

expenditures for health however still account for considerable expenses for households and unequally affect low-income families. In 2014, 5.3% of households experienced such high health costs that they had to forego paying for non-health related goods. The cost of medicines was one of the main contributors to this, as only certain medicines are available free of charge under the SUS.²⁸

Two Brazilian families were interviewed. A father with an 8 year old boy and a mother with a 9 year old daughter.

Direct healthcare costs:

The mother interviewed was a member of a corporate health plan which covered inpatient care. Costs associated with Growth Hormone were paid for by the public health department. However, the costs of therapies are borne by the family. Her child is 9 years old, and didn't need all the therapies that he used to need. The family only pays for psychotherapy which is around \$320 per month.

A father from Brazil reported that Growth Hormone prescriptions were publicly provided, thus free of charge for the family.

However, for medical appointment and therapies, public provision is not good quality. For the father, accessing public services would have been more complicated and his child would not have been able to have all medical appointments and healthcare that he needed. The father has insurance that partially covers this costs (about 70%), however the remaining part is a significant economic burden for the family. For his child, the diagnosis was reimbursed by this insurance. The insurance is an employee benefit.

Direct non-healthcare costs:

Transportation: the mother faced significant costs associated with transportation. They travel to the United States every two years to see a specialist. These costs are not covered by the state.

For the father interviewed, he stated that transport costs were not significant, as all services were available in the city he lives in.

Education: education is one of the greatest costs associated with PWS for the first family interviewed. The woman's daughter with PWS has a private tutor to help with academic progress. The tutor costs about \$380 a month and none of this is reimbursed by the state or by any insurance.

For the father of the 8 year old boy, education is costly as public provision of education is not good in Brazil. However, this is not related to PWS as his son is currently enrolled in a regular school.

²⁸ Ibid

