NHS
Northampton General Hospital
NHS Trust
Restart & Respiratory
Cliftonville
Northampton
NN1 5BD

Direct Dial: (01604) 523266
Switchboard: (01604) 634700
www.northamptongeneral.nhs.uk
NHS Number: 715 397 0614
Our Ref: 616618

Date of clinic: 18/05/2023
Date of letter: 18/05/2023

Wolfson Cystic Fibrosis Unit
City Hospital
Hucknall Road
Nottingham
NG5 1PG

Dear Colleague

Re: [redacted] FREESTONE DoB: [redacted]
26 THE AVENUE WELLINGBOROUGH NORTHAMPTONSHIRE NN8 4ET – Tel: [redacted]

I am writing to refer this gentleman to your Cystic Fibrosis Team. He has been diagnosed as having an atypical form of cystic fibrosis by a private consultant in London and is being referred to Nottingham as he is due to start an MSc in September and is keen to have ongoing care once he starts this. He was born at 35 weeks gestation and was in a special care baby unit with jaundice and poor feeding.

He was subsequently diagnosed with gastro-oesophageal reflux disease at 9 months and has been allergic to dairy products since 6 months.

[redacted]

I understand that at some points in the investigations as a child he had a cystic fibrosis screen and was essentially told it was normal.

He was referred to the adult respiratory team in 2017 when the main issue was of cough. He was found to have some problems with his sinuses. His cough was attributed to postnasal drip at that time.

In 2021 he was referred to the neurologists with numbness and weakness in his legs which had developed since the beginning of 2020, resulting in him becoming essentially immobile even when walking with crutches. He has essentially used a wheelchair since then. He had a normal MRI brain and spine. I enclose a copy of the letter from Dr Tomlinson dated the 3rd August 2021 and I think essentially the diagnosis at the moment is of previous Guillain-Barre syndrome.

He has had ongoing treatment for his asthma but at the same time had asked to see a private consultant in London to reconsider the possibility of cystic fibrosis, as he was concerned about this.

He saw Professor Michael Loebinger at the Brompton who has reported a faecal pancreatic elastase 1 of 8 microgram EI/G and a sweat chloride level of 61 mmol/L. He has documented in his letter that he feels this is consistent with a diagnosis of atypical cystic fibrosis. He had started [redacted] on Creon as well as mucus clear nebulisers 6% and Salbutamol nebulisers. He found significant benefit from being on these but is understandably very shocked by the diagnosis.

I enclose Professor Loebinger's letter, as well as a letter from UCL where he has also been seen. I very much appreciate your opinion and input into [redacted] care to ensure that he is on the right treatment regime and his nutrition as he is struggling to maintain weight even though the Creon has improved his symptoms significantly.

Many thanks for your help.

Yours sincerely

Please accept electronically authorised

Dr Fiona McCann
Consultant Respiratory Physician

Encs. Last lung function tests and copies of all of the letters

CC:
Dr J Cox
THE REDWELL MEDICAL CENTRE
REDWELL MEDICAL CENTRE
1 TURNER ROAD
WELLINGBOROUGH
NN8 4UT

Private & Confidential
CC:
[redacted] FREESTONE
26 THE AVENUE
WELLINGBOROUGH
NORTHAMPTONSHIRE
NN8 4ET