News from Scandiatransplant office

May 2016

Introduction

Main topics in this newsletter

- Updates in existing YASWA modules
  - New parameter in infection serology - Anti-MV IgG (Morbilli virus antibody)
  - Liver registry – New QC
  - Temporarily of the waiting list for a specified period

- NEW Articles of Association Scandiatransplant

- First step - Information on urgent heart, lung and liver patients by SMS and email

All previous newsletters can be found on the Scandiatransplant web page
http://www.scandiatransplant.org/news/newsletters

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4 The articles of the Association Scandiatransplant
5 Urgent patient information on SMS and email

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.

Scandiatransplant
Aarhus Universitetshospital, Skejby
8200 Aarhus N
Denmark
www.scandiatransplant.org
Updates in existing YASWA modules

New parameter in infection serology - Anti-MV IgG (Morbilli virus antibody)

In all infection serology entries donor, recipients and follow up registries anti-MV IgG – Morbilli virus antibody has been added.

<table>
<thead>
<tr>
<th>Specific data</th>
<th>Infection serology</th>
<th>Urgency History</th>
<th>Termination</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Infection serology</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serology Code</td>
<td>Result</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CMV: Anti-CMV (Cytomegalovirus)</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EBV: Anti-EBV IgG (Epstein-Barr)</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HBe: Anti-HBe (antibody)</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HBlm: Hepatitis B vaccinated</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HBlmAb: Anti-HBlm (antibody)</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HBlmAg: Hepatitis B antigen</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HCV: Anti-HCV (antibody)</td>
<td>ND: Not done</td>
<td></td>
<td></td>
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<tr>
<td>HCVAg: Hepatitis C antigen (RNA)</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIVb: Anti-HIV (antibody)</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIVag: HIV antigen</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LUES: Syphilis antibody</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MV: Anti-MV (Morbilli virus antibody)</strong></td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOXO: Toxoplasma antibodies</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VZV: Varicella zoster virus</td>
<td>ND: Not done</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Liver registry – New QC

A new quality control has been added in the database which discloses living liver donor were split usage have not been registered. We urge you to follow up on these missing registrations.
Temporarily of the waiting list for a specified period

On patients with an active kidney, kidney-pancreas or pancreas waiting list you now have the following possibilities:

- When the patient is transplantable –> To set a future temporarily withdrawn date
- When the patient is transplantable –> To set a future temporarily withdrawn date in combination with a future re-entry date
- When the patient is not transplantable –> To set a future activation data

When the patient is transplantable –> To set a future temporarily withdrawn date

You enter a future date in ‘Future Withdrawn from’ from which the patient will be not transplantable. If you insert 24-May-2016 the status will change at midnight between the 23rd and 24th of May.

When the patient is transplantable –> To set a future temporarily withdrawn date in combination with a future re-entry date

You enter a future date in ‘Future Withdrawn from’ from which the patient will be not transplantable and you enter a date in ‘Future Withdrawn to:’ at which date the patient will be active on the waiting list again.
When the patient is not transplanable -> To set a future activation data

You enter a date in ‘Future Withdrawn to:’ at which date the patient will be active on the waiting list again.

(You also need to enter a future date in ‘Future Withdrawn from’, however the patient will stay inactive until ‘Future Withdrawn to’ date)

The urgency status ‘WU: Temporarily Withdrawn until’ will stay unchanged meaning that the patient will be temporarily withdrawn when you save data until the ‘until’ specified date.

The Articles of the Association Scandiatransplant

At the Scandiatransplant Council of representatives meeting May 11, 2016 the revised articles were presented and approved. The major changes being rewriting of the purpose of Scandiatransplant, changing how the composition of the council is calculated, medical decisions are placed in groups, addition of an article on the office, groups and possibility of associate membership.

The new articles are now available on the Scandiatransplant homepage for all to read:

http://www.scandiatransplant.org/about-scandiatransplant/organisation/ArticlesofAssociationforForeningenScandiatransplant.pdf
First step - Information on urgent heart, lung and liver patients by SMS and email

The office has started working on a solution for sending out information by SMS and mail on urgent heart, lung and liver recipients, instead of fax that is currently used.

When a recipient changes status in YASWA to or from urgent an email and a SMS is sent to all coordinators that currently receives organ offers.

The email contains the following recipient information: waiting list type, urgency status change, Scandinavian number, age, blood group, gender, weight, height and diagnosis.

Example

WL-type Li: Urgency HU to T
To: lise.duus.wenreich@scandiatransplant.org

SMS notification to: 4525535823
RECIPIENT INFORMATION - change of urgency
From: HU Highly urgent (to be transplanted within 3 days)
To: T Transplantable
Scandinumber:
Age: 66, Blood group: A
Gender: F, Weight: 55, Height: 168
Urgentic: A/A Post-operative

NEW URGENT-LIST:
Heart SCF1013: Center: DD ABO: O Highly Urgent (mechanical assist) changed 24-May-2016 08:19 Weight: 104 Height: 176
Liver SCF195: Center: DD ABO: A Urgent (to be transplanted within 3 days) changed 19-May-2016 10:23 Weight: 55 Height: 170
Liver SCF194: Center: DD ABO: O Highly urgent (to be transplanted within 3 days) changed 24-May-2016 08:19 Weight: 104 Height: 176
Liver SCF195: Center: DD ABO: A Urgent (to be transplanted within 3 days) changed 23-May-2016 11:10 Weight: 81 Height: 168
Liver SCF95: Center: DD ABO: A Urgent (rapid progression of lung failure) changed 21-May-2016 19:23 Weight: 75 Height: 164

The SMS only contains information on waiting list type and urgency change.

Examples:

WL-type Li: Urgency HU to RQ
Full message mailed to: lise.duus.wenreich@scandiatransplant.org

WL-type HE: Urgency 3 to 0
Full message mailed to: lise.duus.wenreich@scandiatransplant.org

WL-type Li: Urgency NIA to HU
Full message mailed to: lise.duus.wenreich@scandiatransplant.org

WL-type Li: Urgency HU to T
Full message mailed to: lise.duus.wenreich@scandiatransplant.org

Please know that this is the first step, more information will be included (donor requirements, more recipient information etc.) and you should keep your current solutions running parallel until further notice.