

## **BSPGHAN Innovation Grant:**

### **Paed eBANS administrator – Final report**

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The formation of the eBANS working group and support from nutrition and intestinal failure working group has been instrumental in developing this platform and we are grateful for the continued support from BSPGHAN. The aim was to develop robust national outcome data making us the first country with a complete national registry for patients with type III intestinal failure.

The grant was used to appoint a Band 5 administrator providing funding for 7.5 hours per week. The post was filled in February 2018 to organise the conduction of a complete survey of children receiving home parenteral nutrition in England and Wales. The funding was used solely to fund the post which ended in November 2020, taking in account a period of vacancy.

Funding the appointment of an administrator has made it possible to achieve engagement from all centres across the country to improve data collected recording demographics and outcome.

The eBANS dataset is migrating to the N3 network where it will be collocated with adult IF dataset supervised by NHS England. To facilitate the migration has been a herculean task involving closing the current database. The administrator supported IF centres across the country to update the database to capture all their patients and provide the outcome at the time of closure.

#### **The key achievements are**

1. Establishment of a contemporaneous database of patients on Home parenteral nutrition.
2. Over the 3 last year there has been further improvement in engagement and 77% patient records were updated annually over this period.
3. A designated lead for entering data has been identified in all centres and there is now an up to date mailing list for all centres in England, Scotland, Wales and Northern Ireland.
4. A report describing the data collected through the process has been submitted for consideration for publication to Clinical Nutrition.
5. With the establishment of a network of IF centres further sub projects were undertaken e.g. further investigation of number of children on HPN because of ultrashort bowel syndrome and Feed intolerance secondary to neurodisability.

#### **Results Summary**

- A total of 525 children on HPN from England, Wales and N Ireland had data recorded on e-BANS over the 5 years of recording.
- A complete national (England) dataset was achieved in October 2018, since when units have updated their results, usually at 6 monthly intervals. In 2017, 71% and 2018, 77% of centres updated data.
- At the time of data extraction in September 2019, 369 children were receiving HPN, 20 further patients were receiving HPN in Scotland putting the total number of patients receiving HPN in UK at 389 with a prevalence of 30 per million children
- There were 18 tertiary paediatric gastroenterology units managing children on HPN in England; patients were managed by 3 networks in Scotland, 3 units in Wales, and a single hospital in N. Ireland.
- The largest diagnostic category of patients, accounting for 185/389 (48%) was short bowel syndrome, followed by 77/389 (20%) with neuromuscular disorders, and 39/389 (10%) with congenital enterocyte disorders

Outcomes for 525 Children from Paediatric EBANS Dataset between 2015 and 2019.

	Total Number of cases	Achieved Enteral Autonomy (%)	Transitioned to Adult Care (%)	Intestinal Transplant (%)	Died (%)
Short Bowel Syndrome	257	68 (26.5)	6 (2.3)	3 (1.2)	4 (1.6)
Neuromuscular Disorder	93	11 (11.8)	5 (5.4)	0	5 (5.4)
Congenital enterocyte disorders	47	3 (6.4)	1 (2.1)	0	5 (10.6)
Other Diagnosis	128	27 (21.1)	7 (5.5)	2 (1.6)	9 (7.0)
Totals	525	109 (20.8)	19 (3.6)	5 (1.0)	23 (4.4)

#### Conclusion

eBANS was able to collect and collate prevalence and outcome data for children across UK. As a result of contribution for all IF centres supported by the administrator a complete case ascertainment was achieved. This was validated against number of children on HPN registered with homecare companies. We hope that with continued engagement with each centre, national contemporaneous long term outcomes can be described for this group of patients.

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