RED FLAGS 4 GENETICS SURVEY DATA

Mountain States
REGIONAL GENETICS NETWORK

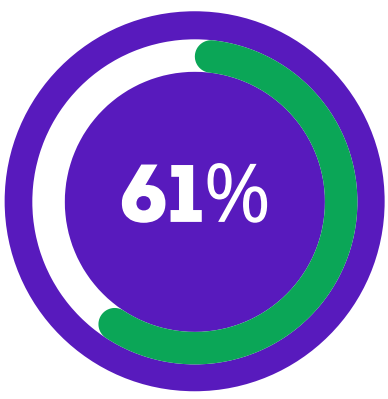
In 2021, MSRGN asked families to tell us about their experience with Red Flags for Genetics (indicators, symptoms, warning signs). Below is some of what we learned:

89% of reported Red Flags were noted before 4 years of age.

114 FAMILIES SHARED 479 RED FLAGS

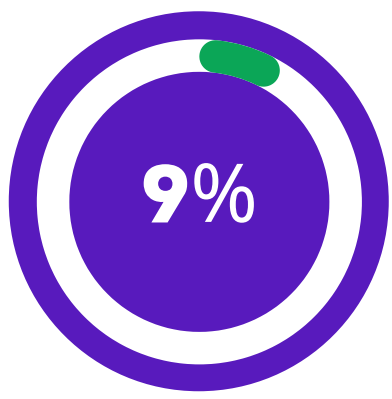
On average, families reported it took 6 years to receive a diagnosis after noticing their first Red Flag indicator.

WHO MADE THE DIAGNOSIS?



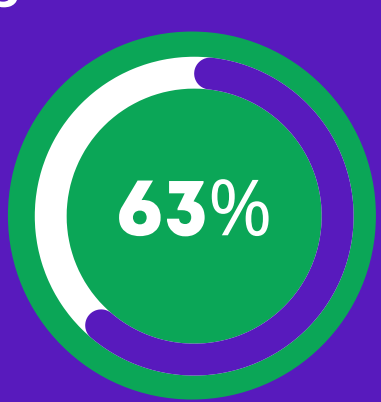
GENETICIST

SUB-SPECIALIST



PRIMARY CARE PHYSICIAN

63% reported having to travel to a children's hospital or university for their diagnosis



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To see the 'Red Flags" the families shared, scan the QR code or go to:
www.mountainstatesgenetics.org/redflag

RED FLAGS 4 GENETICS SURVEY SUMMARY

10 Commonly Reported Diagnoses

in the Red Flags 4 Genetics Survey

- Vascular Ehlers Danlos Syndrome
- Mosaic Turners Syndrome
- Cobalamin Disorders (C,F, & X)
- Rett Syndrome
- Hurler Syndrome
- Autism Spectrum Disorder
- Williams Syndrome
- Methylmalonic Acidemia
- Trisomy (9 & 10)

ADDITIONAL DIAGNOSIS

- Apert Syndrome
- Classical Homocystinuria
- Conradi Hunermann Syndrome
- Genetic Mutation ARPC4
- Propionic acidemia
- Genetic Mutation ZBTB18
- Thalassemia Minor
- Russell-Silver Syndrome
- Genetic Mutation IQSEC2
- Fabry's disease
- Dravet syndrome
- Treacher Collins Syndrome

TOP 7 CHROMOSOMAL CONDITIONS REPORTED IN SURVEY

- Dup 15q
- 16p.11.2
- 22q.11.2
- 22q
- 2q 24.3
- 7q 11.23
- 7p 14.1-12.3

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