Kufor Rakeb syndrome is considered an ultra-rare disorder. Fewer than 50 individuals have been reported in the literature. Because KRS is a rare and complex disease, it is possibly underdiagnosed and the real prevalence of the disease is therefore hard to estimate. As it is the case for all autosomal recessive disorders, children of parents who are blood relatives are at an increased risk of developing the disease, as they are more likely to receive the same copy of a disease-causing (pathogenic) mutation from each parent.