Author's response to reviews

Title: Ocular gene transfer in the spotlight: implications of newspaper content for clinical communications

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Version: 2 Date: 22 May 2013

Author's response to reviews: see over
May 21, 2013

RE: Ocular gene transfer in the spotlight: implications of newspaper content for clinical communications

To the Editor,

I am writing to propose a research article for publication in *BMC Medical Ethics*. Our paper addresses the contemporary case of newspaper coverage of ocular gene transfer (gene therapy) research. It illustrates ongoing challenges in media coverage of novel biotechnologies as they reach clinical application and makes recommendations for communications between media and researchers. However, it is novel in providing recommendations for clinician-patient communications, especially in the context of recruiting ocular gene transfer clinical trials that take account of the media landscape.

The field of gene transfer has been subject to adverse events, such as cases of leukemia and deaths, as well as abuses, including non-disclosure of adverse events in clinical trials to regulatory agencies and highly publicized conflicts-of-interest [1]. These have damaged the reputation of gene transfer [1-3], eroded public trust in the biotechnology, and presented significant setbacks for its clinical development [4,5]. At this time, the first tangible successes are beginning to materialize in the area of ocular gene transfer. Current gene transfer clinical trials address a variety of ocular genetic diseases including Leber congenital amaurosis (clinicaltrials.gov: NCT00999609); Stargardt disease (clinicaltrials.gov: NCT01367444); retinitis pigmentosa (clinicaltrials.gov: NCT01482195); Usher syndrome (clinicaltrials.gov: NCT01505062); and choroideremia (clinicaltrials.gov: NCT01461213). In response to the checkered history of gene transfer, the emergence of successes in recent clinical trials necessitates ethical communications that promote public trust for the sustainable translation of gene transfer efforts.

Our study investigates the communications landscape of newspaper media about ocular gene transfer research, as media is the most accessible source of information about biomedical research to patients [6]. Several studies have suggested that media sensationalizes biomedical research, most prominently through omission of details rather than outright errors in reporting [7-9]. Our study shows little improvement in media communications about gene transfer in the past decade, despite past initiatives to improve journalism on novel health technologies [9-15]. Media reports continue to be overly optimistic and framed as human interest stories, whether from the perspective of the heroic researcher or hopeful patient. Most concerning, however, is the continued lack of coverage of issues closely tied to public trust, such as funding and conflicts of interest. Given the history of gene transfer, such issues should be at the forefront.
Most significantly, our study discusses how media exaggeration of medical benefits may compromise the integrity of informed consent in enrolling clinical trials. Our discussion, therefore, focuses improving communications between clinicians / clinical trial investigators and their patients / potential clinical trial participants in light of overly positive media coverage. We discuss the implications for the informed consent process.

Our expertise lies in science communications about novel biotechnologies. Additionally, we have significant experience working with the ocular genetics clinical and patient communalities. We are enthusiastic about publishing this original research study in *BMC Medical Ethics*. To our knowledge, a longitudinal analysis of ocular gene transfer media communications has not been published. Moreover, our approach of addressing media communications in clinical settings and in the context of enrolling clinical trials is novel. As such we believe our proposed analysis is timely and will be of interest to your readership.

We would like to suggest the following experts as peer reviewers for our manuscript:

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Thank you for your consideration.

Yours sincerely,

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References: