Key Takeaways

Navigating Vacation & Travel

Facilitated by Jennifer Schaefer, CAPSW, and featuring HIE Peer Support Mentors Allison Moise and Stephanie Linde

This panel series features dedicated members of the HIE community who offer valuable insights into their experiences with the various impacts and outcomes of HIE.

HOPE **for HIE**

HIE Peer Perspective Series

1

WHEN CHOOSING A DESTINATION, ACCESSIBILITY MATTERS!

- Confirm whether **"ADA accessible"** actually meets your child's specific needs—call hotels, cruise lines, *etc.*, directly.
  - **Look for wheelchair or mobility-accessible lodging** (ramps, elevators, wide doorways, ADA bathrooms.)
  - **Ask about specific features** (like bathtubs vs. showers, in-room refrigerators for medications, and extra space for equipment.)
- Consider your proximity to medical care.
  - Some plan trips based on proximity to known hospitals or cities with good medical infrastructure, just in case!

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- Early signs of DCP often emerge in infancy (some have noticed stiffness and exaggerated arm movements by 4 to 6 months of age).
  - Some like to choose quieter, less crowded places or those with sensory-friendly options.
  - Consider prioritizing locations where your child can still access familiar routines and calming environments.

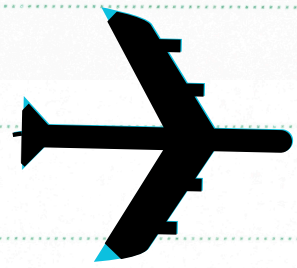
"Accessible" means different things to different places and families. What one venue calls "ADA accessible" may fall short of what your child actually needs, so it's always worth checking the details for yourself!

2

WHETHER YOU'RE FLYING OR DRIVING, FAMILIES AGREE

thoughtful preparation can make the journey much smoother.

TIPS FOR FLYING:



- **Notify the airline in advance:** Let them know about your child's medical and mobility needs.
  - Ask about bulkhead seating, early boarding, and if they allow special travel seats or equipment onboard.

- **Use TSA Cares (highly recommended):** Call at least 72 hours before your flight to arrange support at security.
  - Be prepared for a longer call—review what medical supplies, formula, or equipment you're bringing.

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- When you arrive, TSA Cares agents walk you through security with less stress.

Pack Strategically: Don't check anything essential (like medications, feeding supplies, specialty formula.)

- Use a dedicated medical bag—TSA allows exceptions for medical items and liquids over 3oz.
- Label and track where items are packed (e.g., which bag holds chargers, meds, etc.).

Consider in-flight logistics: Some travel with special seating like a Special Tomato or travel-friendly car seat—check with airline first.

- Bulkhead seats give extra floor space if needed for changing, diapering, or stretching.
- Use soft collars, toddler pillows, or cushions for trunk/head support in the seat.

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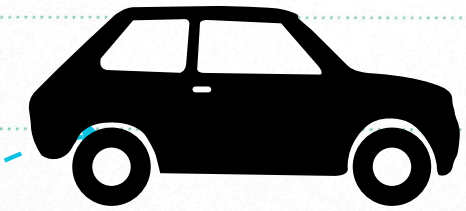
- Many airplane restrooms don't accommodate older kids. Some families discreetly change on the floor when needed or "double diaper" for longer flights.

Consider using backup gear: Consider bringing a backup or loaner wheelchair so your primary custom one isn't damaged.

- Call ahead to clarify how medical gear will be stowed—bring batteries, chargers, and backups.
- If you do use your own gear, take photos of it in advance in case it gets damaged.

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TIPS FOR DRIVING:



Pack Strategically: Don't check anything essential (like medications, feeding supplies, specialty formula.)

- Use a dedicated medical bag—TSA allows exceptions for medical items and liquids over 3oz.
- Label and track where items are packed (e.g., which bag holds chargers, meds, etc.).

DRIVING PROS:

There are no baggage restrictions—bring as much gear, food, or medical supplies as needed — and you have more control over your environment, can make more stops, and can stay within reach of familiar hospitals!

3

SMART MEDICAL PREP HELPS YOU STAY AHEAD OF POTENTIAL STRESS.

Pack extras of everything:

- Medications, feeding supplies, formula, syringes, tubing, incontinence products—bring more than you think you'll need in case of delays or loss.

Organize meds by dose & day to make it easier during busy or unpredictable travel days.

- Pre-sort medications by time of day (e.g., AM, noon, PM, bedtime) and group them by day in a labeled bag, then group all days in a larger container or organizer.

- Check refill dates and coordinate with your care team and insurance company to obtain travel overrides or emergency backups, especially if travel spans refill windows.

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Account for sensitive meds:

- Some medications can't be pre-dosed (e.g., light-sensitive meds)—plan ahead for how to pack and administer them safely on the go.

Get a letter from your doctor to help with airport security or unplanned emergency care visits:

- This can include a child's medical needs, medications, equipment, etc.

Create an emergency care plan:

- Write down your child's routines, diagnoses, and special considerations.
- Get it signed by your provider—this gives added weight when sharing info with unfamiliar providers in a new place.

Airlines usually allow you to carry on or check medical supply bags at no cost—just let them know what's inside. Label your medical bag clearly.

4

PACKING EFFICIENTLY AND EFFECTIVELY TAKES YOU OUT OF REACTION MODE

so you're free to be more present!

Pack feeding and medical supplies generously:

Include backup items—extra connectors, syringes, tubing, and feeding bags. It's better to overpack than risk being without something essential.

Plan for equipment needs:

Travel versions of key gear (like a different wheelchair or portable oxygen concentrator) can make a big difference. Research rentals or talk with your provider team.

Bring comfort items:

Favorite toys, blankets, and sensory aids help create familiarity in unfamiliar places.

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Think about spare clothing:

Consider packing extra clothes or diapers (especially via carry-on). Accidents happen, bags get delayed—extras provide peace of mind.

- Don't forget laundry detergent and dryer sheets if you'll need to wash on the go.

Organize wisely:

Use clear storage bags and label them. Or consider having a list that outlines which item is packed in which bag.

- Consider space-saving hacks, like an over-the-door shoe hanger for supplies.

You'll rarely regret packing too much, so don't be afraid to pack for comfort and contingencies!

5

KEEP PLANS FLEXIBLE, AND EXPECT THE UNEXPECTED.

Every trip teaches something new. With each experience, families gain confidence, refine their strategies, and discover more ways to make travel possible and enjoyable.

With that said, here are some tried-and-true tips and strategies to help guide you

- **Build in extra downtime** and don't try to pack too much into one day. A slower pace often leads to a more enjoyable trip for everyone.
- **Meltdowns, schedule changes, and weather disruptions are normal.** Planning with these in mind can help keep stress lower when they happen.

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Create backup plans. This could include things like...

- Knowing the location of the nearest hospitals or urgent care centers.
- Bringing extra supplies and a copy of your child's care plan or emergency summary.
- Keeping important medical items in your carry-on and not in checked bags.

Protect your important equipment.

- Take photos of wheelchairs, communication devices, and other key gear before you travel. (Airlines are responsible for damaged equipment, but documentation helps.)
- Some families bring basic repair tools or tape for temporary fixes.

6

HERE ARE SOME HELPFUL RESOURCES FOR RELIABLE INFORMATION & SUPPORT

- **Courageous Parents Network** has a downloadable travel guide for parents traveling with medically complex children.
  >>> CourageousParentsnetwork.org >> Search >> Travel Guide

- **RedTreeHouse.Org** is a hub of vetted links covering TSA guidance, accessible lodging, travel safety, and more.
  >>> RedTreeHouse.org >> Parent & Pro Tips >> Special Needs Travel

- **Hope for HIE's specialized online support forums** offer a space for families to connect, share experiences, and receive guidance on every part of your journey.
  >>>Tinyurl.com/HopeforHIEgroups

SUPPORT SPOT BY CHILD LIFE ON CALL

FREE access to the SupportSpot app for ALL Hope for HIE families!

If you cannot access the app, please connect with all of our child life resources at HIE.SUPPORT

support spot by child life ON CALL

tinyurl.com/CLOCforIOS

tinyurl.com/CLOCforAndroid

1. Sign up as a Parent
2. Choose Facility: Hope for HIE
3. Enter Code: 048325

HOPE for HIE

SUPPORT PROGRAMS & SERVICES

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