

## TIPS & TOOLS FOR SUCCESSFUL PROCEDURES

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Using years of practical experience, a group of study coordinators from Down syndrome-specific clinics came together to create a list of best practices. These tips include advice on inter-departmental coordination, scheduling, comfort measures, and planning suggestions that can contribute to successful procedures and meaningful data collection while working with individuals with Down syndrome and their caregivers.

### When scheduling with the Phlebotomy Lab

- Ask if a participant is able to tolerate blood draws and make notes on the participant's record after consultation with the participant and/or caregiver. This helps the lab team to prepare.
- Arrange to have the lab personnel come to the clinic visit room to draw the participant's blood whenever possible.
- Lab personnel should be familiar with best practices for working with individuals with Down syndrome.
- Have Lab personnel advise on and incorporate comfort measures to alleviate anxiety whenever possible.
- Consider using a 20-gauge needle for blood draws, as red blood cells tend to be larger for people with Down syndrome.

### Plan ahead for imaging

- Plan for delays and a slow pace. Every step will take extra time, and it is recommended to pad 10 minutes into each step.
- Keep headphones or ear plugs ready to help reduce the noise of the scanner. Ears of adults with Down syndrome tend to be small, so have pediatric-size headphones available.
- If giving a PET scan, prepare the caregiver in advance if they will not be allowed to remain in the room due to radioactive exposure risk.
- If conducting an MRI, know in advance if your institution will allow a caregiver to remain in the scanning room during the procedure, or if they must step out and return later.
- Consider height and weight ahead of time, as some participants may not fit into certain scanners.
- Advise the participant to wear comfortable clothes with no metal; the clinical team will verify
- Show the participant a preparation/walkthrough video before the procedure to show the process.
- Prepare the participant for the sound of the scanner; advance exposure to the sound may help.
- Take the participant for a tour and allow them to see the machine in advance if possible.
- If using a head cage/coil, practice ahead of time to help acclimate the participant.

- Have a warm blanket available as a comfort measure.
- Allow a personal stuffed animal or non-metallic comfort item in the scanner if permitted.

## Scheduling imaging

- Emphasize the importance of keeping the scheduled appointment and arriving on time with the participant and caregiver.
- Explain the timelines for cancellation of appointments – i.e. 48 hours in advance of scheduled appointment.
- Efforts should be made to co-localize the MRI and PET scan.
- When the imaging center is located in another part of the institution, the Study Coordinator should meet the participant and the caregiver at arrival and accompany them to the imaging center. This may mean the caregiver will need the Study Coordinator’s phone number to arrange a meeting point, and the Study Coordinator may have to follow the family in their car if the imaging center is a distance too far to walk.
- Arrive 1 hour prior to the start of a scheduled PET scan for the placement of the IV. This includes the Study Coordinator, imaging center staff, and the participant.

## Sequence of images & tips for scan preparation

- MRI scans may last about 45 minutes, and PET scans about 30 minutes; it is generally not recommended to exceed one hour for any scan.
- MRI should always be done first, and sequencing importance should be determined in advance in case the participant cannot tolerate the scan. Quality of MRI is paramount.
- Arrange the sequencing in the order of importance to ensure the most critical sequence is obtained in the event the participant is unable to complete the entire MRI.
- Prepare the participant for volume and duration of MRI noise: Many individuals with Down syndrome have a hard time keeping still and the noise from the imaging machine might stimulate them. Some individuals have difficulty gauging time, and from their perspective, the noise is unrelenting for what feels like eternity.
- Be mindful with directions, and use demonstrations while narrating, because a demonstration is more effective than just an explanation. Individuals with Down syndrome tend to process information more slowly than others. They usually do best with concrete instructions. It is suggested to point to a spot and say: “please put your hip here” instead of “please move to your left.”
- Test the participant’s ability to use the “squeeze bulb” to alert the technician they need assistance.
- Be aware if a participant has sleep apnea as they are required to lie flat for the scan and this could potentially block their airway.
- Prepare the Imaging team to chatter: Technicians should try to constantly engage the participant during the scan so as to: a) establish trust and comfort and b) prevent the participant from falling asleep. Many

individuals with Down syndrome also have sleep apnea, if they fall asleep their jerks and movements will disrupt imaging. It's very important to keep the participant awake.

- Allow the participant to watch a video during imaging if possible. Avoid videos with comedy or music as it could cause them to move with laughter or dance.
- Have the caregiver, if allowed to remain in the room, stand next to the participant (at thigh level) and hold their hand.
- Although the PET scan dosing is usually done 30 minutes prior to the scan, the placement of the IV can take time, so plan accordingly.
- Be alert for signs of participant anxiety and be ready to take a brief break during tracer administration, before the participant's level of anxiety escalates.
- Never leave the participant alone during the IV placement and the 30-minute wait period for the uptake of the tracer. Someone should always be sitting and chatting with them.
- Distract with a non-stimulating video, or provide other low-key entertainment (e.g., tablets, games, coloring) if allowed during the PET uptake waiting period.
- Participants with Down syndrome may have positioning challenges due to shorter necks; assist with positioning in the head coil as needed.
- Consider extra padding, head straps, or motion-correction MRI sequences for participants who are wiggly.
- Caregivers may provide verbal reminders or reassurance to help the participant, if permitted.
- Be aware that GI discomfort and orthopedic discomfort are common factors that impact scan quality and the ability to remain still.
- Provide meals or snacks with sufficient buffer time before scans to reduce reflux or GI discomfort.
- It is important to ask the imaging staff (in advance) if they would be willing to remain in the room with the participant during the PET.

## After imaging

- After the scan, use caution before allowing an individual with Down syndrome to stand up. Oftentimes, they have low blood pressure.
- Have the participant sit up first, then have them dangle their legs over the edge of the table and swing their feet for a bit.
- If they do not exhibit dizziness/lightheadedness, allow them to stand next to the table before they leave.
- **Congratulate the participant on completing their scans!** Most research participants will feel proud because they accomplished something big and kind of scary. It is a mark of validation and affirmation for participants when the healthcare professional values their participation.

## Lumbar puncture/CSF collection/Intrathecal administration

- Use all IRB-approved tools, explainers, and videos to help ensure participants and their families understand the key elements of the Lumbar Puncture (LP) procedure. Many may not be familiar with the purpose of an LP.
- It is recommended to cover the tray of the tools, especially needles, when the person enters the room.
- Do a run-through ahead of time to orient the participant and the caregiver/study partner to the room where the procedure will take place, if possible. Show them where the participant will sit or lie down and even rehearse how the participant is to climb into the chair, or up onto the examination table.
- If site policy allows, it is almost always preferable to have the participant's study partner (caregiver or other) in the room, facing the participant during the procedure, and coaching them through it. The study partner can also help interpret the participant's reactions for the clinician and study coordinator.
- When performing the LP, narrate each step slowly, with enough time for the person to absorb, understand, and prepare for the sensation. "You are going to feel something cold on your back. That's me, washing your skin with a cold solution. It won't hurt."
- Provide distractions whenever possible, like a game or an iPad, or allow the participant to use their phone during the procedure.
- Be sure to consistently check in with the participant to assess their comfort level, and to provide reassurance and encouragement.