

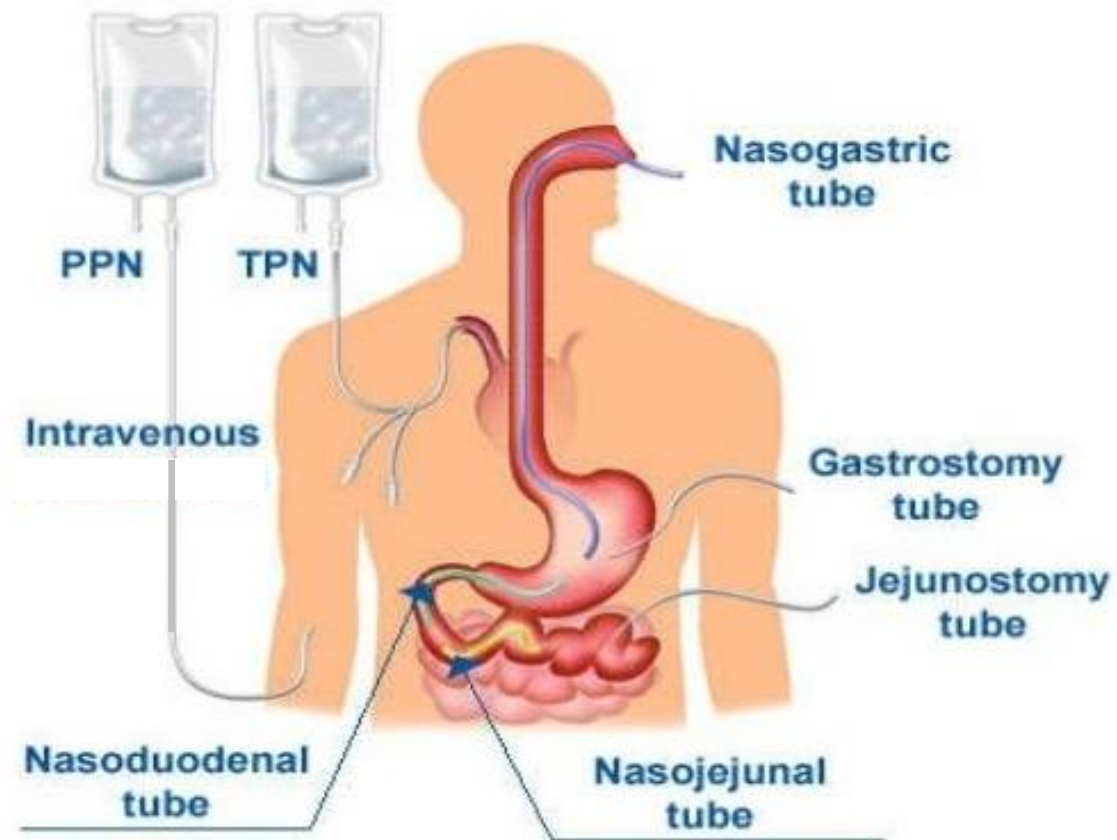
Carolyn Wheatley
HPN patient - Chair PINNT

**Improving the patient experience
for those receiving home
artificial nutrition**

Twitter/Facebook: @PINNTcharity

**TPN/HPN (Total/Home Parenteral Nutrition) Home Enteral tube feeding (PEG, Button etc)
Support and Advocacy**

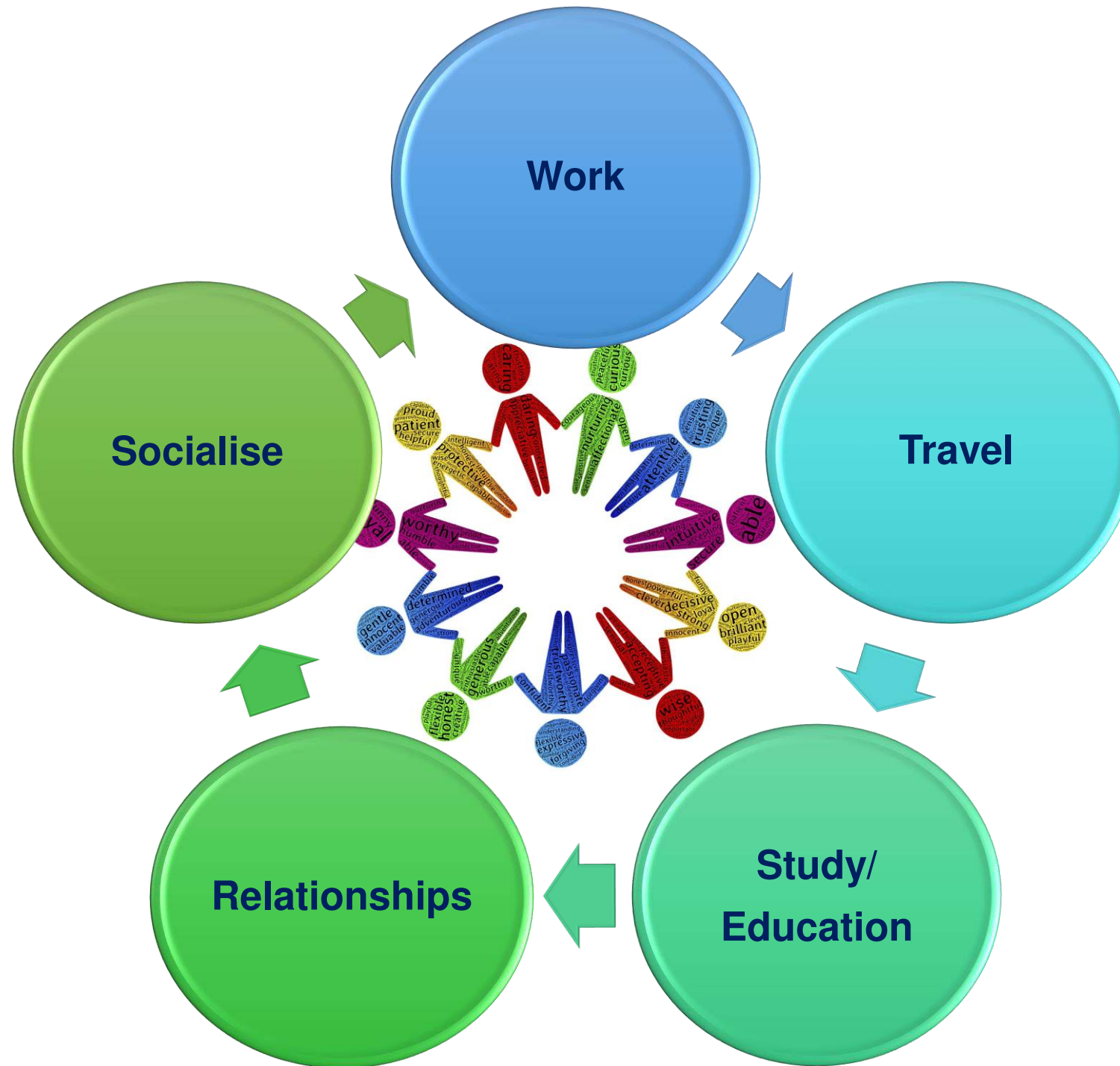
Artificial feeding routes



Types of feeding systems



- Patient are discharged and overwhelmed with information, hope and expectation
- Parenteral and enteral patients use ambulatory pumps
- Often told 'it's an overnight feed'
- 'You can return home and get back to ***normal***'
- What is normal?
- 12-14 hour feed + additional IV fluids
- Different lifestyles...




Many PINNT members were reporting issues in respect of ambulatory rucksacks in terms of security screening in public places!

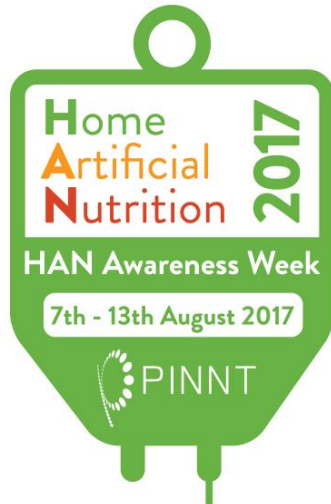
Rucksacks with tubing, pumps, batteries noises/alarms

- People need/want to infuse in public
- We wanted to support patients, the public and security services
- Support people to live as they so wish
- Integrate into the community, not be excluded from it.





*How could
we help with
this?*



- A dedicated tag for ambulatory feeding rucksacks to verify genuine medical equipment
- A free resource for PINNT members
- To provide security for PINNT members, the general public and security services
- It was agreed that it would be launched during our **Home Artificial Awareness Week** in 2017

Phase 1: PN ambulatory pumps

- Invited the three suppliers/distributors to support the project: BD (formerly CME Medical Ltd, Inspiration Healthcare and Fresenius Kabi)



- All agreed to work as equal partners for the good of patients
- A bespoke medical tag and info card was designed



Name:

Email:

Telephone:



Charity Number: 1157655

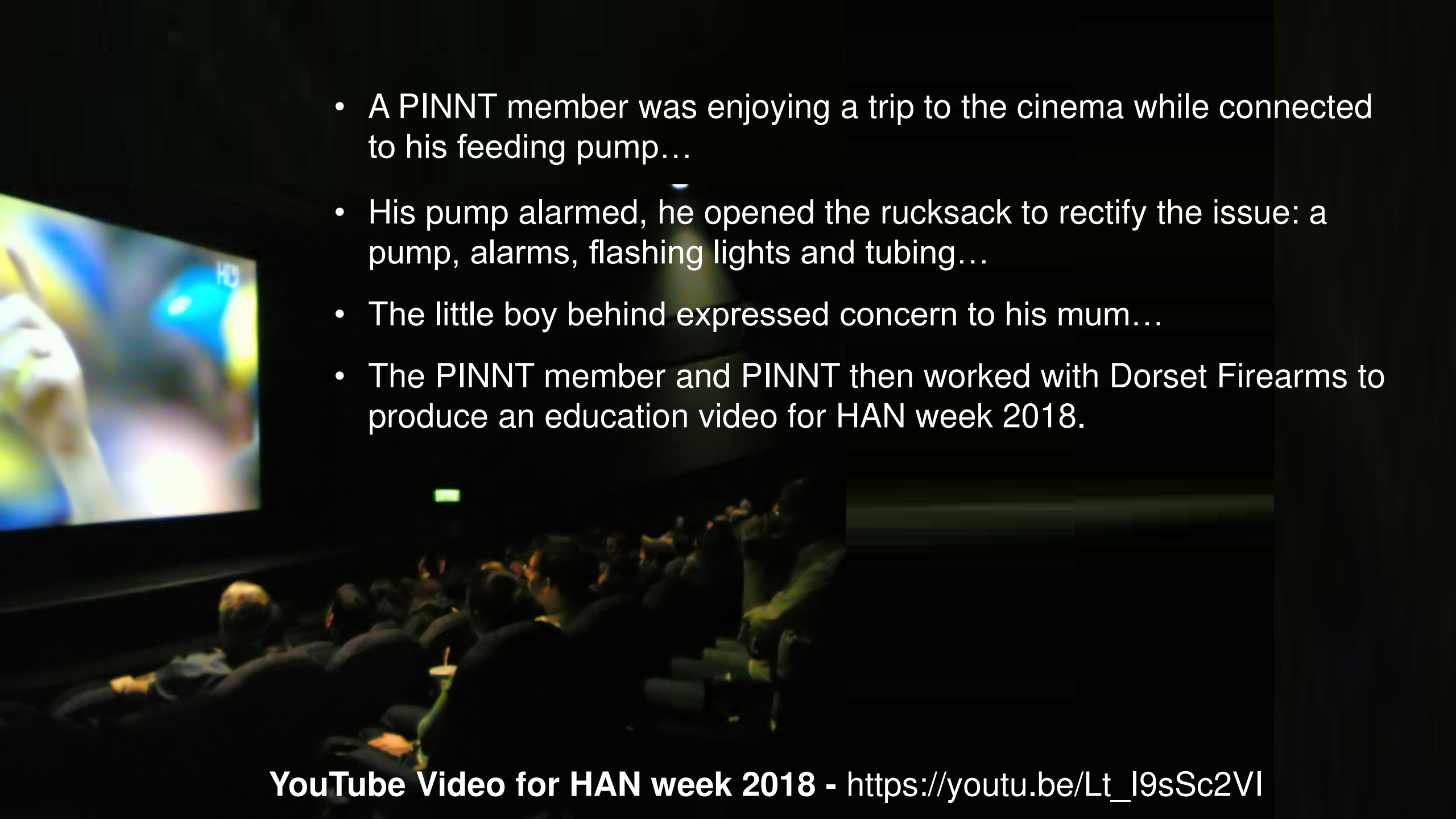


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- A person is seen from behind, sitting in a dark cinema or lecture hall, watching a video on a large screen. The video on the screen shows a close-up of a person's face, possibly a child, with a blue light source visible in the background. The person in the foreground is wearing a dark jacket and has their hands clasped in their lap. The screen is on the left side of the frame, and the rest of the room is dark.
- A PINNT member was enjoying a trip to the cinema while connected to his feeding pump...
 - His pump alarmed, he opened the rucksack to rectify the issue: a pump, alarms, flashing lights and tubing...
 - The little boy behind expressed concern to his mum...
 - The PINNT member and PINNT then worked with Dorset Firearms to produce an education video for HAN week 2018.

YouTube Video for HAN week 2018 - https://youtu.be/Lt_I9sSc2VI



Medical tag & card



On a variety of PN rucksacks



Out and about...

#verify

PINNT medical tag – home enteral and parenteral feeding
For ambulatory life-saving medical rucksacks

WHERE ARE WE NOW?



- All EN ambulatory pumps were added to the system in May 2018
- One year after we launched it we have achieved our goals
- Tags have been sent all over the UK, Europe, South Africa and Australia
- We are already looking to upgrade the tag and information in 2019
- Working with police colleges to education officers about rucksacks for essential medical equipment and feeding.



The medical tag has gone onto my sons' rucksack. He's deaf, as is his carer so it's a great help. The letter and card have been put inside too. It's hard for them to explain with the communication barrier so this is perfect, thanks.



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