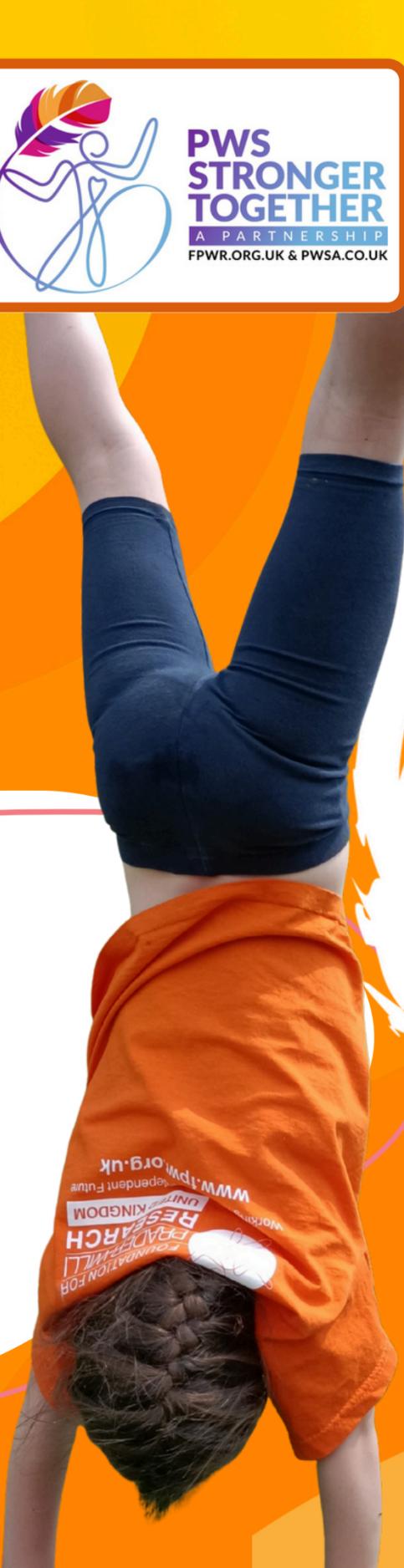




WILL YOU GO ORANGE FOR PWS?



What is PWS?

PWS is short for **Prader-Willi Syndrome** and is a something that some people are born with.

Not many people have PWS so lots of people may never have heard of it. Have you?

People with PWS can have lots of different symptoms. It can affect your muscles, eyes, breathing, sleep, how you feel pain and temperatures, how you behave and how your bones form and grow.

A big symptom of PWS though is that most people always feel hungry- really hungry- all of the time.



What does it feel like to have PWS?



Your tummy always feels empty even after you have eaten.

Even more cruel - you can't eat as much as other children as your body doesn't burn calories as it should. So you are really hungry- but can't eat as much as other people.

Chocolate, cake and sweet treats will make you put on weight very quickly and this might make you poorly.

Adults have to help to make sure you don't have too much food or have foods that aren't good for you.

It might make you upset to see some people eating when your tummy is telling your brain that you are hungry too.

And it's not just food...

Your muscles have to work harder to move. This makes it hard to run and climb and sometimes even to talk and walk.

You might feel very upset when things are different to what you expect.

You might find it harder to learn things at school than other people in your class.

Making friends can be difficult because you find it hard to understand what people mean and how to play with other children.



Do people with PWS ever get better?



PWS is a genetic syndrome, which means it is something you are born with in your DNA. So it isn't like being poorly- it is a part of you and people with PWS will have it for their whole life.

Some people with PWS have injections every single night to help them grow and help their muscles. But that is the only medicine that Doctors can give and that doesn't help with the hungry feeling and what you are allowed to eat.

There is **no cure** for PWS, but with research into medicines and ways to help, life can be made easier for people with PWS.

How can you help If you know someone with PWS?

Be careful what you are eating when you are with someone with PWS and don't offer them food- it might seem like you are being kind but they are probably on a special diet.

Make an effort to play together at playtime and include them in conversations – they might want to join in but don't know how.

Be patient – your friend might take a while to answer but it doesn't mean they aren't interested in what you are saying, it just can take a bit longer for their brain work out how to answer you.





How else can I help?

You can help by raising money to help people with PWS.

Your school has agreed that you can wear something **ORANGE** for the day to raise funds and awareness of PWS. We **GO ORANGE** as orange is a colour that represents hunger- a big issue for people with PWS.

By wearing something **ORANGE** you can help to pay for research into medicines and ways to make life easier for people with PWS.

Also, now you know all about PWS you can tell other people about it too. It is quite rare to have PWS so not everyone knows about it. You can help to change that!





**Thank
You**



www.pwsstrongertogether.co.uk
www.pwsa.co.uk www.fpwr.org.uk