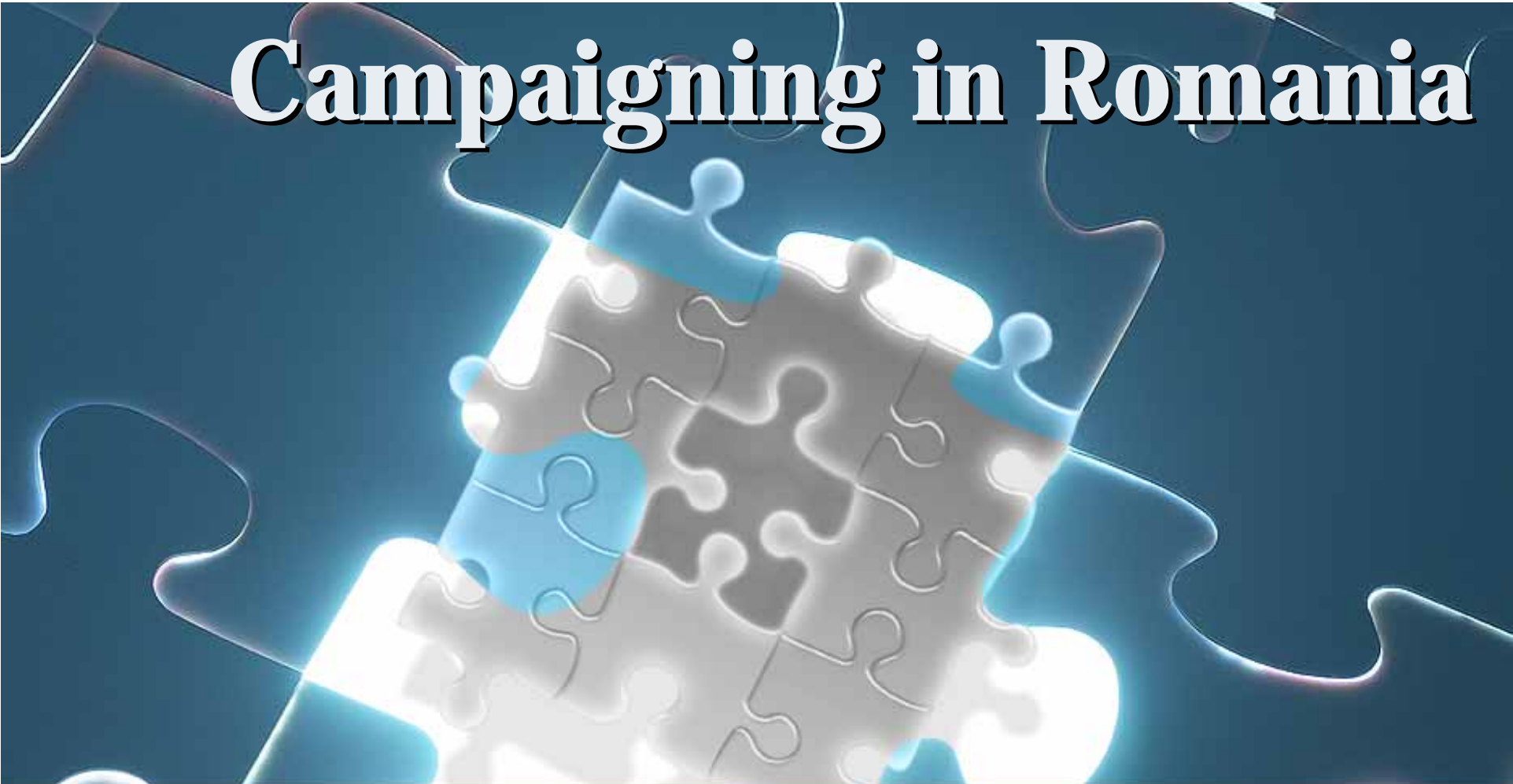


Campaigning in Romania

A 3D puzzle of a map of Romania is shown against a dark blue background. The puzzle pieces are white and blue, with some pieces highlighted in a bright blue glow. The puzzle is tilted and appears to be in the process of being assembled or disassembled.

Gelu Stănculescu-Topai
Romania



The situation in the urban area

- Although we are about to become a member of the EU we have to admit that Romanian towns seem to be very large villages. Even in towns you can find streets without pavement, without sewerage, filled with stray dogs and filth. Efforts are being made to change this situation, but it seems that things are moving far too slowly. And if things were to change in the following years, we still have mentalities to deal with.
- The rural and urban areas are very intricate. Many of the people who live in the towns come from the rural areas. This is why the mentality of the people who live in the rural areas greatly influences that of those who live in the urban area.



e.g. Situation of the streets in Bucharest

Nr. crt.	Type of material	No. of streets	Length of streets (km)	Surface (thousands of square meters)	Surface (%)
1	Asphalt and concrete	1532	622	9059,9	46,5
2	Pavement of refined stone	401	193,1	2008,9	10,3
3	Pavement of stone	1735	496	4885,8	25
4	Paved	947	433,1	2143,7	11
5	Earthen	725	165,6	1401,6	7,2
	TOTAL	5340	1820,8	19499,9	100



The situation in the rural area

- **In 2005 the Romanian Foundation for an Open Society did a survey and the data they were able to gather show the following:**
 - 3% of the houses have no electricity. In the remote villages in the mountains things are even worse. There still are children who do their homework at candle light.
 - 84% of the houses do not have sewerage. The other 16% represent the villages located immediately near big towns.
 - In 50% of the villages people still use water from wells; 18% don't even have their own well, but there is one for more people, or maybe even the entire village. 15% of the houses have a sewerage system in their yard and 16% have a sewerage system inside their homes. Again, the 16% are probably the villages very near to towns.
 - 85% have the toilet in the back yard; 2% don't even have a toilet. Only 12% have a toilet inside the house. The 12% percent are probably the villages close to towns.





Epilepsy in Romania

- The main issue regarding epilepsy in Romania is that the problems of people with epilepsy are not known
- Setting up initiatives and collaborations is difficult when nobody knows what are the main problems to be addressed
- **The first step in solving problems is to well define the problem**
- In the past year our organization has been defining problems and setting up collaborations that will help solve those problems
- In what follows I will present **the problems**



The problems

1. **Authorities lack information about epilepsy**

- most of the data they can provide is either incorrect or incomplete
- authorities lack the capability of gathering correct data
e.g.: there is no unique system of centralizing data about persons with epilepsy; reports from GPs and neurologists are compiled, although the data is overlapping, thus all results are invalid



2. As much as 20% of people with epilepsy don't take prescribed medication regularly (according to reports from GPs)
3. People with epilepsy are rarely seen by a neurologist
 - in some extreme cases people with epilepsy have not seen a neurologist or adjusted treatment in 30-35 years



The reasons for this are the following:

- There are too few neurologists and people have to wait too long to get a consultation.
- Often people have to travel big distances to get to a neurologist (this is true especially for the remote villages in the mountain area)
- The quality of medical services and attitude toward patients are often questionable
- The lack of any clear requirements regarding visits to the neurologist from both GPs and neurologists
- The lack of information about the need for regular visits to the doctor



4. **Too few people are diagnosed with epilepsy**

- The greatest problems are with children; in the rural areas very few children are diagnosed with epilepsy and most of the diagnosed ones are with grand mal seizures
- **Possible reasons:**
 - The lack of knowledge about epilepsy; seizures are not recognized as a medical problem, thus no attempt is made to visit a doctor
 - Sociological and anthropological factors:
 - stigma
 - in the villages children have to take care of themselves from a very early age



- there are too few child neurologists
- the health system does not facilitate access for people from rural areas; they are treated mostly by GPs who sometimes take on the prerogatives of specialists (diagnosing epilepsy, making treatment changes etc.)

5. The health care system is underfinanced

- precarious endowment
- lack of medical supplies
- lack of modern equipments
- doctors are underpaid thus their motivation is quite low; corruption is facilitated by this



Some comparative data

	Romania	Bulgaria	Poland	The Czech Republic	Slovakia
General population	21.700.000	8.000.000	38.000.000	10.000.000	5.000.000
Total number of people with epilepsy	174.000	70.000	400.000	100.000	50.000
Patients treated(%)	55,0%	85,0%	90,0%	95%	85%
Value of AEDs prescribed in 2004 (in EURO)	7.973.000	10.927.000	58.000.000	17.971.000	8.597.000
Expenses/patient/year -2004	46	156	145	180	172
New AED prescriptions	2%	14%	14%	13%	20%











6. **The doctor-patient relationship**

- some doctors lack interest in their work which leads to poor quality services, which drives some patients away from doctors
- follow up is done very rarely – this contributes to losing track of people with epilepsy; only 35% of GPs see each of their patients at least once a year, although are required to do so by law
- Patients, especially those living in the rural areas are often not interested in learning about their disorder; this makes things a lot more difficult for the doctors



7. Religion and stigma

- religion is very important for Romanian people
 - One survey shows that out of the people interviewed 91% said that God is important or very important
 - the relationship with the Church is very important as well; only 4% stated that they only go to Church once a year or less and only 1% never.



Church vs. epilepsy

- We have seen that in the villages in the mountains epilepsy is seen as the Devil's disease, people with epilepsy are seen as possessed by the Devil. Those who contribute to sustaining these beliefs are the priests and they do this with verses from the Bible.
- The official website of the Orthodox Church www.sfaturiertodoxe.ro gives us a clear picture of how epilepsy is perceived:

„Saul was the emperor of Israel and he had epilepsy, he had the evil spirit, because often he fell to the ground and had foam around the mouth, because God had left him since he killed emperor Ahab. David came and sang to him psalms with the harp and cast out the evil spirit from Saul and made him healthy and he soothed him. But did Saul thank David for chasing the devil out? No. The Devil, hearing the power of psalms, left Saul and ran. And Saul soothed, but his enmity did not.”



Church vs. epilepsy

- In many villages priests have declared that when a person has epilepsy, the devil has to be chased out through religious ceremonies
- In many monasteries like the one in Sambata de Sus (Sibiu County) special exorcism ceremonies are being performed in order to rid the person from epilepsy. We have even personally attended such ceremonies in which the devil was chased out of people not further than 35 km from Cluj (Nadasel).
- Such ceremonies take place all over Romania. Often the Church is too involved in the problem of epilepsy, but with catastrophic results.
- Some Theological Universities don't accept people with epilepsy (e.g. Craiova)



Consequences

- discrimination; people with epilepsy are strongly rejected from public life, sometimes are rejected by their own families

Related to seizure frequency

- employment issues
 - poverty
 - dependency
- noncompliance
 - being ill makes a person eligible for a state pension; for a person that has no chance of finding employment a pension seems to be the only solution



What should be done ?

- Working closely with the doctors in order to make changes possible
 - Starting with July 2006 our organization has joined forces with ILAE Romania for campaigns of advocacy and raising awareness
 - Organizing conferences through which doctors can receive new and important information
 - Better explaining the notion of patient organization, as well as its importance
- Educating mass media about epilepsy and using the mass media to educate the general public



- Expanding the educational campaigns to a national level. At present our organization is conducting such educational campaigns in schools and kindergartens in 50% of the country
- Changing the Church's and priests' perception of epilepsy. Such a campaign will be initiated in 2007.



- Finding external allies for advocacy campaigns
- Advocacy campaigns will aim at:
 - Changing driving legislation
 - Changing legislation regarding employment of people with epilepsy and state pensions
 - Addressing the issue of rejection of children with epilepsy from the public education system; a collaboration with the Ministry of Education has already been initiated
 - Addressing the issue of the under financing of the health care system



Other issues to be addressed:

- Offering an alternative to the health care system by founding the first epilepsy clinic in Romania

