

# **Newsletter: September 2022**

#### **Dear ESCIF Colleagues**

It is a while ago since you heard from ESCIF. In the meantime we had constructive first meetings with Lucy Robinson as new board member. Also, our project "Ukrainian SCI" relief is still running and proves to be a need. However, due to problems to find enough SCI experts who work in the house we will not prolong the project and end it September 30st. The ESCIF board wishes you a good read through the newsletter including project info, next congress and coming events.

#### Changes in the board

Our previous Vice President, Nutti Hilltunnen stepped down from his position at the last assembly in Samorin, Slovakia. We are grateful for his service to the board and all he did for the SCI people in Europe. The assembly has appointed Miriam Kanalec to the Vice President role. The assembly also elected Lucy Robinson as new board member and as the treasurer. We are looking forward to work together with Lucy to achieve the most for persons with SCI in Europe.



Lucy Robinson (left) & Mirjam Kanalec

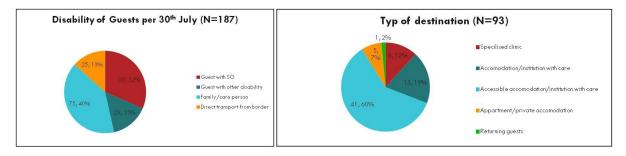
#### **ESCIF Help Alliance: Ukrainian SCI Relief**

April 1<sup>st</sup> we started our project "Ukrainian SCI Relief" which runs a safe house in Poland. In the house basic medical needs are assesst and treated. Also, accommodation needs are assesst in order to find accurate housing or treatment in the different ESCIF member countries. In a last step the project organises the transport to the final destination in Europe.

Thanks to the generous support of the Swiss Paraplegic Group and the "Fördergemeinschaft der Querschnittgelähmten" in Germany and other sponsors, we were able to run the project. Germany welcomed by far the biggest share of Ukrainian guests and organised the transports from Poland to the final destination. The organisations of the Swiss Praplegic Group (Association, Foundation, Hospital and Orthotec) helped finance the project and sent material and many staff to the safe house. A huge **THANK YOU** to all the individuals who worked at the safe house and to the ESCIF members who helped accommodate refugees.



So far, we were able to transport 187 refugees to 5 ESCIF member countries e.g. Germany, Switzerland, Nederland, Finland, England. We are still looking for ESCIF members who could help with accommodation. If you could organise accommodation please write to: <a href="mailto:secretary@escif.org">secretary@escif.org</a>



Seeing what it meant for the guests to have a warm, welcoming and safe environment was overwhelming and shows how important the project is. Although there are much more people waiting to be evacuated we have due to resource constraints (staffing, accommodation and finances) to close the safe house end of September. However, the steering group (Stefan Jorlev, Kevin Schultes, Felix Schulte and Albert Marti) are already working on an in-country follow up project. For more info about the current project please visit <a href="https://www.protectthevulnerable.org">www.protectthevulnerable.org</a>.

## **Next ESCIF Forum: Transanal Irrigation, September 12<sup>th</sup>, 6pm**

Transanal Irrigation as regime for bowel management can be a "game changer" for people with a spinal-cord injury and paves the way for higher quality-of-life. Research shows that the bowel significantly affects daily life physically as well as psychologically; and research shows that more than 50% should consider contacting their healthcare professionals and discuss to change method of bowel management. Transanal Irrigation is unknown to potential users and many healthcare professionals. It is not a normal element of the follow-up procedures following a spinal-cord injury. RYK – Spinal-Cord Injured Denmark has published a set of videos to enlighten on this regime for bowel management.

The presenters in this forum will be: Stig Langvad, RYK – Spinal-Cord Injured Denmark & Klaus Krogh, MD, PhD, DMSc

To participate use this link: https://us06web.zoom.us/j/89349367626 or visit www.escif.org



#### Payment of membership- and congress fee

We would like to remind all ESCIF members that the membership- and congress fees are now due. If you have not yet paid please send this by the end of September the latest. The yearly membership fee is 375 euro.

#### **Project accessible electric car charging stations**

It is almost a year since we started the work on guidelines for accessible electric car charging stations. Unfortunately we waited a long time for additional expert information which just materialised last week. On top, the workload and priority for the Ukrainian SCI Relief project slowed the project down. But now we can move on. Until end of October we will create a subpage on our website with the project and all material we collected. Finally we will also create a flyer which highlights the problem of not accessible charging stations and can be distributed in all member countries.

#### Safe the date for next ESCIF congress:

The ESCIF board meat from 2<sup>nd</sup> to 3<sup>rd</sup> September in Thessaloniki in order to inspect the venue of next year's congress and to work on our future strategy. It was a very productive meeting and we saw a lot of good possibilities for the congress. We are sure that we will have an inspiring congress with good hospitality.



Please safe the date for our next annual meeting

in Thessaloniki, Greece. Date: Wednesday 31st May to Saturday, 3rd June 2023. Title: Reach

beyond your limits: Keep on wheeling. For more info please visit: www.thesspaspa.gr



## **Ambassador programm**

At the congress in Samorin members mentioned that it would be important to know their respective contact from the ambassador program. The goal of the ambassador program is to facilitate and improve the contact and information exchange among ESCIF members. Please find the current list at the end of the newsletter.

For the Executive Board

Stan O. John

Stefan Jorlev, ESCIF president



## **ESCIF** members and their ambassadors

	Mirjam	Bojana
	mirjam.kanalec@escif.org	bojana.gladovic@escif.org
Country	Croatia	Albania
Organisation	Hrvatska udruga paraplegičara i tetraplegičara	ALSCIA
		РРТТА
Country	Finland	Denmark
Organisation	Akson	RYK
	Invalidiliitto (The Finnish Association of People with Physical Disability)	UlykkesPatientForenin gen
Country	Italy	Germany
Organisation	FAIP – Federazione Associazioni Italiane Para-	FGQ
Country	Austria	Spain
Organisation	Verband der Querschnittgelähmten Österreichs – VQÖ	ASPAYM
Country	Netherlands	Spain
	Dwarslaesie Organisatie Nederland (DON)	Fundación LM
Country	Sweden	Slovakia
Organisation	Personskadeförbundet (RTP)	Paraplegické motivačné centrum
Country	Belgium	Turkey



Organisation	VZW	Turkish Spinal Cord Injury Association
Country	Slovenia	Cyprus
Organisation	Paraplegics Association of Slovenia	Cyprus paraplegics organization
Country	Bosnia & Herzegovina	Czech Republic
Organisation	Unija paraplegičara i oboljelih od dječije paralize BiH	CZEPA
Country	Norway	Czech Republic
Organisation	Landsforeningen for Ryggmargsskadde (LARS)	ParaCENTRUM
Country	Ireland	Switzerland
Organisation	Spinal Injuries Ireland	Schweizer Paraplegiker-Vereinigung
Country	England	Greece
Organisation	The Spinal Injuries Association (SIA)	Panhellenic association of paraplegics annex of Macedonia - thrace
Country	Lithuania	Romania
Organisation	Lithuanian Paraplegic Association	ROSCoS
Country	Scotland	Serbia
Organisation	Spinal Injuries Scotland	SPIKS
Country		Ukraine
Organisation		Agape