

RARE DISEASE CAREGIVING IN AMERICA

WHEN

Thursday, May 17, 2018

WHERE

7:30 am – 9:00 am
Rayburn House Office Building, Room 2044
45 Independence Avenue, SW
Washington, DC

9:00 am – 10:30 am
Dirksen Senate Office Building, Room 562
2nd Street, NE
Washington, DC

SPEAKERS

C. Grace Whiting, JD, President & CEO, National Alliance for Caregiving
Angie Rowe, MS, Chief Operating Officer, Global Genes
Lisa Weber-Raley, MA, Greenwald & Associates
Senator Joni Ernst (R-IA)
Senator Amy Klobuchar (D-MN) (invited)
Representative Michelle Lujan Grisham (D-NM)
Representative Leonard Lance (R-NJ) (invited)

67%

Say providing care is emotionally stressful

22%

Use respite care services

59%

Exhausted their personal savings

89%

Educate HC professionals about recipient's rare disease

53%

Report feeling alone

41%

Report fair or poor emotional or mental health

The National Alliance for Caregiving, in collaboration with Global Genes, invites you to attend policy briefings on the recently released research study, Rare Disease Caregiving in America. This important new study captures the experiences of more than 1,400 family caregivers of children and adults with a rare disease, condition, or disorder across 400 different diseases.

Breakfast will be provided

RSVP

https://raredisease_house.eventbrite.com
https://raredisease_senate.eventbrite.com

