

THE HIDDEN EPIDEMIC

LIFE WITH AN UNDIAGNOSED OR RARE DISEORDER

LIFE UNDIAGNOSED

30-40%

OF CHILDREN WITH SPECIAL NEEDS DO NOT HAVE A DIAGNOSIS³

IT CAN TAKE UP TO SEVEN YEARS TO FIND A DIAGNOSIS⁴



PATIENTS SEE UP TO 8 SPECIALISTS BEFORE RECEIVING A PROPER DIAGNOSIS⁴

THERE ARE OFTEN 2-3 MISDIAGNOSES⁴

83% OF PHYSICIANS SAY GENETIC TESTING IS USEFUL IN FINDING A DIAGNOSIS⁵

BUT, GENETIC TESTING IS NOT COVERED BY MANY INSURANCE COMPANIES TESTING IS ELECTIVE OR EXPERIMENTAL

GENETIC TESTING CAN COST \$10,000 OR MORE



60% OF PATIENTS EXPERIENCE UNEXPECTED FINANCIAL BURDEN⁵

29% GO INTO DEBT⁵

39% PAY FOR INEFFECTIVE TREATMENTS DUE TO LACK OF OR IMPROPER DIAGNOSIS⁵

HIDDEN COSTS

TIME OFF WORK | PARKING FEES
SPECIALIZED CHILD CARE | GAS
LOSS OF INSURANCE COVERAGE
NO ACCESS TO SOCIAL SERVICES
INEFFECTIVE TREATMENTS

30 MILLION PEOPLE IN THE U.S. AFFECTED BY RARE DISEASE



WHICH MEANS 1 IN 10 AMERICANS LIVING WITH RARE DISEASE¹

IN THE UNITED STATES, A RARE DISEASE IS A CONDITION THAT AFFECTS LESS THAN 200,000 PEOPLE¹

TWO-THIRDS OF RARE DISEASE PATIENTS ARE CHILDREN¹



30% OF CHILDREN WITH A RARE DISEASE DO NOT LIVE TO SEE THEIR 5TH BIRTHDAY¹

35% OF DEATHS IN THE FIRST YEAR ARE CAUSED BY RARE DISEASE¹

THERE ARE CURRENTLY 7,000 IDENTIFIED RARE DISEASES¹

95% DO NOT HAVE AN FDA APPROVED TREATMENT²



CURRENTLY, ONLY 350 OUT OF 7,000 HAVE FDA APPROVED TREATMENTS



50% OF RARE DIAGNOSES DO NOT HAVE A DISEASE SPECIFIC FOUNDATION DEDICATED TO SUPPORTING OR ADVANCING RESEARCH²

HOW U.R. OUR HOPE IS MAKING AN IMPACT

ONE OF THE ONLY ORGANIZATIONS DEDICATED TO UNDIAGNOSED AND RARE DISEASE, SO OUR PATIENTS ARE FROM ALL OVER THE WORLD

OVER 75 ACTIVE FAMILIES AND COUNTING



CURRENTLY HELPING FAMILIES IN 10 DIFFERENT STATES MOST ARE IN CENTRAL TEXAS



4 DIFFERENT COUNTRIES



WE PROVIDE



GAS/MEAL CARDS TO THOSE TRAVELING OUT OF TOWN FOR MEDICAL VISITS

PROVIDE MEALS DURING HOSPITALIZATIONS OR DURING TIMES OF CRISIS



CONNECT FAMILIES WITH RESEARCH PROGRAMS, MEDICAL RESOURCES, GRANTS

OUR NEWEST PROJECT AIMS TO HELP FAMILIES COVER THE COSTS OF GENETIC TESTING IN HOPES OF FINDING A PROPER DIAGNOSIS



HOW YOU CAN HELP



MAKE A DONATION TODAY WITH ONE OF OUR LOCAL PARTNERS OR ON OUR WEBSITE

LEARN MORE AT WWW.UROURHOPE.ORG & JOIN US AT UPCOMING EVENTS!



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SOURCES: 1. rarediseases.org ; 2. globalgenes.org ; 3. files.eric.ed.gov/fulltext/EJ828952.pdf ; 4. sireinteractive.com ; 5. Gandomi SK and Esplin ED. Rare Disease Diagnosis Obstacles: Patient Perspective and Physician Findings; Presented at ACMG Annual Meeting, 2016



AND OUR PARTNERS



PROUDLY SUPPORT
U.R. Our Hope
www.UROURHOPE.org