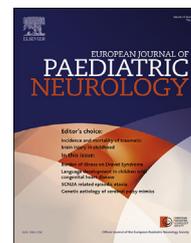




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## Editorial

# Dravet syndrome – Time to consider the burden beyond the disease

Dravet syndrome is a severe developmental and epileptic encephalopathy associated with difficult-to-treat seizures and often profound intellectual disability, that carries one of the highest risks of sudden unexpected death in epilepsy.<sup>1,2</sup> Research over the last two decades has mainly focussed on seizure control and understanding the disease biology. Unfortunately, evidence-based treatment strategies have – so far – failed to substantially alter or improve the disease outcome. More recently novel treatments, including new medications, have been shown to be effective in Dravet syndrome and the prospect of gene therapy is emerging on the horizon. It is likely that early intervention will be critical to prevent the neurodevelopmental comorbidities of Dravet syndrome.<sup>3</sup>

In this issue of EJP, Strzelczyk et al. looked beyond the disease and focussed on the burden-of-illness and cost-driving factors in Dravet syndrome in Germany.<sup>4</sup> The authors surveyed 93 patients and families assessing quality of life, parental health, direct healthcare cost such as inpatient visits and medication costs, as well as indirect costs including productivity losses due to days off, quitting work, early retirement and reduction in working hours due to Dravet syndrome. As expected, the quality of life in Dravet syndrome was significantly reduced compared to the general population. Direct health care costs were considerable with an average of €2000 per month, mainly due to inpatient stay, disability allowance and medication expenditure. Factors predicting high total direct healthcare costs were increased seizure frequency, occurrence of status epilepticus, and the degree of nursing care required. Notably, the total indirect costs were equally substantial amounting to €1600 per month, and almost as high as direct health care costs. This was driven by carers quitting their work, reducing their working hours or missing days from work. Mothers were tenfold more affected by these losses in productivity costs compared to fathers, illustrating that the toll on families and caregivers is significant, with many carers reporting high levels of anxiety and clinical depression.

Dravet syndrome imposes a substantial disease burden on affected individuals and carers. Expenditures are high due to significant direct and indirect healthcare costs, contributing to the low quality of life among patients and caregivers. It appears justified, both from a clinical and from a health economic perspective, that treatment efforts in Dravet syndrome not only focus on therapeutic interventions and investment in new treatments, but also on comorbidities, and improved caregiver support.

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