NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

LIVER ADVISORY GROUP

UPDATE ON THE PRIORITISED PAEDIATRICS REGISTRATION TIER

1. A process to formally prioritise clinically deteriorating paediatric paediatrics was successfully introduced in October 2020. The process is shown in **Appendix A** and is also on the ODT website (https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/policies-and-guidance/). Transplant centres are responsible for ensuring patients meet the eligibility criteria and deciding whether the patient should be removed from the waiting list.

2. As at 1 November 2023, there have been 31 requests for formal prioritisation with 30 UK elective registrations on the Prioritised Paediatric tier since October 2020. Mean age of patients was 4 years (range 0 - 17). **Figure 1** shows the registration outcome as at 23 November 2023 and shows that 29 patients received a DBD liver only transplant and 1 patient received a living donor transplant.

3. The median waiting time to transplant was 8 days and ranged between 2 and 246 days.

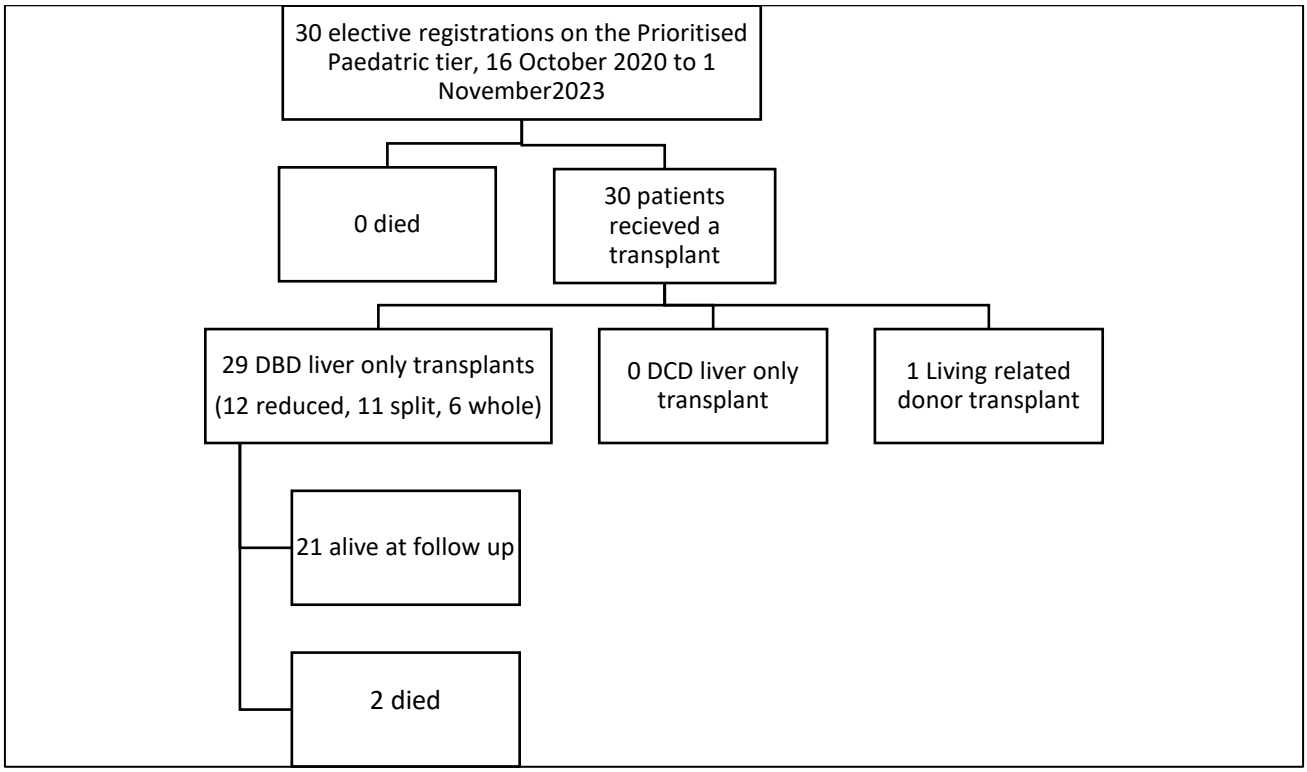
4. Of the 29 transplanted patients who received a liver from a donor after brain-death, 21 were known to be alive at their last follow up. Two patients passed away 384 days and 129 days post liver transplant respectively.

5. There was one patient who received a transplant through living donation of a relative.

6. Median patient survival for the 23 recipients with follow up information was 304 days (range 66-929; mean 334). Median length of post-transplant ICU stay was 8 days (range 1-62; mean 14) and median length of hospital stay was 29 days (range 9-85; mean 36).

7. One patient was requested to join the prioritised paediatric registration tier on 24th October 2023 but was subsequently not agreed.

Figure 1 Registration outcome for 30 UK elective registrations on the Prioritised Paediatric tier, 16 October 2020 to 1 November 2023



8. **Table 1** summarises registration and post-transplant outcomes for the 30 UK elective registrations on the Prioritised Paediatric tier. Registrations since the last report are highlighted.

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23 November 2023

Table 1 **Summary of registration and post-transplant outcomes for the 30 patients who were registered on the Prioritised Paediatric tier between 16 October 2020 – 23 November 2023, as at 23 November 2023**

Patient number	Centre	Age at registration	Primary liver disease	Registered prior to Prioritised elevation?	Registration outcome	Donor type if transplanted	Time on Prioritised waiting tier	Overall time on list prior to Prioritised elevation	Post-transplant outcome
1	1	0	Cryptogenic Cirrhosis	Yes	Transplanted	DBD	5	27	Alive post LT day 630
2	2	1	Cryptogenic Cirrhosis	Yes	Transplanted	DBD	16	48	Alive post LT day 721
3	1	15	Chronic Rejection	Yes	Transplanted	DBD	3	4	Alive post LT day 929
4	2	0	Biliary Atresia	Yes	Transplanted	DBD	14	71	Died post LT day 384
5	2	4	Other	No	Transplanted	DBD	15	-	Alive post LT day 741
6	2	0	Biliary Atresia	Yes	Transplanted	DBD	37	405	Alive post LT day 767
7	2	10	Neonatal Sclerosing Cholangitis	Yes	Transplanted	DBD	4	7	Alive post LT day 297
8	3	8	Paediatric cholestatic liver disease	Yes	Transplanted	DBD	6	51	Alive post LT day 404
9	1	0	Other	No	Transplanted	DBD	11	-	Died post LT day 129
10	2	0	Biliary Atresia	Yes	Transplanted	DBD	10	120	Alive post LT day 379
11	1	0	Biliary Atresia	Yes	Transplanted	DBD	9	4	Alive post LT day 312
12	3	0	Biliary Atresia	Yes	Transplanted	DBD	12	323	Alive post LT day 359
13	1	17	Hepatic Artery Thrombosis	No	Transplanted	DBD	2	-	Alive post LT day 48
14	2	0	Biliary Atresia	Yes	Transplanted	DBD	82	65	Alive post LT day 393
15	2	12	Progressive familial intrahepatic cholestasis	Yes	Transplanted	DBD	12	27	Alive post LT day 114
16	1	0	Biliary Atresia	Yes	Transplanted	DBD	23	49	Alive post LT day 71
17	3	0	Biliary Atresia	Yes	Transplanted	DBD	4	13	Alive post LT day 92
18	2	0	Biliary Atresia	Yes	Transplanted	DBD	3	65	-
19	3	4	Neonatal Sclerosing Cholangitis	Yes	Transplanted	DBD	3	55	-
20	3	13	Alagilles syndrome	Yes	Transplanted	DBD	4	192	Alive post LT day 120

21	2	1	Hepatoblastoma	No	Transplanted	DBD	246	-	-
22	2	12	Hepatoblastoma	Yes	Transplanted	DBD	6	1	Alive post LT day 90
23	1	15	Other	Yes	Transplanted	DBD	11	7	Alive post LT day 154
24	1	0	Biliary atresia	Yes	Transplanted	DBD	2	31	Alive post LT day 137
25	1	9	Other	Yes	Transplanted	DBD	43	29	Alive post LT day 72
26	1	0	Biliary atresia	Yes	Transplanted	DBD	2	35	Alive post LT day 66
27	1	0	Alpha-1-antitrypsin deficiency	Yes	Transplanted	DBD	3	19	-
28	2	0	Biliary atresia	Yes	Transplanted	DBD	7	462	-
29	3	0	Hepatoblastoma	Yes	Transplanted	Living related	12	24	-
30	3	10	Progressive familial intrahepatic cholestasis	Yes	Transplanted	DBD	3	111	-

APPENDIX A: from the Hepatoblastoma, Prioritised Paediatric and ACLF Registration Process – SOP5907

Introduction

Weekly teleconferences were established in April 2020 involving adult and paediatric representation from all 7 UK liver transplant centres and NHS England to discuss and maintain a national liver transplant service during COVID-19. Requests were received from all three paediatric centres to either formally or informally prioritise individual paediatric patients who are clinically deteriorating but do not meet the super-urgent criteria.

Informal prioritisation allows a paediatric centre with support of one or both of the other paediatric centres to seek prioritisation of a specific recipient and to receive offers of organs made to another paediatric centre for that informally prioritised recipient. It should be noted that transplant centres maintain the responsibility to ask ODT Hub Operations to offer to the transplant centre where the patient is registered when offered organs. The patients position on the transplant list will not be changed.

Formal prioritisation of paediatric recipients requires agreement of all three paediatric centres. If unanimously agreed, paediatric patients formally prioritised would be registered in the hepatoblastoma tier after genuine hepatoblastoma tier.

Note that this is for paediatric patients aged 16 years or under.

Approval

Requests to formally prioritise paediatric patients who are clinically deteriorating will be managed and overseen by the requesting transplant centre who will provide the following with information required

- agreed representatives from the other UK paediatric transplant centres
- Chair and Deputy Chair of the National Appeals Panel
- Head of Service Delivery - ODT Hub
- Lead Statistician for Liver Transplantation

The request should include patient identifiable data (e.g., hospital number, NHS number, date of birth, initials), age, weight and ODT recip_id (if applicable).

It is anticipated that a decision should be made within 72 hours. Once agreed, the registration (including amendment) process below should be followed within working hours Monday to Friday.

Registration

Transplant centres wishing to register a prioritised paediatric patient should complete the Elective Liver Recipient Registration Form (FRM4332) with the following indications and submit the form to NHS Blood and Transplant on ODT Online.

- 444 (hepatoblastoma) as primary indication
- True primary disease as secondary indication

- 498 (Other, please specify) as tertiary indication with "PRIORITISED PAEDIATRIC PATIENT" in the free text

Transplant centres should subsequently email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) after submitting the form to inform ODT Hub: Information Services that they have registered a prioritised paediatric patient *along with the agreement from the other centres*.

Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Research during working hours (10am - 4pm Monday - Friday).

Also, note that a report is automatically produced every day showing the patients that are active on the elective transplant list with hepatoblastoma as the primary indication. Therefore, transplant centres should be aware that although the patient will appear on the active elective waiting list once the registration form is committed, they may not appear in the correct position on the hepatoblastoma tier until additional waiting time is added and there may be a delay if transplant centres do not email ODT Hub: Information Services.

ODT Hub: Information Services will then contact Statistical Enquiries (statistical.enquiries@nhsbt.nhs.uk) and the Lead Statistician for Liver Transplantation to confirm the type of patient. Either the Statistical Enquiries Lead or Lead Statistician for Liver Transplantation will check that the patient is a prioritised paediatric patient and, if necessary, confirm with the transplant centre.

The process above should be followed for both new patients and patients already registered on the liver transplant list.

Additional Waiting Time

Once confirmed, a Lead from Statistics & Clinical Studies will email ODT Hub: Information Services to inform them that it has been confirmed and that 5000 additional waiting days should be added.

If it is confirmed that the patient is not a prioritised paediatric patient but is either genuine hepatoblastoma or has ACLF then the Lead from Statistics & Clinical Studies will email ODT Hub: Information Services and the transplant centre to inform them of any changes required to the registration form and that 9000 and 0, respectively, additional waiting days should be added.

ODT Hub: Information Services will confirm receipt of the email and add the additional waiting time. The waiting time will be automatically updated when the waiting time batch-job is next run. The additional waiting time will be removed, as per SOP3839, once the transplant centre confirms the patient has received a liver transplant