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QUARTERLY NEWSLETTER

Letter from the Chairs



Claude Hemphill, MD, MAS



DaiWai Olson, PhD, RN

This is our first Curing Coma® Newsletter, sent on the cusp of what will be a very exciting spring of 2022. I'm sure that everyone knows the analogies. Spring is about new growth, rebirth, rainbows, and unicorns. But, so too, spring is about prognosis, recovery, and collaboration.

Every 2nd of February the world turns its attention to Punxsutawney, Pennsylvania to see if some poor unsuspecting rodent will see his shadow. From this we hope to accurately prognosticate a long winter versus an early spring. Having originated in Europe as "Imbolg"- this rather flawed practice of predicting recovery as a dichotomous event based on a single observation is not uniquely American. From the very first Curing Coma® Campaign meeting we have known that the really important question about coma centers around prognostication. The family members want to know the outcome. The staff want to know the outcome.

For the most part, clinicians avoid discussing outcomes as dichotomous. We know from experience that the range in outcomes goes from early death to late complete recovery. We know that for most patients, recovery will not happen all on one day. We know that a late March snowstorm doesn't mean we won't see the sun again, and we know that a patient with coma often takes two steps forward and one step back. We know that if we can just work together for a little bit longer, we can get to where we want to be.

Spring is a good time to work together. Soon the first bees will begin to swarm. Beekeepers will tell you that during a spring swarm is perhaps the most friendly a bee can be. They work together to collaborate and start new teams that will grow into successful colonies.

As the Curing Coma® Campaign pushes forth into 2022, we encourage you to embrace all fun and sometimes silly folklore about spring, and please be sure to join us on March 22 for

World Coma Day to learn about the new science and scientific directions that will help us to bring about a cure.

UPCOMING EVENTS

World Coma Day

March 22, 2022

12:00 a.m. – 11:59 p.m. GMT

[Register for World Coma Day](#)

FUNDRAISING TOTAL



To date, we're proud to share that the Curing Coma® Campaign has raised **\$1,608**

[Donate to Curing Coma](#)

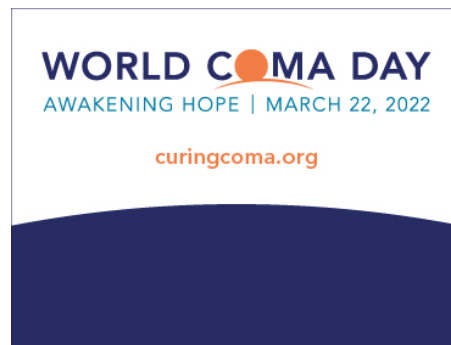


WORLD COMA DAY UPDATES

World Coma Day Update

Planning is currently underway for the 2nd annual **World Coma Day**, taking place on March 22.

World Coma Day is an all-day global online event featuring stories of remarkable recovery, science talks by medical experts, educational sessions for patients and families, and "shout out" videos from providers, patients, and families around the world.



This year's event will again feature an 8-hour block of sessions, repeated 3 times over the 24 hour period, with opportunities for live discussion with fellow neurocritical care providers.

Stay tuned for more information, including the schedule, coming in the next few weeks.

[Register for World Coma Day](#)



RESEARCH UPDATES

COME TOGETHER Survey Release

We are excited to announce the release of the final survey results and report from the Curing Coma Campaign® COME TOGETHER Survey. This survey, conducted between September 2020 and January 2021, was an anonymous, international, cross-sectional global survey of health care professionals caring for patients with coma and disorders of consciousness in the acute, subacute, or chronic setting.

[Read the Survey Report](#)

Member Sites Module of the Curing Coma® Campaign

Chethan P. Venkatasubba Rao, MD, FNCS; Briana Witherspoon, DNP, APRN, ACNP

The Member Sites Module is a platform to engage and facilitate interaction of clinicians and researchers providing care for patients with coma and disorders of consciousness (DoC) from various centers of care such as hospitals, academic institutions, and health care systems. Our module is comprised of a diverse group of clinicians including neurologists, neurointensivists, anesthesiologists, neurosurgeons, intensivists, physiatrists, advanced practice providers, nurses, pharmacists, physical, occupational and speech therapists; representing various specialties who influence outcomes for patients with coma and DoC.

To enhance the global footprint of CCC, we have successfully obtained representation from Latin American Brain Injury Consortium (LABIC), Sociedad Argentina De Terapia Intensiva (SATI), Brazilian Research in Intensive Care Network (BRiCNET), Australia and New Zealand Intensive Care Society (ANZICS), and Canadian Critical Care Trials Group (CCTG), who have enthusiastically advanced our initiatives.

As a result, our module has achieved several milestones: we have successfully advocated for and contributed to the first and second NINDS-Curing Coma research conferences; enrolled sites and participants to the COMEtoGETHER study; enhanced global participation for the first world coma day; included centers from Africa through our ambassadors from the Ethiopian Neurological Association; and we have generated sessions promoting CCC in regional meetings in Italy and Colombia.

Our module continues to evolve and support the mission of CCC in 1) creating awareness and representation of CCC in regional and international professional organizations, 2) identifying centers caring for patients with coma and DoC, 3) collating research capabilities of study sites evaluating coma and DoC, 4) ascertaining regional interests in CCC activities and finally to 5) coordinating such regional interests with appropriate CCC modules.

Implementation Science Module Update

Risa Nakase-Richardson, PhD, FACRM, FNAN; Lori K. Madden, PhD, ACNP-BC

Disseminating and implementing evidence-based care into practice is necessary to achieve a return on investment in the research enterprise. Recent work has highlighted that a small proportion (14%) of high-quality evidence (RCTs) is integrated into clinical practice.¹ For the evidence that reaches the patient's bedside, the average timeframe is 15-17 years highlighting a poor return on investment.^{1,2} As such, the Implementation Science (IS) Module of the Curing Coma Campaign was activated in 2021.

The module leads are Lori K. Madden, Ph.D., ACNP-BC, Director/Clinical Nurse Scientist, Center for Nursing Science, UC Davis Health, Sacramento, CA, and Risa Nakase-Richardson, Ph.D., Professor, Department of Internal Medicine, Pulmonary and Sleep Medicine, University of South Florida and James A. Haley Veterans Hospital in Tampa, FL.

The primary objectives of the IS module are to promote guidance, develop policies, and identify mechanisms for promoting research translation to the bedside. Activities underway include a) conduct of an environmental scan of evidence-based guidelines and policies relevant to persons with Disorders of Consciousness (DOC) that can be disseminated to key DOC stakeholders, b) development of an implementation readiness checklist that can be used by researchers to quicken research translation, and c) proposal for development of an interactive stakeholder engagement tool for use in all stages of DOC research planning.

1. Committee on Quality of Health Care in America, Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press; 2001.

2. Khan S, Chambers D, Neta G. Revisiting time to translation: implementation of evidence-based practices (EBPs) in cancer control. *Cancer Causes Control*, 2021; 32(3): 221-230.

Prospective Studies Working Group of the Curing Coma® Campaign

Molly McNett, PhD, RN, CNRN, FNCS, FAAN; Raimund Hebok, MD, PD

A key tenet of the Curing Coma® Campaign includes collaborative, international work among diverse teams to advance care and improve outcomes for patients who experience coma and provide educational and support structure to their families.

The Prospective Studies working group within the CCC was established to advance these goals and provide a platform for observational studies and future clinical trial research on disorders of consciousness (DOC) across the continuum of care. The first study completed by this interdisciplinary group of clinicians and scientists was the international survey on Coma Epidemiology, Evaluation and Therapy (COME TOGETHER) study. The aims of the study were to gather data on current practices for coma diagnosis, treatment strategies, and prognosis across an international network of participating sites. Findings will be published in *The Neurocritical Care* journal, and demonstrate significant variations in clinician-reported definitions of coma, routine treatments offered to patients, and current approaches to prognostication.

Our team has also recently completed a second study using a crowdsourcing approach to evaluate the prevalence and incidence of coma in the United States and the United Kingdom. Publication of this work is in progress, and findings provide important estimates on burden of coma across various etiologies and settings. To further advance this initial work, the Prospective Studies working group has established a 5 year plan that includes: (1) Completing an international observational cohort study to characterize the incidence, prevalence, demographic distribution, clinical characteristics and treatment mechanisms for coma; (2) Designing and executing comparative effectiveness research to determine impact of current treatment modalities on outcomes of coma across an international network of sites; and (3) Designing and conducting future clinical trials to test mechanisms of therapies and their impact on outcomes globally. While current coma practices vary substantially, our group seeks to advance both the science and the practice of coma care across healthcare teams and settings.



FEATURED STORY OF HOPE

Stories of Hope: Alex

Robert Alexander Bodroghy, MD; Lauren Koffman DO, MS

Read the latest *Story of Hope*, published on [Currents](#). This article features Alex's story of how a summertime bike ride changed his world forever, and inspired him to focus his undergraduate studies on neurology.

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