| Name and Degree(s) | Association or Role on the RDAC |
|--------------------------------|---|
| Michele Spencer-Manzon, MD, | Role: MD Genetics expert |
| Chair | Associate Professor of Genetics and of Pediatrics; Associate Chief of |
| | Clinical Genetics Operations; Pediatric Genomics Discovery |
| | Program |
| Lesley Bennett, Vice Chair | Role: Rare disease patient advocate; |
| | RDAC Coalition Leader, Connecticut Rare Disease Advocates; 2014- |
| | 2023 NORD CT-Rare Action Network State Ambassador |
| Colleen Brunetti, M.Ed, C.H.C. | Role: Adult living with a rare disease |
| | Pulmonary Hypertension Association Board, Chair (2023) |
| Jim Carson, MPA | Department of Insurance Representative |
| Mary Caruso | Role: Caregiver of two adult children living with a rare disease |
| | Friedreich's Ataxia Research Alliance Founding Member |
| Kevin Felice, DO, FANA | Role: Hospital Administrator |
| | Director of the Neuromuscular Center at Hospital for Special Care |
| Joanna Gell, MD | Role: Research Scientist |
| | Pediatric Oncologist and Hematologist at Connecticut Children's |
| | Hospital, and Research Scientist at Jackson Laboratories |
| Emily Germain-Lee, M.D. | Role: Physician treating rare disease patients, |
| | Professor of Pediatrics at the University of Connecticut School of |
| | Medicine and Division Head of Endocrinology & Diabetes at |
| | Connecticut Children's |
| Dorian Long, MSW | Department of Social Services Representative |
| Craig Miller, MS | Role: Biopharmaceutical industry representative |
| | Director of Biomarker Discovery & Portfolio Strategy at Boehringer- |
| | Ingelheim Pharmaceuticals |
| Miriam Miller, MPH | Department of Public Health Representative |
| James Rawlings, R.PH., MPH | Role: Patient organization representative |
| | President/CEO of Sickle Cell Disease Association of America, |
| | Connecticut, Michelle's House |
| Saurabh Vaidya, MCS | Role: Parent of pediatric rare disease patient |
| | Connecticut Hemophilia Society President |

https://hopeinfocus.org/connecticut-rare-disease-advisory-council-begins-to-take-shape/