

# OUR ADVENTURE WITH HEMLIBRA<sup>®</sup>

(emicizumab)

# KO TĀTOU HAERENGA ME HEMLIBRA<sup>®</sup>

(emicizumab)

A guide for carers of children prescribed HEMLIBRA for their  
haemophilia A with or without inhibitors to factor VIII



# ABOUT THIS BOOKLET

Your child has been prescribed HEMLIBRA (emicizumab) to help manage their haemophilia A.<sup>1,2</sup>

This booklet is designed to help you, as a carer, understand haemophilia A and get the most for your child from HEMLIBRA treatment. It may not answer all of the questions you have about HEMLIBRA. Please refer to the HEMLIBRA Consumer Medicine Information available at [www.medsafe.govt.nz](http://www.medsafe.govt.nz), or talk to your child's haemophilia doctor or haemophilia nurse if there is anything else you would like to find out.

**WARNING: HEMLIBRA increases the potential for your child's blood to clot. Stop prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your doctor's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause serious side effects when used with FEIBA-NF® (see the 'Serious side effects' section inside this booklet for more information).**

# OUR HEALTHCARE TEAM

Use this space to note down the contact details of your child's healthcare team.

## **Haemophilia doctor:**

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

After-hours phone: \_\_\_\_\_

## **Haemophilia nurse/Haemophilia treatment centre:**

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

After-hours phone: \_\_\_\_\_

Email: \_\_\_\_\_

## **General practitioner (GP):**

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

After-hours phone: \_\_\_\_\_

## **Pharmacy:**

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

After-hours phone: \_\_\_\_\_

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# 01

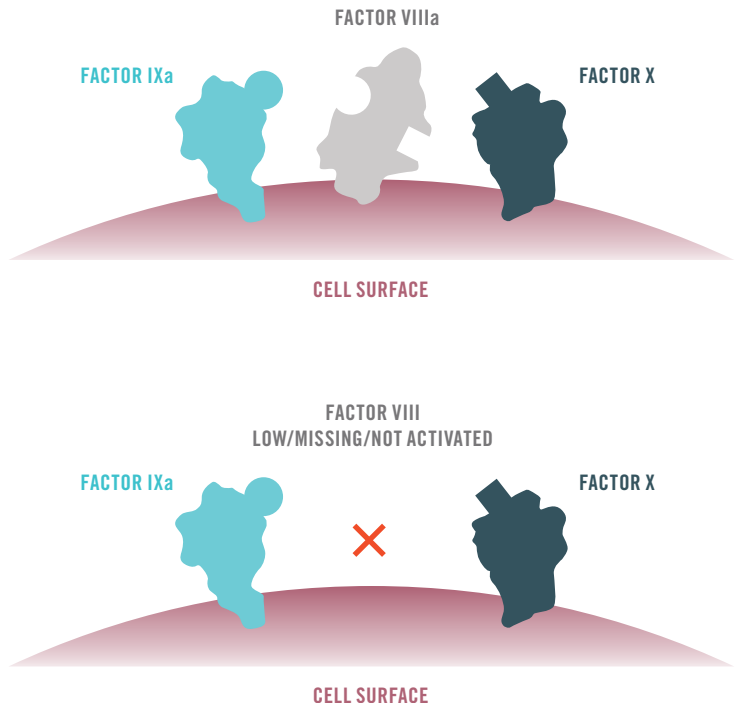
## WHAT IS HAEMOPHILIA A?

Haemophilia A is a bleeding disorder that means your child's blood cannot clot properly. Blood contains many clotting factors which interact with each other in a sequence called the clotting cascade to make a clot form.<sup>1,3</sup>

**People with haemophilia A do not have enough of one of these clotting factors – factor eight (VIII).<sup>4</sup>**

## HOW FACTOR VIII WORKS IN THE CLOTTING CASCADE

The role of factor VIII is to bring together two other molecules in the clotting cascade. When factor VIII is activated (FVIIIa), it helps connect activated factor IX (FIXa) with factor X. If levels of factor VIII are low, if it is missing, or if factor VIII is not activated, the rest of the clotting cascade cannot continue, and blood will not form clots properly.<sup>5,6</sup>



# HAEMOPHILIA A AND FACTOR VIII

Haemophilia A is usually managed with factor VIII replacement therapy to help blood to clot in response to injury or spontaneous bleeds. When taken regularly, it can also prevent bleeds from occurring.<sup>4</sup>

Factor VIII replacement therapy is not fully identical to factor VIII which is naturally produced by the body. As such, your child's immune system can treat it as 'foreign' and develop antibodies against factor VIII. Approximately 30% of people with haemophilia A will develop inhibitors in their lifetime.<sup>4,7</sup>

**If your child's immune system develops these antibodies to factor VIII, they are known as 'inhibitors'.<sup>4</sup>**

**Inhibitors reduce the effect of factor VIII.<sup>7</sup>** In some people, inhibitors can stop factor VIII from working.<sup>1</sup>

**UP TO 1 IN 3 PEOPLE WITH SEVERE  
HAEMOPHILIA A DEVELOP INHIBITORS TO  
FACTOR VIII AT SOME POINT IN THEIR LIVES.<sup>4</sup>**

In many people with haemophilia A who have inhibitors to factor VIII, bypassing agents are used to help manage bleeds. These include activated recombinant factor seven (rFVIIa i.e. NovoSeven) or activated prothrombin complex concentrate (FEIBA-NF).<sup>1</sup>



# 02

## GETTING TO KNOW HEMLIBRA

HEMLIBRA is not a cure for haemophilia A, but when used routinely as prophylaxis as prescribed, HEMLIBRA may help to reduce and prevent bleeding episodes in people with this condition.<sup>1,2</sup>

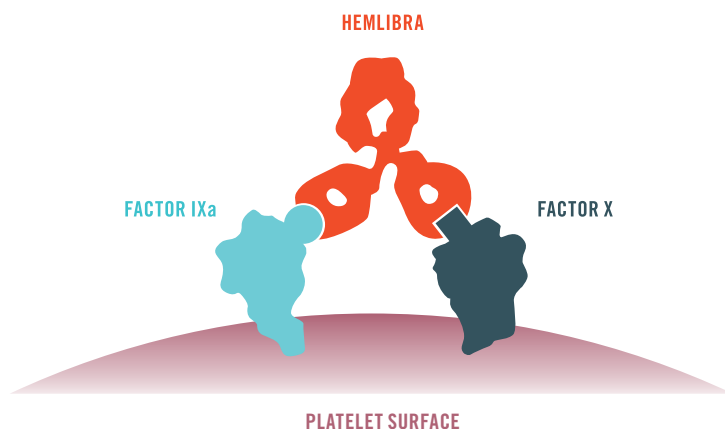
HEMLIBRA contains the active substance emicizumab. This belongs to a group of medicines called monoclonal antibodies. Monoclonal antibodies are a type of protein that recognise and bind to a target in the body.<sup>1</sup>

# UNDERSTANDING HOW HEMLIBRA WORKS FOR YOUR CHILD'S HAEMOPHILIA A

- HEMLIBRA is a therapeutic antibody that is a treatment for people with haemophilia A with or without inhibitors to factor VIII.<sup>2,8</sup>
- HEMLIBRA binds to factor IXa and factor X and mimics the effect of factor VIIIa in the body.<sup>2,8</sup>
- HEMLIBRA links factor IXa and factor X, and the clotting pathway can continue.<sup>2,8</sup>
- HEMLIBRA is not the same as factor VIII replacement therapy, so it is thought that factor VIII inhibitors will not affect HEMLIBRA.<sup>9</sup>
- HEMLIBRA is not an on-demand treatment. HEMLIBRA is given by prophylaxis (once a week, once every two weeks or once every four weeks) as decided by your healthcare practitioner.

## REMEMBER THE CLOTTING CASCADE?

HEMLIBRA takes the place of the factor VIIIa in the cascade so that the cascade can continue and blood clots can form.<sup>8</sup>



# DOSING WITH HEMLIBRA

HEMLIBRA is given as a subcutaneous injection (injection into the fat layer under the skin), and your child's dose is based on their body weight.<sup>1</sup>

Any treatment with bypassing agents (e.g. FEIBA-NF and rFVIIa NovoSeven) must be discontinued at least 24 hours before starting HEMLIBRA and not taken again unless directed by your healthcare practitioner.<sup>2</sup>

Treatment with factor VIII prophylaxis may be continued for the first 7 days of treatment with HEMLIBRA.<sup>2</sup>

## LOADING DOSE<sup>1</sup>

For the first 4 weeks your child will be given a 'loading dose' of HEMLIBRA, as prescribed by their haemophilia doctor.



## MAINTENANCE DOSE<sup>1</sup>

From week 5 onwards, your child will carry on with a regular maintenance dose, as prescribed by their haemophilia doctor.



OR



OR



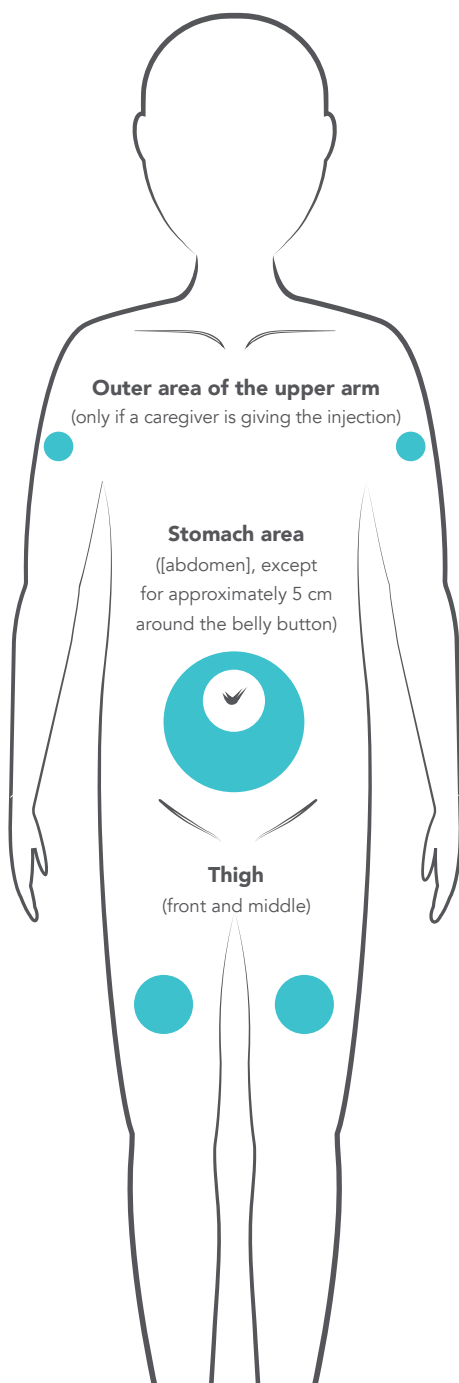
\*of body weight

# INJECTING HEMLIBRA

There are a few things to remember about giving HEMLIBRA as a subcutaneous injection:<sup>1,2,10</sup>

- Subcutaneous means 'under the skin' so it is very important you don't inject HEMLIBRA into a vein.
- Do not inject your child or someone else unless you have been shown how to by their haemophilia doctor or nurse.
- Only use injection equipment provided by your haemophilia treatment centre.
- Do not inject into areas that could be irritated by a belt or waistband, do not inject into moles, scars, bruises, or areas where the skin is tender, red, hard or the skin is broken.
- Do not combine medicine from the 30 mg/mL (Blue) vial with any other vials (turquoise, purple, or brown) of HEMLIBRA in the same syringe as this would result in an inaccurate dose preparation and administration. If other vials are needed as well as the 30 mg/mL (Blue) vial, use a different syringe for the 30 mg/mL (Blue) vial.<sup>2</sup>

HEMLIBRA INJECTIONS SHOULD ONLY BE GIVEN TO CERTAIN PARTS OF THE BODY<sup>1,10</sup>



# GETTING STARTED ON HEMLIBRA

HEMLIBRA is only prescribed as routine prophylaxis. It is essential to give HEMLIBRA exactly as prescribed by your child's haemophilia doctor to have a better chance of preventing bleeds and to ensure a safe outcome.<sup>1,2</sup>

## DOs<sup>1,10</sup>



You should give HEMLIBRA as prescribed by your child's haemophilia doctor for maintenance – either once a week, once every 2 weeks or once every 4 weeks (after the initial loading dose).



Give HEMLIBRA as prescribed, even if your child hasn't had a bleed in a while.



If your child's prescribed dose is more than 2 mL, they will need to have more than one subcutaneous injection of HEMLIBRA/dose. You should not inject more than 2 mL volume into one subcutaneous site. These injections must be given on the same day, with each injection at least 2.5 cm away from the area used for the previous one.

## DON'Ts<sup>1</sup>



**Don't** take extra HEMLIBRA, even if your child does have a bleed. They **MUST** only take HEMLIBRA at the dose prescribed.



**Don't** combine medicine from vials that contain different concentrations of HEMLIBRA.



**Don't** adjust the dose of HEMLIBRA, for example, if your child is planning to take part in sports or physical exercise.

**Don't** use more than the dose required, even if there is liquid left in the vial.

## HOW TO INJECT HEMLIBRA

Instructions on how to inject HEMLIBRA can be found in the 'How to Inject' patient video available online at [www.hemlibra.co.nz](http://www.hemlibra.co.nz).

Alternatively, you can follow the 'Instructions for Use' booklet found inside your child's HEMLIBRA pack. Your child's haemophilia treatment centre will also provide you with the appropriate teaching and guidance on how to inject and where to inject.

# CONTINUING ON HEMLIBRA

Once your child has taken HEMLIBRA for 4 weeks at their starting dose, they will continue to receive HEMLIBRA at their maintenance dose as prescribed by their haemophilia doctor.<sup>1</sup>



If your child is going to have blood tests, advise the healthcare practitioners involved in your child's care that they are taking HEMLIBRA, as it can interfere with some laboratory tests, leading to inaccurate results.<sup>1</sup>



Blood test results should be discussed with your healthcare practitioner to help understand the implications.

## TIPS FOR REMEMBERING YOUR CHILD'S INJECTIONS



Set reminders on your phone or computer.



Schedule their injection day around an activity that they do once a week, once every 2 weeks or once every 4 weeks.

# 03

## IMPORTANT SAFETY INFORMATION

This medicine helps most people with haemophilia A with or without inhibitors, but it may have unwanted side effects in a few people. All medicines can have side effects.

Sometimes they are serious, most of the time they are not. Your child may need medical attention if they get some of these side effects. Do not be alarmed by the following lists of side effects. Your child may not experience any of them.

**Remember to tell your child's haemophilia doctor or haemophilia nurse and contact your haemophilia treatment centre as soon as possible if your child does not feel well while they are taking HEMLIBRA.**

**If your child mentions or if you notice any of the following side effects and they worry you, tell your child's haemophilia doctor or nurse:<sup>1</sup>**

- Redness, itching, pain in the area the injection was given
- Headache
- Fever
- Joint pain
- Muscle aches
- Diarrhoea
- Hives (Urticaria)
- Rash
- Swollen lips, mouth, face, tongue and/or throat and/or difficulty in swallowing and breathing (angioedema)

Other side effects not listed above or on the next page may also occur in some people.

# SERIOUS SIDE EFFECTS



IF YOU NEED TO TAKE YOUR CHILD TO HOSPITAL FOR A BLEED, make sure you tell the healthcare team that they are taking HEMLIBRA. Remember to take their Alert card with you.



## USING BYPASSING AGENTS WITH HEMLIBRA: **PATIENTS WITH INHIBITORS**

In clinical trials, serious side effects were seen in people taking HEMLIBRA and using FEIBA-NF. Use of FEIBA-NF should be avoided unless no other treatment options/alternatives are available.<sup>1,2</sup>

**If FEIBA-NF is needed while your child is taking HEMLIBRA, carefully follow the instructions of their haemophilia doctor. FEIBA-NF is only to be used as prescribed by their haemophilia doctor.**

If your child is given bypassing agents, be aware of the possible symptoms of thrombotic microangiopathy and blood clots which have occurred after use of FEIBA-NF in people receiving HEMLIBRA:<sup>1</sup>

- Thrombotic microangiopathy (TMA): A serious and potentially life-threatening condition where the lining of the blood vessels is damaged resulting in clots in small blood vessels. In some cases, this can cause damage to the kidneys and/or other organs.
- Blood clots: Blood clots may form. In rare cases, a blood clot can block blood vessels and may be life-threatening.



**Stop giving your child HEMLIBRA and FEIBA-NF and talk to a haemophilia doctor immediately if you or your child notices/mentions any of the following side effects.<sup>1</sup>**

**If any of the following happen, tell your child's haemophilia doctor and/or haemophilia care team immediately or go to Accident and Emergency at your nearest hospital:<sup>1</sup>**

- Confusion, weakness, swelling of arms and legs, yellowing of skin and eyes, abdominal or back pain, feeling sick (nausea), being sick (vomiting) or urinating less – these may be signs of TMA.
- Swelling, warmth, pain or redness – these may be signs of a blood clot in a vein near the surface of the skin.
- Headache, numbness in their face, eye pain or swelling or problems with your vision – these may be signs of a blood clot in a vein behind their eye.
- Blackening of the skin – this may be a sign of severe damage to the skin tissue.
- Loss of consciousness

# MANAGING A BLEED WHILE TAKING HEMLIBRA

Speak to your child's haemophilia treatment centre to ensure you have a plan in place for managing a bleed while your child is on HEMLIBRA.



**If your child does have a bleed, do NOT give extra HEMLIBRA.<sup>1</sup>**

Before your child starts taking HEMLIBRA, make sure you are ready for an emergency situation if it occurs.

If your child has inhibitors, it is very important you talk to your child's haemophilia doctor or haemophilia nurse about when and how to use bypassing agents if they have a bleed while taking HEMLIBRA. This may be different from how you used them in the past.

**Refer to your emergency plan at the back of this booklet.**



**HEMLIBRA increases the ability of your child's blood to clot. Therefore, the dose of bypassing agent required may be lower than the dose you used before starting HEMLIBRA.<sup>1,2</sup>**

# 04 SIDE EFFECTS DIARY

Side effects/symptoms should be reported as soon as possible to your child's haemophilia doctor or haemophilia nurse. Side effects or symptoms we want to discuss with our healthcare team:

| WHAT<br>What was the problem?                                                                                                                                                                                                    | WHEN<br>When did it occur? | HOW LONG FOR | NOTES |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------|--------------|-------|
| <b>INTENSITY</b> <div> <div>1</div> <div>2</div> <div>3</div> <div>4</div> <div>5</div> <div>6</div> <div>7</div> <div>8</div> <div>9</div> <div>10</div> </div> <div> <div>Very faint</div> <div>Extremely intense</div> </div> |                            |              |       |
| <b>HOW WE MANAGED IT:</b>                                                                                                                                                                                                        |                            |              |       |
| <b>DID THAT WORK?</b> <input type="checkbox"/> YES <input type="checkbox"/> NO                                                                                                                                                   |                            |              |       |

| WHAT<br>What was the problem?                                                                                                                                                                                                    | WHEN<br>When did it occur? | HOW LONG FOR | NOTES |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------|--------------|-------|
| <b>INTENSITY</b> <div> <div>1</div> <div>2</div> <div>3</div> <div>4</div> <div>5</div> <div>6</div> <div>7</div> <div>8</div> <div>9</div> <div>10</div> </div> <div> <div>Very faint</div> <div>Extremely intense</div> </div> |                            |              |       |
| <b>HOW WE MANAGED IT:</b>                                                                                                                                                                                                        |                            |              |       |
| <b>DID THAT WORK?</b> <input type="checkbox"/> YES <input type="checkbox"/> NO                                                                                                                                                   |                            |              |       |

# SIDE EFFECTS DIARY

Side effects/symptoms should be reported as soon as possible to your child's haemophilia doctor or haemophilia nurse. Side effects or symptoms we want to discuss with our healthcare team:

| WHAT<br>What was the problem?                                                                                                                                                                                | WHEN<br>When did it occur? | HOW LONG FOR | NOTES |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------|--------------|-------|
| <div>INTENSITY</div> <div><div>1</div><div>2</div><div>3</div><div>4</div><div>5</div><div>6</div><div>7</div><div>8</div><div>9</div><div>10</div></div> <div>Very faint</div> <div>Extremely intense</div> |                            |              |       |
| <div>HOW WE MANAGED IT:</div>                                                                                                                                                                                |                            |              |       |
|                                                                                                                                                                                                              |                            |              |       |
| <div>DID THAT WORK?</div> <div><input type="checkbox"/> YES</div> <div><input type="checkbox"/> NO</div>                                                                                                     |                            |              |       |

| WHAT<br>What was the problem?                                                                                                                                                                                | WHEN<br>When did it occur? | HOW LONG FOR | NOTES |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------|--------------|-------|
| <div>INTENSITY</div> <div><div>1</div><div>2</div><div>3</div><div>4</div><div>5</div><div>6</div><div>7</div><div>8</div><div>9</div><div>10</div></div> <div>Very faint</div> <div>Extremely intense</div> |                            |              |       |
| <div>HOW WE MANAGED IT:</div>                                                                                                                                                                                |                            |              |       |
|                                                                                                                                                                                                              |                            |              |       |
| <div>DID THAT WORK?</div> <div><input type="checkbox"/> YES</div> <div><input type="checkbox"/> NO</div>                                                                                                     |                            |              |       |

# 05 FREQUENTLY ASKED QUESTIONS

## INJECTING HEMLIBRA

### Who should I tell if I'm having trouble with subcutaneous injections?

Once you have been trained, you should be able to inject your child with HEMLIBRA at home. You can also watch the 'How to Inject' video or read the 'Instructions For Use' to refresh your memory. Tell your child's haemophilia doctor or haemophilia nurse if you are not confident with performing subcutaneous injections or if problems arise.<sup>1</sup>

### What if I break a vial or it is not sealed well?

Inspect each vial before use. Do not use if they appear damaged, the cap covering the stopper is missing or if they have been dropped. Contact your child's haemophilia treatment centre and provide the batch details of the affected vial. Keep the vial in the correct storage conditions as you may need to return it to your child's haemophilia doctor or haemophilia nurse.<sup>10</sup>

### What if the liquid looks strange?

Before using HEMLIBRA, check the solution for particles or discolouration. The solution should be colourless to slightly yellow. Do not use if it is cloudy, hazy, discoloured or contains visible particles. Contact your child's haemophilia treatment centre and provide the batch details of the affected vial. Keep the vial in the correct storage conditions as you may need to return it to your child's haemophilia doctor.<sup>1</sup>

### Do I have to wait to administer the injection after drawing up the solution in to the syringe?

No. Once the syringe has been filled with HEMLIBRA, the injection must be given immediately. Do not refrigerate the solution in the syringe.<sup>1</sup>

### How long can HEMLIBRA be in the syringe before I cannot use it?

Use HEMLIBRA straight away after transferring it from the vial to the syringe. Do not refrigerate the solution in the syringe. If the syringe is not used within 5 minutes, it should be disposed in the sharps container and a new dose should be prepared.<sup>1</sup>

### How should I dispose of the sharps, needles and used vials?

Put any used vials, needles, vial/injection needle caps and used syringes in a sharps bin or puncture-proof container.<sup>1</sup> Vials, needle caps and vial caps can be disposed of in the rubbish.

### Can I save a part-used HEMLIBRA vial for my child's next injection?

No. Only use the vial once. After you inject their dose, throw away any unused HEMLIBRA left in the vial. Do not save unused medicine in the vial for later use.<sup>10</sup> HEMLIBRA does not contain any antimicrobial preservative,<sup>2</sup> therefore there is a risk of contamination once the vial has been opened.

### My child keeps getting soreness after injections, what should I do?

Injection site reactions are a very common side effect that some people get with HEMLIBRA. Make sure that you rotate the injection site with each injection and don't inject too close to the belly button. If your child has signs of redness, itching or pain at the injection site, tell their haemophilia doctor or haemophilia nurse.<sup>1,2</sup>

## TAKING HEMLIBRA

### **Should I tell people that my child has started taking HEMLIBRA/changed medications?**

Your child's regular haemophilia care team and their GP will be updated when they change medications. It is up to you whether you want to tell you and your child's friends and family about how you are treating their haemophilia, but it may help to talk to people that are close to you so that they can support you both.

### **Are there any other medications that my child should not take with HEMLIBRA, or need to be careful with?**

Stop giving any treatment with bypassing agents (FEIBA-NF and rFVIIa NovoSeven) the day before starting HEMLIBRA. Because HEMLIBRA helps your child's blood to clot, taking other clotting medicines at the same time can make the blood clot too much. You should only use FEIBA-NF if advised to do so by your child's haemophilia care team.<sup>1</sup> See page 16 of this booklet for additional information about using bypassing agents when your child is taking HEMLIBRA.

### **What happens as my child's weight changes? How will this alter my child's dose of HEMLIBRA?**

The dose of HEMLIBRA is dependent on your child's weight and their haemophilia doctor will tell you how much to inject. If your child's weight changes, please speak to their haemophilia doctor as this may affect how much HEMLIBRA you are required to inject.<sup>1</sup>

### **Should I give more HEMLIBRA if my child is going to play sport?**

No. HEMLIBRA is not an on-demand treatment. You must give it only on the day that your child's haemophilia doctor has told you. Prophylaxis with HEMLIBRA makes sure that the levels in your child's blood are stable for the whole time that they are on treatment. Prophylaxis with HEMLIBRA helps to control your child's condition, and it is important to give them their medication regularly as directed by their haemophilia doctor.<sup>2</sup>

### **What should I do if I forget to give HEMLIBRA?**

If you forget your child's scheduled injection, inject the forgotten dose as soon as possible before the day of the next scheduled dose. Then, continue to inject the medicine as scheduled. Do not inject a double dose to make up for a forgotten dose. If you are not sure what to do, ask your child's haemophilia doctor or haemophilia nurse.<sup>1</sup>

### **How long will my child be on HEMLIBRA for?**

HEMLIBRA is intended for long-term treatment. Usually your child will continue taking HEMLIBRA as long as they and their haemophilia doctor or haemophilia nurse are happy with how their treatment is going.

### **What happens if my child is going to have surgery?**

If your child requires surgery while receiving treatment with HEMLIBRA, we recommend that you discuss their treatment options with their haemophilia doctor.

### **Can my child have a treatment break?**

Do not stop giving HEMLIBRA without talking to your child's haemophilia doctor.<sup>1</sup>

### **How do I explain treatment with HEMLIBRA to my child?**

Roche (the maker of HEMLIBRA) have developed some activity books and posters to help you explain treatment with HEMLIBRA to your child. There are options for both younger (under 7 years) and older (7–12 years) children. Ask your child's haemophilia doctor or haemophilia nurse if you would like a copy of these books. They may be given to you with your child's HEMLIBRA pack.

## STORING HEMLIBRA

### How do I store HEMLIBRA at home?

Store HEMLIBRA in your fridge between 2°C and 8°C in the original box to protect from light. Do not freeze HEMLIBRA and do not shake the vials. Keep out of the sight and reach of children. Do not use after the expiry date stated on the side of the box and the vial label (the date refers to the last day of the month).<sup>1,10</sup> Speak to your child's haemophilia treatment centre if you would like more information on storing medications at home.

### Can I take HEMLIBRA out of the fridge?

Once removed from the fridge, unopened vials can be kept at room temperature (below 30°C) for a total of 7 cumulative days. Discard any vial that has been kept at room temperature for more than 7 days or have been in temperatures above 30°C.<sup>1</sup>

### Where should I keep the injection supplies?

Keep injection equipment safe and stored away in a cool, dry environment. It is a good idea to keep everything together in a box. Make sure that all supplies are kept out of the sight and reach of children.<sup>10</sup>

## LIFESTYLE

### Should I change my child's diet?

You do not need to change your child's diet on account of taking HEMLIBRA, but it is important for anyone with haemophilia to try to be as healthy as they can; eat well and keep hydrated. The World Federation of Hemophilia have lots of resources on trying to maintain a healthy diet.<sup>11</sup>

### What exercise is OK to do?

Your child does not need to change their exercise routine on account of taking HEMLIBRA, but it is really beneficial to stay active when they can. Encourage your child to include muscle strengthening, coordination, balance, physical functioning and general fitness into their lifestyle. Always talk to your child's haemophilia doctor or haemophilia nurse or physio before starting new activities.<sup>4</sup>



## TRAVELLING WITH HEMLIBRA

### What do we need to know when travelling with HEMLIBRA?

If you and your child need to travel with HEMLIBRA, remember that it can remain out of the fridge (below 30°C) for up to 7 cumulative days if necessary. However, it is recommended the HEMLIBRA vials are stored in a fridge whenever possible, even when travelling. Remember to also take your injection supplies and sharps bin with you to safely dispose of any used syringes, needles and vials.<sup>1</sup> Talk to your haemophilia treatment centre about how best to package and store your HEMLIBRA when travelling.

### Can we take HEMLIBRA on a plane?

If you and your child are travelling by plane, talk to your child's haemophilia doctor or haemophilia nurse about any documentation you may need to carry with you and give to the airline. If you and your child are on a long flight, it is recommended you ask your airline if they are able to store the medication in a fridge. You should carry your child's HEMLIBRA vials in your hand luggage so that they do not get shaken, lost or damaged.<sup>12</sup>



**Remember,** you may also need to carry supplies to manage a bleed, if your child has one.

Talk to their haemophilia doctor or haemophilia nurse if you need advice.

# SUPPORT AND RESOURCES

## HAEMOPHILIA FOUNDATION NEW ZEALAND

The national body representing people with haemophilia, von Willebrand disease and other bleeding disorders and their families through education, representation, advocacy and promotion of research.

[www.haemophilia.org.nz](http://www.haemophilia.org.nz)

## HEMLIBRA PATIENT WEBSITE

Visit [www.hemlibra.co.nz](http://www.hemlibra.co.nz) for more information on dosing and treatment with HEMLIBRA. Here you can also:

- Download patient resources
- Watch 'How to Inject' instruction video
- Learn more about haemophilia A
- Connect with other resources to help you manage your condition

Scan the  
QR code to go to  
[www.hemlibra.co.nz](http://www.hemlibra.co.nz)



If you would like this information in a digital format please ask your Haemophilia Treatment Centre about MedWallet, your digital medication passport.

**Med**WALLET

# GLOSSARY

**Antibody:** A protein produced in the blood that helps to fight infection by removing things seen as 'foreign'.<sup>12</sup>

**Bypassing agent:** A type of treatment given to people with inhibitors to factor VIII. Bypassing agents help the blood form a normal clot by going around (or bypassing) the factor VIII that has been inhibited.<sup>12</sup>

**Clotting:** The process by which blood changes from a liquid to a gel, forming a blood clot.<sup>11</sup>

**Clotting cascade or pathway:** The sequence in which clotting factors interact with each other in order to form a clot.<sup>11</sup>

**Factor VIII:** One type of clotting factor that is missing or exists at very low levels in people with haemophilia A.<sup>11</sup>

**Factor VIII replacement therapy:** A treatment that replaces the low or missing factor VIII in people with haemophilia A to help blood clot in response to an injury or a spontaneous bleed.<sup>12</sup>

**FEIBA-NF:** Factor VIII inhibitor bypassing fraction (also known as activated prothrombin complex concentrate or aPCC) is a bypassing agent for people with haemophilia A with inhibitors to factor VIII. It contains a mixture of different clotting factors.<sup>1,11</sup>

**Haemophilia A:** A bleeding disorder where factor VIII is either partly or completely missing. Haemophilia A can be classed as mild, moderate or severe depending on the amount of factor VIII available in the blood.<sup>1,11</sup>

**Immune system:** The cells and tissues in the body that allow protection from infections and foreign substances.<sup>13</sup>

**Inhibitor:** A type of antibody made by the body to fight things it sees as 'foreign'. These antibodies inhibit a blood clotting factor.<sup>11</sup>

**On-demand:** The use of a treatment as needed. In haemophilia A with inhibitors to factor VIII, bypassing agents are given immediately after a bleed is recognised to help clotting and stop bleeding.<sup>4</sup>

**Prophylaxis:** The regular use of a treatment to prevent illness. In haemophilia A, prophylaxis is intended to prevent bleeding from occurring or reduce the number of bleeds.<sup>4</sup>

**rFVIIa (NovoSeven):** Recombinant factor VIIa is a bypassing agent that is synthetically made and has to be administered every 2 to 3 hours.<sup>11</sup>

**Subcutaneous:** Under the skin.<sup>11</sup>

**Therapeutic antibody:** Therapeutic antibodies, often referred to as monoclonal antibodies, are designed to bind to specific molecules to help treat a disease.<sup>1</sup>

# EMERGENCY PLAN

## IF YOUR CHILD HAS A BLEED

Please keep this booklet in a safe place so you can refer back to the emergency plan.

There is space to write down your emergency contacts and to write down a reminder of your child's personalised plan for what to do in an emergency and whether to give them any medications. **Important note:** this does not replace any emergency care plan letter given to you by your child's haemophilia doctor/haemophilia nurse or their emergency ABDR card.

### Emergency contacts:

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Relationship: \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Relationship: \_\_\_\_\_

Name of haemophilia doctor: \_\_\_\_\_

Name of haemophilia nurse: \_\_\_\_\_

## IN CASE OF EMERGENCY WE NEED TO:

**References used in this booklet:** **1.** HEMLIBRA® Consumer Medicine Information. Available at: [www.medsafe.govt.nz/Consumers/CMI/h/HEMLIBRA.pdf](http://www.medsafe.govt.nz/Consumers/CMI/h/HEMLIBRA.pdf) **2.** HEMLIBRA® data sheet. Available at: <https://medsafe.govt.nz/profs/Datasheet/h/HEMLIBRAinj.pdf> **3.** Achnock HE, et al. *Circulation* 2010; 122:2068–77. **4.** Australian Haemophilia Centre Director's Organisation, Guidelines for the management of haemophilia in Australia. 2016. **5.** Escobar M and Sallah S. *J Thromb Haemost* 2013; 11(8):1449–53. **6.** Bowen DJ. *Mol Pathol* 2002; 55(2):127–44. **7.** Reipert BM, et al. *Br J Haematol* 2007; 136(1):12–25. **8.** Kitazawa T, et al. *Thromb Haemost* 2017; 117(7):1348–57. **9.** Oldenburg J, et al. *N Engl J Med* 2017; 377:809–18. **10.** HEMLIBRA® Instructions for Use, Data on file REF NZ0782. **11.** World Federation of Hemophilia (website). Available at: <https://www.wfh.org> (Accessed October 2018). **12.** Haemophilia Foundation Australia, Haemophilia: A guide for parents of a newly diagnosed child. October 2017. Available at: [www.haemophilia.org.au](http://www.haemophilia.org.au) (Accessed October 2018). **13.** BetterHealth Channel, Immune system explained, Updated December 2017. Available at: [www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/immune-system](http://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/immune-system) (Accessed October 2018).

Hemlibra® (emicizumab), 30 mg in 1 mL, 60 mg in 0.4 mL, 105 mg in 0.7 mL and 150 mg in 1 mL ready-to-use solution for subcutaneous (SC) injection, is a **Prescription Medicine** used to prevent bleeding or reduce the frequency of bleeding in people with haemophilia A with or without factor VIII inhibitors

**Ask your doctor if Hemlibra® is right for you.**

**HEMLIBRA is funded for patients with haemophilia A with and without inhibitors, who meet predefined criteria.**

Use only as directed. If symptoms continue or you have side effects, see your healthcare professional. For more information about Hemlibra®:

- talk to your health professional; or
- visit [medsafe.govt.nz](https://www.medsafe.govt.nz) for Hemlibra® Consumer Medicine Information; or
- visit [roche.co.nz](https://www.roche.co.nz) or call Roche on 0800 276 243.

**Hemlibra® has risks and benefits.**

**Possible common side effects include:** injection site reactions, headache, joint pains, high temperature or fever, diarrhoea, muscle aches, hives (urticaria), rash; swollen lips, mouth, face, tongue and/or throat and/or difficulty in swallowing and breathing (angioedema)

**Do not use Hemlibra® if:** you have had an allergic reaction to HEMLIBRA or any of the ingredients, or to any medicines that are made using Chinese hamster ovary cells.

**Tell your doctor if:** you have allergies to any other medicines, foods, preservatives or dyes; you are taking bypassing agents or any other blood product; you are pregnant or plan to become pregnant or are breastfeeding; you are using any other medicines, including any that you get without a prescription from your pharmacy, supermarket or health food shop.

**Tell your doctor immediately or go to your nearest Accident and Emergency Centre if you notice any of the following:** confusion, weakness, swelling of arms and legs, yellowing of skin and eyes, abdominal or back pain, feeling sick (nausea), being sick (vomiting) or urinating less – may be signs of thrombotic microangiopathy (TMA); swelling, warmth, pain or redness – may be signs of a blood clot in a vein near the surface of the skin; headache, numbness in your face, eye pain or swelling or vision impairment – may be signs of a blood clot in a vein behind your eye; blackening of the skin – may be a sign of severe damage to the skin tissue; loss of consciousness; if it appears that HEMLIBRA is no longer working for you – an uncommon occurrence of antibody production against HEMLIBRA.

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The information contained in this brochure does not provide medical advice or take the place of speaking with your healthcare practitioner about your medical condition or treatment. For any questions about this booklet or Hemlibra (emicizumab), contact Roche Medical Information on 0800 276 243 or [medinfo.roche.com](https://www.medinfo.roche.com)

Please see the HEMLIBRA Consumer Medicines Information (CMI) on [www.medsafe.govt.nz](https://www.medsafe.govt.nz) for Important Safety Information, including Serious Side Effects



Scan the QR  
code to go to  
Medsafe CMI



**HEMLIBRA®**  
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