



**WEAR JEANS  
CHANGE LIVES.  
FRI 22 SEPT**

**RAISING MONEY FOR GENETIC DISORDERS UK**

# **LIFE WITH ZELLWEGER SYNDROME**



Charity number: 1166300



Supporting families  
impacted by  
Zellweger Spectrum Disorder



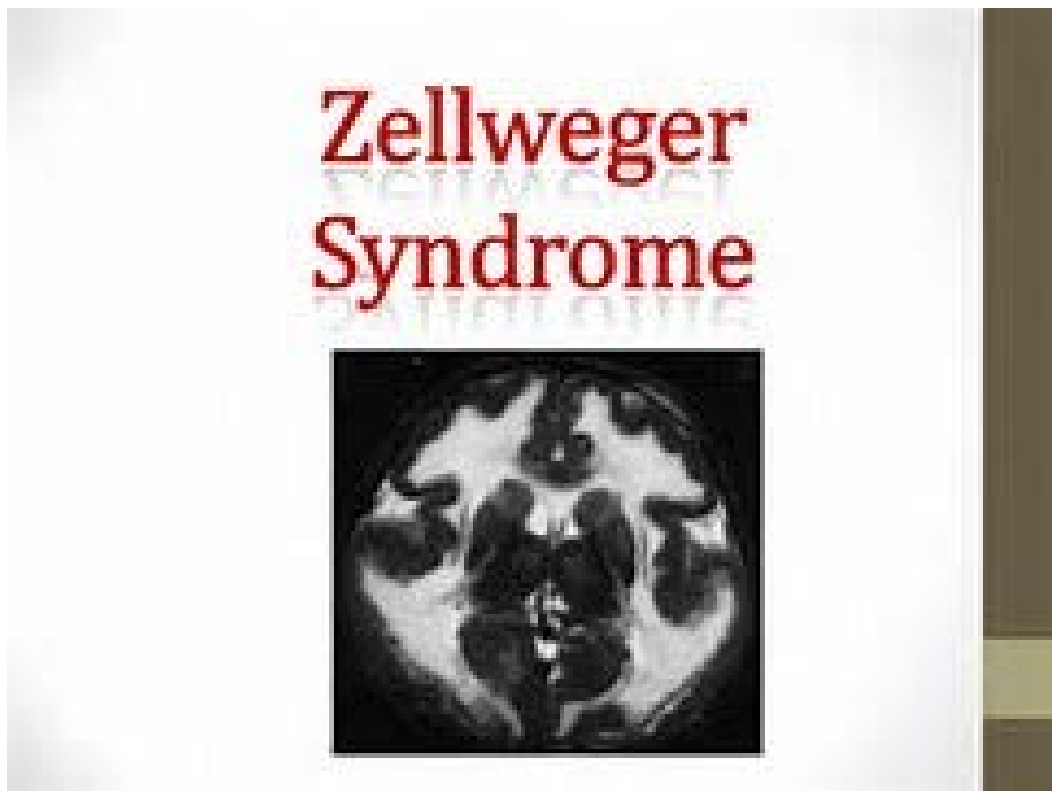
[www.zellweger.org.uk](http://www.zellweger.org.uk)

# **ZELLWEGER UK**

# WHAT IS ZELLWEGER SYNDROME?

Zellweger syndrome is also more commonly known as ZSD (Zellweger spectrum disorder). Zellweger syndrome affects children with all different types of disorders such as liver and kidney problems. However, there is a large spectrum that contains the complicated and sadly life-threatening disorders and problems. Despite this unfortunate side to Zellweger there are also more fortunate children with more minor difficulties on the spectrum. For example, I am deaf, partially sighted and have been diagnosed with Asperger's syndrome. The unfortunate result of Zellweger syndrome is that most children with the disorder will not live into adulthood.

Within the spectrum of Zellweger syndrome there are multiple different condition. Despite the large large spectrum Zellweger syndrome only affects 1 in every 50,000 live births.



# HOW AM I PERSONALLY AFFECTED?

## Deaf (Hard of hearing)

One of the ways I am affected by this disorder is being deaf. Being deaf has many ways of support for example I myself have hearing aids to help me hear.

It was found out that I was deaf in the years of 2006 when I was just at the age of 2 years and 6 months old. Because of this I have an annual hearing test to make sure any changes are noted and to make sure my hearing is on track. However, it is not as bad as you may think as now I get to see a lovely doctor called Caroline she is super nice. Despite sometimes she is not in she is most of the time.



The first sound I ever heard was a song playing on the radio on the car on the way home. That is the story behind the fact that I love music so much.

## Partially sighted

The second way the disorder can affect me is that I am partially sighted. The way this is dealt with is that I wear glasses.

I got my first pair of glasses at the age of 3 so by this point I had both hearing aids and glasses before I started school. Because of this I now have a sight test every year to keep an eye on my sight. Because of my conditions with my eyes I must go to a hospital in London called Great Ormond Street Hospital for children. But recently I have been diverted of into Bristol's royal infirmary for children.



### Asperger syndrome

I was diagnosed with the disorder that is known as Asperger's syndrome in November of 2016. The doctor asked me a series of questions related to whether I had Asperger syndrome or not. As she did this she had a camera to record our discussion so she could query it with her colleagues. The way that this is described to children is to imagine landing on a different planet.



Explained to children- <https://www.youtube.com/watch?v=s9eATBV-1g&t=54s>

Positive side to aspergers- <https://www.youtube.com/watch?v=RQvN0o7qof4&t=155s>

### Tendon pains

I have had tendon pains since I was a baby. This includes pains in the joints and down my legs. Sometimes this can have an impact that I struggle to walk at times. There have been many trips to accidents and emergencies over the years.

Despite this I am very grateful in the fact that I can actually walk because many children with my condition can not walk or talk.

### Over all

If I was to sit here and type all of my conditions it would take a while so I have just written about the key disabilities.

# 12 YEARS OF HELL

Hopefully from reading what you have read you know what surcumstances and stage we are at. I am now 13 years of age however it was only recently that it was 100% serified that I officially had Zellweger syndrome. The reason being is that I don't face the obstacle that others face. For example I am the tallest and healthiest child with this disability known to doctors. However to find this out there have been multiple test over the years but now we are happy to know it's all over. NEARLY

**KEEP CALM**

**I ONLY HAVE**

**Zellweger syndrome**

# PHOTOS OF ME GROWING UP



Matthew Thomas