MEDICAL RESEARCH NETWORK

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RARE DISEASE CLINICAL TRIALS

FACTS

THERE ARE APPROXIMATELY **7,000 RARE DISEASES**

ONLY OF RARE DISEASES HAVE **5% FDA APPROVED TREATMENTS**

50% AFFECTED ARE **CHILDREN**

RARE DISEASES ARE RESPONSIBLE FOR **35%** OF DEATHS IN THE FIRST YEAR OF LIFE

*Source: globalgenes.org February 2017

PATIENT RECRUITMENT AND RETENTION CHALLENGES

1 Small patient pool, requiring high percentage of patients with the disease to be enrolled into the trial.

2 Patients are often not located near investigator sites, resulting in frequent long distance travel or lodging.

3 Pediatric trials pose unique challenges such as social/family dynamics, emotional barriers, and practical issues including transportation, drug administration, and scheduling.

HOME CLINICAL TRIAL VISITS ARE THE SOLUTION

They ensure all patients, regardless of geographic location or access to appropriate travel, can participate in safe and secure clinical trials.

MRN EXPERIENCE

OVER **1,200** RARE DISEASE **PATIENTS TREATED**

OVER **14,000** HOME CLINICAL **TRIAL VISITS PERFORMED**

TOP 5 INDICATIONS WORKED ON

- LYSOSOMAL AND METABOLIC STORAGE DISORDERS
- NEUROLOGICAL DISORDERS
- BLOOD DISORDERS
- MUSCULOSKELETAL
- IMMUNOLOGY

*MRN Data February 2017

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