

Duvyzat® ▼ (givinostat)

This medicine is subject to additional monitoring

MUSCLETOWN

A story about your muscles and
how treatment can help keep you moving

Information about reporting side effects can be found on the
back page. If you have any questions about dosing or administering
Duvyzat®, please speak with your healthcare team.



Story written and illustrated by Sauce Health

WELCOME

You're here because your doctor has prescribed Duvyzat® (givinostat), a medicine designed to help slow down the effects of Duchenne muscular dystrophy (DMD). This booklet is your guide and not intended to replace the support you get from your NHS healthcare team. Think of it as your roadmap for the journey ahead.

Here's what you'll find inside:

- A story about muscles and how Duvyzat® works
- How to take Duvyzat® safely and make it part of your daily routine
- What to expect during treatment, including check-ups and monitoring
- Tips for staying on track

Duvyzat® is not a cure for Duchenne muscular dystrophy, but it can help slow down how quickly the condition progresses. It works by targeting a protein called HDAC, which is overly active in DMD. By calming HDAC down, Duvyzat® helps your muscles stay stronger for longer.

This medicine is taken at home as a liquid (called an oral suspension), and it is for children aged 6 and older.

Ready to learn more?

First, you can explore Muscletown, a fun way to understand how your muscles work and what Duvyzat® does. Then, we'll give you all the practical details you need to take your medicine safely and confidently.

Let's get started!

IT'S TIME TO EXPLORE



A TOWN IN TURMOIL

Muscle town wasn't always big. It started as a small village and soon grew into a thriving town, buzzing, and bursting with energy.

Roads zipped like racing snakes, bridges stretched like silver ribbons, and power stations hummed like bees on a sugar rush. Neon lights blinked in perfect rhythm, and traffic signals danced like TikTok influencers who'd nailed the choreography.

In most other towns, things rarely stop working because all the roads and bridges are quite flexible, making them strong and resistant to damage. Every rush of traffic, every bounce of a bus, every zoom of a sports car puts stress on the roads, but the flexible shock absorbers in the road (dystrophin proteins) soak it all up, keeping the town smooth and strong.

But, Muscle town was different because it was a Duchenne muscular dystrophy town. It didn't have those shock absorbers. And that hidden fact was about to change everything.

It was early Saturday morning when a crack appeared in the High Street. Just a hairline fracture at first, like a scratch on a phone screen. Then...CRACK...it spread like lightning!

Henry, a young town planner, skidded to a halt. "What the.....?" he said, staring at the jagged crack slicing through the tarmac.

Guide Note:

Shock absorbers = Dystrophin proteins: Without these, muscle fibres (roads and bridges) become unstable and tear (crack or break) under stress.



CRACKS EVERYWHERE

By lunchtime, cracks were popping up like popcorn. Bridges leaned like tired giraffes. Pavements buckled.

Henry ran to find the repair team. "Patch it up!" He yelled.

The foreman shook his head, helmet slipping over one eye. "We can't keep up...every time we fix a crack, two more appear!"

Henry frowned. "Why?"

"Because the town's blueprint (genes) was missing a key component," the foreman said grimly. "There are no shock absorbers!"

Cars swerved like startled cats. A delivery drone crashed into a lamppost. Sparks flew.

"Great," Henry muttered sarcastically. "This place is turning into a demolition derby."

Guide Note:

Blueprint = Genes

Shock absorbers = Dystrophin protein



LOCKED AWAY

It was beginning to get dark, and repair crews huddled around a glowing laptop. "We need the instruction manuals!" One said.

"They're in the town's digital vaults," replied another. "But there appear to be so many passwords (HDAC enzymes) the instructions are not accessible!"

Henry blinked. "How many passwords are we talking?"

"Too many...every time we try to open a manual, another password pops up. It's like they're multiplying!"

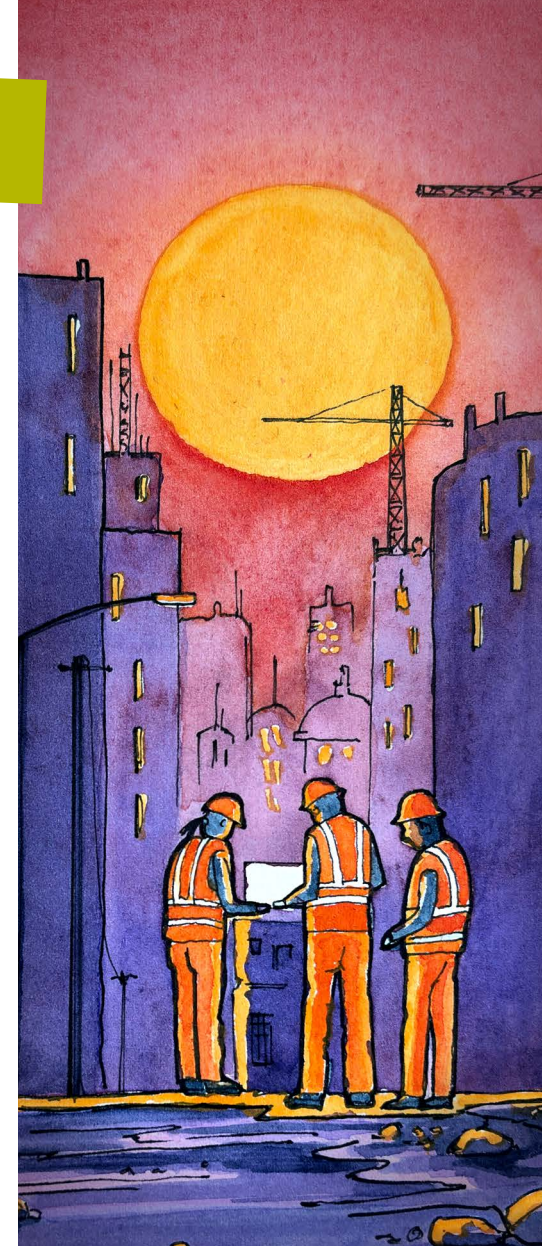
One crew member slammed her laptop. "Who designed this system? A sadistic game designer?!"

The crews laughed nervously, but frustration hung in the air like smog. Without instructions, they couldn't fix the roads properly.

Guide Note:

Passwords = HDAC enzymes

DNA holds repair instructions. HDAC enzymes normally manage access, but in Duchenne, HDAC activity skyrockets (passwords) and stop the DNA from releasing (expressing) the instructions (proteins) that help repair the muscles (roads).





POWER PLANTS FLICKER

Henry raced to the 'Power District'. Normally, the plants hummed like happy bees. Today, they coughed and sputtered like old engines.

"Out of juice!" Shouted an engineer, wiping sweat from his brow.

"We can't keep the lights on!"

Traffic lights blinked nonsense. Cars crashed. Signals fizzled.

SIRENS EVERYWHERE

Sirens screamed. Emergency trucks zoomed past like angry hornets.

"Why so many alarms?" Henry asked.

"Because the calming signals aren't coming," muttered the foreman.

"The instructions are locked away, so the system thinks it's still an emergency."

The crews were panicking, rushing everywhere, making things worse.

One worker yelled, "I thought I had fixed that bridge!"

Another shouted back, "Well, it's broken again!"

Henry rubbed his temples. "This town needs to chill out."

CREWS GIVE UP

"We tried," resigned the foreman, tossing his helmet. "But the cracks keep coming."

Some crews dumped rubble into empty cracks and potholes, while others started building scaffolding everywhere.

Henry stared. "This isn't fixing the problem - it's making it worse!"

"Best we can do," the foreman shrugged.

One worker muttered, "At this rate, we'll all struggle to walk home."

Guide Note:

Power plants = Mitochondria: When damaged, muscles lose energy and can't repair themselves.

FAP cells malfunction, STEM cells fail → fat replaces muscle (rubble).

FAP cells overproduce connective tissue → fibrosis (too much scaffolding).

ENTER DUVYZAT®

A calm voice cut through the chaos.

“What seems to be the trouble?” Asked a figure wearing a red cap and cape. It was Duvyzat®

“I’m here to update the system,” Duvyzat® said. “Let’s remove those extra passwords.”

The vaults blinked. Passwords vanished. Manuals opened.

Calming signals flowed through the town and crews got back to work. Power plants hummed again and Sirens faded.

One worker whispered, “Finally. Someone who knows what they’re doing.”

A TOWN WITH HOPE

Muscle town wasn’t perfect. It still had some issues, but the town was calm, strong, and ready to keep moving.

Henry smiled. “We can’t change the blueprint of this town” he said, “but we can make the best of what we’ve got.”

“We should give Duvyzat® a place in this town,” said the foreman.

“Maybe even the penthouse suite.”

“I’d love her to stick around for as long as the town needs her help.”

Everyone laughed. For the first time in days, the town felt alive again.

Guide Note:

Duvyzat® inhibits HDAC activity, restoring balance - DNA unwraps, repair genes are expressed, inflammation reduces, and muscle regeneration improves.

Now that you’ve seen how Muscle town works, and how Duvyzat® can help keep things running, it’s time to bring the story into your real world. Your muscles are just like that town: busy, hardworking, and sometimes under pressure. Duvyzat® is here to help, but it only works if you know how to use it properly. So let’s switch gears and talk about what this means for your daily life; how to take Duvyzat®, what to expect, and how to stay on track.

Ready? Let’s go!



1. TAKING DUVYZAT®

Duvyzat® should be taken two times each day as part of your regular routine. Each dose must be taken with food, ideally during main meals such as breakfast and dinner. Why? Because food helps to avoid the bitter taste of the medicine, and let's be honest, it's easier to remember when you're already sitting down to eat.

How do you take it?

- Use the dosing syringe provided with the medicine.
- After each dose, rinse the syringe with water so it's clean and ready for next time.

Who decides the dose?

- Your doctor. The amount depends on your weight and may change over time.

Important:

- Never change the dose yourself. Always follow your doctor's instructions; no DIY experiments here!

Helpful Extras:

- Download the *How to administer Duvyzat®* PDF or watch the administration video for step-by-step guidance. They're like cheat codes for medicine-taking.

2. MAKING IT YOUR ROUTINE

Taking medicine every day can feel like a big task, but here are some tips to make it easier and part of your daily routine:

- Link it to meals and take with food.
- Use reminders, phone alarms, sticky notes, or a chart on the fridge.
- Keep the syringe clean and ready for the next dose.
- Ask your family to help you stay on track.

Think of it like brushing your teeth: soon you won't even think about it.



3. MONITORING AND SAFETY

Taking Duvyzat® means regular check-ups to keep you safe.

Before starting:

- Your healthcare team will check if Duvyzat® is right for you.

After starting:

You'll have blood tests to monitor your health and spot any side effects early.

- At first, tests happen every 2 weeks. Later, they'll be less frequent.
- Some tests may require that you have an empty stomach, so ask before your appointment (because nobody likes surprise fasting).

Your healthcare team may recommend additional ECG monitoring due to underlying cardiac disease or other medications you are taking.

4. INTERACTIONS WITH OTHER MEDICINES

Some medicines can affect how Duvyzat® works, or make side effects more likely. Always tell your doctor about any other medicines you take. Even vitamins and supplements count, don't keep secrets!

5. POSSIBLE SIDE EFFECTS

Not everyone gets side effects, but here are some to watch for:

Low platelet count (thrombocytopenia):

- Look for unusual bleeding or small red/purple spots on the skin.

High blood fat levels (triglycerides):

- Usually no symptoms, found during blood tests.

Diarrhoea:

- Track how often and how severe. Stay hydrated and tell your healthcare team.

Reporting side effects:

- Check the Patient Information Leaflet for details.

6. STAYING ON TRACK

- Make Duvyzat® part of your routine, e.g. link it to meals.
- Use reminders (phone alarms, charts).
- Keep talking to your healthcare team - they're here to help.

REPORTING SIDE EFFECTS:

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at: <https://yellowcard.mhra.gov.uk>

By reporting side effects, you can help provide more information on the safety of this medicine. This medicine is subject to additional monitoring. This will allow quick identification of new safety information. You can help by reporting any side effects you may get. See <https://yellowcard.mhra.gov.uk> for how to report side effects.



This booklet has been created and funded by ITF Pharma Ltd. It is intended to provide helpful information and should not replace advice from your healthcare team.

