

# KENT MESSENGER

## Rare Diseases

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The other day the estimable Karen Harris, who's pilates class I join most Thursday evenings in the Red Cross hall in the Avenue, told me about an event in the House of Commons, to raise awareness of rare diseases. So I took a little time to find out more.

Rare diseases are conditions that affect less than 1 in 2000 people. There are currently between 6000 and 8000 identified rare diseases but this number is continually growing - so having a rare disease is not in itself rare.

One rare disease group that has a membership of over 400 families and is supported by Gravesham volunteers is charity is called The British Porphyrin Association and supports patients and their families. Porphyrin patients have a genetic fault affecting the processing of porphyrins. Various external influences can then cause porphyrins to build up in the body, thus causing them to have a 'toxic' affect on all body systems. Mild symptoms may include aching joints, back pain, blisters, headache and nausea. Acute symptoms may include acute abdominal pain, vomiting, diarrhoea, breathing difficulties, paralysis and even death if untreated. ([www.porphyrin.org.uk](http://www.porphyrin.org.uk))

Diseases of this sort affect over 3.5 million people in the UK at some point in their lives. But because they each affect small numbers of people, research funds and facilities are extremely limited. Specialist centres for treatment and diagnosis are few. Drug treatments may be very expensive and be denied by the NHS.

