

Gabrielle Conecker, MPH is mom to Elliott, a teenager who is profoundly impacted by SCN8A-DEE. She is a patient advocate, nonprofit leader, and lay-researcher dedicated to improving the lives of individuals affected by SCN8A and rare developmental and epileptic encephalopathies (DEEs). She is the Executive Director and Co-Founder of Decoding Developmental Epilepsies, which houses a number of collaborative efforts aimed at improving care, quality of life and treatments for those with rare epilepsies - the International SCN8A Alliance, DEE-P Connections and The Inchstone Project. She is currently the Chair Ex-Officio of the Epilepsy Leadership Council and deeply involved with the work of the Epilepsies Action Network.

Since 2014, Gabi has collaborated with families, leading scientists and clinicians worldwide authoring and contributing to peer-reviewed studies on topics ranging from managing care for those with SCN8A to quality of life for individuals with severe neurodevelopmental conditions. Her passion is advancing work that sits at the intersection of science, advocacy, and community-building — ensuring that patient and caregiver perspectives shape the development of therapies and clinical trial design for some of the most complex and underserved rare diseases.