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**Despite a year of treatment, 80% of Irish patients participating in European study still suffering from chronic pain**

**More than 15% of patients with chronic pain feel their pain is sometimes so bad they want to die**

**European Federation of Chapters of the International Association for the Study of Pain (EFIC) Congress, Lisbon (10 September 2009):** A new survey, the first of its kind to track the impact of ongoing chronic pain on patients' lives over the course of a year, has found that despite a year of treatment for their pain, 80% surveyed are still suffering from chronic pain. And worryingly, more than 15% feel their pain is so sometimes so bad they want to die.

The survey, entitled PainSTORY (**Pain Study Tracking Ongoing Responses for a Year**), involved 294 patients in 13 European countries, including 25 Irish patients. The results demonstrate that the emotional impact of pain and the effect it has on social relationships is as, if not more, detrimental than the physical impact. Patients reported feeling trapped by a pain which may vary in intensity, but continuously affects every aspect of their life.

Alarming, despite continuing to suffer from chronic pain, a high proportion of the patients accept it as a permanent part of their lives that cannot be challenged. While one in four claim they are taking the most appropriate level of medication for their pain a huge proportion (80%) are still suffering inordinate levels of pain.

Commenting on the findings of the survey, **Hans Kress, President Elect, European Federation of Chapters of the International Association for the Study of Pain** said: "This research presents a unique insight into patients' year-long journey through pain. It is shocking to observe that after 12 months, patients are still trapped in an ongoing cycle of pain and a large proportion seem to be accepting the severe impact their pain has on their lives, and losing hope".

Patients surveyed said they mostly feel frustrated by their loss of independence and freedom in everyday life. Overall the study revealed that 86% of Irish patients felt that pain had a detrimental effect on their quality of life.

By the end of the year, 46% of patients reported feeling alone in tackling their pain and 55% of the Irish patients involved in the study feel anxious or depressed as a result of their pain. Patients highlighted the ongoing challenges with everyday activities such as childcare, with 21% reporting difficulties in looking after their children by the end of the research. The participating patients also revealed that pain has a significant impact on their ability to work with 77% of Irish patients surveyed worrying that their pain will mean they will eventually have to stop work completely.

Michael Bohill, Chairperson of the Irish Chronic Pain Association commented, "Chronic Pain sufferers need to be seen and diagnosed at the earliest possible stage so that appropriate treatments can be put in place to manage the pain and to alleviate some of the suffering.

"Chronic Pain can affect every aspect of a person's life. There are not only the physical aspects of the pain that need to be addressed but also the emotional and psychological strain it puts on their social life and their relationships. The feeling of isolation experienced by many chronic pain sufferers can be the hardest aspect to deal with. Chronic Pain patients need to be made aware that there is support available for all of those that want to share their experience with others."

The research also unveiled that one year on, chronic pain controls the life of six in ten patients, with more than half of patients' pain levels failing to improve. For 14% of the Irish patients, their pain has become even worse.

The survey findings point to a number of reasons for patients' ongoing suffering. Many patients may not be receiving the appropriate medication to control their pain - despite a year of treatment 80% of patients are still suffering from moderate to severe chronic pain, only 6% had been prescribed strong opioid medication at the end of the year-long research, with 64% resorting to over the counter (OTC) medication to try to manage their pain either alone or in combination with other therapies.

Commenting on the survey findings, ***Dr Tony O'Brien, Consultant Physician in Palliative Medicine at Cork University Hospital***, said: 'It is very distressing to note that such a large proportion of patients continue to experience uncontrolled pain. Sadly, many may suffer in silence. The human cost is immeasurable. These patients must have ready access to skilled health care professionals and be fully evaluated and assessed.

"In selected patients, a supervised trial of opioid medication will be necessary in order to achieve an optimal level of pain control. In this regard, care must be taken to prevent predictable opioid side effects, including constipation. Effective treatments are available and patients are encouraged to seek medical opinion at the earliest opportunity.'

More than half of all patients taking prescription medication report side effects, the most common of which is constipation<sup>1</sup>. Although highly effective in controlling pain, opioids can be associated with opioid-induced constipation (OIC). The research indicates that 26% of patients taking opioid medication turn to laxatives to help relieve their constipation, which may alleviate symptoms of OIC but will not address the cause of the problem.

Almost two fifths of patients in Ireland do not take their medication as prescribed which is the highest of all markets involved in the study. One main reason for this may be the experience of treatment side effects can have a major influence on patients' attitude to pain management.

Patients' contact with physicians may also be less frequent than is needed. Despite the high proportion of patients continuing to suffer pain, the number of patients visiting a doctor declined over the course of the year from 95% at the beginning of the year to 68% at the end. Of the 68% of patients who consistently consulted a healthcare professional across the year, only 2% had consulted a pain specialist consistently throughout the year by the end of the research.

**-ENDS-**

### **Note to editors**

#### **About the survey**

PainSTORY (**Pain Study Tracking Ongoing Responses for a Year**) is the first study of its kind to track patients with chronic pain over one year, providing in depth insight into how pain impacts the daily lives of patients and the management of pain in 13 European countries.

The PainSTORY survey was conducted by an independent research company, Ipsos MORI, in collaboration with the following independent third parties:

- European Federation of IASP Chapters
- World Institute of Pain
- OPEN Minds

#### **Methodology**

294 patients suffering from non-malignant (osteoarthritis, back pain / lower back pain, osteoporosis, neuropathic pain, mixed pain, other long term pain), chronic pain (i.e. lasting for more than three months) rating  $\geq 5$ -10 on a pain scale at screening stage (where 0 = no pain and 10 = the worst pain imaginable) completed the survey. Respondents were studied for 12 months with the research being carried out in 13 countries across Europe: United Kingdom, France, Germany, Switzerland, Italy, Spain, Ireland, Belgium, Sweden, Denmark, Finland, Netherlands and Norway by an independent research company, Ipsos MORI.

The study consisted of four waves of qualitative interviews between April 2008 and May 2009. Interim engagement activities such as diaries and 'life books' were sent to patients between the

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<sup>1</sup> The term 'constipation' incorporated bloating, stomach ache and stomach cramps

four waves to provide additional insight. Comparisons between baseline data and subsequent wave results showed how the impact of pain and pain management changes over the course of a year.

**Please visit [www.painstory.org](http://www.painstory.org) for further information, or contact:**

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