

What is the cost of rare diseases such as Friedreich's Ataxia?

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What is the cost of rare diseases such as Friedreich's Ataxia? By analyzing direct and indirect costs of care research in BioMed Central's open access journal *Orphanet Journal of Rare Diseases* calculated that conservatively this rare disease costs between £11,000 and £19,000 per person per year. Proper understanding resource allocation is important in minimizing the effect of Friedreich's Ataxia on people's lives while maximizing their quality of life.

Diseases are classified as 'rare' if they affect less than 1 in 2000 people. Lack of [scientific knowledge](#) means that these diseases can be difficult to diagnose and treatment options are limited. Rare Disease Day, February 28th, aims to raise awareness of [rare diseases](#) and their impact on people's lives.

Friedreich's Ataxia, caused by mutations in the gene encoding the protein frataxin, results in progressive damage to the nervous system. Although rare, it affects one in 50,000 people, and consequently is the most frequent of the inherited ataxias, which all affect a person's ability to control their muscles. Symptoms usually begin in childhood, and affected people need continual monitoring to assess and assist with developing problems.

Dr Paola Giunti from the UCL Institute of Neurology and UCLH, explained, "The costs of more common progressive diseases such as Parkinson's Disease are known but it is not really possible to base budget allocations of one disease on the expectations of another without

understanding the differences in need."

People with Friedreich's Ataxia need specialists, nurses and carers, and there are direct and indirect [medical costs](#), home modifications and loss of earnings to be considered. On the 75 people in the study alone, the UK spent £240,000 on medical care and £300,000 on [educational support](#), respite care, and other support in one year.

But the costs are not just medical. Loss of employment due to Friedreich's Ataxia is estimated at over half a million pounds each year. There are also hidden costs as many people with Friedreich's Ataxia are children and young adults who are predominantly cared for at home by their families.

Dr Paola Giunti continued, "Our results show that the needs of people with Friedreich's Ataxia are different, with different costs, to people with Parkinson's Disease and that a 'one size fits all' strategy is unlikely to provide the best care to people with rare diseases."

More information: Impact of Friedreich's Ataxia on health-care resource utilization in the United Kingdom and Germany Paola Giunti, Julia Greenfield, Alison J Stevenson, Michael H Parkinson, Jodie L Hartmann, Ruediger Sandtmann, James Piercy, Jamie O'Hara, Leo Ruiz Casas and Fiona M Smith, *Orphanet Journal of Rare Diseases* (in press)

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