# **PROVINCE WIDE SERVICES**

# Activities and Outcomes 2004 Annual Report



Province Wide Services Working Group September 2005





## Preface

The Province Wide Services (PWS) Annual Report is compiled by the Health Funding and Economics Branch of Alberta Health and Wellness.

The report indicates what is being achieved with the dollars targeted for key services. For the 2005/2006 fiscal year, funding amounted to \$509 million, so it is important to demonstrate the types of services being delivered and the health outcomes achieved through this investment.

This publication includes activity data from the 2003/2004 fiscal year, as well as the funding proposed or already provided for 2004/2005 and 2005/2006. The primary source for all types of data is the Province Wide Services Annual Reports received individually from Capital Health and the Calgary Health Region. There is also

additional information on changes to the programs during the year, and key decisions of the Province Wide Services Working Group, the advisory committee that assists in overseeing these programs.

The Special Features Report section for the 2004 Annual Report highlights Calgary Health Region's Alberta Transplant Program (ALTRA), Capital Health's Living Donor Lung Transplant Program, and a joint submission from the Home Enteral Nutrition programs in both urban regions. In all cases, the mandate of these programs is to deliver these key life-saving treatments to the entire province through centralized planning and service delivery. We would like to express our thanks to those people who have committed significant time and effort to produce these feature articles.

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### **Overview of Province Wide Services**

Province Wide Services (PWS) are a group of specialized medical services which includes a select number of hospital-based interventions, clinics and home services, high-cost drugs, and medical devices.

Hospital-based services include such things as bone marrow transplants, organ transplants, major cardiac surgery, neurosurgery, and care for very small infants. Other non-inpatient services include dialysis, specialized home care for children requiring life sustaining therapies, transplant drugs, and cochlear implants for the hearing impaired. A full listing of these services is contained in the "Inventory of Current Province Wide Services". In all cases, the expectation of these programs is that they develop and maintain the necessary skills and supports to allow services to be delivered equitably and efficiently to all Albertans. PWS is separated from regional health authority population-based funding and funded under its own regime. This allows special attention and support to be provided to these services, while allowing a provincial approach to planning. The Province Wide Services Working Group (PWSWG) is an advisory committee with representation from the two urban regions (Calgary and Capital), a rural representative, and Alberta Health and Wellness staff. They work to monitor existing services and review applications for new proposed services. A large part of their mandate is to use clinical and financial expertise to assess the status of emerging technologies, to monitor growth of existing ones, and make recommendations to the ministry on how best to deliver those services.

Given the central mandate of PWS to deliver services to all Albertans, this report will present extensive information on patient region of residence.



Figure 1 illustrates the high-cost nature of the inpatient services when compared to other hospital-based care. (Note: the costs shown are those incurred by the regional health authorities and exclude any physician fee-for-service claims).

## **Province Wide Services Mission Statement**

Province Wide Services (PWS) is intended to fund a narrow band of high cost services that, because of their nature, can only be effectively provided at one or two sites in Alberta. PWS activities are planned collaboratively between Alberta Health and Wellness, the Calgary and Capital health authorities, and all health regions to ensure these highly specialized services are provided in the best interests of the province as a whole, with proper medical and financial accountability. PWS is patient-focused and equitably accessed by all Albertans.

### 2004 Inventory of Province Wide Services

### **Inpatient Services**

- Organ and Bone Marrow Transplants
- Selected Tertiary Services for:
  - Trauma and Burns
    - Neurosurgery
    - Cardiovascular Procedures
    - Neonatology (low birthweight infants)
    - Oncology

(Detailed Case Mix Groups (CMGs) for 2004 are listed in Appendix "A")

### **Clinics and Home Services**

- Dialysis and Renal Program
- Dialysis Prevention
- Pre-and-Post Transplant Activities
- Medical Genetics
- Islet Cell Transplantation
- HIV Clinics
- STD/TB Clinics
- 1-800 AIDS Hotline
- Poison and Drug Information Services (PADIS)
- Home Enteral Nutritional Therapy
- Craniofacial Osseointegration (COMPRU)
- Children with Complex Healthcare Needs
- Education Resource Centre
- Pediatric Transport

### **High-Cost Drugs**

- Immunosuppressants (Cyclosporine, Tacrolimus, Sirolimus, Mycophenolate, Basiliximab, Daclizumab, IKT-3, ATGAM, Ondansetron and Filgrastim)
- HIV Antiretrovirals
- Human Growth Hormone for Chronic Renal Failure and Growth Hormone Deficiency
- Pulmozyme for Cystic Fibrosis
- Flolan and Tracleer for Primary Pulmonary Hypertension

### **High-Cost Devices**

- Cochlear Implants
- Implanted Cardiac Defibrillators
- Cranioplasty

### **Rosehaven Provincial Program**

• Located in Camrose, this program provides special behavioural care within the continuing care system throughout Alberta

### **Ocular Photodynamic (Visudyne) Therapy**

 Laser-activated drug (Visudyne) treatment of classic wet age-related macular degeneration

### Alberta Provincial Project for Outcomes Assessment in Coronary Heart Disease (APPROACH)

## **Province Wide Services Working Group (PWSWG)**

Originally established in 1997 as the Province Wide Services Advisory Committee, this group was mandated to develop budget recommendations, review proposals for new services, ensure development of action plans for provision of services, and promote accountability and monitor performance outcomes for these activities.

In March 2002, the Advisory Committee was replaced with a smaller Province Wide Services Working Group (PWSWG) reporting to the Deputy Minister of Alberta Health and Wellness. The current membership is listed in Appendix A, and consists of:

- Chair appointed by the Minister of Health and Wellness
- Chief Medical Officers for Calgary Health Region and Capital Health
- Chief Financial Officers for Calgary Health Region, Capital Health, and one non-urban health region
- Assistant Deputy Minister of Finance and Corporate Services for Alberta Health and Wellness
- Secretariat and staff support by Alberta Health and Wellness





## **Highlights**

### 2003/2004 Results

#### Inpatient Services:

CAPITAL HEALTH – results for the 2003/2004 fiscal year showed Capital Health serving a total of 6,046 PWS inpatient cases. This represents an increase of 9.7 percent from the previous year and 300 cases above funded levels. Much of this volume growth was attributed to more cardiac surgery than expected, especially angioplasties and cardiac valve replacement surgery. Higher than expected growth was also recorded in oncology cases. Heart and lung transplants, however, were significantly lower than the historical trend with only 37 cases performed, compared to the projected 70. The major contributing factor was believed to be a reduction in available organs for transplant.

CALGARY HEALTH REGION - Calgary served a total of 4,994 PWS inpatient cases in 2003/2004, which is less than a 1 percent increase from the previous year. Projections and corresponding funding for the year had estimated total service delivery at 5,476 (9.6 percent higher than what was actually provided), so this is a significant decrease from the volumes expected. In most service categories, volumes remained at or near the projected level, but there were lower than anticipated volumes in cardiac bypass surgeries, aortic replacements, hysterectomies, and bone marrow transplants. Calgary saw more cases than projected in the expensive categories of extremely small neonates (under 1000 grams at birth) and lung resections.

### 2005/2006 Budget

A PWS budget totaling \$508.8 million for 2005/2006 was announced in April 2005, representing a 12 percent increase from the previous year.

### **Inpatient Services Review**

In the fall of 2002, the Office of the Auditor General recommended that PWS review its list of inpatient services. These cases had been identified using a Case Mix Grouping (CMG) method that was often questioned because it did not seem to be entirely thorough in identifying all like cases. Through the spring and summer of 2004, a subcommittee of the PWSWG was struck to review the current method for identifying the inpatient services funded through PWS. The group consisted of physicians, health records professionals, and financial experts to make recommendations for improvement.

Under the chairmanship of Dr. Paul Greenwood, this Technical Advisory Group developed a method for identifying PWS inpatient cases by the actual surgical procedures performed. The group reviewed over 17,000 procedure codes used by the International Classification of Disease (ICD version 10) coding system.

As an example of how this method differed from the old method, consider the Case Mix Group method identified a total of 3,986 inpatient cases in 2003/2004 with a CMG of "Angioplasty" (CMG of 188 or 189). Using the procedure-based method, there were 4,165 angioplasty procedures. This means nearly 180 cases were potentially missed because of nuances to the CMG grouping methodology that would now be captured.

## **PROVINCE WIDE SERVICES**

# **Activities and Outcomes**

## **Activities and Outcomes**

### **Inpatient Services**

An "inpatient" is one who must reside in a hospital for the duration of their care. The inpatient services funded through PWS are a relatively small group of surgical procedures or types of care that were selected because of their highly specialized and/or high-cost nature. To be considered, the services should also benefit from provincial co-ordination, as opposed to the vast majority of services which are almost entirely within the jurisdiction of the individual regional health authority. Specialized areas include such things as bone marrow transplants, organ transplants, heart surgeries, selected neurosurgical procedures, neonatology (low birthweight infants), and selected oncology services.

These key services are funded under the premise that only one or two regions in the province should conceivably be offering it, for reasons of safety, provider proficiency, and efficiency. Attention is given to ensuring equitable access to these services by all residents of Alberta, regardless of their geographic proximity to the specialized program.



Table 1: PWS Inpatient Services (current PWS list) Activity Trends								
		AVERAGE ANNUAL						
			ACTUALS			GROWTH		
	1999/00	2000/01	2001/02	2002/03	2003/04	99/00 - 03/04		
Organ & Bone Marrow Transplants	351	356	384	385	379	1.9%		
Trauma and Burns	403	417	474	518	445	2.5%		
Neurosurgery	1,716	1,793	1,773	1,769	1,800	1.2%		
Cardiovascular	5,264	5,392	5,418	6,457	6,762	6.5%		
Neonatology	477	605	585	611	620	6.8%		
Oncology	197	207	658	704	768	40.5%		
Total Inpatient Cases	8,408	8,770	9,292	10,444	10,774	6.4%		

Source: CIHI Morbidity Data and PWS Budgets

Note: Caution should be used in interpreting the trends because of changes to both the ICD coding system and the corresponding CMG groups over this time period. Cardiovascular numbers have been supplemented with ambulatory care activity for angioplasty cases where the inpatient visit occurred at a different site than the surgical procedure.

Table 1 illustrates volume growth in broad categories of inpatient surgeries over the past five years and the number of cases projected for 2004/2005. Highest growth areas have been neonatology (low birthweight babies) and cardiology.



Figure 2 provides a side-by-side comparison of the population percentage residing in each regional health authority alongside the percent of their residents receiving these services.

## Organ and Bone Marrow Transplants

Organ transplantation is perhaps one of the highest profile advancements of modern medicine. It is a continually evolving field of research where new discoveries are constantly improving the quality of life and lifespan of patients who receive this life-saving intervention.

Currently, PWS funds transplantation of the following organs:

- heart
- lung
- liver
- kidney
- bone marrow for patients who have undergone radiation and/or chemotherapy
- islet cell transplants harvested from pancreatic tissue

In recent years, additional focus has been put on the ability to acquire entire organs or lobes of organs from living donors. This compassionate gesture, usually from a patient's family member, is gradually emerging as one of the growth areas in transplantation as organs from cadaveric donors have stabilized and even fallen off in recent years. Evolving laparoscopic kidney removal techniques are further facilitating and promoting live donation as this procedure requires less invasive surgery, less recovery time, and is all around less painful to the donor.

Calgary Health Region, in particular, has been demonstrating the benefits of this surgical technique and plans to train two additional surgeons to perform them in the upcoming year.

The Canadian Organ Replacement Register (CORR) is a national database maintained by the Canadian Institute of Health Information (CIHI) in Ottawa. The CORR annual and guarterly reports show that overall transplants have remained relatively stable nationally over the past five vears, and in fact, could be declining if it were not for the continued growth in living donor transplants in the areas of lung, liver, and kidnevs. As a proportion of total transplants. living donor transplants accounted for 46 percent of all donated kidneys and 10 percent of lung transplants. Both of these statistics demonstrate the importance of living donors in the overall transplant system and, just as important, the necessity of continued promotion of signing organ donor cards.

The following indicates the number of individuals waiting for an organ transplant as of March 31, 2004:

heart	14
kidney	88
liver	71
lung(s)	38
heart and lung	2

• h	eart ar	id lung	
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Table 2: PWS Organ and Bone Marrow Transplants							
	98/99	99/00	00/01	01/02	02/03	03/04	04/05 Predicted
Heart/Lung (Capital)	33	35	50	58	55	39	50
Kidney (Capital, Calgary)	143	134	117	143	127	139	152
Liver (Capital)	47	55	40	45	50	51	54
Bone Marrow (Calgary)	130	127	149	138	153	148	177
Total Transplants	353	351	356	384	385	377	433
Source: CIHI Morbidity Data							

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Table 2 shows the total number of transplants performed in 2003/2004 funded by Province Wide Services. Under the new method of identifying inpatient Province Wide Services cases, there would have been approximately ten additional transplants (primarily kidney) that were not identified using the existing CMG method.

## **Heart and Lung Transplants**

Due to the Case Mix Grouping method used by CIHI to summarize hospital visits, the figures for heart transplants and lung transplants are combined into one statistic. Of the 39 inpatient cases shown for 2003/2004, there were a total of 17 heart transplants and 20 lung transplants provided to adult patients, and 2 heart or lung transplants for pediatric patients. All heart and lung transplants are performed at the University of Alberta Hospital in Edmonton.

In contrast with prior years, where a growing number of donor hearts and lungs were being obtained through the United States, 2003/2004 was a year of significant decline in available donors and, consequently, the number of patients who could be transplanted. Figure 3 illustrates this drop, primarily attributed to policy changes in the United States, which gives first priority to American patients for available U.S. organs.

This drop in organ availability only increases the need for continued promotion and education in the area of organ donation. While many polls done over the past five years indicate that a majority of Canadians support organ donation, the availability of organs tells a different story. People must take the final step of signing an organ donor card and discussing this issue clearly and openly with their families.



## **Kidney Transplants**

Kidney failure can result from any number of conditions, ranging from unmanaged diabetes to inherited conditions to trauma. Regardless of the cause, patients experiencing what is referred to as '*end stage renal disease*' have a variety of different treatments available to manage this chronic condition. For those who are awaiting transplant, or are unable to be transplanted, there are a variety of forms of dialysis to help the body compensate for loss of kidney function. These different dialysis modalities are described later in this report, in the section outlining the activities of the Northern and Southern Alberta Renal Programs. Kidney transplant is seen as the best treatment available for these patients, as it offers the least lifestyle restrictions and is the most cost-effective treatment available once the transplant itself is finished. The major limiting factor, as in all transplants, is organ availability. In the past decade, procurement of kidneys from living donors has seen incredible growth, to the point where it has now reached 40 percent of all kidney transplants nationally.

All kidney transplants in Alberta are performed by the Calgary Health Region or Capital Health.

Table 3: 200 by	3/2004 Kidı Region of F	ney Transplant Recipients – Residence	
Health Regi	on		
Region 1	6	Region 6	50
Region 2	3	Region 7	13
Region 3	44	Region 8	3
Region 4	11	Region 9	1
Region 5	2	TOTAL	133
Source: CIHI 20	003/2004 Mork	bidity File	

Table 3 shows the health region residency of kidney transplant recipients in 2003/2004.

### **Liver Transplants**

The University of Alberta Hospital in Edmonton is responsible for all liver transplants performed in the Province. Liver failure can be caused by any number of factors, but the most common are: Hepatitis B and C, medication overdose (especially acetaminophen), history of excessive alcohol consumption, cirrhosis, hemochromatosis, or malnutrition. In some cases, a person who has begun to experience liver failure can be treated and the extent of liver damage limited. However, once the liver has fully failed, the only treatment option is transplant. For those who are experiencing liver failure and waiting for transplant, symptoms can range from jaundice (yellowing of the skin) and fatigue to confusion and even coma.

As of December 31, 2004, there were a total of 58 Albertans waiting for a liver, with 3 of those waiting under the age of 18. During the 2003/2004 fiscal year, the program was able to perform a total of 51 transplant procedures. The sobering side to these figures is the fact that, according to CIHI, 13 Albertans died in 2003 while waiting for a liver transplant and a further seven died in the first six months of 2004. These statistics are not a reflection of the transplant program's inability to perform enough transplants, but a reflection of **the need for increased organ donation**.

Table 4: 2003/2004 Liver Transplant Recipients – by Region of Residence						
Health Regi	on					
Region 1	2	Region 6	20			
Region 2	2	Region 7	2			
Region 3	14	Region 8	2			
Region 4	3	Region 9	1			
Region 5	1	TOTAL	51			
Source: CIHI 2	003/2004 Morb	idity File				

Table 4 shows the distribution of liver transplant recipients across Alberta (patient's home region was not identified in four cases).



Figure 4 shows the historical trend in liver transplants since 1994/95.

### **Bone Marrow Transplants**

Bone marrow transplant can be an effective course of treatment for patients recovering from treatments for leukemia, lymphoma, or a number of other disorders. A major role of stem cells in bone marrow is the manufacturing of red blood cells, white blood cells, and platelets. Following chemotherapy and/or radiation, the body's ability to produce these vital cells is greatly reduced. A bone marrow transplant, whether through autologous (patient's own marrow) or allogenic (marrow from another person) sources, is intended to restore the body's ability to produce these vital blood components.

Calgary Health Region and the Tom Baker Cancer Centre (Calgary) are responsible for all PWS-funded bone marrow transplants in the Province. The majority of cancer care in the Province is the responsibility of the Alberta Cancer Board, but allogenic bone marrow transplants require a combination of hospitalbased care within the Foothills Hospital and extensive outpatient clinic visits to the Tom Baker Cancer Centre before and after the transplant.

Potential donors of bone marrow must be matched to the prospective recipient on a variety of genetic and laboratory tests before they are approved as a donor. Once the patient has completed their course of radiation and/or chemotherapy, the transplant can occur, which involves infusion of stem cells through a vein. The majority of work in bone marrow transplantation is non-surgical and takes place in a laboratory before the transplant procedure even occurs.



Figure 5 shows the historical trend in the number of Albertans who received bone marrow transplants. A major and exciting factor that may be causing bone marrow transplant volumes to level off and potentially even decline in the future is the emergence of monoclonal antibodies, such as the drug Rituximab, as a frontline therapy for certain disorders like non-Hodgkin's lymphoma. This emerging field of research is creating new hope that certain forms of cancer could be significantly reduced or eliminated in the future, with reductions in the sheer number of bone marrow transplants being performed.

### Trauma and Burns

Unlike other inpatient categories of PWS, where the activity is a single surgical procedure such as a transplant or cardiac bypass, trauma and burn patients are much more likely to require many smaller treatments in order to address the sheer magnitude of their injuries.

The trauma and burn cases addressed through PWS are only those with very high needs who require the majority of their treatment to be done by a specialized trauma program in Edmonton or Calgary. In many cases, these patients require both intense initial treatment followed by lengthy rehabilitation, resulting in many cases with costs exceeding \$100,000. There is also need for a variety of consulting clinical programs to address the range of issues these patients face, from orthopedics to internal medicine, plastic surgery to neurology. Many patients also require life support for part or all of their stay in hospital, such as tracheostomies and/or gastrostomies to assist with airway and digestive issues.

Trauma and burn cases can be very difficult to predict from one year to the next. A single tragedy like a tornado or building fire can have an immediate effect on the total annual number of these cases. The solution to preventing these cases is multi-faceted and crosses many sectors of government, private industry, and personal responsibility. Building codes, fire regulations, speed limits, traffic enforcement, occupational health and safety, and many other sectors play a vital role in prevention. Beyond laws and regulations, individuals must take responsibility for their actions and try to manage the risk they subject themselves and others to by their driving habits, recreation choices, overall commitment to safe communities and workplaces.



Figure 6 illustrates the distribution of Trauma and Burn patients. The total volume of these cases was 445, a slight decrease from the 468 seen in 2002/2003. This drop in hospital activity was consistent for both Capital Health and the Calgary Health Region facilities. As in past years, there appears to be quite a marked difference between the utilization of these services by Calgary residents (Region 3) and their relative proportion of the provincial population. The opposite appears true for Regions 4 and 7 (David Thompson Health Region and Peace Country Health), where their utilization of trauma and burn services surpassed their population proportion by over 50 percent. There appears to be a generally higher proportion of trauma and burn services required for residents of the rural health regions.

### **Neurosurgery**

Craniotomies, intracranial vascular procedures, ventricular shunt revisions, and spinal procedures are just a few of the neurosurgical procedures funded through PWS. If the names alone do not indicate the specialization of these procedures, it should be reiterated that such activities truly involve a high level of specialization in terms of the clinical team, the facilities required, and the tools used. These surgeries are only performed in Edmonton and Calgary for all Albertans, and are isolated to a very finite number of facilities even within these urban centres. This type of planning is at the core of why Province Wide Services exists: to ensure that specific services are centralized enough to maintain such things as provider proficiency and economic efficiencies through adequate surgical volumes.

In 2003/2004, a total of 1,800 PWS neurosurgical procedures were performed, up just 1.8 percent from the 1,769 performed in the previous year. There was, however, significantly higher growth in neurosurgery volumes for Capital during the period (5.9 percent) combined with a decrease in volumes for Calgary Health Region (-3.1 percent). Both health regions state that volumes in this area may be somewhat understated because of the Case Mix Group method that was used to identify neurosurgical cases during this period. It is believed that these neurosurgical volumes would be more accurately identified if Province Wide Services were selected by procedure code.



Figure 7 shows the historical volumes of neurosurgery cases by the two providing health regions.

### **Cardiovascular Services**

Most of the PWS Cardiovascular Services category include: angioplasties (PTCAs), coronary bypass surgeries (CABGs), cardiac valve surgeries, and other open heart procedures. The causes of cardiovascular problems are varied, but many cases are considered preventable because they result from manageable problems such as obesity, high blood pressure, smoking, cholesterol, and physical inactivity. The growth in PWS cardiac services outpaces virtually every other inpatient area, with an average annual growth near 10 percent. The costs in this area are also escalating because of continually evolving technologies for treating these patients.

A key technology used to treat cardiac patients today is the angioplasty, a procedure that has evolved quickly over the past two decades. This technology is part of an ever expanding field of medicine known as Interventional Cardiology, which is based on the simultaneous use of diagnostic imaging (i.e. x-ray, Computed Tomography, and Magnetic Resonance Imaging) and surgical techniques to produce a far less invasive treatment of conditions that might otherwise have required extensive thoracic surgery. In the case of angioplasty, a patient can have a blocked vein or artery near their heart almost completely opened with the only stitches needed being put in their leg or arm where the cardiac catheter is inserted. In this procedure, the physician is able to first literally see the location and extent of the blockage using an angiogram, a 'live' x-ray of the patient's blood vessels. From the angiogram, a route is then plotted for insertion of the cardiac catheter. The catheter has a tip that expands like a tubular balloon and is blown up once it is positioned inside the constricted area (See Figure 8a and 8b). The outward pressure exerted by the balloon widens the narrowed blood vessel, and the balloon is then deflated and removed (See Figure 8c).

Traditional angioplasty included only the balloon dilator to expand the arterial wall, more current methods use the balloon to expand a stainless steel mesh tube (called a stent) which not only







Figure 8b: Inflation of the Balloon Dilator



Improved Blood Flow Through Bigger Opening

Figure 8c: Vessel After Removal of the Balloon Dilator



Figure 9: Inflation of the Balloon Dilator with Stent

opens the narrowed vessel, but is left behind permanently to provide greater insurance that the vessel will not narrow once again (restenosis). An even more current innovation is the development of a drug-eluting stent, which essentially coats the standard stainless steel mesh with a medication that will further prevent restenosis in high risk cardiac patients. In 2003/2004, there were over 4,000 angioplasty procedures performed in the Province, which is more than a 9 percent increase from 2002/2003. This growth rate has been fairly consistent for the past five years, as both health regions providing this service have continued to increase their capacity to meet the corresponding growth in demand. Coronary Bypass surgery, in contrast, decreased in total volume from 1,658 procedures in 2002/2003 to 1,582 in 2003/2004. Although difficult to say with certainty, it is believed that this

decrease in bypass surgery can be partially attributed to the growing popularity of angioplasty as an alternative treatment for opening constricted blood vessels around the heart. Clinicians will emphasize that these two treatment methods generally treat different types of cardiac patients, but there appears to be at least some movement in the line between those who would have historically needed bypass surgery and can now be treated safely with angioplasty.



Figure 10 displays overall volume growth in cardiovascular services which has continued the same upward trend that has been fairly consistent since 1996/1997.

## **Cardiac Waitlists**

A major initiative of Alberta Health and Wellness over the past several years has been the development of a consistent method for identifying and tracking the length of time people are waiting for key surgeries. Open-heart surgery is one of the major categories being followed closely.

People who are in need of emergency cardiac surgery are not put onto a waitlist and are provided with service right away. Patients are prioritized based on the severity of their need. These patients range from individuals who cannot leave an intensive care unit to those who are stable enough to go home while they wait for treatment. The goal for the lowest priority "Planned Outpatients" is that they receive treatment within six weeks. During their wait, these patients are monitored regularly and, if needed, are moved to higher priority categories based on any change in their health status.



Figure 11: Adult Open-Heart Surgery Volume and Number of Persons Waiting April/June 2001 to July/September 2004

#### Source: Alberta Health and Wellness, Quality and Accountability Branch

Figure 11 illustrates the significant in-roads made in reducing the waitlist for open heart surgery.

### Neonatology

There are nearly one hundred hospitals in the Province that deliver close to 35,000 babies each and every year. A high percent of these babies are born healthy and are followed up very soon in the community by a pediatrician or family doctor. For a very small group of babies, however, it is not such a smooth transition from hospital to home. Babies who are born prematurely, those with inherited disorders, or those born with a very low birthweight, require additional care, and their stay in the hospital can be lengthened significantly.

Although definitions vary, a baby born with a birthweight less than 2,500 grams (5.5 pounds) is considered to be low birthweight and at increased risk. Many of the larger regional hospitals across

the Province are equipped with Special Care Nurseries that can look after a fairly high proportion of these babies. An even smaller proportion of these infants, however, must be cared for by the highly specialized neonatology programs found in Edmonton and Calgary. For the specialty neonatology program funded through PWS, these infants are typically less than 1.500 grams (3.3 pounds) and/or have some type of diagnosis that makes them extremely fragile. This might include inherited cardiac, genetic, or neurological disorders, or might be the result of trauma or infection arising from the actual birth event. The programs that deal with these fragile infants must be equipped with intensive care treatment areas that are specifically equipped and staffed for dealing with complex neonates.



Figure 12 shows the distribution of neonatology cases by the health region where they reside, and compares that figure to the relative population proportion for the region. What is quite striking about this graph is just how closely the percentage of neonatology cases for each region mirrors its population percentage.





The total number of PWS neonatology cases has seen a fairly steady increase over the past ten years, as indicated by Figure 13. Because of the multi-faceted determinants of health affecting these figures, it is very difficult to forecast volumes. Some of the greatest risk factors presumed to be influencing this upward trend include: higher numbers of multiple births (i.e. twins, triplets, etc.), assisted reproductive technologies, high or low maternal age, and substance use during pregnancy, including: alcohol, illicit drugs, and tobacco.

## Oncology

Although most cancer care in the Province is the responsibility of the Alberta Cancer Board, there are some instances where the regional health authorities are needed to perform specialty surgery on cancer patients.

PWS funds the Capital and Calgary Health Regions to perform a select group of orthopedic surgeries, radical hysterectomies and vulvectomies, laryngectomies and glossectomies, major head and neck procedures, and lung resections.



Figure 14 shows a steady increase in these surgery volumes, with more than five percent average annual growth since 2000/2001.



Figure 15 highlights the distribution of these cancer patients by their region of residence.

## **PROVINCE WIDE SERVICES**

# **Special Feature Reports**

Each year, this section of the report is made up of submissions authored by individual PWS programs themselves, allowing them to highlight some of their recent accomplishments and their plans for the future. In last year's report, we highlighted the Alberta Trauma Program and Capital Health's Pediatric Cardiac Surgery program. This year, we are pleased to present information that has been provided by:

- I. Home Enteral Nutrition Programs (HENP) a joint submission of the programs being coordinated by the Calgary Health Region and Capital Health.
- II. Southern Alberta Transplant Program (ALTRA) a newly redeveloped transplant service operated by the Calgary Health Region
- III. Living Lung Transplant Program a brief description of this cutting edge service being developed and provided by Capital Health, which allows patients to receive a life-saving lung transplant from a living donor.

## **Special Feature Reports**

### Home Enteral Nutrition Programs (HENP)

A Joint Submission of The Northern and Southern Alberta HENP for Adults and Children

Enteral nutrition (feeding by tube) is the preferred method for individuals who cannot eat, or eat enough, by mouth. Enteral nutrition preserves and promotes integrity of the absorptive bowel surface and it is markedly less expensive than intravenous feeding. The Northern and Southern Alberta HENP facilitate safe delivery of enteral nutrition to children and adults at home. Education, clinical support, and enteral feeding supplies and equipment for patients are provided by the programs.



"This child is three and a half years old, and was having problems with aspiration when he ate orally. A tube was placed in his stomach to feed him and he has been on the Pediatric Home Nutrition Support Program since May of 2004. Staff continue to work with his parents and other health care professionals to try to get him eating adequately by mouth in the future."





Programs are staffed by an interdisciplinary group of highly trained personnel, including physicians, dietitians, registered nurses, speech language pathologists, pharmacists, occupational therapists and social workers. Programs actively involve the individuals and/or families to ensure safe tube feeding at home. HENP staff partner with home care nursing and allied health disciplines can provide services in the community where the patient resides if they are unable to travel to the HENP clinic.

The Alberta Home Enteral Nutrition Programs adhere to the standards of practice of the American Society for Parenteral and Enteral Nutrition.

Standardized admission criteria include:

- Patients are medically stable, to allow monitoring at home.
- Patient/family are willing to participate and have access to appropriate caregiver support.
- Patients and/or caregivers consent to devote adequate time to be educated in the principles and safe practices related to tube feeding.
- Patients have a primary care or sub-specialist physician who assumes responsibility for medical follow-up.
- Patient/family agree to a co-pay for the nutritional solutions where this requirement exists.

Upon referral for Home Enteral Nutrition, patients are clinically assessed and taught to ensure:

- program admission criteria are met,
- the home is safe and appropriate for HEN,
- they receive the appropriate nutrient intake based on individual requirements and nutritional goals
- the patient and/or caregiver can follow the HENP educational program to provide home tube feeding in a safe, competent manner

## Differences in service delivery between pediatric and adults patients:

Major differences between the pediatric and adult programs relate to the following:

- pediatric clients originate in one of the two children's hospitals in the province, the Alberta Children's Hospital in Calgary or the Stollery Children's Hospital in Edmonton, whereas adults can be referred and admitted from almost any acute care hospital across the Province.
- higher ratios of pediatric clients have a skinlevel feeding device inserted. These result in higher supply costs related to tubes for this population. These tubes, however, reduce the risk of the child pulling at the tube and accidentally removing it and needing reinsertion.
- more home visits may be required by the adult teams because of the difficulty in transporting patients to hospital when they require significant assistance. For example, clients who have had a stroke or have advanced ALS may require home visits by a HENP team member, which can reduce the need for expensive ambulance transport to the HENP clinic.

# Current challenges and pressures facing the program

Specific to the Pediatric HEN population, managers have been in dialogue with representatives from the Alberta Children's Services ministry and Family Support for Children with Disabilities (FSCD). FSCD and other programs have undertaken changes in eligibility criteria that will result in the loss of funding support for some children requiring HEN. HENP has been working with Alberta Health and Wellness to identify an alternative funding mechanism for these children who do not have visible 'physical or mental disabilities' but have medical nutritional needs requiring HEN. Presently, the pediatric program in Southern Alberta is implementing formula distribution in their service, as the adult program in the South and the adult and pediatric programs in the North have been doing.

The pediatric programs in Northern Alberta have seen a significant increase in admissions related to treatment of tracheo and laryngomalacia in premature infants as well as the full-term infant population. These clients are defined as shortterm clients who require a higher level of support and intervention (i.e. follow up biweekly rather than every few months). This specific group consumes a higher level of resources per patient therapy day. However, the net result is a significantly higher rate of oral feeding resumption, thereby reducing the ongoing support required by the health care system. A trend is now emerging that shows an increase in pediatric HENP clients in the North returning to oral feeds and a reduction in the number of deaths in this specific population group.

Minimal financial assistance programs exist for adult clients on HEN, other than Assured Income for the Severely Handicapped (AISH) or Supports For Independence (SFI). Adults on limited incomes who require HEN experience hardship when expected to pay for nutritional solutions if they do not have adequate financial resources.

# Initiatives taken and noteworthy new approaches

Today's consumers reflect the current societal trend toward independence, self directed health decisions, active health information seeking and a belief in the right to access the best available avenue of health promoting treatment or device. The Alberta HENP support mobility and the achievement of personal goals by providing small portable feeding pumps that allow children and adults to attend school and continue active professional and social involvements. Skin level feeding devices are a better option that is now replacing many of the large, intrusive feeding tubes which are difficult to secure under clothing. The more user friendly devices contribute to individuals actively participating in the cultural fabric of their community and the economy of the province. Ongoing funding for these devices (tubes and pumps) will be required in order to ensure that clients are best served at home and in the community rather than within the institutional health care systems.



### **Program successes**

The Northern and Southern Alberta's HENP programs are the most comprehensive and well organized provincial programs in Canada. They are able to improve healthcare efficiency through decreasing length of hospital stays, processing referrals guickly, and supporting patients in their own homes. Future hospital admissions and reliance on the healthcare system are reduced by supporting these clients with interdisciplinary teams that specialize in enteral feeding and assisting with the return to oral feeding whenever possible. The coordinated nature of the programs also optimizes support for individuals making the transition from pediatric to adult programs at age eighteen. The Alberta Program provides the benchmark of integrated home enteral nutrition support and has captured the interest of other provinces that recognize the efficiency and effectiveness of the Alberta model. We attribute our success to our fundamental mandate of providing optimal nutrition and quality of life for individuals whose illnesses preclude adequate oral nutrition.

The significantly lower cost per day of therapy and minimal complication risk of home-based enteral nutrition in relation to other options warrants continued support for these services.

### Emerging changes in service provision

Recent trends in the Alberta HENP Programs indicate a slower rate of growth in therapy days but a steeper rate of growth in new admissions to the programs. This can be attributed to a greater awareness amongst referring physicians to the benefits of short term nutritional support. Patients undergoing treatments such as surgery, radiation, chemotherapy or neuromuscular rehabilitation are able to access nutritional services at home which were not previously available outside of the hospital system. In this way, hospital lengths of stay are averted or shortened, rehabilitation enhanced, and recovery time shortened. HENP Program personnel recognize that the additional activity resulting from short term admissions to the HENP Programs has a higher professional/ clinical cost than supporting stable, long duration patients on enteral therapy. Because of these changes, greater use of the program data will be required to identify the impact on program resources in order to sustain the programs.

The use of videoconferencing with rural regions has allowed the HENP Programs clinical staff to provide not only educational sessions to staff in these regions, but also to provide clinical monitoring and guidance from a distance. With the extensive network of telehealth capabilities across Alberta, an increasing number of clients no longer need to travel to the HENP Programs in an urban region to receive the benefits of the Programs' expertise.

### **Future Directions**

Continued development and improvements of a comprehensive provincial database for both HEN Programs will provide information to support the systematic review of the outcomes for patients receiving enteral nutrition services. Because the clinical outcome for an individual on HEN is also reflective of the underlying disease, it is difficult to separate nutrition-related outcomes from diseaserelated outcomes. Nonetheless, data that can identify the duration of therapy, reasons for stopping, complications, and rehospitalizations for each patient by diagnostic group will inform future decisions aimed at maximizing positive outcomes and optimizing service efficiency. Setting benchmarks for service outcomes and standardization of processes will also be directly influenced by these evaluations.

The significant number of clients in both the adult and pediatric HEN programs in Alberta are a huge untapped resource for research in homebased nutrition services. Promotion and publication of research from these programs in the future have the potential to provide invaluable information to policy makers and clinicians both nationally and internationally.

## Southern Alberta Transplant Program (ALTRA)

Calgary Health Region

ALTRA stands for "Alberta Transplant" and is the new name of the Southern Alberta Transplant Program.

ALTRA evolved out of the kidney transplant program that had its origins in the 1970's. By 1997, the Division of Transplant Surgery was founded and the first pancreas transplant was performed in 1998. In 2002, the Calgary Health Region decided to consolidate all adult pre- and post- transplant services for Southern Alberta at one site, under the umbrella of one program: AL-TRA.

The objective of ALTRA was to create a unique service delivery model and become a "Transplant Program" rather than continuing with the existing model where each transplant service was contained within a number of separate smaller programs.



#### **Overview**

Adult kidney, kidney/pancreas, liver, heart and lung transplant patients are followed at one clinic location at the Foothills Medical Centre and admitted to one inpatient unit (with the exception of lung transplant patients). Pediatric patients are followed at the Alberta Children's Hospital in Calgary. This centralized approach utilizes the services of a multidisciplinary team who are experts in transplant medicine, in order to provide outstanding patient care.

Kidney and kidney/pancreas transplants are performed at the Foothills Medical Centre while liver, heart and lung transplant are performed at the University of Alberta Hospital in Edmonton. ALTRA, however, provides pre and post transplant services to all organ groups in this population.

### Clinics

The service delivery model that ALTRA has developed is currently being utilized for the kidney and kidney pancreas population. Transplant patients are followed in clinic using a multidisciplinary approach. Patients can be seen by a physician, nurse, pharmacist, dietician and social worker at a single clinic. This team approach allows the patient access to each health care professional's area of expertise while having their care coordinated into one visit. Research has demonstrated the pharmacist plays a key role in affecting outcomes in terms of medication compliance and reporting of adverse effects with post transplant patients.

The liver, heart and lung transplant patients do not have access to a pharmacist and dietician during clinic visits. Nurses must take on this role, which adds to the nursing burden of care. When additional funding is obtained, ALTRA will add these health care professionals to the team in order to provide the same level of care offered to the kidney and kidney/pancreas population.

The following graph illustrates the number of post transplant patients by organ group that ALTRA is following:

### **Living Donation**

The Living Donor service was transferred from the HOPE Program (Human Organ Procurement and Exchange) to ALTRA in 2003. The current staff mix includes a nurse coordinator, secretary and social worker. The goal is for 40 - 50percent of all kidney transplants to be provided by living donors. Teaching booklets and pamphlets are currently under revision and development.

The following tables illustrate the survival rates for ALTRA kidney transplant patients:

## Unadjusted One to Five year Patient Survival Rates for Kidney Transplant Patients between 1997 and 2005

	Deceased Donor	Living Donor	Total
1 year	97.87	98.65	98.13
2 years	96.19	96.96	96.44
3 years	96.19	96.96	96.44
4 years	94.97	96.96	95.63
5 years	91.47	96.96	93.36

#### Kidney Graft Survival Rates for Kidney Transplant Patients between 1997-2005

	Deceased Donor	Living Donor	Total
1 year	94.49	95.43	94.81
2 years	92.01	92.95	92.33
3 years	90.04	91.98	90.71
4 years	88.23	89.37	88.63
5 years	81.55	89.37	84.35

Source: ALTRAbase

### **Data Management**

The in-house designed database, ALTRAbase, was first constructed in 1997. At the time, it was a small database partially meeting the needs of the Kidney/Pancreas transplant group. Since then, the database has expanded to incorporate other transplant related needs: organ procurement, tissue typing, research, dialysis, and administration. Due to its ease of use and an increase demand for databases in this environment, the transplant program's server also hosts databases outside of the direct scope: a resident surgical database, and a database for colorectal surgery and radiology.

ALTRAbase has been undergoing many changes since the conception of ALTRA. The database is being expanded to encompass the entire transplant program. Furthermore, a collective transplant databank will ease patient care and provide advanced management and utilization tracking.

### Successes

The first Solid Pancreas transplant was performed in 1998; the first laparoscopic donor nephrectomy (removal of a kidney) was performed in 2001. Today, approximately 70 - 80 percent of all living donor kidney transplants are performed using this technique. The Co-morbidity Clinic was launched in December 2002 and is the first in Canada to offer this unique service to post kidney and kidney/ pancreas transplant patients. The goal of this clinic is to manage hypertension, lipids profiles, bone density, diabetes and other co-morbid complications of the transplant population. Problems and potential problems will be addressed with early interventions to maintain a healthier population.

In January 2004 the first Southern Alberta lung transplant clinic was held in the ALTRA clinic site. The nurse coordinator and lung transplant physicians worked collaboratively with the Edmonton lung transplant service to coordinate post transplant follow up to Southern Albertans who had been previously followed in Edmonton or through individual physicians.

The liver and lung services are expanding their role in 2004/2005 to pre liver and lung transplant assessment and follow-up. The team will assess patients for transplant and follow them monthly or as required. In addition, the physician-nurse team will attend monthly listing rounds in Edmonton for all patients waiting for liver or lung transplant in Alberta. There were 60 pre liver transplant patients as of December 31, 2004.



### **Current Challenges**

New immunosuppressant drug therapies and emerging drugs are reducing organ rejection episodes: therefore, patients are living longer. This critical mass of the transplant population is becoming a challenge to manage within the current resources. With the growth in both patients and staff, there will be need in the future to ensure adequate clinical and support space is available to deliver the full range of services required. Despite the ALTRA program bringing together the transplant services from a number of organ-specific programs under a single administration, there is still a need to complete this consolidation by bringing the clinics, staff, and support areas together into a common, adequate-sized physical location.



### **Future Direction**

ALTRA is developing a Clinical Fellowship Program for Multi-Organ Transplantation and a Pathology Fellowship Program for Transplantation and Molecular Pathology Methods in Transplantation and Research Fellowship. In addition, ALTRA is participating in undergraduate studies with courses in transplantation medicine.

ALTRA will optimize patient care by development of novel therapies to improve long-term patient and graft survival using translational research platforms by collaborating with the University of Calgary and Industry. The future holds the potential to perform Phase I/II studies in a single center milieu with online follow-up using our ALTRAbase Database.

The sheer volume of follow up visits required for the post transplant population will soon exceed the capability of physicians to manage these volumes. An alternative to physician recruitment is the nurse practitioner; transplant nurse practitioners are a viable option for ALTRA.

The co-morbidity clinic will be expanding to Lethbridge in 2005. In the future heart, liver and lung transplant patients will attend co-morbidity clinics.

ALTRA is currently revisiting all outpatient teaching materials emphasizing modern webbased technologies. In addition, group teaching sessions are being developed for different patient groups utilizing a multidisciplinary approach.

The Calgary Health Region is addressing space and growth concerns. There is currently an initiative underway to move the entire transplant program to the Peter Lougheed Hospital site in 2007. A working group composed of representatives from administration, planning and transplantation are currently conducting a feasibility study of this initiative.

## **Living Lobar Lung Transplantation**

**Capital Health** 



Jessie McQuitty received a living lobar lung transplant in November 2004. The operation lasted eight hours and was the second successful living donor lung transplant at Capital Health, and the third in Canada. Here is Jessie with her transplant donors: (right: mother, Joan McQuitty), (left: aunt, Lynn Lokos) and Cardiothoracic Surgeon: Dr. John Mullen (printed with permission)

Cadaveric organ donation of lungs has not kept pace with the demand for organs. As of March 31, 2004 there were 61 patients on the University of Alberta Hospital's waiting list for lung transplantation. From 1997-2004, 28 percent of patients died while awaiting lung transplantation, 51 percent were transplanted, 3 percent were removed for other reasons, and 18 percent are still waiting.

Living lobar lung transplants are a relatively new and rare surgical procedure. World-wide, an estimated 150 of these procedures have been performed. All Province Wide Services living lung transplants are performed at the University of Alberta Hospital, the only centre in Canada that currently performs this procedure. The University of Alberta Hospital performed its first living lobar lung transplant in 2001/2002.

Living lobar lung transplantation requires two living donors to each donate one lobe of their lung to the recipient. The surgery was developed as an alternative to whole lung transplantation in children. However, the improving survival rates and quality of life for recipients have made living lobar lung transplantation an option for select children and small adults.

Living lobar lung transplantation requires a small recipient and relatively larger donors in order for the lobes to be sufficient in size. As such, this procedure is limited to a select set of recipients. The procedure exposes two healthy individuals to the risks associated with major thoracic surgery. Also, larger surgical teams are required to perform living lobar lung transplants.

The successful procedure that has been completed at the University of Alberta Hospital and the continued survival of the recipient defines this as a viable treatment option for end-stage lung disease. Completion of more living lobar transplant procedures may help to expand the donor pool, shorten waiting times and reduce mortality rates of patients on the waiting list. Therefore, it is hoped that increased numbers of living lobar lung transplants can be accommodated in the future. **PROVINCE WIDE SERVICES** 

# **Clinics and Home Services**

## **Clinics and Home Services**

The Province Wide Services Clinics and Home Services area includes: pre and post transplant activities, islet cell transplants, renal dialysis and dialysis prevention, HIV and STD/TB Clinics, genetics testing and clinics, children with complex healthcare needs (CCHN), craniofacial osseointegration (COMPRU), poison and drug information service (PADIS), and pediatric transport.

## **Renal (Kidney) Dialysis**

### **Overview**

The coordination of dialysis care across the Province is delegated to the Northern and Southern Alberta Renal Programs (NARP and SARP), who deliver dialysis care to patients experiencing renal failure. For most patients, the treatment of choice for renal failure is a kidney transplant, due to the lifestyle freedoms it permits when compared to most forms of dialysis. For those patients experiencing renal failure, and are not eligible for transplant or are waiting for a transplant, dialysis is the only treatment option available.

Treating renal failure has evolved quickly over the past half century, growing from a diagnosis that was virtually a death sentence to one where patients are now living longer and better quality lives all the time. Despite this remarkable evolution, dialysis patients are still quite constrained by the regimented lives that any form of dialysis imposes on them. As new modes and innovations in dialysis have continued to develop in recent years, patients are able to choose from a wider variety of treatment options and the benefits/challenges associated with each.

At the core of dialysis, there are essentially two modes of performing the required function of filtering the bloodstream of waste products: peritoneal dialysis and hemodialysis.

In peritoneal dialysis (PD), a great deal of emphasis is placed on the patient being able to do their own 'self-care', because they are required to exchange (fill and drain) dialysate solution to their abdominal cavity several times each day. Peritoneal dialysis makes use of the peritoneal membrane in the abdomen to act as a filter through which the dialysate solution can draw waste products and excess water out of the bloodstream. PD patients have a significant advantage of increased mobility over those on hemodialysis, but this freedom is somewhat tempered by the fact that they must perform exchanges many times throughout the week and must travel with sufficient solution and supplies for even short trips. In most cases, these patients must dialyze anywhere from 3 to 6 times during the day, and then switch to a machine at night that circulates fresh solution to their abdomen while they are sleeping.

Hemodialysis is, perhaps, the better known form of 'renal replacement therapy', and dates back to World War II when Dr. Willem Kolff designed the first machine in German-occupied Holland. From this original invention has come many different forms of hemodialysis, which differ more in the administration and level of convenience from one another than in the root technology they employ to perform the basic filtering function. Hemodialysis is essentially the process of circulating a patient's blood through an external machine where a membrane allows the flow of waste products out of the blood, while protecting the vital components like the red and white blood cells and platelets.

Factors ranging from expense to convenience have caused dialysis programs to look at many different models for delivering dialysis care in a safe but efficient manner. In Alberta, hemodialysis is delivered by one of four means: in-centre dialysis units, satellite dialysis units, home hemodialysis, and a new emerging form called home nocturnal dialysis. Both in-centre and satellite dialysis units utilize specialized staffing, equipment, and facilities, and require the patient to travel to a hospital or community-based setting to receive their dialysis care. The primary difference between these modalities is the cost and location. In-centre hemodialysis is by far the more expensive and takes place inside of a large hospital, while satellite clinics are located in less costly settings throughout the Province, including community-based health centres and rural hospitals.

Home hemodialysis and home nocturnal dialysis, in contrast, are closer to peritoneal dialysis in terms of increased freedom and greater reliance on the patient and/or their caregiver to manage much of their own day-to-day care. Both options are rapidly growing areas of service delivery as patients opt for more frequent dialysis treatment in the comfort and scheduling of their own homes. The increased frequency of dialysis runs means patients have less of a feeling of fatigue between treatments. Home-based dialysis also allows a patient to participate in everyday activities with their loved ones while they dialyze, prevents them from having to drive to clinic 3 to 4 times a week. and overall promotes a more desirable quality of life. Unfortunately, there will always be a need for medically fragile or less independent patients to continue treatments in facility-based clinics, so home-based options will likely never be able to fully replace the need for traditional dialysis units. At present, there is much research and evaluation occurring on the safety, effectiveness, and efficiency (i.e. cost effectiveness) of these homebased options. Preliminary results are showing that there are significant up-front costs associated with purchasing equipment and educating

patients on self-care, but that much of this cost is recouped in later years as they require less dependence on expensive facilities and staff. Beyond cost, a key factor in these evaluations is the improvements in quality of life for patients on different types of dialysis.

### **Dialysis Patients**

As with many areas of PWS expenditure growth, a major factor is not necessarily the growth in cost of treating a single patient, but rather the cost of treating an ever-increasing pool of patients who are living longer and longer because of life-sustaining technologies. The total number of Albertans dialyzing has grown from 703 patients in 1993/94 to 1,873 in 2003/2004, a growth of 166 percent over the 10-year period, meaning the number of patients requiring dialysis is doubling every 7 to 8 years. In 2003/2004, the average cost to treat a patient on hemodialysis was around \$59,000 per year versus \$31,900 per year for a patient on peritoneal dialysis. As stated previously, there are many evaluations occurring on the various types of hemodialysis, and it is hoped we can include some of the results of those analyses in next year's report. Table 5 shows the number of actual hemodialysis runs done by these patients each year since 1997/98 (i.e. figures include all forms of hemodialysis, but not peritoneal).

Table 5: Historical Hemodialysis Runs by Region								
	1997/98	1998/99	1999/00	2000/01	2001/02	2002/03	2003/04	
Capital	50,028	56,942	63,709	69,360	79,715	91,715	102,848	
Calgary	50,017	59,243	69,775	74,234	82,165	89,768	99,833	
Source: CH and CH	Source: CH and CHR PWS Annual Reports							

**Budget** – Not surprisingly, the funding for the renal programs has had to increase at a very high rate in order to keep up with surging patient demand for dialysis services. Funding for the renal programs is expected to cover all dialysis costs, as well as clinic visits and education sessions to support patients in renal failure. The renal budget for 2003/2004 was just over \$93.8 million, which is up from \$38.8 million just 4 years ago in 1999/2000, an alarming average annual growth of nearly 20 percent.



Figure 17: Hemodialysis Centres in Alberta (March 2005)

## **Dialysis Delay/Prevention**

In response to the dramatic growth in dialysis patients and the recognition that perhaps more could be done upstream to prevent or delay patients from needing these services, Province Wide Services approved funding in 2001 for two disease prevention programs. The initial commitment of \$3.2 million was split between Capital Health and the Calgary Health Region to allow them to develop initiatives aimed at early identification of at-risk individuals and intervention strategies to delay the onset of renal disease or avoid it altogether.

Two of the major risk factors for end stage renal disease are diabetes and high blood pressure. Since 2001, both programs have targeted these and other risk groups through a variety of screening and recruitment strategies. Once they have identified a target population, the goal is to provide education and support in the areas of nutrition, exercise, smoking cessation, blood pressure reduction, control of cholesterol, and many other areas where these individuals may be putting themselves at increased risk for kidney failure.

In 2003/2004, both programs continued to evolve as they strive to find the best model(s) for both identifying at-risk patients from across the Province and providing the right services that will be transferable to their home communities. Both programs have begun to establish referral networks of community physicians to identify these individuals, and both are using multidisciplinary teams to provide a wide range of education and treatment options.

In 2003/2004, the End Stage Kidney Disease (ESKD) program in Calgary Health Region served

a total of 589 people throughout Southern Alberta. They anticipate even stronger growth for 2005/2006, with as many as 960 active patients in the program, 200 physicians in the referral network, and home care providing a key bridge with follow-up visits in the homes of patients.

During the same 2003/2004 period, Capital Health had a slower start and only began seeing patients in the second half of the fiscal year. By the end of March, 2004, they had a total of 36 physicians enrolled in their referral network, with 69 active patients participating in the program. Their "Renal and Cardiovascular Protection In Diabetes" (RAPID) program is focused heavily on the development or enhancement of permanent clinics across Northern Alberta which can serve patients near to their home community. The locations targeted for regularly scheduled clinic are: 2 locations in Edmonton (University Hospital site and Northeast Community Health Centre), Wetaskiwin, Red Deer, Vermillion, Hinton, and Edson. In several instances, the RAPID program is an enhancement to existing diabetes clinics already offered by the local health region.

A challenge to both the Northern and Southern programs will be in the area of data collection and evaluation as they have both embarked on nontraditional models of care that cross many of the historical dividing lines between hospital-based care, home care, and community-based programs. As their success builds, it will be important for both of these programs to document their successes and challenges so that their experience can inform a new generation of programs that will in all likelihood be created to address the needs of our aging population.

### **Pre- and Post- Transplant**

The transplant surgery is, for many patients, the marquis event that transitions them from a life of chronic illness to one that is far less restrictive. What many members of the general public may not realize, however, is the sheer amount of work that must take place both prior to the surgery and in long-term follow-up following the transplant in order to plan for and maintain the viability of the new organ. For all prospective transplant patients, this means a lengthy series of laboratory tests, education sessions, clinic visits, and time away from their family to satisfy the transplant programs that the patient is fully prepared for both the surgery and the life that follows.

For those who are fortunate enough to receive a transplant from a living donor, whether it is a full organ (i.e. kidney) or portion of an organ (i.e. liver or lung), usually a close family member, many of the same lab tests must be performed on the prospective donor.

Following the transplant, there is also a strong emphasis on ensuring the viability of the new organ through continued monitoring of its function, stabilizing of immune-suppressing medications, and continual promotion of healthy lifestyle choices by the patient.

For 2005/2006, Province Wide Services provided \$16.4 million to Capital Health and Calgary Health Region to provide this range of services. A review of the funding schemes was undertaken during 2004/2005 with both health regions undertaking an analysis of all the costs associated with providing services to these patients. In the end, funding was increased by just over 20 percent to address the changes proposed by the review. This does not include some portion of transplant-related costs funded outside of Province Wide Services.



### Islet Cell Transplant

While many specialized medical procedures, including organ transplants, are available in Alberta, very few of them have the distinction of being developed right here in the Province with its specialists sought the world over to train other programs in what has been dubbed "The Edmonton Protocol". As current as February 2005, the Islet Cell program and its founders continue to capture headlines around the world, pioneering the worlds first islet cell transplant from a living donor. Performed in Kyoto, Japan by Alberta's own Dr. James Shapiro, this procedure potentially opens yet another avenue for treating patients with Type 1 Diabetes.

At the root of the Edmonton Protocol is the isolation of islet cells in a laboratory from a donor pancreas or, in the case of the new living donor transplant, from a portion of a pancreas. Even with the successes of the process, a great deal of effort has continued in refining the process of isolating the islet cells so that as many as possible from each pancreas can be preserved. Like other organ programs, one of the islet cell program's greatest limitations is the shortage of donated organs. The more efficiently the lab isolation process is in acquiring healthy islet cells from a single organ, the greater the number of procedures the program can perform. Currently, the success rate for transplants (defined as complete independence from insulin and excellent control of blood glucose at one-year post transplant) is between 80 and 85 percent.

In 2003/2004, a total of \$2.2 million was provided to Capital Health for operation of the islet cell transplant program. The program was able to perform 20 islet cell procedures on Albertans during that year.

### Medical Genetics

In the world of medical scientific discoveries, there are few fields that can keep pace with the exponentially expanding area of medical genetics. Despite its discovery in 1953 by James Watson and Francis Crick, the mysteries of deoxyribonucleic acid (DNA) and its vast potential for diagnosing and treating illness was largely unrealized until recent years.

Province Wide Services funding is primarily used for genetic testing and counseling, that is, the use of genetic techniques to accurately diagnose a vast array of disorders and then provide appropriate support to the patients and families affected. The diagnosing and counseling services are provided by the Departments of Medical Genetics at the University of Calgary and University of Alberta. Table 6 shows medical genetics activity for 2003/2004. There were large increases in reported molecular and bio-chemical testing over previous year. Fro 2005/2006, Province Wide Services is providing \$17.6 million in funding, an increase of 30 percent over the previous year. Genetic testing falls into three main categories, which are described below:

- A. Cytogenetics, one of the earliest forms of genetic testing, examines the entire chromosome rather than specific spots along a DNA strand. A typical human cell contains 23 pairs of chromosomes in its nucleus, and each individual chromosome contains DNA. By examining the chromosomes under a microscope, one is able to detect differences in the number, shape, and 'staining pattern' of the chromosomes. There are many common and rare disorders that can be diagnosed by looking at these three elements. Perhaps the best known condition that is confirmed using cytogenetics is Down's Syndrome. A child born with Down's Syndrome will have an extra chromosome at chromosome 21 (also called 'trisomy', because of the chromosomes appearing in a group of three, rather than a chromosome pair).
- B. Molecular Genetics is perhaps the branch of medical genetics that is the most specialized, since it deals with diagnosis of gene mutations on the actual DNA strand. The 'gene' is, at its simplest, a small segment along a strand of DNA which contains the information instructing a cell to create a certain protein. Each DNA strand holds thousands of genes, which are amazingly comprised of only 4 possible chemical compounds arranged in an infinite number of combinations. It is through this diversity of combinations that we have our uniqueness as

individual human beings. However, there are many combinations that have been found to be common amongst people with similar traits, including those suffering from similar illnesses. Molecular Genetics is concerned with testing people who have inherited one of the combinations that appears to be correlated with a specific disease. Some of the better known disorders that can be diagnosed or further confirmed with molecular genetics testing are breast cancer, cystic fibrosis, muscular dystrophy, and Huntington's Disease. In addition to diagnosis, a key role of molecular genetics is to identify 'carriers' of certain diseases, that is, people who may merely carry the gene for a disease but not necessarily suffer from it. In such circumstances, prospective parents who are known to be carriers may be better informed of the risks they take if they choose to have children of their own.

C. **Bio-Chemical Genetic Testing** is a step removed from molecular genetics, where the test is actually looking at the product(s) of a specific gene, rather than the section of DNA itself. Although genes are responsible for manufacturing every component of the human body, bio-chemical testing is primarily interested in enzymes, the key components directing metabolism in the body. By looking at these gene products, it provides geneticists with yet another tool for diagnosis of metabolic disorders.

Table 6: PWS Medical Genetics – 2003/2004 Expenditure Activity							
	Calgary	Capital	Increase from Previous Year				
Expenditure	\$8.6 million	\$6.8 million	7.7%				
Genetic Tests							
- Cytogenetics	2,722	2,455	0.7%				
- Molecular	3,315	3,053	29.7%				
- Biochemical	8,642	-	26.6%				
- Newborn Screening	-	125,717	4.2%				
Clinical Genetics Consulting - Patients	2.056	1.981	0.0%				

## Human Immunodeficiency Virus (HIV) Clinics

Province Wide Services provides funding (\$3.2 million 2005/2006) for the Northern and Southern Alberta HIV Clinics in Edmonton and Calgary. The primary goal of these clinics is to improve the quality and length of life for people living with HIV infection (predominantly males), and facilitate easy access to the antiretroviral agents used for staging HIV infection (see PWS high cost drugs). The clinics provide comprehensive multi-disciplinary outpatient care, and serve as centres of knowledge, research and education related to HIV. Clinic staff deal with a largely marginalized community who also require income support, housing and resources for substance abuse and mental illness.

Since the mid 1990s, improved HIV drug therapy has dramatically increased the length and quality of life for HIV patients, along with a dramatic reduction in the number of newly diagnosed AIDS cases. Newly diagnosed AIDS in Alberta declined from a peak of about 94 cases per year during the period 1989-1995, to an average of only 35 new cases per year for the period since 1998. In addition, there has been a dramatic reduction in AIDS related deaths. From 1991 to 1995, an average of 81 persons died annually from AIDS. This dropped to only 4 deaths in each of 2002 and 2003. Because HIV is almost completely preventable with proper education and prevention, the number of new cases of HIV infection are still too high with high associated treatment costs. Prevention initiatives can save millions of dollars downstream.

One of the main stories for the HIV clinics is that the markedly improved survival rate is having a significant cumulative impact on the total number of AIDS patients and the HIV drug budget. Since 1995, even though the rate of new cases has dropped, the cumulative number of existing AIDS patients has increased at an average rate of 4.6 percent per year, well above general population growth.

For 2003/2004, the Calgary HIV clinic reported a substantial 15 percent increase in patient contacts. They also noted that they continue to manage more complex patients – high risk pregnancies, homelessness, intravenous drug use and disease co-infections. This has required forging closer relationships with community health partners in Southern Alberta. Capital Health reported a 5.8 percent increase in clinic patients.



## **Poison and Drug Information Service (PADIS)**

Check the first page of any phone book in Alberta (white or yellow pages), and you will find the provincial Poison Centre distress line (1-800-332-1414). This is perhaps the best known and most visible service provided by the Poison and Drug Information Service (PADIS). Beyond this vital service, PADIS provides several other key services to clinical professionals, employers, and the general public in the area of drug and toxin information.

The PADIS program is operated under the umbrella of the Calgary Health Region, with a mandate to serve the entire Province. PADIS is being funded \$2.89 million for the 2005/2006 fiscal year to provide the following three services:

 Alberta Poison Centre – poisoning can refer to swallowing, breathing in, or any number of exposures to a toxic substance. Whether that substance is a commercial cleaner, an inhaled gas, or a prescribed drug, there are many obvious and not so obvious ways that people can experience poisoning and require immediate assistance. The Alberta Poison Centre is staffed 24 hours a day by experts in toxicology, ranging from pharmacists to physicians to nurses who are prepared to assist both members of the general public and other health providers in dealing with virtually any poisoning query that could arise.

- Drug Information a service primarily directed to health professionals to provide information and direction on prescribing drug therapies
- Toxline a service for employers and employees seeking advice and consultation on toxins in the workplace, especially in healthcare facilities.

An ongoing challenge for PADIS is maintaining sufficient profile in the public eye. A public awareness campaign was launched in late 2002 that appears to have contributed to a resurgence of call volumes and consults in 2003/2004. Overall activity volumes had fallen gradually since 1997/1998 from 39,712 calls to 32,601 in 2002/2003, but appear to have regained that ground with 44,357 calls or consults in 2003/2004. Figure 18 shows where these calls originated from across the Province, by region, and compares the percentage of calls to the provincial population proportion in that region. Most regions in the Province have call volumes that closely match their population, with the exception of Capital Health and Aspen Health. For Aspen (Region 7), call volumes are nearly double their population share. Capital Health, on the other hand, is nearly 10 percent below the call volumes that might have been expected. The call volume drop in Capital may be due to the success the region has had in promoting HealthLink, the provincial nurse-on-call service.



NOTE: These figures do not include 1,489 contacts out of a total of 44,357 in the year, because the RHA where the call originated is not known.

## Home Enteral Nutrition Programs (HENP)

Enteral nutrition therapy is a means of providing nutritional requirements to a person who, for any number of reasons, is unable to eat, swallow properly, or otherwise is unable to ingest food by normal means. Typically, this means they must get their nutritional replacement through a semipermanent tube inserted through the abdominal wall, or a temporary tube inserted through the nose, that allows the fluid to be injected directly into the stomach. This home-based therapy reduces the need for hospitalizations, thereby enhancing the freedom and quality of life for the patient and family while reducing overall costs to the health system.

The HENP programs are delivered through Capital Health and Calgary Health Region to both adult and pediatric patients from across the Province. PWS funding is increased significantly in 2005/2006 to \$5.34 million, to address growth issues for these programs. PWS funding for this program has been increased from \$3.0 million in 2002/2003 to \$5.1 million in 2005/2006. For 2003/2004, Calgary reported a 9.2 percent increase in total therapy days on formula, and a 20.7 percent increase in program expenditure. Capital reported a 6.4 percent increase in total therapy days on formula, and a 19.9 percent increase in program expenditure. Improved technologies and increased use of disposable supplies have also added to the budget requirements over the years.

Please refer to the Special Feature Article on Home Enteral Nutrition in this report for additional information on current and future developments in the program.

### COMPRU

The Craniofacial Osseointegration and Maxillofacial Prosthetic Rehabilitation Unit (COMPRU), is located at the Misericordia Hospital in Edmonton. This program has established itself as a world leader in reconstruction and prosthetics for the neck and head region. The term 'osseointegration' refers to the mechanism by which certain prosthetics or devices are anchored directly to the bone. In 2002, the world-leading manufacturer of craniofacial implants selected COMPRU as the first recipient of its Centre of Excellence Award.

Province Wide Services only funds COMPRU's high-end osseo-integrated implant biotechnologies. The large funding increase from \$1.2 million in 2003/2004 (mostly bone anchored hearing aids) to \$1.9 million in 2004/2005, was intended to help cover COMPRU's intraoral osseointegrated implant care (mostly jaws) for head and neck cancer and complex trauma patients. These services help facially disfigured patients lead a normal life.

COMPRU's workload is escalating from the cumulative effect of maintaining previous

patients. Once an implant is surgically placed, both the implant and facial prosthesis attached to it must be maintained on a lifetime basis. COMPRU reported about 5.5 visits per week in 2003/2004, and about 17.3 continuing care (osseo and non-osseo integration) visits per week.

COMPRU also reported 47 new osseointegration Alberta patients (29 from Capital), with 26 of these being recipients of bone-anchored hearing aids. Wait times continue to be long. COMPRU reported 88 patients waiting for initial assessment at year end (April 1, 2004), with a wait time of up to five years, depending on the case type. For patients who have had a full work-up and are just waiting for an operating room to become available, the wait time for a bone anchored hearing aid improved to three months. However, there were also 53 extraoral and intraoral patients requiring a prosthesis retreatment with a wait time of 3-5 years.

For 2005/2006, PWS funding for COMPRU was set at \$1.9 million.

## **Children with Complex Health Needs (CCHN)**

For children heavily dependent on costly technology and/or the need for 24-hour caregivers, the traditional solution was to continue their care indefinitely in an intensive care hospital environment. This approach, if the patient is otherwise medically stable, is neither cost-effective nor ideal for the patient's quality of life and the lives of their family members. The CCHN program, under the supervision of the Pediatric Advisory Team (PAT), was developed to provide home-based services to these children with complex needs.

The members of the PAT team make decisions on a child-by-child basis as to their eligibility for CCHN funding, primarily on the basis of the safety and availability of all the necessary resources to provide adequate home-based care around the clock. A key factor in the application and ongoing approval for CCHN service provision is the partnership with parents, and especially the reinforcement of their role as the primary guardian and caregiver to their own child. The Calgary Health Region handles the administration of funding for the CCHN program and disperses necessary dollars to all health regions in the Province who are providing home care services to an approved child.

The number of children assisted by CCHN has increased from an average of just eleven children per month in 1997/1998, to an average of 51 children per month projected for 2005/2006. The number of funded cases continues to grow at a high rate, as technological advances continue to increase the survival rate of children with complex needs. One limiting factor to growth is the availability of trained care providers. The average cost per funded child month has grown from \$5,413 per child month in 1997/1998 to \$7,615 per child month projected for 2005/2006.

### **Pediatric Transport**

When a child is in need of emergency transportation beyond that available through standard ambulance services, the Pediatric Transport teams in Capital Health and Calgary Health Region are called in. Typically staffed by a nurse specialist, a respiratory therapist, and a pediatric emergency physician, the team is most often called in to safely transport a medically unstable child from an outlying hospital to one of the larger tertiary care facilities in Edmonton or Calgary. PWS funding of the teams is limited to transportation of children who are being brought in from outside of the immediate metro areas of Edmonton and Calgary. In 2003/2004, the team in Capital Health was called 105 times to assist with transporting a child from outside their own region, and approximately two-thirds of these trips involved the use of aircraft (helicopter or plane). In the same period, the Calgary team provided 109 trips, but state that they had to defer nearly 50 calls during the year due to the lack of availability of adequate staff.

The total funding for the Pediatric Transport teams for 2005/2006 is \$1.1 million.

## **PROVINCE WIDE SERVICES**

# **High Cost Drugs**

## **High Cost Drugs**

Province Wide Services funds a select group of high cost drugs, which are primarily in support of PWS programs. The highest drug expenditures are in the area of immunosuppression drugs for transplant patients and antiretroviral medications for patients living with HIV disease. Other medications included in this list are:

**Pulmozyme** – prescribed for patients with cystic fibrosis

Flolan/Tracleer – for patients with primary pulmonary hypertension

Human Growth Hormone – for children who are not growing due to hormone deficiency or who have chronic renal failure In addition to the drug costs themselves, there are additional distribution costs incurred by the outpatient pharmacies in Capital Health and Calgary Health Region to ensure that Albertans in every corner of the Province have a consistent supply of these life-saving therapies.

Table 7: PWS High Cost Drugs Expenditure Trend										
	CAPITAL				CALGARY					
	2001/2002	2002/2003	2003/2004	2005/2006	2001/2002	2002/2003	2003/2004	2005/2006		
	Actual	Actual	Actual	Funded	Actual	Actual	Actual	Funded		
Immunosuppressives	8,870,996	9,622,770	12,627,274	14,353,950	5,212,582	6,567,286	7,730,737	8,745,100		
HIV Antiretrovirals	4,938,938	5,027,673	5,972,378	8,097,500	5,320,529	5,583,256	6,056,740	7,753,200		
Pulmozyme	714,910	790,405	847,875	928,500	551,905	512,557	507,224	522,500		
Flolan/Tracleer/HGH	878,432	1,063,998	1,686,185	2,250,400	812,855	939,441	1,237,336	2,393,100		
Distribution Costs	307,695	335,191	475,159	351,750	365,088	370,000	239,717	351,750		
Total Drugs	15,710,971	16,840,037	21,608,871	25,982,100	12,262,959	13,972,540	15,771,754	19,765,650		
Source: CHR and CH Annual PWS reports, 2005/2006 PWS Budget										

## **Transplant Drugs**

Immunosuppression medications are critical to both the initial success and long-term viability of an organ, bone marrow, or islet cell transplant. The human body is incredibly sensitive to even the tiniest of foreign invaders like a flu virus or a sliver in ones finger, and mounts an immune response to try to get rid of it or minimize the damage it can do. After a transplant surgery, the potential for a similar immune response is equally high and can very quickly cause the body to reject the new organ or tissue because it is deemed to be a foreign body.

Transplant medications are a bit of a doubleedged sword and must be managed very closely by medical specialists to balance the protection the drugs provide to the transplanted organ with the increased patient susceptibility to other infections. Patients living with a transplant must undergo many blood tests in the months immediately following the transplant, and then continue with regular monitoring of lab work for the rest of their lives to ensure drug levels stay at an appropriate level and their transplant continues to function properly. These transplant medications are costly. Escalation of costs in this area is influenced by many factors, but a significant portion of the growth results from the sheer number of people added each year to the pool of people living successfully with transplants. The drug dosage required by transplant patients can often be reduced over the first year post-transplant, but they will require immunosuppression medication for the life of the new organ or tissue. In addition, new medications continue to be developed which, although more expensive than their predecessors, show tremendous promise in improving patient outcomes and the long-term live of the transplanted organ or tissue.

Transplant drug expenditures represent the fastest growing component of the Province Wide Services high cost drug budget, increasing at an average annual rate in excess of 14 percent. For 2003/2004, \$20.4 million of transplant drugs were provided to transplant patients, and increase of 25.7 percent from the previous year. Funding was increased to \$23.1 million for 2005/2006.



## **HIV Antiretroviral Drugs**

Antiretrovirals are intended to sustain the length and quality of life for patients whose HIV infection has caused their immune system to become suppressed or deactivated. An antiretroviral acts against 'retroviruses' such as HIV, which can alter a cell's DNA once it has infected it. An antiretroviral does not kill the virus, but slows down its spread. Although these medications are merely a treatment and not a cure for HIV and AIDS, as they neither kill the virus nor restore the lost function of the person's immune system, they do provide people living with the disease with much longer and healthier lives.

As the years of experience working with these medications increases, so does the understanding of the infectious disease experts. Through many drug studies and increased experience with patients, researchers have found that the best results are achieved when several drugs are administered together. For most patients undergoing therapy with antiretrovirals, they are prescribed a three-drug combination. For the patient, this can cause somewhat of a complex drug routine.

Despite the successful reduction in the number of new HIV cases seen each year, the improved outcomes for HIV patients from new drug therapies means there is an ever growing pool of people requiring the costly drug therapies. For 2003/2004, \$12.0 million of antiretrovirals were provided to 1,182 HIV patients, an increase of 13.3 percent from the previous year. Funding was increased to \$15.9 million for 2005/2006, a 25 percent increase.

## **PROVINCE WIDE SERVICES**

# **High Cost Devices**

## **High Cost Devices**

### **Cochlear Implants**

For profoundly deaf individuals who experience little or no benefit from standard hearing aids, the cochlear implant is a technological marvel. This tiny device, unlike a traditional hearing aid, actually has both an internal and external component. A hearing aid works solely by amplifying sound that is received by an external microphone. A cochlear implant receives the same signal by microphone but converts it into electrical impulses that are transmitted by wire to an electrode placed in the inner ear, which directly stimulates the hearing nerves. During 2003/2004, cochlear implants were provided to 33 Albertans – 14 David Thompson residents, 7 Calgary residents, 7 Capital residents, and 5 residents of other regions. For the young, this assistive device is particularly important to their educational and social development. Funding is approved for 36 implants in 2005/2006 at an average device cost of \$34,000.





### Cranioplasts

In rare cases where a child's skull is misshapen, a specialized headband can be used to correct the abnormal shape. This cranioplast can only be used during the period when the child is quite young and their skull plates are still malleable enough to allow for movement. In 2003/2004, 192 infants received cranioplasts funded by Province Wide Services – 153 for residents of Calgary, 26 for Capital residents, and 13 for children in other regions. For 2005/2006, funding for cranioplasty was significantly reduced.

## Implantable Cardioverter Defibrillators (ICDs)

The implantable cardioverter defibrillator (ICD) is a device, much like a highly advance pacemaker, that is implanted into the chest to monitor the heart rhythm for abnormalities and, if necessary, correct them. The device consists of a main battery unit that includes the pulse generator and one or more special wires (leads) that are threaded through blood vessels to the heart muscles. The ICD's internal batteries will typically last between 4 and 7 years, depending on how often it is required to discharge an electric impulse.

There are three key functions that an ICD can play in diagnosing and correcting heart rhythm abnormalities. The first function is to act as a continuous monitor of the heart's rhythm, and keep a log of any occurrences when the rhythm becomes erratic. This data can be downloaded to a computer and analyzed whenever the patient sees their doctor or clinic. The second function is called 'cardioversion', which is similar to the function of a pacemaker. When the ICD senses the heart is beating too quickly (tachycardia), or at an irregular rate, a small shock is used to reset the heart back to a more normal rate. The third function, and perhaps best known, is the ICD's ability to act as a defibrillator. When the device senses the heart has completely lost its rhythm and is merely quivering ineffectively, it is able to send a much stronger shock or series of shocks to the heart to attempt to restart a normal rhythm and head off the potential of sudden cardiac death.

Much research has been done over the last ten years on the types of patients that would benefit the most from receiving an ICD. Wide variances in insertion rates from country to country would suggest this new technology and its high cost are causing decision-makers to really look at the size of the patient population that could benefit from them.

In light of research evidence suggesting defibrillator use is low in Alberta, Province Wide Services increased funding for these devices in 2005/2006 by 85.2 percent. Calgary and Capital





## **PROVINCE WIDE SERVICES**

# **Other PWS Programs**

## **Other Province Wide Services**

### Rosehaven

Located in the city of Camrose, the Rosehaven Care Centre operates 100 beds with a mandate to provide behaviour management services for individuals who are not able to be served in their continuing care home because of psychiatric or behavioural issues. There are two components to the program: one focuses on the inpatient assessment and treatment for patients who need to be admitted to the Rosehaven facility for short or longer-term care, and the other is an outreach program to provide clinical and educational support to the continuing care system across Alberta. A great deal of effort is being put into expansion and promotion of the outreach component of Rosehaven's mandate, with the intent of enabling continuing care providers across the province to better manage the behavioural issues they encounter, and hopefully allow more long-term care residents to be treated in their home community. \$9.2 million was allocated to East Central Health for Rosehaven for 2005/2006, and increase of 11 percent from the previous year.



## **Visudyne Therapy**

Degeneration in the macular region of the eye is a common disease of persons over the age of fifty. "Wet" age-related macular degeneration (AMD), a less common type of AMD, involves the formation of weak blood vessels which leak fluid under the retina, leading to loss of vision. AMD is the leading cause of blindness in Canadians over the age of fifty.

Ocular photodynamic therapy utilizes the laseractivated drug Visudyne to restrict the deterioration of visual acuity in wet AMD patients who have the "classic" form – the only condition for which Visudyne treatment is currently approved by Health Canada. For 2003/2004, 461 Visudyne treatments were provided to residents of the Capital Health Region, 466 treatments to patients of the Calgary Health Region, and 498 treatments to residents of other regions.

For the 2005/2006 budget year, funding for Visudyne therapy was maintained at \$3.4 million (\$2,350 per treatment).



### Equipment

Some funding is provided to Calgary and Capital for Province Wide Services equipment above and beyond other sources of funding and the equipment amortization already included in the cost weights used in funding calculations. For the 2005/2006 fiscal year, \$2.0 million is allocated to each of Capital Health and the Calgary Health Region.

### **APPROACH**

The use of new technologies in cardiac care over the past two decades has resulted in the need for quality evaluations of the effectiveness and outcomes for the patients who receive them. The Alberta Provincial Project for Outcomes Assessment in Coronary Heart Disease (APPROACH) was developed by cardiac care specialists to collect data on all patients who undergo cardiac catheterization. Data is collected at all cardiac catheter labs in the Calgary Health Region and in Capital Health, and provides researchers and decision-makers with high-quality evidence that can be used to improve the care of patients with coronary artery disease. The chart below is based on APPROACH data and is just a small example of the types of indicators Province Wide Services is planning to use as part of its accountability and outcome reporting to the public in future years. This chart illustrates the rates per 100,000 population of angioplasty (PTCA) and cardiac bypass surgery (CABG) for residents of each health region in 2003. For next year's PWS Annual Report, it is intended that there will be cardiac indicators on waiting times, revascularization, implantable cardioverter defibrillators (ICDs), and complications (including deaths).

Annual funding of \$150,000 has been provided to support the APPROACH program.



**PROVINCE WIDE SERVICES** 

# **Appendices**

## APPENDIX A Province Wide Services Working Group (2003/2004)

Dr. Paul Greenwood, Chair Province Wide Services Working Group

Dr. Ken Gardener VP Medical Affairs Capital Health

Mr. Allaudin Merali Executive Vice President and Chief Financial Officer Capital Health

Dr. Robert V. Johnston Senior Vice President and Chief Medical Officer Calgary Health Region

Ms. Kay Best Executive Vice President, Risk Management and Chief Financial Officer Calgary Health Region

Mr. Bryan Judd Vice President and Chief Operating Officer, Corporate Services David Thompson Regional Health Authority

Mr. Bruce M. Perry Assistant Deputy Minister, Corporate Operations Division Alberta Health and Wellness

Mr. Tapan Chowdhury Director, Health Funding and Economics Branch Alberta Health and Wellness

Mr. Dennis Stang Acting Executive Director, Health Authority Funding and Financial Accountability Alberta Health and Wellness

Mr. Sean Delaney Manager, Province Wide Services, Health Funding and Economics Branch Alberta Health and Wellness

## APPENDIX B Province Wide Services Working Group Terms of Reference (Charter)

### **Overview and Purpose**

The Province Wide Services Working Group (PWSWG) advises/reports to the Deputy Minister of Alberta Health and Wellness (AHW). More specifically, the PWSWG monitors, evaluates, advises, recommends and advocates, in accordance with these terms of reference, on matters affecting the scope, priorities, budget, delivery and reporting for Province Wide Services.

### **Duties and Responsibilities**

### Charter/Workplan

- 1. Review PWSWG charter every August/September and make changes if necessary.
- Set workplan every August/September for determining PWS budget recommendations for the upcoming fiscal year, including ongoing identification and addressing of significant issues and risks for the delivery of Province Wide Services.
- 3. Set workplan every March/April for post-budget issues.
- 4. Review annually PWSWG sub-committees and their progress.
- 5. Review annually effectiveness of the PWSWG against the terms of reference.

### **Principles**

- 1. Review funding principles on an annual basis, and as need arises, including eligibility criteria for new PWS.
- 2. Update PWS Funding Procedures and Definitions Manual containing operational rules for determining the PWS budget every two years.
- 3. Review inpatient cost methodology.

### **Basket of Funded Services**

- Proposals for new PWS are submitted jointly by Capital Health (CH)/Calgary Health Region (CHR) (who are to collaborate in the optimal delivery of new PWS), or by AHW, to PWSWG for recommendation/consideration. Submissions for new proposals should be based on established templates.
- 2. PWSWG may request health technology assessments or Expert Committee on Drug Evaluation and Therapeutics review.
- 3. Consider potential deletions of PWS on an annual basis.
- 4. Review annually impact of inpatient grouper changes, and assess the need for changes to the basket of funded services.

### **PWS Budget**

- 1. Alberta Health and Wellness develops, in early Fall, a three year forecast of PWS funding requirements based on growth rates of macro budget drivers.
- AHW, with input from CH/CHR, develops initial PWS budget projections for upcoming fiscal year, on a line item basis, in accordance with established principles, by November, for review by PWSWG.
- 3. The PWSWG may appoint specialty task groups to address specific issues of a technical nature.
- 4. Where differences of opinion exist between PWSWG members on budget allocations, PWSWG chair makes final recommendation.
- 5. Budget recommendations of PWSWG are forwarded by chair to Deputy Minister in a letter reviewed by PWSWG. PWSWG chair will distinguish between recommendations of the Working Group and the Chair's own comments.
- 6. PWSWG sets final service priorities when informed by Alberta Health and Wellness of budget target. Final funding determination rests with government and Ministry.
- 7. On a post-budget basis, PWSWG shall advise of any additional mid-year funding pressures for PWS, as well as the allocation of any unallocated PWS funding or other matters of financial content.

### **Reporting (Financial Accountability)**

- CH/CHR reports to PWSWG annually, by mid-August, on PWS activities for the preceding fiscal year, according to established reporting templates and standardized definitions. Reporting templates for newly funded services are developed collaboratively between AHW, CH and CHR.
- 2. PWSWG reviews the financial and activity results of operations, analyzes information on significant variances, and provides appropriate reports.
- 3. Annual activities of the PWSWG are reflected in the PWS Annual Report developed by AHW and released after Budget Day. Annual Report distribution list includes all regional health authorities.

### **Outcomes (Medical Accountability)**

- 1. Continue to develop and implement annual reporting of key indicators of PWS health outcomes.
- 2. PWS outcomes are reflected in the PWS Annual Report.
- 3. PWS symposium on activities and outcomes held during May-June time period.
- 4. Annual review of preventative strategies.

### Communications

1. Develop communication strategies.

## Membership

Membership of the Working Group shall consist of:

- a chair (appointed by Alberta Health and Wellness)
- the Chief Financial Officer and Chief Medical Officer of Capital Health and the Calgary Health Region
- a non-Capital/Calgary RHA representative (appointed by Council of CEOs)
- the Assistant Deputy Minister of Finance and Corporate Services
- support staff from Alberta Health and Wellness

### **Meetings**

- 1. PWSWG meets on a regular basis, with a minimum of four (4) meetings a year. Meeting dates determined by PWSWG Chair in consultation with AHW, CH and CHR.
- 2. A provisional meeting agenda is determined by PWSWG Chair in consultation with AHW, and distributed prior to meetings. AHW support is responsible for delivery of notices, agendas and available related materials to the PWSWG prior to meetings. Any PWSWG member may add additional agenda items or suggest changes.
- 3. Alternates are allowed for PWSWG members at meetings.
- 4. Meeting minutes are developed by AHW and circulated to all PWSWG members, who can suggest revisions. At the next meeting the minutes are submitted for approval. Final minutes are provided to the Deputy Minister.

January 2004



## APPENDIX C Province Wide Services 2005/2006 Budget

	CAPITAL	CALGARY	TOTAL
INPATIENT SERVICES	146,248,018	126,298,235	272,546,253
Neurosurgery Physician Payment	1,000,000	1,000,000	2,000,000
Inpatient Services	145,248,018	125,298,235	270,546,253
CLINICS & HOME SERVICES	81,929,626	82,536,471	164,466,097
Renal Program	51,190,126	49,036,471	100,226,597
Dialysis Delay / Prevention	1,500,000	1,650,000	3,150,000
Pre and Post Transplant	8,200,000	8,200,000	16,400,000
Islet Cell Transplantation	1,968,300	0	1,968,300
Medical Genetics	8,600,000	9,000,000	17,600,000
HIV Clinics	1,478,400	1,740,400	3,218,800
PADIS	0	2,881,500	2,881,500
COMPRU (osseointegration)	1,946,100	0	1,946,100
Home Enteral Nutritional Therapy	3,029,100	2,352,500	5,381,600
Pediatric Transport	821,500	261,400	1,082,900
1-800 AIDS Hotline	149,000	0	149,000
Education Centre	0	685,000	685,000
STD/TB Clinics	1,200,000	1,150,000	2,350,000
Visudyne Therapy	1,847,100	1,679,200	3,526,300
Children w/Complex Health Needs	0	3,900,000	3,900,000
HIGH COST DRUGS	25,982,100	19,765,650	45,747,750
Transplant Drugs	14,353,950	8,745,100	23,099,050
HIV Drugs	8,097,500	7,753,200	15,850,700
Pulmozyne	928,500	522,500	1,451,000
Human Growth Hormone	552,700	672,700	1,225,400
Flolan/Tracleer	1,697,700	1,720,400	3,418,100
Distribution costs	351,750	351,750	703,500
HIGH COST DEVICES	6,107,600	5,909,300	12,016,900
Implantable Cardiac Defibrillators	5,376,000	5,376,000	10,752,000
Cranioplasty	61,600	30,800	92,400
Cochlear Implants	670,000	502,500	1,172,500
EQUIPMENT	2,000,000	2,000,000	4,000,000
APPROACH	0	150,000	150,000
ROSEHAVEN (East Central)	0	0	9,200,000
UNALLOCATED FUNDS*	450,000	250,000	700,000
TOTAL PWS	262,717,344	236,909,656	508,827,000