



## Elevidys Patient Journey: Checklist of What to Expect Before and After Treatment

This family education sheet explains important steps that will happen before and during your child's Elevidys<sup>®</sup> gene therapy at Boston Children's Hospital.

### How do I find out if my child is a good fit for Elevidys gene therapy?

- **Consult appointment:** You'll have a consult appointment with Boston Children's Neuromuscular Clinic.
- **Genetic testing:** Your child will have genetic testing to confirm that they have Duchenne Muscular Dystrophy (DMD) and ensure they are eligible for treatment.
  - If your child had genetic testing, you'll learn the test results.
- **Get AAVrh74 testing:** Your child will have a blood test to make sure that they don't have high levels of adeno-associated virus (AAVrh74) antibodies (cells that fight infections). We test for this because it's used in Elevidys gene therapy.
- **Have updated vaccines:** Your child will need to be up-to-date vaccines (including flu).
- **Give consent:** We will ask you to sign a consent (permission) form. This allows us to contact your health insurance company to see if they cover this therapy. This is called a prior authorization.
- **Do a prior authorization:** Boston Children's Finance Department will contact your health insurance company for prior authorization. This is to see if your insurance will cover the cost of Elevidys gene therapy.
  - **If your insurance company approves the cost and your child meets all the health requirements,** we'll schedule an appointment to give the treatment.
  - **If your insurance doesn't approve the cost,** we will file an appeal. We can't schedule the treatment yet.

### How do I prepare for my child's Elevidys therapy?

- **Make accommodations (if needed):** We give Elevidys gene therapy early in the morning. You'll need to be within a close distance of the hospital for the first 24 hours after treatment. If you don't live close by, please contact Boston Children's Hale Family Center for Families at (617) 355-6279 or [center.families@childrens.harvard.edu](mailto:center.families@childrens.harvard.edu).

- If you need more help, please talk to a member of your team in Boston Children's Neuromuscular Clinic or Duchenne Muscular Dystrophy Program. They can connect you with a social worker.
- **Fever-free:** Your child needs to have a regular temperature (no fever) for the 3 days before the Elevidys gene therapy. We consider a fever to be 100.4°F/38°C.
  - If your child has a fever, we'll need to reschedule the treatment.

### What happens when my child gets Elevidys gene therapy?

- **Run an insurance check:** Our Financial Services team will do a final check of your health insurance to make sure that it's active.
  - If your insurance isn't active, we'll need to reschedule the treatment.
- **Go to infusion clinic:** You'll go to Boston Children's Outpatient Infusion and Day Treatment clinic. Your child's medical team will tell you what time to be there. They'll do a basic exam and check to see if your child has a fever.
- **Get IVs:** A nurse will place an IV (intravenous) needle in your child's veins.
- **Give medicine:** A nurse will give the Elevidys gene therapy through the IV. The treatment takes about 1 hour.
- **Monitor:** A nurse will monitor your child for 3 hours after the treatment.
- **Go home:** After monitoring, a nurse will remove the IV needles and you/your child will go home.

### What do I do after the Elevidys gene therapy?

- **Go to follow-up appointments:** Your child will have blood work 4 days after the treatment, and then weekly for the first 2 months.
- **Continue to give steroids:** You'll continue to give your child a higher dose of steroids at home after treatment for several weeks. Our medical team will explain how much to give.

*This Family Education Sheet is available in Spanish.*