

A faint, light blue world map is visible in the background of the slide, showing the continents and oceans.

# Traveling with Home Nutrition Support: Advice from a Dietitian, Person with ALS and Caregiver

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# Disclosures

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## **Stephanie Dobak**

- Grant funding: Dietitians in Nutrition Support DPG & ALS Association
- Speaker honoraria: Functional Formularies

## **Ronald Brady**

- No disclosures

## **Carla Hill-Brady**

- No disclosures

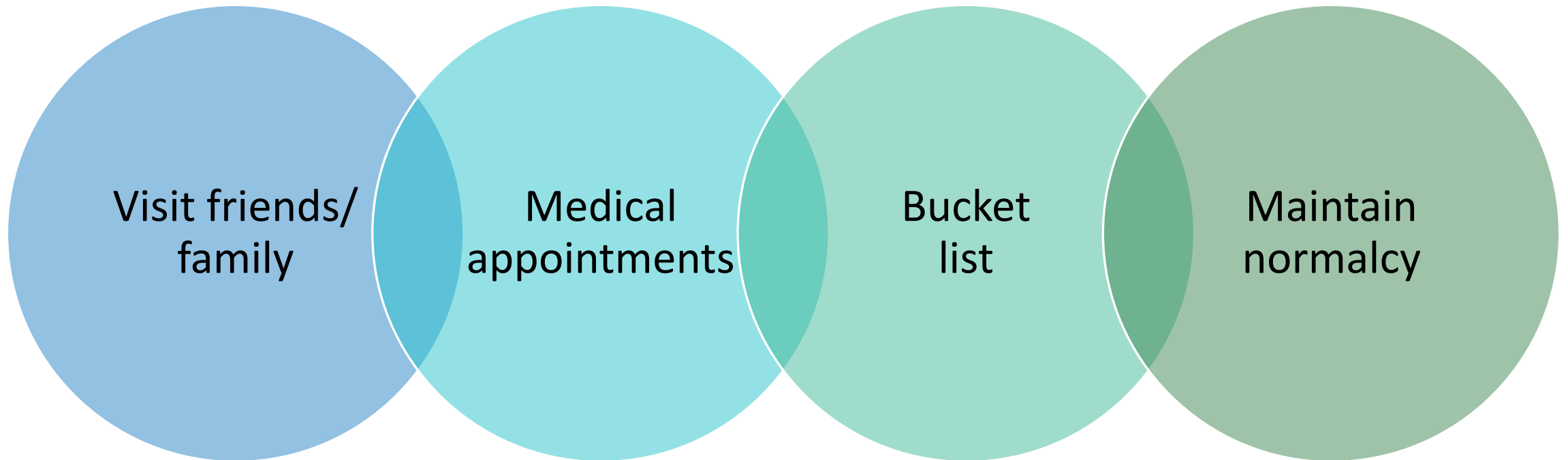
# Objectives

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- List travel considerations with home parenteral and enteral nutrition (HPEN)
- Troubleshoot common home EN complications
- Understand traveling with home EN from the perspective of a person with amyotrophic lateral sclerosis (PALS) and caregiver (CALS)

# Why Travel with HPEN?

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# Reasons to Ask About Travel Plans

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- Because PALS are probably doing it anyway!
- Advise on safety of traveling
- Save PALS time and frustration in planning
- Help prevent foreseeable mishaps
- Provide troubleshooting, if needed
- Learn from others' travel experiences

# Medical Concerns for Traveling

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Medical fragility or lack of clearance from other providers (e.g., cardiology)



Perilous lab values



Significant fluid accumulations



Nutrition support site access issues

# Start Planning Early

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Destination



Trip mode  
& length



Complexity

# Clinical Travel Considerations

- Formula transportation
- Laboratory draws
- Nursing care
- Prescriptions
- Contingency planning



# Formula and Supply Transportation

	Pros	Cons
<b>Carried On</b>	<ul style="list-style-type: none"><li>- More control</li></ul>	<ul style="list-style-type: none"><li>- Bulky</li><li>- Compounded PN only stable 9 days; requires travel cooler</li><li>- Temperature control, especially for home blenderized EN</li></ul>
<b>Shipped</b>	<ul style="list-style-type: none"><li>- Can travel lightly</li></ul>	<ul style="list-style-type: none"><li>- Costly</li><li>- Could be delayed or mishandled during shipping</li><li>- Some countries may have liquid importation rules</li><li>- Requires trust-worthy recipient</li></ul>
<b>Purchased at destination</b>	<ul style="list-style-type: none"><li>- Can travel lightly</li></ul>	<ul style="list-style-type: none"><li>- Product may not be the same or available</li><li>- Varying cuisines, if traveling with blender for home blends</li></ul>



## Laboratory Draws

- Extend time between draws, if appropriate
- Identify outpatient labs prior to travel
- Most labs accept orders from out-of-state providers



## Nursing Care

- Train patient on dressing changes, other care
- Identify nursing care prior to travel
- Often requires in-state/country provider orders

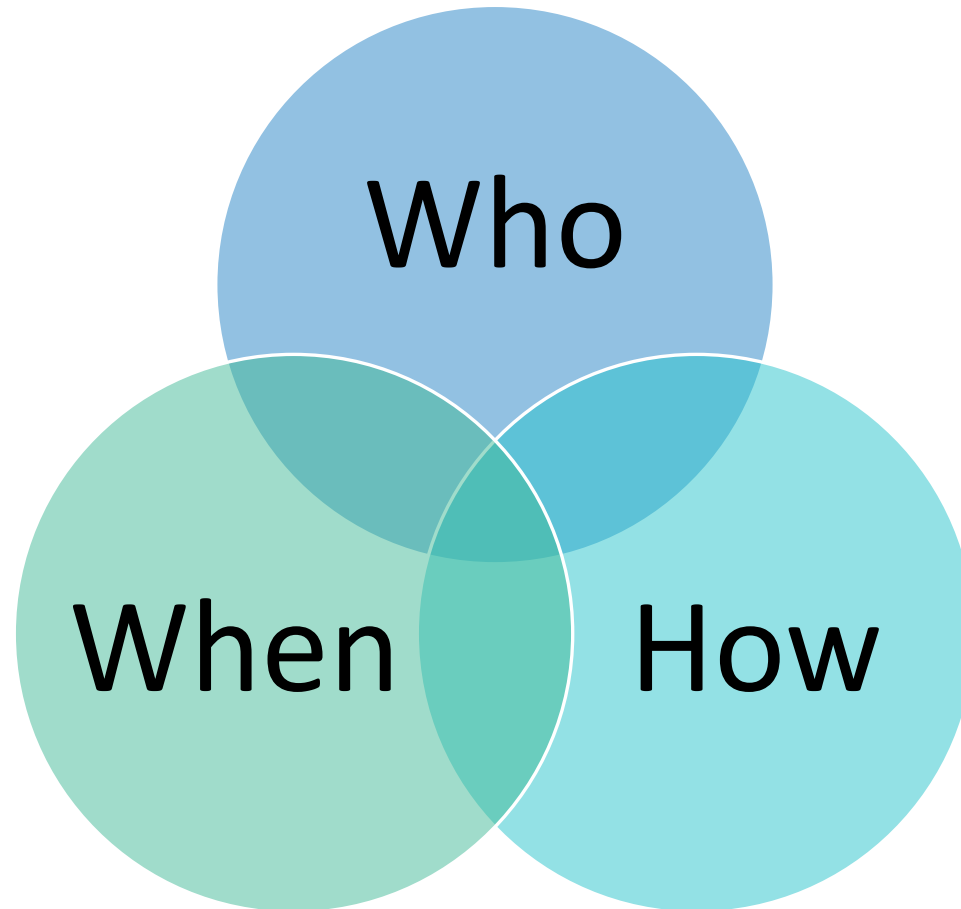


## Prescriptions

- Order and fill known prescriptions ahead of travel
- May require in-state/country provider orders
- Can get scripts from local MD or urgent care if needed

# Contingency Planning

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# Troubleshooting EN: N/V/D

## Potential Causes

- Formula ingredients/concentration intolerance
- Formula/water spoiled/contaminated
- GI infection (e.g., *C.diff*)
- Administration: too fast or cold
- Not EN related (GI issues, meds)

## Action

- Stop feeding, vent tube if able, prevent dehydration
- Ensure formula is not spoiled/contaminated and appropriate handling techniques were used
- Ensure formula/water is administered at room temperature and not too quickly
- Rule out infection, if possible
- If symptoms persist, contact provider vs visit local facility

# Who to Contact?

## Team versus Local Facility

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Constipation or diarrhea  
Bright red blood in stool  
Pain, oozing, leakage at access site  
Blood sugar fluctuations



Dehydration  
Tube/line displacement  
Black, tarry stool or vomiting blood



# Non-clinical Travel Considerations

- Air travel rules
- Packing/baggage considerations
- Communicating medical needs
- Travel insurance

# Air Travel Thoughts and Rules

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- Build extra time into schedules



- TSA allows HPEN, medications, equipment, and medically necessary liquids over the 3-1-1 limit in “reasonable amounts”



- TSA screening assistance should be requested through TSA Cares
- TSA notification cards to discreetly notify TSA officers of medical conditions
- Travelers may request a private screening if they wish



# Checked Baggage- What to Know

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- Though TSA may approve baggage, airlines may have stricter size/weight limits
- Check with airline beforehand to see if medical baggage fees can be waived
- Consider wheelchair assistance
- Consider medical documentation for proof of medical stability, supplies, en route infusion needs



# Packing/Baggage Considerations

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- Pack some supplies in carry-on (formula, syringe, charger)
- Create list of supplies:
  - Formula
  - Syringes, low profile tube extension sets (if needed)
  - Gravity feeds: bags, IV pole (if needed)
  - Pump feeds: bags, IV pole, pump, charger, batteries
  - PN: pump, additional fluids/additives (if needed), fridge
  - Site care supplies
  - Clean water supply
  - Hand sanitizer vs soap and clean water for hand washing
  - Medications and list (names and doses)

# Communication of Medical Needs

## Sample Travel Letter for HEN (Tube-fed) Consumers

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City, ST Zip \_\_\_\_\_

Date: \_\_\_\_\_

To Whom It May Concern:

My patient, \_\_\_\_\_ *patient name* \_\_\_\_\_, requires specialized nutrition support to sustain their life. They have an enteral feeding tube placed in their abdomen and sustain themselves by pumping a nutritional formula through this tube.

**\*\* If you will need to pump formula during the flight add:** Because of their medical condition, they will need to infuse formula through their tube during the flight.

They may be traveling with any combination of the supplies listed below:

- Feeding pump
- Formula
- Syringes
- Tubing and feeding bags, etc.

These supplies are medically necessary and could be difficult to obtain while they are away from their local physicians and suppliers; therefore I request that they be allowed to carry them onboard.

Please do not hesitate to contact me at (\_\_\_\_\_) \_\_\_\_\_ – \_\_\_\_\_ if you have any questions or need additional information.

Very sincerely,

\_\_\_\_\_  
*physician's name*

\_\_\_\_\_  
*physician's title*

## 4. Nutrition Related Information

### Feeding Schedule:

I use the following brand of formula: \_\_\_\_\_  
(Attach a label from your can/carton.)

Method: (check one) \_\_\_\_\_ Bolus \_\_\_\_\_ Gravity \_\_\_\_\_ Pump

Infusion Vol.: \_\_\_\_\_ Rate: \_\_\_\_\_ Over \_\_\_\_\_ # hrs.

I have \_\_\_\_\_ # of feedings/day

Total Volume fed in 24 hours: \_\_\_\_\_

I tube feed \_\_\_\_\_ #days/week

Time: (check one)

\_\_\_\_\_ Overnight \_\_\_\_\_ Daytime \_\_\_\_\_ Around the Clock

### Other Pertinent Information:

Recent Lab Values: (See attached *Lab Results*)

### Daily Input/Output:

Usual Weight \_\_\_\_\_ (may be a range)

#### Input Volume:

Oral \_\_\_\_\_

IV \_\_\_\_\_

Tube \_\_\_\_\_

Total \_\_\_\_\_

#### Output Volume:

Urine \_\_\_\_\_

Ostomy \_\_\_\_\_

Other \_\_\_\_\_

Total \_\_\_\_\_

## HEN (Tube-fed) Consumers Only

## 5. Access Information/Protocols

### Feeding Tube:

Type: (check one)

\_\_\_\_\_ N/G \_\_\_\_\_ N/J \_\_\_\_\_ G-Tube

\_\_\_\_\_ G-Button \_\_\_\_\_ J-Tube \_\_\_\_\_ G/J- Tube

Brand Name: \_\_\_\_\_ Size \_\_\_\_\_

Date Inserted \_\_\_\_/\_\_\_\_/\_\_\_\_

Inserted at Institution: \_\_\_\_\_

By: \_\_\_\_\_ Surgeon \_\_\_\_\_ Intervent'l Radiologist

\_\_\_\_\_ Gastroenterologist \_\_\_\_\_ Other \_\_\_\_\_

Phone #: (\_\_\_\_\_) \_\_\_\_\_ — \_\_\_\_\_

### Flushing Protocol:

Solution: (i.e. water, saline) \_\_\_\_\_

Amount: \_\_\_\_\_

Frequency: \_\_\_\_\_

### Dressing Change Protocol:

Frequency: \_\_\_\_\_

Dressing Type: \_\_\_\_\_

Skin Prep Solution: \_\_\_\_\_

EN Tube Securement Method: (check one)

\_\_\_\_\_ Attachment Device \_\_\_\_\_ Tape

\_\_\_\_\_ Sutures \_\_\_\_\_ None

I use gloves when changing my dressing: (check one)

\_\_\_\_\_ Yes \_\_\_\_\_ No

## 6. EN Pump & Sup

1. Brand: \_\_\_\_\_ M

Pump Tubing Brand & Reorder

\_\_\_\_\_

Attachment Tubing (for EN bu

\_\_\_\_\_

## 7. Ostomy (Output Protocol

Type of Ostomy: (check one)

\_\_\_\_\_ Jejunostomy \_\_\_\_\_ Ile

Date Created: \_\_\_\_/\_\_\_\_/\_\_\_\_

Institution/Surgeon: \_\_\_\_\_

Phone #: (\_\_\_\_\_) \_\_\_\_\_

I use the following for my

Type of Pouch: \_\_\_\_\_

Type of Wafer: \_\_\_\_\_

Type of Skin Prep: \_\_\_\_\_

I change my dressing/pouch ev

I use gloves when changing my

\_\_\_\_\_ Yes \_\_\_\_\_ No (check one)



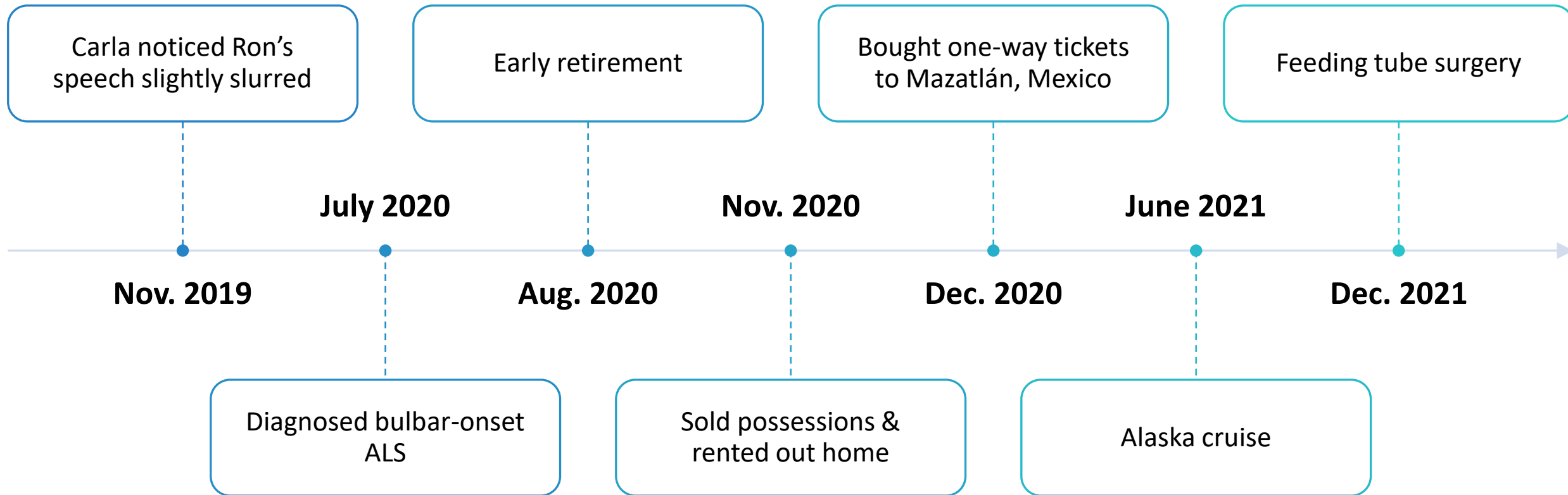


# Our Experience

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# Diagnosis & Decisions

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# World Adventure - March to June 2022

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- **Destinations:** Mexico, Dallas, Egypt, Miami, Colombia, Panama Canal, Costa Rica, Guatemala, Las Vegas, Philadelphia, New Jersey, Maine, New York City, Boston & El Salvador
- **Modes of Transportation:** Cars, airplanes, cruise ships & charter buses



# Lessons Learned

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1. Plan Ahead

2. Carry a Doctor's  
Letter

3. Medical  
Equipment and  
Supplies Fly Free

4. Use Airline  
Support for  
Disabled  
Passengers

5. Nursing Mothers  
are the Model

6. Cruises are Great

7. Rest

8. TSA PreCheck®

9. Packing.

10. Ask for Help.

# Summary

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- Traveling with HPEN is doable
- Providing PALS/CALS with travel resources upfront saves time and headache
- Be proactive in talking with PALS about travel, have them plan early, and learn from them

# References and Resources

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