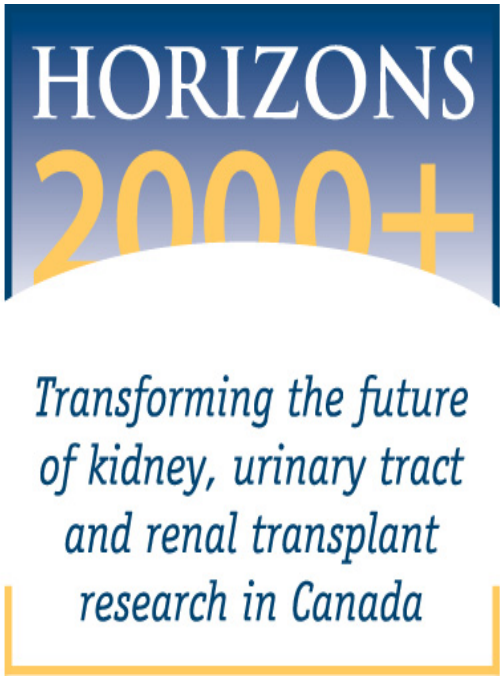

Consensus Conference
November 13-15, 1999
Toronto

FINAL REPORT

1. INTRODUCTION

Kidney and genitourinary (GU) disease represent a significant health care burden and contribute to accelerating health costs in Canada. In 1998, the direct cost of treating kidney failure with dialysis was $1.2 billion[1]. The number of Canadians on dialysis has increased by 10-12% per year over the last 10 years. At this rate, by the year 2005 the cost of dialysis will exceed $2.1 billion. Kidney failure affects all age groups from infants to the elderly. Diabetes is the leading cause of kidney failure (30-40%) and the incidence is highest among Aboriginal Canadians and those over 65 years of age. Although kidney transplantation is the most cost-effective treatment for kidney failure and provides a higher quality of life than chronic dialysis, the rate of organ donation in Canada for kidney transplantation is well below all other G-7 countries. Following kidney transplantation, chronic rejection, cardiovascular disease and increased cancer rates due to immunosupression are the major causes of morbidity and mortality.

Prevention and early intervention related to kidney and GU disease are the key strategies for reducing the current and future disease burden. Discovery of basic disease mechanisms is necessary for the development of new diagnostic tools and therapies. Clinical evaluative and health services research are critical for effective primary and secondary prevention. Targeted research, both basic and clinical, in diabetic nephropathy, transplant rejection and GU cancer may have the highest impact on disease prevention. Transformation will require a national commitment of all stakeholders to substantially increase, integrate and target research on prevention.

[1] Cost derived from national prevalence data from the Canadian Institute for Health Information (CIHI) and the average cost of dialysis of $50,000/patient/year (Ontario Ministry of Health).

2. OVERVIEW OF THE NATIONAL CONSENSUS CONFERENCE

Background and Rationale

Research in the fields of kidney disease, urinary tract disease and kidney transplantation is currently funded by the KFoC, Medical Research Council of Canada (MRC), industry and by universities throughout Canada. The KFoC has played a pivotal role in establishing and sustaining the research programs of many investigators, particularly as funding from the MRC declined over the last decade. The advent of the CIHR brings new hope for significantly improved research funding from the federal government.

Two important events served as catalysts for the organization of this conference. The first was the extensive review of the KFoC research program, completed in June 1999. The second was the creation of the CIHR Opportunities Fund by the MRC providing a unique opportunity for groups of Canadian investigators to apply for support of planning initiatives to focus on the mission of the CIHR in the context of their fields of research. With the strong administrative and financial support of the KFoC and full backing from their professional organizations, a group of investigators in nephrology, urology and kidney transplantation submitted a proposal to the MRC for funding of a national conference. The principal goal was to build consensus among research stakeholders about strategies to *transform the future of kidney/genitourinary/kidney transplant research in Canada*. Successful funding through peer-review at the MRC strongly endorsed the goal of the conference.

Participants and Process

The purpose of this 2-day conference was to assemble, for the first time, all the stakeholders in K/GU/KT research in Canada. This conference was organized in response to the emergence of the CIHR and the potential opportunity to engage in research priority planning.

The planning committee included scientists from across Canada in full partnership with the KFoC, Canadian Society of Nephrology (CSN), Canadian Association of Pediatric Nephrologists (CAPN), Canadian Urological Association (CUA), CUA Scholarship Foundation, and 12 industries (AMGEN, AstraZeneca, Baxter, Bristol-Myers Squibb, Fresenius Medical Care Canada, Fujisawa, Janssen-Ortho, Novartis, Hoffmann-La Roche, Pfizer, Sangstat, Wyeth-Ayerst).

The conference was funded jointly by the MRC, KFoC and industry. The participants included: 6 Allied Health Investigators; 45 MD, or MD/PhD investigators; 5 PhD investigators; Presidents of the KFoC, CSN, CAPN and CUA; representatives of the KFoC National Executive and all Provincial Branches; 12 industry representatives; 12 professional facilitators; representatives from the MRC, Canadian Diabetes Association (CDA), Heart and Stroke Foundation of Canada (HSFC); and, representatives from Provincial Ministries of Health.

HORIZONS 2000+

Dr. Henry Friesen, President of the MRC, addressed the participants describing the evolution and planning status of the CIHR. The current needs for K/GU/KT research were presented by Dr. Phil Halloran (Kidney Transplant Clinician-Scientist, University of Alberta), Dr. Rosalie Starzomski

(Allied Health Investigator, University of Victoria); Marcia Bell (Past-President of the KFoC - representing Canadians with kidney/GU disease and kidney transplants); and, Murray Elston (President, Canada's Research-Based Pharmaceutical Rx&D - representing industry).

The participants were divided into 5 working groups based on research expertise and personal interest, representing the entire spectrum of K/GU/KT research:

a) Molecular/Genetic/Physiological Mechanisms of Disease;
b) Kidney Transplantation;
c) Genitourinary (GU) Disease - basic and clinical;
d) Clinical and Evaluative Outcomes; and,
e) Health Services, Economics and Policy.

These groups worked together in successive breakout sessions (10 per group) lead by professional facilitators and aided by specific content facilitators, to establish critical factors for success in K/GU/KT-related research, to prioritize outcomes and to propose strategies to achieve these outcomes in the next 5 years.

Consensor technology was then used to address key questions about recommendations arising from all the groups and specific questions from each group and revealed that:

- 97% of the participants believed that a National Strategy to secure the future of K/GU/KT research in Canada was absolutely necessary or important;
- 86% believed it important to recognize the significant disease burden by recommending specific representation of K/GU/KT research in a CIHR institute;
- the number one priority for enhancing K/GU/KT research was felt by 92% of participants to be a significant increase in funding and facilitation of researcher interaction;
- the majority of participants (61%) felt that a realistic guideline for federal support of K/GU/KT research is to link funding to burden of disease; and,
- alternative benchmarks included linkage to international comparisons, e.g., USA (22%), or to Canada's gross national product (17%).

The Horizons 2000+ conference was formally evaluated by the participants (Appendix A) and, overall, the process was highly rated.

3. SUMMARY OF KEY RECOMMENDATIONS

General recommendations

HORIZONS 2000+

Health research in Canada will be ***transforming*** if it has a significant impact on the burden of disease. We recommend that transformative research in kidney(K)/ genitourinary (GU) disease and kidney transplantation(KT) be promoted by the formation of a **K/GU/KT Research Alliance**

with public, investigator, professional, academic, governmental and industry representation to advocate for:

- **enhanced research capacity** through significant increase in number of investigators, funding and infrastructure;

- a **National K/GU/KT Research Strategy**; and,

- **strong K/GU/KT representation in a CIHR institute** uniquely able to direct and provide relevant peer-review of research efforts toward the improved kidney and urological health of Canadians.

The community of investigators and The Kidney Foundation of Canada (KFoC) are committed and well positioned to act on these recommendations. We propose implementation as a demonstration of multidisciplinary alignment of investigators within the CIHR.

Specific recommendations from the working groups

Molecular/Genomic/Physiological Mechanisms of Disease

- Establish a national research training program in molecular/genomic/physiological kidney disease mechanisms for MDs and PhDs throughout Canada funded jointly through partnerships among CIHR, KFoC and industry.
- Ensure that the composition of the CIHR peer review committee handling K/GU/KT-related applications has at least 40-50% representation by experts in this field.
- Establish a national alliance of stakeholders with the mandate of: promoting committed leadership for integrated and collaborative research (including molecular/genetic/physiologic) across Canada; educating the public and Members of Parliament; and, providing membership on the CIHR Institute Boards.

Kidney Transplantation

- Seek CIHR Chairs in Renal Transplantation and target research funding to reflect the magnitude of the clinical problem and promote cost savings of successful kidney transplantation.
- Partner CIHR, KFoC and industry for research fellowship and investigator awards to be directed to research in kidney transplantation.
- Align with CIHR institutes serving kidney/GU and immunology/transplantation.
- Aggressively target recruitment of new investigators (MDs, PhDs and Allied Health professionals) to address organ donation rates, ischemic injury, xenotransplantation, chronic rejection, comorbidity including vascular injury and quality of life.
- Increase research funding from all sources and promote partnering with industry.

Genitourinary (GU) Research - basic and clinical

- Form a national alliance of stakeholders with the mandate to "improve kidney/GU health of Canadians through research" by proactive education of the public and Members of Parliament, and by forming alliances with other organizations, e.g., Canadian Prostate Cancer Alliance.
- Ensure representation of urology researchers on CIHR peer review panels and Institute Boards.
- Develop a national database of GU disease for access by clinical and health services investigators that will provide accurate information for promotion of public and political awareness.

Clinical and Evaluative Outcomes

- Establish a national network of Clinical Investigators to develop Clinical Research Units and Centers of Excellence for Data Management and Biostatistics.
- Significantly increase the number of investigators and funding (one-half of 1% of spending on K/GU disease) through:

- an effective national advocacy and public awareness strategy spearheaded by an alliance of stakeholders;
- national recruitment, mentoring and full funding of new investigators; and
- guaranteed career support for established and future investigators.

Health Services, Economics and Policy

- Build capacity in health services and economics research by:

- recruiting new investigators both fromwithin and outside the disciplines of K/GU/KT investigation;
- significantly increasing targeted funds; and
- by establishing national partnerships within the CIHR.

- Expand the national database to include information relevant for clinical outcomes and health services and economics research, funded by national stakeholders.

4. REPORTS AND RECOMMENDATIONS OF THE INDIVIDUAL WORKING GROUPS

4.1 Immediate report to the Interim Governing Council of the CIHR

The MRC required a 5-page report summarizing the utilization of the Opportunities Fund grant. This report was prepared by the Organizing Committee, circulated in draft form to all the working group leaders, and finalized by Dec 10, 1999. This report was forwarded

to the MRC (Henry Friesen, Mark Bisby) and all members of the Interim Governing Council of the CIHR. It was distributed to all participants of Horizons 2000+ conference and to the KFoC National Executive Committee. The members of the Organizing Committee were requested to circulate the 5 page report within their own universities, particularly to chief administrators who influence research directions and local funding.

4.2 Request by the CIHR Interim Governing Council to recommend the list of CIHR Institutes

The recipients of the MRC awards from the CIHR Opportunities Fund were invited to submit a recommendation for the list of CIHR Institute names in January 2000. Recommendations were also invited from the major research Universities in Canada. The Conference Organization Committee obtained the working lists from many of the Universities and discovered that the majority listed "kidney" or "renal" with other groups of similar size, e.g., diabetes, gastrointestinal. The recommendation submitted by our group strongly emphasized the need to have K/GU/KT in the name of an institute or institutes and chose the following slate of CIHR names with our groups listed with logical partners based on research fields and current size of these research efforts in Canada :

- *Cancer*
- *Neurosciences and Mental Health*
- *Immunology, Transplantation (including **Kidney Transplantation**) and Infectious Disease*
- *Heart and Lung*
- ***Kidney/Urinary Tract**, Diabetes, Hormones, Nutrition and Digestive System*
- *Arthritis and Musculoskeletal System*
- *Genetics and Development*
- *Aging*
- *Child and Maternal Health*
- *Population Health and Health Systems*

4.3 Final reports of the working groups

Following the conference the content facilitators prepared a detailed summary of the discussions and recommendations for each of the 5 working groups. The next section provides the names and affiliations of the participants, the full reports and the final recommendations of each group.