

THE GREEN LANE PAEDIATRIC AND CONGENITAL CARDIAC SERVICE

STARSHIP CHILDREN'S HOSPITAL

ANNUAL REPORT

JULY 2007 – JUNE 2009



Collated by Dr Tom Gentles, Clinical Director

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1. EXECUTIVE SUMMARY

2007-09 has seen a continuation of excellent surgical results, and further development of national programmes for Adult Congenital Heart Disease, and the diagnosis and management of Cardiac Inherited Disease. The department's performance is dependent on the expertise and dedication of its medical, nursing, technical, and support staff, and also on staff in the intensive care unit, anaesthesia, and involved paediatricians and cardiologists throughout the country.

Service development has focussed on subspecialisation with the aim of providing the best possible care for children with heart disease. This has included development of a dedicated paediatric nursing teams in the cardiac catheterisation laboratory and the paediatric cardiac operating rooms, establishment of nurse practitioner positions in the paediatric cardiac and adult congenital heart programme, and the appointment of an additional paediatric cardiologist and paediatric cardiac surgeon. Further development of outreach to the Pacific Islands has been beneficial for clinicians and patients in this region, and has improved the cost effectiveness of treatment.

Support from the Starship Foundation and the District Health Board has allowed acquisition of new technology including 3D echocardiography, 3D electrophysiological mapping tools, and equipment for transcatheter valve perforation, while Heart Children New Zealand provides support to the home INR monitoring programme, and professional support to nursing and technical staff through the Heart Children NZ Advancement Programme. Interaction with funding agencies has resulted in increased availability of medications for the treatment of pulmonary hypertension, and an agreement to fund transcatheter pulmonary valve implantation.

Academic activities have benefited from the appointment of an externally funded research fellow in cardiology, and from grant funding from a number of agencies including the National Heart Foundation of New Zealand, and the Green Lane Research and Education Fund. The World Congress of Paediatric Cardiology and Cardiac Surgery was held in Cairns and was organised by a team from Australia and New Zealand. Many medical, nursing, and technical staff were involved in organisation of the conference and the department made a substantial contribution to the scientific programme.

2. BACKGROUND

The Green Lane Paediatric and Congenital Cardiac Service is a national service based at the Starship Children's Hospital.

It is the sole provider of cardiology and cardiac surgical services for infants and children with congenital and acquired heart disease in New Zealand and also provides a fetal cardiology service and investigation and treatment of those born with congenital heart disease who are now adults. The service provides an extensive network of outreach clinics throughout New Zealand and the South Pacific, and provides consultation and support to clinicians caring for patients within the regional hospital setting.

In addition there is an active clinical research and audit programme that includes collaborative ventures with academic groups nationally and internationally.

3. SERVICE COMPONENTS

3.1. SUMMARY

The service has a number of interrelated components including:

- Paediatric inpatient (medical and surgical)
- Paediatric and congenital cardiac treatment (surgical and catheter based)
- Paediatric Outpatient
- Peripheral Clinics (paediatric and adult congenital)
- Fetal Cardiology
- Adult Congenital Cardiology
- Cardiac Inherited Disease

Investigative Services include

- Echocardiography
- Cardiac Catheterisation
- Exercise testing
- Cardiac MRI

Ancillary services contracted from adult cardiology

- Electrophysiology laboratory
- Pacemaker diagnostics
- Electrophysiology and electrocardiography technical staff
- Cardiac catheterisation laboratory support staff

Ancillary services contracted from Adult Cardiothoracic Surgery and Operating Theatres.

- Cardiac Perfusion
- Theatre nurses
- Anaesthetists & anaesthetic technicians

3.2. PAEDIATRIC INPATIENTS

There is a dedicated 22 bed ward including a 4 bed High Dependency Unit. Nursing resource allows for staffing of 16 of these beds. The service shares a 16 bed paediatric intensive care unit, utilising on average 4 beds. The intensive care unit is staffed by paediatric intensivists.

All inpatient referrals are tertiary in nature, with the majority originating outside the Northern Region.

3.3. PAEDIATRIC AND CONGENITAL CARDIAC SURGERY

Paediatric cardiac surgery is undertaken in one of two cardiac operating theatres at Starship Children's Hospital under the leadership of Kirsten Finucane. Adult congenital cardiac surgery is undertaken by the same surgical team in the Level 4 cardiac operating theatres of Auckland City Hospital (adjoining Starship Children's Hospital). Postoperative patients are transferred to the paediatric or cardiac (adult) intensive care unit.

Surgical volumes and outcomes

The following statistics are counts of admissions that result in cardiac surgery and exclude patients cannulated for ECMO for non cardiac reasons, and premature neonates who underwent ligation of a patent ductus arteriosus in the neonatal intensive care unit.

The surgical numbers for bypass and non-bypass cases are relatively stable over the past decade. (Figure 1).

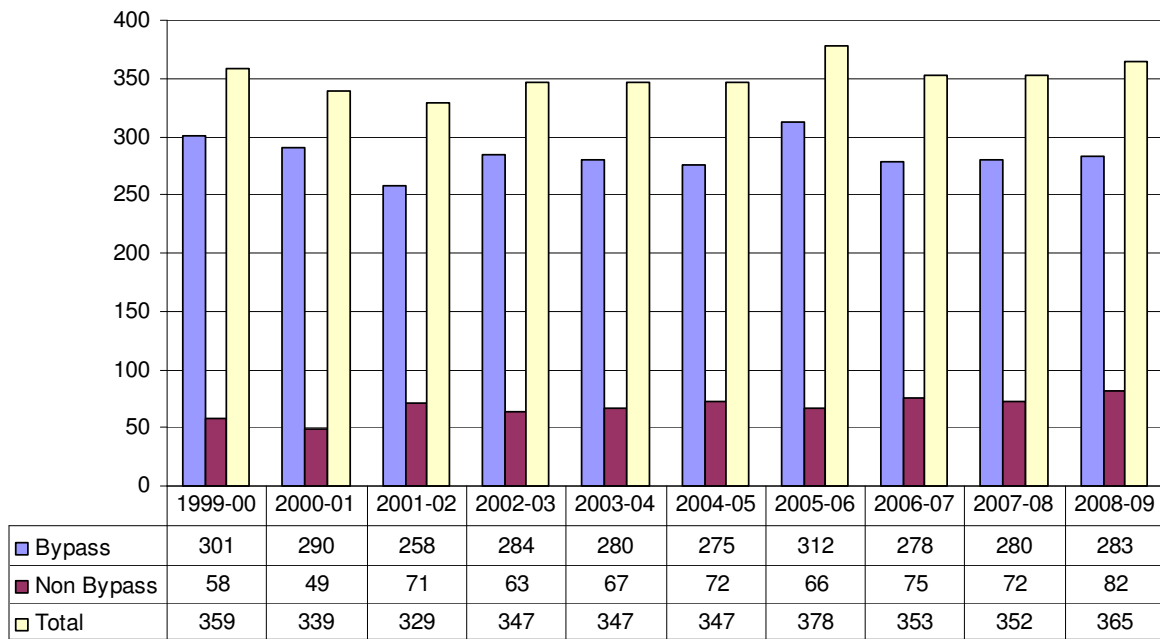


Figure 1. Surgical admissions by year and type of procedure

Approximately one half of surgical admissions are for infants aged <1 year, and 10% are for adults with congenital heart disease (age ≥15 years) (Figure 2).

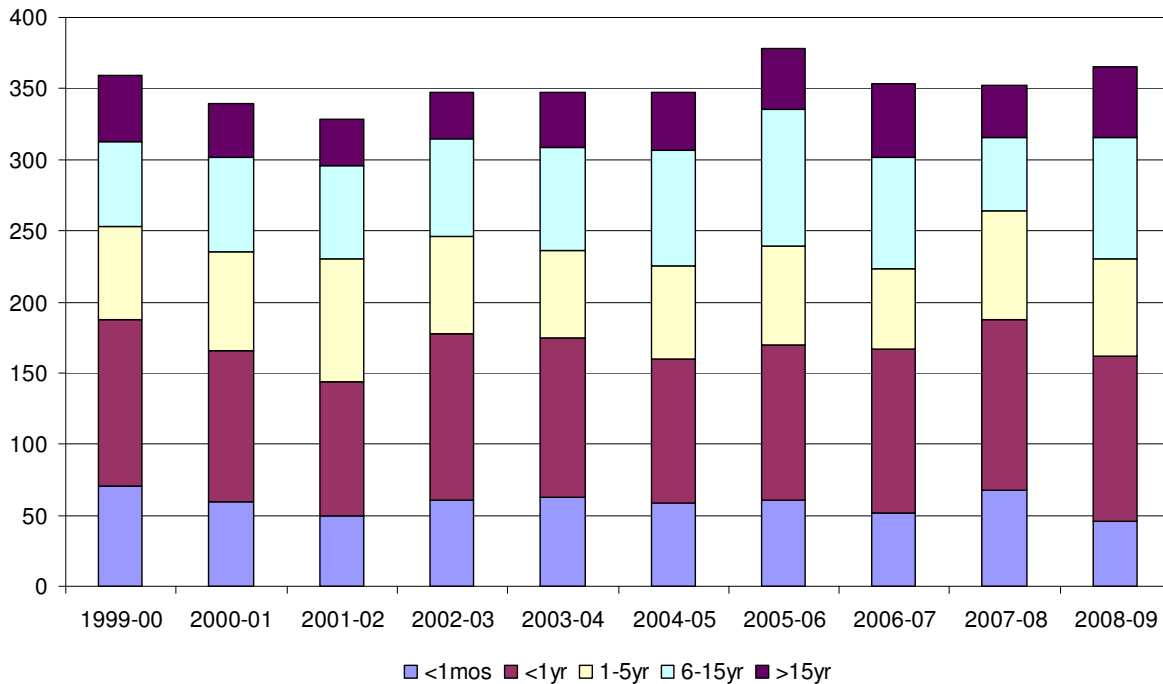


Figure 2. Surgical admissions by age

Surgical mortality is low and has remained 2% or less in the past five years. Early mortality rates quoted below relate to deaths during the surgical admission or within 30 days of operation. Patients are counted once per admission even if they had multiple procedures during an admission (Tables 1-4). After a series of deaths in

infants undergoing aortopulmonary shunt procedures, a protocol for care has been established. This, and the improved outcome in low birth weight infants (Table 4), has contributed to the improved early mortality from 2.2% to 1.4% in the latest cohort. (Table 2)

Table 1. Early Mortality by Year

Year	Early Mortality	Total	Percent Early Mortality
1999-00	15	359	4.2%
2000-01	10	339	2.9%
2001-02	12	329	3.6%
2002-03	4	347	1.2%
2003-04	9	347	2.6%
2004-05	7	347	2.0%
2005-06	5	378	1.3%
2006-07	7	353	2.0%
2007-08	5	352	1.4%
2008-09	6	365	1.6%
Total	80	3516	2.28%

Table 2. Early mortality by Operation Type

Year	Bypass			Non Bypass		
1997-01	40	1144	3.5%	4	262	1.5%
2001-05	26	1097	2.4%	6	273	2.2%
2005-09	19	1153	1.6%	4	295	1.4%
Total	85	3394	2.5%	14	830	1.7%

Table 3. Early mortality by age

	<1month	1-12 month	1-5 years	6-15 years	>15 years
1997-01	10.6%	2.2%	0.0%	1.5%	3.4%
2001-05	6.0%	2.8%	0.7%	0.3%	2.1%
2005-09	6.6%	0.9%	0.4%	0.0%	1.7%

Table 4. Early Mortality for low birth weight (less than 2500g)

Period	Early Death	Total	% Early mortality	Low Birth Weight % of cases aged <1 year
1997-01	3	32	9.4%	4.9%
2001-05	3	36	8.3%	5.5%
2005-09	1	41	2.4%	6.0%

Early mortality has fallen in the context of stable volumes and disease severity (figure 3 and 4).

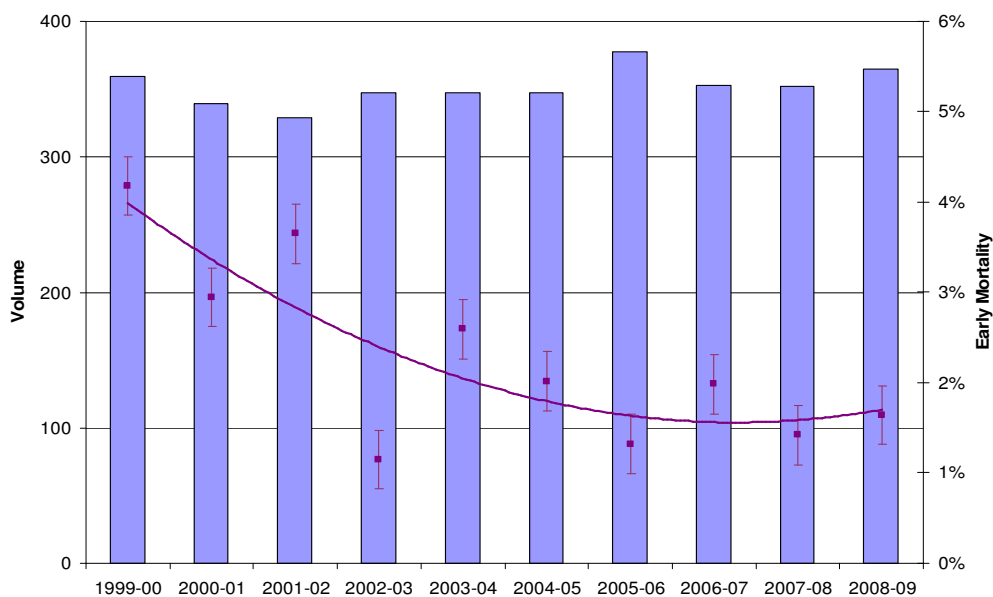


Figure 3. Volumes (surgical admissions) in blue and early mortality (maroon). Bars are +/- SE and lines indicate polynomial trends (black for volume and maroon for early mortality).

Complexity has not changed over the past 14 years, but there has been a decrease in mortality in the most complex cases as demonstrated by RACHS scoring (Figures 4 and 5). (RACHS is a complexity scoring tool, the higher number indicating more complex surgery. It has been applied to patients with congenital heart disease aged less than 18 years).



Figure 4. RACHS codes and Admissions over 3 time periods. Class 5 has too few numbers for analysis.

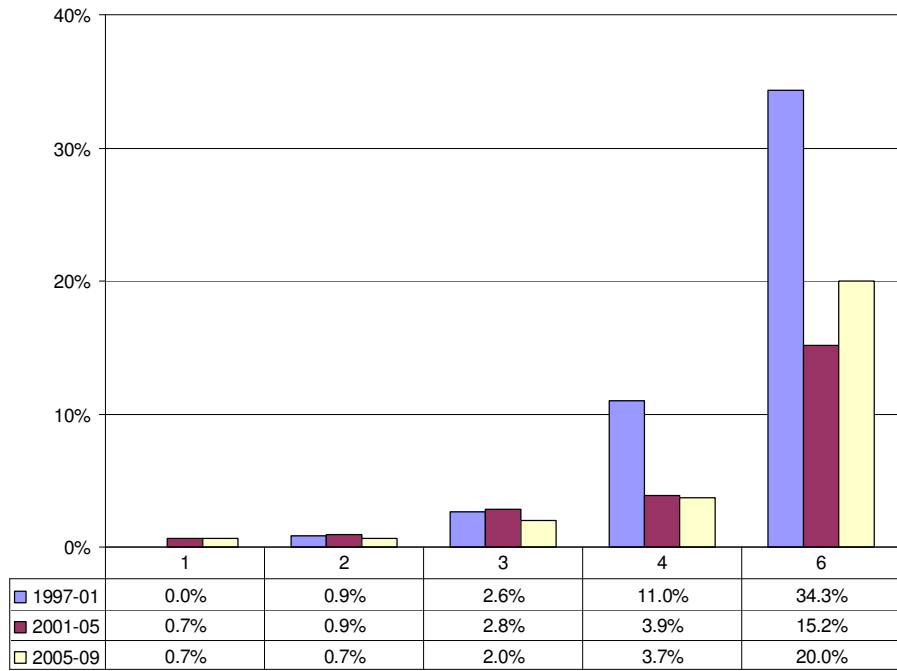


Figure 5: Early mortality by RACHS classification over 3 time periods

Low mortality figures have been maintained over the past few years, particularly in neonates and low birth weight infants, shifting the focus on to neurologic outcomes. The Auckland MRI study is nearing completion with analysis of results in progress, and one publication to date.

An increase in Norwood mortality over the 2008 year prompted a careful review of all cases (in 2009) and the recent adjustment of ICU, ward and discharge protocols.

A surveillance programme has been developed for infants returning home after the Norwood Procedure or single ventricle shunt surgery. Parents receive intensive education and special scales and an oximeter machine are taken home with the intent to enable daily recordings. Limits are set and the local paediatrician, district nurses and cardiac liaison nurses work together to advise parents and arrange readmission if there are concerns. The early results of this programme are encouraging with decrease in the interval death rate. Parental acceptance and ability to cope is also being measured to ensure the programme is not creating unreasonable stress for families.

Surgical patients are admitted include those from neighbouring South Pacific Island nations. In the past the majority have rheumatic valve disease but neonates and infants with congenital heart disease are being diagnosed in the poorer Pacific nations in time for transfer for cardiac surgery.

Our programme maintains a strong focus on valve repair with the development of rheumatic aortic valve repair techniques. Over 90% of mitral rheumatic valve cases are repaired at their first procedure.

Close collaboration with Pacific Island referring physicians, and case-management has aimed at improving efficiency and reducing costs of surgery without compromising outcome.

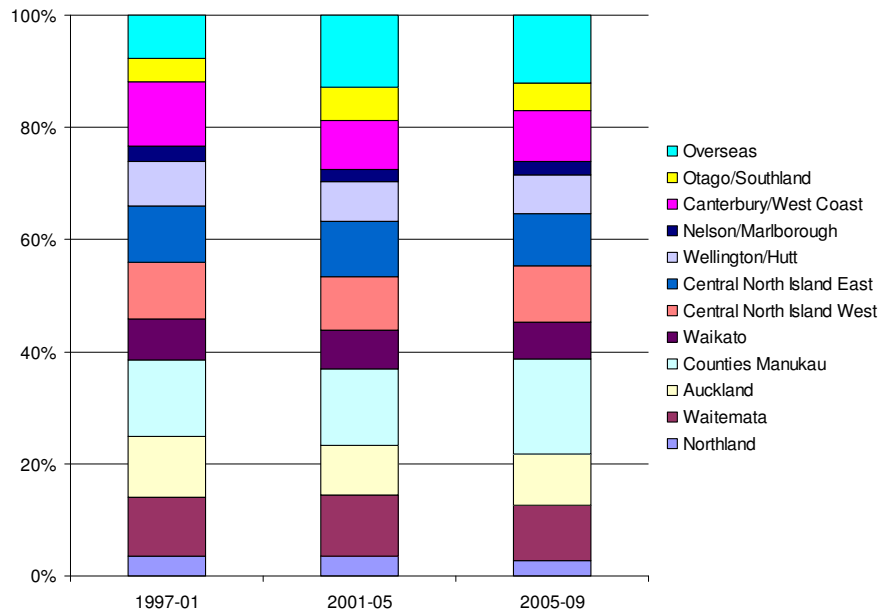


Figure 6: Domicile of surgical patients

One of the major tasks for 2008 was the search for a third full time paediatric congenital cardiac surgeon which resulted in the appointment of Dr John Artrip from The Children's Hospital of the King's Daughter, Norfolk, Virginia. Many overseas colleagues were spoken to during the process and contacts made that are proving valuable for the future.

Good progress has been made by our Paediatric theatre charge nurse (Rita Pinto), towards developing a specialised nursing group who cope well with the elective load and are now covering much of the afterhours work also, with excellent rostering and allocation of cases. The cardiac operating theatres remain a popular place to work.

There are three cardiac surgical trainee positions including a New Zealand trainee registrar post. The purpose of the latter is to expose New Zealanders early to the speciality, and encourage those with the right skills to return. A junior New Zealand registrar can complement the skills of more senior overseas fellows and allow more flexibility and security for leave/sickness. Medical Council registration of overseas trainees has been a challenge, and has resulted in overseas doctors becoming more and more difficult to efficiently utilise.

In 2009 the overseas patient load appeared to be increasing and the team continues to work to increase the cost-efficiency of these Pacific Island patients without compromising outcomes.

3.4. PAEDIATRIC OUTPATIENTS

There are 8 paediatric cardiology outpatient clinics per week, including an arrhythmia clinic and two Day Stay sessions. Eighty percent of outpatients are tertiary (referred from paediatricians or cardiologists). Secondary referrals reside almost entirely in the Auckland District Health Board region.

Volumes have increased over the past 5 years (Figure 6). This has largely been related to an increase in follow-up visits. These trends are indicative of multiple changes in practice.

- Primary referrals from out of region have been devolved to paediatricians in West, North, and South Auckland
- There has been an increasing trend for heart disease to be diagnosed prenatally or in the new born nursery
- Increased numbers of infants and children are surviving complex cardiac surgery
- More intensive surveillance of at risk groups has resulted in earlier treatment and reduction in long-term morbidity and mortality.

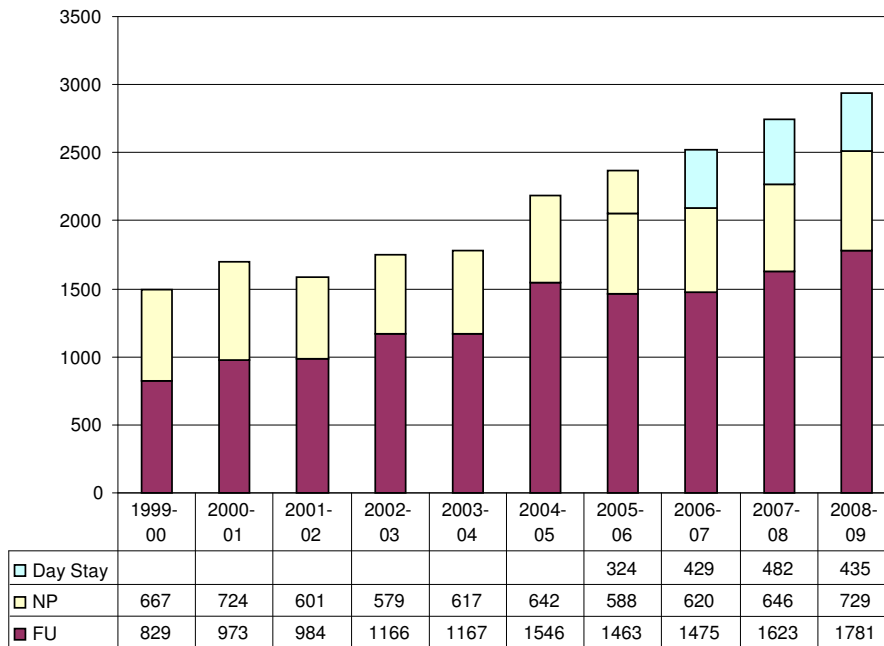


Figure 7: Paediatric Cardiology Outpatient Visits. (NP = new patient, FU = follow-up. Day Stays were included with outpatient visits prior to 2005-06)

3.5. PERIPHERAL CLINICS

Peripheral paediatric cardiology clinics are undertaken in all major metropolitan centres and in most regional centres. There are 102 clinic days per year including seven adult congenital clinics. Patients seen in these clinics are solely the result of referral from secondary and tertiary sources. There is a continuing, albeit small, unmet need for visiting clinics and it is likely numbers will increase further in 2010 with the addition of a further cardiologist to the team.

Clinic	2002-2003	2003-2004	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009
Blenheim		1	1	1	2	3	1
Christchurch	47	44	44	30	32	39	37
Dunedin		1	4	4	4	6	8
Gisborne	3	1	2	2	2	4	3
Hastings	5	3	5	4	5	5	5
Invercargill	2	2	3	3	3	3	3
Nelson		1	1	1	1	1	1
Palmerston North	4	6	5	5	4	7	5
Rotorua	4	3	4	4	3	2	4
Tahiti	3	5	5	4	5	5	5
Taranaki	4	4	4	5	4	5	5
Tauranga	2	2	4	5	5	6	5
Waikato	11	8	7	10	6	7	7
Wellington	5	6	6	6	7	6	6
Whakatane	2	1	1	1	1	1	2
Whangarei	5	3	7	5	4	6	5
Total	97	91	103	90	88	106	102

In addition to outreach clinics the service places considerable emphasis on maintaining children in their home regions. Although there are no paediatric cardiologists resident outside Auckland there are a number of paediatricians and cardiologists with subspecialty skills in this area who provide high quality surveillance for

cardiac children. There is close liaison between these clinicians and the Green Lane Paediatric and Congenital Cardiac Service. The degree of support is considerable and involves telephone consultation and frequent review of echocardiograms, electrocardiograms and other cardiac investigations. Consultation of this nature that resulted in written response are summarised below (Figure 8). These consultations, together with the peripheral clinics form the basis of an informal clinical network.

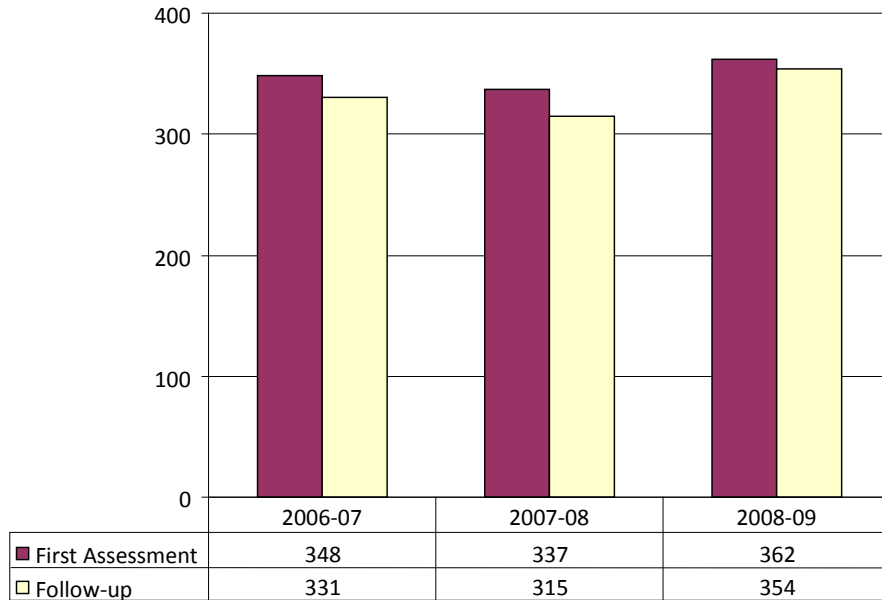


Figure 8. Consultation where the patient was not seen by a cardiologist but a written opinion was given based on review of patient data (clinical summary, and/or echocardiogram, MRI, Holter monitor, or electrocardiogram)

3.6. FETAL CARDIOLOGY

There are 2 clinics per week in conjunction with the high risk obstetric service. Fetal cardiology referral patterns have changed following a decision to restrict referrals to those with suspected fetal heart disease. This decision was in part dictated by the limited cardiology resource (a single fetal cardiologist, Tom Gentles) but also recognises the expertise of the tertiary obstetric scanning team at Auckland City Hospital. (Figure 9 and 10).

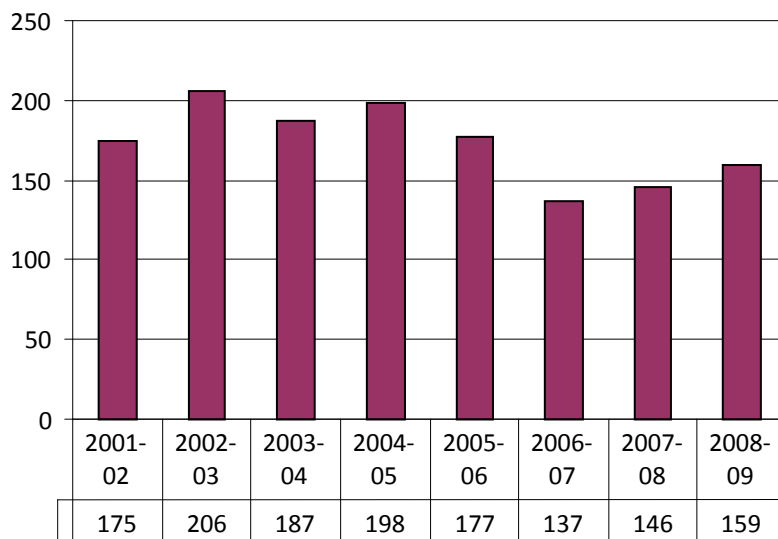


Figure 9. Fetal Cardiology outpatient volumes

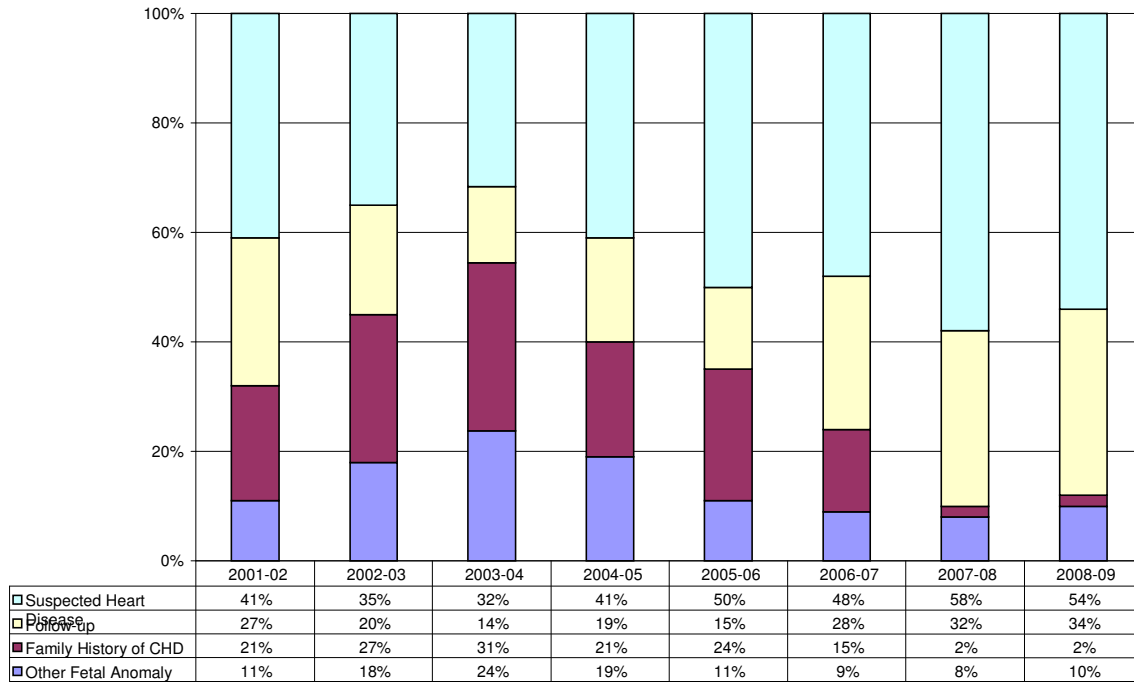


Figure 10. Indications for fetal cardiology outpatient referrals

Patients are referred from throughout the country for assessment in Auckland. Often this occurs following diagnosis elsewhere. Distant consultations are provided via digital link and the use of videoconferencing for counselling. Figure 11 details the domicile of women seen in the fetal cardiology clinic in Auckland, while Figure 12 details those in whom a consultation was undertaken at a distance via review of a scan from another institution and/or counselling via telephone or video link.

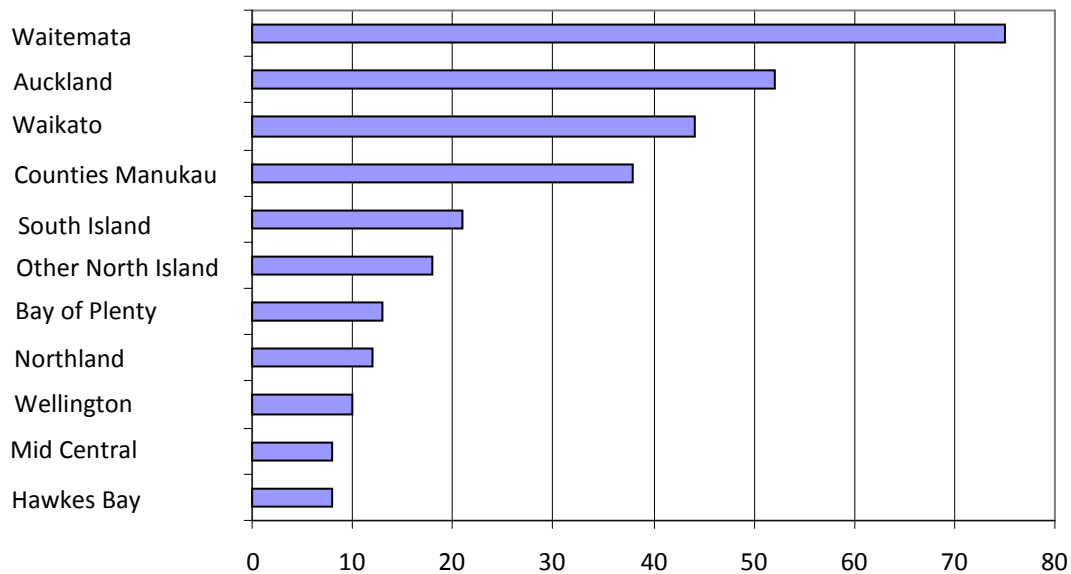


Figure 11. Domicile of patients seen in fetal cardiology clinic July 2007 – June 2009

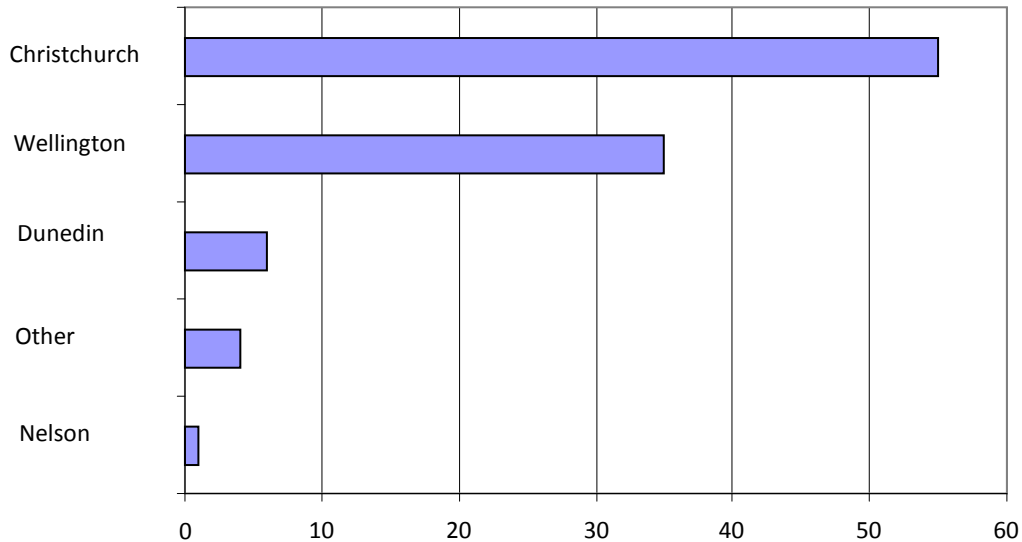


Figure 12. Domicile of fetal "distant consultation" July 2007 – 2009

3.7. ADULT CONGENITAL HEART DISEASE SERVICE

The Adult Congenital Heart Disease (ACHD) Service has continued to develop in response to the needs of a rapidly expanding population. The core team comprises two cardiologists (Drs Tim Hornung and Clare O'Donnell) from the Paediatric & Congenital Cardiac Service, Dr Ivor Gerber from the Adult Cardiac Service and the ACHD Nurse Practitioner Annette Neugebauer, who work closely with the Paediatric & Congenital Cardiac Service surgical and ICU teams. Dr Boris Lowe will be joining the service later in 2009 after completing an ACHD fellowship at McGill University, Montreal, Canada. The ACHD cardiologists work closely together so that the mix of paediatric and adult cardiology backgrounds adds to the overall standard of care. In addition, an adult cardiac registrar is rotated to the Paediatric & Congenital Cardiac Service team and spends much of their attachment gaining experience with this group of patients. The service also has access to a health psychologist.

Cardiac surgeons from the Paediatric and Congenital Cardiac Service (Mrs Finucane and Mrs Rumball) undertake surgical procedures on these patients in the adult cardiology operating theatres. Patients convalesce in the adult cardiac ICU and adult cardiac surgical ward.

Inpatients over the age of 15 are accommodated in Wards 31, 42 and the Cardiothoracic ICU at Auckland City Hospital and a number of study days have been held to assist staff from these and other departments in the hospital in caring for these complex patients.

Outpatient clinics occur once a week at the Green Lane Clinical Centre where up to 16 patients are seen in each session. Numbers are constrained by the availability of echocardiography, and with increasing waiting time for routine assessment (currently 4-5 months), a second weekly clinic is clearly required, and this clinic is expected to commence in the latter part of 2009. Each clinic will be staffed by one adult and one paediatric cardiologist as well as the nurse practitioner, ACHD registrar and psychologist.

In addition to the above, there are four arrhythmia clinics per year, staffed by the ACHD consultants with Dr Jon Skinner from the Arrhythmia Service, and two to three transition clinics at Starship Children's Hospital.

There is an expanding network of Outreach Clinics (Table 5). We are fortunate to have cardiologists with an interest in congenital heart disease in a number of centres around the country and close liaison is maintained to assist with evaluation and care of adult congenital patients, with transfer to Auckland as necessary for assessment or treatment.

Region	2007-2008	2008-2009
Palmerston North	1	1
Taranaki	1	2
Tauranga	1	1
Waikato	2	2
Wellington	1	1
Whangarei	1	1
Total	7	8

Table 5. ACHD Outreach Clinics

3.7.1. Current Volumes

Inpatient volumes have shown an increase, both in terms of bed days and patient numbers, as have outpatient numbers. (Figures 13 and 14). Approximately 120 patients transfer from the paediatric to the adult congenital service each year. Outpatient numbers have been constrained by clinic capacity; a further increase in numbers is forecast with the opening of an additional clinic later in the year.

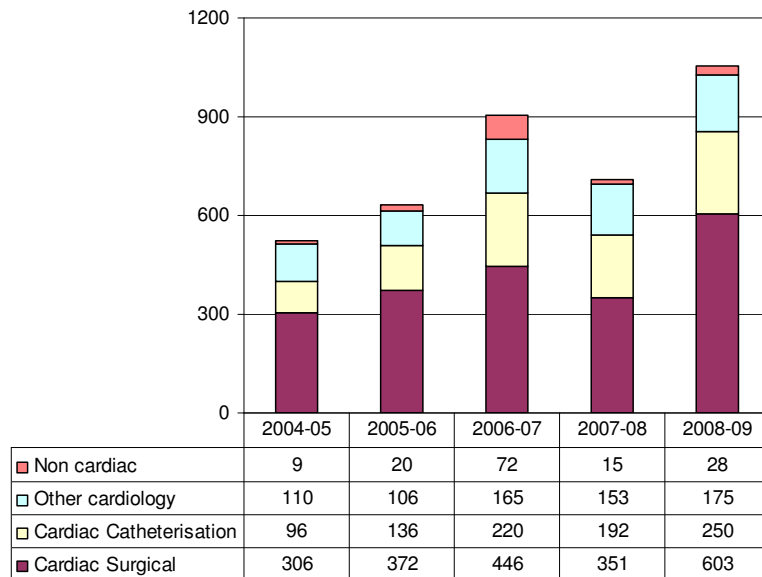


Figure 13. Inpatient bed days

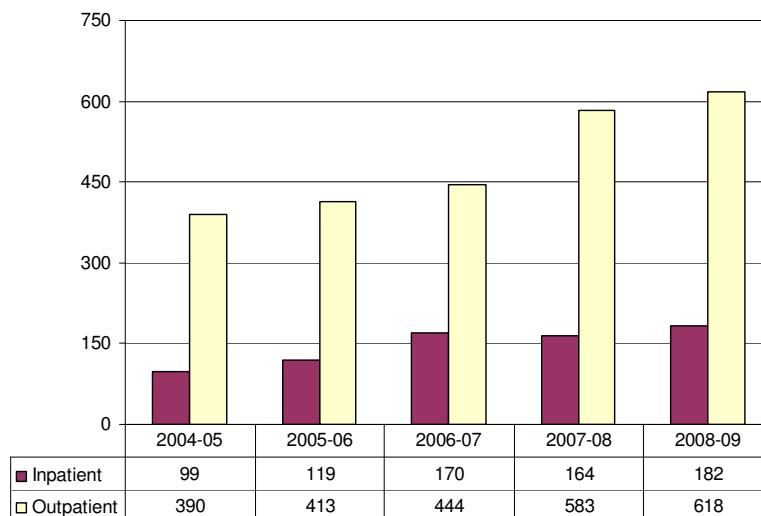


Figure 14. Inpatient and outpatient

3.7.2. Education

The team provides study days, group sessions and individual teaching sessions for nurses in the adult cardiology and cardiac surgical services. Annette Rief facilitates a biannual 8-hour study day to assist staff from these and other departments in the hospital in caring for these complex patients. She also organises resource nurse development in the adult cardiothoracic wards and regular staff teaching on an ongoing basis. Educational material continues to be developed and is available for staff including the now-complete ACHD workbook. Policies and recommended best practices related to ACHD patients in the hospital are updated regularly.

3.7.3. New initiatives

1. Nurse Practitioner role

Due to increased clinic workload Annette Rief has been seeing a full patient load at the outpatient clinic. This compromises the nurse practitioner's patient education role; when the second clinic starts later this year Annette will be able to return to her key education role.

Plans have been developed for an ACHD nurse practitioner clinic to be held on Thursday morning and supported by the ACHD consultant staff. This will also provide an opportunity to see pregnant ACHD patients who usually attend their obstetric medicine appointments that day. The nurse practitioner is also involved in the Whangarei ACHD outreach clinic.

The nurse practitioner workload is significant and further nursing appointments are anticipated.

2. Resource Nurse Development

Training on the adult cardiac surgical wards (Ward 42/46) is ongoing and involves regular meetings with education sessions and day-to-day support. Dedicated part-time ACHD resource nurse roles would be helpful. Christchurch Hospital remains the only hospital in the country to employ a part time ACHD resource nurse, Alison Herman, to work with Dr. Lainchbury throughout the year at the Christchurch ACHD clinics. Annette gives ongoing support for the role development.

3. Outreach Transition clinics

Outreach transition clinics are held in Christchurch and Wellington once per year and are run by the ACHD team with local cardiologists and nursing staff in attendance.

4. Second ACHD clinic

A second ACHD clinic will be held at Starship Children's Hospital on Tuesday mornings commencing September 2009.

5. Educational resources for patients

The "Health Navigator" website for patients and Primary Health Care Providers is completed.

6. Patient support groups

Heart Children New Zealand has employed a national teenage and young adult coordinator, Wendy Graham. She is based in Auckland and supports ACHD patients nationally. A national support network linked to the existing branches is in progress.

7. Out of hours on-call service

Further consideration is being given to establishing an out of hours ACHD cardiologist consultation service with the appointment of a fourth cardiologist.

3.8. CARDIAC INHERITED DISEASE GROUP (CIDG)

The Cardiac Inherited Disease Group (CIDG) is lead by Dr Jon Skinner and includes a co-ordinator (Jackie Crawford), team support, and Carey Evans at the university laboratory. Salary support from Cure Kids is provided fulltime for Carey and 20% for Dr Skinner. The group also includes a number of cardiologists, pathologists and geneticists throughout the country, and meets by teleconference at a national level each quarter with a weekly meeting in Auckland.

The laboratory diagnostics for Long QT Syndrome were transferred from the University of Auckland to the Auckland District Health Board (Lab Plus), following a period where it was necessary to send proband samples to Norway for testing.

A hypertrophic cardiomyopathy genetic counselling clinic run by Dr Jim Stewart and Jenny Warrington from the clinical genetics department, continues to expand, while an inherited arrhythmic syndromes clinic is held quarterly, by Drs Jon Skinner, Warren Smith (Adult Cardiology) and Ian Hayes (Clinical Genetics).

The CIDG database (funded by Cure Kids) is in regular use as a clinical tool. The registry includes 197 families with long QT syndrome, 84 with hypertrophic Cardiomyopathy, 40 with arrhythmogenic right ventricular cardiomyopathy, and 8 with CPVT.

There have been 436 cases of young sudden death reported to CIDG for post-mortem genetic investigation. The Northern Regional collaboration with forensic pathology has now spread to cover all of New Zealand. A two year collaboration to investigate Sudden Unexplained Death in Young People (SUDY) involves post-mortem LQTS genetic testing and cardiac screening of family members. Of the eighty DNA samples analysed the diagnostic rate was 8% in those aged < one year ("Sudden Infant Death Syndrome"), 36% in 1-18 year olds, and 22% in 1-40 year olds (Figure 15).

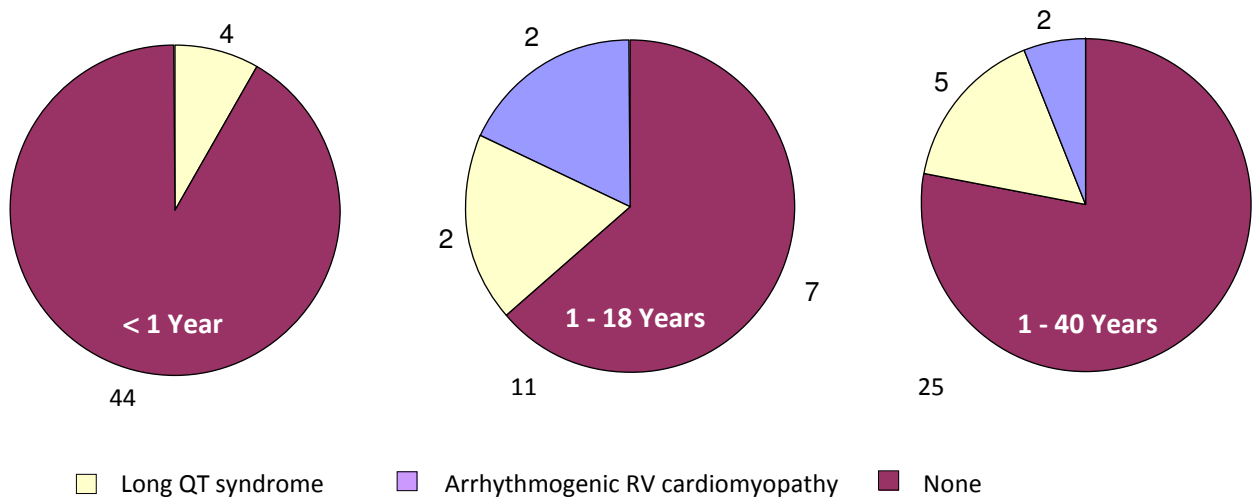


Figure 15. Yield of Investigation of Sudden Unexpected Death by age group

CIDG provides a two stage investigation process in post mortem negative sudden deaths:

1. Family investigation
2. Genetic tests for long QT syndrome undertaken using DNA stored at post-mortem

The low diagnostic rate among SIDS is disappointing, and may lead to the discontinuation of this service, allowing CIDG members more time to investigate the deaths in 1-40 year olds.

Originally funded by Cure Kids, data from this on-going project has resulted in a Ministry of Justice decision to fund posthumous LQT genetic testing from July 2008.

Applications for further funding

CIDG applied for development funds from the Ministry of Health through the National Services and Technology Review Process (NSTR) in April 2008 for three liaison nurses and funding for the database development. This process continues.

CIDG research

Carey Anne Evans is working towards her PhD which should be completed in March 2010.

The collaboration with TRAGADY has led to the procurement of significant philanthropic funds and a significant NHMRC grant (\$200,000 Au per year for three years) for Australian and NZ prospective study of young sudden death.

Collaboration with Professor Dan Roden, Vanderbilt University Nashville investigating the cellular electrophysiology of new variants in our LQT gene cohort has led two publications. These results are of great clinical value.

In total CIDG has seven publications during these two years in significant journals as a result of national and international collaborations.

3.9. RHEUMATIC HEART DISEASE

All cardiologists and surgeons are involved with clinical care of children with the severe rheumatic heart disease.

Clinical activities include:

- Cardiac assessment of children admitted to the Starship Children's Hospital with suspected or confirmed acute rheumatic fever.
- Tertiary opinion for paediatricians and cardiologists managing children with rheumatic heart disease.
- Inpatient management of acute rheumatic fever and severe carditis in the cardiac ward.
- Cardiac surgery for chronic (and occasionally acute) rheumatic heart disease. Surgical procedures favour valve repair whenever possible and include an increasing number of aortic valve repairs. From July 2007 to June 2009 there were 41 operations on 40 patients aged 3 to 24 years. There were no deaths. Six were reoperations (including the one patient who had the initial operation during that time period). Single valve surgery was undertaken in 18, double in 19 and triple in 4. Procedures are detailed in Table 6.

Mitral valve	Repair	28
	Mechanical	4
Aortic Valve	Homograft	10
	Repair	11
Tricuspid valve	Mechanical	5
	Repair	10

Table 6. Rheumatic valve surgical procedures.

3.9.1. Future developments and current issues:

The case load is dependent on the local prevalence of rheumatic heart disease, and on the availability of funding for children from the Pacific Islands.

- The local prevalence may be impacted by recent screening projects (see below). Although these projects are likely to identify more cases in the short term, in the longer term penicillin prophylaxis of those with mild disease will reduce the prevalence of more severe disease. Currently screening is a research directed tool, but it is likely it will be adopted as a public health measure in at risk populations.
- The number of referrals from the Pacific Islands is dependent on funding and on surgical capacity. Over the past two years there has been significant development in the outreach programme to the Pacific Islands with visiting clinics to Samoa Tonga, Tahiti, and the Cook Islands funded by local governments and/or NZ Aid. These clinics have facilitated communication with local clinicians, and improved follow-up for children who have returned to their homes after cardiac surgery. An ongoing screening programme

accompanied by secondary penicillin prophylaxis has the potential to reduce the prevalence of severe rheumatic heart disease. Access to cardiac surgery for Pacific Island peoples is limited by funding issues, excepting for those from the Cook Islands (a New Zealand territory) and Tahiti. The Paediatric and Congenital Cardiac Service case manages children from the Pacific Islands in an attempt to minimise hospital costs without impacting outcomes.

3.9.2. Rheumatic Heart Disease Research

Rachel Webb was the Rheumatic Heart Disease fellow in 2007-8 and was supervised by Dr Nigel Wilson. Her projects included:

- School based RHD screening in South Auckland (Decile 9 and 10 children)
- Follow up of rheumatic heart valve surgery in children (with Drs Kirsten Finucane and Tom Gentles)
- Normal data of valve thickness in children

Future initiatives:

- Project grant applications have been made for RHD screening in South Auckland, Lakes, Bay of Plenty and Hawkes Bay District Health Boards. Many of these centres are in the Central North Island, a region that has been shown to have the widest health inequalities in New Zealand.
- Standardisation of RHD echocardiography – Consensus is needed for defining echocardiographic diagnostic criteria when screening for rheumatic heart disease. Nigel Wilson will be leading an international study involving cardiologists from 6-9 regions. Inter- and intra observer studies will utilise a panel of experts to establish a gold standard real-time reference for normal, subclinical, mild to severe disease, and to produce a DVD for distribution. Dr Bo Remenyi has received a two year research fellowship from the National Heart Foundation of New Zealand, from July 2009, to work with Dr Wilson.

4. INVESTIGATIVE SERVICES

4.1. ECHOCARDIOGRAPHY

The service employs 5 Sonographers working 4.4 FTE. A rotating position with the adult echocardiography department no longer exists so that all Sonographers are dedicated cardiac congenital Sonographers. During 2009 Megan Burrows was appointed charge sonographer.

Equipment includes 6 cardiac ultrasound systems comprising three Philips iE33's, a Sonos 5500, a portable Vivid E system (purchased with a research grant from the Starship Foundation and used predominantly in the school rheumatic heart disease screening programme) and a Sonosite for use in the catheterisation laboratory. All iE33 systems have live real time 3D transthoracic and transoesophageal capabilities. There are two paediatric, two adult 3D transthoracic probes and one 3D transoesophageal probe. Software upgrades include Mitral Valve Quantification (MVQ), 2D Strain, and TomTec allowing offline analysis of 3D RV and LV volumes and mitral valve analysis. The Starship Foundation have been very generous in their support of paediatric echocardiography.

All inpatient echocardiograms for children and adults with congenital heart disease as well as paediatric outpatient echocardiograms are performed at Starship Children's Hospital. In addition the sonographers staff an Adult Congenital clinic held at the Green Lane Clinical Centre once per week. On occasion paediatric Cardiac Sonographers cover paediatric echocardiography clinics held at other centres including Middlemore, Gisborne, Rotorua and Tonga.

The number of echocardiograms has continued to increase reflecting the growing importance of echocardiography in diagnosis and surveillance and a significant increase in adult congenital and paediatric inpatient and outpatient attendances. Figures 16-18.

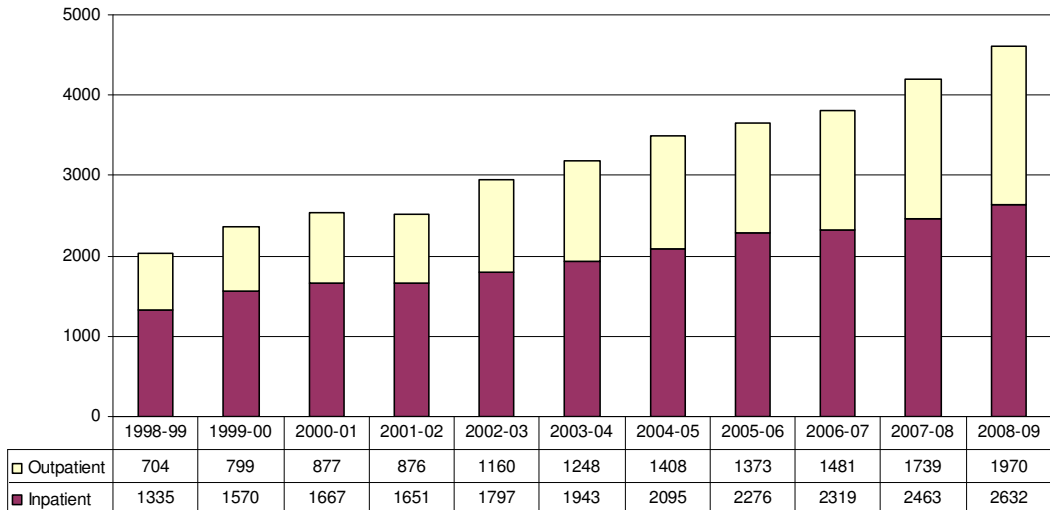


Figure 16. Total number of echocardiograms (paediatric and adult congenital)

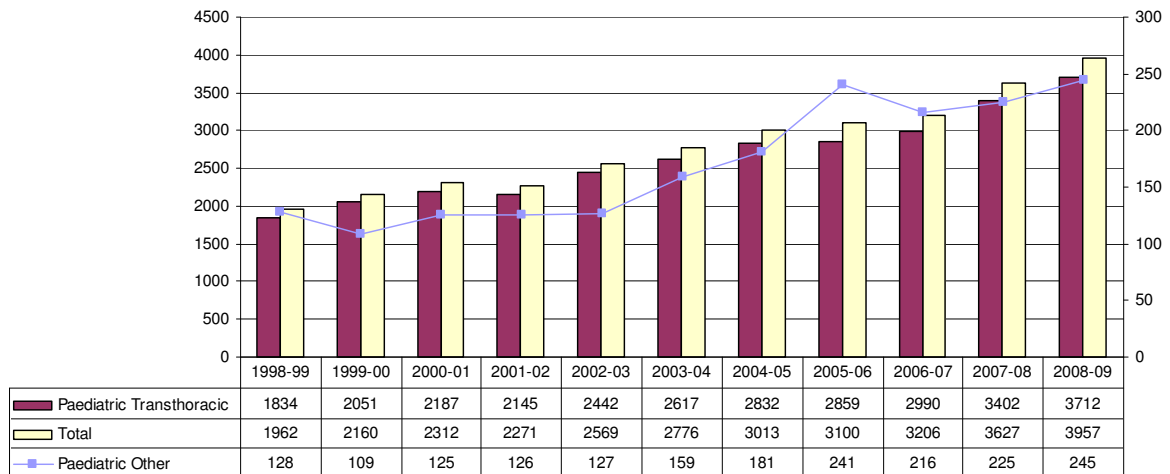


Figure 17. Paediatric echocardiograms: transthoracic and total on left axis and epicardial and transoesophageal ("other") on right axis

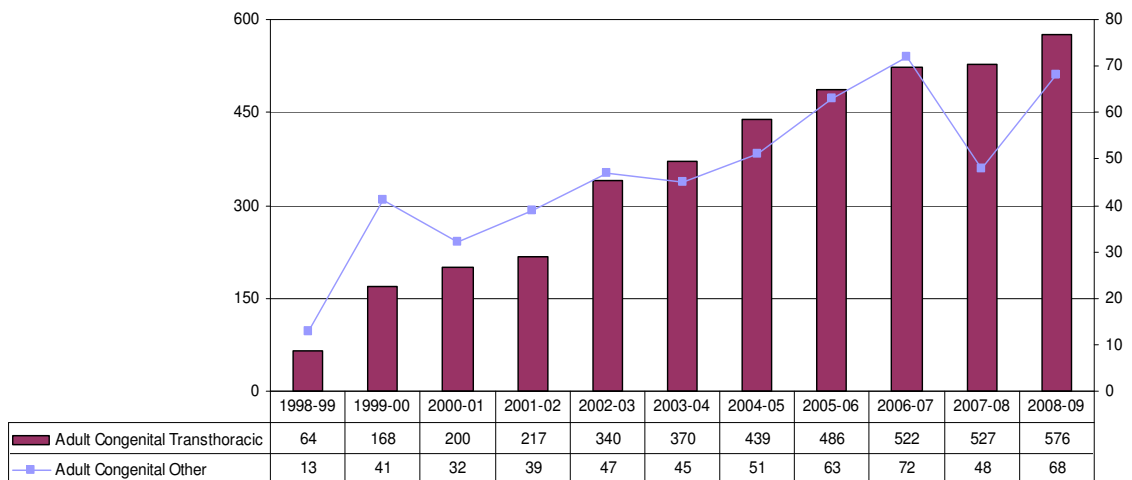


Figure 18. Adult Congenital Heart Disease echocardiograms

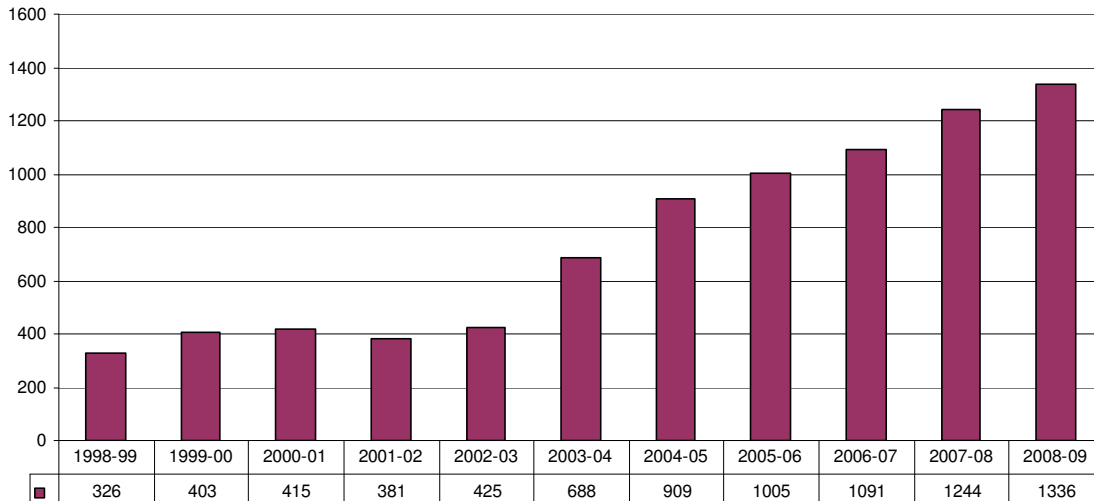


Figure 19. Echocardiograms for other services.

The number of echocardiograms undertaken for other services continue to increase since moving to The Starship Children's Hospital from Green Lane Hospital in late 2003 (Figure 19).

4.2. CARDIAC MRI

The Cardiac MR Service is run by Dr Chris Occleshaw and Dr Tim Hornung. Not included in the volumes in Figure 20, are cardiac MRI studies performed for patients residing outside Auckland, either in Christchurch or at the Centre for Advanced MRI at Auckland University. Numbers have decreased over the past 3 years following the opening of a Cardiac MRI facility in Christchurch, staffed by a radiologist with congenital cardiac training (Dr Sharyn MacDonald), and Wellington (Dr Katherine Ferrier), both of whom work with close support from the Auckland MR team.

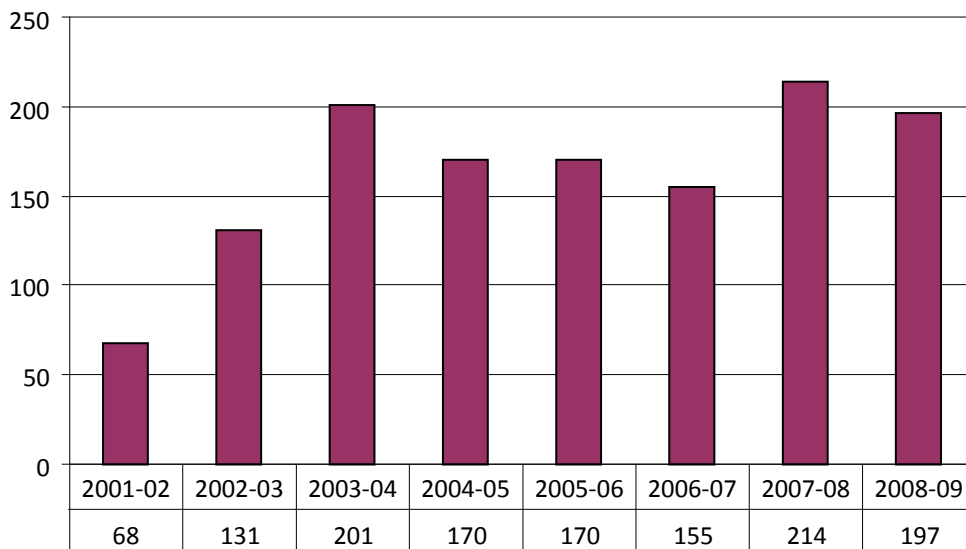


Figure 20. Cardiac MRI in children and adults with congenital cardiac disease

4.3. CARDIAC CATHETERISATION

Paediatric and adult congenital cardiac catheterisation is undertaken in a dedicated catheterisation suite at Starship Children's Hospital under the leadership of Dr Nigel Wilson with Dr Clare O'Donnell in a senior interventional and administrative role. A number of personnel are involved in addition to the catheterising cardiologist including nursing staff, physiology technicians, radiographers, anaesthesia staff and a cardiac radiologist.

Paediatric and adult congenital electrophysiology studies and interventions are undertaken in the electrophysiology laboratory in the adult cardiology catheterisation suite and are detailed elsewhere.

The number of interventional and diagnostic procedures are detailed in Figure 21.

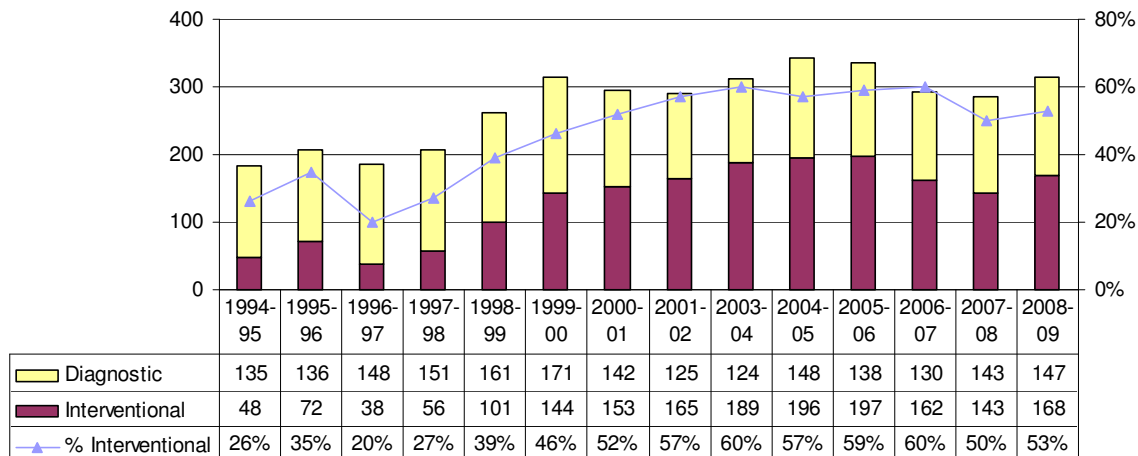


Figure 21. Cardiac catheterisation volumes 1994-2009.

The majority of patients undergoing cardiac catheterisation are infants or children but there is a significant minority of adults, 50% of whom were catheterised for an interventional procedure. (Table 7)

Age	Number	% Interventional
0-1 year	177	48%
1-15 years	312	50%
>15 years	111	64%

Table 7: Cardiac Catheterisation procedures by age and type (July 2007-June 2009)

Over the past 2 years cardiac catheterisation expertise there has been a deliberate policy to of subspecialisation so that the catheter procedures are now undertaken by 3 operators with Dr Peter Ruygrok continuing his involvement with adult ASD procedures assisted by a paediatric cardiology staff providing echocardiography (Figure 22).

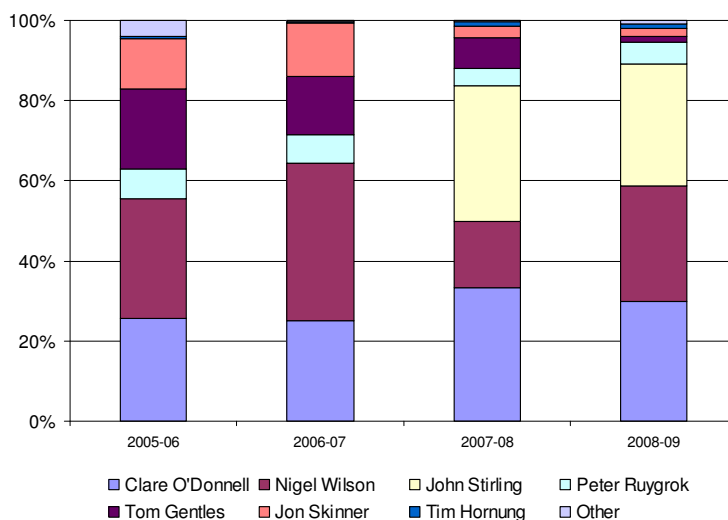


Figure 22. Cardiac catheterisation procedures 2005-09 by catheterising cardiologist

Fluroscopy and Procedure times are detailed in Figures 23 and 24.

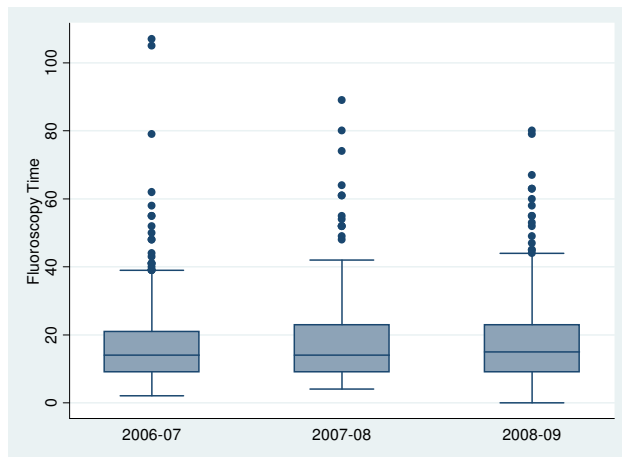


Figure 23: Fluroscopy times

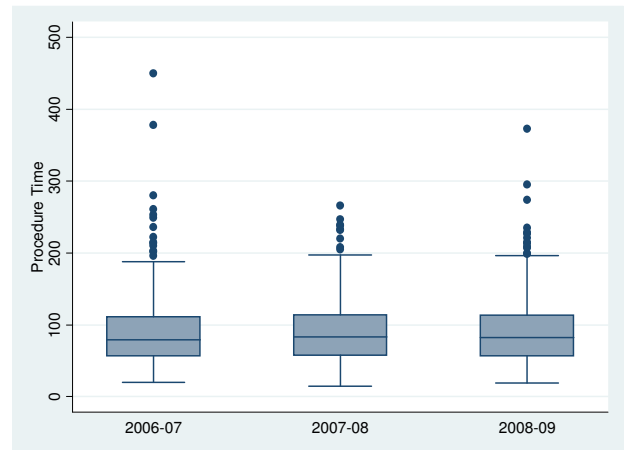


Figure 24: Procedure times

Between July 2007 and June 2009 there were 376 interventional procedures undertaken during 357 cardiac catheterisation studies. These are detailed in Table 8.

Table 8. Interventional Procedures

		2005-06	2006-07	2007-08	2008-09
Vessel Occlusion	IMA	10	14	13	22
	Coil AP collated	4	6	2	4
	Coronary artery fistula close	1	1	2	
	Vein		2		2
Angioplasty	Pulmonary artery	22	18	16	28
	Native and Re-coarctation	8	8	4	8
	SVC		1		1
	Systemic to PA shunt	1			
	RV-PA Conduit	1	1		3
	Other		1	1	
Valvuloplasty	Aortic valve	6	4	6	3
	Pulmonary valve	18	14	14	11
	RVOT in Tetralogy of Fallot		1	1	1
Stent	Pulmonary artery	15	8	4	7
	Native or Re-coarctation	7	4	5	4
	SVC				2
	Systemic to PA shunt		1		
	Other		1		
ASD closure		57	50	25	39
Fenestration closure		7	7	14	10
Balloon Atrial Septostomy		10	12	21	15

Complications occurred in 18 cases (5%) and are summarised in Tables 9 and 10. The incidence of complications is less than in 2006-7 (11%); cardiologists and fellows are encouraged to record in the log book even the most minor complications. There have been two deaths related to cardiac catheterisation over the last 10 years, both in high risk patients. Major complications are rare.

There are 3 catheterisation morbidity and mortality meetings per year.

Table 9. Complications

	2006-07	2007-08	2008-09
Major life threatening	5	1	2
Significant	5	4	4
Minor	7	6	1

Table 10. Classification of Complications

Complications 2008-09	
Major/life threatening	Low cardiac output after neonatal pulmonary valvuloplasty.
Major/life threatening	Death following subsequent cardiac surgery.
Significant	Embolization of device retrieved surgically
Significant	Hemolysis after PDA closure. Surgical revision.
Significant	Embolization of device retrieved by surgically
Significant	Mediastinal haematoma after coarctation angioplasty
Significant	Atrial flutter requiring DC cardioversion
Complications 2007-08	
Major/life threatening	Hypotension requiring COR
Significant	PA stent migration
Significant	Access related complication
Significant	Access related complication
Significant	AV block and bradycardia requiring CPR

4.4. ELECTROPHYSIOLOGY

Paediatric and congenital electrophysiology utilises a biplane electrophysiology laboratory within the adult cardiac catheterisation suite, and is lead by Dr Jon Skinner. Technical staff are drawn from the cardiac physiology department. Complex procedures are done in collaboration with adult electrophysiologist Dr Nigel Lever, and Dr Skinner similarly will assist with some complex adult cases.

Of the 382 ablations over the past 7 years (Figure 25) there have been 31 failures (8%). There was one post-procedure death related to a cerebrovascular accident, and no other major complications.

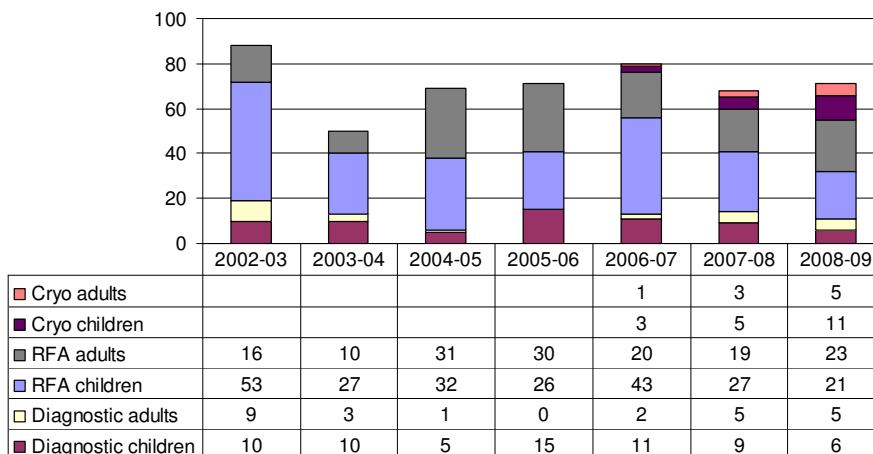


Figure 25. Electrophysiology studies. Numbers were reduced 2003-04 because of move to the new hospital.

A generous donation from the Starship Foundation allowed purchase of both the Ensite 3D mapping system and cryoablation equipment. 3D mapping has been a major advancement in the treatment of complex cases, and redo cases, and has been used a total of 17 times over the two years, while cryoablation has reduced the risk of the procedure in young children with AV node re-entrant tachycardia and in all age groups with

parahisian accessory pathways, by avoiding AV node damage and the need for a pacemaker. This combined approach may have contributed to the slightly higher success rate (90 ablations with 4 failures; 4.5%) over this time.

4.5. PACEMAKER

Pacing procedures are performed either by the paediatric cardiac surgical team for epicardial systems, or by the adult electrophysiologists in the case of endocardial systems (older children and adults with congenital heart disease). Supervision and follow up is provided by Dr Skinner and the cardiac technologists led by Fiona Riddell.

Staff from the Department of Cardiac Physiology provide technical support during implantation of devices such as permanent pacemakers, implantable loop recorders and implantable defibrillators. Technical staff perform the follow-up checks on these devices within the Auckland, Northland and Hawkes Bay region. They also advise other pacemaker follow-up centres throughout NZ with regard to programming, troubleshooting and planning of further pacemaker surgery.

The number of new pacemaker and ICD implantations has remained stable over the past 3 years, while 2008-09 has seen an increase in unit and lead replacement procedures (Figure 26). This in part related to the small but increasing number of ICD implants, and the age range of patients requiring pacemaker implantation.

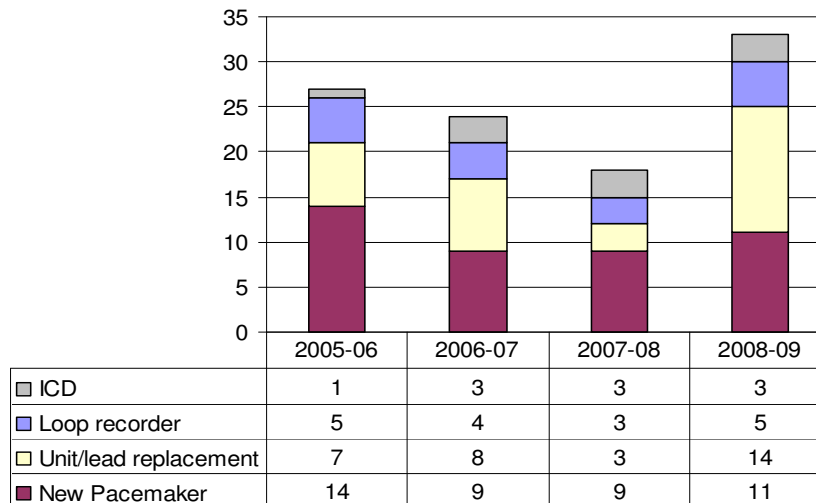


Figure 26. Pacemaker and associated procedures.

4.6. CARDIAC REGISTRY

Dr Calder ran teaching sessions for the Cardiology and CTSU Registrars and Fellows. These were held annually over nine weeks in 1 ½ hour sessions and were very well received. Other teaching opportunities included:

- The 4th Advanced Congenital Echocardiography Course 13th – 15th March 2008
- PICU Course for Registered Nurses 11th April 2008
- University Cardiac Course 1st May 2008

One specimen was added to the Heart Registry. There were two new enquiries and five specimens were returned to families. A total of 1166 organs were accessed for study or teaching purposes over the two years.

The scientific data base and the original card file system are accessible to answer specific questions.

Governance group meetings are held every three months. In May 2007 the HRGG was approached by the Tissue Management Group who asked us to oversee and provide oversight to Tissue Management and Retention issues within ADHB. The combined group meet bi-annually.

The annual checkers update was completed in May and involved going over the initial enquiry / checking / return procedures with staff who have agreed to be checkers.

5. NURSING

5.1. NURSING LEADERSHIP

The Green Lane Paediatric and Congenital Cardiac Service is a national service based at the Starship Children's Hospital. Over the past two years the service has developed a robust nursing infrastructure. Nursing leadership is visible and active across the service continuum.

- Stephanie Hlohovsky, Nurse Manager PCCS
- Christine Orchard, Clinical Charge Nurse 23B
- Jane Key Clinical, Charge Nurse 23B
- Elizabeth Tilton, Clinical Specialty Nurse Cardiac Investigations Unit
- Christine Armstrong, Nurse Educator
- Heather Spinetto, Paediatric Cardiac Nurse Specialist
- Julie Stubbs, Paediatric Cardiac Nurse Specialist
- Rosalie Charman, Paediatric Cardiac Nurse Specialist (Parental Leave)
- Annette Rief (nee Neugebauer), Nurse Practitioner Adult Congenital Heart
- Ana Kennedy, Nurse Practitioner Acute Care PCCS
- Marion Hamer, Nurse Specialist Acute Care PCCS

The Green Lane Paediatric and Congenital Cardiac Service is a national service based at the Starship Children's Hospital. Over the past two years the service has developed a robust nursing infrastructure. Nursing leadership is visible and active across the service continuum.

5.2. VISION

"To provide leadership and excellence in care that respects and honours heart children and their families."

Integrity

We are open, fair honest and transparent in everything we do

Respect

We care about and will be responsive to the needs of our diverse people and communities

Innovation

We will provide an environment where people can challenge current processes and generate new ways of learning and working

Effectiveness

We will apply our learning and resources to achieve better outcomes

5.3. INPATIENT

Ward 23B has 22 beds, 10 single rooms, 2 double rooms, one 4 bedded room and a high dependency unit with 4 beds. The high dependency unit often flexes up to 6 beds.

Ward 23B is resourced to run at 70% occupancy (16 beds) Monday-Friday and 55% occupancy Saturday and Sunday (12 beds). Average occupancy 2007-2008 was 99.2% of resourced beds and 2008-2009 was 104% of resourced beds.

	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	April	May	June
2007/2008	87%	87%	97%	100%	112%	103%	83%	86%	117%	108%	109%	101%
2008/2009	102%	113%	121%	102%	114%	93%	92%	98%	104%	90%	107%	114%

Ward 23B has a model of care with a strong nurse led focus. There are 2 clinical charge nurses who manage the clinical operations day to day; manage the daily staffing resource; involved in planning, implementing and monitoring operational and clinical process initiatives. There is one Nurse Practitioner (NP) and one Nurse Specialist Acute Care (in training Nurse practitioner). The NP manages 40% of inpatient clinical workload and is the key driver in the development of nurse led ward rounds on 23B.

5.4. NURSING EDUCATION

Nursing staff each attended 3-5 days of ongoing education offered through Learning and Development at ADHB. We also provided two days of Cardiac Nursing Specific Education.

Consistent with our vision of providing ongoing clinical support and education at the bedside nursing staff attend weekly education sessions every Wednesday at 1500.

A pathway for postgraduate study specialising in Paediatric Cardiac Nursing was developed in partnership with Auckland University.

In 2008 six nurses in PCCS completed the clinical specialty paper in Paediatric Cardiac Nursing. Senior Nurses from PCCS have been involved with providing education to other clinical areas within ADHB as well as for The University of Auckland, Auckland University of Technology and Massey University.

5.5. NURSING LED INITIATIVES

Neurodevelopment Follow Up For High Risk Cardiac Surgical Patients

The Neurodevelopmental Follow up Program started in January 2008 and is coordinated by Ana Kennedy NP. The goals for this programme were three fold; to provide a service to families so children receive timely intervention; to have accurate local data for the purposes of audit; and to benchmark our cardiac surgical outcomes against international standards.

The criteria for referral to a psychologist for neurodevelopmental assessment at age 2 and 4 years are 1) all neonatal bypass surgery, 2) infants and children who had aortic arch surgery, 3) circulatory arrest or regional cerebral perfusion, 4) pre and or post-operative significant low output and or arrest; need for mechanical support post-operatively, 5) prolonged intensive care stay, 6) late postoperative signs of neurodevelopmental delay or abnormalities.

From January 1st 2008 to 1st September 2009, 55 Auckland children under 5 met the criteria for referral. 23 children, (88% of those due for assessment) have been assessed. 3 died before they could be assessed. Of those assessed 1 had severe disability, 4 had motor delay and 18 were within normal range on developmental testing.

5.6. CLINICAL EFFECTIVENESS

Nurse Led Quality Initiatives

Review and updating of current PCCS guidelines and protocols and the development of secure site for PCCS guidelines on intranet under Starship Clinical Guidelines - coordinated by M Hamer

New Guidelines

- Immunisations for Cardiac Infants New guideline -*June 2009*
- Medication Discharge – advanced planning -*September 2008*
- Fluids post cardiac surgery -*October 2008*
- Admissions – surgery - *October 2008*
- Anticoagulation for Cavopulmonary and Aortopulmonary shunts and valves -*March 2009*
- Exercise Stress Test - *August 2008*
- Marfan's Diagnostic assessment guideline - *August 2008*

Developed referral system between NICU and PCCS to improve communication between areas - Coordination /liaison of cardiac babies in the Newborn services

Development of NICU preoperative cardiac surgical protocols for New born website

CPR training for parents

Bereavement protocol / process for PCCS

Pertussis immunisation of PCCS staff

Immunisation resource group developed

Nursing Journal Club initiated

Nursing Care Plans

Paediatric non-surgical cardiac care plan
Ace-inhibitor /beta-blocker increase care plan
Arrhythmia management care plan
Cardiac surgery care plan

Recommended Best Practice

Management of Tet spell
Management of SVT

Parent Information Pamphlets

Understanding Heart failure
Understanding SVT
Information for families on anticoagulation therapy
Getting ready to go home discharge information pamphlet

5.7. HOME INR TESTING

This programme has been running since 2000 and currently 243 children have machines in their homes or are being tested in their homes by nurses. Since 2000, a further 33 children have discontinued warfarin and transferred to aspirin, 11 children have died, 3 have had heart transplants and 6 returned machines prior to moving overseas. The program is coordinated by the clinical nurse specialists.

Each family is trained in Auckland before discharge from hospital and handed over to the local paediatric service for local management. In Wellington patients are managed by the adult anticoagulation service and in a few rural areas patients are managed by their general practitioner. Young adults reaching 15 years are transitioned to being monitored by their general practitioner.

When a family is unable to manage the blood test or reliably ring through the results then a local homecare nurse monitors the results and feedback to the local medical team

Two booklets are being developed; Warfarin information for families, and a general information booklet for teachers.

5.8. HOME MONITORING PROGRAMME

This programme was established in 2006 and modified in February 2007 to monitor children with single ventricle anatomy that are shunt dependant cardiac conditions between Stage one and stage two repair (approximately 0 – 3 months). The objective of the program is to improve survival for these babies and to detect physiological variations over the period between the Stage 1 and Bi-directional Glenn operations.

At home, parents monitor the daily weight (for dehydration) and weekly weight gain and oxygen saturations of the baby. Using this information parents and local health personnel are able to identify early warning signs of deteriorating condition and activate early intervention.

The program has recently been audited comparing patients on the home monitoring program from January 2007 – December 2008 (HOME MONITORING GROUP) and patients prior to the home monitoring program from January 2003 – December 2004 (Control Group).

Although not statistically significant (numbers are small), more patients in the home monitoring group survived to their Stage Two operation, a finding concordant with other centres that have identified a reduction in mortality with home monitoring of Norwood patients.

The programme is coordinated by the clinical nurse specialists. The programme was presented at the Women's and Children's Hospitals Association Conference 2008 in Sydney Australia.

5.9. FETAL SERVICE

Two Paediatric Cardiac service Nurse Specialists are present at diagnosis and involved in consultation and follow up of confirmed complex cardiac cases.

PCCS Nurse Specialist discussions with families are recorded on a designed template and Nurse Specialist follow-up clinic appointments are being organised at each midwifery visit.

The fetal database has been combined and updated.

A family information pamphlet has been reviewed and updated and incorporated in the information pack given to the families.

Nurse Specialists also advise the obstetrician of the delivery and diagnosis of cardiac babies being born out of their local area.

5.10. PROFESSIONAL DEVELOPMENT

Attained Nurse Practitioner in Cardiac care with prescribing – *A Kennedy*

Associated Clinical Educator – University of Auckland – *A Kennedy*

Completion of Nurse practitioner in hospital training program in PCCS - *M Hamer*

Nurse Practitioner training internship of one month duration in Boston and Edmonton- *M Hamer*

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1. **Skinner JR.** Guidelines for physicians in the management of long QT syndrome. A link on the website of the Cardiac Society of Australia and New Zealand.
www.csanz.edu.au/guidelines/practice/Long_QT_guidelines.
2. **Skinner JR.** Sudden Death in the Young. Post-mortem Best Practice Guidelines 2008 (Published with TRAGADY, available on RCPA and CIDG websites; www.cidg.org). **Skinner JR.** "Syncope in Children: How to pick the bad Ones" Consult Magazine. Autumn 2008. (Australian Magazine for specialists and GP's). A product of [virtualmedicalcentre.com](http://www.virtualmedicalcentre.com). –e publication :
<http://www.virtualmedicalcentre.com/news.asp?artid=11515>.
3. **Skinner JR.** "Cardiac Inherited Disease Group" website. Contribution to design, and content. Contains news, information sheets, consent sheets, and links. www.cidg.org.

6.4. INVITED PRESENTATIONS

1. **Calder AL.** 4th Advanced Congenital Echocardiography Course – 13 to 15 March 2008 –
 - Anatomy of the normal heart
 - Pulmonary and systemic venous connections
 - Atria and atrial septum
 - Atrioventricular valves
 - Pathology Practical – hands on
 - Ventricular morphology, D and L loops
 - Ventricular septal defects and conotruncal abnormalities
 - Pathology practical – hands on
 - Arterial abnormalities
 - Pathology practical – hands on
2. **Calder AL.** The Congenital Heart Registry – talk, demonstrations and hands-on session for PICU Nurses Cardiac Study Day – 11 April 2008.
3. **Calder AL.** History of Cardiology and Heart Surgery and Heart Registry and review of heart defects – for Post Graduate 730 Cardiac Specialty Paper, School of Nursing, University of Auckland, 1 May, 2008.
4. **Calder AL.** Hands-on, anatomical session (talk and demonstrations) for Post Graduate 730 Cardiac Speciality Paper, School of Nursing, University of Auckland 1 August, 2008.
5. **Calder AL.** A few examples of congenital heart defects and Cardiac embryology – Neonatal Science and Clinical Care of the Neonate 2, Massey University, 8 April, 2009.
6. **Calder AL.** Anatomy symposium: Congenitally Corrected Transposition of Great Arteries – 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, June 2009.
7. **Finucane AK.** Aortic Mitral Valve Repair outcomes in Rheumatic Heart Disease. Cardiac Society of Australia and New Zealand, Annual Scientific Meeting, Wellington, June 2009.
8. **Finucane AK.** Technique of intramural coronary artery transfer in arterial switch for TGA. 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, Australia, June 2009.
9. **Gentles TL.** 3D Transoesophageal Echocardiography and the Mitral Valve. 3D Echocardiography course, Auckland March 2009.

10. **Gentles TL.** 3D Transoesophageal Echocardiography in the Operating Room. 3D Echocardiography course, Auckland March 2009.
 11. **Gentles TL.** Evaluation of Acquired Valve Disease with 3D Echocardiography. Cardiac Society of Australia and New Zealand Annual Scientific Meeting, Christchurch, August 2007.
 12. **Gentles TL.** How Echocardiography Assists in the Timing of Surgery and Suitability for Mitral Valve Repair. 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, Australia, June 2009.
 13. **Gentles TL.** Identifying the at Risk Neonate. 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, Australia, June 2009.
 14. **Gentles TL.** Timing and Indications for the Fontan Operation. 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, Australia, June 2009.
 15. **Hlohovsky S.** *Building a leadership team around patient needs*, 5th World Congress of Paediatric Cardiology and Cardiac Surgery, June 2009
 16. **Hornung TS.** Imaging in Adult Congenital Heart Disease. Sydney Advanced Echo Symposium. April 2008.
 17. **Hornung TS.** Long term issues in the Single Ventricle Patient. Cardiac Society of Australia and New Zealand Annual Scientific Meeting. Adelaide. August 2008.
 18. **Hornung TS.** Magnetic Resonance Imaging in Paediatric Heart Disease. Paediatric Society of New Zealand Annual Scientific Meeting. Waitangi. October 2008.
 19. **Hornung TS.** Negotiating the Maze: Sinus Node Function after Fontan Conversion. World Congress of Paediatric Cardiology and Cardiac Surgery. Cairns. June 2009.
 20. **Hornung TS.** Pulmonary Valve Replacement after Repair of Tetralogy of Fallot: When and Why? Cardiac Society of Australia and New Zealand Annual Scientific Meeting. Christchurch. August 2007.
 21. **Hornung TS.** Rheumatic Heart Disease. Cook Islands Annual Health Conference. July 2008.
 22. **Kennedy A.** *The role of the NP in a Paediatric cardiac program*, 5th World Congress of Paediatric Cardiology and Cardiac Surgery, June 2009
 23. **O'Donnell C.** NZ PAH annual meeting July 2007 "Pitfalls in reviewing echos and right heart studies".
 24. **O'Donnell C.** Asia Pacific Congress of Paediatric and Adult Congenital Cardiology. Talks delivered on – "ACHD in New Zealand", "Marfan Syndrome Medical Management" and "Rheumatic Fever". May 2008.
 25. **O'Donnell C.** Australia and New Zealand Intensive Care Society/ACCCN ASM Rotorua "ACHD and the future" October 2007.
 26. **O'Donnell C.** Cardiac Society Christchurch "Late Outcomes for patients with Tetralogy Pulmonary Atresia" August 2007.
 27. **O'Donnell C.** CSANZ 14th June invited speaker "ACHD- a New Zealand perspective".
 28. **O'Donnell C.** Heart Children Annual Conference "ACHD, pregnancy and contraception" Sept 2007.
 29. **O'Donnell C.** NZ PAH Annual Meeting June 2008 "PAH in younger patients".
 30. **Rumball EM.** RACS professional development workshops/courses. From the flight deck. 13 June 2008
 31. **Rumball EM.** RACS professional development workshops/courses. Mastering professional interactions. 15 October 2007
 32. **Rumball EM.** RACS professional development workshops/courses. Mastering adverse outcomes. 16 October 2007
 33. **Rumball EM.** RACS professional development workshops/courses. Mastering difficult patient interactions. 16 October 2007
 34. **Rumball EM.** Pulmonary valve replacement after tetralogy repair. Cardiac Society of Australia and New Zealand. 07 August 2008.
 35. **Skinner JR.** "Blackouts, funny turns and indifferent ECGs – Picking out the bad ones" – Paediatric update for senior paediatricians. Clinical Education centre, Auckland Hospital. 6 & 7 March 2008.
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36. **Skinner JR.** "Blackouts, funny turns and indifferent ECGs – Picking out the bad ones" Emergency Paediatricians. April 10th 2008. Emergency Department, Starship Hospital.
37. **Skinner JR.** "Burning and freezing in four dimensions" - Green Lane Scientific Meeting, Auckland City Hospital, Auckland, New Zealand. 14th September 2007.
38. **Skinner JR.** "Cardiac Inherited Diseases- from the cradle to the grave". New Zealand Pacing and Electrophysiology Group Christchurch Sept 2008.
39. **Skinner JR.** "Cardiac Inherited Diseases: what the adult cardiologist needs to know" - CSANZ Wellington June 2009.
40. **Skinner JR.** "Cardiac Sodium channel disease" World Congress Paediatric Cardiology and Cardiac Surgery, Cairns, June 2009.
41. **Skinner JR.** "Genetics of long QT syndrome" - Murdoch Genetics Institute, Melbourne, Australia. 21st September 2007.
42. **Skinner JR.** "How can genetic diagnoses reduce sudden death in the young?" - Human Genetic Society of Australasia, Sky City Auckland Convention Centre, Auckland New Zealand. 18th July 2007.
43. **Skinner JR.** "Implications of Genetic testing: managing and disclosing risk". Session on Sudden Cardiac Death. CSANZ (Sydney, Australia) August 2009.
44. **Skinner JR.** "Inherited Heart Diseases" July 29, 2008. Post Graduate nursing course in Cardiology. Auckland school of nursing.
45. **Skinner JR.** "Investigation of young sudden death- integration of family investigations" World Congress Paediatric Cardiology and Cardiac Surgery, Cairns June 2009.
46. **Skinner JR.** "Investigation of young sudden death" - Royal College of Pathologists of Australasia. Napier, New Zealand. 28th September 2007.
47. **Skinner JR.** "Long QT and Ion Channelopathies" - Cardiac Genetics Symposium, Cardiac Society of Australia and New Zealand, Christchurch, New Zealand. 9th - 12th August 2007.
48. **Skinner JR.** "Mechanisms of arrhythmia" August 1, 2008. Post Graduate nursing course (730) in paediatric Cardiology and Cardiac Surgery. Auckland School of Nursing.
49. **Skinner JR.** "Modern techniques in catheter ablation of cardiac arrhythmias" April 9th 2008. New Zealand National Paediatric Update weekly meeting (teleconference). Fisher and Paykel Education centre, Auckland Hospital.
50. **Skinner JR.** "Paediatric Sudden Death" in Congenital arrhythmias, Paediatric cardiology session. CSANZ Adelaide May 2008.
51. **Skinner JR.** "Problems with the investigation of young sudden death" – New Zealand Pacing and Electrophysiology Group, Rotorua, New Zealand. 31st August 2007 - 1st September 2007.
52. **Skinner JR.** "Sodium Channel Mutations and Arrhythmias". Monogenetically mediated heart disease session in clinical (adult) cardiology. CSANZ Adelaide May 2008.
53. **Skinner JR.** "Sudden Death of Children In New Zealand" Paediatric Society, Paihia, October 2008.
54. **Skinner JR.** Debate "Mass infant ECG screening is a waste of health service resources" World Congress Paediatric Cardiology and Cardiac Surgery, Cairns June 2009.
55. **Spinetto H.** *Giving bad news to families*, Australasian Society for Ultrasound in Medicine. September 2008
56. **Spinetto H.** *Learning from medication errors*, ADHB Nursing Grand round April 2009
57. **Spinetto H.** *Cross Cultural Nursing*, 5th World Congress of Paediatric Cardiology and Cardiac Surgery, June 2009
58. **Wilson NJ.** Echocardiography and Screening for Rheumatic Heart Disease. Tōmaiōra Seminar. School of Population Health. University of AKLD. May 19, 2008.

59. **Wilson NJ.** Pacific experience” and “echocardiography – diagnosis, severity and therapeutic options” at Better care for ARF/RHD for clinicians. Alice Springs, Australia 16 August 2008.
60. **Wilson NJ.** RHD screening with Echocardiography. Workshop NHF, Auckland June 2009.
61. **Wilson NJ.** Screening for RHD in children. Paediatric Society of NZ, Paihia. 31 October 2008.
62. **Wilson NJ.** Standardization of Echo RHD screening. World Congress Paediatric Cardiology and Cardiac Surgery, Cairns 24 June 2009.
63. **Wilson NJ.** The diagnosis of RHD by echo screening - WHF/WHO RHD Echo workshop, Fiji. Feb 08.

6.5. ABSTRACTS

1. **Calder AL.** A study of aortic size in cases with bicuspid valves compared to tricuspid ones. 2nd Asian Pacific Congress of Paediatric Cardiology and Surgery, Korea, May 2008
2. **Calder AL.** A study of aortic size in cases with bicuspid aortic valves compared to unicuspid or tricuspid ones. 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, June 2009
3. **Calder AL.** Systemic and Pulmonary Venous Connections in Heterotaxy. 5th World Congress of Paediatric cardiology and Cardiac Surgery, Cairns, June 2009
4. Ganeshalingham A, Finucane AK, **Hornung T.** Isolated Congenital Mitral Valve Regurgitation Presenting in the First Year of Life. World Congress of Paediatric Cardiology and Cardiac Surgery. Cairns. June 2009.
5. Van Den Boom J, Battin M, **Hornung T.** Twin-to-Twin Transfusion Syndrome and Coarctation of the Aorta. World Congress of Paediatric Cardiology and Cardiac Surgery. Cairns. June 2009.
6. Steer A, Batzloff M, Good M, Kado J, Jenney A, Mulholland K, Tuiketeei T, Waqatakirewa L, **Wilson N,** Carapetis J, The prevalence of Rheumatic Heart Disease in Children Fiji XVII Lancefield International Symposium on Streptococci & Streptococcal Diseases Greece, June 2008,183
7. Webb R, Lean F, Zeng I, **Wilson N.** Echocardiographic measurement of mitral valve thickness in children: implications for the diagnosis of rheumatic heart disease XVII Lancefield International Symposium on Streptococci & Streptococcal Diseases Greece, June 2008,185
8. Carapetis J, Hardy M, Fakakovikaetau T, Nicholson M, Kothari D, Alfurqani A, **Wilson N,** A two-year follow up study of children with mild or subclinical rheumatic heart disease, XVII Lancefield International Symposium on Streptococci & Streptococcal Diseases Greece, June 2008, 197
9. **Webb R, Wilson N,** Lennon D, Trenholme A, Wilson E, Nicholson R, Gentles T, O'Donnell C, Stirling J, Zeng. Rheumatic Heart Disease in children from a high risk New Zealand population detected by echocardiographic screening: preliminary results indicate a high burden of previously undiagnosed disease. Paediatric Society of New Zealand 60th Annual Scientific Meeting, Bay of Islands, October 2008.
10. Sampson R, Jellyman T, O'Donnell C, Gentles T, **Wilson N.** Follow up after Balloon Aortic Valvuloplasty in the 1990s – a single centre 10 year cohort. WCPCCS Cairns, June 2009
11. **Skinner JR,** Eddy C-A, MacCormick J, Chung S-k, Crawford JR, Love DR, Rees MI, Shelling AN. Identification of large gene deletions and duplications in patients with long QT syndrome. Heart Rhythm 2008;5, May Supplement, AB36-2.
12. **Skinner JR,** Crawford J, Vaughan A, Gladding P, Eddy C-A, Love D, Rees M, Shelling A. Posthumous diagnosis of long QT syndrome from the neonatal screening card. Heart, Lung and Circulation 2009;18S:181 (Abstract)
13. Watanabe H, Yang T, Atack T, Hasdemir C, Crawford J, **Skinner JR,** Roden D. Divergent Biophysical Effects of Cardiac Sodium Channel Mutations in the N-terminus. Heart Rhythm 2009. May Supplement (Abstract).
14. Wood A, Kuschel C, **Gentles TL.** Are echocardiograms performed by neonatologists reliable at detecting neonatal cardiac disease? Perinatal Society of Australia and New Zealand 11th Annual Congress, Melbourne, April 2007.

15. Samson R, Jellyman T, **O'Donnell C, Gentles TL**, Wilson N. Follow-up after balloon aortic valvuloplasty in the 1990's – A single centre 10 year cohort. 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, Australia, June 2009
16. **Mervis J, Gentles TL**, Beca J, **Finucane AK**. Emergency Arterial Switch Operation for Transposition of the great arteries as an alternative to ECMO. 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, Australia, June 2009
17. **Gentles TL, Finucane AK, Mervis J, Wilson NJ**. Outcome of the LV in children and young adults with severe combined aortic and mitral valve regurgitation compared to isolated lesions. 5th World Congress of Paediatric Cardiology and Cardiac Surgery, Cairns, Australia, June 2009
18. Moyagh A, **O'Donnell C**, Finucane K, Crozier C. Multimodality imaging – Its use in the diagnosis and treatment of Biventricular Outflow Tract Obstruction in a Patient with Leopard syndrome – CSANZ meeting Adelaide Aug 2008
19. **Mervis J**, Beca J, **Gentles TL, Finucane AK**. Poster: Emergency Arterial Switch Operation for Transposition of the Great Vessels as an Alternative to ECMO.
20. **Hamer M**. Riding the emotional rollercoaster: Caring for the child with hypoplastic left heart syndrome, Embracing Innovative Nursing Practice, May 2008
21. **Hlohovsky S. and Kennedy A**. *A Pilot Clinical Paediatric Acute Care Nurse Practitioner Program*, Embracing Innovative Nursing Practice, May 2008
22. **Charman R**. *Bumps bypass and beyond*, WHACHA Sydney, Australia, November 2008
23. **Hamer M**. Riding the emotional rollercoaster: Caring for the child with hypoplastic left heart syndrome, The Paediatric Society of NZ, November 2008
24. **Hlohovsky S**. A pilot Clinical Paediatric Acute Care Nurse Practitioner Program To Support Nurses in the Transition to the Role of Nurse Practitioner, 5th International Council of International Nurse Practitioner/Advanced Nursing Practice Network, Toronto, Canada, Sept 2008

6.6. GRANTS AWARDED

Title:	“Histological Examination Of Small Sections Of Aortic Wall Tissue Stained With 3 Special Stains From Heart Specimens With And Without Bicuspid Aortic Valves”
Principal Investigator:	Dr Louise Calder
Co-investigators:	Dr. Jane Zuccollo
Funding Agency:	Green Lane Research And Educational Fund Board
Amount:	\$6500

Title:	Getting To The Heart Of The Problem (A Magnetic Resonance Study Of Cardiovascular Function In Type 1 Diabetic Adolescents)
Principal Investigator:	Hoffman P
Co-Investigators:	Cutfield W, Hornung T
Funding Agency:	National Heart Foundation
Amount:	\$15,000

Title:	Getting To The Heart Of The Problem (A Magnetic Resonance Study Of Cardiovascular Function In Type 1 Diabetic Adolescents)
Principal Investigator:	Hoffman P
Co-Investigators:	Cutfield W, Hornung T
Funding Agency:	Maurice and Phyllis Paykel Trust
Amount:	\$10,000

Title:	Getting To The Heart Of The Problem (A Magnetic Resonance Study Of Cardiovascular Function In Type 1 Diabetic Adolescents)
Principal Investigator:	Hoffman P
Co-Investigators:	Cutfield W, Hornung T
Funding Agency:	Centre for Advanced MRI (Pilot study grant)
Amount:	\$2,000

Title:	Getting To The Heart Of The Problem (A Magnetic Resonance Study Of Cardiovascular Function In Type 1 Diabetic Adolescents)
Principal Investigator:	Hoffman P
Co-Investigators:	Cutfield W, Hornung T
Funding Agency:	University of Auckland fund
Amount:	\$18,000

Title:	Can a 5-Month Intensive Exercise Programme in Type 1 Diabetic Adolescents Improve Cardiac and Peripheral Vascular Function?.
Principal Investigator:	Hoffman P
Co-Investigators:	Gusso S, Jeffries C, Hornung T
Funding Agency:	Australasian Paediatric Endocrine Group
Amount:	\$30,000

Title:	Prevalence of RHD in South Auckland Children
Principal Investigator:	Nigel Wilson
Co-Investigators:	Rachel Webb, Elizabeth Wilson, Diana Lennon, Ross Nicholson, Adrian Trenholme, John Stirling, Clare O'Donnell, Tom Gentles, Irene Zeng
Funding Agency:	2008 Project Grant - ADHB Charitable Trust
Amount:	\$29,513

Title:	Prevalence of RHD in students from a low-risk New Zealand population
Principal Investigator:	Nigel Wilson
Co-Investigators:	Rachel Webb, Elizabeth Wilson, Diana Lennon, Ross Nicholson, Adrian Trenholme, John Stirling, Clare O'Donnell, Tom Gentles, Irene Zeng
Funding Agency:	2009 Project Grant – Green Lane Research And Educational Fund Board
Amount:	\$33 343

Title:	Research Fellowship, Rheumatic Heart Disease
Principal Investigator:	Rachel Webb
Supervisor:	Nigel Wilson
Funding Agency:	Mary Jane Reynolds Trust, University of Auckland
Amount:	Salary support

Title:	Prevention of Sudden death in the Young-Cardiac Inherited Disease Group.
Principal Investigator:	Jon Skinner
Co-Investigators:	Andrew Shelling
Funding Agency:	Cure Kids New Zealand
Amount:	Ongoing support of the group and Posthumous Long QT genetic Testing, commitment 2007-9 was approximately \$300,000

6.7. COMMITTEES

Gentles TL. Australia and New Zealand Children's Heart Research Centre (ANZCHRC). Board Member.

Gentles TL. Australia New Zealand Paediatric Cardiac Association. Executive committee member.

Gentles TL. Heart Children New Zealand. Trustee.

Gentles TL. RACP/CSANZ Curriculum Development for Paediatric Cardiology Training. Committee member.

Gentles TL. Specialist Advisory Committee Cardiology. Member.

Hornung T. Cardiac Society of Australia and New Zealand Annual Scientific Meeting 2008. Organising Committee.

Hornung T. Cardiac Society of Australia and New Zealand, New Zealand Committee Paediatric Representative.

Hornung T. National Heart Foundation Advisory Group: "Prevention of Infective Endocarditis Associated with Dental and Other Medical Interventions".

Hornung T. World Congress of Paediatric Cardiology and Cardiac Surgery 2009, Organising Committee.

O'Donnell C. Paediatric Society of New Zealand – Cardiology Special Interest Group Chair.

O'Donnell C. Pharmac PAH Advisory Group.

Skinner JR. Chair, Cardiac Inherited Disease group New Zealand (CIDGNZ).

Skinner JR. Chair, Trans-Tasman Response Against Sudden Death in the Young (TRAGADY).

Wilson N. Board of GLREF - PCCS trustee (from January 2007).

Wilson N. Heart Registry Governance committee - PCCS - delegate for the Clinical Director (2003-).

6.8. OTHER

Awards and Honours

- Paediatric Society of New Zealand 60th Annual Scientific Meeting - young investigator award 2008. **Webb R.**
- Auckland District Health Board New Investigator Presentations, best presentation 2008. **Webb R**
- Royal Australasian College of Physicians New Investigator Award 2009. **Webb R**
- 2008 Starship Children's Research Centre Award. **Webb R**
- History of Cardiothoracic Nursing at Green Lane Hospital, Green Lane Research and Educational Fund Board and Auckland District Health Board Trust Fund. Principal Investigator: **Spinetto H**, Co-Investigator: Margaret Horsburgh
- Judith Philipson Education Scholarship - 2009 - **Kennedy A and Hamer M**

- HealthX 2008 - Faculty of Medical Health and Sciences, University of Auckland award for best presentation - September 2008 - **Hamer M**

Courses and workshops convened

- Echo workshop of the WHF/WHO RHD Fiji. Chair. **Wilson N.**
- Rheumatic Fever workshop – Auckland June 09. Co-chair. **Wilson N.**
- Starship Hospital Advanced Echocardiography Course (2.5 days) March 2008. Course Convener **Gentles TL.**
- Maternal Fetal Medicine Education Day – Focus on cardiac (1 day) June 2008. Course Co-convener. **Gentles TL.**
- 3D transoesophageal Echocardiography (1 day). March 2009. Course Convener. **Gentles TL.**
- 5th World Congress of Paediatric Cardiology and Cardiac Surgery - Imaging Subspecialty. Meeting Scientific Committee. Chair. **Gentles TL.**
- Fellow and Registrar Cardiac Morphology Course 2008 and 2009. **Calder AL**

Current Research Projects

- Prevalence of rheumatic heart disease among children from a high risk New Zealand population detected by echocardiographic screening. **Webb R, Wilson N**
- Cardiac MRI During Exercise: Ventricular and Vascular Function – Principal investigator Young A. Co-investigator **O'Donnell C.**
- Australian and New Zealand Paediatric Pulmonary Hypertension Registry. Co-investigator **O'Donnell C**
- Early Cardiac detection of Rheumatic Fever. Principal investigator Wilson N. Co-investigator **O'Donnell C**
- Ventricular Remodelling after neonatal cardiac surgery. Principal investigator **Gentles TL.**
- Early prediction of brain damage after heart surgery in infants. Co-investigators **Gentles TL, Finucane AK.**

MD student supervisor

- FRACP and MD supervisor for Dr Rachel Webb, RHD fellow. **Wilson N.**

Reviews

- Paediatric Cardiac Surgery Audit. Royal Children's Hospital, Melbourne 2007-08. Chair Review Panel. **Gentles TL.**
- Australian Norwood National Funding Application 2009. Member of Review Panel. **Gentles TL.**

7. MEDICAL STAFF

7.1. CONSULTANT CARDIOLOGISTS

Tom Gentles	Clinical Director Paediatric & Congenital Cardiac Service Director, Paediatric Cardiology	Echocardiography Fetal Cardiology Interventional Cardiology
Louise Calder	Paediatric Cardiologist	Cardiac Morphology
Tim Hornung	Co-Team Leader - Adult congenital heart disease	Adult Congenital Heart Disease Cardiac Magnetic Resonance Imaging
Clare O'Donnell	Co-Team Leader Adult congenital heart disease Junior Medical Staff Co-ordinator	Interventional Cardiology Adult Congenital Heart Disease Pulmonary Hypertension
Jon Skinner	Team Leader - Electrophysiology	Invasive and non-invasive electrophysiology Pacing Inherited Cardiac Disease
John Stirling	Paediatric Cardiologist	Interventional Cardiology
Nigel Wilson	Team Leader: Cardiac catheterisation	Interventional cardiology Fetal cardiology
Denise Kitchiner	Locum Cardiologist	Fetal cardiology

7.2. CONSULTANT CARDIOTHORACIC SURGEONS

Kirsten Finucane	Director - Paediatric Cardiac Surgery	Paediatric and Congenital Cardiothoracic Surgery
Elizabeth Rumball		Paediatric and Congenital Cardiothoracic Surgery

7.3. OTHER CLINICAL STAFF

Paediatric Cardiology Fellows

Danielle Brown
Nee Khoo
Judith MacCormick
Jonathan Mervis
Kathryn Rice
Ricardo Samson

Cardiac Surgical Fellows

Suresh Babu
Yuvaraj Davidson
Gnanachandramoorthy Gandhiji
Pranav Kandachar
Alessandra Oggianu
Sylvio Provenzano
Simon Vari
Girish Warriier

Paediatric Registrars

Peter Beggs
Helen Bailie
Stephen Butler
Elza Cloete
Martin de Bock
Olwen Gilbert
Michael Herd
Winnie Ip
Naomi Jones
Gina O'Grady
Bronwyn Rosie
Sasha Rossaye
Anand Sharma
Juliet Taylor
Joan Yeung

Research Fellow

Rachel Webb

Cardiology Registrars

James Fu
Tim Glenie
Khang Li Looi
Luay Samaraie

Sonographers

Megan Burrows
Fiona Lean
Weili Leong
Sandy Long
Marcus Silbery

7.4. CONTRIBUTORS TO THE ANNUAL REPORT

Cardiac Surgery	Kirsten Finucane
Adult Congenital Heart Disease	Annette Rief
Cardiac Inherited Disease Group	Jon Skinner
Rheumatic Heart Disease	Nigel Wilson
Cardiac MRI	Chris Occleshaw
Cardiac Catheterisation	Nigel Wilson
Electrophysiology	Jon Skinner
Pacemaker	Jon Skinner / Fiona Riddell
Cardiac Registry	Louise Calder / Christine Orchard
Nursing	Stephanie Hlohovsky
Echocardiography	Megan Burrows