

NEUROLOGY

Alexandra Johnson MBBS BSc(Med) FRACP MMed
Paediatric Neurologist
(Provider No: 2663561F)

Via Department: (02) 9382.1549 (option 4)
Secretary: (02) 9382.1547
Fax: (02) 9382.1580



15th July 2021

Dr Dawood Issa
Punchbowl Family Health Care
Email: info@pfhc.com.au
Fax 82069096

Dear Dawood

Re: Elias TANNOUS DOB 14/5/2019
71 Highview Ave, Greenacre NSW 2190

MRN 10879738

Issues

- 1) Genetic epileptic encephalopathy – ARV1 mutation
- 2) Epilepsy – focal seizures, spasms, apnoeic clusters
- 3) Global developmental delay
- 4) Poor feeding – PEG insertion 2021

Meds (15 kg)

Carbamazepine 100 mg tds
Clonazepam 0.3 mg tds
Keppra 2.3ml (230 mg) bd
Phenobarbitone 90mg (10ml) nocte
Topiramate 75mg bd
CBD (Tilray) 0.8 ml = 80 mg bd
PRN Midazolam 5mg buccal / nasal with clustering seizures

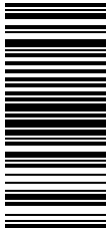
Previous

Lacosamide (recently ceased, not effective)
Pyridoxine / folinic acid – possible role in ARV1
Steroids (spasms), Vigabatrin, phenytoin, clonazepam

I was pleased to see Elias today whilst he was in hospital following his PEG insertion. This seems to have gone well and his mother has been pleased with the result. He was supposed to be seen in follow-up in outpatients but I've taken the opportunity to see him today whilst he was here.

He remains very hypotonic in general with marked head lag on lifting him.

We have redone his scripts today and I have given a further CBD script to pharmacy. I will continue his other medications at the current doses for now as I would like to give him a period of relative stability rather than trying to decrease anything at this point in time. It would be nice to see him in about 3 months and can then consider whether we slowly decrease any of the medications.



SCN90102

Yours Sincerely,

A handwritten signature in black ink, appearing to read 'Alex Johnson', with a stylized, cursive script.

Dr Alexandra Johnson
Paediatric Neurologist
Provider No: 2663561F

cc.
Medical records, Neurology file

Family of Elias Tannous 71 Highview Avenue Greenacre NSW 2190
Email: rebeccasukkar@hotmail.com

Dr Jason Pinner, Genetics team, SCH

Dr Antonia Milner, general paediatrics, SCH

Dr Matthew Spargo, ophthalmology SCH

Dr Dylan Wanaguru, SCH

Ms Alison Kennedy, Stoma CNC, SCH

Ms Erin Bevis, Epilepsy CNC SCH