Dear Sirs,

We have been, just before closure of the deadline made aware of a formal EU project on mobility of patients and health services/workers that is certainly dealing with important and, for us and for our patients, essential issues, thus a most welcome activity. We summarize our experience and express our willingness to collaborate in future on the issues here presented.

Due to demographic small size of Slovenia it would not be rational to develop special and subspecial professional facilities for health problems requiring complex multidisciplinary teams and a high enough turnover enabling them to acquire and maintain their skill end expertise . Such being the case of **epilepsy surgery, especially in children**, where cost – effectiveness has been demonstrated for larger populations – when referrals are enabling a team to perform at least 25 surgeries per year – and a correspondingly larger number of pre-surgical investigations in (more numerous) candidates with refractory epilepsy. Thus, in a small population, even a relatively frequent disease - and its rare subcategories – for which modern scientific understanding and professional solutions are available, become an orphan disease when viewed from the practical angle of feasibility and accessibility of practical medical acts in a given health system.

We have therefore developed, over more than 15 years, first at the Centre for Epilepsies (Children and Adolescents) and later at the similar Centre for Epilepsy (Adults), at the Ljubljana Clinical Centre, Slovenia, a team **model of collaboration with foreign specialized institutions for Epilepsy** (Canada to start with, then UK, later mostly France and Germany) and we have collected considerable experience with around 50 patients referred abroad for resistant epilepsy, presurgical and surgical. We are therefore most keenly aware of a number of unsolved questions related to this kind of activity.

Fortunately enough, Slovenia has **a health system and insurance** that allows such an activity, and Europe has some centres of excellent quality in the field.
The **Slovenian National Health Insurance** Agency has been willing to cooperate quite smoothly and with due understanding for the patients and the complexity of issues to be solved at the administrative and financial levels.
Unaccustome themselves to the task, and obliged to cooperate with foreign partners not always any more than themselves skilled in the field, they were happy to rely upon the health workers who, involved themselves in the task professionally, often saw no choice but to take over functions upon themselves that would have normally been performed by skilled coordinator nurses, administrative staff and financial services of respective insurances and hospitals.

The Authorities of **the Hospital** were aware of the activity, and very often notified about the numerous related difficulties in organizing it, in their response hardly ever more than morally supportive and – true to say – more often than not, unsupportive. The requirement by the Insurance that a professional service performed for a patient abroad has to be financially covered by the referring medical institution has clearly not been put into function in this case; obviously the financial burder being too high for a hospital. One understands that the financial burden should be weighted differently in a unit usually dealing with such a population than in a unit only exceptionally facing this kind of task. However, exception made for a very rare Head of Department of Child Neurology trying to proceed the problem to the decisionmaker, no action or results followed our proposals.

Most dramatic among **the un-resolved issues about health workers' mobility** is the **example of neuropsychology performed abroad**. Our attempts to make authorities understand the role of neuropsychology, an essential pre-surgical investigation in a candidate for epilepsy surgery, has not been successful at all. This role was never properly evaluated and the work performed thus never paid, not even when promised. This testing has quite often to be performed in a neuroradiological setting preferably of the (to-be-) surgical institution: Wada test = intracarotid injection of sodium amytal allows to assess cognitive risks (on memory, language) of the planned surgical procedure and has obviously to be performed in the patient's mother language. It could be done before referral in his own country but many multidisciplinary presurgical teams prefer it to be done following protocoles they have been used to at the institution where surgery is planned. We agreed that this may in fact be the best for the patient's safety.
The patients with severe epilepsy are not exceptionally at risk for cognitive / behavioural / psychiatric complications. **Comorbidity with epilepsy** makes it necessary that a professional able to deal with these issues competently in the patient's language accompanies him/her.

Support to the parents has been an integral issue of our model, either via telephone lines or e-mailing even when parents were travelling unaccompanied (knowing the language themselves). In one case, a mother was at the time of signing by herself for her son's surgery in such a distress that an instant solution had to be found: the husband of the paediatrician accompanying the mother and child took a few days holiday and flew abroad with the patient's father and help decision to be taken and signed. The boy has been seizure free for many years. The account could be filled with anecdotes, not always but most often resolved favourably due to enthusiastic personal committment of the team.

Language skills are but one of the missing chains on this agenda.

The **others issues often not resolved in practice** include:

- clear agreements between Insurances and hospitals,
- lack of knowhow at the hospital accountant level
- lack of standardized multi-lingual forms,
- agreements on existing (and not ever changing) regulations (local and European),
- difference between health systems in terms of hospital function and related expected behaviours (a lot of issues untold and self-expected from both the parties)
- some of the foreign institutions send quite complete information and questionnaires aforehand, others do not.
- some of the institutions do, most do not employ coordinator staff (most welcome, but not always saving situations).
- protocoles and scenarios of hand-over in case of complications
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Legal issues regarding

- informed consent,
- information about risks,
- responsibilities,
- rights to claim coverage of dammage in a case of complication or medical error,
- still require a lot of further discussion and adapted arrangements.

Seen the **language barrier**, as indeed none of subspecialist institutions abroad offers a translator for the Slovenian language, we – at The Slovenian Chapter of International League against Epilepsy - developed a **voluntary student accompaniment service** seeking university students (medicine, psychology) and covering their living with a modest of money that we can acquire as a non - governmental organization. This has proved a most valuable experience for the patients and for the volunteers, of which some will hopefully be able to join some of the activities in neurology later. Most of our patients do not speak foreign languages and none of the foreign nursing staff speak Slovenian, and only rare speak English.

Difficulty to accept new models of work by authorities, neglect in making arrangements acording to new requirements

The most stringing issue for us being indeed that this activity has not been wiewed as a complex and labour intensive work by the local hospital administration nor by any other health authority. It is not sure whether the same indeed happens in the hosting institution abroad where as well much of additonal work falls on the teams. This has mockingly been referred to by the members of the team here as medical »non-act« (a medical »act« being an officially scored procedure for Insurance thus theoretically financiable). Therefore, most of the work done in developing and maintaining the model had to be done on an »amateur« basis (unpaid, during extra hours) by highly trained professionals.

An example of this kind of improvised arrangements: while the adult neurologist accepted to travel abroad (and staying abroad with his patients), paid as if working regularly at home and insurance for travel covered by his hospital, the League against Epilepsy was covering the accompanying student. The money to cover the testing performed was used to cover travel expense, and the neuropsychologist's time and work were in fact a donation to the patient. Even when the hospital was theoretically liable to receive money from the Insurance's funds, it has never reached the person who did the job. Obviously, Hospital authorities and Insurances should **find arrangements acceptable to professionals willing and able to move and perform accross borders**. It canot be expected that unpaid highly skillful work will continue.

Other possibile sources. Seen the difficulties in financing this kind of networking, we have for some time been supported by a **bilateral Slovenian French bilateral cooperation project** Proteus led in parallel to referrals of our patients. So our team would accompany the patient and learn new specialist skills alongside.

Side Consequences. As one of the results, offers to join in a research project ensued that we were unable to join. A Practical Epilepsy Summerschool was initiated by both parties and supported (scholarships) by the Commission of European Affairs of the International League against Epilepsy. In another cooperation project, scholarships were offered to our residents to

train abroad. Advantages and possible disadvantages (brain drain) should be considered and the possible consequences and safety measures included in such a planning.
Plans. **Teleconferences** have been discussed as a regular means of exchange of data and shared decision making. Offers have been advanced to collaborate in the planned **supranational reference institutions** (e.g.Lyon Institute des Epilesies de l'Enfant, IDEE).

Intermediary role in networking . Our team has, due to longlasting contacts of our team with centres from 3 or 4 (English, French, German, Italian) linguistic environments, knowledge of their protocoles and experience, developed an advisory service function also sought by patients from other countries. Thus we had been serving as an intermediary relay centre counselling to families and to patients from other South Eastern European (exYugoslav) states (speaking Croatian – Serbian - Bosnian, Macedonian) .

Presentation of the experience. Our experience had been presented at a WHO Travel Medicine Meeting in Florence a few years ago. More recently, a meeting of the patients, families and accompanying students and professionals has made us aware of the importance of the project as led with only support of the Slovenian League against Epilepsy and dedicated professionals of the Ljubljana Clinical Centre, in spite of very poor if any support from the Hospital authorioties.

Future proposals

We think that a very large scope of experience gathered from Montreal to Marseille (via London , Paris Ste Anne, Paris Rothschild, Grenoble, Rennes, Bielefeld, Erlangen, Vogtareuth and Bonn, Prague considered), familiarity with the teams and know-how information about the patients' and professionals' mobility, has enabled us to make valuable contributions to the project. The Slovenian Chapter of International League against Epilepsy with the professional teams in charge of severe epilepsy in Paediatric/Adolescent and Adult Neurology would **be willing to organize an international meeting on the above topics: on European networks of reference epilepsy centres from the point of view of the referrring centre dedicated to quality of care in these situations, professional organization of referrals and optimized communication between institutions,** within the next 2 years in Slovenia.

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