

## FEATURE

## Is cancer fundraising fuelling quackery?

Crowdfunding sites are helping people with advanced cancer spend thousands of pounds on unproved and alternative treatments. **Melanie Newman** examines calls to help ensure patients and their donors are not being exploited

Melanie Newman *freelance journalist, London, UK*

Doctors face difficult conversations with patients with metastatic cancer for whom NHS treatment has failed. A growing problem is how to advise patients who opt to pursue expensive, experimental treatments in the private sector, including orthodox therapies given in unproved combinations and doses but also alternative therapies with no evidence behind their use. *The BMJ* today publishes figures that show how crowdfunding for alternative cancer therapies has soared in recent years (tables 1 and 2). 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 2300 UK cancer related appeals were set up on its site in 2016, a sevenfold rise on the number for 2015.

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. But 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."

Hundreds of thousands of pounds have been crowdfunded for UK patients' treatment at the controversial Burzynski clinic in Texas, which US authorities have pursued for years over its marketing of unproved treatment and research trial failings. The US Food and Drug Administration issued warning letters to the clinic in 2009 and 2013 listing numerous concerns about the clinic's research trials, including failure to report adverse events.<sup>1,2</sup> In 2012 the clinic was criticised by the FDA over violations of regulations relating to claims on the clinic's website,<sup>3</sup> and in 2017 the clinic's owner was sanctioned by the Texas Medical Board for misleading clients.<sup>4</sup>

Other appeals included in the dataset were for Gerson therapy, which involves coffee enemas and frequent juice drinks and is not only unproved but can harm patients.<sup>5</sup>

"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," Marshall said.

JustGiving charges a fee of 5% on donations, and GoFundMe did the same until January 2018, when it became fee-free.

### Better protection

Good Thinking 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." Marshall says: "If a fundraiser is for treatment for a serious or life threatening condition such as cancer, it ought to be reviewed before it is sent live, especially if it contains terminology that raises red flags for quackery."

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. "Crowdfunding for a terror attack is out of the question," he said. "Crowdfunding for cancer quackery is not any better and must be stopped."

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.

"Ultimately, we'll be monitoring content of this kind more closely in order to provide tailored advice," a spokesman said. But JustGiving told *The BMJ*, "We don't believe we have the expertise to make a judgment on this."

### Value of hope

Any moves to limit fundraising for alternative therapies by patients with terminal cancer will attract the ire of people like Sarah Thorp. She set up a GoFundMe account to pay for her sister Andrea Kelly's treatment at the Integrative Whole Health Clinic in Tijuana, Mexico. The clinic offers a range of alternative therapies, including coffee and flax seed enemas, vitamin and mineral infusions, and an "Alpha-2010 Spa System" alongside

whole body hyperthermia, hyperbaric oxygen, and “extracorporeal photopheresis.”<sup>6</sup>

Its lead clinician, Jose Henrique, claims a “75% success rate” since 2000 in patients with stage 4 cancers like Andrea.<sup>7</sup> 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.

Although the sisters became “disillusioned” with the clinic and ended the treatment a week early, Thorp tells *The BMJ* that she remains convinced the trip extended Andrea’s life. “It gave her hope at a point when we had none,” she says. Andrea’s faith in the NHS was damaged after she felt her concerns that the cancer had returned were repeatedly dismissed by her doctors. When the disease was finally detected Thorp claims her oncologist was unsympathetic.

She believes Andrea was helped as much by the feeling of being in control as by the treatments she received. “That empowerment was so useful,” she says. “That was not false hope.” The very process of searching for alternative therapies had a positive effect, Thorp believes. “She was always looking into new things; it kept her going. Doctors shouldn’t disregard or be pessimistic about people exploring these options.”

Working out how best to protect patients and donors—while supporting their informed choices—will be no simple task for the crowdfunding platforms, as David Gorski, a US surgical oncologist who campaigns for evidence based science, explains.

“I support the concept of not allowing crowdfunding for treatment at quack clinics but must admit that I struggle to see how it would work in practice for some of these centres,” he said. “How would they deal with clinics that offer conventional treatments alongside quackery?”

Alternative centres do not usually publish data on treatment efficacy but instead provide testimonials, in which patients often describe being given a short time to live before starting the treatment that “saved” them. “Patients often don’t understand that not enough time has passed to say with any confidence that they are survivors,” Gorski explains.

## Hallwang clinic

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

The Hallwang carries out diagnostic tests on patients’ tumours and treats them with a combination of experimental immunotherapy, peptide vaccines said to train the immune system to attack cancerous cells, and unproved therapies such as vitamin infusions.<sup>8</sup> Drugs offered include bevacizumab, which inhibits growth of tumours’ blood vessels, and pembrolizumab and ipilimumab, two members of a new class of biological therapy known as checkpoint inhibitors. All three drugs have proved benefits for certain types of tumour.

Costs are high: a patient was recently quoted more than €100 000 for an initial 10 day visit.<sup>9</sup> However, the clinic states it offers intensive treatment monitoring, with a nurse to patient ratio of 1:2, in a highly private setting and in extremely challenging situations. It says many of its patients arrive with serious complications such as sepsis, tumour associated bleeding, or bowel obstruction, which it treats and manages. It also says that its innovative treatments are purchased at a high price, and because the costs are not met by any third parties such as

insurers or charities, they have to be paid by patients. It insists patients only pay for and are given treatments after thorough discussion and with the patients’ explicit approval and consent.

Christian Ottensmeier, professor in experimental cancer treatment at the University of Southampton, has been approached by and treated former Hallwang patients. He uses some of the same immunotherapy drugs prescribed at the Hallwang in his standard clinical practice but in different doses and combinations.

“In my experience 20-25% of the Hallwang’s patients with advanced cancer could see some benefit from taking them,” he says. The Hallwang also uses the drugs for diseases in which they have not yet been tested. “I don’t have a problem with that,” says Ottensmeier. “But it needs a careful conversation with the patient about the chances, the risk, and the costs.”

The Hallwang says that when referring to treatment outcomes, it is important to distinguish between partial and complete remission, and that in cases where life expectancy is only a few weeks or months, a gain in quality of life or being given a few extra months to live is considered a success and something that patients are happy with. The clinic does not publish survival rates.

Ottensmeier does not think Hallwang patients should be banned from crowdfunding pages but says that patients and their donors must be much better informed about what they are paying for. The fundraising sites suggest that some Hallwang patients have had exaggerated notions of their prospects of long term survival. Anastasia Leslie’s Buy Another Day GoFundMe page said she was told by the Hallwang that “all of the ovarian cancer patients (approx 20 to 25 per year in the last 15 years) ... are still alive, doing well and in remission.” Despite apparently spending £100 000 in just one week<sup>10</sup> at the clinic, her death was announced on the funding page within months of her first trip to Germany. Her appeal raised £155 000.

Rekha Banerji’s appeal for her daughter Rebecca, who had stage 4 breast cancer, said: “Although in the UK, this is a hopeless case, the German doctors are extremely confident Rebecca will gain full remission.”<sup>11</sup> The appeal raised £14 645, but her daughter also died within months of starting treatment, according to her GoFundMe page.

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.

Ottensmeier also questions Hallwang’s prices. “For a much smaller sum you can buy the same immunotherapy drugs and have them administered in the UK,” he says.

Patricia Peat, a former oncology nurse who has advised people (box 1) to go to the Hallwang after visiting the clinic herself, says she has now stopped recommending it to her clients.

**Box 1: The Majors' story**

Sally Major had stage 4 bowel cancer diagnosed when she was 32, after her concerns were repeatedly dismissed by the NHS. The youngest of her four children was just 2 years old.

Sally and her husband, Liam, sought the advice of former oncology nurse Patricia Peat, who now runs Cancer Options, a Nottingham based consultancy that claims to help patients navigate alternative approaches to the disease. Peat recommended the Majors go to the Hallwang Private Oncology Clinic in Germany.

There was a catch though—the Hallwang was extraordinarily expensive. Peat advised it could cost around £80 000. Over the course of the next year, the family spent more than four times that: £350 000, Liam tells *The BMJ*. They re-mortgaged their home, took out bank loans, sold their car, and set up an appeal on the crowdfunding site [YouCaring](#).

As the year went by Liam's pleas on the site and in the media, which covered Sally's quest and the fundraising effort extensively, became increasingly desperate. "This week has cost us €26 000...our money has finally run out," he said in a *Mirror* story in March 2017.<sup>12</sup> "Sally can barely stand ... we're not able to get her home. Equally we can't afford to stay here so have no option. I am literally begging."

A few weeks later Sally died while still under treatment at the Hallwang. Less than a year had passed since her first visit.

On Sally's first visit to Germany in July 2016, Liam was taken aback by the Hallwang's charges. "We spent around £1000 a day on top of the treatment costs," he says. But the Hallwang advised that its staff had experience of his wife's particular cancer and that they hoped to put her into remission, so he wasn't going to argue over money. "They told us positive stories and never mentioned anyone who had died," he says. "I did ask for figures on survival rates but was told patients did not want to share their data. If I wasn't in a desperate situation I might have asked more questions." He was also asked not to show or discuss his invoices to anyone else, which he thought was "not right."

The peptide vaccine treatments were the single biggest cost, at €11 000 each, he says. These were not administered by the clinical staff but by clinic manager Maike Luz. The Majors were not told exactly what was in them. "Maike came into Sally's room on one occasion to give her a vaccine we hadn't asked for. I stopped her," Liam says.

The experience of another crowdfunded patient, Claire Cunningham, dispelled his doubts. Claire arrived at the clinic with advanced breast cancer in November 2016 unable to walk or talk and having been offered end-of-life care by the NHS. She recovered sufficiently to return to work and her testimony features on the Hallwang website. She was one of a group of 14 patients, including Sally, who bonded as a group through their shared Hallwang experience.

Today, Claire is seemingly the only one of that group left alive. *The BMJ* was unable to speak to her but it was reported earlier this year that tumours had returned to her lungs and spine and she was very ill.<sup>13</sup>

"There's one man who spent €1.5m. His wife got an extra two or three months," Liam tells *The BMJ*. He believes Sally's treatment bought her "four or five months" and dismisses the suggestion that the extra time Hallwang patients seem to have bought may simply reflect the challenges of making an accurate prognosis. When he first took his wife to the Hallwang "she was about to die," he says. "I could see that. And she did improve."

Around two weeks before Sally died Liam asked the Hallwang's senior oncologist Jens Nolting to re-test her tumours to see if any other drugs might be suitable.

"He agreed to it," Major says. The cost was around €17 000. "A different doctor pulled me out of the room and told me if the treatment Sally was already receiving didn't work there was nothing else left to try, so we didn't go ahead."

Despite all the energy the Major family and friends spent on fundraising, the family was left £70 000 in the red after Sally's death, forcing Liam to set up a new appeal to help cover these debts.

If he had a second chance he says he would speak to the clinic about its costs before going ahead.

The fact that patients' families will pull out all stops to get the treatment is part of their business model, he suggests, because if it were not for crowdfunding people wouldn't be able to raise the funds.

He now thinks the crowdfunding sites should carry warnings or provisos about alternative treatment centres like the Hallwang.

"Having that support from someone who had been involved in a number of cases would have made me think twice. And I'd have been asking questions at the Hallwang rather than just handing over money."

"The lack of transparency and communication about both costs and how long they may offer treatment for at the outset is both confusing and misleading," she tells *The BMJ*.

Families who embark on treatment at a clinic and are then subject to increasing costs without a clear idea of the likely outcomes are put in a "massively difficult and emotive position," she says. "The Hallwang is the worst example of this I've come across."

Peat also supports the Good Thinking's call for crowdfunding vetting. "Something has to be done," she says. "The pressure on families to achieve a target is enormous. It's morally unacceptable."

**Role of the media**

Newspaper and TV reports on people with cancer drive donors to the crowdfunding sites, sometimes attracting the attention of celebrities, who boost funds. They also encourage others to seek the same treatment. "These reports may look like uplifting human interest stories, but the reality can be much darker," says the Good Thinking Society's Michael Marshall. "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."

Many stories follow a familiar narrative: a tragic patient, with everything to live for, is on the mend after "miracle" treatment denied them by the NHS. Gemma Nuttall is one example. *The Daily Mail* and ITV<sup>14 15</sup> reported the young mother was now "cancer free" in February 2018, a few months after treatment at the Hallwang clinic, which was funded in part by film star Kate Winslet. Sadly, a recent update on Gemma's GoFundMe page said the cancer had returned. This has not been reported.

"If the media want to report on medical fundraising stories, they should seek the advice of qualified medical experts," Marshall said.

Competing interests: I have read and understood BMJ policy on declaration of interests and have no relevant interests to declare.

Provenance and peer review: Commissioned; externally peer reviewed.

- 1 FDA. Inspections, compliance, enforcement, and criminal investigations: Burzynski research institute/irb. Warning letter 5 Oct 2009. [https://www.ratbags.com/soles/history/2012/0818burzynski\\_irb.pdf](https://www.ratbags.com/soles/history/2012/0818burzynski_irb.pdf)
- 2 FDA. Warning letter to Stansilaw Burzynski, 3 Dec 2013. <https://www.fda.gov/iceci/enforcementactions/warningletters/2013/ucm378237.htm>
- 3 FDA. Letter re antineoplastons A10 and AS2-1 injections. 18 Oct 2012. [http://www.circare.org/info/bri/burzynski\\_fdauntitled\\_2012.pdf](http://www.circare.org/info/bri/burzynski_fdauntitled_2012.pdf)
- 4 Chang J. Texas Medical Board sanctions controversial cancer doctor Burzynski. *Statesman* 2017 Mar 3. <https://www.statesman.com/news/texas-medical-board-sanctions-controversial-cancer-doctor-burzynski/sxUP7GZ8XbYR4KzPTH5aCJ/>
- 5 Cancer Research UK. Gerson therapy. <https://about-cancer.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/complementary-alternative-therapies/individual-therapies/gerson>
- 6 Integrative Whole Health Clinic. Anti-cancer program in Mexico. <http://www.iwhclinic.com/treatments/anti-cancer-program/>
- 7 Integrative Whole Health Clinic. Jose A Henriquez. <http://www.iwhclinic.com/about-j-henriquez/>
- 8 Hallwang Private Oncology Clinic. Your tests. <https://www.hallwang-clinic.com/your-oncological-journey-cancer-treatment/diagnostic-tests.html>
- 9 Ornell's battle with cancer. <https://uk.gofundme.com/desiretolive>
- 10 Saul H. Woman raises £100 000 for immunotherapy by asking: "buy another day of my life." *i news* 2017 Mar 16. <https://inews.co.uk/news/health/woman-raises-100000-immunotherapy-asking-people-buy-another-day-life/>
- 11 Rebecca Chakraborty's cancer appeal. <https://uk.gofundme.com/my-daughters-cancer-treatmet-2vfzvjv>
- 12 Bullen J. "I'm literally begging": husband's desperate appeal after wife's cancer was missed by doctors 12 times. *Mirror* 2017 Mar 9. <https://www.mirror.co.uk/news/uk-news/husband-woman-whose-cancer-missed-10060114>
- 13 Gellman L. The last resort. Mar 2018. <https://longreads.com/2018/03/22/the-last-resort/>
- 14 Southern K. "Thank you. You saved my life": mother breaks down as she thanks Kate Winslet for setting up a charity to raise £300 000 and helping her become cancer free. *Daily Mail* 2018 Feb 4. <http://www.dailymail.co.uk/news/article-5349581/Kate-Winslet-Leo-Di-Caprio-step-help-cancer-mum.html>
- 15 Titanic's Kate and Leo saved my life after doctors said they couldn't. *This Morning* 5 Feb 2018. <https://www.itv.com/thismorning/hot-topics/titanics-kate-and-leo-saved-my-life-after-doctors-said-they-couldnt>

Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>

## Tables

**Table 1 | Total raised by GoFundMe and JustGiving by country of clinic or treatment up to 1 July 2018**

Country	GoFundMe (£)	JustGiving (£)
Canada	NA	2 050
Ecuador	NA	850
France	706	NA
Germany	3 627 418	1 350 115
Hungary	37 561	1 280
India	97 034	1 355
Latvia	13 593	4 072
Mexico	328 707	164 714
Netherlands	9 436	NA
Poland	18 383	75
Portugal	51 260	NA
Spain	8 998	3 296
Turkey	18 427	109 007
UK	541 039	218 728
USA	179 643	347 104
South America	1 230	NA
Unknown	179 474	148 550
Total	5 112 909	2 351 196

Table 2| Amount raised by date fundraiser was opened

Year	GoFundMe (£)	JustGiving (£)
2009	—	7 206
2010	—	2 226
2011	—	2 629
2012	—	291 639
2013	34 073	27 281
2014	8 576	172 812
2015	164 907	62 590
2016	2 573 177	489 877
2017	1 599 773	893 974
2018*	629 181	319 905
Unknown	103 222	81 055
Total	5 112 909	2 351 196

\* Up to end of June.