

On 13th August 2019, PINNT was invited to meet with Dr Aidan Fowler, National Patient Safety Director; NHS England and NHS Improvement, along with the Deputy Chief Pharmaceutical Officer for NHS England/Ireland (NHSE/I); Director of Inspections, Enforcement and Standards, Senior Expert Inspector Medicines and Healthcare Products Regulatory Agency (MHRA), Senior Pharmacist for Medicine Supply Department of Health and Social Care (DHSC), members of the communication and media relation team for NHSE/I and a member of the Incident Management Team.

Ongoing communication with the National Working Group has allowed PINNT to provide the patient/parent/carer concerns which we feel most strongly need to be heard and appreciated by all those managing this unprecedented situation.

PINNT concerns remain focused on the immediate situation especially as the initial suggested four-week period of temporary fluids has passed. How are those in need of their PN or the replacement multi-chamber bags being managed and what plans are being put in place to reduce the burden at this difficult time?

The fears and concerns of PINNT members were reiterated during the meeting, inefficient and ineffectual communications from Calea; unreliable and inaccurate information being circulated via various means, which gives no assurance of any guaranteed deliveries.

We made it clear that all those involved with home parenteral nutrition (HPN) were educated in their personal medical needs and those of their child. This situation increases their vulnerability; long-term HPN is challenging but under such difficult circumstances the additional burden is immense. The situation is leading to grave concerns about personal health issues which are also having an impact on quality of life for all concerned.

We were assured and accepted that short, medium and long-term national coordinated management plans had been drawn up and continue to be updated as the situation evolves. It was unanimously accepted that there wasn't a quick fix to this situation.

We pleaded for more timely and coordinated communications to patients/parents/carers; they needed a trustworthy source; many have lost faith in anything being issued by Calea. The pressure on nutrition teams to circulate communications from NHSE/I, DHSC, MHRA or the comms team added pressure on already overworked healthcare professionals.

While we understand the sensitivity of some of the information and planning; not wanting to make promises that may become undeliverable, we made a simple request 'please show all those involved that you care and understand their situation', current information was - understandably - carefully considered and written but needed to reach out to those involved and show humanity.

It was made clear that PINNT did not represent all the Calea patients affected but has been in touch with many non-PINNT members and provided some support. During this difficult time, it is vital that we all work together in a constructive way to represent the needs of patients/parents/carers.

Lines of communication remain open for PINNT to continue to feed into the National Working Group as well as those who attended this meeting.

PINNT

Support and Advocacy not for profit charity for people on Home Artificial Nutrition (HAN)

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