



Tips from the “IV League”

Fabry community members receiving ERT

Planning:	<ul style="list-style-type: none">• Discuss with your doctor or nurse what to expect in advance.• Ask your doctor about IV access or port access for your infusions.• Ask to tour the infusion space before your first infusion.
Packing:	<ul style="list-style-type: none">• Pack your bag beforehand to avoid being in a rush on the day of.<ul style="list-style-type: none">◦ <u>Entertainment</u>: Take books, magazines, music, games, laptop, tablet, headphones, device chargers. Some clinic will have TVs.◦ <u>Provisions</u>: Take snacks and/or lunch, water and/or other drinks.
Before:	<ul style="list-style-type: none">• Drink plenty of water for one and two days before your infusion.• Plan to wear comfortable clothing (layers recommended) and footwear.• Take your pre-meds as prescribed to avoid infusion reactions.• To make the IV stick easier, many clinics warm up the area beforehand.• Visit the bathroom before your infusion starts.
During:	<ul style="list-style-type: none">• Speak up promptly about side effects during your infusion, such as chills, shaking, dizziness, shortness of breath, rash, pain, etc.• You may choose to have a friend or family member keep you company.<ul style="list-style-type: none">◦ Some families schedule their infusions at the same time and socialize.• Keep entertained with your supplies or infusion center resources.• Once you are more comfortable with infusions, consider a taking a nap.• Be sure to move around once in a while! Do sit-to-stand exercises or light stretches.
After:	<ul style="list-style-type: none">• Don't be in a rush afterward.• Some people report being tired for that evening; plan easy meals and time to rest.<ul style="list-style-type: none">◦ Many people report taking a nap or going to bed early on the day of their infusion.
General:	<ul style="list-style-type: none">• Treat your nurses well!• Always keep your appointments / don't skip infusions for the best outcomes.• Create a routine or ritual around infusion day so it feels less disruptive of your schedule.<ul style="list-style-type: none">◦ Some people go out for a meal and spend time planning their next culinary adventure.
Kids:	<ul style="list-style-type: none">• If possible, allow your child to meet the nurse before their infusion.• Bring comforting items like a blanket or stuffed animal.• <u>Give your child as much control as possible</u>, let them pick where to poke when possible, what order to take pre-meds, what activities they want to do.• Consider asking your doctor or IV nurse about using a numbing cream or spray before the IV is given.<ul style="list-style-type: none">◦ One family reported their children do well with the vibrating buzzy bee ice pack.• Give small rewards for getting through treatment (prizes, special snacks).