

# Biologics for juvenile idiopathic arthritis

- Biologics are a newer type of medication used to treat conditions like juvenile idiopathic arthritis
- They've been created to target specific cells and proteins in your body that are causing inflammation and damage
- Like all medications, they can have side effects
- It's important you understand as much about your condition and treatments (including medications) as possible so that you know what's happening and can be in control

Your doctor has prescribed a new medication to treat your juvenile idiopathic arthritis (JIA). It's called a biological disease modifying anti-rheumatic drugs (bDMARD), also known as a biologic. Confused? This information sheet will help you understand more about these medications and how they can help you.

## The immune system

To understand what biologics are and how they work, you need to understand a bit about your immune system.

First - it's complicated! There are many different types of immune cells and proteins doing many different jobs to protect you against disease and infection. When your body detects the presence of germs, like a bacteria or virus, your immune system springs into action and defends your body against these invaders. Once they deal with the germs, they switch off. And everything goes back to normal.

However sometimes with conditions like JIA, the immune system goes a little haywire and attacks the healthy tissues and cells it's supposed to protect. Your immune system launches an attack, but doesn't stop. This causes inflammation, pain and joint damage.

# What are biologics?

Biologics are a new type of medication. They've been genetically-engineered from human genes, so that they work in a very specific, targeted way.

They work differently to the other medications that you may be taking, or have taken in the past. Some medications, like methotrexate, target the entire immune system, while biologics work by targeting specific cells that are causing the inflammation and damage.

# How do they work?

Biologics work by targeting the proteins and cells that cause inflammation and pain, and by slowing down your overactive immune system. They reduce the symptoms you experience and help prevent future problems.

## Why do I have to take a biologic?

Your doctor has prescribed a biologic for you because other medications haven't worked, or haven't worked well enough.

You might be prescribed a biologic to take on its own, or you might take it along with other medications like methotrexate. It all depends on your condition, and your own unique set of symptoms.

## How do I take them?

Biologics are given by an injection under the skin or an infusion into the vein.

Injections can be done at home. You and your family will be taught how to do this. Infusions are only done in a medical setting, like a hospital. Infusions usually take a couple of hours, so be prepared and take your phone, tablet, book or something that'll keep you entertained during this time.

Depending on the biologic you've been prescribed, you may have to take it daily, weekly, fortnightly or monthly. Different medications have different schedules. Make sure you know and understand the schedule for your specific biologic.

Injections and infusions sound scary, but they're not. Once you've had your first few treatments, you'll know what to expect, and it just becomes something you do.



The benefits are that hopefully the biologic will improve your condition so that you can do all the things you want to do - sports, school, hang out with friends and family - with less pain, fatigue and inflammation.

## Are there any side effects?

Medications can have side effects, but most people who take biologics handle them really well. Some people may never experience any side effects, while others have mild side effects. It's important that you know what the side effects are. You should talk with your doctor and parents about them so you know what you need to be on the lookout for. Let them know immediately if you experience anything out of the ordinary or feel different in any way when taking your biologic.

The most common side effects that you may experience are mild pain, itching and swelling at the place you had your injection. These reactions are easily dealt with using ice or a medicated cream.

With an infusion, there's a potential for an allergic reaction. That's why you're closely monitored while you receive your infusion, and for some time afterwards. You may feel hot or cold, itchy or short of breath. While this sounds frightening, the effects are usually mild, and most people don't experience them. But you should let someone know straight away if you feel at all strange while having your infusion.

Another side effect of biologics is they make it harder for you to fight infections, like a cold or sinus infection. This is because biologics suppress your immune system. If you develop an infection, or get sick while taking biologics, see your doctor straight away.

# What else do I need to know about biologics? Medical history

Before you start taking a biologic, your paediatric rheumatologist will talk with you and take your medical history. They want to make sure that you're as healthy as possible before starting the biologic. You won't be able to start if you're sick or have an infection. You'll also need to be up-to-date with all of your normal vaccinations.

Your doctor may also do some tests to make sure you haven't been in contact with anyone who has had the disease 'tuberculosis'.

## **Vaccinations**

Having a flu vaccination is important when you have JIA. It's even more important when you're taking a biologic because you're much more susceptible to catching the flu. A flu vaccination will help prevent this.

While taking biologics, you can't have any live vaccinations. Common live vaccinations include measles, mumps and rubella (MMR), chickenpox (varicella), yellow fever and shingles. Live vaccinations contain a weakened form of a virus or bacteria. People with a healthy immune system develop an immunity to the bacteria or virus when they're given these weakened forms of it. However because your immune system has been suppressed, live vaccines need to be avoided.

### *Illness* and infections

While you're taking a biologic, you're more susceptible to germs and infections. If you develop an infection like a cough or skin infection, talk with your doctor about whether this needs to be treated before you can continue taking your biologic.

You should also let your doctor know straight away if you're in contact with someone who has chicken pox or shingles. You can be treated for these conditions if they're identified early.

#### Other medications

Let your doctor know about any other medications you're taking, even things you've bought off-the-shelf in a supermarket, pharmacy or health food store. Different medications and supplements can interact with each other and can make you sick. Or they can prevent your medications from working properly.

#### Regular check-ups

You'll need to visit your doctor regularly so they can keep an eye on how the biologics are going - if they're working and if you're having any side effects. This will include blood tests every now and then.

#### Body piercing and tattoos

If you're wanting to get a body piercing or tattoo, talk with your doctor first. Both piercing and tattooing carry a risk of infection, and with a suppressed immune system, this can be a big problem. So before you go anywhere near a needle, get some advice from your doctor first.

#### Contraception

Biologics are still relatively new medications, so we don't know if they're safe in pregnancy. If you're sexually active (whether you're male or female), you should talk with your doctor and/or parents about contraception and always use a condom.

If you're wanting to become pregnant, speak with your doctor first.



#### **Ask questions**

You should ask your doctor or nurse any questions you have about your condition, medications and other treatments. You're the one living with JIA, so you need to have all the answers. Write them down so you don't forget, especially if you don't see your doctor very often.

Some questions you may want to ask your doctor about your medications are:

- Why am I taking this medication?
- How long will I need to take it?
- What are the side effects?
- What happens if I miss a dose?
- How will I know if it's working?
- What if it doesn't work?
- Are there any long term effects?

## What about the future?

There's a lot of research happening to try and understand why some people develop JIA and to find better ways to treat it.

Biologics are a big step forward in the way we treat JIA. For most people, they greatly improve how they feel, and lessen the impact of arthritis on their life.

It's important that you remember to always take your medication as prescribed. Combined with exercise, a healthy diet and staying involved with school, sports and friends, your medications can help you live well with your arthritis.

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## More to explore

There are a lot of people, organisations and websites where you can get help and more information including:

- Your parents/carers
- Your doctor
- Your paediatric rheumatologist and nurse
- Musculoskeletal Australia
   MSK Help Line 1800 263 265

#### Websites

- Musculoskeletal Australia www.msk.org.au
- Arthritis Ireland www.juvenilearthritis.ie
- Kids get arthritis too (Arthritis Foundation USA) www.kidsgetarthritistoo.org
- PainBytes
   www.aci.health.nsw.gov.au/chronic-pain/painbytes

#### **Useful resources**

- Beyondblue <u>www.youthbeyondblue.com</u> 24/7 help line 1300 224 636
- Headspace www.headspace.org.au
  9.00am to 1.00am/7 days 1800 650 890
- Kids Help Line
   <a href="https://kidshelpline.com.au/teens">https://kidshelpline.com.au/teens</a>
   24/7 help line 1800 551 800
- Smiling Mind
   Mindfulness and meditation
   https://smilingmind.com.au

# **Apps**

- Track and React Arthritis Foundation (USA)
   Available through iTunes and Google Play
- iBeatPain for Teens
   Available through iTunes

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