Series: Medicine and Biology Vol.9, No 1, 2002, pp. 31 - 33

## BALKAN ENDEMIC NEPHROPATHY IN BOSNIA AND HERCEGOVINA

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**Summary**. It has been estimated that around 2.000 patients have been affected by BEN in Bosnia before the war 1992-1995 so that the need for the assessment of the current situation has emerged for the first time after a decade of BEN enigma in Bosnia. Therefore, the medical team from Tuzla University Clinical Centre Renal Unit has visited the affected municipalities and corresponding medical centers in order to make that assessment. The main results coming out of this initiative are that BEN Dispansaries, that used to function before the war, do not function nowadays at all so that fairly often new BEN cases are detected for the first time at later stages of the disease when they already require either preparation for replacement therapy or even urgent life-saving measures. It is necessary to re-establish the system of surveillance of BEN patients that existed before the war as soon as possible. Therefore, the Project Proposal has been prepared to accomplish that goal.

**Key words**: Balkan endemic nephropathy, epidemiology, research

#### Introduction

Apart from affecting other countries in the Balkan Peninsula, BEN can be encountered in Bosnia in the following municipalities: Bijeljina, Brcko, Samac, Odzak, Orasje, Derventa, Modrica, Srbac, Gradiska. (Fig. and (1)) It has always been not only the medical, but socioeconomic problem, too. Before the war in Bosnia 1992-1995, about 2.000 people were affected by this disease (1) and they used to be monitored on a regular basis in BEN Dispensaries, in the majority of the affected municipalities. The main reference center was Tuzla University Clinical Center for later stages of the disease where preparation for maintenance dialysis as well as various dialysis procedures themselves used to be carried out. Banjaluka Clinical Centre was dealing with this problem, but to a much less extent. A scientific approach has also been exercised in Tuzla University Clinical Center whereby as many as 120 patients underwent thorough functional assessment, proteinuria analysis and kidney biopsies in cooperation with Belgrade Chemistry Institute and Liubliana Clinical Centre and headed by Prof. Hall (Ohio University). The work has been published in Kidney Int. in Nov. 1991. as Supplement (2).

The health care system infrastructure has been considerably destroyed during the war in Bosnia thereby necessarily affecting the problem of BEN patients and their surveillance. Furthermore, we have witnessed a natural experiment during the wartime whereby people were forced to move out of an endemic area and others were moving in.

The purpose of this study is to make a survey on the current situation regarding BEN in Bosnia and, based on

that, to prepare a Project Proposal on re-establishment and further improvement of the control and follow-up system regarding monitoring and surveillance of BEN patients in Bosnia in the near future. On the basis of that Proposal, it will be possible hopefully in the near future to follow up on 120 patients that underwent kidney biopsy 10 years ago (2). Also, given migrations that took place during the war in Bosnia, it will be interesting to follow up on migrated population thereby drawing possible conclusions on genetic as opposed to environmental factors influencing this disease.



Fig 1. Distribution of endemic municipalities in Bosnia (names of municipalities are encircled)

Municipality -	Number of inhabitants			Total No of	Registered	On HD	Deceased	Tx
	City	Village	Refugees	inhabitants	with BEN	BEN/Tot	with BEN	1 X
Samac	5.000	14.000	7.000	26.000	100	34/59	12	0
Brcko	45.000	55.000	22.000	122.000	28	20/50	_	4
Orasje	5.307	20.350	0	25.657	0	26/26	_	2
Domaljevac	0	6.000	0	6.000	0	16/16	_	1
Odzak	4.000	14.000	0	18.000	0	83/88	_	0
Bijeljina	44.000	68.000	45.000	157.000	1.762	74/98	_	2
Modrica	_	_	_	_	_	_	_	_
Derventa	_	_	_	_	_	_	_	_
Brod	_	_	_	_	_	_	_	_
Gradiska	_	_	_	_	_	_	_	_
Srbac	_	_	_	_	_	_	_	_
Total	103.307	177.350	74.000	354.657	1.890	253/337	12	9

Table 1. Population and patients breakdown throughout the endemic regions

Legend: – no data available Tx renal transplants

#### Methods

Delegation from Tuzla University Clinical Centre (Renal Unit) has visited local hospitals in the towns of Bijeljina, Brcko, Odzak, Orasje, Bos. Samac and Domaljevac (new municipality, established after the war) and got a clear picture of the current situation regarding functioning of the health care system in the respective municipalities. The Delegation has collected all data necessary for the analysis and preparation of the Project Proposal on BEN.

# Results

The main result coming out of our survey was that BEN Dispensaries did not function at all so that fairly often new BEN cases used to be detected for the first time at later stages of the disease when they already required either preparation for maintenance dialysis or even urgent life-saving measures. The statistical current data necessary for the analysis are presented in the table 1.

The youngest patient registered with BEN in our study was born in 1960. On the basis of those data, a Project Proposal has been made whereby about 300.000 (three hundred thousand) people (all inhabitants from the endemic region) will be tested on urinalysis initially, primarily screened for proteinuria. For that purpose, the teams made up of a doctor, lab. technician and a driver will be doing fields trips. As many as 2.000 (two thousand) emigrants will be tested, too. That will be the first phase. Some 10-15.000 of those with LMW proteinuria are expected to enter the second phase which will take place at 7 regional medical centers throughout Federation and RS where non-BEN diseases will be ruled out on the basis of available capacity (lab, sonography, excretory urography...). We estimate that around 300 (three hundred) those diagnosed with BEN will enter the third phase that will take place at Clinical Centers in Tuzla and Banjaluka where they will be classified according to the level of renal functional impairment and where renal biopsy will be performed eventually. The Project implementation will last till up to June, 2004 when the Symposium on BEN will be held in the town of Tuzla.

#### **Discussion**

In a post-war period the situation is rather desperate when it comes to BEN control. It is not only the poor economic situation adversely affecting health care system in Bosnia, but also the new administrative borders established after the war that separated the health care system in two entities and one separate district (Fig. 1). The majority of patients are currently coming from Republika Srpska, but Tuzla University Clinical Center, which used to be the reference center for BEN before the war, is located in the other administrative entity which is called Federation. So, the links and the entire system of BEN patients' follow-up and control have been totally disrupted.

Two acute problems requiring the work on them seem to have emerged out of this study. First, the need for re-establishing the disrupted links between the health care systems of the entities and the district and the lack of financial resources to run the Project implementation.

We strongly believe that re-establishing of those links would produce a variety of effects that are far beyond purely medical ones, i.e. would re-connect health care workers, re-unite doctors with their patients, re-unite authorities in their respective entities, actually re-unite people!

It is too optimistic to expect from the state at the moment to take part in resolving the financial problem. Therefore, it is our intention to approach various international organizations currently engaged in Bosnia in order to get the financial support. There are still some ideological obstacles by certain authorities that are opposing the idea of any co-operation between the separated administrative units in Bosnia & Hercegovina, but we believe that with considerable money support injected from the international community as well as with

new generations to come, those obstacles should be eventually overcome.

Acknowledgments. We thank Dr Dragisa Savic (Bijeljina), Dr Ljubica Vucicevic (Brcko), Dr Slavko Pecirep (Domaljevac), Dr Zeljko Stipancic (Odzak), Dr Kruno Vukovic (Orasje), and Dr Nenad Petkovic (Samac) for their support as well as Mr. Silvio Cosic (OSCE Mission in B&H) and Mr. Edin Halilovic (Tuzla) for their technical assistance.

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