

PORTRAIT OF A RARE CAREGIVER

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

59%

Receive help from at least one other unpaid caregiver

29%

Have plans in place for their care recipient's future care

24%

Report unpaid care from at least one youth under age 18

10%

Are students who often struggle with school responsibilities

THE RIPPLE EFFECT

The ripple effect of rare caregiving extends beyond day-to-day tasks of providing care and creates the need for others in the family to pitch in.



IN PARTNERSHIP WITH



www.caregiving.org
www.globalgenes.org

Rare Disease Caregiving in America, February 2018
Get the study at: www.caregiving.org/rare