

Rare disease gets first UK meetup

Friday 2 June, 2017

UK sufferers of super-rare disease acromegaly are to be united for the first time ever to share their experiences in a special conference in Birmingham on the 1st of July.

The condition is caused by excessive release of growth hormones from a benign tumour in the pituitary gland underneath the brain.

Symptoms are enlarged hands and feet, change in facial appearance, visual impairment, enlargement of organs (including the heart) and more.

In some cases acromegaly (called gigantism in youth) can cause huge growth spurts.

Famous sufferers include Andre the Giant, James Bond star Richard Kiel and Robert Wadlow, the tallest man ever.

Acromegaly is thought to affect just 50-70 people per million.

Dan Jeffries, an acromegaly survivor and author who is organising the event said: "It can take years until you discover you have acromegaly, and the impact on your life can be huge - it will be emotional to get everyone together for the first time.

"We normally use social media to support each other but it would be a real achievement to get as many of us in the same room as possible.

"There's nothing quite like bringing people together to share experiences, listen to one another and offer support and guidance. We're hoping it will be a fun yet invaluable experience," he said.

The day will include talks from acromegaly patients who will share their experiences of living with a rare condition, as well as pituitary and endocrine experts from Queen Elizabeth Hospital.

Menai Owen-Jones, Chief Executive Office of The Pituitary Foundation said: "This will be a great social event dedicated to people affected by acromegaly.

"It will provide an excellent opportunity for people to talk and share with others, who understand and have similar experiences of living with acromegaly and make new friends."

The event is on the 1st July 2017 at the Queen Elizabeth Hospital Conference Centre in Birmingham between 11.30am and 5pm. Tickets are £10 + booking fee.

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