

PRESS RELEASE

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Sisters doing it for each other: Wrexham sisters with same rare disease help raise awareness of uncommon illnesses

Two young sisters from Wrexham born with the same rare genetic disorder are supporting International Rare Disease Day by highlighting their own personal stories.

The 28 February will be the twelfth international Rare Disease Day where hundreds of organisations across the world will hold awareness-raising activities. There are between 6,000-8,000 rare diseases affecting over 3.5 million people in the UK and approximately five new rare diseases are described in medical literature each week.

Ceri Owens, the mother of two young girls who have both been diagnosed with a rare disease, tells us how National Lottery funding has enabled them to get involved with a lifechanging project.

Same but Different is a Mold-based organisation that uses the arts to create awareness of the people behind disabilities and rare diseases. One aspect of the project is a photography and video campaign called Rare Aware.

Rare Aware was founded to highlight the stories of those affected by rare disease through photography and encourages the public to look beyond first impressions.

Two sisters from Wrexham, Poppy, 8 and Ffion, 5 live with Marfan Syndrome and have been taking part in the Rare Aware project. Their rare disease is a genetic disorder that affects the body's connective tissue which holds all the body's cells, organs and tissue together.

Their mother, Ceri Owens, 38, said: "Poppy was one years old when we found out that she had a rare disease and we only recently found out that Ffion has the same syndrome. It can affect the heart, the eyes, skeletal features and give the girls joint pain. It's difficult in the winter because their joints are very fragile and they can't take part in sports and need plenty of breaks. There's endless doctors' appointments and we pretty much live at hospital.

"Like any parents, you're wishfully thinking that they haven't got it and it can be lonely because, with rare diseases, nobody understands what you are going through as a family. There's plenty of times I've cried. Getting involved with Rare Aware has been incredible and it's amazing to know that there's someone out there determined to raise awareness of rare diseases."

An award of £253,787 thanks to National Lottery players through the National Lottery Community Fund has helped Rare Aware reach families living with rare diseases from all parts of the UK. The project was founded by photographer Ceridwen Hughes from Mold whose son, Isaac, also lives with a rare disease.

Ceridwen said: "What I found most difficult was that people would judge Isaac based on how he looks and I desperately wanted to help people in similar situations. One of the most difficult things about living with a rare disease is that you can feel incredibly isolated. I feel very lucky to have been able to take photos of so many wonderful children living with rare diseases with the aim of showing the person in front of the camera, not the condition.

“The National Lottery funding has allowed us to make a real difference and without it, we wouldn’t have been able to start the organisation in the first place. It’s given us the ability to really make a difference to peoples’ lives.

“It’s been an absolute joy working with Poppy and Ffion and we feel privileged that people let us into their lives and help them share their stories through the images and narratives we produce. The project cannot make people better or help them find a cure but it can help people who feel isolated and in need to reach out to their community, breaking down barriers of isolation which can be life changing.”

In Wrexham and Flintshire alone, the National Lottery has awarded around £101m to over 4,600 good causes since it was launched 25 years ago. Charities, community groups, grassroots sports projects, arts organisations, athletes, film makers, and heritage sites have reaped rewards from the funding.

Keep an eye in local media and on National Lottery Good Causes on Facebook, Twitter and Instagram and the hashtags #LotteryLovesWrexham #LotteryLovesFlintshire #Chwedlau’rLoteri over the next month for more inspirational stories like Rare Aware which illustrates how National Lottery funding has helped to change the lives of people in Wrexham and Flintshire for the better.

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Notes to Editors

- National Lottery players raise £30 million every week for good causes across the UK, funding a wide and varied range of good causes – they support local communities, build world-class facilities and visitor destinations, power sports teams, protect the environment, unleash creative talent, look after the elderly and unlock youthful potential. In addition, support from the National Lottery wins Olympic medals and Oscars.
- Over £1.75 billion of National Lottery funding has been invested into around 50,000 arts, heritage, sport and community projects in Wales since 1994