

# Results From a Multicenter Survey on PTLD in Pediatric OHT Patients at Pediatric Heart Transplant Study (PHTS) Centers: Should There be a National Consensus on Screening for, Treating and Surveillance of Pediatric Patients with PTLD?

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# Disclosures: None



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# Background

- Post-transplant lymphoproliferative disorders (PTLD) are an unfortunate complication that can occur in pediatric OHT patients.
- Currently there are no widely-accepted guidelines in pediatric OHT patients for:
  - Screening for PTLD
  - Treating PTLD
  - Post-treatment surveillance after PTLD.



# Prior literature

- A 16 year multi-institutional study was performed looking at the role of EBV status on PTLN incidence in the the 3170 pediatric primary heart transplants between 1993 and 2009 (Chinnock et al, 2012).
  - There were 35 PHTS institutions at the time
  - 151 first malignancy events reported, and of these 147 were PTLN.

Chinnock et al. **A 16-Year Multi-Institutional Study of the Role of Age and EBV Status on PTLN Incidence Among Pediatric Heart Transplant Recipients.** *American Journal of Transplantation* 2012



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# Objectives

1. Search for overall practice trends in PHTS institutions in identifying, treating, and following their patients who are diagnosed with PTLD.
2. Describe the collective experiences of these institutions regarding their patients who have developed PTLD.
3. Determine if further research is needed to develop treatment and surveillance guidelines.



# Methods

- Study design
  - Multi-center, retrospective, anonymous survey sent by email in March 2019 to all PHTS institutions
  - Data transfer through REDCap
- 23 of 56 PHTS institutions answered at least part of the survey.
- All questions were aimed towards illustrating each institution's collective experience with PTLD in their OHT patients
- Survey questions and answers did not include any patient- or institution-identifying information.



# Methods

- Definitions
  - **Induction therapy:** A lymphocyte cytolytic agent used at the time of transplant



# Results – Transplant Induction therapy

- The most common induction therapy used by 19 respondents was Rabbit ATG (17) and basiliximab (6).
- 14 of 20 respondents give induction therapy to all patients prior to transplant, and 3 give induction therapy to patients with high PRAs.





# Results – Making the Diagnosis

- **All 23 participating institutions indicated that PTLD cannot be diagnosed solely based on high EBV load.**
  - All but two of 18 respondents did not have lab value cut-offs for a positive diagnosis of PTLD.
- Whole blood quantitative EBV PCR was the most common EBV PCR used (15 of 19 respondents)
- **13 of 18 respondents indicated that the only routine screening lab they use to screen for PTLD is EBV PCR.**
- 6 of 18 respondents screen for EBV routinely at every or every other clinic visit, 7 routinely screen more than once a year, but less than every other clinic visit and 3 screened EBV annually.



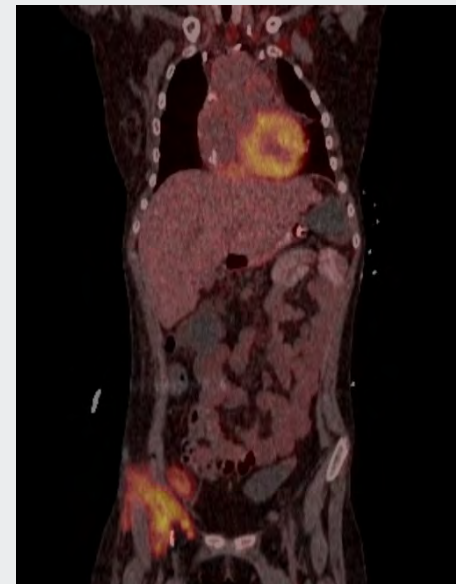
# Results – Making the Diagnosis (continued)

- Most of the 19 respondents did not routinely screen any particular sub-populations of pediatric OHT patients for PTLD more closely.
- Amongst 19 respondents, the most common post-discharge indications for obtaining a CT and/or PET scan in OHT patients were:
  - Substantially elevated EBV viremia of any level (9)
  - Persistent substantially elevated EBV viremia (8)
  - Only when PTLD was clinically suspected (7).



# Results – Post diagnosis surveillance after initial diagnosis of PTLD

- Of the 17 respondents:
  - 7 followed LDH
  - 14 followed EBV PCR
  - 11 followed serial CT imaging
  - 10 followed serial PET scan imaging
  - 1 followed clinical impression only.



PET scan of a pediatric OHT patient with PTLD



# Results – Treatment

- **Reduction of immune suppression**

- 12 of the 23 respondents indicated that every pediatric OHT patient with persistent lymphadenopathy and EBV viremia at their institution would have a biopsy before reduction in immune suppression
- 19 of 23 respondents indicated that a pathologic confirmation of PTLD is not needed prior to reduction in immune suppression to treat EBV viremia.
- 14 of 19 respondents require a positive lymph node biopsy to make a positive diagnosis of PTLD.



# Results – Treatment (continued)

- **When faced with symptomatic EBV viremia...**
  - 17 of 22 respondents would decrease immune suppression
  - 8 would treat patients' symptoms
  - 5 would give rituximab
  - 1 would give steroids
  - 1 would give IVIg



# Results – Following patients after treatment for PTLD

- 10 of 15 respondents indicated that their post-PTLD treatment surveillance lab and visit schedule differs from that of patients who have not had PTLD.



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# Conclusions

- Limited by sample size and participants' ability to recall details about their institution's practices with regard to PTLD
- Succeeds in highlighting the variability of screening for, treating and surveying pediatric OHT patients following successful PTLD treatment.
- Demonstrates the need for further research to come up with uniform treatment and surveillance guidelines for this patient population.



# Future directions

- Given the results of this survey, we feel this area merits further investigation.
- Several survey participants have reached out to express interest
  - Currently we are working on setting up a multicenter study to investigate this area in greater detail
  - We welcome future collaboration





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THANK  
YOU



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