Feeding Difficulties And Gastrostomy In Dravet Syndrome,
A UK Single centre experience
Bahare Azadi 1, Lisa M Clayton 2, Robert Robinson1, Sanjay M Sisodiya 2
1 Great Ormond Street Hospital, London, UK; 2 UCL Queen Square Institute of Neurology, London, UK

Introduction:
- Dravet Syndrome (DS) is characterised by seizure onset around 6 months and mild to moderate severe intellectual disability.
- Co-morbid conditions include ASD, behavioural difficulties, sleep disorders, cardiac abnormalities, and gait impairment.
- Feeding difficulties are frequently reported but have received little attention.
- In a population-based study of DS in Norway, 25% of individuals were reported to have a “gastro-tube” for nutrition and drug administration.
- DSUK survey (2022) in children and adult with DS showed 26/65 (40%) had a gastrostomy, 85% undertaken in childhood. This shows that feeding difficulties can be a lifelong challenge and can emerge at any age.

Objective
- To assess the burden of feeding difficulties and gastrostomy requirement in children with DS at GOSH.

Methods
- 91 children with SCN1A-related DS were identified from the electronic patient record, and the feeding history reviewed.
- Potential risk factors for gastrostomy requirement were assessed.

Results
- N=72 individuals included in final analysis.
- Mean age at last follow-up was 8.6 years (range 1-20). 51.3% were female.
- Feeding difficulties were reported in 33/72 (45.8%), median age of onset 4 years.
- Poor appetite and failure to weight gain were the most common symptoms, occurring in 51% and 63% of individuals, respectively.
- Medication refusal was reported in 8/33 (24%) (Chart 1).
- 8/33 (24%) individuals required hospital admission for feeding difficulties.
- Of 33 individuals with feeding difficulties, 10 had a gastrostomy, and 4 were awaiting gastrostomy (14/33, 42%), constituting 19% (14/72) of all individuals with SCN1A-related DS.
- The lag time from the onset of FD to gastrostomy insertion was 6 months - 4.5 years (Median: 1.3 years).
- The median age of gastrostomy insertion was 4 years (range 2.5 – 11).
- No specific risk factors for gastrostomy requirement were identified.

Discussion
- A range of feeding difficulties are reported in individuals with DS, with multiple contributing factors.
- Around 20% of individuals with DS may require gastrostomy.
- It is essential that caregivers are provided with information about feeding difficulties and the potential need for gastrostomy early on, to help mitigate anxiety surrounding challenging feeding.
- Greater awareness of feeding difficulties in DS is needed to ensure that these issues are identified early, contributing factors are addressed, and gastrostomy is considered when appropriate.

References: