





### OBJECTIVES

The purpose of this education modules is to provide users with an opportunity to critically challenge assumptions, values and beliefs about philanthropic organizations through the use of a variety of approaches, including...

#### The Documentary:

- + **Pink Ribbons, Inc.**

#### Associated Video Clips from the Documentary on Related Themes:

- + The politics of research funding
- + The women’s health movement and pinkwashing
- + Bioethics—the case for orphan cancers

#### Suggested Readings

#### Sample Case Studies

#### Sample Assignments and Grading Matrices

### OUTCOMES

Expected outcomes from these education modules for learners include but are not limited to:

- + Enhanced critical thinking and problem-solving skills through various models of “questioning”
- + Enhanced professional development through an environment that creates, fosters and sustains “questioning insight” as a mechanism for knowledge acquisition, integration and practice change
- + Enhanced ability to engage in reflective practice
- + Broadened world view through the integration of socio-cultural, socio-political and bioethical world views

Expected outcomes from these education modules for educators include but are not limited to:

- + Ability to integrate an Action Learning approach within the educational setting to increase transfer of knowledge and stimulate critical thinking and reflective practice
- + Exposure to alternative mechanisms for evaluating knowledge acquisition and application
- + Integration of an interpretive pedagogical approach to learning through the creation of an environment within which both educator and student learn to become inquirers; ability to be free to explore, co-create and uncover new knowledge

### INTRODUCTION

One of the most successful awareness campaigns targeting cancer is related to breast cancer. The Pink Ribbon Campaign has grown beyond a grassroots movement founded by 68-year-old activist Charlotte Haley in an effort to raise awareness about breast cancer and the need for funding to support prevention research. But has the campaign met its objectives? Barbara Brenner of San Francisco, who for 15 years led the advocacy group Breast Cancer Action, known for its Think Before You Pink campaign launched in 2002, said, that “if people really knew what was happening, they would be really pissed off” (*Pink Ribbons, Inc.*, 2011).

Furthermore, the landscape of philanthropy has shifted from grassroots initiatives, such as the Canadian Cancer Society (which was founded in the 1950s and funded by board members, private donors and the community), to models that more closely reflect government policy and corporatization. The pink ribbon has come to exemplify a capitalist philosophy by creating a viable link between business and breast cancer, with the “bottom line” as the new objective. It is not uncommon for businesses to support breast cancer advocacy and/or awareness on the one hand, while marketing products with known carcinogenic agents that may increase the risk of developing cancer on the other.

Although the Pink Ribbon Campaign may appear to be about connecting, communicating and conquering breast cancer, the actual message may be misleading. Is it about cure and survivorship, or is it about how pink sells? Has research made a difference in identifying a cure? Has behaviour changed? How much emphasis has gone into prevention strategies? Are all groups of affected women and men reflected equally in the campaign? Where do women and men diagnosed with locally advanced and metastatic disease fit within a philosophy focused on survivorship and cure?

Interestingly, the status quo has remained relatively unchanged despite the millions of dollars invested in research targeting a cure, with only 15 per cent of fundraising going to prevention, and five per cent of that supporting research into possible environmental causes of the disease. More importantly, researchers suggest that more than 50 per cent of breast cancer patients do not have known risk factors. Does finding a cure sound nobler than prevention and risk identification?

Activists suggest the campaign has been successful in creating a culture wherein breast cancer appears to target ultrafeminine, middle-class women. Who else could be associated with soft pastel pink? The pink-wash message appears comforting and nonthreatening—everything breast cancer notably is not. It’s about quick fixes diverting us from what is currently beyond our control: survivorship and cure.

#### CREDITS

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The documentary challenges us to see the faces of breast cancer rather than the pink ribbons. It encourages us to think critically and call into question the meaning and purpose of the campaign. It is provocative, discomforting and noncomplacent—a heady mix guaranteed to stimulate debate and encourage us to more closely examine social activism and how easily it can become corporatized under the umbrella of philanthropy. It is our hope that these education modules, with associated suggestions, will be used to open dialogue among students and educators alike. More importantly, they may afford a starting point for action to take place. It is not about ending the campaign but about changing the message—a process that starts with open dialogue.

We invite educators to draw on these modules as a starting point around which a meaningful series of discussions and evaluation exercises relevant to their discipline or field of practice can be built. They are not meant to be used as prescribed exercises but rather as springboards to innovation. While many of the examples have been created within the context of nursing, the documentary (*Pink Ribbons, Inc.*, 2011) and modules can be modified for use within a broad range of disciplines, from the arts and social sciences to medicine, epidemiology and the environmental sciences. By setting these modules within a framework of interpretive pedagogy and Action Learning, knowledge acquisition becomes a process of transformation that includes the learner's ability to become free to "play" (Caputo, 1987). Our approach is intended to move learning from a prescriptive, rote and detached method to one that fosters creativity, exploration and inquiry. The modules have purposely been left flexible, with a variety of suggestions that are open to unique interpretation. In essence, the content arises from the process of inquiry and engagement between learner and educator (Hartrick Doane, 2002).

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## FRAMEWORK

This learning module takes an Action Learning approach, which provides a continuous process for learners to:

Work on real issues;

Reflect on past actions;

Plan future actions.

Action Learning promotes a connection between reflection and action to support change. The concept of Action Learning originated in the pioneering work of Reg Revans in the 1940s (Smith, 2001). It is described as a continuous process that supports an environment where "set members" (group members) work on real issues, reflect on past actions and plan future actions (McGill and Brockbank, 2004). Reflection, action

and learning are achieved through "double-loop learning" when there is a desire for major change. In double-loop learning, the subjective world of the participant and the taken-for-granted world of practice are challenged. Set members' ways of seeing the world would change if the issues presented focused on the system rather than the individual. Individuals or set members learn from their experiences and transfer this learning into practice. Change from the learning is likely to occur through members' reinterpretation of previous experiences rather than through the simple acquisition of new knowledge (Revans, 1998). Thus, Action Learning is a highly structured approach.

It is intended that learners will create an environment of high challenge through the questions they and their colleagues pose regarding one another's approaches to clinical care and working with others. Students will listen to one another present "their" issues. In order for the students to understand the presenter's issue, they will use reflection and questioning in response to the presenter.

Students' questions are intended to benefit the presenter and not to serve the remaining members' desire for more detail about the issue. The focus during a presentation is to support the presenter. Questioning is intended to further the presenter's thinking and awareness of his or her respective issue. Establishing ground rules will support only one set member speaking at a time and encourage all members to respect comments from the others.

As a supportive and challenging group-learning process, Action Learning also incorporates each set member's world and the "social context of their everyday life" (McGill and Brockbank, 2004, p. 14). Participants in an Action Learning process complete a double-loop learning cycle. Initially, the participants undergo a single-loop learning cycle: reflection, generalization, testing and experience. Once the set members have completed the single-loop learning cycle, they enter double-loop learning. During this shift, participants question one another on the knowledge that is "taken for granted." It is believed that this questioning will permit a better view of the participants' "way of seeing the world" and ultimately will lead to a change in practice if this new view is not compatible with current practice. Through this lens, set members can identify inhibitors to current practice and can then plan action for future behaviour. For example, single-loop learning asks, "How can we do what we are doing better?" Double-loop learning asks, "Why do we think this is the right thing to do?" and involves scrutinizing values, thinking and assumptions.

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## THE POLITICS OF RESEARCH FUNDING

The patients' advocacy movement informing research policies initially began in the 1980s. Its focus was primarily risk reduction for participants and the public; less emphasis was placed on benefits arising from research (Dresser, 2001). Advocates supported government policies that enhanced access to experimental interventions as a mechanism for renewed hope through improved treatment options. In his testimony to the U.S. Senate inquiry on research, cancer survivor and activist Michael Milken stressed the need for expanded research opportunities:

"If we have a real war on cancer, then why not issue 'cancer war bonds'? Why not extend patent lives, accelerate FDA approvals and authorize direct contracting with corporations for research and development? That kind of public-private partnership helped win World War II, and it can win World War Cancer." (June 16, 1999, cited in Dresser, 2001, p. 47)

As advocates became more firmly involved in the reshaping of research policies, the landscape of research funding began to shift. By the 1990s, funding moved from the public and researchers as beneficiaries of research to individuals and individual diseases (Best, 2012). Well-organized advocacy groups with articulate spokespeople saw dramatic increases in research funding. Furthermore, in the United States, the National Institutes of Health came under increasing political pressure from lobbyists as well as individual-disease advocacy groups to use mortality as the measure for funding allocation. Advocates challenged scientific autonomy (Guston, 2000), increased the influential power of lay knowledge (Epstein, 1996) and ultimately changed how medical knowledge was not only produced but disseminated (Clarke et al., 2003; Epstein, 2007).

While disease advocacy groups changed the landscape of science and knowledge production, an understanding of the overall effect of such groups on medical policy-making remained nebulous (Gross, Anderson and Powe, 1999; Hedge, 2009; Best, 2012). Arguments for funding were now based on "deservedness," with nonstigmatized diseases benefiting based on suffering. In contrast, diseases associated with personal responsibility, such as lung cancer, cervical cancer or liver disease, required advocacy groups representing these constituencies to expend considerable time and energy diffusing stigma, which placed them at a significant disadvantage (Kromm, Smith and Singer, 2007; Best, 2012).

Rebecca Dresser has written extensively on the changing landscape of research as a result of disease advocacy groups. In a 2003 paper, she identifies five general themes evident in advocacy activities. First, advocates frequently fail to clearly distinguish between proven and investigational interventions for medical care by stressing the positive aspects of biomedical research. When patients suggest that research "can end the suffering and deprivation inflicted by illness" (Dresser, 2003, p. 240), they promote a widely held misconception that research will invariably produce useful results, and vastly underestimate the time it takes to realize practical applications.

Second, advocacy groups tend to evaluate the quality of research by its ability to humanize and democratize; that is, they shift the focus from scientific curiosity and career advancement to patients' health-care needs. Although this shift may be perceived as improving research, it carries a downside: emphasis is placed on applied and/or interventional studies, with fewer dollars allocated to bench science, the underpinning for translational research. One example was the introduction of bone-marrow transplantation for the management of advanced and metastatic breast cancer in the United States in the early to mid-1990s (Bergh, 2000). It would appear that American culture supports a philosophy whereby a "more is better" approach should be taken (Lerner, 2001). As a result, more harm than benefit may ensue when well-intentioned advocates push for interventions that have not been clearly proven to show benefit, such as in the case of bone-marrow transplantation.

Third, Dresser points to the dilemma of deciding who has legitimacy as an advocacy representative in the research process, and what knowledge they bring to the table. Lay knowledge, or experiential knowledge, has been the primary driving force behind much of the patient advocacy movement. As a result, members of these groups may rely on personal experience, assumptions about what might be best or, in some cases, a close alliance with Big Pharma.

In Canada, the debate around the pharmaceutical industry's role in research decision-making has come under close scrutiny recently with the appointment of Pfizer's vice-president and medical director, Dr. Bernard Prigent, to the Canadian Institute for Health Research (CIHR) governing council (Silversides, 2009). Three Dalhousie University bioethicists argue that this appointment undermined CIHR's ability to intervene credibly in the complicated debate over a novel surgical procedure that some believe can alleviate the suffering of multiple sclerosis (MS) patients (commentary by Herder, Downey and Baylis, 2009). Dr. Ashton Embry, the father of an MS patient and one of the co-founders of DirectMS, suggests that many of the participants in a recent meeting between CIHR and the MS Society were in "overt conflict of interest," which, in his view, biased them against nondrug therapies such as the surgical procedure advocated by Dr. Paolo Zamboni ([noveltechethics.ca/files/files/ELA2/MScontro-versy.pdf](http://noveltechethics.ca/files/files/ELA2/MScontro-versy.pdf)). Furthermore, according to the three ethicists at Dalhousie, the relationship between CIHR and Pfizer, through Prigent's appointment, may taint the "legitimacy and integrity of CIHR's decision-making" in the minds of some members of the public.

Fourth, Dresser suggests that advocacy is designed to ensure fairness by reinforcing the values and preferences of those directly affected by research programs. However, if advocates are not well-informed and rely heavily on experience or on others with targeted agendas such as Big Pharma, they may actually increase unfairness in research decision-making by disadvantaging certain groups such as marginalized or stigmatized populations, or those with advanced and metastatic disease who have little hope for cure.

Finally, Dresser highlights the role of—and tensions in—the relationship between advocacy groups and bioethicists. Ethicists place emphasis on harm as well as benefit, she states, whereas advocates tend to emphasize the latter. While Dresser's arguments may have carried more weight in 2003, some advocates today are as critical of cheerleading approaches to medical research as the ethicists she cites.



If we consider the role and strategies employed by advocacy groups, then it should come as no surprise when researchers in the documentary **Pink Ribbons, Inc.** highlight the inequalities in research funding. Where is the support for men diagnosed with breast cancer, or women whose breast cancer is no longer curable? Although emphasis on cure remains a primary focus, achievement of this goal has changed little in the past 25 years. Charlotte Haley first proposed breast cancer advocacy as a mechanism to support development of prevention strategies to decrease the risk, yet less than 15 per cent of research monies raised through the movement goes toward prevention. Perhaps more disconcerting is that only five per cent of research goes toward exploring the environmental links with breast cancer, despite the fact that known risk factors, such as BRCA1 and BRCA2 genes and hormonal factors, only provide a partial picture of our risks.

In considering research priorities, sociologist David Hess writes about “undone science [which] refers to absences of scientific research that social movement and other civil society organizations find when attempting to make epistemic claims in the political field” (Hess, 2009, p. 306). Advocacy groups seeking to address the need for change frequently encounter research agendas that reflect the priorities of political and economic elites (Hess, 2009). Advocates, granting bodies, universities and large corporations such as those represented by Big Pharma frequently disagree over what research deserves funding and what research questions should be explored. A prime example of undone science may be found within the breast cancer movement, where environmental risk factors as contributors to breast cancer etiology remain marginalized as a focus for research (Frickel et al., 2010), despite the lack of progress on other risk factors (Poole, 2011).

### QUESTIONS

- 1 The film discusses research showing a link between workplace carcinogens and breast cancer, and suggests that pink ribbon marketing may contribute to the dearth of research funds invested in such studies. Do you agree? Outline the argument made and your reasons for agreeing or disagreeing.
- 2 “The causal agencies most commonly invoked [with respect to cancer] are too often defined as physical substances without social context: tobacco, asbestos, dioxin, and so forth. Insufficient attention is given to causal factors that transcend the physical: elections, advertisements, policies, and so forth.” (Proctor, 1995, p. 73)

Drawing from the film, discuss whether cause marketing should be considered a “causal factor that transcends the physical.”

### ADDITIONAL PERSPECTIVES FOR DISCUSSION

Films and article discussing the science on cancer and environmental exposure to toxic chemicals and radiation:

- 1 *Toxic Trespass and Exposure: Environmental Links to Breast Cancer* [womenshealthyenvironments.ca/programs/films](http://womenshealthyenvironments.ca/programs/films)
- 2 *Living Downstream* [livingdownstream.com](http://livingdownstream.com)
- 3 Story in the *Toronto Star* about the study of auto workers, featuring researchers Margaret Keith and James Brophy: [thestar.com/news/canada/article/1290646-researchers-behind-windsor-breast-cancer-study-not-shy-about-advocating-for-female-workers](http://thestar.com/news/canada/article/1290646-researchers-behind-windsor-breast-cancer-study-not-shy-about-advocating-for-female-workers)

See also: [thestar.com/news/canada/article/1289694-auto-plastics-industry-linked-to-breast-cancer-new-study-shows](http://thestar.com/news/canada/article/1289694-auto-plastics-industry-linked-to-breast-cancer-new-study-shows)

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## THE CULTURE OF PINKWASHING

The first breast cancer ribbon, created by Charlotte Haley in 1990, was peach-coloured and designed to raise awareness of the limited amount of funds allocated for breast cancer research. No one, however, could have predicted the level of popularity breast cancer awareness campaigns would achieve, or that breast cancer would become a model for cause-related marketing. In 1991, Estée Lauder and *Self Magazine* changed the colour from peach to pink in an effort to soften the disease and reflect its primarily female and feminine nature. Although the ribbon has become a symbol of strength, hope, responsibility and empathy for many, for others it reinforces a lack of “fit,” isolation, stigma and vulnerability for those diagnosed with advanced/metastatic disease and for men diagnosed with the disease.

The pink ribbon has also given the public a way to view breast cancer without having to envision the tumours, pain and side effects of treatment. Some authors, advocacy groups and researchers argue that the breast cancer ribbon has helped to shift the cultural landscape of the disease from one of stigma, secrecy and blame to one that honours breast cancer survivors. Paradoxically, however, the same campaign that encourages women to reject the “cultural code of silence and invisibility, that breast cancer is not shameful, that it is survivable, and that it is neither disfiguring nor defeminizing” (*Pink Ribbons, Inc.*, 2011) seldom shows mastectomy scars or disfigured bodies. In fact, women are encouraged to have reconstructive surgery or wear prosthetics and cosmetics in order to project an image of wholeness and femininity (Lorde, 1980; Batt, 1994).

The concept of “survivorship” is also of concern. While it can be used as a tool for constructing a frame of reference and attributing meaning to the breast cancer experience, the term can be alienating to those who succumb to the disease or who have a poor prognosis. The survivor is often represented as a person who is triumphant, happy, healthy and feminine. Barg and Grier (2008) speculate that the prevailing image of breast cancer survivorship is that of a young, professional, white and heterosexual woman. However, what about those who do not fit that image? For example, males make up one per cent of the population diagnosed with breast cancer, yet they have largely been neglected in breast cancer research and the media. This oversight has led to delays in diagnosis for males, as health-care practitioners and their patients are largely unaware that men may get breast cancer. This lack of focus has led to inadequate information specific to males with breast cancer, who may be provided with information covering topics such as menstruation, breast reconstruction and bra fittings. One result can be increased stigma for getting a “woman’s disease,” which in turn alters the amount of disclosure to family and friends and decreases emotional support.

One might also question how the gay and lesbian communities are integrated into the pink ribbon culture. Do they fit the stereotypical model for the pink ribbon? Pink is associated with femininity, sexuality, innocence and romance. However, lesbians frequently comment on their dislike of the colour pink, and use it as a means to tease each other. Canadian researcher Christina Sinding and colleagues interviewed lesbians with cancer and found the system of care did not address their psychosocial realities (Sinding, Barnoff and Grassau, 2004). For many males, the colour pink is anathema, perhaps as a result of social acculturation: blue is reflective of masculinity. This preference further supports the alienation of males diagnosed with breast cancer. Interestingly, some studies have

suggested that gay men may prefer the colour and have little difficulty identifying with pink. There is, however, a sense of gender inappropriateness often affiliated with the colour, in that “gay men are assumed to be feminine and gay women to be masculine” (Koller, 2008, p. 409), thus explaining their apparent colour preferences.

It should also be noted that the pink ribbon culture has often excluded black women, despite higher mortality rates when compared with white women. The disparity may be attributed to multiple factors, ranging from access to screening programs, delays in seeking medical care, or misperceptions that breast cancer is a predominantly white woman’s disease (media portrayals). Furthermore, cancer, in general, carries a degree of shame and stigma, despite increased awareness about the disease and associated risk factors.

### VIDEO CLIPS FROM PINK RIBBONS, INC. THAT MAY BE HELPFUL FOR DISCUSSION PURPOSES

#### Susan Love:

- + Media influence

#### Women’s Health – Barbara Brenner:

- + The history of the pink ribbon—the power of a button
- + Pinkwashing (where does the money go; categories of pinkwashers)

#### Charlotte Elliot:

- + The meaning of pink—colour codification
- + Pink softens the message

### SAMPLE QUESTIONS

- 1 How and in what way might pinkwashing erode past work that has helped to change the landscape of women’s health? Is pinkwashing a step backwards for women? Provide the rationale for your answers.
- 2 The film strongly implies that pinkwashing is at odds with the equality and health promotion goals of the women’s health movement. Do you agree?
  - a If not, explain why not.
  - b If you agree, how do you reconcile this inconsistency with the widespread acceptance of pink marketing? Wouldn’t at least some of the women in the film who seem to embrace pink marketing culture be feminists?
- 3 How and in what way does feminizing a disease serve to reinforce stereotypes and further marginalize populations falling outside of this socially constructed norm/perspective? (Consider lesbian, gay, bisexual and transgender people, as well as heterosexual males.)



- 4 What implications might the feminization of breast cancer have on health-care professionals' perceptions of breast cancer patients/survivors? For example, is there truth to the statement that there is a breast cancer patient personality? What might this mean, and how might it influence care delivery?
- 5 Has pinkwashing desensitized a generation to breast cancer? Consider, for example, a group of twentysomething women who were overheard talking about how "sexy" breast cancer was because the movement had all these exciting activities—from dragon-boat races, to Run for the Cure, to pink ribbons. Where might this attitude come from? Is this a cause for concern?
- 6 What role has the media played in the movement? Has it been positive or negative? How?
- 7 Considering the range of pink products marketed in the name of breast cancer and their relationship to women's health, is all pinkwashing counter to feminist ideals? Can a case be made, for example, that pink running shoes or pink tennis balls are "win-win" for the consumer and the seller?

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### ADDITIONAL QUESTIONS TO CONSIDER: DIFFERENT PERSPECTIVES

- 1 Compare and contrast greenwashing with pinkwashing: how are the approaches successful in creating awareness? The following blog may be helpful:  
  
[davidssuzuki.org/blogs/queen-of-green/2010/06/greenwashing-is-so-yesterday-today-its-pinkwashing](http://davidssuzuki.org/blogs/queen-of-green/2010/06/greenwashing-is-so-yesterday-today-its-pinkwashing)
- 2 Identify and discuss key ethical paradoxes within both pinkwashing and greenwashing.
- 3 Have students explore and discuss the various online cancer advocacy websites and forums. How do they serve to enhance our understanding of breast cancer and the women's health movement? What are their key messages?

Examples of various forums and websites include:

[notjustaprettyface.org](http://notjustaprettyface.org)  
[cancerschmancer.org](http://cancerschmancer.org)  
[thinkbeforeyoupink.org](http://thinkbeforeyoupink.org)  
[bcaction.org](http://bcaction.org)  
[bcam.qc.ca](http://bcam.qc.ca)  
[rethinkbreastcancer.com](http://rethinkbreastcancer.com)  
[willow.org/en](http://willow.org/en)  
[cbcn.ca](http://cbcn.ca)

- 4 Have students create their own YouTube video (prezi, GoAnimate or vodcast) conveying key messages or critiques about the role of pinkwashing and greenwashing. They may want to consider creating a video where they ask people on the street what their understanding of pinkwashing is.
- 5 Have students create a short drama that they play out in front of the class. The following article demonstrates how theatre may be used to enhance awareness and teach about metastatic breast cancer:  
  
Gray, R., Sinding, C., Ivonoffski, V., Fitch, M., Hampson, A. and Greenberg, M. (2000). "The Use of Research-Based Theatre in a Project Related to Metastatic Breast Cancer." *Health Expectations*, 3(2), 137–144.



## BIOETHICAL IMPLICATIONS: THE CASE OF ORPHAN CANCERS

As technology and drug prescribing continue to grow, a group of approximately 15 pharmaceutical companies referred to as Big Pharma has come to represent one of the most powerful profit-making industries globally (Sulik, 2011). Cancer drugs are one of the fastest-growing and bestselling categories of drugs, which has led to a heavy investment in oncology-driven research. More expensive drugs and growing markets have increased the “market leverage” for companies such as Pfizer, GlaxoSmithKline and AstraZeneca (Sulik, 2011). For example, Pfizer’s Aromasin, GlaxoSmithKline’s Tykerb and AstraZeneca’s Arimidex are new breast cancer treatment drugs with price tags that far exceed their proven benefits to patients (Cannistra, 2004; Le and Hay, 2009; Smith and Hillner, 2011). The patent life for many of these cancer drugs is relatively short, forcing pharmaceutical companies to explore alternative avenues for application in an effort to extend the patent licence. At the same time, every effort is made to stave off generic competition, which would significantly impact profit margins. The bottom line is that it is less about the patient and disease and more about business and profitability. Controlling how and in what way research is conducted would be to the industry’s advantage.

“The leaders of the cancer industry use pink ribbon culture and its roots in breast cancer advocacy to maintain a strong competitive edge in the cancer marketplace” (Sulik, 2011, p. 203). This has become a double-edged sword whereby pharmaceutical companies spend billions on direct-to-consumer advertising through “ask your doctor about X” campaigns by appealing to emotion, pressuring the medical community to prescribe largely through its patients (who may be less than discriminating in the value-add of the drug) and leading the consumer to believe they are making a difference—the only difference being more money for Big Pharma. As a result, one might ask what incentive there is to focus on rarer cancers, often referred to as orphan cancers, or those with advanced and/or metastatic disease.

The World Health Organization constitution states that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without the distinction of race, religion, political belief, economic, or social condition” (WHO, 2006, p. 1). In reality, those diagnosed with rare diseases or cancer experience significant inequities in care delivery as a result of numerous barriers, from lack of scientific knowledge (limited research focus) to organizational, financial, personal and social barriers (Kole and Faurisson, 2010). Rare-disease advocates frequently find their voices silenced or overshadowed by larger, well-organized, corporatized philanthropic movements such as the breast cancer Pink Ribbon Campaign (Hughes, 2013). For example, every day approximately 27 Canadians are diagnosed with a primary malignant brain tumour (Brain Tumour Foundation of Canada, 2013); few will survive beyond 12 to 14 months (Canadian Cancer Society Statistics, 2011). Brain tumour awareness month is October, the same month as breast cancer awareness and the pink campaign. Certainly, orphan cancers do not fit the preferred mould established by breast cancer advocacy groups, which place emphasis on survivorship and cure.

Advocacy groups have the collective power to promote or silence a cause. For those involved with rare cancers, such as the National Organization for Rare Disorders (NORD), advocacy is about advancing scientific understanding of, and better treatment for, patients diagnosed with rare diseases (Dunkle, Pines and Saltonstall, 2010).

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### QUESTIONS FOR DISCUSSION

- 1 Are the efforts of advocacy groups such as the Pink Ribbon Campaign overshadowing other, rarer forms of cancer, such as neurological cancers?
- 2 What are the implications for orphan cancers when advocacy groups become corporatized in the name of philanthropy?
- 3 Is there a role for social media in enhancing awareness about orphan cancers? Students may want to explore blogs by patients and families to get a sense of what is being talked about.



- 4 Breast cancer attracts marketers in large part because the disease affects so many people; orphan diseases, by definition, will never be able to claim the numbers of a common disease. But if cause marketing itself is problematic, should we be concerned if marketers overlook rare diseases? In fact, research suggests that these diseases have developed non-commercial models to advocate for their needs. Discuss, drawing from literature such as the following:

Black, A. and Baker, M. (2011). "The Impact of Parent Advocacy Groups, the Internet, and Social Networking on Rare Diseases: The IDEA League and IDEA League United Kingdom Example." *Epilepsia*, 52(s2), 102–104. Retrieved from [onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2011.03013.x/full](http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2011.03013.x/full)

Rabeharisoa, V. (2003). "The Struggle against Neuromuscular Diseases in France and the Emergence of the 'Partnership Model' of Patient Organization." *Social Science & Medicine*, 57(11), 2127–2136.

- 5 How should funding for disease-related research and support services be decided and prioritized, if not by the numbers of people affected and their advocacy?

### POSSIBLE ACTIVITIES

- 1 Have students create a short video where they ask members of the public, other students, etc., their opinion of advocacy groups and the impact these groups have on disease awareness, research funding and prevention. They may also want to consider the question of the impact large philanthropic advocacy groups such as the pink ribbon or prostate cancer movements have on rarer cancers. For example, brain tumour awareness month is October, but it is lost in a sea of pink.
- 2 Have students debate the pros and cons of advocacy groups for orphan cancers. Students may want to consider:
  - a The implications: Would this have a watering-down effect? Would it enhance awareness? What about cancers that are associated with stigma and stereotypes, such as lung cancer, cervical cancer, liver cancer?
  - b What role do granting agencies and pharmaceutical companies play in decisions to study these diseases and develop treatments?
  - c When one considers the dominance of the Pink Ribbon Campaign to date, would it be more effective for advocates for orphan cancers/rare cancers to lobby as a collective group or have one large advocacy group representing all rare cancers, as some have done? Are there downsides to such collaborations?

### SUGGESTED READINGS

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### SOME EXAMPLES OF WEBSITES TO EXPLORE, DISCUSS AND HAVE STUDENTS BLOG ON THE ISSUES

This is Novel Tech Ethics' page on the Pfizer issue: [noveltechethics.ca/page.php?page+&sub+650](http://noveltechethics.ca/page.php?page+&sub+650)

From the FDA Law Blog – "Patient Power in Orphan Drug Development": [fdalawblog.net/fda\\_law\\_blog\\_hyman\\_phelps/2013/01/patient-power-in-orphan-drugs.html](http://fdalawblog.net/fda_law_blog_hyman_phelps/2013/01/patient-power-in-orphan-drugs.html)

Orphan Drugonaut Blog: [orphandrugonaut.wordpress.com/2013/01/16/patient-advocacy-groups-and-orphan-drug-development-2](http://orphandrugonaut.wordpress.com/2013/01/16/patient-advocacy-groups-and-orphan-drug-development-2)

National Organization for Rare Disorders: [rarediseases.org](http://rarediseases.org)



## GLOSSARY OF TERMS FOR PINK RIBBONS, INC.

**AstraZeneca** – a global biopharmaceutical company that provides medicine for some of the world’s most serious diseases.

**Avon** – the world’s leading direct seller of beauty and related products, with a global annual turnover of \$11 billion, marketing to women in over 100 countries. Avon’s product line includes beauty products, fashion jewellery and apparel, and features such well-recognized brand names as Avon Color, Anew, Skin-So-Soft, Advance Techniques, Footworks, Avon Naturals and Mark.

**Biology** – a natural science concerned with the study of life and living organisms, including their structure, function, growth, origin, evolution and distribution.

**Biopsy** – the surgical removal and microscopic examination of tissue to see if cancer cells are present. The removal and examination of tissue, cells or fluids from the living body.

**Breast cancer** – a type of cancer originating in breast tissue. Worldwide, breast cancer accounts for 22.9 per cent of all cancers (excluding nonmelanoma skin cancers) in women.

**Breast Cancer Awareness Month** – takes place annually in October to increase awareness about breast cancer and to raise money for research.

**Breast cancer culture** – the activities, attitudes and values that surround and shape the fight against breast cancer in public. The dominant values are selflessness, cheerfulness, unity and optimism.

**Cancer activism** – has become a fixture in the United States, where fundraising events are abundant and government financing of research into the disease has skyrocketed.

**Cancer risk clinics** – clinics that act in studying cancer, some providing aid to cancer patients, survivors, etc.

**Capitalism** – an economic system that is based on private ownership of the means of production and the creation of goods or services for profit.

**Cause** – a person or thing that acts, happens or exists in such a way that some specific thing happens as a result; the producer of an effect.

**Cause marketing** – a type of marketing involving the co-operative efforts of a for-profit business and a non-profit organization for mutual benefit. The term is sometimes used more broadly and generally to refer to any type of marketing effort for social and other charitable causes, including in-house marketing efforts by non-profit organizations. Cause marketing differs from corporate giving (philanthropy), as the latter generally involves a specific donation that is tax-deductible, while cause marketing is a marketing relationship not necessarily based on a donation.

**Cell** – the basic structural and functional unit of all known living organisms. It is the smallest unit of life that is classified as a living thing, and is often called the building block of life.

**Chemical** – a form of matter that has constant composition and characteristic properties. Can be in solid, liquid or gas form.

**Chemical industry** – composed of the companies that produce industrial chemicals, converting raw materials (oil, natural gas, air, water, metals and minerals) into more than 70,000 different products worldwide.

**Chemotherapy** – the treatment of cancer with an antineoplastic drug or with a combination of such drugs into a standardized treatment regimen.

**Cingenta** – a pesticide production company.

**Convenient sample** – a sampling technique where subjects are selected because of their convenient accessibility and proximity to the researcher, disregarding the proper representation of an entire population.

**Corporate philanthropy** – charitable donations of money and resources given by corporations to non-profit organizations.

**Cosmetics** – in the United States, the Food and Drug Administration (FDA), which regulates cosmetics, defines them as “intended to be applied to the human body for cleansing, beautifying, promoting attractiveness or altering the appearance without affecting the body’s structure or functions.”

**Cure** – the state of being healed; the end of a medical condition; the substance or procedure that ends the medical condition.

**Diagnosis** – the identification of the nature and cause of anything, used to determine cause-and-effect relationships.

**Diplomacy** – the art and practice of conducting negotiations between representatives of groups or countries; the conduct of relations with regard to issues of peacemaking, trade, war, economics, culture, environment, health and human rights.

**Early detection** – the act of discovering a disorder or disease before it has fully developed.

**E-mail-based campaign** – involving individuals who write e-mails to companies to spur change.

**Energy industry** – the totality of all the industries involved in the production and sale of energy, including fuel extraction, manufacturing, refining and distribution. Modern society consumes large amounts of fuel, and the energy industry is a crucial part of the infrastructure and maintenance of society in almost all countries.

**Environmental justice groups** – organizations participating in a social movement in North America whose focus is on the fair distribution of environmental benefits and burdens, based on theories of the environment, justice, environmental law and governance, environmental policy and planning, development, sustainability and political ecology.

**Epidemic** – a widespread occurrence of an infectious disease in a community at a particular time.

**Estée Lauder** – the first cosmetics company to use the pink ribbon as a symbol for breast cancer awareness.

**Estrogen** – the primary female sex hormone.



**Etiology** – the study of causation, or origination.

**Federal standards** – standards for products and services that are regulated at a nationwide level.

**Focus groups** – a form of research in which a group of people are asked about their perceptions, opinions, beliefs and attitudes toward a product, service, concept, advertisement or idea. Questions are asked in an interactive group setting where participants are free to talk with other group members.

**Ford Motor Company** – has been active in the fight against breast cancer since 1993, with 100 per cent of the net proceeds from all Ford Warriors in Pink merchandise sales donated to a range of charities.

**Formaldehyde** – a gas (at room temperature) that is known to be a human carcinogen and has a pungent odour.

**Globalization of the breast cancer movement** – producing the culture of breast cancer risk perceptions, taking problematic messaging and spreading it throughout the world.

**Grassroots movement** – often found at the local level and volunteer-run, driven by the politics of a community. The term implies that the creation of the movement and the groups supporting it is natural and spontaneous, which highlights the differences between it and a movement that is orchestrated by traditional power structures.

**Growth hormones** – hormones that stimulate growth, cell reproduction and regeneration in humans and animals; often used in farming production and have been linked to causing cancer.

**Hypocrisy** – the state of promoting or administering moral principles, religious beliefs or standards that one does not actually have or is guilty of violating; considered a lie or contradictory behaviour.

**Infrastructure** – organizational structures needed for the operation of a society or enterprise, including the services and facilities necessary for an economy to function.

**Ingestion** – the consumption of a substance by an organism.

**IV League** – a breast cancer support group in Austin, Texas, for women with metastatic breast cancer. They meet on a regular basis and help each other cope with the rigours of the disease and the realities of dying.

**Lead** – a chemical element in the carbon group, counted as one of the heavy metals. Excessive levels of lead are poisonous to human beings, as they can damage the nervous system and cause brain and blood disorders.

**Lumpectomy** – a surgical operation in which a lump is removed from the breast.

**Mammography** – the process of using low-energy X-rays to examine the human breast, used as a diagnostic and screening tool. The goal of mammography is the early detection of breast cancer.

**Mastectomy** – the surgical removal of one or both breasts, partially or completely, usually done to treat breast cancer.

**Metastasis** – the spread of a disease from one organ or part to another nonadjacent organ or part.

**Militaristic metaphors** – cancer is often portrayed and discussed through the use of military metaphors: as a “battle,” “fight” or “struggle.”

**Misinformation** – false or inaccurate information that is spread unintentionally.

**Mitosis** – a medical term referring to a process whereby a single cell is converted from a normal cell to a cancerous cell.

**Mortality** – the condition of being mortal, or susceptible to death.

**Mythology** – a sacred narrative usually explaining how the world or humankind came to be in its present form; often used to convey idealized experience, to establish behavioural models and to teach.

**Non-profit organization** – an organization that uses surplus revenues to achieve its goals rather than distributing them as profit or dividends.

**Oncology** – the study and medical treatment of tumours.

**Outcomes research** – research that investigates the outcomes of health-care practices. It has been defined as the study of the results of health services, taking patients’ experiences, preferences and values into account. It aims to provide scientific evidence relating to decisions made by all who participate in health care.

**Palliative care** – an area of health care that focuses on relieving and preventing the suffering of terminally ill patients.

**Pathology report** – a medical test detailing, in the case of breast cancer patients, the health of the patient’s breasts.

**Petroleum** – a chemical substance found in a variety of cosmetic and personal care products that is suspected of being a carcinogen. Long-term damage to health and side effects from impurities in the manufacturing process are suggested to be cancer-causing.

**Pinkwasher** – a company or organization that claims to care about breast cancer by promoting a Pink Ribbon product, but at the same time produces, manufactures and/or sells products that are linked to the disease.

**Pinkwashing** – Breast Cancer Action coined the term “pinkwashing” as part of their Think Before You Pink campaign.

**Planned Parenthood** – a non-profit organization providing reproductive health and maternal and child-health services.

**The Plastics Focus Group** – a support group composed of a handful of women who worked in the automotive plastics industry, moulding car parts for the Big Three.

**Precautionary principles** – used when taking action against suspected risks.

**Prevention** – measures taken to prevent disease or injury rather than curing them or treating their symptoms after the fact.



**Prognosis** – a medical term for predicting the likely outcome of an illness.

**Radiation** – the medical use of ionizing radiation, generally as part of cancer treatment to control or kill malignant cells. Radiation therapy may be curative in a number of types of cancer if they are localized to one area of the body.

**Radiologist** – a medical professional who employs imaging to both diagnose and treat disease visualized within the human body.

**Remission** – the state of absence of disease activity in patients with a chronic illness, with the possibility of return of disease activity.

**Research** – creative work undertaken systematically to increase the stock of knowledge, including knowledge of humanity, culture and society.

**Revlon Walk** – The Revlon Run/Walk is held in New York City and Los Angeles to benefit women’s cancer charities. The event features a five-kilometre (three-mile) course that can be run or walked, plus a Health Expo. Celebrities often attend. The aim is to raise awareness and critical funds for women’s cancer research, counselling and outreach programs.

**Risk factor** – a variable associated with an increased risk of disease or infection.

**Saturation point** – the stage beyond which no more of something can be absorbed or accepted, often relating to consumerism, advertising and media.

**“Slash, burn and poison”** – a remark used in the film referring to the medical treatment of cancer, where doctors operate on, sanitize and medicate the cancerous area; it is considered a crude way of dealing with a disease.

**Stage 1 breast cancer** – invasive breast cancer; cancer cells are breaking through to or invading normal surrounding breast tissue.

**Stage 2 breast cancer** – invasive breast cancer in which no tumour can be found in the breast, but cancer cells are found in the lymph nodes under the arm; or a breast tumour measures two centimetres or less and has spread to the axillary lymph nodes; or a breast tumour is larger than two centimetres but smaller than five centimetres and has not spread to the axillary lymph nodes.

**Stage 3 breast cancer** – invasive breast cancer in which the cancer may be any size and has spread to the chest wall and/or skin of the breast; or no tumour is found, but cancer is found in axillary lymph nodes, which are clumped together or sticking to other structures; or cancer may have spread to lymph nodes near the breastbone.

**Stage 4 breast cancer** – the most advanced stage of invasive breast cancer, in which cancer has spread beyond the breast and nearby lymph nodes to other organs of the body, such as the lungs, distant lymph nodes, skin, bones, liver or brain.

**Survivorship** – the state or membership of being a survivor.

**Tomoxifen** – is currently used for the treatment of both early and advanced estrogen-receptor-positive breast cancer in pre- and post-menopausal women. It is also approved by the FDA for the prevention of breast cancer in women at high risk of developing the disease.

**Toxin** – a poisonous substance introduced to or produced within living cells or organisms.

**Uncoordinated spending** – results in the overlap of studies and gaps in research by philanthropists and organizations that are not in proper communication with one another.

**Virus** – a small infectious agent that can replicate only inside the living cells of an organism.

**Yoplait** – a brand of yogourt produced by a company owned by General Mills, which participates in the annual program Save Lids to Save Lives, which raises money for breast cancer research in the United States. Yoplait donates 10 cents per pink foil lid that is mailed to the company, but they state in fine print on all promotional materials that their donations will be capped at \$2.5 million a year. This money is donated to the Susan G. Komen Breast Cancer Foundation.

**SOURCE LIST FOR THE GLOSSARY**

Canadian Cancer Society: [cancer.org](http://cancer.org)  
 Canadian Encyclopedia  
 Educational website: [pink4chee.org/education](http://pink4chee.org/education)  
 Merriam-Webster English Dictionary: [merriam-webster.com](http://merriam-webster.com)  
 North American Association of Central Cancer Registries: [naaccr.org](http://naaccr.org)  
 Online encyclopedia: [wikipedia.ca](http://wikipedia.ca)  
 Online reference: [dictionary.reference.com](http://dictionary.reference.com)  
 Oxford English Dictionary  
 Statistics and resources: [worldwidebreastcancer.com/learn](http://worldwidebreastcancer.com/learn)

## SAMPLE CASE STUDY

Case studies may be used to provide additional mechanisms for discussion, critical thinking and writing.

### CASE STUDY RELATED TO THE WOMEN'S MOVEMENT AND THE POLITICS OF PINK RIBBON CULTURE

Jillian is a university undergraduate who changed universities in her senior year. Following her mother's death from breast cancer in the spring of 2012, she moved from a large-city campus in her home community to live with her aunt in a small town with a university that has an excellent academic reputation. On arrival on campus in September, she sought out the student women's centre with the goal of participating in October breast cancer events.

She particularly wanted to meet students who shared her feminist perspective. During her mother's illness, which began in her second year at university, she became active with a women's health group that looked at breast cancer through a feminist lens. She subsequently enrolled in a women's studies course, where she completed a paper on the pink ribbon culture, drawing from sources like Barbara Ehrenreich's interrogation of positive thinking and cancer, and Samantha King's book *Pink Ribbons, Inc.*, documenting the use of breast cancer for "pink marketing" campaigns. Jillian knew from talking to her mother as she moved through the stages of her illness that she was disturbed by the exploitation of the disease for profit, by the lack of resources directed to understanding breast cancer prevention, and by the celebratory tone of events that seemed to deny the reality of women who were dying. She wanted to honour her mother's memory by continuing to work toward the critical understanding of cancer that strengthened their bond during her last year of life.

Jillian's inquiries through the women's community on campus quickly brought her in touch with a group of women who organize breast cancer awareness events in October. Their plans centre on a breast cancer fundraising event, including a run and the sale of pink ribbon products, with the proceeds going to a breast cancer charity. She learned that a well-liked professor from the university died of breast cancer two years ago; last year, the students mounted a highly successful pink ribbon event in her name that raised more money than a similar event at a larger university nearby. Their goal this year is to raise even more money for the same charity in competition with the rival school. When Jillian proposes a prevention-themed event that will expose the prevalence of commercial ties in breast cancer fundraising, members of the planning committee become upset. They pressure her to join their project and urge her not to act or speak out in ways that might undermine their plans.

### QUESTIONS FOR DISCUSSION

- 1 As a class, discuss how Jillian might negotiate the conflict.
- 2 Following the guidelines in Assignment 1 below, write a critique arguing for or against Jillian's case.
- 3 Following the guidelines in Assignment 2 below, role-play a debate between Jillian and members of the pink ribbon planning committee. [Considering that Jillian will approach the committee as a lone dissident, the debate might be structured to reflect this imbalance (e.g., one student debating seven others, perhaps with one member of the dominant perspective switching sides partway through the discussion, another seeking to mediate the conflict). Students using this scenario could draw on literature that documents the social and psychological pressure brought to bear on dissenting voices.]
- 4 Alternatively, use a traditional 4-4 debate structure.

*Case study created by Dr. Sharon Batt*



## SAMPLE CASE STUDY

Cheryl is a 21-year-old university student studying away from home. During her first semester of her third year, Cheryl's mother was diagnosed with breast cancer. Cheryl's mom convinced her not to leave school to come home, saying there is "nothing you can do here anyway." Cheryl confided in her roommate that she needed to do something.

Cheryl created a Facebook page raising awareness for mothers with breast cancer. She then updated her Facebook status and sent a link to the page, asking her friends to like it and donate to cancer research. Cheryl built her Facebook page to get as many people involved, gain more knowledge about breast cancer and organize a walking event. Her online search took her to [www5.komen.org](http://www5.komen.org). Cheryl found an overabundance of merchandise to purchase, including breast cancer gifts, jewellery and pink ribbon gift ideas for the home. Last year, Cheryl took a women's studies course as an elective. She also made an appointment to see her professor to discuss what she learned about breast cancer and the impacts of culture, religion, politics and social values on women's lives.

Today's corporations operate in an environment of intense media, investor, regulatory and public scrutiny. At the same time, increasing public and stakeholder concern about the social and environmental impacts of business practices is forcing companies to come to terms with a much broader set of interests and expectations. In a 2008 survey of 238 chief financial officers (CFOs), "two-thirds of CFOs and three-quarters of investment professionals agreed that environmental, social and governance activities do create value for their shareholders" (Bonini, Brun and Rosenthal, 2009). Thorne, Ferrell and Ferrell (2011) define cause-related marketing as "donating a percentage of revenues to a specific cause based on the revenue occurring during the announced period of support." While appearing to be symbiotic, the underlying current of this marketing strategy is to increase expected profits for shareholders.

## QUESTIONS

- 1 Consider how the basic rules of society have changed over the last 20–30 years. How have these transformations impacted the way consumers choose their purchases?
- 2 What role has business played in transforming current Canadian society?
- 3 Economist Milton Friedman questioned, "What does it mean to say that 'business' has responsibilities? Only people can have responsibilities. A corporation is an artificial person and in this sense may have artificial responsibilities, but 'business' as a whole cannot be said to have responsibilities, even in this vague sense. The first step toward clarity in examining the doctrine of the social responsibility of business is to ask precisely what it implies for whom." Explore in a group the meaning of this statement within the context of the messages provided in **Pink Ribbons, Inc.**
- 4 Discuss the ethical implications of cause-related marketing with the purchasing power of women to gain profit from breast cancer under the auspices of creating awareness.

## REFERENCES

- 1 Bonini, S., Brun, N. and Rosenthal, M. (2009). "McKinsey Global Survey Results: Valuing Corporate Social Responsibility." *The McKinsey Quarterly*, 1–9.
- 2 Friedman, M. (1970, Sept. 13). "The Social Responsibility of Business Is to Increase Its Profits." Retrieved Feb. 27, 2011, from University of Colorado – *New York Times*: [colorado.edu/studentgroups/libertarians/issues/friedman-soc-resp-business.html](http://colorado.edu/studentgroups/libertarians/issues/friedman-soc-resp-business.html)
- 3 Harvey, J. A. and Strahilevitz, M. A. (2009). "The Power of Pink: Cause-Related Marketing and the Impact on Breast Cancer." *Journal of American College of Radiology*, 6, 26–32.
- 4 Thorne, D. M., Ferrell, O. C. and Ferrell, L. (2011). *Business and Society: A Strategic Approach to Social Responsibility and Ethics* (4th ed.). Mason, Ohio: South-Western Cengage Learning.
- 5 Warner, F. (2006). *Power of the Purse*. Upper Saddle River, New Jersey: Prentice-Hall.

Case study created by Karyn Perry



## SAMPLE ASSIGNMENTS

### 1. CRITIQUE OF THE DOCUMENTARY

#### Critique *Pink Ribbons, Inc.*

Students will write a critique of the documentary *Pink Ribbons, Inc.* Consider 1) what the key take-away messages are; 2) how they may inform your practice (e.g., how you think and interact with cancer patients); 3) what surprised you; 4) how the documentary challenged your values and beliefs; 5) whether you agree or disagree with the documentary's point of view (if so/if not, in what way?). Use 6–8 peer-reviewed journals to support your discussion. Maximum length excludes cover page and references. The use of popular Internet sites such as Wikipedia is discouraged and will not count as supporting documentation.

#### Grading Matrix

GRADE (100)	LOGIC/ ORGANIZATION (30)	FORMAT (10)	UNDERSTANDING OF ARTICLE (30)	PERSONAL REFLECTION (30)
<b>A+ (95–100)</b> <b>A (90–94.9)</b> <b>(85–89.9)</b>	<ul style="list-style-type: none"> <li>+ Critique is well-organized and easy to follow</li> <li>+ No spelling, structural or grammatical errors</li> <li>+ Logical progression of ideas, with transition statements linking them, is evident</li> <li>+ Discussion is clearly articulated, concise and coherent with no redundancy (tight focus)</li> <li>+ Key points to be discussed are clearly articulated</li> </ul>	<ul style="list-style-type: none"> <li>+ Paper follows APA 6th formatting with no errors</li> <li>+ 6–8 peer-reviewed articles cited to support discussion</li> <li>+ Critique does not exceed 10 pages, excluding cover page and references</li> <li>+ Font used: Times New Roman or Arial 12</li> <li>+ Introduction clearly outlines what is to be discussed</li> <li>+ Conclusion clearly summarizes key points</li> </ul>	<ul style="list-style-type: none"> <li>+ Goes beyond paraphrasing article—presents own thoughts that reflect advanced level of knowledge and understanding (evidence of critical thinking)</li> <li>+ References used to support discussion are relevant; connection/linkage made</li> <li>+ Critique presents contrasting perspective to support discussion of points</li> </ul>	<ul style="list-style-type: none"> <li>+ Clearly articulates what has been learned from critiquing article</li> <li>+ Connects to learner's current knowledge and understanding of research concepts, ideas about breast cancer, philanthropic and/or advocacy movements</li> </ul>
<b>B+ (80–84.9)</b> <b>B (75–79.9)</b> <b>B- (70–74.9)</b>	<ul style="list-style-type: none"> <li>+ Overall organization of critique less clear</li> <li>+ Occasional spelling, structural or grammatical errors</li> <li>+ Transition statements do not always evidently link to change of ideas</li> <li>+ Points for discussion identified but less clear</li> </ul>	<ul style="list-style-type: none"> <li>+ Paper follows APA 6th formatting with no errors</li> <li>+ 3–4 peer-reviewed articles to support</li> <li>+ Introduction and conclusion less clear</li> <li>+ Appropriate font used</li> </ul>	<ul style="list-style-type: none"> <li>+ Chosen points paraphrased in student's own words but close to original text</li> <li>+ Contrasting perspective present, but linkage to key points less clear</li> <li>+ References used do not fully support discussion points</li> </ul>	<ul style="list-style-type: none"> <li>+ Learning from critique is presented but not clearly connected to current knowledge and understanding of research concepts, ideas about breast cancer, philanthropic and/or advocacy movements</li> </ul>



GRADE (100)	LOGIC/ ORGANIZATION (30)	FORMAT (10)	UNDERSTANDING OF ARTICLE (30)	PERSONAL REFLECTION (30)
<p><b>C+ (65–69.9)</b></p> <p><b>C (60–64.9)</b></p>	<ul style="list-style-type: none"> <li>+ Organization of critique problematic</li> <li>+ Few transition statements used, making it challenging to follow train of thought</li> <li>+ Errors noted (spelling, structure, grammar)</li> <li>+ Points for discussion not evident</li> </ul>	<ul style="list-style-type: none"> <li>+ APA errors noted</li> <li>+ 1 article used</li> <li>+ Use of non-peer-reviewed articles (Internet sites, Wikipedia, etc.)</li> <li>+ Introduction and/or conclusion missing</li> <li>+ Appropriate font not used</li> </ul>	<ul style="list-style-type: none"> <li>+ Chosen points show limited substantive original thinking</li> <li>+ Contrasting perspective irrelevant to discussion</li> <li>+ References do not fully support discussion—difficult to determine connection</li> </ul>	<ul style="list-style-type: none"> <li>+ Limited self-reflection—tendency toward the superficial</li> </ul>
<p><b>F (&lt;6.0)</b></p>	<ul style="list-style-type: none"> <li>+ Lack of organization</li> <li>+ No use of transition statements</li> <li>+ Significant errors in spelling, grammar, terminology, structure</li> <li>+ Confusing to follow</li> </ul>	<ul style="list-style-type: none"> <li>+ Lack of peer-reviewed nursing articles</li> <li>+ Use of popular Internet sites</li> <li>+ APA not followed</li> <li>+ Introduction and conclusion missing</li> <li>+ Appropriate font not used</li> </ul>	<ul style="list-style-type: none"> <li>+ Errors in terminology</li> <li>+ No contrasting perspective provided</li> <li>+ Lack of (or irrelevant) references to support discussion; frequent misunderstanding of concepts</li> <li>+ Limited knowledge of class information</li> <li>+ No original thinking evident</li> </ul>	<ul style="list-style-type: none"> <li>+ Reflection absent</li> </ul>

**2. DEBATE**

Topics that may lend themselves to debate include but are not limited to:

- + Philanthropic movements associated with diseases enhance awareness and benefit those living with and/or affected by cancer.
- + Philanthropic movements have the potential to marginalize vulnerable groups (e.g., a focus on cure may lead to exclusion and/or alienation of individuals with advanced or metastatic disease).
- + Philanthropic movements such as the Pink Ribbon Campaign may serve as positive models for other cancers or diseases.

The following may prove helpful in developing your debating argument:

**“THE DEBATE”**

The Debate is a contest between two teams, each consisting of four members, arguing a subject of discussion known as “the moot.” The moot is an affirmative statement that is capable of being argued from either the affirmative or negative viewpoint.

The object of each team, the Affirmative and the Negative alike, is to convince the audience that it has the most persuasive argument. To win the debate, certain technical rules must be complied with, and the adjudicator (or judge) will take this into account in addition to the soundness of argument and skill in presentation.

Debating may be compared to building a structure with blocks of stone. The Affirmative team begins the building; whereas the Negative team attempts to take out crucial blocks, causing the Affirmative’s structure to collapse. The Negative team should not try to build a better structure of its own, but needs to counter the argument put forward by the Affirmative, showing the weaknesses of its case. If the Affirmative argument is intact at the end of the debate, the Negative will have failed in its objective.



Debating should be fun. It should be approached by accepting the challenge to persuade an audience of unbiased onlookers. It is an excellent way of improving speaking skills and is particularly helpful in providing experience in developing a convincing argument. It adds a new dimension to the Toastmasters speaking experience, and is recommended for furthering members' speaking experience.

Debating teams comprise three members on each side whose duties are explained in more detail. A subject for the debate (called the "moot") is decided upon, one team taking the Affirmative and the other the Negative case. The teams each need to decide on the speaking order of their members, their strategies and the allocation of subject matter to each speaker. This will normally require a couple of meetings, followed up with telephone discussions, to ensure that each member is fully aware of his/her role in the team effort and where it fits into the strategy. Remember that debating, in addition to being an individual performance, is also very much a team exercise—no team can win on the performance of one member alone.

### SPEAKERS' ROLES: GENERAL

Speakers should open with a strong sentence to gain audience attention. The address should have clearly recognizable points, which should be strongly summarized in a firm conclusion. Speakers need to finish within the allocated time, as judges will not take into account any points made after the time has expired.

The roles of the individual speakers are summarized as follows:

#### 1 Leader of Affirmative

- a** Clearly articulate the point (moot) you will be arguing. Your stance should be one that will be met with general acceptance. This avoids having the debate degenerate into one on the meaning of the moot rather than on the arguments presented by the two teams.
- b** Give a general outline of the team's case and indicate the aspects of the subject to be discussed by each of the team members. For example, "We are affirming the proposition that marriage leads to divorce. As leader, I shall show that only married people become divorced. My second speaker will indicate the reasons for this. And my third speaker will show that single people are free from the problems that lead to divorce."
- c** Develop the introductory arguments for the side—this should represent some 60 per cent of the address.
- d** Summarize.

#### 2 Leader of Negative

- a** Clearly articulate the moot you will be arguing. If it is fair and reasonable, it should be accepted. It will be difficult to create a viable alternative to a reasonable definition put forward by the Affirmative. Remember, it is the moot that is to be debated, not the definition. However, if the Affirmative definition is selective and unreasonable, it is possible to appeal to reason and seek to have the subject debated on what would be generally understood by the wording of the moot.
- b** Outline the team's case and the allocation of each speaker's role.
- c** Rebut any major points put forth by the leader of the Affirmative that can be effectively countered.
- d** Be sure to introduce points that support the Negative case.
- e** Summarize.

#### 3 Second Affirmative

- a** Re-emphasize the major point of your leader.
- b** Develop major points of your team's case—this is the primary role of the second speaker and should occupy 75 per cent of the speaking time.
- c** Rebut any major points put forth by the leader of the Negative that can be effectively countered.
- d** Summarize.

#### 4 Second Negative

- a** Develop rebuttal of previous two Affirmative speakers (up to 50 per cent of speaking time).
- b** Add arguments supporting Negative view.
- c** Support own leader's case. Summarize.

#### 5 Third Affirmative

- a** Develop rebuttal of previous two Negative speakers (at least 50 per cent of speaking time).
- b** Add final arguments supporting Affirmative case.
- c** Support previous Affirmative speakers.
- d** Summarize.

#### 6 Third Negative

- a** Develop rebuttal of all Affirmative speakers' arguments (70 per cent of speaking time). Effectively destroy Affirmative arguments.
- b** Add final arguments supporting Negative case.
- c** Summarize.



**7 Fourth Affirmative**

- a Rebut any major points of Negative third speaker and leader’s reply.
- b Convincingly summarize own team’s arguments—no new material allowable.
- c Forcefully summarize previous rebuttal of Negative case—no new material allowable.
- d Persuasive conclusion to convince audience of superiority of Affirmative case.

**8 Fourth Negative**

- a Convincing summary of own team’s case—no new material allowable.
- b Forceful summary of rebuttal already presented—no new material allowable.
- c Persuasive conclusion to convince audience of superiority of Negative case.

**DEBATING SPEECHES**

As in all speeches, debating speeches have definite component parts. Marks are awarded for each part, and these aspects are covered in the mark sheet. The main points are:

- 1 Content:** The subject matter of the speech. The argument should appeal to a reasonable person. A sound argument wins points by using:
  - + common sense;
  - + logical reasoning;
  - + beliefs, attitudes or feelings that appeal to the audience.

Support for the argument from quoted well-known authorities helps build the case.

All relevant arguments of the opposition should be answered—points not answered are taken as having been conceded.

The definition should not be a lengthy recitation of dictionary quotations. Rather, a logical and concise enunciation of common usage is generally preferred, dictionary support being used in the event of need or dispute.

Quotations should be brief and relevant to the point being made. Well-known authorities are preferred, and for best effect the extracts should be delivered from memory rather than read.

Expert opinion may be used to support arguments but should be from well-known, qualified authorities.

Tabling of material should only be done at the request of the opposition. Tabled material can be viewed by the opposing side during the debate, and it therefore pays to ensure that it cannot be used by the opposition to find an alternative viewpoint, as this tends to destroy the credibility of the point being made.

Airy, general or wild statements unsupported by evidence will not gain marks. Relevance to the subject of the debate and to the team’s strategy is essential.

Teams must attack as well as rebut. Teams need to engage in argument and counter-argument on the subject under discussion.

Humour can appeal if relevant, and will maintain audience interest in the argument being presented.

Rebuttal should be soundly based and effectively counter the opposing argument, but unsupported rebuttal will not be effective.

**2 Interjections:** The acceptance of interjections requires the agreement of both teams. If one team does not wish to accept interjections, they are not to be allowed. It is the chairman’s responsibility to ascertain the wishes of the teams prior to the commencement of the debate.

If interjections are allowed, they may come from both the audience and the opposing team. However, the opposing team may lose valuable rebuttal material if it engages in refuting argument by interjection.

Interjections should always be brief and preferably witty. Five or six words are sufficient—more than that and the impact will be lost.

Heckling (e.g., repetition of such words as “rhubarb,” “boring,” “rubbish” or the like), engaging in a running debate with the speaker, or general interruptions are not allowed. Should they take place and not cease on the chairman’s request, no further interjections of any sort will be allowed. An unruly audience can ruin a good debate, and speakers have a right to be heard.

There are two general ways of dealing with interjections: ignore them and speak over them in a strong voice; respond to them with quick and cutting replies—this is difficult to achieve but will win marks.



**3 Construction:** As in all speeches, there needs to be a structure with:

- + an arresting opening to gain the audience’s attention;
- + the body of the speech, containing the speaker’s points of argument;
- + rebuttal of the opposing argument where appropriate;
- + a strong, positive peroration (or conclusion), which summarizes the whole presentation.

The speech should not be too fully prepared, or it will be difficult to respond to the opposing arguments—the object of the debate is for both teams to engage the topic and persuade the audience that their own standpoint is the more valid.

Timing is important—the peroration should commence soon after the green light is shown, as no marks are gained for any points made after the red light is switched on.

**4 Teamwork:** The speakers for each team must combine to present a cohesive argument. Any material that contradicts a previous speaker of the same side will destroy the team argument.

Each speaker should cover the general area allocated by the leader in his/her introduction.

Marks allocated for teamwork can help swing the debate in favour of the well-organized team and lead to its victory.

**LEADERS’ REPLIES**

No new material is allowed to be introduced by the leaders in their replies, which should summarize what has gone before and show how the speaker’s team has presented the most persuasive argument.

Interjections are not allowed during the speaker’s replies, irrespective of whether they had been allowed during the body of the debate.

**GRADING MATRIX**

The following categories may be used to develop a grading matrix:

CONTENT (VALUE)	DELIVERY (VALUE)	CONSTRUCTION (VALUE)
Subject knowledge	Grammar	Speech structure
Relevance	Pronunciation	Opening
Logic	Appearance	Body
Fair definition (leaders only)	Vocal variety	Peroration
Quotations	Persuasiveness	Strategy
Authorities	Enthusiasm	Adaptability
Topicality	Use of notes	Rebuttal
Humour	Body language	Timing
Rebuttal (except Affirmative leader)	Handling of interjections	

[ada.org.nz/tmguides.php#9](http://ada.org.nz/tmguides.php#9)

**DEVELOPING AN ARGUMENT**

General rules for composing a short argument:

- 1 Distinguish between premise (what you are trying to prove) and conclusion (statement for which you are giving reasons).
- 2 Present ideas in a natural order—each claim should naturally follow the preceding one.
- 3 Start from a reliable premise—is your premise plausible? Do you have well-known examples?
- 4 Be concrete and concise—avoid abstract, vague and general terms.
- 5 Avoid loaded language—don’t appeal to emotion.
- 6 Use consistent terms.
- 7 Stick to one meaning for each term.

Weston, A. (2000). *A Rulebook for Arguments* (3rd ed.). Indianapolis: Hackett Publishing Company.



**3. MEANING THROUGH ART**

Using art as the medium, students could work individually or in groups to convey the meaning, for them, of the documentary *Pink Ribbons, Inc.* They will need to ask the following questions in order to create their work of art:

- 1 What do I/we think?
- 2 What do I/we see?
- 3 What do I/we hear?
- 4 What do I/we feel?

	5	4	2-3	0-1
<b>Elements of art—comprehension of use in project as a whole</b>	No significant omissions; effective use of the elements of art throughout the design process to produce a cohesive project	Project considered in very wide context; reasonable use of the elements of art throughout the design process to create a thoughtful end product	Adequate scope of relevant factors; adequate use of the elements of art throughout the design process to create an end product	Very limited view/focus; unable to use the elements of art as a whole or in part throughout the design process in an attempt to create a product
<b>Craftsmanship</b>	Sophisticated execution; able to convey key messages within meaning in a clear, effective manner	Above-average rendering, with slight deficiencies evident in final product	Average degree of skill demonstrated	Shows some evidence of skill in limited area
<b>Quality of evaluation/critique/review (as evidenced in the 2-3-page accompanying document). APA to be followed in the body of the document and in the references.</b>	Able to produce thoughtful review of design process and associated rationale for medium	Very fair review with few areas of neglect; associated rationale for medium	Adequate review; rationale for medium weak	Only limited ability to review rationale for medium
<b>Project application (and use of peer-reviewed journal articles)</b>	Effective application of concepts, techniques and/or processes to nursing practice/client outcomes	Reasonable application of concepts, techniques and/or processes to nursing practice/client outcomes	Adequate application of concepts, techniques and/or processes to nursing practice/client outcomes	Limited ability to apply concepts, techniques and/or processes to nursing practice/client outcomes

**4. STUDENTS COULD EITHER EXPLORE BLOG SITES OR ENGAGE IN BLOGGING ON A TOPIC**

- A** Have students explore blogs on pinkwashing and greenwashing. Have them consider the following in this exercise:
- 1** How are they similar? How do they differ?
  - 2** Are the messages similar? If not, how do they differ?
  - 3** What tactics/approaches do they use?
  - 4** Are supporters such as large industry, corporations, the pharma industry reflected on both sites?
- B** Have students post a series of blogs on the topic of:
- 1** Pinkwashing
  - 2** Social advocacy and its influence on research
  - 3** Impact of advocacy groups and/or Big Pharma on orphan cancers

**GRADING MATRIX FOR STUDENT BLOGGING**

CRITERIA	EXCELLENT (85–100)	GOOD (70–84)	FAIR (60–69)	UNACCEPTABLE (<60)
<b>Content (value)</b>	Clearly demonstrates critical thinking and analysis; posting shows originality and understanding of subject matter and engagement with topic	Critical thinking and analysis less clear; posting shows understanding of subject matter and engagement with topic	Limited insight, original thought and critical thinking; tendency to rely on description and evidence of rote learning	Lacking critical thinking, originality, understanding of subject matter; lack of engagement with topic
<b>Posts (value)</b>	Posts are frequent, relevant, professional, reflective and link to other online posts	Frequent posts that are relevant and professional; reflection present but superficial in nature; links with other posts	Infrequent postings, at times irrelevant or tangential in nature; reflection tends to be descriptive	Rare or no postings; irrelevant; no evidence of reflection
<b>Design (value)</b>	Creative, well-organized, logical argument; integrates material to enhance discussion	Creative and organized; integrates material to enhance discussion; argument at times less clear	Limited use of creativity and integration of material to enhance discussion; argument tends to appeal to emotion	Lacks creativity and organization; fails to integrate additional material; no evidence of well-informed logical argument—makes sweeping statements and appeals to emotion



CRITERIA	EXCELLENT (85-100)	GOOD (70-84)	FAIR (60-69)	UNACCEPTABLE (<60)
<b>References (value)</b>	Draws on peer-reviewed research to support discussion and build argument	Uses evidence to support discussion and build argument	Limited use of evidence to support discussion	Lack of outside sources and/or evidence to support; no argument developed; if present, not relevant to discussion
<b>Connections (value)</b>	Able to clearly articulate issues and link to course material; posts are more sophisticated and move discussion in new directions	Articulates issues and linkages, but clarity and connections less noticeable	Posts lack sophistication and clarity; limited connection to course material	No connections made



## INTEGRATION OF TECHNOLOGY

The following tools may also be integrated into the education modules as a mechanism for the generation of critical thinking, debate and discussion:

- 1 Wikis
- 2 Twitter
- 3 Blogs and discussion boards
- 4 Videos/vodcasts using online software programs such as prezzi and GoAnimate
  - a GoAnimate: [goanimate.com](http://goanimate.com)
  - b Prezi: [prezi.com/desktop](http://prezi.com/desktop)

### SAMPLE GRADING MATRIX FOR WIKI AND GROUP PARTICIPATION (A SIMILAR FORMAT MAY BE USED TO EVALUATE STUDENT VIDEOS/VODCASTS)

- 1 Create a cover page that respectfully depicts the topic.
- 2 Link to images and videos (if appropriate) that enhance your overview of the subject matter.
- 3 Synthesize your findings from qualitative and quantitative peer-reviewed research articles on this subject to enhance colleagues' understanding of the issues (use APA 6th for references).
- 4 Highlight implications for practice, research and education.
- 5 Demonstrate team collaboration.

CATEGORY	A (8.5-10)	B (7-8.49)	C (6-6.9)	F (<6)
<b>Cover page (value: 1.5%)</b>	Respectful depiction of topic  Demonstrates professionalism	Respectful depiction of topic  Demonstrates professionalism	Presentation draws on "catchy" statements or clichés  Professionalism not clearly reflected	Relies heavily on clichés  Lack of respect and professionalism
<b>Style (value: 2%)</b>	Creative use of text, images and videos (where appropriate to enhance overview of subject)  Uses APA 6th appropriately	Less creative use of images and videos  Uses APA 6th but minor errors noted	Creativity not clearly evidenced  Errors noted with APA 6th	Lack of creativity and innovation  Does not use APA 6th



CATEGORY	A (8.5–10)	B (7–8.49)	C (6–6.9)	F (<6)
<b>Content (value: 4%)</b>	<p>Demonstrates critical thinking and writing</p> <p>Demonstrates understanding of topic</p> <p>Presents topic in a clear, concise and easily understood way</p> <p>Synthesis of research articles follows critiquing approach</p> <p>Argument logical</p>	<p>Demonstration of critical thinking and writing less clear</p> <p>Discussion of topic demonstrates average level of understanding of topic</p> <p>Synthesis of research articles not fully captured</p> <p>Logical flow less clear</p>	<p>Critical thinking and writing not clearly evidenced</p> <p>Understanding of topic under discussion below average</p> <p>Synthesis of research articles not fully captured</p> <p>Use of articles not clearly relevant to topic</p> <p>Logical flow of discussion difficult to follow</p>	<p>No evidence of critical thinking and writing</p> <p>Understanding of topic not evidenced</p> <p>Synthesis not done or incomplete</p> <p>Lack of logical flow to discussion, and difficult-to-follow thinking</p>
<b>Peer assessment (value: 2.5%)</b>	<p>Completes peer assessment to demonstrate team collaboration</p>	<p>Peer assessment completed showing team collaboration</p>	<p>Peer assessment completed but lack of demonstration of team collaboration</p>	<p>Peer assessment not completed</p>



**TEAM COLLABORATION MATRIX  
(STUDENTS EVALUATE THEIR TEAM MEMBERS)**

CATEGORY	2.5 POINTS	2 POINTS	1 POINT	0 POINTS
<b>Contributions</b>	Routinely provides useful ideas when participating in the group; a leader who contributes a lot of effort	Usually provides useful ideas when participating in the group and in classroom discussion; a strong group member who tries hard	Sometimes provides useful ideas when participating in the group and in classroom discussion; a satisfactory group member who does what is required	Rarely provides useful ideas when participating in the group and in classroom discussion; may refuse to participate; a group member who is disengaged
<b>Problem-solving</b>	Actively looks for and suggests solutions to problems	Refines solutions suggested by others	Does not suggest or refine solutions, but is willing to try out solutions suggested by others	Does not try to solve problems or help others solve problems; lets others do the work
<b>Attitude</b>	Is never publicly critical of the project or the work of others; always has a positive attitude about the task	Is rarely publicly critical of the project or the work of others; often has a positive attitude about the task	Is occasionally publicly critical of the project or the work of other members of the group; usually has a positive attitude about the task	Is often publicly critical of the project or the work of other members of the group; is often negative about the task
<b>Focus on the task</b>	Consistently stays focused on the task and what needs to be done; very self-directed	Focuses on the task and what needs to be done most of the time; other group members can count on this person	Focuses on the task and what needs to be done some of the time; other group members must sometimes nag, prod and remind to keep this person on task	Rarely focuses on the task and what needs to be done; lets others do the work
<b>Working with others</b>	Almost always listens to, shares with and supports the efforts of others; tries to keep people working well together	Usually listens to, shares with and supports the efforts of others; does not cause "waves" in the group	Often listens to, shares with and supports the efforts of others, but sometimes is not a good team member	Rarely listens to, shares with and supports the efforts of others; often is not a good team player