

Pediatric Programme

1. Long-Term Outcomes of Pediatric Liver Transplantation (PLTx)

○ Presentation by VBC Copenhagen:

- Historically, **Biliary Atresia (BA)** patients had the poorest outcomes, but currently, patients with **Inborn Errors of Metabolism (IEM)** present more challenges.
- Quality of Life (QoL) improves significantly for IEM patients post-transplant.
- Proposal to hold **quarterly meetings** with Scandi transplant colleagues to discuss outcomes and protocols.
- Suggestion to implement **QoL measurements** and integrate them into the **YASWA** system.

○ Discussion:

- No current QoL measurements in Scandi transplant centers (Helsinki not present to comment).
- Debated the use of specific questionnaires (e.g., SickKids) vs. generic ones (e.g., PedsQL) for internal and external comparisons.
- **Consensus** on the importance of starting QoL measurements.
- **Carl:** The PETER registry may have translated QoL questionnaires available.
- **Pål Dag (Oslo):** Emphasized the need for planned procedures and the use of living donors; mortality risk for segments S2-3 donation is comparable to kidney donors.
- **Nicolai (Copenhagen):** Suggested exploring **S3 living donation**.
- Proposal to start using **Mid-Upper Arm Circumference (MUAC)** as a growth measurement in YASWA.
- Interest in comparing **PLTx protocols** across Scandi transplant centers.
- **Action Items:**
 - **Carl** will send the Swedish national protocol.
 - Oslo to share specific follow-up programs for IEM transplants.

1. Databases and Regulation

- **Ilse** previously addressed this topic.
- Agreement to report to the **European Reference Networks (ERN)** through YASWA.

2. Vaccination Programs

- **Presentation by CW** on vaccination responses in liver, kidney, and heart-transplanted children from Copenhagen.
- **Discussion:**
 - **Gothenburg:**
 - Administers **Varicella-Zoster Virus (VZV)** vaccine post-transplant with criteria slightly stricter than the Suresh paper.
 - Plans to start **measles vaccination** soon.
 - Monitors vaccination antibodies annually.
 - **Stockholm:**
 - Does not use live attenuated vaccines post-transplant.
 - Administers inactivated vaccines after one year.
 - Concerned about vaccinating children on high immunosuppression.
 - **Gothenburg:** Gives live vaccines from **six months** post-transplant.
 - **Copenhagen:** Plans to follow the **Suresh guidelines** for live vaccines.
 - **Carl (Stockholm):** Inquired about the **Number Needed to Treat (NNT)** to prevent infection through vaccination.
 - **Pål Dag (Oslo):** Supports vaccination; rejection issues are minimal. Mentioned a recombinant varicella vaccine per adult nephrologists.
 - **Silvia (Stockholm):**
 - Highlighted that while varicella is treatable, measles is not, making safety data on MMR vaccines crucial.
 - Noted measles are still uncommon in the Scandiatransplant area.
 - **Sweden:** All children receive the **rotavirus vaccine** at six weeks of age.
 - **Denmark:** Hepatitis A and B vaccinations are not standard.
 - **COVID-19 and Influenza Vaccinations:**
 - Sweden does not administer COVID-19 vaccines to transplanted children.
 - Influenza vaccines are given to families 6 months to one year post-transplant if the season aligns.

3. Metabolic Diseases and Liver Transplantation

- **Covered** during the long-term outcomes presentation.

- **General Discussion:**

- Progress on pediatric follow-up data in YASWA.
- **Ilse** to contact **William** to obtain list of suggested additional pediatricians variables in NLTR to be shared with NPLTG.
- Policies on patients returning to institutional care vary from 6 months to 1 year, trending towards less restrictive practices.
- **Carl:** Shared a new Swedish national guideline on "levnadsråd" (lifestyle advice).
- **Sweden:** Has provided **IVIG** to patients traveling to areas like the Middle East who may not have been vaccinated.
- Discussed potential **interactions between cranberries and tacrolimus.**
- **Travel Recommendations Post-Transplant:**
 - Norway advises **no travel in the first year.**
 - Travel to Europe and the U.S. is considered acceptable.

Any Other Business (AOB)

- **Pediatric Research:**
 - **VBC** to provide updates on research initiatives.

Action Points Summary:

- **Carl** to send the Swedish national PLTx protocol.
- **William** for status on additional pediatric parameters in NLTR.
- Centers to consider implementing QoL measurements and MUAC in YASWA.
- Further discussion on standardizing vaccination protocols across centers.

List of participants

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