

**PINNT**  
PO Box 3126  
Christchurch  
Dorset  
BH23 2XS



**Website:** [www.pinnt.com](http://www.pinnt.com)  
**Email:** [comms@pinnt.com](mailto:comms@pinnt.com)

11<sup>th</sup> July 2019

Dear PINNT members

**Re: Calea supply of PN issues**

Further to the statement we made on our closed Facebook page earlier in the week, we feel it's time to comment further.

PINNT has the ability to provide feedback to certain departments within NHS England, and for this issue we have done that following the communications we received from members. We were told that they were fully aware of the guidance from MHRA in respect of the change to the way Calea compounded the feed.

We believe, that while this was done with patient safety paramount to future compounding, the impact this would have on people on home parenteral nutrition may not have been fully considered. Sadly, the need to implement the changes have resulted in the compounding process taking longer which has reduced their ability to compound as many feed bags as they usually do.

We want to reiterate some key points:

- If you are affected, or continue to be affected, contact your/your child's unit/hospital/centre
- Maintain a dialogue with Calea to try and get up to date information about deliveries etc. As we know from members this changes during the day therefore, if in doubt about a delivery – do not hesitate to ring them again!
- Make it clear if you do not have sufficient fluids or PN to meet your/your child's needs
- If you/your child is unlikely to have the fluids or PN, missing normal feeding or hydration, contact the unit/hospital/centre immediately
- It's completely understandable that people will feel angry and emotional during this difficult time. Try to keep conversation to the point and extremely clear about your/your child's needs in terms of fluids and PN
- This situation is far from ideal; the company will be working flat out during this period - we'd expect nothing less.

We previously offered advice on feedback once this difficult time was over, we won't comment further on that now. We'll address that once we are fully assured the delivery of PN and fluids has been restored to all those who need it.

PINNT is aware that Calea has put a notice on their Facebook page to allay fears that this supply issue has nothing to do with contamination of PN.

Registered charity **1157655**



**PINNT: "Supporting people on home artificial nutrition"**

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PINNT is strongly advocating that two things need to happen and fast! We will be reiterating this to relevant bodies:

1. **Improved communications** to their patients/parents/carers and
2. A vast improvement not only in the **co-ordination** of who is getting what and when but improved **co-ordination** between units/hospitals/centres + Calea + the regulatory bodies.

While this necessary change was made, the impact on patients/parents/carers has escalated to a level that has gone beyond initial concern and worry.

We implore you to contact those who have clinical responsibility for you and/or your child; they are the customer in the process, they contract Calea to provide the homecare service. PINNT will continue to represent and listen to members who contact us.

Regards

Carolyn Wheatley

**On behalf of PINNT trustees and Executive Committee**

Registered charity 1157655



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