

Is cancer fundraising fuelling quackery?

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Figures published by *The BMJ* today show how crowdfunding for alternative therapies for patients with terminal cancer has soared in recent years. But there are fears that huge sums are being raised for treatments that are not backed by evidence and which, in some cases, may even do then harm.

As such, there are now calls for crowdfunding sites to vet cancer appeals to help ensure that patients and their donors are not being exploited, writes freelance journalist Melanie Newman.

The figures, collected by the Good Thinking Society, a charity that promotes scientific thinking, show that since 2012 appeals on UK crowdfunding sites for cancer treatment with an alternative health element have raised £8m (€9m; \$10m). Most of this was for treatment abroad.

JustGiving's own figures show more than 2,300 UK cancer related appeals were set up on its site in 2016, a sevenfold rise on the number for 2015.

While the phenomenon has allowed less well-off patients to access expensive, experimental treatments that are not funded by the NHS but have some evidence of benefit, many fear it has also opened up a new and lucrative revenue stream for cranks, charlatans, and conmen who prey on the vulnerable.

The society's project director, Michael Marshall, says: "We are



concerned that so many UK patients are raising huge sums for treatments which are not evidence based and which in some cases may even do them harm."

Good Thinking now wants the crowdfunding sites to vet cancer appeals and "reject outright proposals that refer to specific drugs that have been discredited, extreme dietary regimes, intravenous vitamin C, alkaline therapy and other alternative treatments."

"If these platforms want to continue to benefit from the goodwill of their users—and, indeed, to profit from the fees they charge each of their fundraisers—they have a responsibility to ensure that they do not facilitate the exploitation of vulnerable people," says Marshall.

Edzard Ernst, professor of complementary medicine at Exeter University, supports the move, pointing out that crowdfunding organisations already reject appeals involving violence or illegal activity, such as terror attacks.

GoFundMe, the platform that features most prominently in Good Thinking's dataset, said it is already "taking proactive steps" in the US to make sure users of its site are better informed and will be doing the same globally over the coming months.

JustGiving told *The BMJ*, "We don't believe we have the expertise to make a judgment on this."

In contrast, some argue that the very process of searching for <u>alternative</u> therapies can have a positive effect. Sarah Thorp, who set up a GoFundMe account to pay for her sister Andrea Kelly's treatment at the Integrative Whole Health Clinic in Tijuana, Mexico, believes Andrea was helped as much by the feeling of being in control as by the treatments she received.



Andrea spent three weeks at the clinic at a cost of \$21,000 (£16,000; €18 000) and died just over a year after she returned.

The largest sums by far in Good Thinking's dataset, allegedly accounting for £4.7m of the £8m identified, were raised for trips to the Hallwang Private Oncology Clinic in the Black Forest of southern Germany.

However, the clinic claims that some people have used Hallwang's name to raise money but have not then proceeded to treatment and, in some instances, have done so without ever contacting the clinic.

Some health professionals, including Professor Christian Ottensmeier at the University of Southampton, don't think patients should be banned from visiting such clinics, but say careful conversation with the patient about the chances, the risk, and the costs, are essential.

Others, however, such as Patricia Peat, a former oncology nurse who has advised people to go to the Hallwang after visiting the clinic herself, says she has now stopped recommending it to her clients.

The Hallwang maintains that it never gives guarantees to patients and always provides thorough information on its alternative treatment strategies, which it says are state of the art.

Finally, Michael Marshall also points to the role of the media, whose reports on people with cancer often drive donors to the crowdfunding sites and encourage others to seek the same <u>treatment</u>.

"These reports may look like uplifting human interest stories, but they rarely highlight the dubious and pseudoscientific nature of some of the treatments involved or just how many of the success stories actually ended in tragedy," he says. "If the media want to report on medical fundraising stories, they should seek the advice of qualified medical



experts."

More information: Feature: Is cancer fundraising fuelling quackery? *BMJ* (2018). www.bmj.com/content/362/bmj.k3829

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