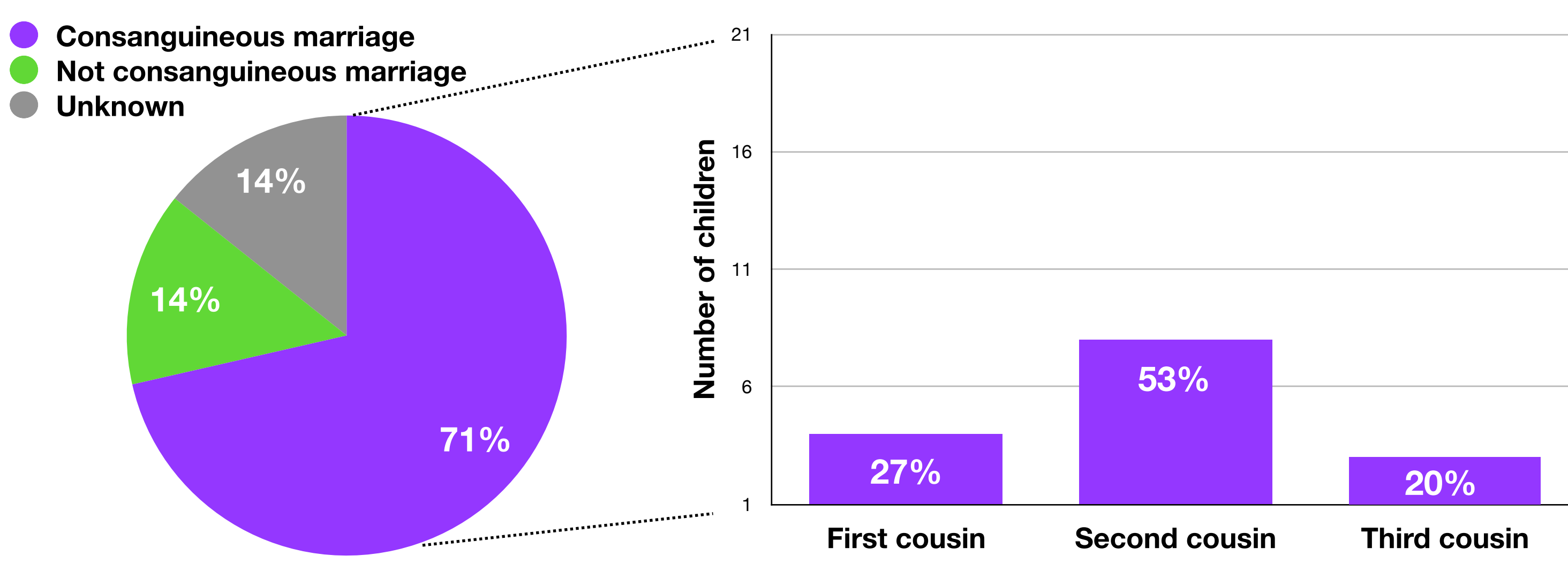


Phenylketonuria (PKU) in Iraq: urgent need for education of health care providers to establish medical support for PKU patients

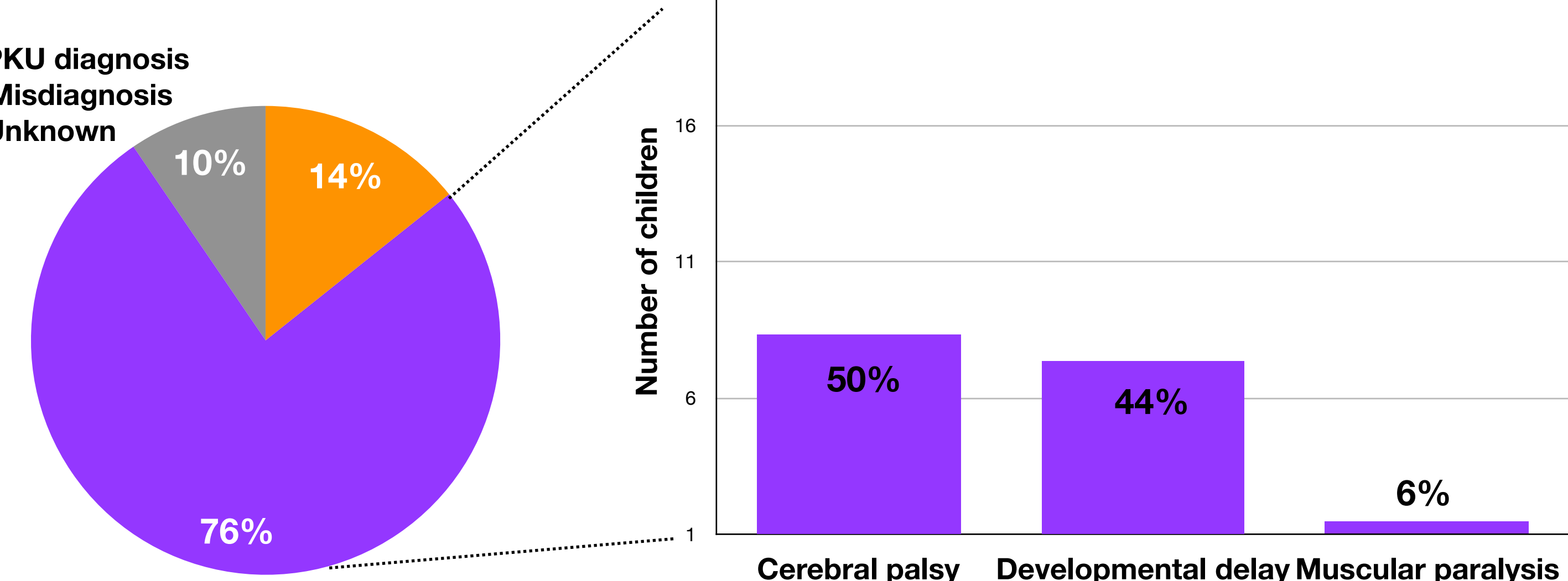
Baker J*, Schatz B, Thompson R, Zandin LDJ, Bausell H, Kozek A, Persike DS.

Background: Early diagnosis and effective treatment of phenylketonuria (PKU) is imperative to avoid neurological impairment and permanent intellectual/motor disability. Newborn screening (NBS), and health care providers (HCPs) including physicians, dietitians, and medical specialists with specific training, are hallmarks of countries with capability to appropriately care for PKU patients. Four decades of conflict have destabilized Iraq's medical capabilities and its university education system, contributing to a lack of metabolic specialists and an inadequate system of care for metabolic disorders. Iraq has a high incidence of PKU that is yet to be adequately measured. This situation is compounded by lack of NBS, high rate of consanguinity, inadequate treatment of PKU, and low awareness among the medical and general populations. **Objectives:** Facilitate early identification and appropriate care for children with PKU in Kurdistan (KRG) and Nineveh Governorate [Northern Iraq (N. Iraq)]. **Case Study:** "The Restoration Act (TRA)", a non-governmental organization, has established an MOU with the Ministry of Health Kurdistan to provide PKU case management, advocacy, and education both to families and the KRG medical community. Several US-based HCPs have been assisting TRA with patient diet management, and education for PKU families and the medical community in N. Iraq. TRA is advocating for NBS and early intervention. **Results:** Since inception of work in 2020, TRA has identified 45 children with PKU, served 23, and has 16 currently in case management for PKU treatment. TRA is at capacity. A medical education conference on PKU targeting HCPs across Northern Iraq, put on by TRA and endorsed by the KRG, is in planning for January 2024. This will accelerate the need for PKU care capability as new cases are identified. **Conclusion:** There is an urgent need for metabolic specialists to assist in training of HCPs to accelerate development of metabolic specialty and care capacity in Northern Iraq. Also, an urgent need for NBS implementation and consistent PKU formula provision are noticeable.

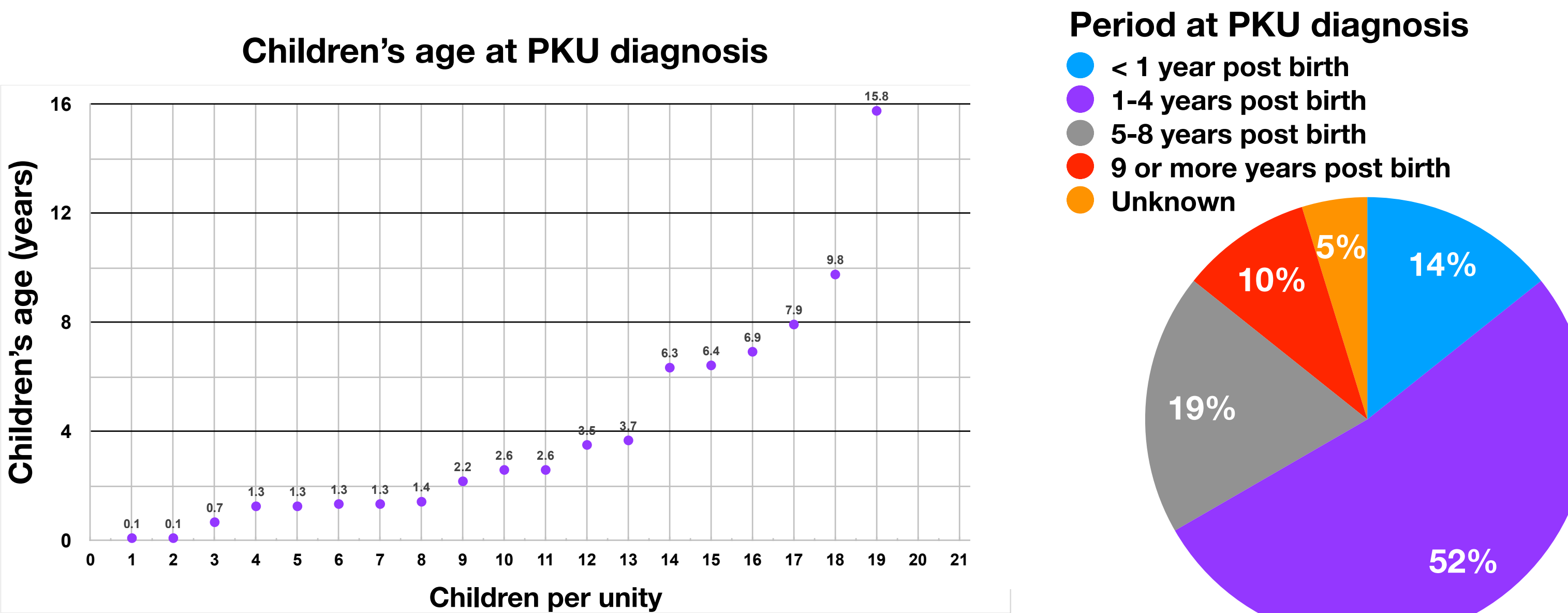
Incidence (%) of consanguineous marriage associated with PKU diagnosis



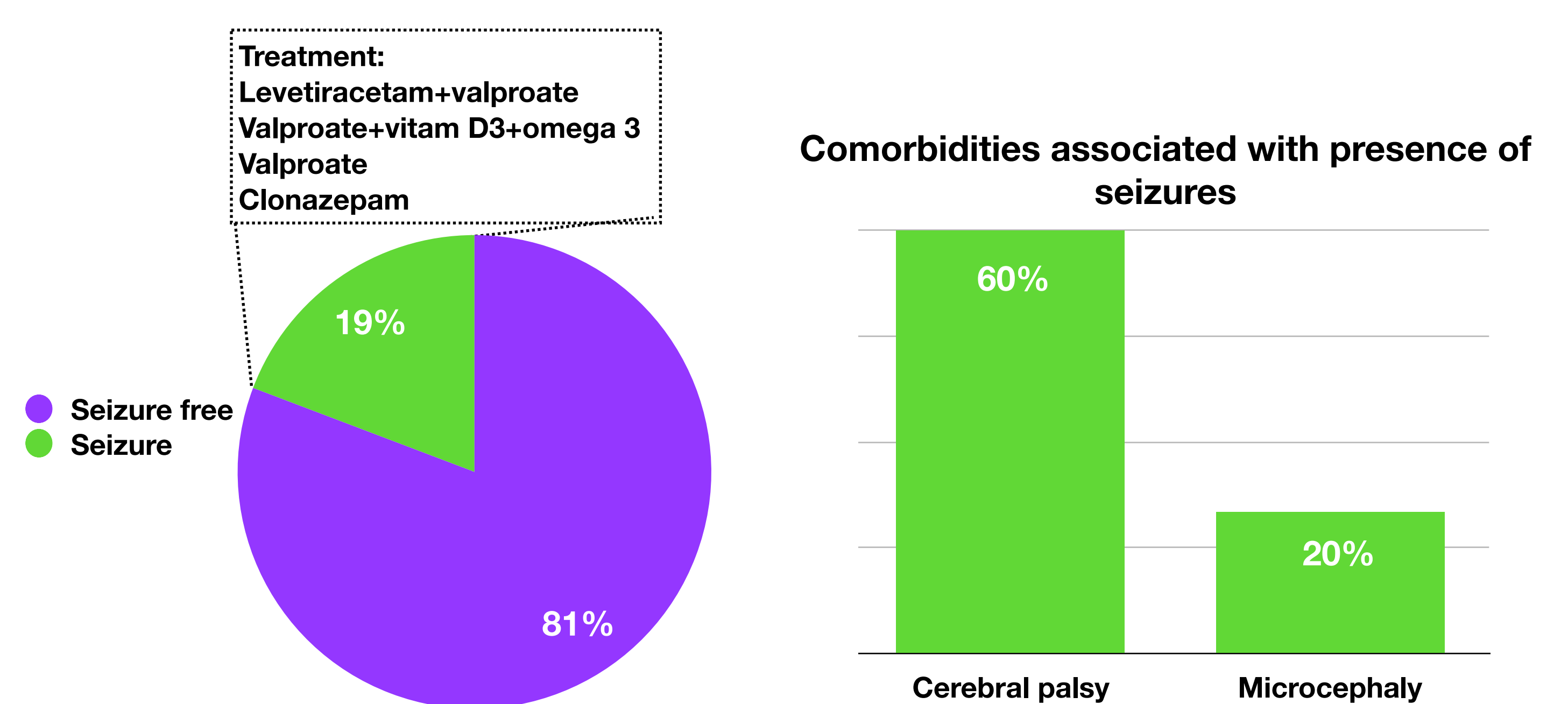
Incidence and main types of misdiagnosis preceding PKU diagnosis



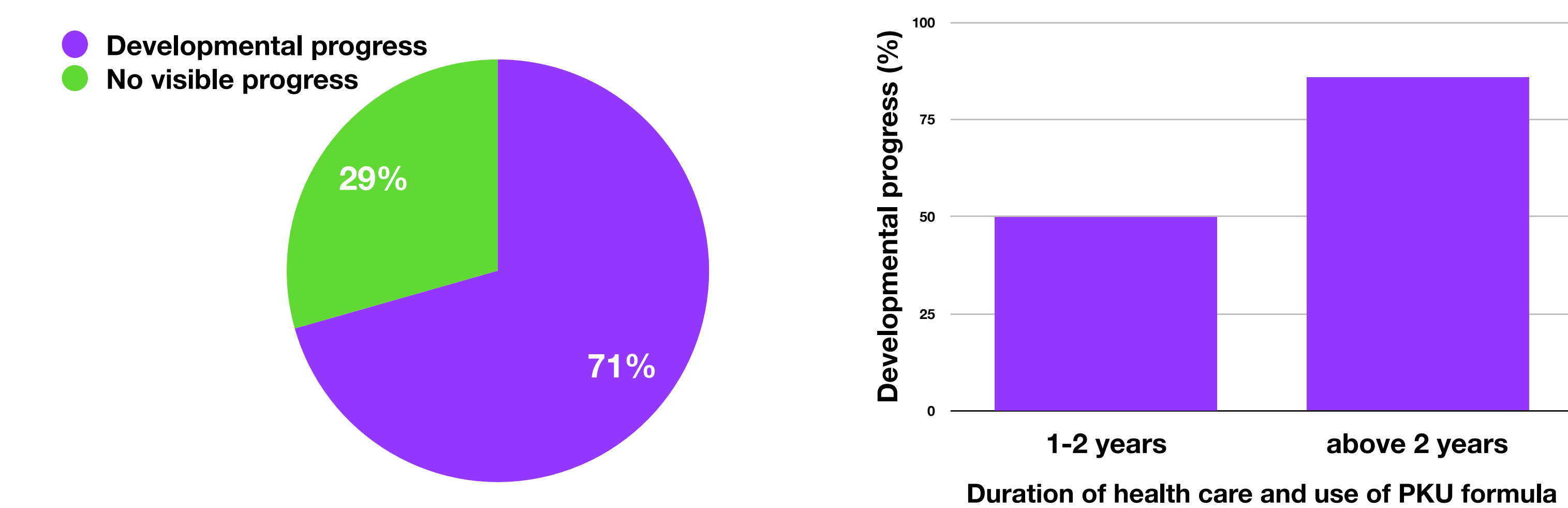
Late PKU diagnosis of children under our care in Northern Iraq



Incidence of seizures and other comorbidities among children diagnosed with PKU



Developmental progress of children receiving health care and PKU formula



Time flow charts showing the process of interaction with children with PKU and their families, interaction with governmental authorities, creation of PKU Task Force and collaborating team

