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Donor specific requests of donors that reside in a different country as the one they were initially registered

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INTRODUCTION

Human migration and mobility within the European Union continues to grow. Regarding Greek citizens, the number of young, working-age movers grew during the economic crisis. This mobility resulted in hurdles to perform donor specific requests (DSRs) for donors that were recruited and registered in one country and were resident in another country at the time of the DSR.

PURPOSE

There are no guidelines how to manage the donor transfer between the registries. Each registry has different requirements in order to integrate a foreign donor into its registry. The aim of this study is to highlight the need for uniform guidelines for donor transferring between the registries

DATA/METHODS

During two year experience (2021-2022) six (6) donors were permanent residents in another European country at the time of the DSR, so they transferred from our donor center (DC) in Patras University (CBMDP-Save a life, WO- number 1041) and the correspondent Hellenic National Registry (ION 4979, WO-number 1040) to a registry of another country and versa.

In all cases, we confronted the questions of

- a) how to transfer personal data and HLA typing results in accordance to GDPR rules,
- b) how to enable donor re-registration in his/her residence registry according to the local rules and
- c) whether our center should be reimbursed for the initial recruitment of the donor, the information session and for providing HLA typing data

RESULTS

- a) All donors wanted to transfer registry in order to became a savelifer
- b) Five (n=5), donors could be re-registered in the new DC / registry and received a new GRID
- c) One (n=1) donor could not speak the local language and could not be registered in the new registry, and thus the DSR was cancelled.
- d) The donor who was transferred to our center could speak the Greek language and the re-registration was easier.
- e) We provided the initial HLA-typing data for our 5 transferred donors to the new registry (n=4) and we received the HLA typing data for the one donor transferred to us.
- f) Agreement regarding reimbursement was performed with only 1 out of the 4 interacting registries/ DCs

CONCLUSIONS

- a) Our experience highlights the need to establish guidelines and procedures within the WMDA which could enable the smooth donors transfer that are residing in a different country as the one they were initially registered and the DSRs completion.
- b) There is a need to create legal pathways and WMDA approved forms that enable this process between the interacting registries, especially the transfer of personal and HLA typing data following the GDPR principles.

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Table 1: Donors who initially registered to CBMDP-Save a Life (DC) and were at the time of the DSR (CT: Confirmatory Typing, WU: Work Up) permanent residents in another European country

					Donor	Donor Consensus to	Donor			
DSR Re	gistry	Donor Registry	Donor DC	DSR	Residence during DSR	transfer registry	Transfer Management	Re-registered Registry/DC	Complete re- registration	Completed DSR
NMDP	-USA	HTO	CBMDP	CT	GERMANY	YES	НТО	ZKRD	Unknown	Unknown
IBMDR-	-ITALY	НТО	CBMDP	WU	CYPRUS	YES	HTO	KARAISKAKIO FOUNDATION	Unknown	Unknown
								SWISS TRANSFUSION		
FGM-FR	RANCE	HTO	CBMDP	CT	SWISS	YES	HTO	SRC Ltd	Unknown	Unknown
NMDP	-USA	НТО	CBMDP	СТ	CYPRUS	YES	НТО	KARAISKAKIO FOUNDATION	Unkown	Unknown
NMDP		НТО	CBMDP	СТ	GERMANY	YES	CBMDP	ZKRD/Würzburg		NO
NMDP	-USA	НТО	CBMDP	СТ	UK	YES	CBMDP	ANTONY NOLAN		Unkown
			KARAISKAKIO				KARAISKAKIO			
ZKRD-GE	RMANY	CYPRUS	FOUNDATION	WU	GREECE	YES	FOUNDATION	CBMDP	YES	YES