A Week in the Life:

WEP Mobile Nurse



From early-morning home visits to flexible visit management and continuity of care, read how one of our lead Mobile Research Nurses helps keep the patient at the center of clinical research efforts.

By Lisa Grass Lead Mobile Research Nurse



Monday: After-School Home Visit

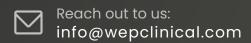
I leave home at 2pm for a visit with one of my pediatric patients participating in a rare disease clinical study. His family books late-afternoon appointments so he can finish a normal school day - one of the advantages of mobile research nursing. We do the best we can to allow families to keep their normal schedule, so they do not have to miss work or school.

I set up at the kitchen table, where I check his vitals, draw blood, process the labs, and then gather his medical information from his parents. While waiting for the blood to clot, he invites me to bake peanut-butter cookies with him. After two previous home visits he is clearly more at ease, and his vocabulary has been improving since starting the study drug. That growing ease isn't accidental – we intentionally keep nurse assignments consistent so patients see the same face each visit. Continuity builds trust and meaningful relationships, especially in long-term or rare-disease studies.

Once the visit is complete, I label the samples, drop them at a courier service, and head to the airport for an evening flight to lowa for a home visit the next day.







<u>Tuesday: Early Morning Home Visit</u>

I have an early morning visit with a new pediatric patient. His dad lets me know they have company over and asks if it is OK for them to be present - which it definitely is. This is another key advantage of mobile research nursing. Families don't have to change their plans to stay enrolled in the study. We can be flexible and work around them.

During the visit, I check my patient's vitals, take his blood draw, do my on-site lab processing, and review his medical history with his parents. After about 90 minutes, I drop samples and source documents at a courier service, then I head back to the airport as I'm flying to Oregon to see another pediatric patient tomorrow.

Airports and the flight are perfect for admin, including staying in touch with our resource coordinators about upcoming visits, reviewing any WEP training materials, and answering questions from other nurses in the field.

Wednesday: Early Morning Home Visit

I am now in Oregon and make my way over in the morning to see a patient I've visited many times. He's waiting at the door, gleefully thanking me for coming. We keep to the routine that works for him - because routine is key for this patient population.

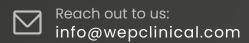
He settles into his recliner and we cue a Beyoncé video, where we sing along while I perform the blood draw - a reliable distraction. Then when the music goes off, we play with the dog, and he proudly shows me his latest artwork and new plushies.

Although he lives two time zones from me, I covered his first few visits until a local nurse could be identified. When we found one, the family asked if I could continue fulfilling the home visits, as he had built a solid bond with me. We are truly *With Every Patient* and I agreed to continue seeing him for the duration of the trial, as it is just as important to me as it is to WEP to build strong relationships with patients and their families.

After I am done with this patient, I head to the airport to fly to my next stop - Idaho.







Thursday: Early Morning Home Visit

I make my way over for my 8:00am visit with a pediatric patient. He is waiting on the couch when I arrive. We move through his vitals and a smooth blood draw. He grins: "OK Lisa, let's do the other arm now." I laugh and reassure him that he did so well and he is so brave, but, luckily, we only need one arm, so he is free to head off and play while I process the labs.

His mum is making breakfast and switching the laundry. Early on, I let her know she can keep her morning routine while I finish the paperwork. We always stress to parents that they are not required to give up their time to keep their children enrolled in the study. Some parents choose to sit and chat over coffee; others choose to tackle chores or get back to working from home.

This is my last visit of the week, so once I am finished, I head over to the airport to fly back home.

Friday: Administrative Day and Remembering the Why

Fridays are my administrative day at home - the anchor that keeps the week ahead moving smoothly. I take meetings and prepare for the next week of travel and patient visits.

It is also a moment to step back and remember why our work matters: these visits go far beyond simply collecting data points. They are about helping children build trust in healthcare providers and fostering meaningful connections with both the patient and their family. Families affected by rare diseases often feel isolated, and having the same nurse visit their home throughout a study can provide much-needed consistency and support.





