



12780 El Camino Real, San Diego, CA 92130 (877) 641-3461

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 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 information about how people with CAH are managed by their providers 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 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 will collect real-world data using de-identified medical records of participants with CAH. This information is collected passively and does not require additional data entry by a provider other than what is done at a routine medical visit. Participants and caregivers may optionally complete online patient reported outcomes (PROs) through the PicnicHealth website. The PicnicHealth research platform will be utilized to collect medical records, keep them up to date over time, and structure data for research purposes. PicnicHealth will de-identify data before sharing it with researchers. 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. While the registry at this time does not include participants with non-classic CAH, CAHtalog may expand to include non-classic as well as participants from Canada in the future. 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:



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1. Congenital Adrenal Hyperplasia (CAH) Registry. PicnicHealth. <https://picnichealth.com/cah> Accessed December 21, 2021.
2. CARES Foundation. Our Mission - CARES Foundation. [online] Available at: <https://caresfoundation.org/our-mission/>. Accessed January 7, 2022.