

What is IKCC afraid of?

Patients must have assurance and trust that the information and advice they receive from not-for-profits about their treatment options is objective, unbiased, and in no way unfairly influenced.

Chicago, Dec 08, 2011 -- Last year, we expressed concern about a new organization in the kidney cancer community that sought to consolidate the activities of many kidney cancer not-for-profits into one "super organization."

Following this group's first meeting in Germany last year, we emailed several times to request some basic information, including questions regarding governance structure, the role of industry in its operations, and full disclosure of the member organizations. We are still waiting for a reply. On its website, IKCC indicates that they will provide feedback and a summary of the evaluation forms from its meeting in Germany. No such information has been provided.

When our organization, the Kidney Cancer Association, was asked to participate, we said "no," quite firmly and quickly. The apparent lack of responsiveness and transparency concerns us. We see that the project is moving forward, with another meeting scheduled in Italy in the spring of 2012. We still think it's a terrible idea. Furthermore, IKCC indicated that more reports -- including a financial report from the 2010 meeting -- would be forthcoming. This has not been done and is such a glaring omission that, clearly, should raise a red flag with past and potential sponsors.

Just as it has from the beginning, this new organization seems to be tone deaf when it comes to the need of placing well-defined barriers between sponsorship and advocacy, as reflected by its unwillingness to make reasonable public disclosures as we requested last year.

None of the organizations represented on IKCC's steering committee appears to be accredited by any recognized authority that would indicate rigid adherence to third-party ethical standards. And that lack of formal accreditation – or a firm ethical footing – remains a genuine concern.

Simply stating that IKCC adheres to a purely voluntary code of conduct, as it does on its website, in the absence of rigorous third-party accreditation, including disclosure of financials, is unacceptable. Patients and their families should be skeptical of the organization and its motives.

We're also troubled by the fact that the very organization that created this "code" –

the ECPC – has, itself, been mired in governance and policy controversies, including the abrupt resignation of its founding-member president and CEO.

Through its lack of true accreditation by an independent authority and its failure to be transparent and adhere to funding practices honored by legitimate members of the not-for-profit community, IKCC is opening a huge door through which outside influence can march, unimpeded. And that's a very bad precedent for all of us.

Patients must have assurance and trust that the information and advice they receive from not-for-profits about their treatment options is objective, unbiased, and in no way unfairly influenced.

As we've said before, that's ethics 101.

We have worked with grantors to ensure the information we provide patients and physicians is accurate and up to date and we will continue to do so in the future. But we do it in the right way – by adhering to standard rules for disclosure and transparency – not to a "code" that allows clear conflicts of interest and does not provide for disclosure of funding.

Unfortunately, IKCC is choosing to go down the wrong path. Shame on them and shame on those who don't demand that this organization clean up its act before it holds another meeting.

Contact Information:

Name: Paula Bowen and Bill Bro

Company: Kidney Cancer Association

Email: iltel@live.com