

Your treatment recommendation: Leukine®

Your doctor has recommended you start on Leukine[®], a treatment for your **pulmonary alveolar proteinosis (PAP)**. PAP is a rare disease where protein builds up in the air sacs in your lungs, making it hard to breathe. Leukine[®] is a medication that you will inhale (breathe in) once a day through a nebulizer. A **nebulizer** is a device that delivers medication in the form of a mist that you inhale into your lungs.

This is an off-label use of this medication (meaning that Leukine[®] has not yet been approved to treat PAP by the Food and Drug Administration, or FDA). However, there are ongoing clinical trials to gather the information needed for FDA approval. The medication is expensive and comes from a specialty pharmacy. The manufacturer can help you get assistance for this medication, even for the off-label use. There are forms for this that you will need to complete. We can help you complete these forms and then fax them for you.

What supplies do I need for my Leukine® treatment?

You will need to refrigerate your Leukine[®] medication until you're ready to use it. To take this medication, you will also need to get other supplies (these will all be ordered by your doctor):

- □ A nebulizer (Pari-LC Plus[®] or a similar type)
- □ 10 millileter (ml) vials of sterile water for injections (which will be used to dilute the medication)
- □ Syringes with needles
- □ Alcohol pads (to clean the medication vials)

□ A hard plastic container (to put the used needles and syringes in)

How do I start on Leukine®?

You will receive education from the clinic's pharmacy and nursing team by phone before you start Leukine[®]. If you feel you need to come to the clinic for in-person instructions for your first dose, we will arrange a nurse visit for you. You would need to bring all of your supplies to this appointment.

Instructions for preparing your Leukine® treatment:

When you're ready to take your medication, take the Leukine[®] vial out of the refrigerator and let it warm up to room temperature. **Do not shake the vial**.

- 1. Flip the plastic cap off of a vial of sterile water. Do not remove the gray rubber stopper.
- 2. Wipe the top of the rubber stopper with a new alcohol swab. Do not touch the rubber stopper with your hands or fingers.
 - If you do touch the stopper, clean it again with a new alcohol swab.
- 3. Flip the plastic cap off of the Leukine[®] vial. Do not remove the gray rubber stopper.
- 4. Wipe the top of the rubber stopper with a new alcohol swab. Do not touch the rubber stopper with your hands or fingers.
 - If you do touch the stopper, clean it again with a new alcohol swab.
- 5. Remove a syringe and needle from its packaging.
- 6. With the cover still on the needle, draw 1 ml of air into the syringe by pulling back on the plunger.
 - The amount of air you draw into the syringe should be equal to your Leukine[®] dose of 1 ml.
- 7. Carefully remove the needle cover. Do not put down the syringe or allow the needle to touch anything.

- If the needle touches anything, including your hands, throw away the needle and syringe in your plastic container and start over with a new syringe and needle.
- 8. Holding the sterile water vial **upright**, insert the needle down into the vial through the center of the gray rubber stopper.
 - Make sure the needle stops above, and does not go into, the sterile water.
- 9. After the needle goes through the gray rubber stopper, push the plunger all the way in to inject the air into the sterile water vial.
 - The air you just injected into the vial will make it easier for you to draw the sterile water into the syringe.
- 10.Keeping the needle in the rubber stopper, turn the sterile water vial **upside down**.
- 11.Slowly pull back on the plunger until the correct dose of 1 ml of sterile water is in the syringe.
- 12.Remove the needle and the syringe from the rubber stopper on the sterile water vial.
- 13. With the Leukine[®] bottle standing upright, insert the needle into the center of the Leukine[®] vial and inject the 1 ml of sterile water into the Leukine[®] vial.
 - Do not remove the needle or syringe from the Leukine® vial at this point.
- 14.Gently tap the side of the Leukine[®] vial to mix the sterile water and the Leukine[®] together. The Leukine[®] should dissolve very quickly.
 - When it is fully dissolved, it is ready to be withdrawn for the treatment.
- 15.Pull back gently on the plunger until all of the Leukine[®] and water mix is drawn into the syringe.
- 16.Carefully take the needle off of the syringe and put it in the hard plastic container.

- The medication in the syringe is the Leukine[®] dose you will take with your nebulizer.
- 17.Attach the nebulizer cup (including mouthpiece) and tubing to the nebulizer machine.
- 18. Open the nebulizer cup. Point the tip of the syringe into the nebulizer cap and press down on the plunger. This will cause the medication to squirt into the nebulizer cup. Close the cup.
- 19.Keep the cup upright. Turn the nebulizer pump on.
- 20.Relax and breathe in the medication through the mouthpiece. Continue until there is no more mist.

Where can I learn more about PAP?

For information on pulmonary alveolar proteinosis (PAP), you can look at the PAP Foundation website: <u>www.papfoundation.org.</u>

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