User manual Nordic Thorax Transplantation Registry

1. Thorax pre transplant

Find and enter the 'Nordic Thorax Transplantation Registry' menu.

ngs •	Misc - Reports -	Donor - Recip	ient - Liver Regist	try Forms 🕶 📃	Thorax Registry Forms 🕶			
_					Thorax pre transplant			
T	orax pre transplant				Thorax transplant		Search Add ne	ew Statistics Reset
	[Enter search parameters]				Thorax follow up Thorax acute rejection			
	Scandianumber:		Person number:		Thorax death reg.	Sex: 👻		
	Surname:				Filst name.			
	Country:		× .	Tx-center	:	*		
	AB0 blood group:	*	Rhesus D:	*				
	Scandianumber	Person number	Surname	First name	Tx-center	Pre tx-date	AB0 blood group	On wait.list
	Page 0 of 0	▶ ▶ Order by:	▼ Scandianumber▼	Treatmentno. 🔻	•			No data to display

When you enter the menu the first screen gives you the possibility to search for recipients that are or have been on the heart/lung waiting list.

You can search on one or combine parameters.

If you do not enter any search parameters and press search or enter you will get a list sorted by Scandia number with the recipients from your own country.

When you have found the recipient you wish to enter data on you click on the line containing recipient information.

rax pre transplant						Search Add	new Statistics Re
[Enter search parameters] —							
Scandianumber	:	Person number:	0202		Sex: 💌		
Surname	e:		Fi	irst name:			
Country	: S: Sweden	~	Tx-center:		*		
AB0 blood group		Rhesus D:	~				
Constitution to a	Denne sure bas	0	E-+	The same bar	Due be data	ADD bland arrows	On weit link
Scandianumber	Person number	Surname	First name	Tx-center	Pre tx-date	ABU DIOOD group	Un wait.list
*		Surname:	First name: A.	GO: Göteborg	09-Nov-2015	0	09-Nov-2015
A A Page 1 of 1	▶ ▶ Order by:	▼ Scandianumber▼	Treatmentno. 🔻 🔻				Displaying 1 - 1 of

2. Registration of information

Now you are able to register new data (and alter data) on the selected heart/lung recipient.

Thorax pre tx					Back	Save F	Reset
Scandia number :			Person number:				
Surname:	Surname: D.		First name: First	t name: G.			
Tx-center:	GO: Göteborg		Country: S: S	Sweden			
Last change:		13-Nov-2015					
Basic info. Diagnose and	status Medical history	Pre transplant Hemodynamic	Walk test+pulmonary func	Infection serology	HLA info.		
- Clinical measurements							
Most recent creatinine:	179 µmol/l		Most rec. creatinin cl. :	ml/sec			
Most recent bilirubin:	51.0 µmol/l		Measured GFR: 32.	0 ml/min 1,73m	2		
Oxygen req at rest:	N: No × ×	l/min	Most recent hemoglobin: 125	i.00 g/l 7.76	mmol/l		
							-
1							

Now and then please click on the save button. If you have made registrations that have not been saved yet the 'save button' will be displayed in black writing. If no alterations have been made the writing will be light grey.

3. Additional Pre transplant form

If you need an additional pre transplant form, please enter the Scandia number and click on the 'add new' button:

TÌ	iorax pre transplant						Se	arch Add new	Statistics	Reset
	[Enter search parameters]									
	Scandianumber:	192725	Person number:			Sex:	~			
	Surname:				First name:					
	Country:	S: Sweden	~	Tx-center:		~				
	AB0 blood group:	~	Rhesus D:	~						

A new empty form will appear.

4. Thorax transplant

The recipients you are able to find in the 'Thorax transplant' menu have been heart/lung transplanted in your own country.

or 🕶	Recipient - Liver	Registry Forms 🕶 📒	Thorax Registry Forms	•				
			Thorax pre transplant					
Thorax	transplant		Thorax transplant					Search Rese
_ [En	ter search narameters] _		Thorax follow up					
L Cu	iter search parameters]		Thorax acute rejection	ı				
	Scandianumbe	er:	Thorax death reg.					
	Surnam	e:		F	First name:			
	Tx-cente	er:	*	Country:)K: Denmark	*		
	Se	x: 💌	AB0 blood grou	up: 💙	Date of transplantation:	:		
	Scandianumber	Person number	Surname	First name	Tx-center	Person number	AB0 blood group	Date of transplant
\rightarrow	19:		Surname:	First name:	AR: Aarhus		0	02-Nov-2015
\rightarrow	19:		Surname:	First name:	CP: København		A	17-Oct-2015
\rightarrow	19:		Surname:	First name:	CP: København		0	17-Aug-2015

Click on the line with the recipient you wish to add, change and/or view data on.

Guiding text will appear where it is available.

Thorax transp	lantation							Back Sa	ive Reset
	Scandia number	:			Person number:				
	Surname	Surname:			First name:	First name:			
	Country	DK: Denmark			Tx-center:	AR: Aarhus			
Basics S	5ept. temperatu	re Haemodynamics	Early post-tx. info.	Post-tx. hospital events	Patient status	Donor info.	Donor infec.sero		
Date	of occurrence:	04-Nov-2015							
	Stroke:	N: No 💌		Perr	m. pacemaker: U	: Unknown	~		
	Dialysis:	N: No 💌		Ot	her surg proc: U	: Unknown	~		
	Reoperation:	Y: Yes 👻	Re-operation cause:					~	
Broncho	opleural fistula:	U: Unknown 🛛 🗙 🔽	Select yes if the patient developed a bronchopleural fistula during the initial hosp. following the						
Prol gra	aft dysfunction:	N: No	transplant operation.						~
		U: Unknown							
Any drug	g tr. rejections:	Y: Yes			P	: Unknown	•		
Infections									
1	Туре			Focus Comments					
V	BAS: Bacterial sepsis			LU					
-									

5. Thorax Follow-up

Add new follow up

To add a new follow you need to enter the Scandia number in the 'Enter search parameters' area and clicking on the 'Add new' button.

Th	orax follow up								Search	Add new Reset
	[Enter search parameters]									
	Scandianumber:	180082	Pers	on number:						
	Surname:				F	First name:				
	Country:	DK: Denn	nark	•	Tx-center:		*	Follow up no.	.:	
	Sex:		¥	ABO blood group:	~	Tx.	date:			
	Scandianumber Persor	n number	Surname	First name	Tx-center	Follow up no.	Person number	AB0 blood gr	Tx. date	Date of follow
	■ Page 1 of 18		Order by: 🔻 S	candianumber▼ Tre	atment number	▼ Follow up no.▼			Displa	iying 1 - 25 of 442

If you do not have the Scandia number, you can find it by entering the 'Thorax transplant' menu and search on the person number. You can now start entering information

Thorax fo	llow-up						Bac	k Save	Reset
	Scandia number	18			Person number:				
	Surname	Surname:			First name:	First name:			
	Country	DK: Denmark			Tx-center:	CP: København			
Basic	Graft function	Immunosuppression	Post tx. events	Renal function					
	Sex:	F: Female		AB0 blood group:	A	Rhesus D:	POS		
	HLA-A:	2		HLA-B:	7 40	HLA-DR:	13	2	
	Tx. date:	24-Nov-2013			Last change:				
— Follow	Date of follow up	:			Follow up no.:				~
— Death r	reg.				17.110.1			1	
	Date of Death Prim. cause	:			Cause of Death:				
— Clinical	info. Weight			Height:	150	BM	11:	ka/m²	
Sy	stolic blood pressure	:		Traight	Diastolic blood pressure:	:			

View/alter old follow up

Enter Scandia number or/and person number and click on search. If follow up has been registered on the recipient they will appear on the list.

horax fo	llow up								Search	Add new Rese
Ente	r search parameter	s]								
	Scandianur	nber:	Pe	arson number: 09	0653					
	Surn	ame:			Firs	t name:				
	Cou	ntry: DK: Den	mark	~	Tx-center:		~	Follow up no.	:	
		Sex:	~	AB0 blood group	p: 💙	Tx. d	date:			
	Scandianumber	Person number	Surname	First name	Tx-center	Follow up no.	Person number	AB0 blood gr	Tx. date	Date of follow
⇒	180		Surname:	First name:	CP: København	2		A	24-Nov-2013	10-Nov-2015
\Rightarrow	180		Surname:	First name:	CP: København	1		А	24-Nov-2013	01-Nov-2015
	Page 1 o	f1 [🕨 🕅	Order by: 🔻 S	Scandianumber▼ Tr	reatment number▼ Fo	ollow up no.▼			Di	splaying 1 - 2 of 2

6. Thorax acute rejection

Add new acute rejection

To add a new acute rejection you need to enter the Scandia number in the `Enter search parameters' area and clicking on the `Add new' button.

Thorax acute rejection							Search	Add new	Reset
[Enter search parameters]									
Scandianumber:	180082	Person number:			Sex:	~			
Surname:			Fi	rst name:					
Country:		v	Tx-center:		*				
Scandianumber Reject	tion nu WL	Person numb	er Surname	First name	Tx-center	Person number	Date of rej.	Tx. date	
Page 0 of 0	▶ ▶ Order by:	▼ Scandianumber▼	 Rejection number 	•				No data to dis	play

If you do not have the Scandia number, you can find it by entering the 'Thorax transplant' menu and search on the person number.

You can now start entering rejection information

Rejection				
R	ejection number:	Date:		Biopsy proven:
— ISHLT reje	ction code			
	Heart:			Lung:
	Antireje	ection immunosu	ppression	
	Immuno suppresion code	(Comments	
	ALG: Anti-lymphocyte globulin			
	ASA: Acetic salicylic acid			
	ATG: Anti-thymocyte globulin			
	AZA: Azathioprin			
	ATRA A 12			

View/alter old acute rejection registration

Enter Scandia number or/and person number and click on search. If follow up has been registered on the recipient they will appear on the list.

7. Thorax death

If you wish to view details or register a recipient death you start by searching for the recipient.

gs 🕶	Misc • Reports •	Donor - Recipien	it - Liver Registry Form	15 🕶 📄	Thorax Registry F	Forms 👻			
_				_	Thorax pre trar	nsplant			
Th	orax death reg.				Thorax transpla	ant			Search Rese
					Thorax follow u	ıp			
	— [Enter search parameters] —				Thorax acute re	ejection			
	Scandianumber	r: 180	Person number:		Thorax death r	eq.	Sex:	~	
	Surname	9:	riist name.						
	Country	/:	▼ T)	x-center:			*	Tx-type:	~
	Scandianumber	Surname	First name	Tx-cente	r	Person r	number	Tx-type	Tx. date
	⇒ 180	Surname:	First name:	CP: Købe	enhavn			LU: Lung	24-Nov-2013
	[4 4 Page 1 of 1	Order by:	🛡 Scandianumber 🔻 🔻						Displaying 1 - 1 of 1

Click on the specific recipient and enter death data information.

Thorax de	ath registration					Back Save F	Reset
	Scandia Number:	18(Person number:		Sex:	F: Female	
	Surname:	Surname		First name:	First name:		
	Country:	DK: Denmark		Tx-center:	CP: København		
	Treatment number:	1		Treatment type:	Lung		
ISHLT	Prim. cause	: 2001: Graft Failure: 👻		Sec. cause	-		
	Comments						
	Cause of Death: Date of Death:	02: Primary graft failure	×	Status:	T: Dead after waiting list termi	ination 🗸	