



the virtual lifeline for proactive cancer patients

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### Background:

The International Cancer Advocacy Network (ICAN) was established in 1997 as a 501(c)(3) charitable organization that has to date, assisted nearly 8000 late stage cancer patients from all 50 contiguous states and 40 different countries in their battle against metastatic cancer. ICAN is very much a volunteer-driven organization; its 700+ volunteers provide world class expertise in many disciplines, including basic, translational and clinical cancer research. ICAN stresses a personalized approach to cancer care for each individual cancer patient. ICAN relies heavily on new and timely data published in peer reviewed publications for the benefit of our cancer patients. An important part of our care is guiding each patient through biomarker and functional testing with the goal of improving their survival. Thus, keeping abreast of the latest developments published in peer reviewed scientific journals is of the utmost importance to ICAN and our patients.

### Addressing Question 6 of FR Doc. 2011-28623:

*How can Federal agencies that fund science maximize the benefit of public access policies to U.S. taxpayers, and their investment in the peer-reviewed literature, while minimizing burden and costs for stakeholders, including awardee institutions, scientists, publishers, Federal agencies, and libraries?*

Federal agencies that fund science maximize the benefit of public access policies to U.S. taxpayers **by eliminating all barriers for free public access to ICAN and similar 501(c)(3) charitable organizations, including access costs and all embargoes on free access.**

ICAN relies heavily on the literature for the most recent advances in cancer research and care. The costs of journal subscriptions are, simply put, overwhelming for ICAN, especially in this current economic climate. ICAN is delayed, often for long periods of time, from accessing state of the art research publications that would otherwise be of immediate help to our patients.

Waiving the cost barrier and embargo period for 501(c)(3) charitable organizations is, without question, a win-win situation for all interested parties, and it absolutely must be considered as a part of this legislation. It will have an immediate short term benefit of extending the survival of at least some of our patients. And, as discussed below, it will ultimately result in the development and discovery of new areas of research and innovative treatment protocols that will expand the scientific literature, thus providing an advantage for publishers.

**Addressing Question 8 of FR Doc. 2011-28623:**

*What is the appropriate embargo period after publication before the public is granted free access to the full content of peer-reviewed scholarly publications resulting from federally funded research? Please describe the empirical basis for the recommended embargo period. Analyses that weigh public and private benefits and account for external market factors, such as competition, price changes, library budgets, and other factors, will be particularly useful. Are there evidence-based arguments that can be made that the delay period should be different for specific disciplines or types of publications?*

As a 501(c)(3) charitable organization that interacts on a daily basis with late stage cancer patients, ICAN absolutely requires timely access to breaking peer-reviewed journal articles. This is a heavy cost burden for both ICAN and our patients and this places an unnecessary and easily correctable financial barrier between our patients and their optimal care.

Considering the many therapeutic advances and accomplishments that were driven by creative and persistent patients and advocacy groups such as ICAN, it is paramount and crucial that 501(c)(3) charitable organizations be exempt from any embargo period placed on peer-reviewed publications attained from federally funded research. The new and novel areas of research and clinical trials resulting from such efforts will undoubtedly open up new chapters for publication in scientific journals, thereby adding to their bottom lines. In summary, creating cost and embargo exemptions for 501(c)(3) charitable organizations are in the best interests of all concerned parties.

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