

AB038. Rare diseases are not orphans in Israel

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Abstract: The big change in Israel accrued in 1995 with the 'National health insurance law'. Since then every citizen is initialed to be insured in one of the 4 health insurance company. The law defines our basket that includes over 3,000 therapeutics. The cost is about 11 billion Euros. We update our Basket every year and everybody can apply. We add new orphan drugs to our basket almost every year. For example was approved in 2007 the drug Meyozyme for 21 patients with Pompe. The cost was almost 150 thousand Euros for each of them. We don't have a price limit for a drug per person, as our law demand 'mutual assistance'. In 2014 I had the honor to lead a committee set by our minister, for rare diseases in Israel. We discussed many aspects of the subject, including definition and wither we need a special law for rare diseases. We agreed about the need of a register and the minister of health office support and pay for it. We found that there is a big problem with genetics examinations; also it is in our basket since 1995. We found that because of the high price of the new exams the health insurance companies are not very happy to provide them. We can't pay the insurance companies for what we

already paid and included in our Basket. As we understand that diagnosis is the basic for everything, the government decided to give an extra 9.5 million Euros a year for this purpose and we pay directly to the laboratories. We have some specialized medical services especially for rare and unique diseases. We found that, much less patients then expected come to these clinics. The peripheral areas where we know we have more patients is missing. We decided to finance 3 new clinics for rare diseases: 2 in the peripheral areas of the country and one in the center. Those clinics are not for one disease but for all the patients. They are multidisciplinary clinics with Drs. Nurses, therapeutic teams, social workers and genetic consultants. The health insurance companies must pay and send there every patient that known to have or has a question on having a rare disease, and wants to be diagnosed or treated there. I want to end with an example from our clinic in the north. The frequency of rare diseases in Israel is slightly higher than the frequency in Western countries because of the high incidence here of marriages between cousins in some of the populations. We have more than 1 million Muslim leaving at the north of the country. Many of them are marry in the family. A new recessive mutation will lead to many affected individuals families and even villages. We send our teams to the villages and they talk to the people. If they agree and want to be valuated we get an informed concern from them, they get the genetics consultation and tests with no charge and the government pays for it all.

Keywords: Rare diseases; health office support; Israel

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