Rare diseases: Being uncommon comes at a cost

Rare diseases are a category of disease that affect very few people in the population but can often cause serious life-long health issues. Some of the more familiar rare diseases are muscular dystrophy, juvenile diabetes, cystic fibrosis and childhood cancers. Rare diseases result in many challenges for the individuals and families living with these conditions and also for the medical community as they can be difficult to diagnose and are often very complex to manage. Only very few of the many rare diseases have drugs to treat them.

The number of people living with a rare disease in Australia and around the world is not well known. A recent study by WA Health, published in *Genetics in Medicine*, gives insight into the number of people living with rare diseases in Western Australia (WA) and how much time they spend in hospital [1].

Over 10 years of information was collected from hospitals in WA. It revealed there were more than 60,000 people with one of a list of 467 rare diseases that went to hospital over that time. In the year 2010, this group of people in WA with a rare disease went to hospital twice as often as a person without a rare disease. People living with rare cancers went to hospital the greatest number of times.

The study then calculated the total cost of these hospital stays over one year (2010). The study group represent only 2% of the WA population; however, the cost of this group of people going to hospital totalled nearly $400 million, which was over 10% of the total hospital spending in WA that year. In reality, the cost to the health system was probably much higher for this group as it did not include visits to out-patient clinics or other services. The results from this study will help Governments to better understand the needs of people living with a rare disease and plan better services in the future.

The study was led by the Office of Population Health Genomics in the Public Health Division, using WA Health’s world class data linkage system. The results reflect the successful partnerships developed across WA Health, including with Genetic Services WA, Telethon Kids Institute and international partners Orphanet France.

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