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INTRODUCTION

Each year, as called for in the 1999 Memorandum of Understanding establishing the Ireland-Northern Ireland-National Cancer Institute Cancer Consortium, the Board of Directors of the Consortium delivers an annual report to account for the progress made toward fulfilling its mandate. That mandate is an ambitious one—to engage the cancer communities of the United States, Ireland, and Northern Ireland in enhancing the island of Ireland’s ability to conduct world-class cancer clinical research and thereby improve cancer care and treatment for the people in all of Ireland. A secondary, but equally important, goal is to encourage collaboration between the governments of Ireland and Northern Ireland through joint programmes in the area of health care, as called for in the Good Friday Peace Accord of 1998.

The Consortium endeavors to accomplish these goals through a robust scholar exchange programme among all three partnering jurisdictions, information technology sharing, cancer registry data harmonisation, and the establishment of a network of hospitals in Northern Ireland and Ireland to conduct joint clinical trials. This report covers activities in those areas from July 2001 through December 2002. Future reports will cover Consortium activities during twelve-month calendar year periods.

The report is provided directly to the Ministers of the Department of Health and Children of Ireland, and of the Department of Health, Social Services and Public Safety of Northern Ireland, and the Secretary of the Department of Health and Human Services of the United States. This document is also meant to inform the research community, policymakers, and anyone else interested in the friendly collaboration among nations in the fight against cancer. We provide this annual report in the hope that all who read it will be inspired by the remarkable progress that can be made when people work together toward defeating a common enemy—such as cancer—that knows no political or geographic boundaries.

MESSAGE FROM THE DIRECTORS

The second year of the Ireland-Northern Ireland-National Cancer Institute Cancer Consortium was one of impressive progress toward implementing the major programmes set forth when we established this unique partnership in 1999. Our goals then were ambitious—even daunting—but it was our hope that the results would bolster the island up in the ranks of its European peers in the ability to provide world-class cancer care to its people. We set out to accomplish this by utilising the vast biomedical research expertise and resources of the U.S. National Cancer Institute and by relying on the firm commitment and collaboration of the health departments of Ireland and Northern Ireland.

No one could have predicted whether bringing three governments together in this manner would work or anticipated the opportunities or obstacles we would encounter as we moved forward. After an initial year of foundation-building, the pace and intensity with which the Consortium has made progress this year continued to amaze us. We are delighted to report that for the period of 2001-2002, the Consortium has in place several tangible initiatives in each of the four major areas—scholar exchange, clinical trials network, information technology sharing, and cancer registry collaboration.

In 2001 and 2002, the Consortium sponsored cancer research training for 43 scholars from Ireland and Northern Ireland. Seven nurses, two epidemiology fellows, and 34 specialists from a variety of disciplines working in cancer prevention on the island trained at the National Cancer Institute on the campus of the United States' National Institutes of Health (NIH) in Bethesda, Maryland.

This year marked a major breakthrough in establishing a clinical trials network in Ireland. This was a critical and time-consuming undertaking, handled adroitly by Ireland's Health Research Board. Under this initiative, Ireland awarded government funding for the first time to nine hospitals to build their capacity to conduct cancer clinical trials. The Irish network will work with Belfast City Hospital and the NCI in conducting joint clinical trials that will benefit the entire island.

In the area of information technology sharing, Belfast City Hospital and St. Luke's Hospital in Dublin achieved full implementation of TELESYNERGY®—a multimedia medical-imaging workstation that enables scientists in multiple laboratories and in multiple locations to interact simultaneously with one another. We are excited about the application of this new technology, which marks the first time it has been installed outside the United States.

After the publication of the first *All-Ireland Cancer Statistics Report*, the Consortium is now sponsoring an all-Ireland case-control study of oesophageal adenocarcinoma and Barrett's oesophagus—a nonmalignant precursor. The report found this cancer to be prevalent on the island of Ireland but poorly understood. The study, known as FINBAR (Factors Influencing Barrett's Adenocarcinoma Relationships), will make use of 10 years of data housed at the Northern Ireland Cancer Registry and is funded by a cross-border grant from the Health Research Board in Dublin and the Research and Development Office in Belfast. It is anticipated that the study will shed light on the apparent increase in oesophageal adenocarcinoma and the determinants of progression to malignancy on the island.

In 2001, the Consortium experienced our first change in leadership among the Board of Directors. In September, we learned of the resignation from NCI and the Consortium Board of our friend and colleague, NCI Director Richard Klausner. Dr. Klausner lent vision, passion, and generosity to the Consortium since its formation, and we deeply appreciate his contributions.

While this year was marked with great achievements, we still have much ground to cover before realising our ultimate goals. We continue to address key issues such as retaining our trained personnel on the island, bringing Ireland's hospital system up to today's standards to conduct clinical trials, and making clinical research a higher priority.

No summary of 2001 would be complete without reflecting on the terrorist attacks of September 11 because indeed they touched us all. The people of the United States and Ireland have a special bond that goes back generations and is as strong as ever. The attacks on our freedom are all the more reason to embrace an initiative such as this, which strives to bring people together in peace toward improving the lives of all.

The theme of this year's annual report is unity. In this report, we celebrate the people who are involved early on in this unique undertaking and who will help bring us a brighter future.

On behalf of the entire Consortium, Henrietta Campbell and James Kiely extend a warm welcome to our new Board member, Andrew von Eschenbach.



Appointed as NCI Director in early 2002, Dr. von Eschenbach is a recognized leader in the challenge to understand cancer and thus improve the care and treatment of people with cancer. Dr. von Eschenbach looks forward to contributing to the Consortium's worthy goals with colleagues from the North and South of Ireland as well as the States.

A long-time leader in the battle against cancer, Dr. von Eschenbach comes to NCI from The University of Texas M. D. Anderson Cancer Center in Houston, where he was Director of the Genitourinary Cancer Center and Director of the Prostate Cancer Research Program. He has also served as Vice President for Academic Affairs at M. D. Anderson and as Executive Vice President and Chief Academic Officer, leading a faculty of almost 1,000 cancer researchers and clinicians. Dr. von Eschenbach has contributed more than 200 articles, books, and chapters to the scientific literature. He is an editorial board member of four leading journals and serves on the board for the National Coalition for Cancer Research. He was a founding member and leader of the National Dialogue on Cancer and, before his appointment as NCI Director, was President-elect of the American Cancer Society.

Dr. James Kiely
Chief Medical Officer
Department of Health and Children
Ireland

Dr. Henrietta Campbell
Chief Medical Officer
Department of Health,
Social Services and Public Safety
Northern Ireland

Dr. Andrew von Eschenbach
Director
National Cancer Institute
United States



HIGHLIGHTS OF PROGRESS: 2001-2002

JULY 2001

NCI hosts Northern Ireland Health Minister

- The Honorable Bairbre de Brún, Minister of Health, Social Services and Public Safety for Northern Ireland, visits NCI

OCTOBER 2001

Annual report

- Consortium publishes its first annual report

DECEMBER 2001

Prevention Working Group established

FEBRUARY 2002

All-Island Cancer Clinical Trials Cooperative Group

- HRB and R&D Office invite ICORG and CRSC to submit joint application to form cooperative group

AUGUST 2001

NCI Summer Curriculum in Cancer Prevention

- First Consortium-funded participants complete NCI Cancer Prevention coursework

NOVEMBER 2001

Cancer clinical research centre awards

- Health Research Board in Dublin announces first awards to hospitals to develop cancer clinical trials capacity
 - Major awards: St. Vincent's University Hospital/St. Luke's Hospital, Dublin; University College Hospital, Galway; Cork University Hospital; Beaumont Hospital, Dublin
 - Planning grants: Limerick Regional Hospital and Mater Misericordiae Hospital, Dublin

JANUARY 2002

New Board of Directors member

- Consortium welcomes new NCI Director Andrew von Eschenbach

Cancer clinical research

- HRB initiates new call for cancer clinical trials development proposals



MAY 2002

First Prevention Working Group meeting, Dublin

- Identifies establishment of cancer prevention fellowship programme as a priority
- Begins formulating initiatives and planning workshops to address prevention of specific cancers

Nursing Working Group Information Day, Dublin

- Showcases Consortium training opportunities

JULY 2002

Palliative care

- Irish delegation attends NIH conference

NOVEMBER 2002

TELESYNERGY®

- Three-way demonstration at St. Luke's Hospital in Dublin launches telemedicine efforts

APRIL 2002

- Belfast City Hospital and St. Luke's Hospital in Dublin form joint clinical users' group as 'TELESYNERGY®' implementation continues
- Launch of Consortium-sponsored all-Ireland case-control study of oesophageal adenocarcinoma and Barrett's oesophagus

Clinical trials training

- Three Irish oncology nurses complete clinical trials training programme at NCI

JUNE 2002

Epidemiology fellowships

- First epidemiology fellows complete year of postdoctoral study in cancer epidemiology at NCI, and return to Northern Ireland and Ireland, respectively, for remaining two years of fellowships

All-Island Cooperative Group

- Panel begins review of ICORG and CRSC application for cooperative group

Clinical trials

- Awards to St. James's Hospital and Mater Misericordiae Hospital
- Planning grants to Adelaide and Meathe Hospitals

OCTOBER 2002

Clinical trials training

- Second round of Irish nurses begin clinical trials training at NCI

Cancer Care 2002 Ireland

- Consortium co-sponsors conference at Waterfront Hall in Belfast

ORIGINS OF THE CONSORTIUM

A Sign of Good Things to Come

The Ireland-Northern Ireland-National Cancer Institute Cancer Consortium was established with high hopes at a ceremony at Northern Ireland's Stormont Parliament Buildings in Belfast in October 1999. The goal of the Consortium was to dramatically enhance cancer research and care across the island of Ireland. The ceremony, attended by more than 200 oncologists, cancer researchers, and government and business officials from the three partnering countries, featured the signing of the Memorandum of Understanding (MOU) by the Health Ministers of Ireland, Northern Ireland, and the United States.

Speaking at the ceremony, former U.S. Senator George Mitchell, who chaired the talks the previous year that led to the Good Friday Agreement in Northern Ireland, praised the MOU, saying the cooperation at the core of the Consortium is a model for political progress on the island. "The people of Northern Ireland deserve a better future, a more stable political and social environment free from violence and despair," he told his audience. "It is not my intention to politicise this or to implicate other areas except to express the hope that when you work together you can do things that you might not be able to do separately." The Good Friday Agreement called for the establishment of a North-South ministerial council and implementation bodies to ensure its success. "This is a good example of the kind of area where cooperation can be mutually beneficial," he said.

George Howarth, former Northern Ireland Health Minister, welcomed the development, saying, "We are certain the outstanding collaboration will benefit us all." Ireland's

Health Minister at the time, Brian Cowen, described the agreement as "a significant step in developing further a cooperative approach to the fight against cancer."

Richard Klausner, NCI Director from 1996 to 2001, said the potential for the agreement "is tremendous. We hope the Consortium sparks a spirit of cooperation in the global quest for a cure for cancer and serves as a model for how countries can work together to improve the quality of life for all their people." He added that, with the agreement signed, the proof of the Consortium's intentions "lies in the work we have ahead of us."

The signing ceremony was covered prominently in the newspapers and broadcasts of the Irish and U.K. news media. It came as hundreds of cancer specialists from Ireland, the United States, Europe, and around the world arrived in Belfast for a three-day cancer conference, the first initiative of the new Consortium and one of the largest of its kind in Europe.

Early Concepts: A Vision Rooted in Friendship

The Consortium was the brainchild of a number of individuals in the Irish and U.S. cancer research communities, many of whom trained and worked together at NCI, including Patrick Johnston, now the Director of the cancer centre at Belfast City Hospital. At the core of their vision was the desire to radically change the state of cancer care on the island of Ireland, where cancer rates are among the highest in the Western world. Cancer is the second biggest killer in Ireland and is set to overtake heart disease as the number one killer in the North. Over time, this group of colleagues took their idea of a collaborative partnership between the three

FUNDING OF CONSORTIUM INITIATIVES

Each partner country directly funds its share of each programme established under the Consortium. Members of the Board of Directors present initiatives to their respective governments for approval and subsequent allocation of funds. Programmes considered for funding must fall within the areas of scholar exchange, information technology, clinical trials, or cancer registries, as identified in the Memorandum of Understanding. Projects must be consistent with policies and strategic cancer plans of the health departments of the partners. Finally, projects must demonstrate benefits to cancer care and research in the three jurisdictions, or serve as a pilot project in one jurisdiction to demonstrate potential for wider applicability.

In 2001 and 2002, the health departments of Ireland and Northern Ireland committed funds in the following areas:

- Palliative care—to underwrite costs for Irish delegation to attend major NIH conference
- Scholar exchange—to support a nurses' clinical research programme, prevention course, and epidemiology fellowships
- Clinical trials network—to fund nine hospitals to develop the capacity for clinical trials
- Information technology—to implement a uniform patient data collection system and TELESYNERGY®
- Cancer registries—to harmonise data systems and spur new epidemiology research

In addition, the National Cancer Institute provided in-kind expenses, travel support, and on-site expenses for information technology installation and scholar exchange programmes.

STATE OF CANCER/ HEALTH SERVICE ON THE ISLAND

Ireland

Hospital care for patients with cancer is free at the point of delivery in Ireland apart from nominal initial charges for some. Patients can, however, insure for private care. Although 40 percent of the 3.9 million Irish citizens have private health insurance, the majority of patients with cancer (more than 80 percent) receive care within the public hospital system. Practically all care is provided within the country.

There are two publicly funded radiotherapy centers—one in Dublin at St. Luke's Hospital and one at Cork University Hospital—and two smaller private centres in Dublin. Currently, plans exist to expand services to include two or perhaps three regional centres, pending a report from the Radiotherapy Review Committee.

Cancer screening programmes are currently limited and evolving. A population-based breast screening programme, Breast-Check, has been offered since 2000 to women aged 50 to 64 years and is currently available to about 50 percent of this population. A cervical screening programme is also being developed and will be piloted in one health-board area. The National Cancer Forum is currently examining screening for colorectal and prostate cancer.

Two major reports will be available shortly—one on palliative care and one on radiotherapy services. These, along with the major initiatives undertaken in the wake of the National Strategy for Cancer Services launched in 1997, will serve as a template for the further development of services for cancer patients in coming years.

There has been a significant increase in medical oncology appointments in the past

four years, with the complement of oncologists increasing from 4 to a total of 18. This has led to additional posts in Dublin, Cork, and Galway, as well as new posts in Letterkenny, Sligo, Limerick, Tullamore, and Waterford.

Northern Ireland

In Northern Ireland, health care is free at the point of delivery. The population of Northern Ireland is approximately 1.7 million, and the population's health services are organised within the National Health Service system. Northern Ireland has four Health and Social Services boards, and a regional Department of Health, Social Services and Public Safety. All residents are registered with a general practitioner that, apart from accidents and emergencies, is the first point of call when a patient has health concerns. Northern Ireland has a relatively small private health care market that represents less than 10 percent of the overall population.

Screening programmes such as population-based breast screening have been offered to all women aged 50-64 since 1993, and population-based cervical screening has been available to all women over the age of 20 since the late 1980s. Discussions are currently under way to consider screening for colorectal cancer and prostate cancer.

Since 1996, cancer clinical services have been significantly reorganised in Northern Ireland following the release of *Cancer Services: Investing for the Future*, also known as the Campbell Report. This report acted as the major catalyst for the redevelopment of cancer services in Northern Ireland and has now resulted in the development of a cancer centre for Northern Ireland at Belfast City Hospital, as well as the opening of four

regional cancer units in Altnagelvin, Antrim, Ulster, and Craigavon Hospitals. The goals of this new cancer clinical service are to coordinate cancer treatment, prevention, screening, education, training, and research programmes throughout Northern Ireland, and to provide a patient-centred service.

Moreover, the construction of the new £60 million cancer centre at Belfast City Hospital is under way, with the facility expected to open in 2005. There are now multidisciplinary specialist cancer teams for each of the major disease subsites in the cancer units and the cancer centre, and integrated patient care pathways are being developed. Day hospital therapy has now become the norm in each of the hospitals, and cancer clinical trials are coordinated through the Clinical Trials Unit within the cancer centre funded by the Department of Health, Social Services and Public Safety. These recent changes have already resulted in a significant improvement in cancer services for people in Northern Ireland. These improvements will increasingly be underpinned by high-quality clinical research and teaching, and a quality patient-centred environment where clinical services are geared towards the needs of the patient.

YEAR IN REVIEW: OUR PROGRAMMES IN PRACTICE

Clinical Trials Network

Scholar Exchange and Training

Cancer Registries

Information Technology Sharing

Nursing

Prevention

Clinical Trials Network

Background

As outlined in the Memorandum of Understanding in 1999, the overarching goal of the Consortium is to foster the provision of better prevention, early detection, and treatment of cancer for all people on the island of Ireland. A key part of achieving this goal involves enabling people with cancer to gain access to clinical trials—the study of the cancer process in humans and the assessment of the effectiveness and toxicity of cancer treatments.

Clinical trials are an essential part of developing better cancer preventive and therapeutic strategies, and are generally acknowledged worldwide as the optimal way to advance cancer care at the bedside.

Clinical trials also play the added role of ensuring uniformity of practise and can even lead to improvements in practise. Thus, as clinical trials become the global standard for effective cancer prevention and care, it is of paramount importance that the island of Ireland enter the mainstream of cancer clinical care by enhancing its abilities to conduct trials, and thus improve patients' access to new therapies.

To facilitate all-island participation in trials and to compete for trials on an international level, the Consortium has started organising a network of hospitals and cancer centres in Ireland and Northern Ireland to build capacity in cancer clinical research. The network, which will be organised through a coordinating body, will involve the Belfast City Hospital Cancer Centre in Northern Ireland and a number of hospitals in Ireland.

Because of the relatively small population on the island (approximately 5.4 million people in Ireland and Northern Ireland combined), it is essential that the two jurisdictions

collaborate with one another and with the United States and other countries in order to create a pool of participants large enough to generate meaningful findings. To participate in multi-centre clinical trials, organisations must demonstrate the requisite sophistication to recruit suitable patient populations, administer the complex therapies, and track the huge volumes of data.

With a robust, all-island clinical trials network that will enhance cancer care as the major goal of the Consortium, all major programmes outlined in the Memorandum of Understanding—enhancement of information technology, sharing of cancer registry data, and scholar exchange—become the building blocks that will enable the network to flourish.

Five years ago, the Northern Ireland Department of Health, Social Services and Public Safety began an effort to restructure cancer services to enhance its clinical research abilities, resulting in a coordinated clinical services programme that includes an integrated regional clinical trials network and a basic cancer research programme.

Under the Campbell Commission, led by Chief Medical Officer Henrietta Campbell, Northern Ireland now has a cancer centre based at Belfast City Hospital and one cancer unit in each of the country's four regional health boards (Altnagelvin, Antrim, Ulster, and Craigavon Hospitals. Belfast City Hospital serves as the coordinating hub of this activity, providing a setting for support and interaction of the research staff, which includes data managers, administrative staff, a research radiographer, and seven clinical research nurses. Under the direction of Patrick Johnston, an NCI-trained oncologist and Professor of Oncology at the Queen's University Belfast, Belfast City Hospital and neighboring Belvoir Park Hospital have opened 50 phase I, phase II, and phase III

clinical trials to patients. These trials involve chemotherapy, vaccine therapy, radiotherapy, and surgery.

In Ireland, despite the major initiatives undertaken under the National Strategy for Cancer Services, cancer care is less centralised and the development of true tertiary care centres has not occurred, especially in the Eastern region. Cancer care takes place mainly at the major academic teaching hospitals in Dublin, Cork, and Galway, regional and county hospitals, and St. Luke's Hospital, Dublin, which functions as a major radiotherapy centre with a national remit. The majority of paediatric cancer care takes place at or is coordinated by the unit at Our Lady's Hospital in Dublin. The report *Cancer Services in Ireland: A National Strategy*, developed in 1996 by the Department of Health and Children, identified organisational issues and personnel shortages as major limiting factors towards full participation by Ireland's hospitals in clinical trials. It was recommended that these deficiencies be corrected by the reorganisation of cancer services and the development of a coordinated approach to clinical research, including clinical trials.

The establishment of the Consortium in 1999 represented an opportunity to build on the initiatives undertaken by the governments of Ireland and Northern Ireland to establish a coordinated approach to cancer research on an all-island basis.

To date, both Northern Ireland and Ireland have committed significant funding to these initiatives, and the National Cancer Institute has been an active and enthusiastic partner in establishing and operating the network. Through the Consortium, NCI provides guidance, training, information technology sharing, and expertise to make the network a reality.

Building Cancer Clinical Trial Capacity in Hospitals

To enhance the capacity of hospitals in the Republic of Ireland to conduct high-quality clinical trials, the first call for proposals for funding was launched by the Health Research Board in May 2001. Eight proposals were received and reviewed by an international panel of experts nominated by NCI. Awards to four hospitals were announced in November 2001—St. Vincent's University Hospital/St. Luke's Hospital, Dublin; Cork University Hospital; University College Hospital, Galway; and Beaumont Hospital, Dublin. Two smaller planning grants were awarded to Mater Misericordiae Hospital, Dublin, and Limerick Regional Hospital to enable them to begin making progress and to compete more effectively in subsequent calls under this initiative. The total funding under this first call amounted to approximately €4.6 million over 3 years. Hospitals have since been actively involved in staff recruitment and training as a result of Consortium funding. They will produce annual reports describing how they are implementing their proposed activities and highlighting the progress achieved during each year of funding. Subject to passing an interim review by the international panel after three years, where the effectiveness of the clinical trials units will be evaluated, further funding may be issued.

As a sign of commitment to this initiative, additional funding was made available by the Department of Health and Children in 2002 to support the next phase of development. A second call for funding to hospitals was issued in January 2002. Six applications were received, and after evaluation by the international review panel in June 2002, awards were made to St. James's Hospital and to Mater Misericordiae Hospital, with two smaller planning grants awarded to the Adelaide and Meath, incorporating the

National Children's Hospital Tallaght (AMNCH), and Waterford Regional Hospital. Funding for this second call amounts to approximately €3 million over three years. The fact that Mater Misericordiae Hospital received a major award in this call highlighted the significant progress that can be achieved in a short time period with a Consortium planning grant.

Establishment of a Clinical Trials Network

In order to reap the dividends of the funding awarded to hospitals across the island, the Consortium's Board of Directors proposed a structure for all-island participation in clinical trials where a network of the major hospitals treating cancer patients on the island would be organised in the manner of the National Cancer Institute Cooperative Groups. This network, which encompasses several major U.S. cancer centres, implements cancer clinical trials at multiple sites throughout the United States. At a meeting in Dublin in May 2000, it was proposed that the Irish Clinical Oncology Research Group (ICORG) could become the coordinating agency for the newly established cancer clinical trials network for the island of Ireland, with offices in Dublin and Belfast. In October 2000, the Health Research Board of Ireland and the Research and Development Office of Northern Ireland proposed to the Consortium's Board of Directors a plan for establishing this network. The objective of the network is the generation and conduct of clinical trials consistent with priorities in Ireland and Northern Ireland, and to provide the organisational, statistical, and scientific support to member hospitals.

The proposal requested that ICORG make a formal application for funding and resources to reorganise itself to serve in the all-island coordinating capacity. A key requirement for

the Cooperative Group model to work effectively is for the statistical and data management function to be provided separately from the headquarters function.

As part of its ongoing commitment to providing infrastructural support to Northern Ireland's Health and Personal Social Services, the Research and Development Office in Belfast has been working to establish a Clinical Research Support Centre (CRSC) to provide a range of support services, including statistical and data management, for a variety of clinical trials. This has provided an opportunity for convergence with the needs of the Cooperative Group. The CRSC will incorporate a dedicated data management service for the Cooperative Group and will be headed by a senior biostatistician who will function as the Group Statistician.

In February 2002, the Health Research Board and the Research and Development Office invited ICORG and the CRSC to submit a collaborative application to form a Cooperative Group to coordinate all-island clinical trials. An international panel began its preliminary review of the application in June 2002. The panel's recommendation was expected early in 2003. Further details of the application are under review by the panel, and recommendations are expected shortly.

Scholar Exchange and Training

Introduction

Developing a core of well-trained cancer research specialists is crucial to enhancing the island's clinical trials infrastructure. Through its scholar exchange programme, the Consortium facilitates the exchange of oncologists, nurses, researchers, and other cancer personnel between their home institutions in Ireland and Northern Ireland

and the U.S. National Cancer Institute in Bethesda, Maryland. Through the Consortium, the governments of Ireland and Northern Ireland have engaged in an intensive effort to allocate funding to fellowships and training courses in areas with the greatest need and having the greatest impact on the proposed clinical trials structure. The Consortium has identified several areas with acute shortages of personnel and training: oncology specialists, clinical trials staff, cancer epidemiologists, and prevention specialists. Joint training programmes in these fields have been developed, or are being planned, ranging from short-term training courses to those in which a substantial period of time may be spent at NCI.

The training opportunities available through the Consortium must demonstrate an identifiable long-term research outcome toward cementing the collaborative nature of the Consortium and present an opportunity for sustained career development and progression upon leaving the programme. Funding for travel, accommodations, and salary/stipend is provided through the scholars' home countries. On-site training costs will be provided by the host country. Outlined below is the substantial progress that has been made over the last 18 months in three major training areas: clinical trials, cancer epidemiology, and prevention.

Clinical Trials

A clinical trials training programme was established as part of the Consortium's effort to create capacity for cancer clinical research on the island. Three clinical oncology nurses—Catherine O'Brien (St. James's Hospital), Marie Sheehan (Mid-Western Health Board), and Naomi Hill (Belfast City Hospital)—completed the three-month programme in April 2002 in the United States. During that time, the nurses rotated between the NCI Clinical Center and

its branch at the National Naval Medical Center in Bethesda, Maryland. The nurses described their experiences at NCI as "rich" and "full."



Irish and U.S. Nurse Participants in the Spring 2002 NCI Clinical Trials Training

In October 2002, four Irish nurses began the three-month second round of Consortium-sponsored clinical trials training. Participants included Ruth Boyd and Mairéad Devine (both from Belfast City Hospital, Belfast), and Marie Cox (University College Hospital, Galway), and Louise Sherwin (St. Luke's Hospital, Dublin).



Second Round of Irish Nurses with Joyce Stocker, Nursing Supervisor of the Navy Medical Oncology Branch of NCI

The educational programme is designed to give oncology nurses with degrees a chance to experience all aspects of working in a cancer clinical trials centre. During their U.S.

training, the nurses, with the help of local oncology nurse-preceptors, focused on managing clinical trials as part of a team.

In May 2002, the Nursing Working Group held an Information Day in Dublin to showcase Consortium training opportunities, including the clinical trials training programme. Interested applicants were in attendance. The Consortium plans to send four more nurses to the United States by the end of the year to receive clinical trials training.

Cancer Epidemiology

The first epidemiology fellows, Peter McCarron of Northern Ireland and Paul Walsh of Ireland, concluded their year of postdoctoral study in cancer epidemiology at NCI. For the remaining two years of their fellowships, Drs. Walsh and McCarron are translating their experiences into cancer research projects on the island. Utilising data from the Northern Ireland Cancer Registry in Belfast, Dr. McCarron plans to study patterns of care for prostate cancer. Dr. Walsh is developing a project on breast cancer survival with the Irish National Cancer Registry in Cork. It is anticipated that the fellows will help to direct collaborative research activity on the island of Ireland, which is a long-term strategy of the Consortium.



Drs. Paul Walsh and Peter McCarron, 2001 Epidemiology Fellows

Prevention

Promoting prevention in the management of cancer is a long-term goal of the Consortium, and as a result, the Consortium encourages scholar exchange in the area of prevention. In 2001, Northern Ireland and Ireland funded 16 positions for NCI's Summer Curriculum in Cancer Prevention. In 2002, 15 Irish and 3 Northern Irish applicants, including physicians, nurses, research fellows, lecturers, and data analysts, participated in the summer programme. The five-week annual course includes a four-week segment on the principles and practises of cancer prevention and control, and a one-week segment on molecular prevention.



*Prevention Working Group Meeting in May 2002
L-R back row: Dr. Kevin Balanda (IR), Dr. Fenton Howell (IR), Dr. Doug Weed (U.S.), Dr. Liam Murray (NI), Dr. Brian Gaffney (NI). L-R front row: Dr. Teresa Maguire (IR), Dr. Patricia Riordan (IR), Dr. Kathy Rowe (NI), Dr. Ruth Barrington (IR)*

The principles and practises course covers the resources, data, methods, and theories related to cancer prevention and control. It includes an international day for participants from around the globe to present to their colleagues the unique characteristics of cancer care and prevention in their home countries. The molecular prevention segment provides participants with information on molecular biology and the genetics of cancer as well as an overview of basic laboratory

The second round of Epidemiology Fellows was re-advertised in the autumn of 2002 and Dr. Deirdre Cronin was appointed. She will be based in Cork and will spend a year at the NCI commencing June 2003.

Funding for the second All-Ireland Cancer Incidence and Prevention Report was provided by the Department of Health and Children, Ireland. A call for a fellowship opportunity to produce the report will be issued early in 2003. The report is expected to be available for distribution in mid-2004.

Information Technology Sharing

The 1999 Memorandum of Understanding identified information technology (IT) exchange as a significant objective that would underpin other strategic areas of cooperative development prioritized within the intergovernmental agreement. In particular, the availability of common informatics tools was recognised as a central requirement for healthcare workers to participate fully in cross-border and U.S.-Ireland clinical trials and educational activities. Two enabling informatics technologies developed within the NIH/NCI were identified as areas of initial investigation and exchange: net-Trials® and TELESYNERGY®.

TELESYNERGY®

TELESYNERGY® is a multimedia medical imaging workstation used within an electronic imaging environment, utilising either prototype Asynchronous Transfer Mode or ISDN telemedicine networks. It is designed for the simultaneous high-resolution display of medical images from numerous diagnostic-imaging modalities. Within the NCI the initial application area for TELESYNERGY® was in support of

treatment planning in a radiation oncology environment; however, TELESYNERGY® also enables remote consultations between geographically distributed oncologists and other medical specialists. Oncologists in separate institutions can consult during the development of a patient treatment plan and can monitor progress during the course of the treatment protocol.

Two TELESYNERGY® systems were installed on the island during 2002 at Belfast City Hospital (BCH) and St. Luke's Hospital (SLH), Dublin. The TELESYNERGY® installations in Dublin and Belfast represented the first use of the system outside the United States. The investigation of the clinical utility of TELESYNERGY® within the NCI-All Ireland Consortium is an important test of the system, particularly in regard to its future international use and development. Prior to the installation, technical support groups at BCH and SLH, in conjunction with colleagues at NCI and the Centre for Information Technology, evaluated and approved system compatibility with European telecommunications standards. The system was installed at BCH in July 2002 and subsequently at SLH in September 2002. On November 13, 2002, a three-way connection to each of the participating jurisdictions and discussion of future TELESYNERGY® projects was convened through SLH with Dr. Elias Zerhouni, Director of the NIH, Dr. Andrew von Eschenbach, Director of the NCI, and Ambassador Richard Egan, U.S. Ambassador to Ireland, in attendance. The three-way link demonstrated the anticipated use of TELESYNERGY® in a number of areas including:

Clinical case management

- Dr. Curly Morris detailed the recent use of the system in facilitating the optimal management of a patient that had presented to Belfast City Hospital with

A Cross-Border Collaborative Study of Barrett's Oesophagus and Oesophageal Adenocarcinoma

FINBAR Study - Factors Influencing Barrett's Adenocarcinoma Relationships

Investigators - Liam Murray, Northern Ireland Cancer Registry, Harry Comber, National Cancer Registry of Ireland

Carcinoma of the oesophagus is a relatively common cancer with a very high mortality rate. It is usually either a squamous cell tumour or an adenocarcinoma. The last two decades have seen a dramatic increase in the incidence of oesophageal adenocarcinoma in the United States and Europe, including Northern Ireland. The recent rate of increase in this cancer exceeds that seen in virtually all cancers at other sites, and this increase has been particularly marked in males. The reason for the increase in incidence of adenocarcinoma is unknown. The majority of oesophageal adenocarcinomas arise in a premalignant precursor known as Barrett's oesophagus, but only a small proportion of cases of Barrett's oesophagus develop malignancy. The epidemiology of Barrett's oesophagus is increasing at a similar rate to oesophageal adenocarcinoma, but the apparent increases may be artefactual.

This study will use 10 years of data from the first truly population-based register of Barrett's oesophagus (maintained by the Northern Ireland Cancer Registry) to conclusively determine whether this condition is increasing or not. If an increase is confirmed, future research in this field can be expected to focus on the determinants of the rise in Barrett's oesophagus and on why some patients with this condition develop a malignancy while others do not.

Using a case-control study approach, this investigation will also examine genetic and environmental factors that may govern this progression. The results of this study will undoubtedly shed light on the reasons for the recent increase in oesophageal adenocarcinoma. This knowledge, combined with the possible identification of triggers and mechanisms involved in malignant progression within Barrett's oesophagus, may provide future opportunities to reverse the upward trend in oesophageal adenocarcinoma.

Natural Killer cell lymphoma. The pathology, radiology, and management plan were discussed with NCI colleagues using the TELESYNERGY® system. This is an example of rare cancer management for which collaborative thinking and access to NCI expertise were essential to achieve the best outcome.

Technology exchange and treatment development

- Dr. Cynthia Menard, on behalf of the Radiation Oncology Branch/Radiation Oncology Sciences Program of the NCI, presented new developments in image-guided prostate cancer brachytherapy, combining a presentation of patient history, pathology, dynamic colour-enhanced MRI imaging, and treatment. This discussion highlighted the interactive and multiplex image capability of TELESYNERGY® and the potential for cutting edge therapeutic approaches to be shared and developed across the three jurisdictions.

Clinical trial development and translational research

- Professor Donal Hollywood presented an outline proposal of the first clinical trial that will use the TELESYNERGY® system. The proposed esophageal protocol combines novel neoadjuvant treatment with prospective genomic and proteomic studies on biopsy specimens obtained from participating patients. This is an early example of an NCI-All Ireland clinical research protocol in which the Consortium partners will develop novel translation research

treatment protocols combined with complex analysis of tissue samples and the utilization of bioinformatics expertise at the NCI.

In parallel with the November 2002 demonstration, multidisciplinary TELESYNERGY® users groups, representing a wide range of clinical disciplines, have regularly convened in Dublin and Belfast, enabling the training of additional staff on the use of the system. Professor Donal Hollywood, Dr. Norman Coleman (NCI), Professor Patrick Johnston, Dr. Seamus McAleer, and colleagues are currently examining the clinical use and potential benefit of TELESYNERGY® particularly in the context of clinical trial development and its potential integration with net-Trials® or any future clinical trials information management system.

net-Trials®

net-Trials® is a web-based information management database that provides a uniform patient data collection system to enable the storage and exchange of complex information related to clinical trials, including trial design, development, and the recording of patient accrual.

The net-Trials® system was installed at the Clinical Trials Unit at Belfast City Hospital during 2000-2001. The Belfast unit has gained important initial experience in testing the system and several ongoing clinical trials have used the web-based system to support clinical protocol development, patient recruitment, patient screening and registration, and preliminary analyses of data. Although the platform has significant strengths, the future use and support of net-Trials® as the preferred clinical trials information management platform is currently under review by the NCI. It is anticipated that the recently approved

clinical trials units in the Republic of Ireland will have early access to net-Trials® or any future development of this clinical trials information management system.

Nursing

The Nursing Working Group welcomed Mary McCarthy in October 2001 as the new Chief Nursing Officer in Dublin, having said a grateful farewell to Peta Taaffe, who has retired.



Chief Nursing Officers Mary McCarthy (IR) and Judith Hill (NI)

Two nurses participated in the summer 2001 cancer prevention programme and brought back a wealth of ideas for local implementation. Three nurses (one from the North and two from the South) attended a 12-week clinical trials training programme—January to April 2002—gaining useful knowledge and experience and sharing ideas with NCI colleagues at both the U.S. National Institutes of Health Clinical Center and the National Naval Medical Center in Bethesda, Maryland. A further four nurses attended a similar programme—September to November 2002—following meetings between the two Chief Nursing Officers and NCI nursing colleagues around the April 2002 Implementation Group and Board meetings in Washington.

A call went out for a special international cancer nursing research fellowship, supported by an information day; however, no fellowship was awarded in 2001 or 2002. The fellowship is currently being reviewed, and it is hoped it will be offered again in a revised format in 2003.

Joyce Stocker and Georgie Cusack from the NCI had the opportunity to meet colleagues in Dublin and contribute to the development of relationships and collaborative work. Ms. Stocker was able to participate in an information day in May when nurses who had been to NCI reported on their experience and encouraged others to seize the opportunities offered by the Consortium. Details of the day can be found on the Consortium Web site.

Work is ongoing to develop opportunities for NCI staff to visit the island of Ireland and undertake a programme in palliative care. Nurses and doctors from the North and South attended the July 2002 State of the Science meeting at NCI, and it is hoped further collaborative work on supportive and palliative care can be initiated.

Nurses participated in a major cancer conference in Belfast in October 2002 and shared their experiences while at the NCI.

The Nursing Group is developing a strategic plan that includes development of a shared research agenda in cancer nursing and continued consolidation of the clinical trials training initiative and palliative care opportunities.

Prevention

The prevention of cancer has been an interest of the Consortium since its inception. Building on a strong foundation of achievements of the Consortium's programmes in clinical trials, scholar

exchange, cancer registries, information technology, and nursing, the Board of Directors established the new Prevention Working Group at its December 2001 meeting. The mission of this working group is to enhance coordination and cooperation on primary, secondary, and tertiary cancer prevention research and practise activities on an all-island basis. The group will stay abreast of existing and developing prevention programmes and activities on the island, and will make recommendations that will advance the Consortium's objectives in this vital area. The composition of the new group is multidisciplinary, with representation from the health ministries at the national and local levels, the cancer registries and health promotion agencies, as well as from academia and from the all-island Institute of Public Health and the U.S. National Cancer Institute.

Progress to Date

At its first meeting, held in spring 2002, Prevention Working Group members discussed prevention activities in their respective jurisdictions and began to formulate initiatives that could be undertaken by the Consortium. Health promotion activities on the island were described; exemplary programmes have been established in tobacco control and in the prevention of melanoma. The cancer registries' role in prevention was discussed. These registries provide valuable data on the incidence, mortality, and survival rates of cancer patients across the island, information vital to the assessment of progress against cancer through prevention and treatment. Prevention activities of academic institutions, the Institute of Public Health, and the National Cancer Institute filled out the meeting's agenda.

The group identified several areas of need. These include better coordination of current

prevention efforts in the North and South, and the training of scientists, public health investigators, clinicians, nurses, and other health care personnel in all aspects of prevention. A specific need for postdoctoral research training opportunities in prevention was identified. Members were particularly interested in continuing efforts to participate in the NCI's Summer Curriculum in Cancer Prevention—a Consortium-sponsored activity under way since summer 2001. The group was also keen to take advantage of NCI's Cancer Prevention Fellowship Program, a highly competitive programme that trains individuals from many health science and medical disciplines in the field of cancer prevention and control through structured didactic education, mentored research, and leadership training.

Members of the Working Group recognise the many dimensions of cancer prevention, from basic molecular prevention science through epidemiology and behavioral science to the application of scientific

findings in health promotion activities and in population-based policymaking. Cancer prevention is, in theory, an old idea and, in practise, a relatively new facet of cancer research, cancer care, and public health. As a way to increase awareness of the dimensions of prevention and to elicit support from the many communities involved, members are considering holding a series of workshops on the island. These Consortium-sponsored workshops would focus on the prevention of specific cancers or on cancer risk factors such as smoking and would serve to raise awareness of the many dimensions of cancer prevention among researchers, practitioners, and policymakers alike. Initial workshops may, for example, address those cancers that utilise the greatest amount of resources or that have the highest rates of morbidity and mortality as described in the Consortium-sponsored All-Ireland Cancer Statistics Report. Prevention will also be a featured topic at the Consortium's upcoming 2003 All Ireland Cancer Conference in Cork.

HOW THE CONSORTIUM OPERATES

The Memorandum of Understanding

The Consortium operates under guidelines outlined in the Memorandum of Understanding (MOU) signed in 1999. (Refer to the appendix for a copy of the MOU.)

The major objective of the Ireland-Northern Ireland-National Cancer Institute Cancer Consortium is to intensify cooperation in cancer treatment and research that will lead to improved scientific programmes in each partnering country in the areas of education and training, cancer treatment and research, information dissemination, epidemiology, cancer prevention, surveillance, early detection, quality control, and interactions aimed at enhanced public health and patient care.

To meet those objectives, the participating countries have continued to focus on four initial programmes:

1. Establishment of a clinical trials network among cancer centres and hospitals in Ireland and Northern Ireland
2. Scholar exchange and training between institutions in Ireland, Northern Ireland, and the U.S. National Cancer Institute
3. Information technology enhancement to enable collaboration on clinical trials
4. Data sharing and collaboration among the island's two cancer registries

Consortium Governing Structure

Board of Directors

The Consortium is governed by a Board of Directors comprised of the Chief Medical

Officers of Ireland and Northern Ireland, and the Director of the National Cancer Institute.

The Consortium Board of Directors:

- Determines the Consortium's scope of activities
- Evaluates and oversees contributions by each jurisdiction
- Establishes working groups to carry out programmes where necessary
- Monitors progress of activities in accordance with the Consortium's mission
- Submits an annual report to the participating health departments

The Board must meet at least two times each year. Chairmanship rotates each year between the Chief Medical Officers of Ireland and Northern Ireland. In 2002, the Chair was James Kiely of Ireland. In 2001, the Chair was Henrietta Campbell of Northern Ireland.

Implementation Group

The Implementation Group advises the Board, and establishes and manages specific programmes. Its responsibilities are to:

- Develop the detailed plans to assure that the overall goals of the Consortium are met
- Call together the necessary expertise to assess issues and develop workable plans for the Board to consider
- Identify areas that require the attention of the Board members and their respective governments
- Serve as liaison between the working groups and the Board of Directors

The Implementation Group meets at least four times per year, in person or by conference call. In 2001-2002, the Implementation Group was chaired by Joe

Harford, Director of the National Cancer Institute's Office of International Affairs. Its members include the Chief Nursing Officers of Ireland and Northern Ireland, as well as scientific and administrative representatives of the Health Research Board of Ireland and the Research and Development Office of Northern Ireland, the National Cancer Institute, and the major hospitals and health boards of Ireland and Northern Ireland.

Working Groups

When necessary to advise on a specific issue, the Board establishes *ad hoc* working groups whose role is to stay abreast of needs and activities within their designated areas and to make recommendations on activities that will enhance the Consortium's objectives. *Ad hoc* working groups convened in 2001-2002 covered the areas of nursing, telecommunications/information technology, cancer registries, scholar exchange, prevention, and clinical trials.

July 2001 - December 2002 Governance Meeting Schedule	
October 2001	Implementation Group, conference call
December 2001	Board of Directors, London
March 2002	Implementation Group, conference call
April 2002	Implementation Group, Washington, D.C. Board of Directors, Washington, D.C.
July 2002	Implementation Group, conference call
October 2002	Implementation Group, Belfast Board of Directors, Belfast

SPOTLIGHT ON CONSORTIUM SCHOLARS

In 2001 and 2002, the Consortium sponsored three scholar exchange programmes in disciplines identified as having significant need for advanced training in Ireland and Northern Ireland: research nursing, cancer prevention, and cancer epidemiology (population studies). The concept behind each training programme is for scholars to gain in-depth knowledge in these areas of research so that they can apply new perspectives and techniques to their positions at their home institutions.

Various Consortium working groups conceptualised the training programmes and worked with personnel at NCI, and at the hospitals, cancer centres, and cancer registries in Ireland and Northern Ireland to develop the course descriptions and define eligibility requirements, travel logistics, and certification details for the scholars to train in the United States. A total of 21 scholars from Ireland and Northern Ireland participated in the first year's programmes at NCI. Profiled here are several scholars who describe their experience at NCI and how they are sharing their newfound knowledge in cancer research with their peers at home.

Epidemiology Fellowship

Epidemiology - the study of disease trends and patterns in the population - is growing in importance on the island of Ireland as both North and South strive toward a better understanding of cancer trends among the entire population. The number of trained epidemiologists on the island is critically low, accounting for only a handful of experts trained in interpreting the statistics compiled by the two cancer registries. In winter 2001, the Consortium awarded its first epidemiology fellowships to Peter McCarron of Northern Ireland and Paul Walsh of Ireland. In summer 2002, the two scientists concluded their first year of postdoctoral

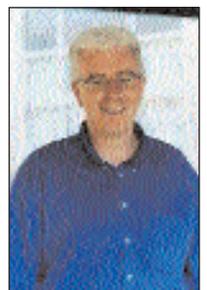
study in cancer epidemiology at NCI. They will spend years two and three of their three-year fellowships translating their experiences into cancer research projects on the island. Utilising data from the Northern Ireland Cancer Registry in Belfast, Dr. McCarron plans to study patterns of care for prostate cancer. Dr. Walsh is developing a breast cancer project with the Irish National Cancer Registry in Cork. It is anticipated that the fellows will help to direct collaborative research activity on the island of Ireland.

Peter McCarron, epidemiologist, Northern Ireland Cancer Registry, Belfast

Though I grew up in Derry, I had never worked in Northern Ireland. I had received my training in Dublin and in other parts of the U.K. I learned about the opportunity to apply for the Consortium's fellowship in cancer epidemiology through the *British Medical Journal* and jumped on it, thinking it would be a good opportunity to learn more about a growing field and apply my expertise at home.

Until a few years ago, most of my career had been in public health medicine and cardiovascular epidemiology. With the startup of the cancer registries in Ireland and Northern Ireland in the 1990s, there is a great chance to study cancer epidemiology in Ireland. Strengths such as coverage of the whole island and the genetic homogeneity of the population provide potential for contributing to the understanding of cancer etiology and enhancing preventive efforts. For a researcher, the emphasis on collaboration between North and South, and on improving public health, provides enormous opportunity to train in cancer epidemiology here in Northern Ireland.

“With our current emphasis on collaboration between North and South, and on improving public health, there is enormous opportunity to train in cancer epidemiology here in Northern Ireland.”



Back in Belfast after a year at NCI, Peter McCarron is working on a study of gene-environment interactions in the etiology of prostate cancer.

I applied for the three-year fellowship and within a short period of time found myself at the National Cancer Institute just outside of Washington, D.C. During the first portion of the fellowship, I collaborated with a number of U.S. researchers, analyzing data from a large ongoing cancer study and writing research papers. While at NCI, I also took three courses in biostatistics and one in genetics at the Johns Hopkins School of Public Health in Baltimore. In addition, I participated in the six-week summer cancer prevention course taught at NCI, and took a course on the methods used in cancer registration. These courses were all enjoyable and extremely useful, and the biostatistics courses were very challenging, requiring me to revisit mathematical concepts I had long forgotten.

After my time in the States, I am back in Belfast where I am continuing my fellowship. I am currently working with a clinician here on a study of gene-environment interactions in the etiology of melanoma. We are planning to write a grant application, to extend this study by possibly investigating the differing contribution of genetic and environmental factors among people who develop melanoma in the United States and in Ireland. In addition, using unique data on prostate-specific antigen (PSA), I am collaborating with a number of colleagues in Belfast to determine the trends in PSA testing in Northern Ireland, and the outcomes for men undergoing the test. Also, along with my fellow colleague from Ireland, Paul Walsh, who was the main contributor to the recent *All-Ireland Cancer Statistics Report*, I will likely write a paper on some of the important findings contained in the report.

Perhaps the best part about the fellowship was the contacts I made with population studies experts at NCI. They have been invaluable in designing our research project and offering ongoing advice.

Paul Walsh, Consortium Fellow, Cancer Epidemiology, National Cancer Registry (Ireland)

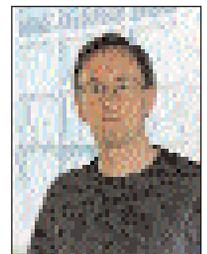
My involvement with the Consortium began with work on compiling the *All-Ireland Cancer Statistics Report*. While collaborating on the report, I heard about the scholar exchange programme. I didn't think I had a chance of being selected, but colleagues encouraged me to apply. And I was learning a good deal from working on the report, so enthusiasm about that project carried me forward to seek new opportunities.

My background is in zoology, and I was looking forward to the opportunity to gain formal training in cancer epidemiology. The sciences of zoology and cancer epidemiology overlap in that they use similar statistical techniques to analyse population-based data. I wanted to apply and expand my existing knowledge, and to gain exposure to research at NCI.

I benefited from both the formal training in epidemiology and prevention techniques, and the informal exposure to NCI researchers. You can't find a larger concentration of cancer researchers anywhere else in the world. NCI's SEER database is an impressive tool. And I learned about statistical techniques not yet available in Ireland because they are newly developed at NCI. Access to other programmes, such as the Johns Hopkins University School of Public Health, was also valuable.

The potential for our registry to take advantage of NCI's SEER data, and their potential to inform data collection and analysis in Ireland, is exciting. For example, I have been working with Irish data tabulated in SEER format in order to use SEER data analysis techniques. This will allow us to create survival analyses, and we are already making detailed comparisons with U.S. data.

"I look forward to continuing to exchange ideas and share experiences with colleagues from the North and the South as well as the States."



As an Epidemiology Fellow, Paul Walsh participated in the NCI's Summer Curriculum in Cancer Prevention.

I also hope to link data to risk factors, and to undertake case-control and cohort studies.

I remain in touch by e-mail with people I met, and look forward to continuing to exchange ideas and share experiences with colleagues from the North and the South as well as the States.

Nurses' Clinical Trials Programme

Ireland and Northern Ireland—like the United States and other parts of the world—face a severe shortage of nurses. Hospitals and clinics throughout the island find themselves launching international recruitment efforts, looking for nurses to relocate from remote places such as Africa and the Philippines. Early on, the Consortium's Board of Directors recognised the need to retain Irish nurses who are already working in clinical research and to provide them with special training opportunities to maintain a strong nursing workforce. It placed as a priority a scholar exchange programme in the area of clinical research nursing to enhance the skills of Irish nurses, who in turn would train future nurses in cancer research.

The field of research nursing is fairly new to the island because neither North nor South has launched a significant clinical trials system until recently. The board recognised that each country needed an ample number of well-trained research nurses versed in a uniform system of practises and methodologies to sustain a clinical trials system linking hospitals and cancer centres throughout the island. As a result, three clinical oncology nurses—Catherine O'Brien, St. James's Hospital, Dublin; Marie Sheehan, Mid-Western Health Board, Limerick; and Naomi Hill, Belfast City Hospital—applied for and completed the

three-month nurses' clinical research programme in the United States. From February to April 2002, the nurses shadowed a research team in gastrointestinal cancers carrying out clinical trials at NCI's 500-bed Clinical Center in Bethesda, Maryland, and at the National Naval Medical Center, where NCI conducts a clinical research programme.

The training programme gave the nurses the opportunity to experience firsthand all aspects of working in a clinical trials setting. During their course, the nurses worked closely with NCI clinical and research nurses, under the direction of NCI nurses Joyce Stocker and Georgie Cusack, on managing trials as part of a team of scientists, oncologists, statisticians, pharmacologists, and other technical experts. The course provided the fundamentals of clinical research, including the different phases of clinical trials, ethical issues, patient education, and trial documentation, as well as an understanding of how treatment options are decided and protocols are reviewed, and the importance of clear communications among all research team members.

Upon the nurses' return to their home institutions, in May 2002, the Consortium's Nursing Working Group held an Information Day at St. James's Hospital and Belfast City Hospital to introduce NCI and the nurses' programme to staff nurses.

Catherine O'Brien, Clinical Nurse Specialist in Oncology, St. James's Hospital, Dublin

Having worked in oncology for more than eight years, a large part of that in the clinical trials setting, I was eager for the opportunity to train at the National Cancer Institute to learn more about how we could enhance the nurse's role in clinical research in Ireland. I

“The experience has highlighted for me the importance of clinical trials in advancing cancer care in Ireland. Research and clinical nurses have a huge role to play in making this happen.”

found there was a gap between the role of the research nurse and that of the clinical nurse. My main objective was to observe how these two roles integrated in the U.S. and hopefully identify ways to strengthen collaboration between both groups in Ireland. At St. James's, we have about 60 clinical nurses and only 3 research nurses, a position introduced here about 5 years ago. In Ireland, we do not initiate and coordinate many of our own clinical trials yet. Typically, they originate in the U.K. or another country, and we participate in them. In the future, St. James's and other Irish hospitals plan to coordinate more trials from here. When that happens, the nurses will be a core group that helps to set the trials up and enables them to run smoothly.

The experience that I gained at NCI was excellent. Through my job as a clinical nurse here, I had a good understanding of the role of the research nurse. But after spending time actually being part of the NCI team, I developed a much clearer insight into the different roles that *each* member of a clinical research team plays. When we first arrived, NCI hosted a three-day course on the fundamentals of clinical trials that walked us through the life cycle of a clinical trial, from the initial concept, through recruiting patients, to enrolling them and initiating the trial. We attended lectures and in-service training days that were very beneficial. Then, we followed and participated in trials as part of the research team. I had never been involved in this before. The experience will be extremely helpful when the time comes for us to initiate more trials in Ireland.

Since I returned to Ireland, I have conducted presentations for our staff about my experience. I brought back with me folders full of materials on cancer, clinical trials, and other information from NCI, so I am a resource for others in the hospital. My goal is to make sure every nurse in our oncology unit is briefed about the course and has a

chance to learn what I learned at NCI. These kinds of training programmes are excellent, and I would not have had this opportunity if it weren't for the Consortium.

I did not realise the huge role that nurses play in initiating and running a clinical trial. Having a limited experience in this area at St. James's, the NCI experience exposed me to the whole picture. I see opportunities now, for how both clinical and research nurses in Ireland can become more involved in clinical trials. I have identified ways to strengthen collaborations between both roles and, hence, bridge that gap.

I would like to enhance my role as a clinical nurse in the clinical trials setting, particularly in the area of patient education and making people aware that clinical trials are an option for them. I want to shed some light on the importance of clinical trials in advancing cancer care and treatment. At NCI, I got a look into the future of cancer care. It convinced me that there are a lot of exciting things happening—new treatment possibilities on the horizon. I am hopeful that there will be a huge role for clinical research in Ireland very soon.

Naomi Hill, Clinical Research Nurse, Northern Ireland Cancer Clinical Trials Unit, Belfast City Hospital

My main objective in taking part in the scholarship was to learn about phase I clinical trials. The objective of a phase I trial is to determine a safe dose that is appropriate for use in phase II trials. In Northern Ireland, we have conducted mainly phase II and phase III clinical trials, and are now further developing phase I clinical trials. The Northern Ireland Cancer Clinical Trials Unit has set up a team of clinicians and research nurses who are involved and interested in this area. The experience I

“Most importantly, I developed contacts with many cancer research experts in the U.S. who I still call upon for help and advice. That has been indispensable.”

such as hormonal carcinogenesis and the use of microarrays and proteomics. An understanding of these areas will be essential for the future of cancer prevention and also for improving the diagnosis and treatment of cancer patients.

The cancer centre at Belfast City Hospital is now a major centre of excellence within Europe. Our goal is to become a leader of clinical research, particularly with an interest in the translation of basic science into clinical practise. My attendance at the NCI cancer prevention course provided me with a greater understanding of how cancer prevention could be better applied in the future as well as enhancing my own research ideas in terms of the clinic. In summary, the cancer prevention course is a unique, informative and enjoyable experience combined with the opportunity to experience NCI and Washington, D.C. I would therefore strongly recommend this course and other scholar exchange programs to postdocs, principal investigators, and specialist registrars.

Gerald O’Sullivan, Oncology Surgeon at Mercy Hospital, Cork, and Director of Cork Cancer Research Centre, Cork, Ireland

Our focus at the Cork Cancer Research Centre is on developing insights into new treatments and prevention measures for cancer. We are in the process of developing a cancer prevention clinic in Cork that will study the epidemiology of cancer, early diagnosis, and ways to prevent cancer from developing in the first place through prevention.

This year, we are completing our first study on probiotics and epithelial functions in gene expression in colon cancer. We have just completed the field work and now will begin the lab work in the probiotics study,

which involves the feeding of live bacteria—the bacteria that are good for you—to people on study to test their effectiveness in preventing colon cancer. That is just one example. Our role in the larger picture will be to apply some of our key findings from prevention studies to relevant cancer prevention campaigns coordinated through the Department of Health and Children.

Our hopes are high that we can build a strong prevention programme here. We have a good cohort of people, strong U.S. ties that provide us training and guidance, and the willingness of the people to succeed. We must motivate people here to invest in careers in cancer prevention. In my observation, the Irish cancer community is becoming better established. Recently, many of our scientists have published well-respected papers in international peer-reviewed publications. We have high quality medical care and a stable community, so there is no reason why Ireland cannot become a major cancer research community.

I found the Consortium’s cancer prevention programme to be quite helpful. I have a background in biostatistics, so the course helped bring everything together in a prevention and epidemiological context. At my stage in life, you need to embrace life and take advantage of opportunities like this to expand personally and professionally, and to share with younger people building their careers.



Professor Gerald O’Sullivan and colleagues are developing a cancer prevention clinic in Cork to study the epidemiology, early diagnosis, and prevention of cancer.

“Ireland has high quality medical care and a stable population so there is no reason why Ireland cannot become a major cancer research community. We just need more skilled people entering the profession. We could do great work.”

“The discussion sessions with scholars from NCI and around the world—from Germany, France, the Czech Republic, India, China—really opened my eyes to the different approaches that different countries take toward cancer prevention.”



Siobhan O'Sullivan, University College Cork, Department of Epidemiology and Public Health, participated in the six-week cancer prevention course at NCI.

Siobhan O'Sullivan, Senior Researcher, Genetic Epidemiology, University College Cork, Department of Epidemiology and Public Health

I became interested in the programme because of my work in epidemiology. My chief research area currently is the study of cardiovascular disease. There is a strong overlap between cardiovascular and cancer prevention, especially in the area of diet and genetics, so the course was extremely helpful to all that I do. I have a genuine interest in disease prevention. With a Ph.D. in biochemistry and lots of experience in lab work, I was anxious to learn the broader aspects of prevention, including nutrition and prevention awareness.

The programme was superb. I couldn't say enough about it. The lectures were excellent and very well organised. We had the opportunity to talk to the lecturers each day to learn more about their topics of interest. We also participated in discussion groups with people from different countries to learn how they approached cancer prevention. It was especially interesting to see how other countries deal with this topic. Participants included people from France, Italy, Germany, Romania, Turkey, and China. I have kept in touch with many of the people I met. Back in Ireland, we have even had reunions of some of the Irish participants. It was a great opportunity to meet other Irish people working in the area—I found that some were geographically quite close to where I work, but we had never met before.

The best part of the course for me was the dietary and the molecular prevention section. I also got a lot out of the section on biometric statistics and methodology, which covered their applications to clinical trials. Back home, I use my course manuals a lot as

reference material when giving lectures on genetic epidemiology. I bring in examples I learned through the course.

People interested in furthering their career need expertise and often need to go away to get it. NCI has bigger departments, more people, more money, so naturally they have the resources, critical mass, and expertise, and they are willing to share this through this excellent programme. Genetic epidemiology is a relatively new discipline in Ireland. We are doing very good research in epidemiology here, and with more exchange programmes, it will be possible for Ireland to become an internationally competitive country in the field of cancer research.

PARTNERS AND INSTITUTIONAL MEMBERS

Ireland

Department of Health and Children

Ireland's Department of Health was established in 1947, under the Ministers and Secretaries (Amendment) Act of 1946. Before 1947, the public health services were the responsibility of the Department of Local Government and Public Health, and continued to be administered by local authorities until 1970. The Health Act, 1970, which established eight health boards and abolished the Hospitals Commission, increased the Department's direct involvement in the execution of health policy. The emphasis on the curative and regulatory aspects of the health services, and on the need to develop the acute hospital sector in particular, remained one of the defining characteristics of health policy in the decade following the passing of the Act. The period from 1970 to the mid-1980s was marked by a consistent development of services in accordance with the policy commitments in the 1966 white paper *The Health Services and Their Further Development*.

The publication of the health strategy *Shaping a Healthier Future*, in 1994, was the culmination of a reappraisal of the health services that had commenced in 1986 with the discussion document *Health: The Wider Dimensions*. *Shaping a Healthier Future* signaled a significant change in direction, with its emphasis on the achievement and measurement of health gain and social gain and its commitment to organise and manage the system as an integrated whole.

A new health strategy for the next 7 to 10 years, *Quality and Fairness*, was launched in 2001. The new strategy is based on the principles of equity, people-centredness, quality, and accountability. Key elements include the largest expansion in hospital bed capacity in the health service's history; a new Treatment Purchase Fund to buy treatment for public patients waiting more than three

months from initial referral; the addition of more day care places, respite care places, and residential capacity for people with disabilities; development of an Action Plan on Age; a statutory complaints procedures; and establishment of a new National Hospitals Agency and an independent Health Information and Quality Authority.

The Department of Health became the Department of Health and Children in 1997. Ireland's Health Minister is Micheál Martin.

Northern Ireland

Department of Health, Social Services and Public Safety

Northern Ireland's Department of Health, Social Services and Public Safety (DHSSPS) was established by the Department (NI) Order 1999. The Department administers the business of Health and Personal Social Services (HPSS), which covers hospitals, family practitioner services, community health and personal services; Public Health, which promotes and protects the health and well-being of the population of Northern Ireland; and Public Safety, which encompasses the Fire Authority, food safety, and emergency planning. The Department endeavors to improve the health and social well-being of the people of Northern Ireland by ensuring the provision of appropriate health and social care services, both in clinical settings, such as hospitals and GPs' surgeries, and in the community, through nursing, social work, and other professional services. It also supports programmes of health promotion and education to encourage the community to adopt activities, behaviours, and attitudes that will lead to better health and well-being.

The Department has in place a three-tiered corporate planning programme:

1. DHSSPS Corporate Strategic Plan (1998/99-2002/03) to set strategic direction

2. Regional Strategy (1997-2002), which provides strategic direction for HPSS, and *Well into 2000*, a 1997 publication that sets the government's strategic aim and vision for HPSS
3. DHSSPS Corporate Key Challenges, which sets priorities for the year ahead, and HPSS Management Plan, which identifies priorities for HPSS for 1999-2002

A 2002 initiative, *Investing for Health*, for the first time addresses issues of prevention of ill health by adopting comprehensive policies across government departments, rather than the treatment of ill health after it happens. The initiative aims to reduce inequalities and improve the entire population's health.

The administration of the Department is advised by a number of professional groups. The Medical and Nursing Groups are represented on the Consortium. The Health Minister for Northern Ireland is Angela Smith.

United States

National Cancer Institute

Department of Health and Human Services

The National Cancer Institute (NCI) is the largest of the 27 branches of the United States' National Institutes of Health (NIH), the world's largest biomedical research facility. NCI is responsible for overseeing all U.S. government-sponsored cancer research through two key programmes. Its intramural programme encompasses the work of more than 400 principal investigators working in NCI's own clinics and laboratories, the majority of which are located on the NIH campus in Bethesda, Maryland, and its extramural programme, which encompasses thousands of investigators at more than 50 cancer centres nationwide that receive funding for clinical research through NCI. NCI-supported scientists conduct research around the cause, diagnosis, prevention, and

treatment of cancer, and communicate findings to the medical community and the public.

Tommy Thompson is the Secretary of the U.S. Department of Health and Human Services, under which the National Institutes of Health is organised.

Other Major Participating Agencies

Ireland's Health Research Board

Ireland's Health Research Board, in conjunction with Northern Ireland's Research and Development Office, is responsible for funding many Consortium programmes, including the clinical trials network and scholar exchange programmes. The Health Research Board was established in 1986 by Ireland's Minister of Health. Its main functions are to promote, assist, commission, or conduct medical, epidemiological, health, and health services research.

Northern Ireland's Research and Development Office

Northern Ireland's Research and Development Office provides overall direction for Health and Personal Social Services research and development and liaises with national statutory bodies and health-related organisations, including the Department of Health. The office also supports a wide range of research and development initiatives, from education and training to direct commissioning. The Research and Development Office is part of the Northern Ireland Health and Social Services Central Services Agency, established to promote, coordinate, and support research and development within the field of health and social care. Its mandate is to encompass the research needs of all sectors of health and social care within Northern Ireland, including those of the Department of Health, Social Services and Public Safety.

CONSORTIUM PARTICIPANTS

Board of Directors

Dr. Henrietta Campbell

Chief Medical Officer

Department of Health, Social Services and Public Safety, Northern Ireland
Chairperson 2001

Dr. James Kiely

Chief Medical Officer

Department of Health and Children, Ireland
Chairperson 2002

Dr. Andrew von Eschenbach

Director

National Cancer Institute, Department of Health and Human Services, United States

Implementation Group

Ireland

Dr. Ruth Barrington

Chief Executive

Health Research Board, Dublin

Dr. David Fennelly

Consultant Medical Oncologist

Dublin

Professor Donal Hollywood

Professor of Clinical Oncology

Trinity College Dublin

Dr. Mary Hynes

Regional Manager

Acute Services, Western Health Board,
Department of Public Health, Galway

Professor Mark Lawler

Associate Professor of Experimental

Hematology

Department of Hematology and Institute for Molecular Medicine, St James's Hospital and Trinity College, Dublin

Chief Molecular Geneticist and Director

Cancer Molecular Diagnostics Laboratory,
St James's Hospital, Dublin

Ms. Mary McCarthy

Chief Nursing Officer

Department of Health and Children, Dublin

Northern Ireland

Dr. Anna Gavin

Director

Northern Ireland Cancer Registry, Belfast

Ms. Judith Hill

Chief Nursing Officer

Department of Health, Social Services and Public Safety, Belfast

Professor Patrick Johnston

Director, Cancer Research Centre

Queen's University Belfast, Belfast City Hospital

Mr. Raymond McMillen (Former Member)

Regional Project Manager

The Campbell Commissioning Project,
Belfast

(Retired August 2002)

Professor Robert Stout

Director, Research and Development

Northern Ireland Department of Health,
Social Services and Public Safety, Belfast

United States **(National Cancer Institute)**

Dr. Gregory Curt (Former Member)

Clinical Director

Center for Cancer Research

Bethesda, Maryland

(Retired August 2002)

Dr. Joe Harford

Director

Office of International Affairs

Bethesda, Maryland

Dr. Richard S. Kaplan

Chief

Clinical Investigations Branch,

Cancer Therapy Evaluation Program

Bethesda, Maryland

Dr. Douglas Weed

Chief

Office of Preventive Oncology

Bethesda, Maryland

Working Group **Chairpersons**

Cancer Registries

Dr. Anna Gavin

Director

Northern Ireland Cancer Registry, Belfast

Clinical Trials

Dr. Ruth Barrington

Chief Executive

Health Research Board, Dublin

Information Technology

Professor Donal Hollywood

Professor of Clinical Oncology

Trinity College Dublin

Nursing

Ms. Judith Hill

Chief Nursing Officer

Department of Health, Social Services and

Public Safety, Belfast

Prevention

Dr. Douglas Weed

Chief

Office of Preventive Oncology

National Cancer Institute

Bethesda, Maryland

Scholar Exchange

Professor Patrick Johnston

Director of the Cancer Research Centre

Queen's University Belfast, Belfast City

Hospital

ABOUT THE IMPLEMENTATION GROUP MEMBERS

To assure that the Consortium adopts programmes that are practical in nature, the Implementation Group is made up of representatives of the partners' departments of health, the National Cancer Institute, and the island's major hospitals, cancer registries, health boards, and cancer centres. The Implementation Group meets at least four times a year to review and set in motion the major programmes of the Consortium. It serves as an advisory group to the Consortium's Board of Directors, working out the details of activities initiated by the working groups and recommending direction for the Board to approve and act upon.

Ireland

“The Consortium provides a unique opportunity to build cancer research capacity on the island of Ireland, in association with NCI. Hospitals and established researchers benefit from the Consortium’s clinical trials initiative, whereas young researchers can take advantage of training opportunities.”



Ruth Barrington, Ph.D.
Chief Executive
Health Research Board, Dublin

Dr. Barrington leads the Health Research Board (HRB), the body charged with responsibility for supporting and promoting health research in Ireland. With strong links to the research community in Northern Ireland, the HRB is well placed to assist the Consortium to achieve its goal of increasing cancer research capacity on the island of Ireland. The HRB has worked closely with its Northern Ireland counterpart, the Department of Health, Social Services and Public Safety's Research and Development Office, to build capacity for clinical trials, to encourage participation in NCI's summer programme in cancer prevention, and to sponsor fellowships in cancer epidemiology in association with the two cancer registries.



David W. Fennelly, M.D., F.R.C.P.I.
Consultant Medical Oncologist
Dublin

Dr. Fennelly serves as Consultant Medical Oncologist at several Dublin health care facilities, including St. Vincent's Hospital, St. Luke's Hospital, St. Vincent's Consultants' Private Clinic, and the National Maternity Hospital. Dr. Fennelly is widely published in the scientific literature and belongs to the Irish Society of Medical Oncologists (ISMO). With the help of the National Cancer Forum, ISMO has been pivotal in directing the National Cancer Strategy. To further develop training programmes in medical oncology, ISMO has recently initiated a specialist registrar programme.

“I hope that with the input of the Consortium, we may be able to further direct and enhance delivery of care to patients throughout the country.”



Donal Hollywood, M.B., M.R.C.P.I., F.F.R.R.C.S.I., F.R.C.R., M.D., Ph.D.
Marie Curie Professor of Clinical Oncology
Trinity College Dublin

Professor Hollywood is a Professor of Clinical Oncology at Trinity College Dublin and also serves as Head of the college's Academic Oncology Unit. For the Consortium, he chairs the Information Technology Working Group. Professor Hollywood's research interests include molecular biology and the genetics of solid

“The TELESYNERGY® system and the combined clinical expertise will facilitate the delivery of optimal clinical care to patients, which we envisage as an innovative method of enhancing the adoption of uniformly high standards of care.”

tumours; the molecular basis of the radiation response in tumour and normal tissues; novel gene therapy and gene-targeting strategies; and integration of molecular therapies with physical dose optimisation of radiation treatment.

“My hope is that the Consortium will result in having better information available in relation to all aspects of cancer in Ireland so that we will be in a better position to plan services for our population, participate in clinical trials in an informed way, and compete in the leading edge of cancer care in a way that would not be otherwise possible.”



Mary Hynes, M.B., D.C.H., M.R.C.P.I., M.P.H., F.F.P.H.M.I.

Regional Manager

Acute Services, Western Health Board,
Department of Public Health, Galway

Dr. Hynes, as regional manager in the Western Health Board, is responsible for funding and coordinating the four acute hospitals and the primary care unit of the Western Health Board, the region along Ireland's West Coast that includes Galway and surrounding rural areas. She brings to the Consortium more than 25 years of experience in public health in Ireland, looking at the needs of the population as a whole, from health promotion and prevention, to screening, diagnosis, treatment, and palliative care. Through her role on the Implementation Group, she advises the Consortium on training, infrastructure enhancements, and other needs that exist in Irish hospitals, and offers input into practical solutions that affect service providers and patients.



Professor Mark Lawler

Associate Professor of Experimental Hematology

Department of Hematology and Institute for Molecular Medicine, St James's Hospital and Trinity College, Dublin

Chief Molecular Geneticist and Director
Cancer Molecular Diagnostics Laboratory,
St James's Hospital, Dublin

Professor Mark Lawler joined the Implementation Group in September 2002. Currently the Honorary Secretary of the Irish Association for Cancer Research, he represents research scientists in Ireland on the Implementation Group. He is Chairman of the St. James's Hospital Cancer Strategy Group and also directs the Cancer Molecular Diagnostics Laboratory there, the first of its type in Ireland. He has an active research group working on the molecular basis of cancer, particularly haematological malignancy. His work on chimerism and minimal residual disease has been honoured with awards such as the Ulster Cancer Foundation lecture, the Eli Lilly Prize, and the Vander Molen Prize for Leukemia Research. He is the Lead Investigator of the Cancer Programme for the Dublin Molecular Medicine Centre and a Visiting lecturer in Human Genetics, G'D'Annuzio University of Chieti in Italy. He is both the co-ordinator of the MSc in Molecular Medicine and an Honorary lecturer in Oncogenetics, Genetics Department, both at Trinity College Dublin. He is also Scientific Secretary of the Haematology Association of Ireland and is a member of the European Cancer Research Forum.

"It is important that research scientists participate fully in the NCI-All Ireland Consortium as there are superb opportunities for cancer researchers to contribute significantly to the consortium goals in the areas of training, education and research."

United States (National Cancer Institute)

“Cancer knows no borders and respects no political affiliation. As clinical trials often represent the standard of care for cancer treatment, this effort has the potential to improve the quality and quantity of life for people diagnosed with cancer on the island of Ireland.”



Gregory Curt, M.D. (Former Member)
Clinical Director
Center for Cancer Research
Bethesda, Maryland
(Retired August 2002)

Dr. Curt oversees the largest clinical programme at the Bethesda campus of the National Institutes of Health, where some 400 NCI principal investigators carry out more than 150 active cancer clinical trials. Dr. Curt's office is responsible for NCI's intramural research programme, which translates basic laboratory research to the clinic and maintains a special focus on long-term epidemiologic and genetics studies. Through the Implementation Group, Dr. Curt assists the island's nascent clinical trials network in organising its resources to initiate island-wide clinical trials, advising on such topics as protocol review and monitoring, setting scientific standards for new clinical studies, tracking adverse events, ensuring regulatory compliance and quality control, filing new drug applications, and managing patient referral and recruitment.

Dr. Curt retired from the NCI in August 2002.



Joe Harford, Ph.D.
Director
Office of International Affairs
Bethesda, Maryland

Dr. Harford serves as Director of the Office of International Affairs of the National Cancer Institute. In this capacity, he has responsibility for a number of bilateral and multilateral interactions between NCI and foreign cancer research institutions. His office also tracks all funding going to foreign investigators through NCI grants and contracts, as well as other forms of international collaboration, including training. Dr. Harford serves as the Chair of the Implementation Group of the Ireland-Northern Ireland-NCI Cancer Consortium and is a member of the Scholar Exchange Working Group.



Richard S. Kaplan, M.D., F.A.C.P.
Chief
Clinical Investigations Branch, Cancer
Therapy Evaluation Program
Bethesda, Maryland

Dr. Kaplan leads the Clinical Investigations Branch (CIB) of the Cancer Therapy Evaluation Program (CTEP), the unit in NCI's extramural programme responsible for coordination of large-scale therapeutic trials,

“Their individual talents notwithstanding, the most heartening aspect of working with the Implementation Group is the synergy that is so apparent – as the individuals are, the whole is greater than the sum of the parts.”

“I hope that my hard-won experience will prove of value in strengthening the clinical trial infrastructure on the island of Ireland, and in building collaborations with U.S. investigators and studies. The goal as I see it is to have a robust set of capabilities in Ireland and Northern Ireland that can support anything from conducting small-scale developmental trials of novel agents to leading international randomised trials.”

including those falling under the realm of the Clinical Trials Cooperative Group Program. Enrolling 28,000 patients annually, these trials study a variety of therapies. The Cooperative Groups conduct prevention and cancer control studies as well. Dr. Kaplan brings to CIB extensive experience with clinical trial design, development, logistics, and analysis. His responsibilities include overseeing CIB's role as the linkage point for collaborations with international clinical trial organisations.

“Prevention is an important facet of cancer research, cancer care, and public health promotion. While in theory a long-held idea, in practise cancer prevention is relatively new. Building a strong infrastructure for the future of prevention is critical. With a robust Consortium-sponsored initiative, the health of the people will benefit.”



Douglas L. Weed, M.D., Ph.D.
Dean, Education and Training
Chief, Office of Preventive Oncology
Director, Cancer Prevention Fellowship Program
Division of Cancer Prevention
Bethesda, Maryland

Dr. Weed plays a multifaceted role in the Division of Cancer Prevention, NCI's primary unit devoted to cancer research prevention, serving as Dean of Education and Training, Chief of the Office of Preventive Oncology, and Director of the Cancer Prevention Fellowship Program. The Office of Preventive Oncology develops cancer prevention and control principles and practises for oncologists, other practising physicians, and public health professionals. The Office's activities include the Cancer Prevention Fellowship Program, which provides state-of-the-art postdoctoral research training in cancer prevention and control.

OUTREACH

The Consortium makes a priority of keeping the public, cancer professionals, and public health professionals in the three partnering countries apprised of its activities and programmes. The Consortium accomplishes this through its Web site, newsletter, and Help Desk.

Consortium Web Site www.allirelandnci.org



The Consortium's Web site is updated on a regular basis with news and information about the Consortium's programmes. Oncologists, nurses, scientists, students, policymakers, and others can access information about training and education opportunities, download publications (such as the first *All-Ireland Cancer Statistics Report* from 2001), learn about upcoming meetings, and more. In addition, the site provides links to the partner organisations, including comprehensive cancer information for health professionals and the public from the National Cancer Institute.

Newsletter

The Consortium published the second issue of its newsletter in 2002. The newsletter is disseminated to a broad group of cancer researchers, health care practitioners, and other interested individuals and

organisations in the three jurisdictions and elsewhere. The newsletter covers recent activities, highlights people involved in the Consortium, features photographs of meetings and other events, and contains information on contacting the Consortium. The Consortium seeks to expand its mailing list for the newsletter and invites interested recipients to provide their contact information through the Web site or Help Desk.



Help Desk

The Consortium manages a Help Desk through which anyone interested in the Consortium can be connected to the participating partners. The Help Desk provides telephone and e-mail concierge service, where a Consortium representative will direct you to the right person to talk to for training opportunities or to get answers to general questions about Consortium programmes.

Telephone: 001-301-496-5534
E-mail: consortium@cancer.gov



CONSORTIUM IN THE NEWS

The year 2001 saw the publication of two articles featuring Consortium activities in *The Oncologist*. And in 2002, U.S. Secretary of Health and Human Services (HHS) Tommy G. Thompson highlighted the Consortium's activities in his 7 February address to the HHS U.S.–Irish Business Summit in Washington, D.C.

“The NCI-Ireland Consortium”

Consortium members Patrick Johnston and Peter Daly authored “The NCI-Ireland Consortium: A Unique International Partnership in Cancer Care.”* The article outlines the Consortium's history, goals, programmes, progress, and future plans, and also provides information on cancer services and morbidity and mortality on the island of Ireland.

Dr. Johnston of Northern Ireland and Dr. Daly of Ireland conclude, “There is no doubt that the NCI All Ireland Agreement...has become a major milestone agreement for international cancer care. The Consortium has successfully begun to join both jurisdictions with the U.S. in a quest toward improved cancer care and treatment for our people and in the process has fostered improved relations... Already cancer patients and their families on the island of Ireland are beginning to benefit from this initiative.”

“Broadcast Quality Teleconferencing for Oncology”

Also published in *The Oncologist*, “Broadcast Quality Teleconferencing for Oncology”** was co-authored by Donal Hollywood and Desmond O’Loan, members of the Consortium’s Information Technology

Working Group, in conjunction with James J. A. McAleer. The article describes how the Memorandum of Understanding establishing the Consortium facilitated the export of the NIH-developed TELESYNERGY® teleconferencing system to Ireland and Northern Ireland.

The authors identify professional applications of TELESYNERGY®, including clinical case conferences, grand rounds, expert case review, multicentre radiotherapy planning, clinical management protocol development, distance learning, seminars, patient screening for clinical trials, and non-oncology applications. “The TELESYNERGY® system,” they explain, “ensures that each patient, regardless of location, will receive an expert assessment and be given optimal therapy.”

U.S. HHS Secretary Tommy Thompson’s Remarks

Secretary Thompson’s 7 February 2002 remarks about the Consortium were addressed to the HHS U.S.-Irish Business Summit. The summit brought together business and scientific leaders on behalf of establishing better ties among the United States, Ireland, and Northern Ireland.

Secretary Thompson described the Consortium as “an exciting research initiative” begun in October 1999. “We forged this partnership to enhance cancer research, care, and treatment on the island of Ireland and to promote an international dialogue in a quest for the cure,” he explained. “The project involves scholar exchange, nursing, information technology, cancer registries, clinical trials, and prevention. Working together on cancer research, we can save lives.”

* Patrick G. Johnston, Peter A. Daly, “The NCI-Ireland Consortium: A Unique International Partnership in Cancer Care.” *The Oncologist* 6:453-458. Available online at www.theoncologist.com.

** James J. A. McAleer, Desmond O’Loan, Donal P. Hollywood, “Broadcast Quality Technology for Oncology,” *The Oncologist* 6:459-462. Available online at www.theoncologist.com.

2003 ALL IRELAND CANCER CONFERENCE

Plans are underway for the second All Ireland Cancer Conference, to be held 20-22 October 2003 in Cork, Ireland. The scientific conference will feature distinguished speakers from throughout Ireland, Northern Ireland, and the United States. It will be open to oncologists, researchers, nurses, students, and other health care professionals with an interest in learning about and enhancing cancer research on the island of Ireland.

This multidisciplinary conference is being developed around the following themes:

- Cancer epidemiology
- Treatment and clinical trials
- Cancer prevention
- Translational research
- Molecular bases for cancer
- Survivorship and aftercare
- Diagnosis and screening

The conference will offer a forum for the exchange of views and ideas between professionals from the cancer care and research communities in the U.S. and the island of Ireland and cancer experts from around the world. Attendees will have access to the latest updates on developments in cancer care and research.

Information is available on the Consortium Web site.

APPENDIX

Memorandum of Understanding Implementation Plan



MEMORANDUM
OF
UNDERSTANDING

among

The Department of Health and Children of Ireland, The
Department of Health and Social Services for Northern Ireland,
and The National Cancer Institute of the United
States Department of Health and Human Services

The Department of Health and Children of Ireland, the Department of Health and Social Services for Northern Ireland, and the National Cancer Institute (NCI) of the United States Department of Health and Human Services (hereinafter referred to as the Participants):

- Recognising that cancer is a major public health/health care problem causing premature morbidity and mortality;
- Recognising the necessity to apply the most effective preventive and therapeutic strategies to the management of this disease;
- Further recognising that these strategies can be most effectively implemented on an international and collaborative basis;

have decided to establish a multilateral partnership to continue and intensify co-operation in relation to cancer, that will lead to improved scientific programs in their jurisdictions, including the areas of:

- epidemiology
- prevention
- surveillance
- early detection
- treatment and research
- quality control
- education and training
- information collection and dissemination; and
- interactions aimed at enhanced public health and patient care.

and hereby establish an Ireland-Northern Ireland-NCI Cancer Consortium.

I. Scope of Understanding

The Participants intend to:

- Identify infrastructure improvements necessary for the island of Ireland to further cancer research and clinical cancer investigations;
- Formalize and facilitate interactions among the U.S., Irish, and Northern Ireland cancer research communities;
- Develop joint programmes that will enhance the environment for clinical cancer research with the anticipated outcome of improved patient care;
- Develop educational exchange programmes for cancer personnel.

II. Programmes

A. Initial Programmes: While the scope of activities will evolve, several initial programme areas will be highlighted.

1. The enhancement and co-ordination of tumour registries in Northern Ireland and in Ireland.

A requirement for successful epidemiological and health services research in cancer is the presence of an active tumour registry that can monitor population trends in cancer incidence and mortality. The programmes will accelerate the advances made by the Northern Ireland and Irish tumour registries through the sharing of expertise and technology and will also expand efforts to co-ordinate data collection, analysis, and reporting between the two tumour registries.

2. *The enhancement of the informatics infrastructure to support co-ordinated clinical trials throughout the island of Ireland.*

For the informatics initiative, attention will be focused on two areas:

- (a) **Telecommunications:** The identification of the requirements necessary to establish capacity for advanced telecommunications to permit remote co-ordination of clinical trials, especially in the field of radiation oncology.
- (b) **Clinical Trials Information System:** Information technology is a fundamental requirement for the advanced management of clinical studies. It is proposed, therefore, to establish a unified informatics approach for cancer clinical trials. Cancer centres in Northern Ireland and Ireland will participate in the development of the Clinical Trials Information System (CTIS) ongoing at the NCI. When completed, the CTIS will provide the information framework for collaborative clinical investigations among the signatories.

3. *Development of education/training and scholar exchange programmes.*

Programmes will be established for joint training and scholar exchange in cancer research. Exchanges will be arranged among NCI and Irish and Northern Ireland institutions that involve basic, clinical, and epidemiological investigations and that include the training of personnel, such as research nurses and clinical investigators, critical to the clinical trials process.

- B. New Programmes:** New programmes will be developed as appropriate, including the establishment of appropriate partnerships with advocacy groups, non-governmental organisations, and industry.

III. Governance

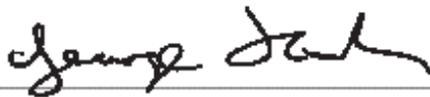
The collaborative programmes developed under this Memorandum will be overseen by a Board comprising representatives of the Department of Health and Children of Ireland, the Northern Ireland Department of Health and Social Services, and the National Cancer Institute of the U.S. Department of Health and Human Services.

- A. Membership:** The Irish Chief Medical Officer, the Northern Ireland Chief Medical Officer, and the Director of the National Cancer Institute, who may designate an alternate member to represent them. The Chair will alternate yearly between the Chief Medical Officers of Ireland and Northern Ireland, and management of the Board will be the responsibility of the Chair.
- B. Responsibilities:** The Board will determine the scope and priority of actions provided for in this Memorandum, including the development of strategic plans for cancer research. In conducting its work, the Board will consult with appropriate organisations and individuals, engage consultants, and establish working groups as required. The Board will implement and provide oversight of the programmes developed under this Memorandum. The Board will make arrangements for the transfer and distribution of funds, when appropriate, and Board members, representing the Participants, will determine the funding contributions necessary to support its activities, subject to resource allocation processes outlined in the resources section of this Memorandum (III C).

- C. Resources: Subject to the laws and regulations of the Participants, the availability of resources under the annual fiscal arrangements of the Participants, and the fiscal and operating procedures of each Participant, the Participants expect to provide funding to support the priority activities identified by the Board. Once funds are identified and approved for a project, the respective rights and responsibilities of each participant will be clearly specified in separate project arrangements.
- D. Meetings: The Board will meet within three months of the signing of this Memorandum and biennially thereafter. At the first meetings, the Board will develop procedures to support the conduct of its business.
- E. Reporting: The Board will submit an annual report to their respective departments.

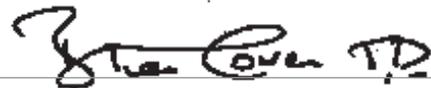
IV. Duration

Activities under this Memorandum will commence upon signature and continue for five years. It may be amended or extended by written consent of the Participants.



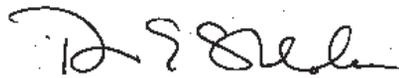
MR. GEORGE HOWARTH, M.P.
Parliamentary Under Secretary of State, Northern
Ireland Office of the Government of the United
Kingdom of Great Britain and Northern Ireland,
on behalf of the Department of Health and Social
Services

Date 3 October 1999 location Belfast



MR. BRIAN COWEN, T.D.
Minister for Health and Children, Government of
Ireland, on behalf of the Department of Health
and Children of Ireland

Date 3 October 1999 location Belfast



DYNNA E. SHALALA, Secretary of Health and
Human Services, United States of America

Date 29 September 1999 location Washington, D.C.



Ireland-Northern Ireland-National Cancer Institute Cancer Consortium

IMPLEMENTATION PLAN

I. DESCRIPTION OF CONSORTIUM

A. Membership

The Ireland-Northern Ireland-National Cancer Institute Cancer Consortium consists of representatives of the Department of Health and Children of Ireland, the Department of Health, Social Services and Public Safety of Northern Ireland, and the National Cancer Institute of the United States Department of Health and Human Services.

B. Origin

The Consortium was established as a result of a Memorandum of Understanding (MOU) between the three governments, signed in Belfast in October 1999. This MOU was a result of detailed consultation between the three governments which recognised the fact that cancer was a major public health and health-care problem causing premature morbidity and mortality in all three jurisdictions and recognising that preventive and therapeutic strategies could most effectively be implemented utilizing an international and collaborative forum. The potential for such collaboration, particularly between the two Departments of Health on the island of Ireland, was enhanced by developments in the broader framework of relations, which were being devised under the terms of the Belfast Agreement.

C. Duration

Under the terms of the MOU, the Consortium will, in the first instance, exist for five years from the signing of the MOU.

II. MISSION

The Consortium's mission is to continue to intensify co-operation between the Department of Health and Children of Ireland; the Department of Health, Social Services and Public Safety of Northern Ireland; and the National Cancer Institute of the United States, in relation to cancer, that will lead to improved scientific programmes in their respective jurisdictions, including the areas of:

- Education and training
- Treatment and research
- Information dissemination
- Epidemiology
- Cancer prevention
- Surveillance
- Early detection
- Quality control
- Interactions aimed at enhanced public health and patient care

III. SCOPE OF CONSORTIUM

- A. Identify infrastructure improvements necessary for the island of Ireland to further cancer research and clinical cancer investigations
- B. Formalise and facilitate interactions between cancer research communities in the United States and the island of Ireland
- C. Develop joint programmes that will enhance the environment for clinical cancer research leading to improved patient care
- D. Develop educational exchange programmes for cancer personnel

IV. GOVERNANCE

- A. The activities comprehended within the MOU will be managed by the Consortium Board of Directors, which will initially consist of the Chief Medical Officer of Ireland, the Chief Medical Officer of Northern Ireland, and the Director of the National Cancer Institute who each may designate alternate members to represent them. The Chair will alternate annually between the Chief Medical Officers of Ireland and Northern Ireland, and the management of the Board's activities will be the responsibility of the Chair for that period.
- B. While the Board will generally utilize the consensus method to obtain decision, there may be instances when a vote of the majority is required. Each Board member has one vote.
- C. There will be, at least, two meetings of the Board per year and communication between meetings will be transacted by means of conference calls between Board members at a frequency to be decided by the Board.
- D. The Board will submit an annual report to the participating departments.

V. ACTIVITIES

- A. The creation of the Consortium was to ensure the implementation and funding of programmes, projects and training that facilitate the objectives outlined in the MOU. In the first instance, the Consortium will identify and develop potential for co-operation in the following areas:
 - 1. The enhancement and co-ordination of cancer registries in Northern Ireland and Ireland
 - 2. The enhancement of informatics and other infrastructure improvements to support the conduct and co-ordination of clinical trials throughout the island of Ireland

3. Development of education/training and scholar exchange programmes
- B. This implementation plan outlines the two methods that will be used to establish, review and approve all Consortium-sponsored initiatives.
 1. **Working Groups:** The Board, at its discretion, will establish ad hoc working groups in areas designated under the MOU. The Chair, duration, responsibilities and membership of these groups will be agreed upon by the Board. Generally, the responsibility of these groups will be to stay abreast of needs and activities within their designated areas and to make recommendations to the Board on activities that will enhance the Consortium's objectives in that area. Proposals submitted by a working group should fully outline the proposed initiative, funding required (including staffing, supplies, travel, space and/or other resources required) and their recommendation for funding sources and/or cost sharing by Consortium parties.
 2. **Request for Applications:** The Board will be responsible for identifying targeted Consortium initiatives, where an open and competitive review and award process is desired. For each initiative, the Board will identify the scope of the project, funding available, size and scope of awards and the specific procedures associated with advertising the opportunity, application process and scientific/ administrative review of the proposals. The Board may also decide to handle proposals made by the working group, in a competitive manner.

VI. PROJECT FUNDING GUIDELINES

- A. Proposals must fall within the areas of activity identified in the MOU.
- B. Projects must be consistent with policies and strategic cancer plans of the health departments of the partners.
- C. Projects must demonstrate the benefits to cancer research in all three jurisdictions or, serving as a pilot project in one jurisdiction, demonstrate potential for wider applicability.
- D. Generally, each partner will directly fund its share of each

project, keeping accountability for the use of funds within existing monitoring agencies at the funding source.

VII. BOARD APPROVAL PROCESS

- A. All proposals, irrespective of origin, will be submitted to the Board through its administrative unit.
- B. Members of the Board, after initial consideration, based on the guidelines outlined above and/or in the light of available resources or other relevant information, may decide to accept or reject any proposal. Alternatively, the Board may refer the proposal for further review and recommendation to an independent assessor, or refer it to the appropriate Department for action.
- C. Those who have submitted proposals will be notified of the Board's decision via a document bearing the Chair's signature, which will be prepared by the administrative unit.
- D. Successful applicants will be expected to report progress on their funded projects by way of written submission to the Board, at least on an annual basis or as otherwise requested by the Board.

VIII. ADMINISTRATION AND CONTACTS

(Note: Tasks/level of effort must be within NCI-funded level for this contract. Therefore, specific tasks should be coordinated through NCI.)

- A. The Board has a centralised record-keeping and administrative unit whose role it is to:
 - 1. Maintain centralised correspondence files
 - 2. Co-ordinate Board meetings and conference calls
 - 3. Write, distribute, and file Board conference call and meeting minutes
 - 4. Maintain and distribute budget spreadsheets
 - 5. Prepare correspondence as requested by Board
 - 6. Prepare and distribute annual report
 - 7. Manage project applications process

- B. The Board operates a Help Desk/Information Clearinghouse to:
1. Collate pertinent educational opportunities for cancer investigators and students in Ireland, Northern Ireland and at the NCI
 2. Prepare relevant brochures to disseminate knowledge of programmes
 3. Develop and maintain a Web site for Consortium Board to include education opportunities, and updates on information technology development, all-Ireland clinical trials group, cancer registries, Board activity, and proposal funding opportunities
 4. Triage requests to appropriate authorities
 5. Answer procedural questions
 6. Track satisfaction of students and mentors in Scholar Exchange programme
 7. Maintain demographic records of scholars in Scholar Exchange programme
 8. Provide broker function between candidates and potential training programmes
 9. Maintain activity log of all inquiries and status of requests
 10. Report monthly to Board

