

Introduction: All Ireland Fatigue Coalition

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ABSTRACT

The first professional meeting and educational symposium of the All Ireland Fatigue Coalition (AIFC) convened in Dublin in September 2002, with an attendance of 350 health professionals who work in cancer research and cancer patient care. The AIFC is a multidisciplinary team of doctors, nurses, and other health care professionals from Ireland, Northern Ireland, and the U.S. whose mission is to champion the proactive

management of cancer-related fatigue. The major goals of the symposium were to better understand the status and prevalence of cancer fatigue on the island of Ireland and to learn how to better assess and manage fatigue in cancer patients. An international faculty presented on topics ranging from defining the condition to developing an international protocol implementing a fatigue algorithm. *The Oncologist* 2003;8(suppl 1):1-2

INTRODUCTION

On September 13-14, 2002, over 350 doctors, nurses, and other health care professionals came together in Dublin, Ireland for the first professional meeting and educational symposium of the All Ireland Fatigue Coalition (AIFC) to discuss the issue of cancer-related fatigue. The AIFC was formed under the auspices of the Ireland-Northern Ireland-National Cancer Institute (NCI) Cancer Consortium in recognition of the importance of cancer-related fatigue. Government interest and support from both Ireland and Northern Ireland were evident in the remarks made by *Dr. Henrietta Campbell*, Chief Medical Officer of Northern Ireland, and by *Mr. Brian Lenihan*, Minister of State for Children, and *Dr. Tony Holohan*, Deputy Chief Medical Officer of the Department Health and Children, both from Ireland.

There is an increasing recognition that cancer-related fatigue poses a major problem for patients, not only during their treatment but also during recovery and for many years thereafter. Fatigue is a devastating side effect of cancer treatment and the most important undertreated symptom in cancer patients, affecting over 80% of the patient population. Defining fatigue has not been easy, and because fatigue is a multifaceted problem, a comprehensive and succinct description still eludes us. Patients, however, frequently offer compelling descriptions of fatigue, which should lead

us to vigorously seek the means by which it can be alleviated. A striking description is offered by a patient who still contends with this problem 10 years after definitive cancer treatment:

Normal physical or mental exercise produces a tiredness which has a sense of well-being at its center. Postchemotherapy tiredness creates a negative sensation of being drained. Indeed, the experience of this kind of exhaustion has the sensation of water going out of a bath. I get about 10 minutes notice of energy running out. There is an almost physical sensation of the reservoir of energy being drained. In the early days, this experience created panic. Now, one lives with it knowing that the very immediate consequences will be a slurring of speech and the jumbling of words, a sense of leadenness, and the refusal of one's legs to do more than slither past one another in short mechanical steps. The only thing to do is to lie down and go to sleep. It is difficult to convey this sensation to others. Think of things conjured up by the word "groan," and you may begin to understand the profound sensations that cancer-related fatigue entails. Reflecting on my own efforts over more than 10 years to convey verbally that which I was feeling, I recollect using

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“I’m tired out,” “I’m exhausted,” “I feel drained,” “I feel completely and absolutely drained,” “I’m done,” which is a colloquial North of Ireland expression used to convey extreme tiredness, frequently used by old folk approaching death, and “I’m beaten,” a similar North of Ireland expression that encapsulates the sense that one may never again be able to engage in the game of life.

The organizing committee of the AIFC developed a program for this symposium, with three major goals: A) to understand the prevalence of fatigue in cancer patients and some biological and physiological effects of fatigue; B) to understand the status of cancer fatigue on the island of Ireland, based on results of patient and professional surveys, and C) to learn how to assess and manage cancer fatigue in patients. To achieve these aims, the AIFC convened a faculty of experts from the U.S., from Ireland and Northern Ireland, and elsewhere in Europe. The papers that follow in this publication were presented at that meeting. *Henning Flechtner*, M.D., Ph.D., Chair of the Joint Scientific Committee European Organization for the Research and Treatment of Cancer Quality of Life Group, provides insights into fatigue and quality of life [1]. *Ann Berger*, R.N., M.D., Chief of Pain and Palliative Care Services at the National Institutes of Health in the U.S., outlines approaches to treating fatigue in patients with cancer [2]. Focusing specifically on anemia as a cause of cancer-related fatigue, *Terry Lappin*, Ph.D., Chair of Hematology at Queen’s University Belfast, outlines the cellular biology of erythropoietin receptors [3], and *Mario Dicato*, M.D., Head of Hematology-Oncology at the Luxemburg Medical Center, discusses anemia in

cancer [4]. *Ms. Eileen Dillon* and *Ms. Joan Kelly*, leading cancer research nurses from Northern Ireland and Ireland, respectively, present the results of the AIFC surveys of professionals and patients [5].

A key element of this cooperative by the AIFC effort is the development of a research project on implementing a fatigue algorithm in a clinical trial to be conducted in three countries—Ireland, Northern Ireland, and the U.S. This protocol is being designed by the Clinical Trial Subcommittee of the AIFC, consisting of *Dr. Ann Berger* from the U.S. National Cancer Institute, *Dr. Martin Eatock* from Belfast City Hospital, *Dr. Maccon Keane*, University College Hospital in Galway, and *Dr. Maeve O’Reilly*, St. Luke’s Hospital in Dublin. The group presented at the symposium and is working toward a launch of the trial in early 2003.

The AIFC meeting opened with a moving reminder of why we do this work. Former cancer patient *Maureen Gilbert* spoke of her journey with cancer in a live interview by *Elwyn Evans*. Her story is included in this publication [6]. The meeting closed with a commentary on the AIFC initiative and a look toward the future by *Dr. Gregory Curt*, former Clinical Director at the U.S. National Cancer Institute, and *Dr. Patrick Johnston*, Professor of Oncology at Queen’s University Belfast, Director of the Cancer Research Center at Belfast City Hospital, and Co-Chair of the AIFC [7].

It is a source of great satisfaction that the activity of the AIFC has been accepted as a component of the work of the Ireland-Northern Ireland-NCI Cancer Consortium. We hope to flourish under that umbrella and to deliver results that will be of major benefit to cancer patients everywhere.

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