



# #FunFeet4FOP

## Fundraising Pack

There are so many ways in which you can support FOP Friends and the people who are affected by FOP. Find all the information you'll need in our fundraising kit.





FOP Friends exists to help people and families who are affected by the rare genetic condition fibrodysplasia ossificans progressiva, or FOP.

We offer friendship and advice, as well as signposting to other professionals and organisations.

We raise awareness of FOP to reduce misdiagnosis.

We fundraise to support the FOP research team at the University of Oxford, as well as other projects that have the potential to speed up the discovery of a treatment and a cure for FOP.

We have been registered as a charity in England and Wales since 2012, and in Scotland since 2016.

All our past Annual Reports and accounts are available for download, both on our website and the Charity Commission website.



We are registered with the Fundraising Regulator and following the guidance from the Institute of Fundraising to ensure all our activities are in line with best practice.



# A Cure for FOP...

## FINDING A CURE FOR FOP IT'S ONLY THE TIP OF THE ICEBERG

Research into rare diseases helps scientists understand more common medical conditions and could advance the treatment for other diseases.  
Your donation could help  
*change the lives of millions of people....*

### Heterotopic ossification

Following military injuries or surgery

### Childhood brain cancer - DIPG

Chronic anaemia

Atherosclerosis

### Osteoporosis

Joint replacement

Heart disease

Sporting injuries

Burns

#### What is FOP?

Fibrodysplasia ossificans progressiva, or FOP, is one of the cruellest and most disabling genetic conditions known to medicine. It is a painful illness for which there is no treatment or cure. FOP causes the muscles and ligaments turn to bone, restricting the sufferer's movement. Over time FOP progressively imprisons their body in bone: **a healthy mind locked inside a frozen body.**



FOP Friends | Finding a treatment and a cure for FOP | Registered charity 1147704 SC046950



# FOP Awareness Day

23rd April is Global FOP Awareness Day



In recognition of the day the gene responsible for FOP was discovered, FOP Friends launched the #FunFeet4FOP Awareness campaign.

Why not help FOP Friends raise awareness of this cruel disease by holding a #FunFeet4FOP event in the workplace?

This could be as simple as getting people to wear wacky shoes and socks for the day for a small donation.



If you're feeling more adventurous, why not hold a sponsored firewalk or Legowalk?

**We share Fun Facts about FOP throughout the month of April. Share them through your social media channels to help raise awareness of FOP.**

And don't forget to share photos of your toes on social media with the #  
#FunFeet4FOP





# FOP Awareness Day 2022

## 23rd April

WHAT  
WILL  
YOUR  
FEET  
WEAR?

Fibrodysplasia ossificans progressiva, or FOP, is one of the rarest and most disabling conditions known to medicine: there is no known treatment or cure. Over time, bridges of extra bone develop, forming a second skeleton that imprisons the body: a healthy mind locked inside a frozen body. It can cruelly take a child's ability to walk, run or play overnight. There is no way to stop its progression.

**Help us to help those affected by this devastating disease.**



Share your wackiest or most stylish toes!  
#FunFeet4FOP

FOP Friends is a registered charity: England and Wales 1147704 and Scotland SC046950

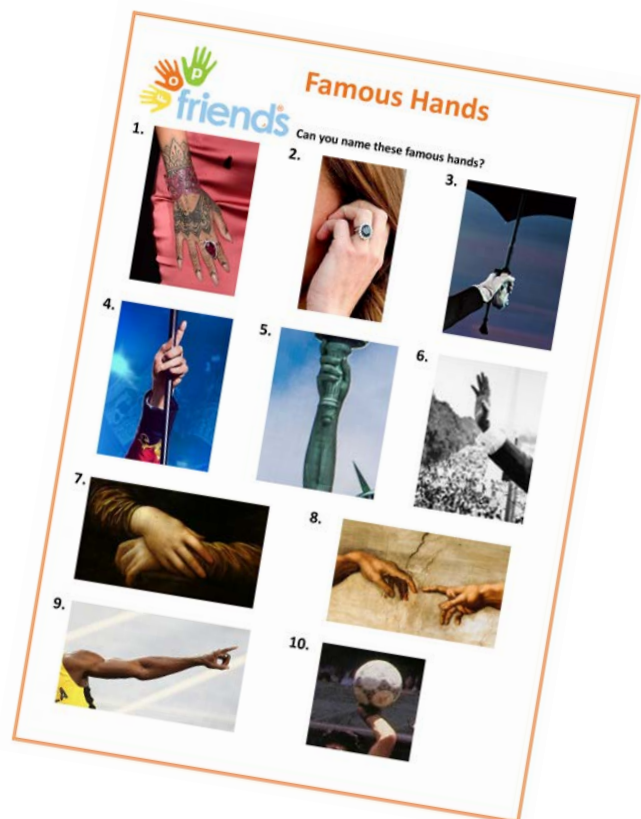


# Quiz Time!

We have a selection of FOP Friends' themed quizzes you can print and use for fundraising!



Get in touch to receive an eVersion of the quiz along with an answer sheet, for your next event.



# Thank you

We are grateful for each and every one of our friends who chooses to support our small but very special charity.

Every pound you raise for FOP Friends truly makes a difference. We are proud to declare that over **95%** of fundraised money goes to our quest to find a treatment and a cure for FOP and to support the families of those affected.



## Keep in touch

**If you would like to find out more about getting involved, please contact us:**

FOP Friends  
1 Cumberland Road  
Sale  
Cheshire  
M33 3FR  
UK  
Tel: +44 (0)161 282 0441  
Email: [info@fopfriends.com](mailto:info@fopfriends.com)

[www.fopfriends.com](http://www.fopfriends.com)



**You can follow us on..**



# Payment details



We are thankful for any amount raised, big or small. Please visit the Institute of Fundraising website for guidance on best practice when handling money.

<https://www.institute-of-fundraising.org.uk/>

Money should not be left unattended at an event. All money should be counted and banked as soon as possible, ideally with two people in attendance.

**GiftAid it!** If people would like to make a personal donation to the charity at your event, please ask them to complete a gift aid form which allows the charity to reclaim an extra 25% back from the Government at no cost to the donor.

**Enthuse** is our preferred fundraising platform.

visit [fopfriends.enthuse.com](http://fopfriends.enthuse.com) to start your fundraising page.

## Cheques should be made payable to:

FOP Friends.

And posted to:

1 Cumberland Road

Sale, Cheshire, M33 3FR

Money can be paid in via Bank transfer:

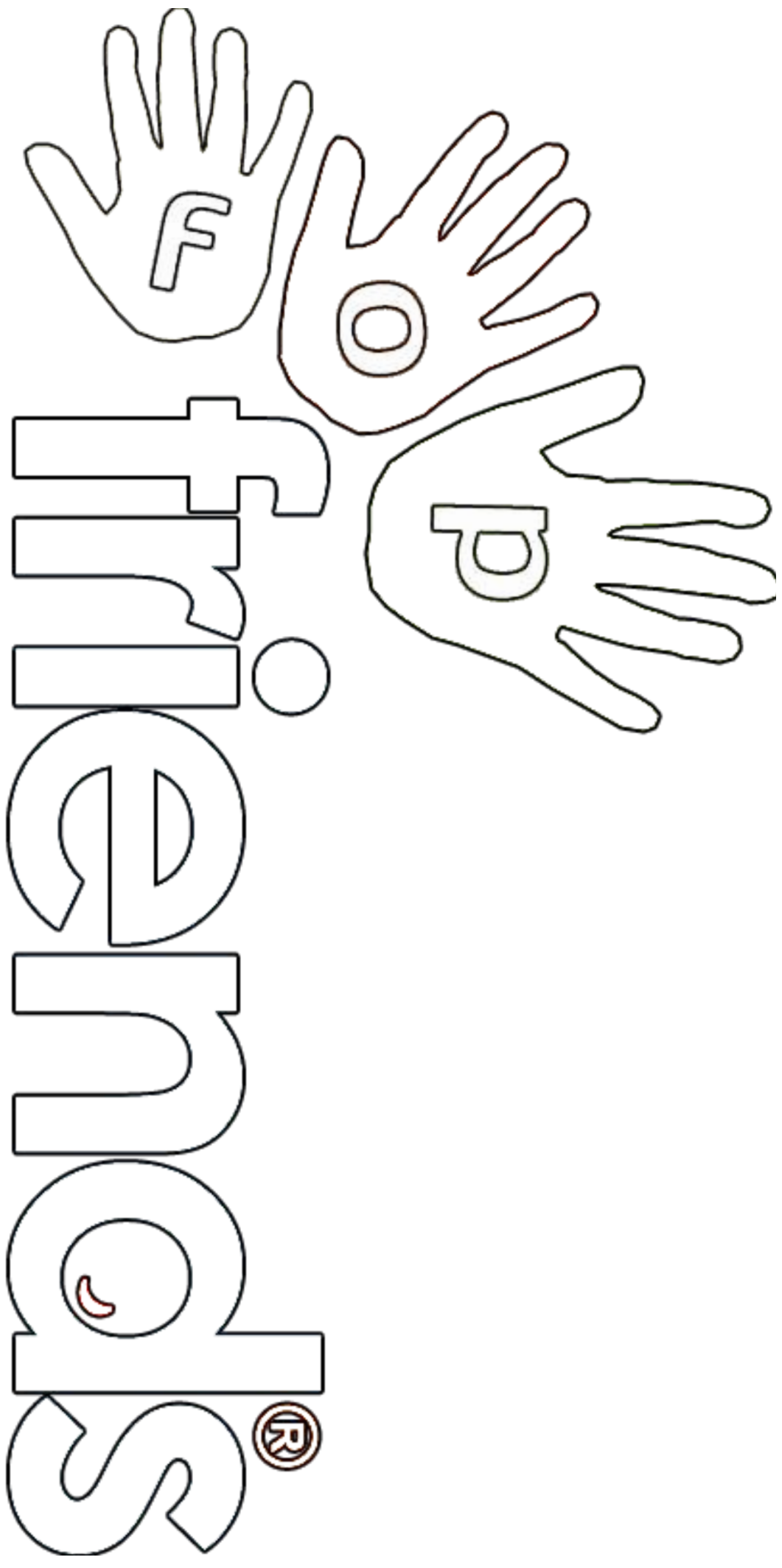
HSBC FOP Friends

a/c 31540947    Sort: 40-31-17



**All monies received by FOP Friends are formally acknowledged by letter and certificate of thanks.**





[www.fopfriends.com](http://www.fopfriends.com)

# What is FOP?



Fibrodysplasia ossificans progressiva, or FOP, is one of the **rarest diseases** known to medicine. It affects around **1 in a million** people. It is a painful and debilitating condition. There is no treatment or cure.

Sufferers appear normal at birth except for the tell-tale **turned-in big toes**.

These, combined with **unexplained swellings** across the body, can be a key indicator of FOP.



Most cases of FOP are **new**. FOP is caused by a fault in the **ACVR1 gene**. This gene mutation happens at conception: it is an accident of nature.



FOP does not affect a sufferer's **intelligence**.



Many people with FOP **struggle with mental well-being**, anxiety, and loneliness.



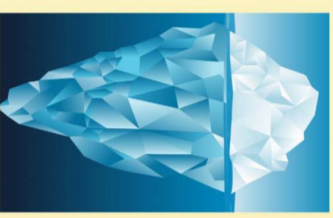
FOP can **significantly shorten the life expectancy** of sufferers.



FOP causes the body to **develop extra bone** to form in muscles, ligaments and soft tissue. This creates painful swellings called flare-ups. Where this occurs across joints it progressively **restricts** the sufferer's movements.

### Tip of the iceberg...

Research into FOP has far-reaching benefits and implications for more common illnesses such as **osteoporosis**, childhood brain cancer, heart disease, **heterotopic ossification** following military injury, and burns. **Research into rare diseases benefits everyone.**



When people with FOP lose movement, it can mean they are **unable to carry out simple every-day tasks** such as washing, feeding, and dressing independently.



Children with FOP can find that they **lose movement** in their shoulders, neck and arms, at a young age, making playing like their friends very difficult. **Children** with FOP often **don't get the chance** to ride a bike or a scooter in case they fall off. Also, children with FOP can't take part in sports such as football as the **risk** of being injured, thus triggering a flare-up, is simply **too great**.



It is **not possible** to **remove** the extra bone growth as the surgery will prompt further flare-ups.

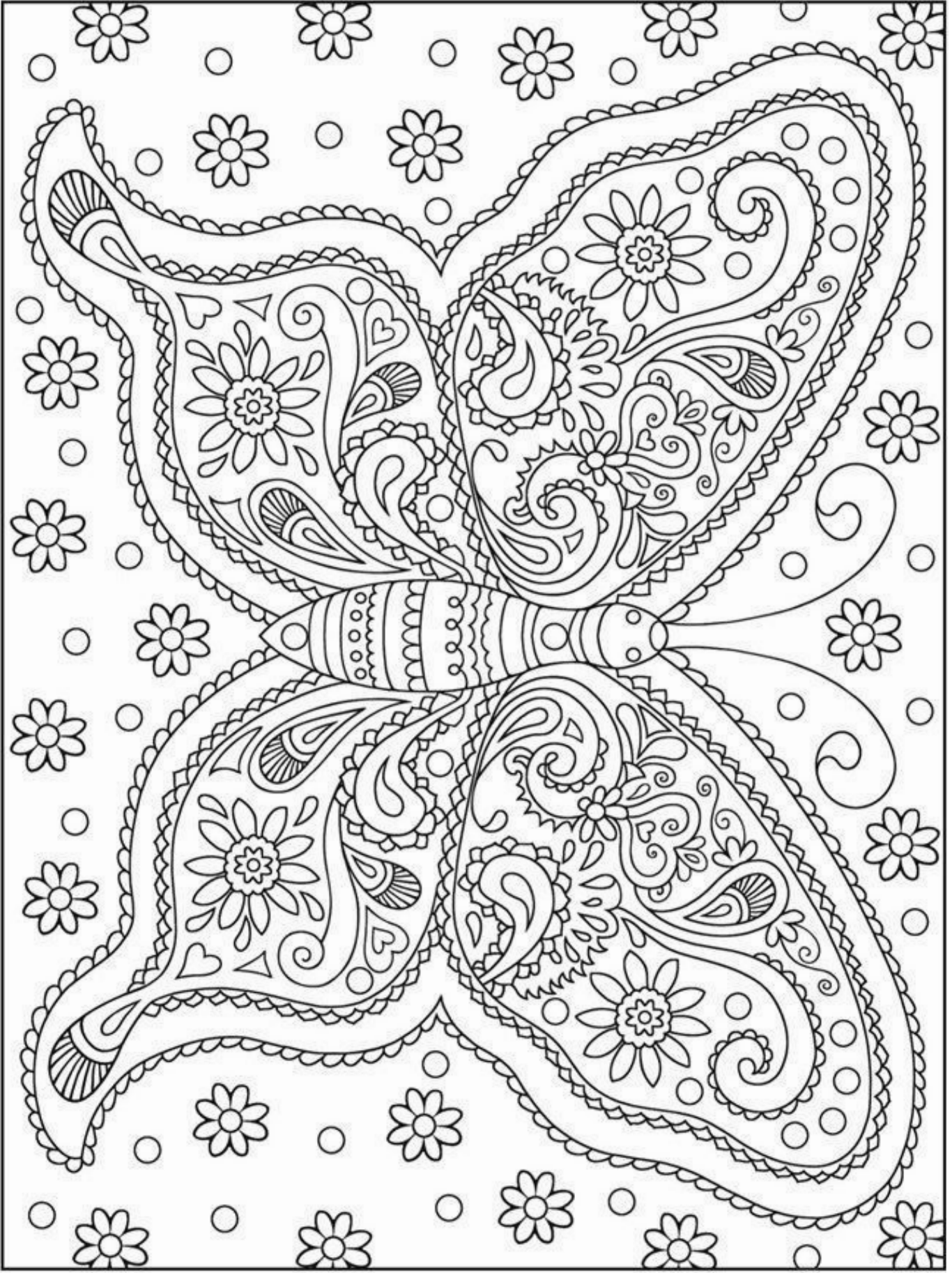


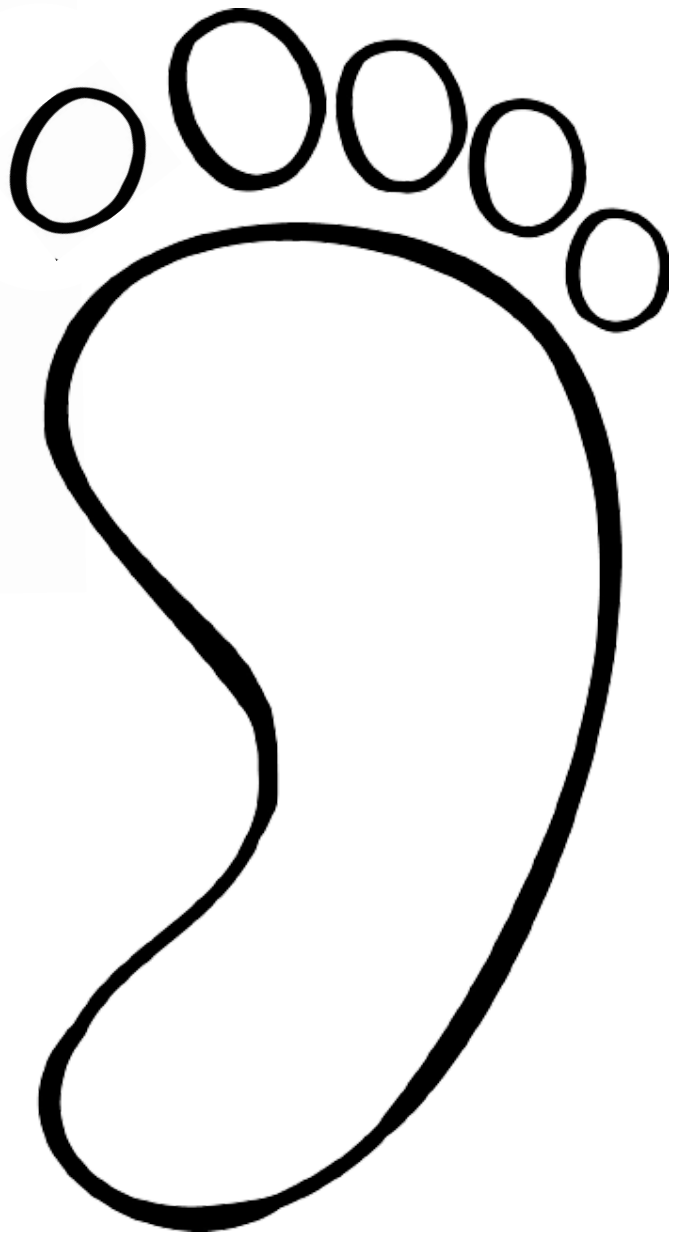
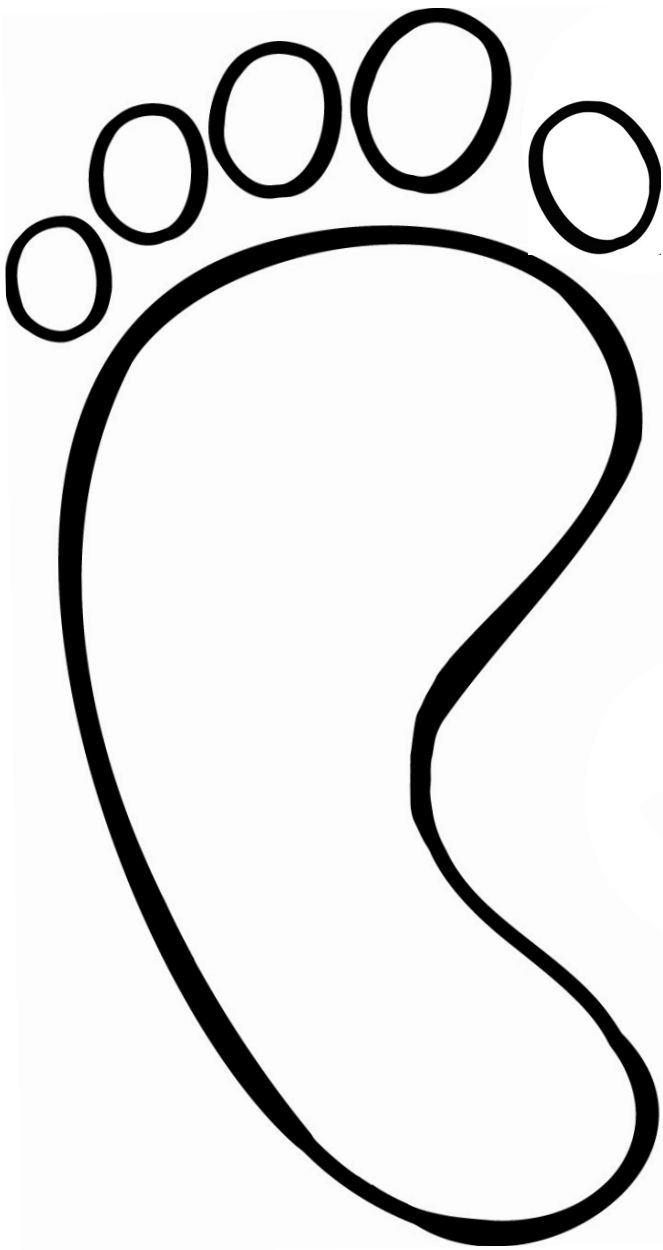
Whilst a flare-up can be caused by an impact, they can also occur **spontaneously**. A child can go to bed one night, then wake up the next morning having lost movement in an arm. Forever.

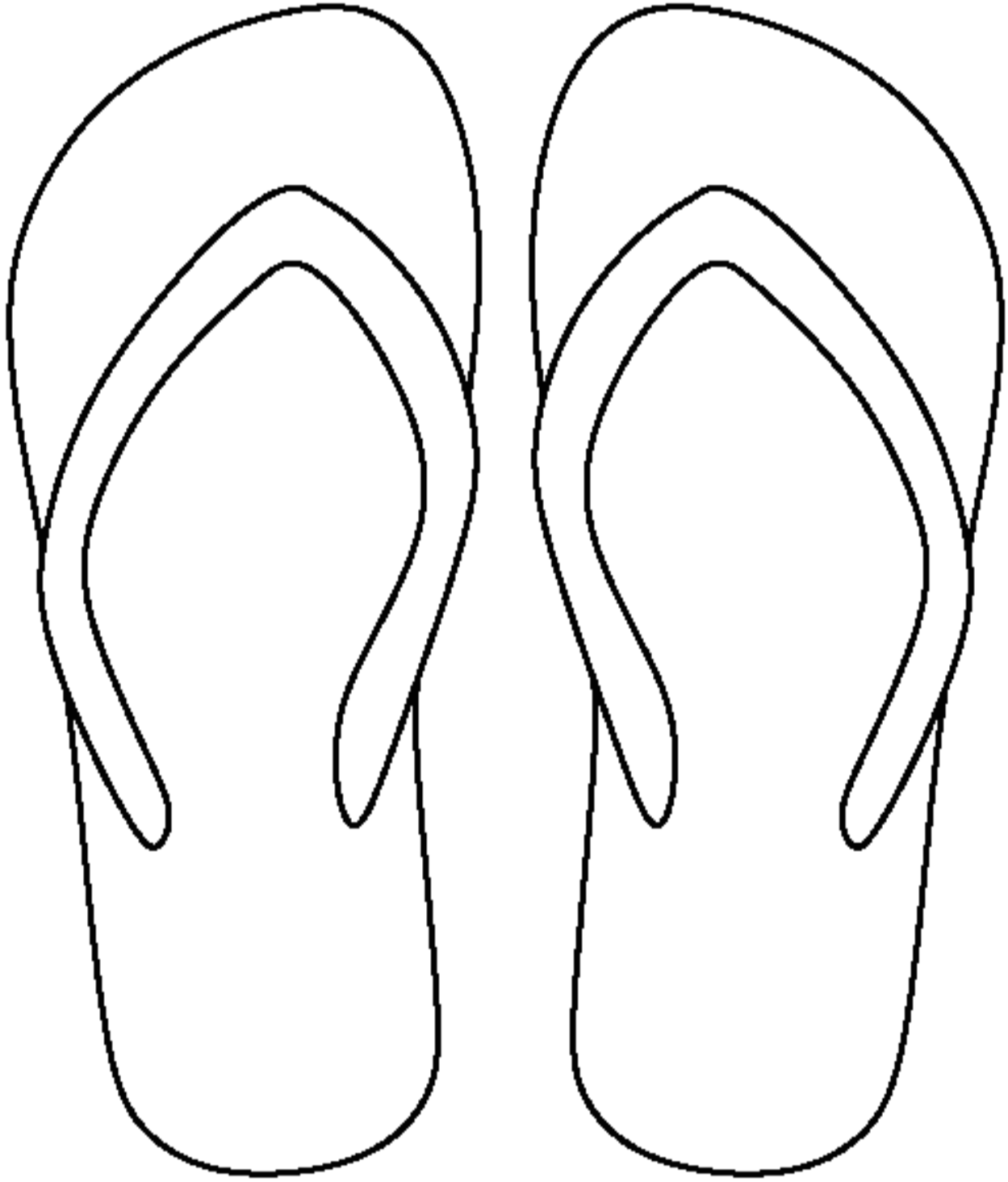


**WE HAVE HOPE!** There's a number of trials underway with more on the horizon. We also have a potential first approved treatment on the way.











Thank you!

