# A Review of Patient Demographics, Indications, Waiting Period and Patient Availability for The Elective Corneal Graft Waiting List at Saint John Eye Hospital

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A dissertation submitted to the Faculty of Health Sciences, University of the Witwatersrand, in the fulfilment of the requirements for the degree of Master of Medicine in Ophthalmology

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**Declaration**

I hereby declare that this dissertation is my own unaided work. It is being submitted for the degree of Master of Medicine in the branch of Ophthalmology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in any other University.

Signed 

This 28 day of August 2020

The work reported in this dissertation was carried out in the Department of Ophthalmology, St John Eye Hospital (Chris Hani Baragwanath Hospital), Johannesburg, South Africa.

The project was approved by the Ethics Committee, University of the Witwatersrand.

**Dedication**

This dissertation is dedicated to my wife, Ipeleng, for her unwavering support throughout the training period.

To my son, Reorapetse, and daughter, Reatlehile, for bringing happiness into my life.

To my late father, Dr Phuthi Abiner Selele, and my mother, Mrs Daphne Selele, for raising me to be the person that I am today.

**Abstract**

**Aim:** To analyse the corneal graft waiting list at St John Eye Hospital and assist the corneal graft team in future assessment and planning of corneal graft procedures via the following objectives:

i. To describe the patient demographics and medical indications of patients on the St John Eye Hospital corneal graft waiting list
ii. To describe the waiting times of patients on the St John Eye Hospital corneal graft waiting list
iii. To determine the willingness of patients on the waiting list to be operated and to determine the reasons for those that are unwilling to proceed with a corneal graft

**Method:** A retrospective descriptive study was conducted using the available corneal graft waiting list at St John Eye Hospital as of the 1st September 2016. Patients on the final St John Eye Hospital corneal graft waiting list were contacted telephonically to determine the following:

i. The availability and willingness of the patient to have the corneal transplant
ii. In the event that the patient was not available or willing to have the corneal transplant, the reasons were elicited

**Results:** There was an almost equal gender distribution, with the female population comprising 50.56% (n=91) while the male population comprised 49.44% (n=89). The average age of patients on the transplant list was 37.16 years (Standard deviation = 18.55) while the median age was 32 years. Patients with keratoconus accounted for 54.44% (n=98) of cases. This was followed by corneal scarring at 22.78% (n=41) while pseudophakic bullous keratopathy accounted for 15.00% (n=27) of all pathologies. The average duration that patients were on the waiting list was 18.07 months (SD 27.16 months). The largest proportion of patients were those that had been on the waiting list for more than 6 months but less than a year (35.56%, n=64), followed by the group that had been on the list for 6 months or less (31.11%, n=56). The average visual acuity of the population was LogMAR acuity of 1.64 (SD 1.19) for the right eye, 1.56 (SD 1.19) for the left eye and 1.60 (SD 1.14) for both eyes. Of the 124 patients contacted, 82.26% (n=102) were still willing to have a corneal transplant. Patients that were unwilling to

have a corneal transplant despite being on the transplant list comprised 14.52% (n=18), while 3.23% (n=4) were unsure.

**Conclusion:** The waiting duration of St John Eye Hospital patients for a corneal graft is long for the period under review. The largest grouping by pathology was keratoconus, accounting for over half the cases awaiting corneal transplant, followed by corneal scarring. The majority of patients awaiting corneal transplantation had significant visual impairment, with the affected eye on average being classified as legally blind. The contactability and willingness of patients on the waiting list was relatively high. This is important for the St John Eye Hospital as they run a corneal graft service with limited resources. Easily contactable and eager patients are required to help decrease the waiting list patient load as and when donor corneal tissue becomes available.

**Acknowledgements**

It is with deep appreciation that the following people be acknowledged:

1. Dr Hemant Kana, my initial supervisor who guided me through the protocol and data collection stages of my research. I thank him for his patience, support and constant encouragement.
2. Dr Aubrey Makgotloe, my final supervisor who guided me through the write up and submission. I thank him for taking over the task and providing guidance and support.
3. Dr Akil Asvat, who suggested this MMed topic and provided the data of the St John corneal graft waiting list. His advice and support along the way is highly appreciated.

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# 1 Literature Review

## 1.1 Corneal Blindness

Corneal blindness is complex and includes an array of causes. Its prevalence varies between countries and within population groups and will depend on a number of factors including accessibility to acceptable levels of eye care.[1]

Blindness as defined by the World Health Organization (WHO) is a Snellen visual acuity of 3/60 or less or a LogMAR equivalent of 1.30. Utilising this definition, it was estimated that in 2001 there were 45 million people worldwide who could be categorised as being blind in both eyes and a further 135 million that were categorised as having bilateral severely impaired vision.[2]

Corneal disease is the third leading cause of global blindness behind cataracts and glaucoma.[2] However, within developing and emerging countries, corneal blindness is often the second most frequent cause of blindness.[3] Corneal disease leading to blindness in both eyes affects 4.9 million persons globally.[4] Estimates for unilateral corneal blindness are not calculated in WHO data, however it is estimated that 23 million people are affected globally.[3] The burden of corneal blindness appears to be heaviest on emerging and developing countries with as much as 98% of bilateral corneal blindness existing outside of developed countries. Regional estimates of bilateral corneal blindness show that India and Africa have the largest percentage of affected people, with over 1 million affected people each.[3] Studies in Africa have corroborated WHO findings of corneal disease as a significant cause of bilateral blindness. Rapoza et al found that corneal scars from trachoma, hypovitaminosis A, and traditional medicine usage in Tanzania caused 44% of bilateral blindness and 39% of monocular blindness[5] while Zerihun found corneal disease from trachoma to be responsible for 21% of cases of blindness in Jimma zone, Ethiopia.[6] In addition, the profile of corneal blindness in developing countries has been found to affect a younger, more economically active section of the population than other forms of blindness.[7]

## 1.2 Corneal Transplantation

The function of corneal transplantation is to restore vision when corneal disease has led to visual impairment that is debilitating to the individual. Corneal transplantation is the main restorative procedure for corneal blindness, with various advances made in recent years in surgical technique. The cornea was the first successfully transplanted solid

tissue.[1] Zirm is credited as the first to have performed and reported a penetrating keratoplasty using human donor tissue in 1906 to visually rehabilitate a patient with alkali burns.[8]

It is not possible to restore sight in all cases of corneal blindness via keratoplasty and the success rate of corneal grafts can be negatively affected by ocular comorbidities. In one study in India, it was found that only 40% of bilateral corneal blindness was potentially treatable with keratoplasty.[9]

It has been postulated that the cornea is the site of "immunologic privilege", with antigen-specific suppression of cell-mediated immunity responsible for corneal grafts being protected from immunologic destruction.[10]

## 1.3 Penetrating Keratoplasty

The procedure of penetrating keratoplasty entails the replacement of full-thickness recipient corneal tissue with donor corneal tissue.

184,576 corneal transplants were performed globally in 2012 and penetrating keratoplasties accounted for 70.3% of cases while lamellar grafts accounted for 29.7% of cases. Penetrating keratoplasty remains the most common surgical approach to corneal grafts globally, with the median rate for penetrating keratoplasty across 95 countries surveyed being 90%.[1] Penetrating keratoplasty as a surgical approach is useful for any type of corneal pathology, particularly in the following cases: [10]

- Patients with combined epithelial, stromal, and endothelial disease
- Patients with a failed corneal graft and high astigmatism
- Patients requiring simultaneous anterior segment reconstruction and corneal surgery

The introduction of femtosecond laser technology has led to advances in penetrating keratoplasty surgery.

### *1.3.1 General indications for penetrating keratoplasty*

Conditions requiring penetrating keratoplasty can be divided into the following:[11]

1. Tectonic: to restore normal corneal thickness
2. Optical: to enhance vision
3. Therapeutic: includes treatment of resistant microbial corneal infection
4. Cosmetic

In a systematic review of indications for penetrating keratoplasty between 1980 and 2000, the top indications in North America were pseudophakic bullous keratopathy (28.0%), repeat corneal graft (16.3%), keratoconus (14.2%) and Fuchs endothelial corneal dystrophy (12.9%). In Europe, the top indications were keratoconus (24.2%), pseudophakic bullous keratopathy (20.6%), keratitis (13.2%), and Fuchs endothelial corneal dystrophy (10.2%). Leading indications in Australasia included keratoconus (33.2%), pseudophakic bullous keratopathy (21.1%) and repeat corneal graft (18.8%). In Asia, the most common indication for penetration keratoplasty was keratitis (32.3%) followed by pseudophakic bullous keratopathy (15.5%) and repeat corneal graft (11.1%). Within Africa, keratoconus (32.4%) was the most common indication followed by keratitis (28.9%) and pseudophakic bullous keratopathy (9.4%). Finally, in South America, keratoconus (22.8%) was the most common indication followed by pseudophakic bullous keratopathy (18.6%), repeat corneal graft (12.6%) and keratitis (8.7%).[12]

### *1.3.2 Indications for PKP in the developing world*

The commonest indication for patients on the eThekwini corneal graft waiting list was keratoconus, which accounted for 64% of the patients, followed by corneal dystrophy (10%), scarring from previous corneal infection (9%) and pseudophakic bullous keratopathy (6%).[13] Keratoconus was the most common indication for corneal grafts at the Kikuyu Eye Hospital in Kenya accounting for 50% of cases and other indications included corneal scarring (11%), previous herpetic keratitis (7.9%) and corneal dystrophy (7.4%).[14] Similar preoperative indications were found in Ethiopia but infections were the most predominant indications.[15] Sharif et al found that the proportion of grafts performed for herpes simplex keratitis (7.8%) was higher than in Western countries, as a result of the greater severity of the disease in Africa, and the relative unavailability of effective treatment.[16] In a review of 1,725 corneal grafts performed in India, it was found that bullous keratopathy (aphakic and pseudophakic) was the leading indication making up 25.5% of the cases while keratoconus only accounted for 6.8% of overall indications.[9] These findings are in keeping with a high cataract surgery rate in India, comparable to rates in developed countries. A large series in Saudi Arabia that reviewed 1,721 corneal grafts found that keratoconus was the main indication, accounting for 50.9% of cases; corneal oedema accounted for 20.7% of

cases; 19.2% were of cases due to stromal scarring, predominantly caused by trachoma; and 9.1% was due to stromal dystrophy.[17]

## 1.4 Eye Banks

Eye banks are responsible for donor cornea retrieval, evaluation, storage, quality, and adherence to medical standards. They are instrumental in corneal graft success.

Currently any organ donation in South Africa is donated altruistically. The donor or the next of kin of the donor donate organs out of free choice. Financial compensation for the donor is not allowed. Consent for eye donation is obtained in accordance with Section 62 of the National Health Act of 2003.

Global eye banking services have remained underdeveloped in all but the most developed countries. There are a variety of reasons for this predicament, including societal and cultural factors associated with organ donation, restrictive laws, the absence of properly skilled human personnel, poorly managed operations, inadequate infrastructure, expensive storage media and equipment, and suboptimal medical standards.[3]

An eye bank is ideally an autonomous organisation and should be run by a board of directors representing a cross section of the community. The board is tasked with the overall responsibility for all activities of the eye bank. Within each eye bank exists an administrative and medical section. Eye banks have specific functions that include:

- Promotion of public awareness about eye tissue donation
- Harvesting corneal tissue
- Evaluating harvested eye tissue
- Eye tissue storage and preservation
- Eye tissue distribution

### *1.4.1 Eye banking storage*

There are four possibilities of storage for corneal grafts in the eye bank of which two are the predominant methods used globally. The organ culture storage technique is prevalent mainly in Western Europe, Australia, and New Zealand while hypothermic storage is prevalent in the rest of the globe including North America. All eye banks in South Africa store donor cornea via the hypothermic technique, with none practicing the organ culture technique. In 2012, 83% of corneas retrieved globally were stored hypothermically and 17% were stored in organ culture medium.[1]

The optimal time in the harvesting of corneal tissue from circulatory failure to tissue preservation is 12 hours for hypothermic storage and 24 hours for organ culture storage.[18] Organ culture storage is a relatively more complex and involved process and is more taxing on eye bank resources than hypothermic storage. The human personnel have to be substantially more skilled and the facilities better equipped. The organ culture technique is based on the preservation of the isolated human cornea under simulated physiological conditions. A recent study in Australia demonstrated that switching from hypothermic storage to organ culture storage improved the availability of corneal donor tissue and reduced the corneal graft waiting list in the period following the switch.[19] This was achieved through increased corneal donor tissue utilization and through a higher donor participation rate. Ultimately, the choice of the storage method for donor cornea is the prerogative of each eye bank and is influenced by multiple factors, especially the number of eye bank personnel, the level of skills possessed by eye bank personnel as well as the financial status of the eye bank.

### *1.4.2 Global eye banking*

In total, 742 eye banks were identified globally in 2012. 16 countries (19%) had more than 5 eye banks; 30 countries (35%) had 2 to 5 banks; and 28 countries (34%) had at least 1 eye bank. In 2012, approximately 12.7 million people were on a corneal graft waiting list, with over 55% of these individuals in India and a further 16% in China. This data covers 134 countries or 91% of the world's population. In the same period, only 283,530 corneas were retrieved in 82 countries. 55% of those donor corneas were retrieved in the United States and India. Nine countries were able to export corneal grafts globally and the number of corneas exported in 2012 amounted to 23,247 or 8% of all retrieved corneas. 85% of global export supply came from the United States of America, a further 9% came from Sri Lanka and 3% was exported from Italy.[1]

### *1.4.3 South African eye banking*

Eye banks in South Africa are non-profit organisations funded by donations and an administration fee paid by recipients. There are currently 5 eye banks operating in South Africa with the first being established in 1975 in Cape Town, namely the Eye Bank Foundation of South Africa. Subsequently four other eye banks were established including the Goosen Eye Bank in Port Elizabeth, the KwaZulu Natal Cornea and Eye

Association in Durban, the Gauteng Cornea and Eye Bank (GCEB) in Johannesburg and the Pretoria Eye Institute Eye Bank in Pretoria.[20]

Unfortunately, the availability of corneal tissue in South Africa is severely limited and this is due to several challenges.

The legal challenges arose as a result of changes in the administration of South African mortuaries. Before 2006, forensic mortuaries were administered by the South African Police Services which allowed eye banks access to information on persons who had died of unnatural causes. In 2006, the Department of Health became responsible for the forensic mortuaries and restricted information of persons that had unnatural deaths and details of their next of kin, removing all access to potential donors. The increase in HIV and hepatitis B and C infections over the past 2 decades has resulted in the proportion of harvested corneas discarded steadily increasing, putting a further strain on a limited local supply of corneal donor tissue. There is a general lack of awareness of the necessity for organ and tissue donation within South African society, due to cultural factors and a level of conservatism within our population. Finally, affordability is a challenge due to the exorbitant costs of eye bank equipment and storage media. Storage media are the largest expense for any eye bank as these media are usually imported and subject to volatile foreign exchange rates and need constant replacement.[21]

# 2 Methods

## 2.1 Aims

- To analyse the corneal graft waiting list at St John Eye Hospital and assist the corneal graft team in future assessment and planning of corneal graft procedures

## 2.2 Research Objectives

- To describe the patient demographics and medical indications of patients on the St John Eye Hospital corneal graft waiting list
- To describe the waiting times of patients on the St John Eye Hospital corneal graft waiting list
- To determine the willingness of patients on the waiting list to be operated and to determine the reasons for those that are unwilling to proceed with a corneal graft

## 2.3 Design

A retrospective descriptive study was conducted using the available corneal graft waiting list at St John Eye Hospital as of the 1st September 2016.

### *2.3.1 Inclusion criteria*

All consecutive cases on the elective corneal graft waiting list at St John Eye Hospital as of the 1st September 2016 were reviewed and analysed.

### *2.3.2 Exclusion criteria*

Cases with incomplete data were excluded.

## 2.4 Data Collection

The corneal graft waiting list data had been transcribed from the patient case files on to an Excel spreadsheet. Data from the telephonic interviews was captured in the same spreadsheet. The data included the following:

a. Identification of patients on the corneal graft waiting list at the St John Eye Hospital with the following parameters:
    - Patient number: patients were assigned a number and names were replaced on the datasheet in view of the ethical considerations.
    - Age of patient
    - Gender of the patient

- Diagnosis primarily responsible for the indication of a corneal graft
- Decimal Snellen visual acuity at the time of booking on the corneal graft waiting list
- Conversion of the decimal visual acuity at the time of the corneal graft booking to the LogMAR (Logarithm of minimum angle of resolution)
- Duration on the corneal graft waiting list

In the event that certain information was missing from the existing waiting list, attempts were made to retrieve the relevant patient case files from the St John Eye Hospital records office with the assistance of the administrative clerks. However, an initial sample of 10 files yielded zero results. This was due to the fact that patients were keeping the case files on their person. This led to patients with data gaps being excluded from the analysis. Duplicates were also identified and also excluded.

b. The remaining patients on the St John Eye Hospital corneal graft waiting list were contacted telephonically to determine the following:
   - The availability and willingness of the patient to have the corneal transplant
   - In the event that the patient was not available or willing to have the corneal transplant, the reasons were elicited

   Patient contact details as entered on the corneal graft waiting list were used to contact patients. Patients were contacted during working hours from Monday to Friday using a mobile phone. Numbers that went to voicemail on 3 attempts or numbers no longer on the service provider network were recorded as not contactable.

## 2.5 Data Management and Statistics

Descriptive statistics were used to describe characteristics such as:

1. Age
2. Gender
3. Initial visual acuity: Snellen visual acuity was converted to the LogMAR scale to assist with statistical analysis
4. Preoperative diagnosis
5. Waiting period
6. Willingness to be operated
7. Reasons for unavailability or unwillingness to be operated

The categories were described into means and percentages for categorical variables. The Student t test was used to compare means between groups.

### 2.6 Staff and Administration

The study was carried out by Dr T M Selele, a registrar from the Department of Ophthalmology at St John Eye Hospital.

The study was supervised by Dr H Kana, a consultant from the Department of Ophthalmology at St John Eye Hospital.

Dr A Asvat, a consultant from the Department of Ophthalmology at St John Eye Hospital, assisted in providing the data file for the corneal graft waiting list at St John Eye Hospital.

### 2.7 Ethical Considerations

The protocol was submitted to the Human Ethics Research Committee of the University of the Witwatersrand for approval. It was passed by the Committee on the 17th February 2017 and the clearance certificate number is M161155.

### 2.8 Budget

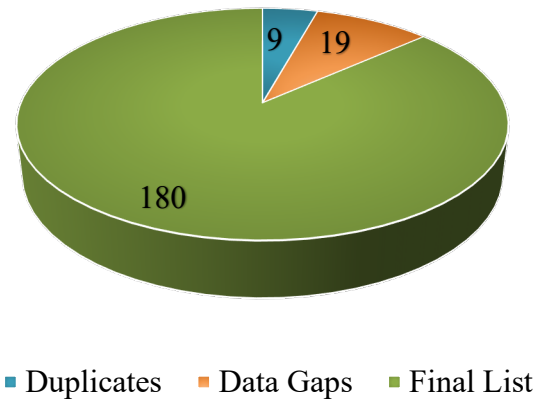
The initial part is a retrospective study, so there is no need for reimbursing participants for any costs. The cost of calls were borne by the primary researcher, Dr Thekiso Selele.

# 3 Results

## 3.1 Total

There was a total of 208 patients on the corneal transplant waiting list as of the 1st September 2016. Duplicates accounted for 9 (4.3%) entries and a further 19 (9.1%) entries had incomplete information which included missing age, visual acuity or primary diagnosis. Following the exclusion of the 28 entries for the reasons stated above, the total data set comprised of 180 (86.5%) patients.

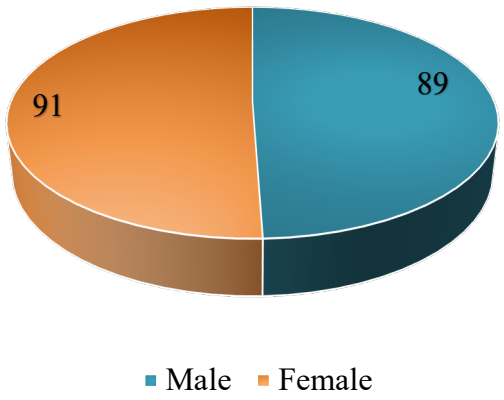
**Figure 3.1**: Total Patients on the Transplant Waiting List




## 3.2 Gender

There was an almost equal gender distribution, with slight female preponderance of 50.56% (n=91) while the male population comprised 49.44% (n=89).

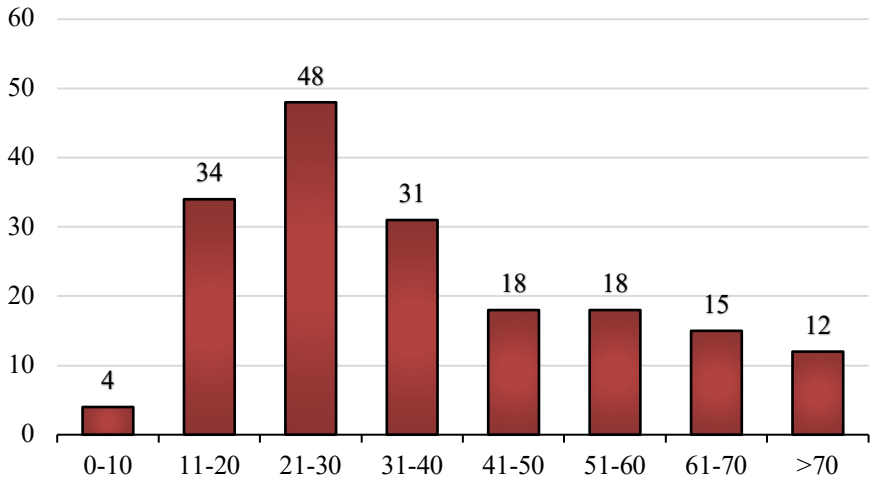
**Figure 3.2:** Transplant Waiting List Gender Distribution




### 3.3 Age

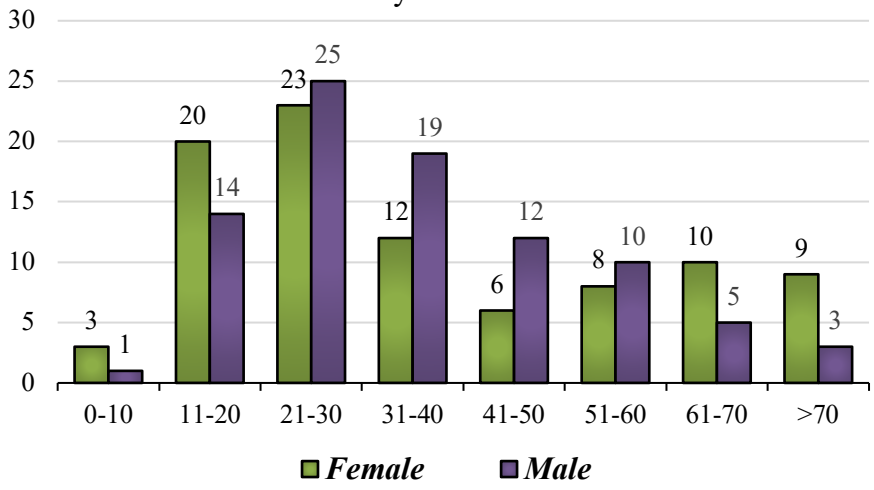
The average age of patients on the transplant list was 37.16 years (Standard deviation = 18.55). The median age was 32 years, with the youngest patient being 1 year and 6 months old and the oldest being 93 years old. The largest age group by decade was the third decade (21 – 30 years), comprising 26.67% (n=48), followed by the second decade with 18.89% (n=34) and the fourth decade with 17.22% (n=31). 85% (n=153) were below the age of 60 years.

**Figure 3.3:** Transplant Waiting List Age Distribution



The oldest and youngest patients were both female, with a wider age distribution for females (Standard deviation = 20.74) vs the male patients, who were more closely clustered in the economically active decades (Standard deviation = 16.31).

**Figure 3.4:** Transplant Waiting List Age Distribution by Gender




## 3.4 Patient Pathology

Keratoconus was the most common pathology that placed patients on the St John Eye Hospital corneal transplant waiting list. Patients with keratoconus accounted for over half of all cases with 54.44% (n=98). This was followed by corneal scarring at 22.78% (n=41) and pseudophakic bullous keratopathy accounted for 15.00% (n=27) of all pathologies, while corneal dystrophy and or previous failed corneal transplants both accounted for 3.89% (n=7) each.

**Table 3.1:** Transplant Waiting List Patient Pathology

| | | |
|---|---|---|
| Keratoconus | 98 | 54.4% |
| Corneal scarring | 41 | 22.8% |
| Bullous keratopathy | 27 | 15.0% |
| Corneal dystrophy | 7 | 3.9% |
| Failed previous graft | 7 | 3.9% |

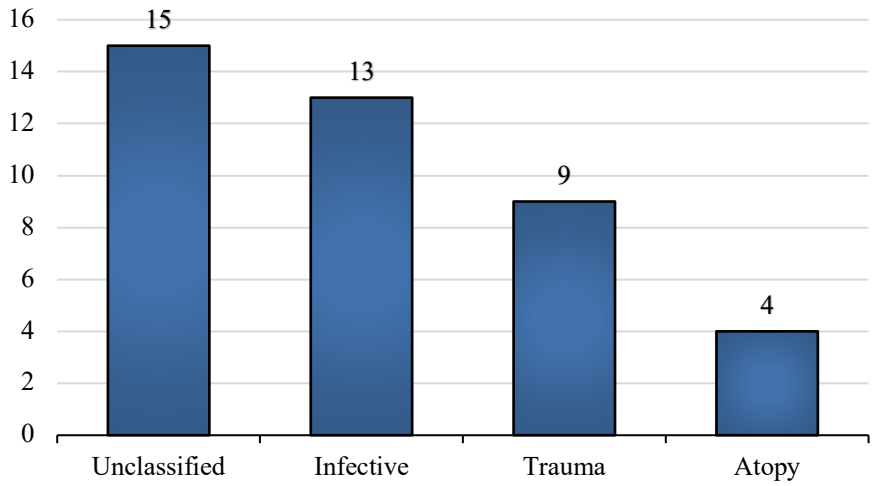
Further analysis was done comparing patients presenting with keratoconus as the primary pathology, which accounts for over half of the population (54.44%), versus

patients that presented with pathology other than keratoconus. The group of patients presenting with keratoconus had an equal gender distribution, while the non-keratoconus population had a slight male predominance. The keratoconus population also had a lower mean age of 28.41 years versus the mean age of 47.74 years for the non-keratoconus population, which was statistically significant ($p$=0.005).

| **Table 3.2:** Keratoconus vs Non-Keratoconus Patient Demographics | | | | |
|---|---|---|---|---|
| | Keratoconus | | Non-Keratoconus | |
| Total number | 98 | 54.4% | 82 | 45.6% |
| Male | 49 | 50% | 43 | 52.4% |
| Female | 49 | 50% | 39 | 47.6% |
| Mean age | 28.41 | | 47.74 | |

Cases within the corneal scarring population were further subdivided as follows; unclassified (36.59%, n=15), infective (31.71%, n=13), trauma (21.95%, n=9) and atopy (9.76%, n=4).

**Figure 3.5:** Corneal Scarring Pathology Subdivision

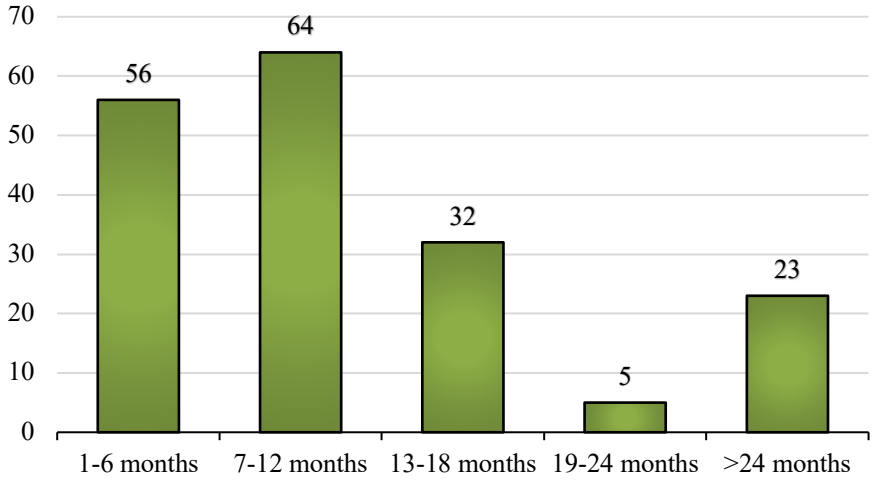



## 3.5 Duration on the Waiting List

The average duration that patients were on the waiting list was 18.07 months (SD 27.16 months), with 7.22% (n=13) of patients having been on the waiting list for less than a month. The largest proportion of patients were those that had been on the waiting list for more than 6 months but less than a year (35.56%, n=64), followed by the group that

had been on the list for up to 6 months (31.11%, n=56). 22 patients were found to have spent more than 60 months on the list, comprising 12.22% of the population. The patient with the longest duration on the waiting list was 150 months.

**Figure 3.6:** Duration on the Transplant Waiting List




The average duration was longer for patients presenting with keratoconus as the primary pathology, at 21.78 months. Patients with non-keratoconus primary pathology had an average waiting list duration of 13.62 months. The difference in duration between the two populations was statistically significant ($p$=0.04). Of the patients that had been on transplant waiting list for more than 24 months (n=23), 65.22% (n=15) presented with keratoconus as the primary diagnosis, while 34.78% (n=8) presented with a non-keratoconus primary diagnosis.

**Table 3.3:** Keratoconus vs Non-Keratoconus Patient Duration

| | Keratoconus | | Non-Keratoconus | |
|---|---|---|---|---|
| Total number | 98 | 54.4% | 82 | 45.6% |
| Mean duration on waiting list | 21.78 | | 13.62 | |

### 3.6 Visual Acuity

The average visual acuity of the population was LogMAR acuity of 1.64 (SD 1.19) for the right eye, 1.56 (SD 1.19) for the left eye and 1.60 (SD 1.14) for both eyes. These LogMAR acuities all translate into approximately 6/240 on the Snellen visual acuity

chart. The difference in LogMAR acuity between the right and let eyes was not statistically significant. The average LogMAR acuity of the worse eye in the population was 2.18 (SD 1.06) which is worse than 6/60 on the Snellen visual acuity chart. Legal blindness in South Africa is defined as a Snellen visual acuity of worse than 6/60. Within our population 76.67% (n=138) were legally blind in one eye and 25.56% (n=46) were legally blind in both eyes.

**Figure 3.7:** Average LogMAR Visual Acuity

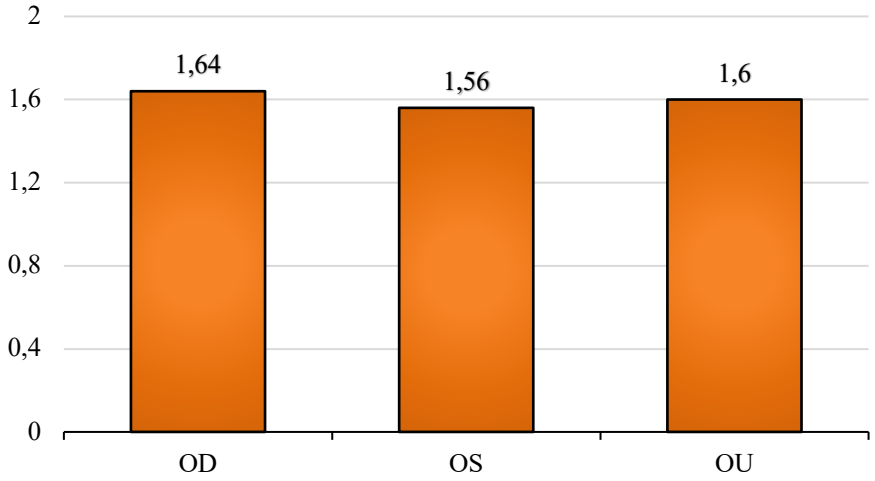
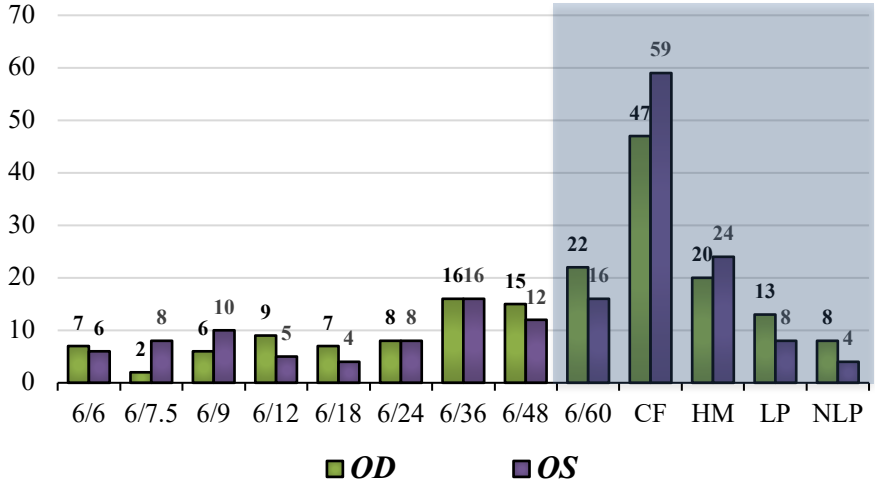



**Figure 3.8:** LogMAR Visual Acuity per Eye



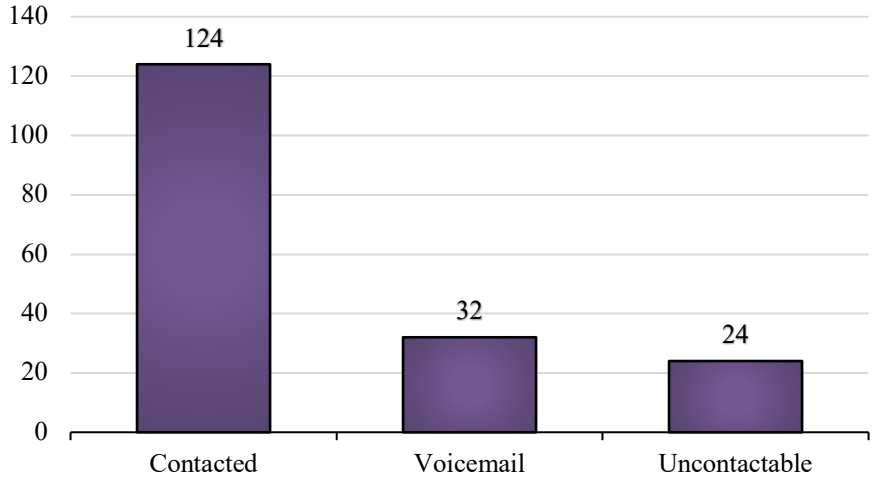

## 3.7 Telephonic Contact

A total number of 124 patients were contacted telephonically, comprising 68.89% of the population. A total of 56 patients were uncontactable, with 17.78% (n=32) of calls diverting to voicemail on 3 repeated attempts on different days and 13.33% (n=24) of

patients totally uncontactable, with the number not being in existence or not being available at the time of the call.

All contacted respondents agreed to participate in the study as per the telephonic script for a 100% participation rate.

**Figure 3.9:** Telephonic Contact




### 3.8 Willingness to be Operated

Of the 124 patients contacted, 82.26% (n=102) were still willing to have a corneal transplant. Patients that were unwilling to be have a corneal transplant despite being on the transplant list comprised 14.52% (n=18), while 3.23% (n=4) were unsure.

| **Table 3.4:** Willingness to Still be Operated | | |
|---|---|---|
| Willing | 102 | 82.3% |
| Not willing | 18 | 14.5% |
| Unsure | 4 | 3.2% |

Those that were unsure of still having a corneal transplant were predominantly patients who had been advised that they had a poor visual prognosis by the medical team at St John Eye Hospital. In the group that was unwilling to undergo a corneal transplant, 50% (n=9) were due to reasons other than those stated in the script and mostly were patients who were advised by the St John medical team that the prognosis was poor or were managing with the current visual function. A further 27.78% (n=5) had the procedure done elsewhere (Predominantly in a private healthcare facility), 16.67%

(n=3) were deceased, while 1 patient had given up on having the procedure done (5.56%).

| **Table 3.5:** Reasons for Unwillingness to Still be Operated | | |
|---|---|---|
| Other reason | 9 | 50.0% |
| Procedure done elsewhere | 5 | 27.8% |
| Deceased | 3 | 16.7% |
| Given up | 1 | 5.6% |

## 4 Discussion

The St John Eye Hospital is the ophthalmology unit of the Chris Hani Baragwanath Hospital, a tertiary academic hospital in Soweto. St John Eye Hospital serves the population of Soweto and the southern parts of the Johannesburg Metro and serves as a referral centre for the Southern regions of the Gauteng province as well as the North West province. Within the tertiary hospitals cluster of the University of the Witwatersrand, the only other hospital that offers corneal transplants is the Charlotte Maxeke Academic Hospital. This facility serves the northern parts of the Johannesburg Metro as well as the eastern regions of the Gauteng province. This study attempts to understand the profile of patients on the St John Eye Hospital corneal graft waiting list, to elicit which of these patients are more likely wait longer for a procedure and when, if at all, patients tend to lose hope of receiving the corneal transplant.

The gender distribution was almost equal, with a slight female predominance and both the youngest and oldest patients were both female. The difference between the genders was not statistically significant. This was similar to studies in Ethiopia and Greece.[22,23]

The mean age of patients on the transplant waiting list was 37.16 years, while the median age was 32 years. Almost half of all our study population (47.78%) was under the age of 30 years, while 65.0% were under the age of 40 years. These results are similar to those of Khan et al, who conducted a similar study in the KwaZulu Natal province of South Africa. That study found that the median age was 31 years, while 48.07% of patients were under the age of 30 years and 67.30% were under the age of 40 years.[13] When one considers the economic impact of corneal blindness, 63.89% of our patients awaiting corneal transplant were in the economically active age group of 20 – 60 years of age. The economic impact on society of corneal blindness is dependent on the cause, severity and duration of the corneal pathology, as well as the availability of alternative financial assistance. Patients afflicted by corneal blindness at an earlier age tend to impose a higher economic cost to society.[24]

Keratoconus was the most common presenting pathology in our study. Patients with keratoconus accounted for over half of all cases with 54.44%. This was followed by corneal scarring, pseudophakic bullous keratopathy, corneal dystrophy and finally

previous failed corneal transplants. This profile was different to the patient profile that Khan et found in their study, with a higher keratoconus patient load on their waiting list.[13] Matthaei et al found a lower incidence of patients requiring corneal transplant for keratoconus in the African region in their systematic review, but the study reviewed 34 years of corneal transplant indications and covered all published data for the African continent.[12] A study in the USA found decreasing corneal transplant rates for keratoconus due to a multitude of factors, but primarily due to advancements in alternative treatment modalities. These include corneal cross-linking, intrastromal ring segments, and the advancement of contact lens technology.[25] With the exception of corneal cross-linking, these other treatment modalities are not available to the St John cornea team. The percentage of our study population presenting with pseudophakic bullous keratopathy was higher than other similar studies on the African continent and more than double the percentage seen in a similar study in KwaZulu Natal.[14,15,24,26] This may reflect a higher cataract surgery rate in the St John catchment area and its referral centres or a higher cataract surgery complication rate and further research would be required to ascertain the cause.

The average duration that patients were on the waiting list was 18.07 months, with 31.11% of patients having been on the waiting list for less than 6 months and two thirds (66.67%) of patients having been on the waiting list for less than a year. Twenty two patients were found to have spent more than 60 months on the list, comprising 12.22% of the population. Other similar studies looked at duration to actual corneal transplantation. Khan et al found the median waiting duration for patients that eventually received a corneal graft in the eThekwini municipality in KwaZulu Natal was 280 days or just over 9 months, but only 20% of the patients on their waiting list received a corneal transplant within a 3 year review period.[13] In Pernambuco, Brazil, 86% of their waiting list patients received a transplant within 6 months and 99% within a year. However, the Brazilian results were skewed by a classification of patients into active, semi-active or inactive according to the clinical assessment, duration on the waiting list and patient dropout or refusal of treatment.[26] The St John Hospital corneal transplant waiting list had no classification or stratification of patients according to any of these criteria. Gain et al calculated a global median waiting duration of 6.5 months (IQR 1-24 months) amongst countries with adequate corneal transplant programmes.[27]

Vision in our study population was universally poor, especially for the eye that required corneal transplantation. The average visual acuity of the population was LogMAR acuity of 1.64 for the right eye, 1.56 for the left eye and 1.60 for both eyes. The average LogMAR acuity of the worse eye in the population was 2.18. Within our study population, over three quarters (76.67%) were legally blind (Snellen visual acuity of 6/60 or worse or LogMAR visual acuity of 1.0 or worse) in one eye and a quarter (25.56%) were legally blind in both eyes. The level of legal blindness was lower than that found in other studies on the continent as Khan et al found that 84% of their study patients awaiting corneal transplant in KwaZulu Natal were legally blind in the eye requiring transplant while Yorston et al found that 87% of patients that received a corneal transplant in the Kikuyu Hospital in Kenya were legally blind pre-operatively.[13,14]

A relatively large proportion of our study patients awaiting corneal transplants were contactable telephonically (69%), despite the long duration many of them had been on the waiting list. This is partly attributable to the St John Eye Hospital corneal team updating the patient details on the waiting list at each patient contact. Of the patients contacted, 82% were still willing and ready to have a corneal transplant. The contactability and readiness of patients to have a corneal transplant are of importance, since corneal donor tissue is in limited supply, is relatively expensive to source and has a finite usable period. Once corneal donor tissue becomes available, the corneal team must identify a suitable candidate and ensure the patient avails themselves to have the procedure performed in a relatively short notice period of hours to days. The high willingness and readiness rate of our patients was in contrast to a study by Palamar et al that found that only 50% of patients were ready and eager to have corneal transplants when they were contacted.[28] The 15% of our study patients who were unwilling to proceed with corneal transplants were most likely to have been advised of a poor visual prognosis by the corneal team, therefore linking eagerness for the procedure with the probability of visual improvement. This was dissimilar to a study in Turkey that found eagerness to have the procedure was inversely related to the duration spent on the waiting list.[28] Patient ability to pay out of pocket for the procedure was limited as evidenced by the low number of patients that eventually had the procedure done elsewhere while on the waiting list (n=5). This is reflective of the relatively high cost

of procuring donor corneal tissue and a suitably qualified ophthalmic surgeon in the South African private healthcare sector.

### 4.1 Keratoconus vs Non-Keratoconus

Given that keratoconus accounted for over half the primary pathology of our study population (54.44%), further analysis was undertaken comparing this subgroup to patients that presented with pathology other than keratoconus. No statistically significant difference was found in gender distribution, but the keratoconus population had a statistically significant lower mean age of 28.41 years versus of 47.74 years. Most keratoconus patients will have onset of the ectasia at puberty or earlier, with gradual progression through adolescence to early adulthood when progression usually stops. The severity of the visual impairment caused by keratoconus is determined by the extent of astigmatism, thinning and scarring.[29] This would account for the younger mean age of the keratoconus subgroup. In contrast, our non-keratoconus subgroup was due to corneal scarring that can occur at any age group depending on the cause, bullous keratopathy most likely secondary to senile cataract surgery and corneal dystrophies that usually become clinically significant in later adulthood.

The average duration on the waiting list was longer for patients in the keratoconus subgroup (22 months vs 14 months), which was statistically significant. Two thirds of our study patients that had waited longer than 2 years for a graft were keratoconus patients. Further studies would need to be done to elicit the cause for the discrepancy as keratoconus patients generally have a good visual prognosis following corneal transplantation. As a referral centre, it may be that the keratoconus patients that present at St John Eye Hospital have experienced complications that worsen the visual prognosis for corneal transplantation.

# 5 Conclusion

The patient demographics of our corneal graft waiting list at St John Eye Hospital are not dissimilar to those in other studies done in South Africa and other sites globally. There was a statistically significant difference in the age of keratoconus patients versus non keratoconus patients and this is was presumably because keratoconus has an earlier onset than the other pathologies. The presenting pathology had a higher percentage of bullous keratopathy patients as compared to other South African and African studies, and further research would be required to elicit the reason for this discrepancy.

The waiting duration of St John Eye Hospital patients for a corneal graft is long for the period under review, and a statistically significant difference exists between the waiting duration for keratoconus versus non keratoconus patients. The economic burden of corneal blindness is more likely to affect the keratoconus subgroup more as they are generally younger and live with corneal blindness for longer. In addition, corneal transplantation usually has a favourable visual prognosis in keratoconus. Further research is therefore required to understand the reasons for the longer waiting duration experienced by keratoconus patients.

The contactability and willingness of patients on the waiting list was relatively high. This is important for the St John Eye Hospital as they run a corneal graft service with limited resources. Easily contactable and eager patients are required to help decrease the waiting list patient load as and when donor corneal tissue becomes available.

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# 7 Appendix

## 7.1 Corneal graft waiting list datasheet

| Patient number | Gender | Age | Diagnosis[i] | VA OD | VA OS | Duration on waiting list | Willingness to be operated[ii] | Reason if refusing operation[iii] |
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Notes:

i. Keratoconus=1, Pseudophakic bullous keratopathy=2, Microbial corneal scarring=3, Corneal dystrophy=4, Repeat graft=5

ii. Yes=1, No=2, Unsure=3, Uncontactable=4

iii. Deceased=1, Procedure done at another facility=2, Given up on being operated=3, Secondary medical illness=4

## 7.2 Questionnaire

Case no. [ ]

READ TO RESPONDENT:

May I speak to {Patient name}? My name is Dr Thekiso Selele and I am a training eye doctor at the St John Eye Hospital. I am currently undertaking a medical study of our patients waiting for a corneal graft.

If you agree to participate in the study, I will be asking a number of questions regarding how long you have been on the waiting list for a corneal graft and whether you are still keen to proceed with the procedure. The questions should not take more than 5 minutes of your time.

The answers you provide will help us better understand the patients on the corneal graft waiting list and improve the planning of future procedures at St John Eye Hospital.

The information you provide is totally confidential and will not be disclosed to anyone. It will be used only for research purposes. Your name will be removed from the questionnaire, and only a code will be used.

Your participation is voluntary and you are free to refuse to answer any of the questions.

Are you willing to participate in this study?

Agreed [ ]

Refused [ ]

Uncontactable [ ]

_____ _____

Primary researcher / / 2017 Witness / / 2017

Question 1

Please confirm your age [ ]

Question 1:

How long have you been waiting for a corneal graft?

[ ] years [ ] months

Question 2

Are you still willing to have the corneal graft?

Yes=1, No=2, Unsure=3 (If no, proceed to question 3)

Question 3

Why are you unwilling to have the procedure done?

Deceased=1, Procedure done at another facility=2, Given up on being operated=3, Secondary medical illness=4, Other=5

## 7.3 Ethical clearance certificate

R14/49 Dr Thekiso Selele

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)**

**CLEARANCE CERTIFICATE NO. M161155**

| | |
|---|---|
| **NAME: (Principal Investigator)** | Dr Thekiso Selele |
| **DEPARTMENT:** | Ophthalmology<br>St John Eye Hospital<br>Chris Hani Baragwanath Academic Hospital |
| **PROJECT TITLE:** | A Review of Patient Demographics, Indications, Waiting Period and Patient Availability for the Elective Corneal Graft Waiting List at Saint John Eye Hospital |
| **DATE CONSIDERED:** | 25/11/2016 |
| **DECISION:** | Approved |
| **CONDITIONS:** | Providing the telephone consent has a witness who is present and signs |
| **SUPERVISOR:** | Dr H. Kana |
| **APPROVED BY:** | Professor P Cleaton-Jones, Chairperson, HREC (Medical) |
| **DATE OF APPROVAL:** | 17/02/2017 |

**This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.**

**DECLARATION OF INVESTIGATORS**

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in November and will therefore be due in the month of November each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

**PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES**