Sixty-percent of patients must see five or more healthcare specialists within one calendar year, and 33% of children must go see a healthcare provider (of any specialty) 8–10 times within one calendar year.

**Conclusions** It is our hope that these results will help clinicians be aware of the possible diagnosis of BCCNS at earlier ages in these children. An earlier diagnosis could provide the social and medical specialty-specific support services that may prevent the development of psychosocial and other medical consequences that arise from the burden of disease of BCCNS.