

# SPIDER - EDE



## Who is Spider-Ede?

Edith is 3 years old, she has an older sister Niamh (4) and a younger brother Leonard (1). Mummy Ashleigh is a nursery nurse and Daddy Stephen is a builder. We all live on the Wirral in the UK.

Edie is a hilarious little girl with a great sense of humour, full of love and life. She loves going to nursery, seeing her friends, visiting the park, anything to do with animals and she loves superheroes with super powers!

## Why are we here?

Edie had been suffering from headaches that got progressively worse and more regular over 6 months. After seeing her GP she was referred to consultant paediatrician at Arrowe Park. Edie was given the preliminary diagnosis of migraines but referred for an MRI scan just to be sure. Results of the MRI scan came back that Edie had a 'lump' found in the brain stem. This is a part of the brain that cannot be operated on because of the location so far centre and the sensitive nature of the area.

The referral was made to Alder Hey children's hospital and after more scans they have told us they are 95% sure that this is a brain tumour called a Diffuse Intrinsic Pontine Glioma (DIPG).

## But there's a problem

DIPG is a rare brain tumour that occurs in children. The location in the centre of the brain means they cannot operate and surgically remove it. Here in the UK chemotherapy is not an option because the levels needed to treat this tumour would poison the rest of the body. Radiotherapy would alleviate symptoms, make her more comfortable and ease any pain but we would inevitably still lose her.

## Our hope

Although here in the UK our options are limited. There are alternative pathways for Edie abroad. At The Instituto de Oncología Intervencionista or "IDOI" in Monterrey, Mexico. They are leaders in intra-arterial treatment for brain tumors and are recognized for DIPG treatment. They use a multi pronged attack, namely intra-arterial chemotherapy and immunotherapy. Nowhere else in the world is using this treatment and nowhere else in the world are having the results that they are. We have recently learned that a second child in as many months has just been given NED status (No Evidence of Disease).

These people are literally super heroes, changing people's fate from a death sentence to life prospects. Making DIPG a previously incurable fatal disease a thing of the past.

## You can join us

Our current goal is to raise approximately £300,000 to cover the cost of flights and treatment for our Edie, which include specialised chemotherapy and immunotherapy but currently this is just a ballpark figure, she may need more, or less than the standard amount of treatments. However we would love to exceed this figure to enable us to help other children and families in the future.