# P-04-570 Inequitable Access to Treatments That Have Not Been Nationally Appraised in NHS Wales

## Petition Wording

We the undersigned call on the National Assembly for Wales to review the use of the "exceptionality rule" in determining whether a patient can access a treatment through the Individual Patient Funding Request process.

**Additional Information**: To access treatments through the IPFR process, a patient population must demonstrate its exceptionality. For common illnesses, it may be possible to identify a subset of patients within the larger population who are more likely to respond to a particular therapy. For rare disease patients, demonstrating that you are a unique patient when you are part of a small group of patients whose condition is considered rare is practically impossible. The exceptionality criteria place an onus on clinicians to provide evidence that the patient's clinical condition is significantly different to the general population of patients with the same condition and is likely to gain significantly more benefit from the intervention than might normally be expected. This evidence requirement is too onerous to apply to patients with rare diseases due to small patient numbers within rare disease populations. Patients with great clinical need are prevented from accessing life-changing/ life-saving treatments.

**Petition raised by:** Genetic Alliance UK, Tuberous Sclerosis Association, Association of Glycogen Storage Disorders

**Date Petition first considered by Committee:** 15 July 2014

**Number of signatures:** 1089