The fear factor in health fundraising

The boy in the poster gasps for air, his face barely above the surface of water. The tagline reads: “Cystic fibrosis is like drowning on the inside.” Another ad from the Canadian Cystic Fibrosis Foundation says that breathing with cystic fibrosis (CF) is like breathing through a straw. “No wonder so many people with CF stop breathing in their early 30s,” the poster states.

Advocacy groups that raise money to combat illnesses often struggle to capture the public’s attention. There are many worthy causes out there, some higher profile than others, and getting people to notice a particular cause is hard enough — getting them to care about it harder still. Using an alarming image or message in an advertising campaign can be an effective means of making people pay attention. A picture of a drowning child is unlikely to go unnoticed.

But startling ads to raise awareness about diseases can have quite a different effect on people suffering from those diseases. For them, such ads can be distressing, reminders of a future that is anything but certain. Some critics claim ads that depict worst-case scenarios border on fear-mongering and, in some cases, don’t even accurately portray those worst-case scenarios.

“The ads for CF have been like this for years,” says Dr. Annie Janvier, a neonatologist and clinical ethicist at Sainte-Justine Hospital in Montreal, Quebec. “Every year, they have very vivid and shocking ads with kids in them that actually hurt families and the kids themselves.”

Janvier says she has encountered parents of children with cystic fibrosis who became very scared after seeing the “drowning on the inside” ads. She says that children with the disease who see the ads may accuse their parents, who focus on giving them the best quality of life, of lying to them about their conditions. Even doctors who treat people with cystic fibrosis tend to dislike the ads, says Janvier, though they don’t criticize the Canadian Cystic Fibrosis Foundation because the group raises money to help their patients.

The ads are not only scary but also misleading, says Janvier (CMAJ 2010; DOI:10.1503/cmaj.110-2082). Cystic fibrosis, a fatal genetic disease that affects about one in 1600 people, causes mucus to accumulate in the lungs, affecting breathing. But according to Janvier, people receiving proper medical care would at no time, not even when dying, feel as if they were drowning or breathing through straws.

“It’s like saying someone is going to choke you at home. It’s shocking people with misinformation,” says Janvier. “Even the worst-case scenario is not like that. You don’t die as if you are drowning. If you die in pain, you have bad medical care. If someone feels like they are breathing through a straw, you have bad medical care.”

But according to June Pierotti, the director of communications for the Canadian Cystic Fibrosis Foundation, the ads are not intended to mislead, scare or hurt anybody.
Adults with cystic fibrosis are consulted on advertising concepts, as well as parents of children with the disease. Most people don’t know much about cystic fibrosis, says Pierotti, and hard-hitting advertisements are necessary to get people to realize it is a serious problem that deserves attention.

“Creating an ad campaign is a huge challenge. The foundation is very mindful of how families affected by CF might receive a campaign message. They are designed with a lot of care,” says Pierotti. “The advertising is aimed at people who don’t know about CF, but you can’t shield people who have CF from seeing the ads.”

Within the cystic fibrosis community, reaction to the foundation’s current advertising campaign, which was launched in 2008 and will run until April 2011, has been mixed.

“Some do not like a hard-hitting ad no matter what the reasoning behind it,” says Pierotti. “Some will say they don’t like it but understand we need to do it to breakthrough to the public. Then there are some with the CF community who think we should be a lot tougher, though they are probably not the majority.”

Controversial health advertising is nothing new, of course. In 2007, for example, the New York University Child Study Center launched its “ransom notes” campaign to raise awareness about several psychiatric disorders that affect children, such as attention-deficit hyperactivity disorder. The ads were written in a way to suggest children were being kidnapped by these disorders. One ad read: “We have your son. We will make sure he will no longer be able to care for himself or interact socially as long as he lives,” and was signed “Autism.”

“We saw this as something that dehumanizes us,” says Ari Ne’eman, president of the Autistic Self Advocacy Network.

Many people protested the “ransom notes” campaign, and it was quickly shut down. According to Ne’eman, ads that succeed in raising public awareness and money for research and treatment for a disability or disease are really failures if they harm the people directly affected.

“It’s putting raising money ahead of bettering the lives of the people they purport to serve,” says Ne’eman. “Through the same means that you are raising money you are making those people less welcome in schools, in workplaces and in their own homes. No matter what you spend that money on, it’s a net loss.” — Roger Collier, CMAJ