

Updates in existing

modules

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New module and QC

News from Scandiatransplant office

December 2016

Introduction

Main topics in this newsletter

- Updates in existing YASWA modules
 - Pediatric liver and multivisceral waiting list
 - New causes of export and 'No liver splitting' added
 - o Genomic haplotype/CWD alleles
 - Room for more characters in genomic HLA type registration

New

- o Nordic Pediatric Renal Registry ready soon
- QC Patient missing urgency status

All previous newsletters can be found on the Scandiatransplant web page

http://www.scandiatransplant.org/news/newsletters

Content

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Purpose

By this information letter, we wish to communicate to you about status and progress related to the database, collaboration with groups related to Scandiatransplant and on-going working projects.

We hope that you will read it and share the information with whom it might concern.

Do not hesitate to contact us for further information, ideas, problems and help.

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Updates in existing YASWA modules

Pediatric liver and multivisceral waiting list

It has been decided by NLTG to include the multivisceral patients on the Pediatric Liver waiting list, as they have been previously.

Multivisceral recipients on the The common Nordic WL

Thus, the menu entrance in YASWA has changed name from 'Pediatric liver waiting list' to 'Pediatric liver and multivisceral waiting list'.

ng donor 🕶	Quality Control 🕶	Recordings -	Misc 🕶	Reports •	Donor 🕶	Recipier	nt 🔹 🛛 L	iver Registry
Pediatric li	ver and multiviscera	l waiting list			_			transplantati d multiviscer
	search parameters] — nor AB0 Blood Group	:	~			Kind I	nt waiting li requests scipients	st
						Searc	h for suitat	ole kidney rec
Sca	ndi Cance Wait	Perso U	rgency	Name		AB0	Entry	Last change

Furthermore, it was made possible in June 2016 to register which 'other' abdominal organs the multivisceral patient is waiting for.

And now the possibility to select if the patient should appear on the 'Pediatric liver and multivisceral waiting list' has been introduced.

Primary diagnosis: SI	BS: Short bowl syndrome			~			
Old diagnosis:							
Other Waitinglist							
Stomach:		Pancreas:	\checkmark	Small intestine:	1	Large bowel:	
Liver:		Spleen:		Kidney:		Other:	

If 'Yes' is selected for 'On ped. Liver and MV list', the recipient will appear as 'Other' on the 'Pediatric liver and multivisceral waiting list' along with the pediatric liver patients.

[Enter searc		· _										
Donor A	B0 Blood (Group:		~								
Scandi	Cance	Wait.d	Perso	Urgency	Name	AB0	Entry	Last change of ur	Tx-ce	Height	Weight	Treat Age
⇒ 1	N: No	1087		T: Transplantable		0	10-De	10-Dec-2013 00:00	CP: Kø	160	61	LI: Liver
⇒ 1	N: No	724		T: Transplantable		0	08-De	08-Dec-2014 00:00	CP: Kø	161	44	LI: Liver
⇒ 1	N: No	566		T: Transplantable		0	15-Ma	15-May-2015 00:00	CP: Kø	126	28	LI: Liver
⇒ 1	N: No	294		T: Transplantable		0	10-Fe	10-Feb-2016 13:40	HE: H	132	30	OT: Ot
⇒ 1	N: No	182		T: Transplantable		0	02-Jun	02-Jun-2016 16:30	ST: St	134	29	LI: Liver
⇒ 1	N: No	176		T: Transplantable		0	08-Jun	08-Jun-2016 10:34	GO: G	129	29	LI: Liver
⇒ 1	N: No	168		T: Transplantable		. 0	16-Jun	16-Jun-2016 11:22	CP: Kø	108	18	LI: Liver
⇒ 1	N: No	161		T: Transplantable		0	22-Jun	23-Jun-2016 08:48	GO: G			OT: Ot
⇒ 1	N: No	161		T: Transplantable		в	23-Jun	23-Jun-2016 15:24	CP: Kø	160	76	LI: Liver
⇒ 1	N: No	155		T: Transplantable		0	29-Jun	29-Jun-2016 11:42	CP: Kø	162	45	LK: Liv
⇒ 1	N: No	127		T: Transplantable		0	27-Jul	27-Jul-2016 10:19	GO: G	168	65	LI: Liver
⇒ 1	N: No	91		T: Transplantable		0	01-Se	01-Sep-2016 16:07	ST: St	165	34	LI: Liver
⇒ 1	N: No	52		T: Transplantable		А	10-Oct	10-Oct-2016 12:04	HE: H	168	62	LI: Liver
⇒ 1	N: No	14		T: Transplantable		0	17-No	17-Nov-2016 17:12	ST: St	89	14	LI: Liver
⇒ 1	N: No	14		T: Transplantable		. 0	17-No	17-Nov-2016 13:26	CP: Kø	161	46	LK: Liv
⇒ s	N: No	10		T: Transplantable		0	21-No	21-Nov-2016 16:12	HE: H	178	64	LI: Liver
⇒ 1	N: No	7		T: Transplantable		A	24-No	24-Nov-2016 14:45	GO: G			OT: 0t

Multivisceral recipients listed as 'Other' Guidelines have been updated

New organ export cause and reason for

not splitting liver

The Liver exchange and pay back rules have been updated accordingly: <u>http://www.scandiatransplant.org/organ-</u> <u>allocation/NLTG_Exchange_payback_rules_01_dec_2016.p</u>

<u>df</u>

New causes of export and 'No liver splitting' added

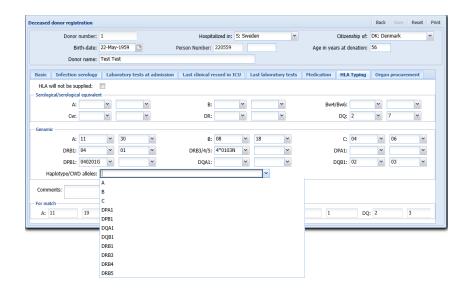
In relation with the Common Nordic Pediatric liver and multivisceral waiting list a few new causes have been added:

New organ export cause: 11: Pediatric liver and MV waiting list

<u>New causes for not splitting the liver:</u> R: Offered but refused by recipient center P: Pediatric donor liver to pediatric recipient

Genomic haplotype/CWD alleles

In all HLA registration screens a new field 'Haplotype/CWD alleles' has been added, as it was decided at the latest tissue typers meeting that best guess (according to haplotype/common-well documented alleles list) on High Resolution result may be added to database. However, it is important to state which results are guessed instead of true High Resolution results.



New field in genomic HLA registration

Room for more characters in genomic HLA type registration

Additional space for characters have been created in the database for genomic HLA type registration.

Please do not hesitate to contact us, if HLA types are missing on the list.

Basic Infection	serology	Labo	oratory test	s at admi	ssion Last clinical r	ecord in ICU	Last laboratory test	s Medication HL	A Typing	Orga	n procu	rement
HLA will not be su	ipplied: 📃	1										
Serological/serologica	al equivalent											
A:		*		~	B:	*	*	Bw4/Bw6		~		~
Cw:		*		*	DR:	~	~	DQ	2	~	7	~
Genomic												
A:	11	~	30	~	B:	08 🗸	18 👻	C	04	*	06	~
DRB1:	04	~	01	~	DRB3/4/5:	4*0103N 💙	~	DPA1		*		*
DPB1:	040201G	~	10501	~	DQA1:	~	*	DQB1	02	*	03	*
Haplotype/CW	D alleles:						*					
Comments:						Calc.	Bw: w6					
For match												
A: 11	19		B: 8		18 Cw: 4	4 6	DR: 4	1	D	Q: 2		3

New

Nordic Pediatric Renal Registry

Nordic Pediatric Renal Transplantation Study Group (NPRTSG), a Scientific subgroup of NKG, has for many years had a follow up registry and in July 2010 the registry were incorporated into the Scandiatransplant database.

The registry was not converted to the new user interface (YASWA) as it needed a major revision.

The new revised registry is now going through the final test runs and will soon be available in production.

QC - Patient missing urgency status

A new QC is now available from the Quality Control menu, it lists all patients which have had the initial waiting list information registered, but have no urgency on the waiting list (= the patienten is not on the waiting list).

HLA typing registrations with more digits

Nordic Pediatric Renal Registry - Final test runs

New quality control