From: [redacted]
To: [redacted]
Subject: ACHD Transplantation
Date: 03 July 2014 14:42:28
Attachments: slides_for_michael.ppt
ATT00001.htm

Michael/John

I read with much interest the paper presented to the CAP and I noted in particular the following comment:

> *We were told that patients who get to adulthood with CHD will rarely get a transplant because whenever a heart becomes available there will always be other potential recipients in whom the operation would be simpler and in whom better long term outcomes are more likely.*

This caused me some concern so I asked for some expert opinion on the topic of transplant from Newcastle. The issue of the considerations of survival of adults with CHD being not good is outdated and something which troubles GUCHs when trying to obtain insurance. It is even more worrying when it affects their ability to get a fair deal when it comes to treatment.

I very strongly align TSF to the following statements about adult CHD transplant (please note PowerPoint attachment):

1) The unconditional survival for ACHD transplant is better than ALL other groups at 10 years. The survival curve from 10 years continues to pull away from all other groups thereafter. IE despite the increased early mortality (see below) ACHD heart transplant survival is the best of all groups at 10 years based upon the most recent ISHLT data (Slide 1) which shows this clearly. Therefore the statement that 'better LONG TERM outcomes are more likely' for other recipients is complete nonsense and the opposite is in fact true.

2) ACHD heart transplant by ISHLT and institutional data does suggest that at many centres there is a higher early mortality from ACHD transplant than for other recipients. Units in the UK are under the microscope for their 90 day survival and so can be unwilling to take on transplants with a higher early mortality (units are not rated on 10 year survival). However this early mortality needs to be balanced against the superior 10 year outcome and the early mortality can be addressed by facing the issue head on instead of avoiding these patients. We have shown that by using a dedicated congenital transplant assessment and transplant team (congenital assessment cardiologists, congenital anaesthetists, and congenital surgeons carrying out the operation- as opposed to tagging on ACHD transplant to a non ACHD transplant programme) the results can be improved. Slide 2 shows this improvement from our paper in Heart, slide 3 shows our current ACHD transplant survival and slide 4 our Fontan (traditionally the highest risk group) transplant survival. The improvement in results is not because of taking on lower risk cases but because of a commitment to the process.
'There will always be other potential recipients in whom the operation would be simpler' is a statement for units who are unwilling to take on or have been unable to change the early mortality for this group of patients. The implication of this is surely that those units should refer to units that have been able to address the early mortality- not to deny the patients transplant.

3) The argument that 'other patients have a simpler operation' has been tested ethically. It is not the patient's fault that they have a condition which results in a more difficult transplant- the fact that it is more difficult for a particular surgeon/ team just means

another surgeon/ team should do it (see above). From the patients point of view the fact that an operation on somebody else is 'simpler' really doesn't cut it (no pun intended!)

4) ACHD heart transplant has represented 5% of all heart transplants in the UK (200-2012) and has been nearer to 10% for the last few years. In my opinion this number is too low but much better than any other country in the first world (US<5%). ACHD heart transplant represents an increasing proportion of our transplant work. Between 2000 and 2012, 78 ACHD transplants were carried out the UK (at least 40 of these at Freeman- my code for congenital is 'stricter' than UKT). Of the 101 patients we assessed between Jan 2000 and Jan 2012, 46 were listed for transplant and 40 of these were transplanted (6 deaths on the waiting list) ie 90% of our ACHD patients listed were transplanted. The others were unsuitable for transplant, didn't want a transplant or didn't need a transplant (yet). None of this represents a situation where ACHD patients 'rarely get a transplant'. This may be the case in some countries and some regions but there is no reason at all that this should be the case. There is of course pressure on this scarce resource and there is an argument that increasing the number of patients on the list does not move the bigger picture forward, but again it is not the individual patients fault that he/she is competing for an organ and to select out ACHD patients not to be transplanted is illogical and unfair- in particular with new options such as VAD available for non ACHD patients. There could be a point that ACHD patients overwhelm the waiting list- however we are not at that point yet. If/ when this situation arises it would put us in a situation where we could drive for other solutions and continue the campaign to increase donor numbers.

5) Cardiac transplant is not just about cardiac transplant. In reality it is an advanced heart failure management process. The assessment is extremely important in looking for other options- in particular conventional surgery and VAD- several of our referrals were suitable for these options with good outcomes for those with a systemic left ventricle (slide 5) and ignoring the transplant process would have been a disservice to these patients.

6) The majority of the patients we transplant have survived a previous era of high risk surgery. Society offered them and their parents hope as babies and young children. They are now facing a similar situation again and many are asking to be given the chance again. We have fiduciary care and for NHS England to have 'been told' this throw away comment which could influence policy based on nothing, which dismisses the transplant option for these patients, irritates me quite a lot! If the comments come from a congenital cardiologist- and that person reallybelieves in the comments then it is their obligation to try and change the situation for their patients- not just to accept it.

I have on a number of occasions both at the CRG and prior to that in the Adult Standards Group asked that the subject of adult CHD transplant be considered properly. There is a disparity in the assessment received depending on where one lives, indeed at the last CRG I stated that my advice to any GUCH asking about transplant was "move to Newcastle". I wish that was just a joke!

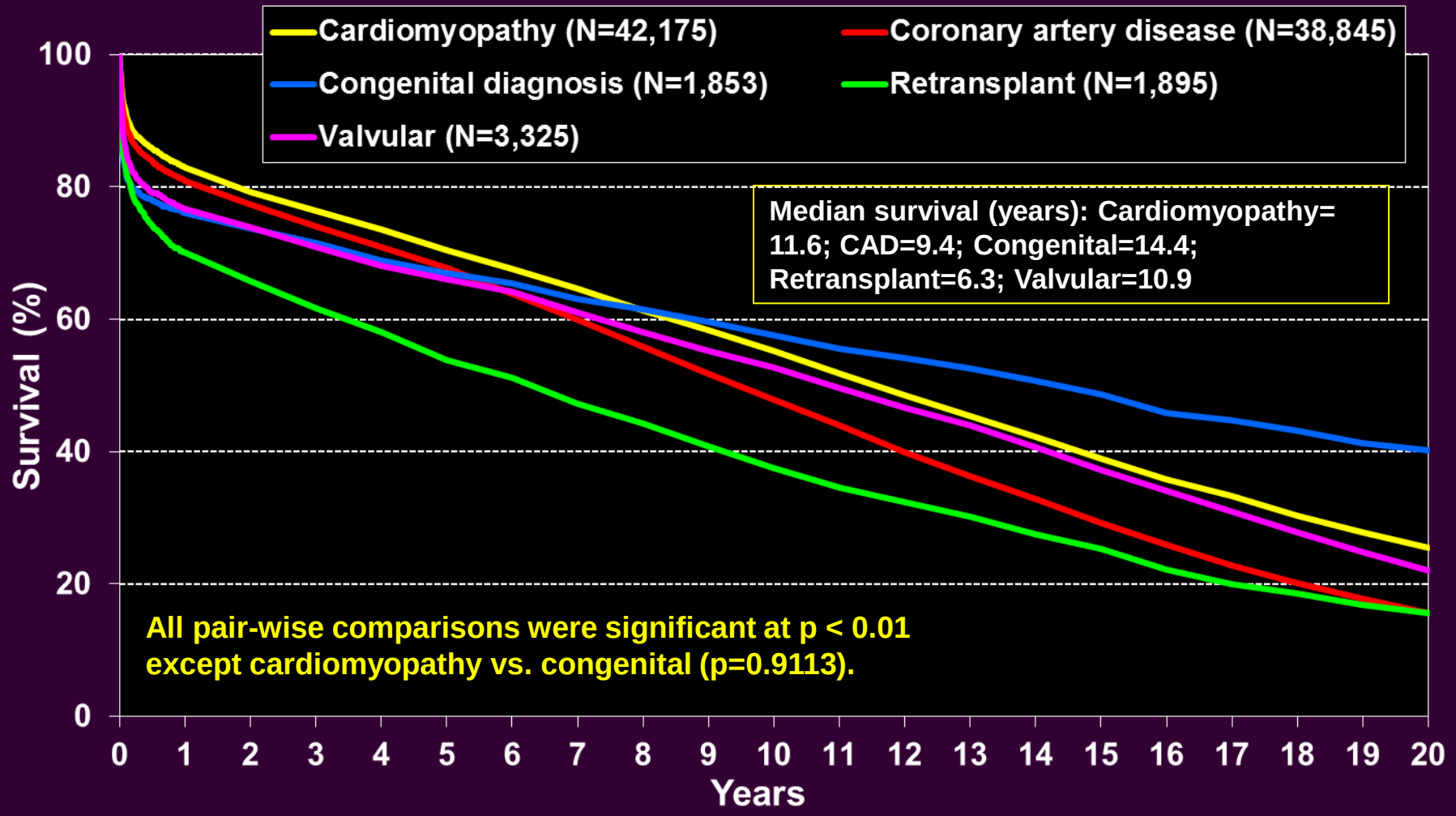
Can we please ensure that these ill informed comments are corrected, ignored and that we treat this matter with the seriousness that it deserves. This one really is a matter of life and death.

Many thanks

Regards
Michael

Michael Cumper
Vice President
The Somerville Foundation

Adult Heart Transplants
Kaplan-Meier Survival by Diagnosis
(Transplants: January 1982 – June 2011)



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2013

JHLT. 2013 Oct; 32(10): 951-964

Cardiac transplantation in adults with congenital heart disease

Heart 2010;**96**:1217—1222.

C Irving, G Parry, J O'Sullivan, J H Dark, R Kirk, D S Crossland, M Chaudhari, M Griselli, J R L Hamilton, A Hasan

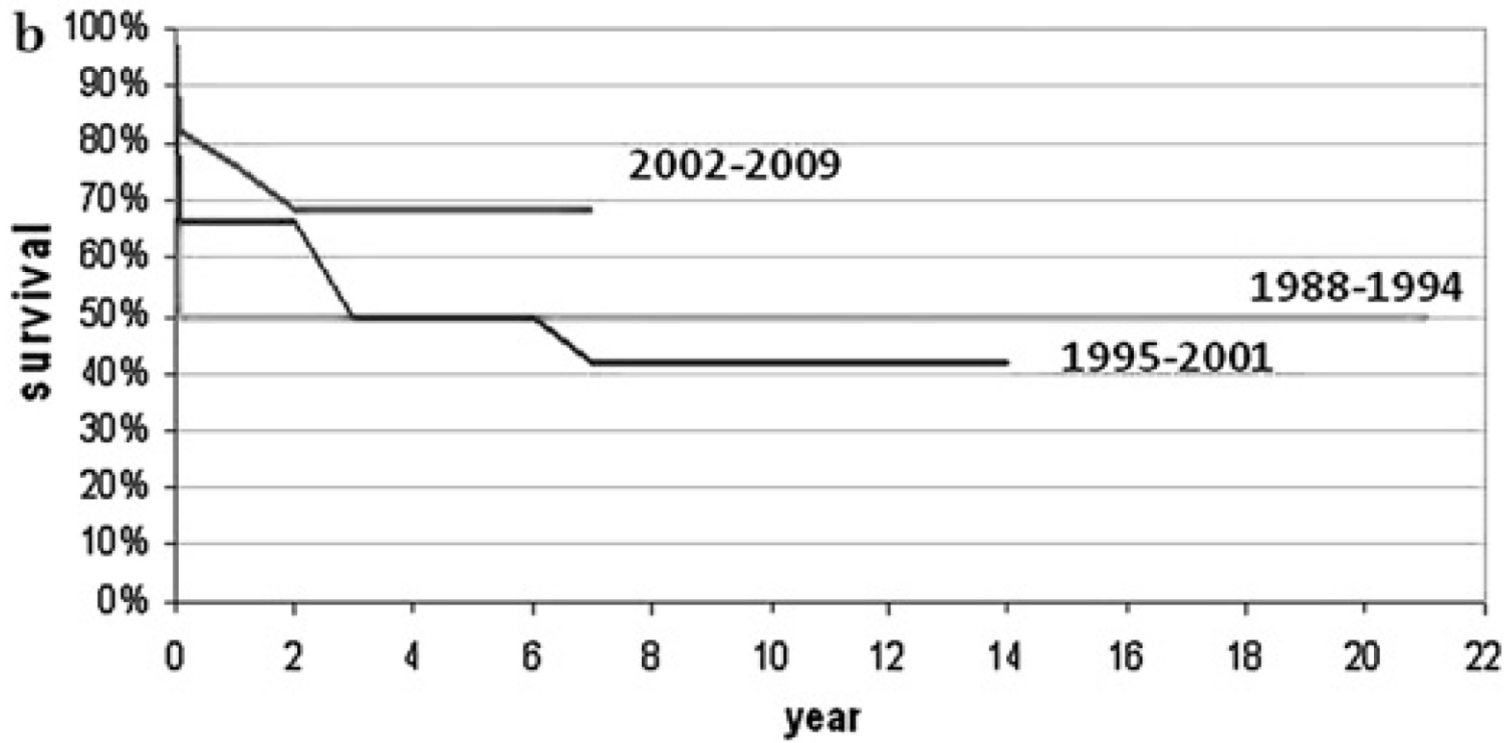
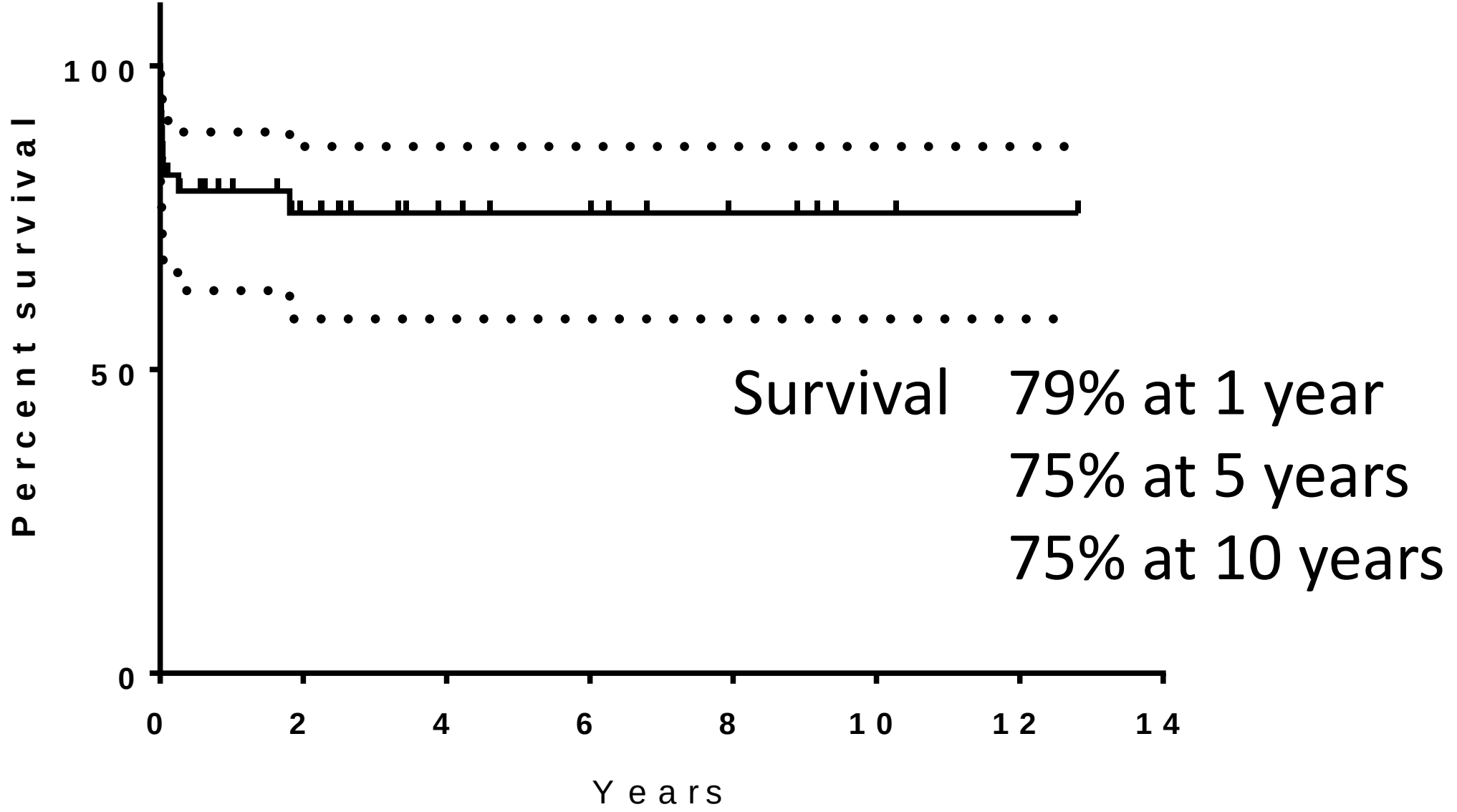


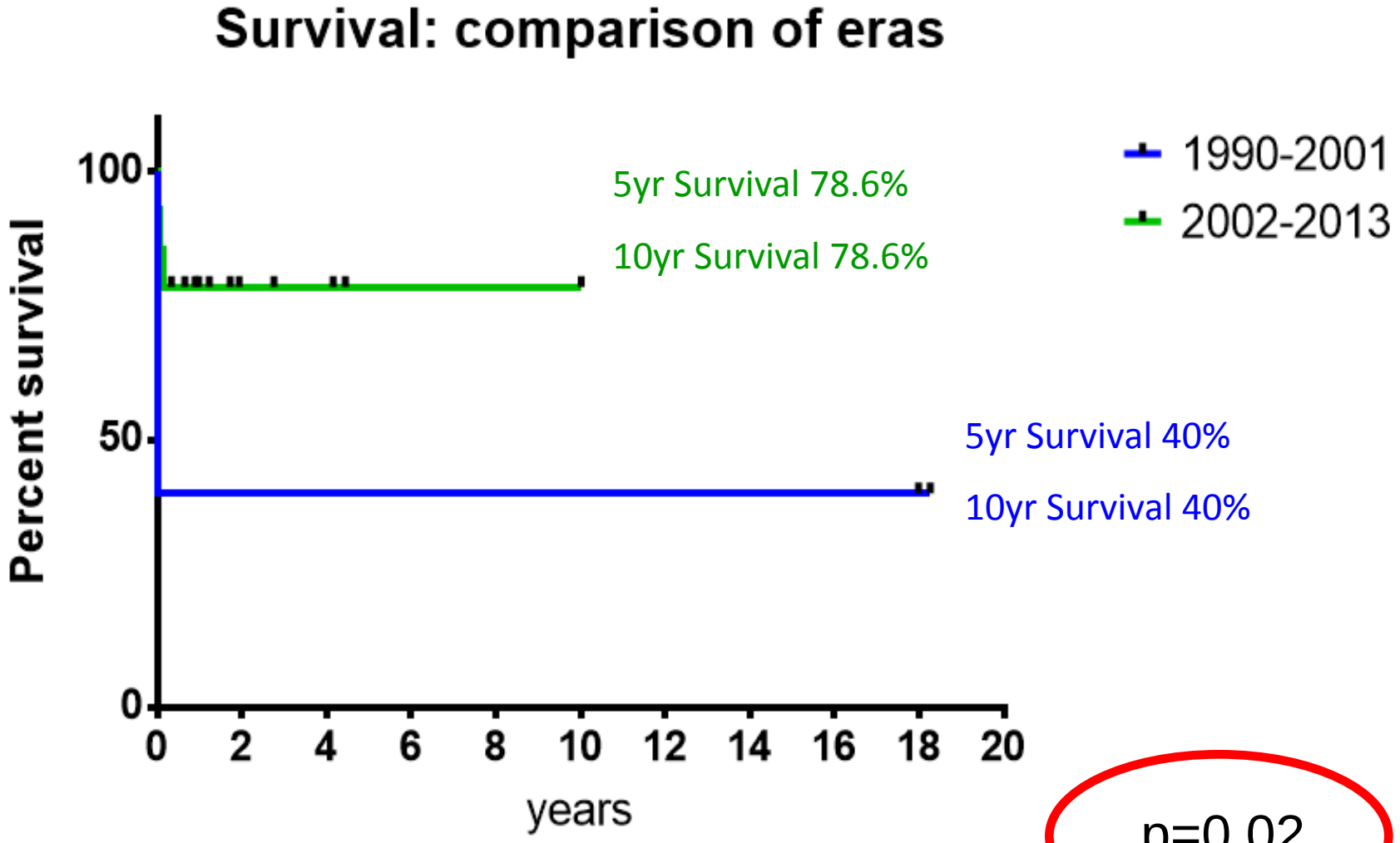
Figure 1 (A) Overall survival and (B) survival by era of transplant.

Freedom from death following ACHD heart transplant 2000-2012 Freeman data



Survival 79% at 1 year
75% at 5 years
75% at 10 years

Survival by era. Fontan transplant. Freeman data



Is alternative cardiac surgery an option in adults with congenital heart disease referred for thoracic organ transplantation?†

Andrew Robert Harper, David Steven Crossland*, Gianluigi Perri, John Jude O'Sullivan, Milind Pralhad Chaudhari, Stephan Schueler, Massimo Griselli and Asif Hasan

European Journal of Cardio-Thoracic Surgery 43 (2013) 344–351