day care and friends. Unsurprisingly, the day Franny was born, Kristina was told "something is wrong with your baby, your baby has ambiguous genitalia". Grappling with not knowing what that could have meant, Kristina simply replied, "is my baby going be alright?" and "is she going to live?" Due to the all too familiar lack of knowledge and professionalism on the hospital's behalf, Kristina was left alone, terrified, contemplating her new life with a baby she had yet to meet.

Catch up on all of the latest episodes from Season 1 & 2 of CAH Pulse!

Recent Episodes:

Season 2 | Episode 8
Season 2 | Episode 8: Lesley and Louise: No Shame! Putting an End to the Secrecy of CAH

Season 2 | Episode 7
Tim: "Go Live Your Life as Normally as Possible" But...Nothing About CAH is Normal

Season 2 | Episode 6
Dr. Su: Words of Wisdom: Clearing up the Confusion of Stress Dosing

Season 2 | Episode 5
Raelie: CAH Does Not Define THIS Ten Year Old!

To listen to these episodes and all past episodes, **scan the QR Code or visit**: cahpulse.podbean.com.

Do you want to be a guest on CAH Pulse?

If you have any interest on being a guest on our podcast, please contact: dina@caresfoundation.org.

Preventing Adrenal Crisis Events

PACE App

Have you downloaded it yet?

The Preventing Adrenal Crisis Events (PACE) app is available to patients, parents/caregivers, and medical professionals and is designed to provide readily accessible information and instructions for effectively managing AI (Adrenal Insufficiency). The app will include stress dosing and intramuscular injection techniques as well as other helpful tools.

Now Available in Spanish

SCAN TO DOWNLOAD!

(APPLE APP STORE)

This application can also be found on the Apple App Store, by searching “PACE by ChaiCore”.

(GOOGLE PLAY STORE)

This application can also be found on the Google Play Store, by searching “PACE by ChaiCore”.

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CAH International
voices of congenital adrenal hyperplasia

Thank you for your support of the CAH Global View newsletter, a publication of CAH International!

We would appreciate your thoughts on this newsletter! If you have ideas for what to include in future editions or if you would like to contribute something, please email: info@cah-international.org.

BUILDING STRONGER GLOBAL CONNECTIONS AND MAKING A DIFFERENCE