

Protecting the progress made against high-risk neuroblastoma (HRNB)

A parent and caregiver resource for postremission care

This is your starting point when it's time to move from upfront therapy into the next phase of care.

Using This Guide



After Achieving Remission



About Maintenance Therapy



IWILFIN FAQs



Preparing for Appointments



WHAT IS IWILFIN?

IWILFIN is a prescription medicine used to reduce the risk of relapse in adults and children with high-risk neuroblastoma (HRNB) who have had at least a partial response to certain prior therapies.

Please see Important Safety Information throughout and the full Prescribing Information and Patient Information at [IWILFIN.com](https://www.iwilfin.com).

Planning the next phase

Guidance after the good news of remission

Words cannot fully express what you and your family are feeling now that your child's HRNB is in remission. It's an amazing moment filled with a range of emotions, but you may have a lot of questions about what comes next.

This guide is here to support you through this transition, helping you feel **more prepared**, **more informed**, and **more confident** as you continue caring for your child.

What you'll find in this guide



Understand what the next phase of care may look like



Prepare for conversations with your care team



Learn how **maintenance therapy, including IWILFIN**, may shape your child's treatment plan



Keep track of what matters, including **questions, patterns, and observations** between visits

Save this guide on your phone for easy reference, or print it out to bring to appointments and jot down notes or questions as they come up.

IMPORTANT SAFETY INFORMATION

Before you take IWILFIN, tell your healthcare provider about your medical conditions, including if you have hearing problems, if you are pregnant or may become pregnant, or if you are breastfeeding.

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The HRNB treatment journey doesn't end at remission

While remission is a major milestone, it does not mean the risk is gone

Reaching remission means your child has made important progress against HRNB. However, the care journey may continue even after active disease is no longer present.

From diagnosis

1 in 2

children with HRNB will eventually relapse

It's important to have a plan to help prevent it.

After earlier upfront therapy, the focus can shift from treating active disease to maintenance therapy that helps protect the progress your child has already made.

It's one treatment journey, and maintenance therapy is part of it

Maintenance therapy is used after the standard phases of upfront therapy are complete. At this point, the goal is different. Instead of treating active disease, maintenance therapy is used to help reduce the risk of the cancer returning.



Follow-up care, ongoing monitoring, and conversations with your child's care team can help guide the next steps

IMPORTANT SAFETY INFORMATION (cont)

If you or your partner are able to become pregnant, use effective birth control during treatment with IWILFIN and for 1 week after the last dose. Tell your healthcare provider right away if you or your partner become pregnant during treatment. Do not breastfeed during treatment with IWILFIN and for 1 week after the last dose.

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Protect the progress with a proactive approach

Your child's HRNB treatment journey from the start of treatment to the path forward

	FROM THE START	THE PATH FORWARD
	START OF TREATMENT	MAINTENANCE THERAPY
 GOAL	Targets active or measurable cancer	Aims to help prevent cancer from returning
 SETTING	Often hospital based	Typically taken at home
 EXPERIENCE	Intense and time-limited	Integrated into everyday routines
 SUPPORT	Multidisciplinary in-clinic care teams	Supported by scheduled monitoring

Your child's care team will look at the following to determine if maintenance therapy is right for your child



Treatment response



Prior therapy



Overall health



Follow-up needs

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IWILFIN is a maintenance therapy your child's doctor may consider

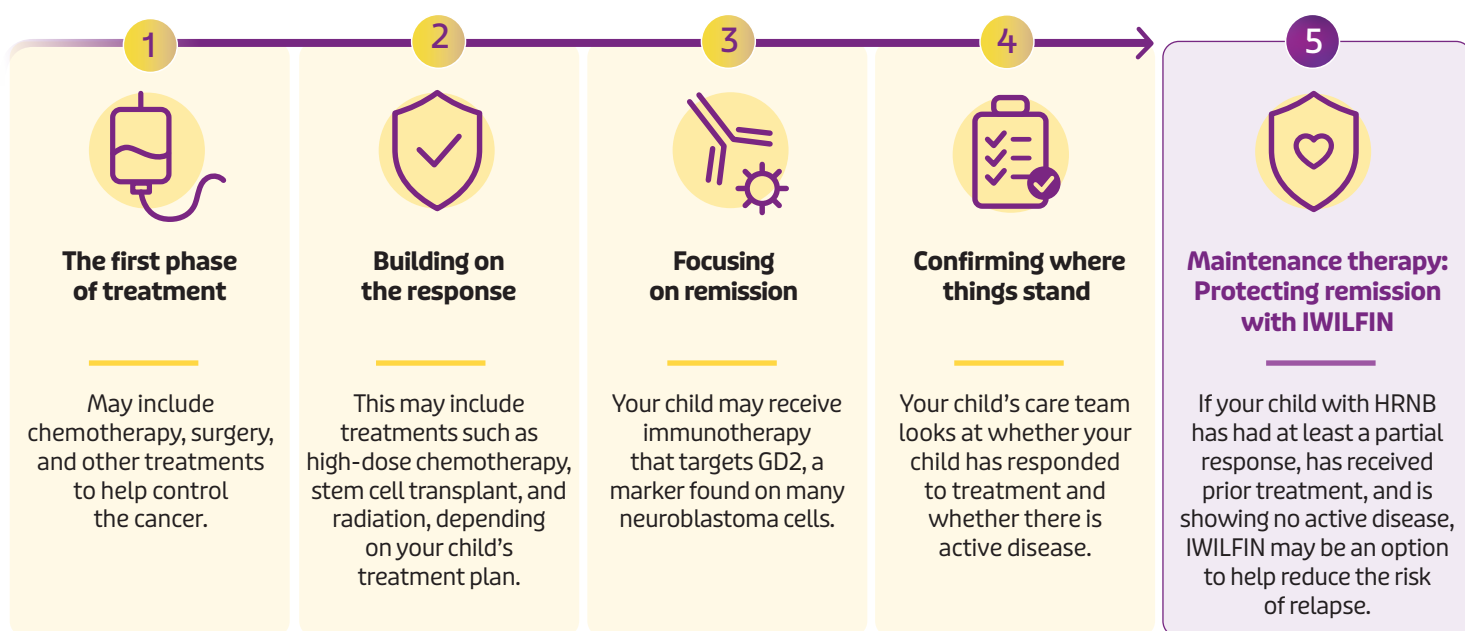
What is IWILFIN?

IWILFIN, also known as eflornithine or DFMO, is a prescription medicine used to reduce the risk of relapse in children and adults with HRNB after standard upfront therapy is complete and there is no presence of active disease.

When is it used?

IWILFIN may be considered after completing standard upfront phases of treatment, when your child's care team is focused on reducing the risk of relapse.

Where IWILFIN may fit into your child's treatment journey



IMPORTANT SAFETY INFORMATION (cont)

IWILFIN can cause liver problems. Tell your healthcare provider right away if you develop symptoms of liver problems, including your skin or white of your eyes turning yellow; dark urine; light-colored stools; nausea or vomiting; easy bruising or bleeding; loss of appetite; or pain, aching, or tenderness on the right side of your abdomen.

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Understanding more about IWILFIN

How does IWILFIN work?

IWILFIN blocks an enzyme called *ornithine decarboxylase* (*OR-ni-theen dee-car-BOX-ih-lase*), or ODC. ODC helps make *polyamines* (*PAH-lee-uh-meenz*), which are involved in cell growth. By blocking ODC, IWILFIN helps reduce polyamine production and is designed to help lower the risk of HRNB coming back after a child has responded to earlier treatment.

How is it taken?

IWILFIN is taken by mouth twice daily, with or without food. IWILFIN tablets may be swallowed whole, chewed, or crushed and mixed with food or liquid.



What could an average day look like?



...> Morning

Your child takes IWILFIN at home as part of the morning routine before school, appointments, or the day ahead.



...> Midday

The focus can shift back to everyday moments, whether it's during school, rest, play, family time, or whatever the day allows.



...> Evening

The second dose can become part of the evening routine, such as dinner, winding down, or getting ready for bed.

IMPORTANT SAFETY INFORMATION (cont)

Hearing loss is common during treatment with IWILFIN and can be serious. Some people have needed to use hearing aids. Tell your healthcare provider right away if you get ringing in your ears or any new or worsening hearing loss.

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What to watch for while taking IWILFIN

How long is treatment?

IWILFIN is taken for a maximum of 2 years. The duration may be shorter if the disease comes back or if side effects become too difficult to manage.

What side effects can occur? How are they monitored?

IWILFIN can cause side effects, including hearing loss, ear infection, fever, pneumonia, and diarrhea. Your child's care team will monitor side effects before and during treatment so they can identify changes early and decide how best to manage them.

How often will your child be monitored?

Before starting IWILFIN, your child should have blood tests, liver function tests, and a baseline hearing test. During treatment, liver tests are done monthly for the first 6 months, then every 3 months or as indicated. Hearing should also be checked before and during treatment.

How can side effects be managed?

If side effects happen, your child's doctor may pause treatment, lower the dose, or stop IWILFIN based on how severe they are. Hearing loss associated with IWILFIN is sometimes reversible with short-term dose interruption and/or reduction.

What can caregivers watch for day to day?

You know your child best. Watch for shifts in energy, appetite, mood, hearing, balance, bruising or bleeding, fever, stomach discomfort, or anything that feels unusual for your child, and contact the care team with any concerns.

IMPORTANT SAFETY INFORMATION (cont)

What are the possible side effects of IWILFIN?

The most common side effects of IWILFIN in Study 3b included ear infection; diarrhea; cough; sinus infection; pneumonia; upper respiratory tract infection; pink eye; vomiting; stuffy, runny, itchy nose or sneezing; fever; skin infection; and urinary tract infection.

These are not all the possible side effects of IWILFIN. Contact your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

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Questions to ask your child's doctor

Keep the conversation going with your child's care team

These are some thought-starters to help you focus on the topics that matter most for your child and your family. A journal may help you organize thoughts and jot down questions and answers.

Thoughts on maintenance therapy

- Is maintenance therapy something you would recommend now?
- What are the goals of maintenance therapy for my child?
- How will the team weigh potential benefits of IWILFIN, monitoring needs, and side effects?

Understanding IWILFIN

- How long may treatment last and what can we expect?
- What are some of the side effects of taking IWILFIN?

Preparing for daily life with IWILFIN

- How may treatment affect school, sleep, meals, travel, and routines?
- What changes in my child's condition should prompt a call (for example, hearing, appetite, bowel habits, sleep, energy, or mood)?

Your family is not alone in the next chapter of HRNB

Your care team, your support system, and other families who have walked this path are all part of your child's journey forward.

Please visit [IWILFIN.com](https://www.iwilfin.com) for more information about IWILFIN and other helpful resources for caregivers, parents, and families.

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