Cultural Challenges in ALS Care

Efrat Carmi, IsrA.L.S
Brussels, 2014
Israel Demography:
Population - 8 millions
80% - Jewish (6.5 mill.)
20% - Arab (1.5 mill.)
ALS population:
About 600
80% Jewish – 480
20% Arab – 120

IsrA.L.S Registry:
450 -ALS patients
95% - Jewish (428)
5% - Arab (22)
Jewish - 428 out of 480 – 90%
Arab - 22 out of 120 – 18%

So where are the rest?
Maybe the % of Arab ALS patients is different?

If not-
Why don’t we know them?
- A low level of awareness of the disease and the possibilities of health services.

- A society that tends to take care of its weaker individuals within the community and within family circles.

- A society that tends to hide family members with fatal diseases, in order to avoid damaging the children's chances of marriage.
- Less exposure to the Internet and the Israeli media.

- A high level of acceptance of the professionals in the community, who are usually unfamiliar with the disease, that lessens the chances that individuals will seek out second opinions by specialists.
“What do you need them for?”
How are we going to find the Arab ALS patients?

1. Hire Arab social worker

2. Establish an ALS clinic dedicated to Arab patients

3. Educate the local teams in the communities about the disease

4. Complete the translation of IsrALS materials in Arabic.
6. Identify and contact the neurologists in the Arab communities and educate them about ALS and IsrALS.

7. Identify and contact ALS patients and introduce them to IsrALS.

8. Develop special programs, services and materials dedicated to the Arab society.

9. Establish relationships with governmental entities that serve this community.
This model can be used in every country with a minority that uses different language and has a different culture.
Thank You!!