

CAHtalog™
Congenital Adrenal Hyperplasia Patient & Clinical Outcomes
in Real-World Practice Settings
Registry for Congenital Adrenal Hyperplasia (CAH)

Thank you for contacting Neurocrine Biosciences with your unsolicited Medical Information request regarding the CAHtalog registry.

The CAHtalog registry is sponsored by Neurocrine Biosciences, Inc., operationalized by PicnicHealth, and supported by CARES Foundation, a patient advocacy foundation that leads in the effort to improve the lives of the CAH community and seeks to advance quality health care through advocacy, education, research, and support.^{1,2}

CAHtalog is not a clinical trial, which typically enrolls a select patient population with the condition of interest who meet additional eligibility criteria. Clinical trials also typically involve administration of an investigational medication. A disease registry, like CAHtalog, seeks to enroll participants with the condition of interest with minimal additional criteria in order to provide a more comprehensive picture of the entire patient population. In addition, CAHtalog does not involve administration of an investigational medication, nor does it specify that participants must take a specific treatment or follow a specific visit schedule. Instead, CAHtalog involves a passive collection of data that would normally be collected as part of the routine standard of care.¹

CAHtalog is a disease registry that collects de-identified medical information of people with CAH from existing medical records into a single, research database. The main purpose of CAHtalog is to obtain standard of care information from the CAH community in a real-world practice setting. This real-world data, which includes data relating to health status and/or the delivery of routine health care, is intended to help support research to improve the quality of care for people with CAH. CAHtalog aims to provide healthcare professionals and the CAH community a better understanding of the natural history of CAH and how CAH is managed.¹

CAHtalog will collect real-world data using de-identified medical records of participants with CAH. This information is collected passively and does not require participants to schedule additional appointments, labwork, or involve any additional data entry by a provider beyond what is done at a routine medical visit. Participants and caregivers may optionally complete online patient-reported outcomes (PROs) or observer-reported outcomes (ObsROs) through the PicnicHealth website. PicnicHealth will collect and de-identify data before combining them into a research database. Participants in CAHtalog will remain anonymous.¹

Eligible participants include adults or children who have been diagnosed with classic CAH and live in the United States. All CAHtalog participants will receive digitized copies (including PDFs) of their medical records from not just one, but multiple medical providers and institutions, all organized in an easy-to-read timeline. Participants may be enrolled by visiting www.picnichealth.com/CAH.¹

For more information on CAHtalog, please visit <https://picnichealth.com/CAH>.

This letter and the enclosed material are provided in response to your unsolicited medical information inquiry. Please feel free to contact Neurocrine Medical Information at (877) 641-3461 or medinfo@neurocrine.com if you would like to request additional information.

References:

1. Congenital Adrenal Hyperplasia (CAH) Registry. PicnicHealth. <https://picnichealth.com/cah>
Accessed July 15, 2024.
2. CARES Foundation. Our Mission - CARES Foundation. [online] Available at:
<https://caresfoundation.org/our-mission/>. Accessed July 15, 2024.