

**The Fundraising Regulator's decision into a complaint about  
Brain Tumour Research**

## **The Complaint**

Mr S and Ms T complained to us about Brain Tumour Research (the charity). They told us that *“through numerous false statements on its website”, the charity may have “gained money by deception from traumatised, vulnerable bereaved family members of brain tumour patients, and has not applied that money in the way that it has described.”*

## **Our Findings**

We have found no evidence to suggest that the charity set out to intentionally deceive donors or that the funds raised by the charity were not ultimately going towards its stated charitable objectives. Nor did we find any evidence that the charity claimed donations would be used solely for research into brain tumours.

However, we did find that the charity should have taken greater care to ensure that all messages to potential donors provided a clear and factually correct context regarding how donations are used.

Our investigation also found that the charity did not address Mr S and Ms T's complaint appropriately.

## **Our Recommendations**

We have recommended that Brain Tumour Research:

- consider the language it uses when describing how it uses the funds raised in light of our findings;
- consider the learning from this complaint and the importance of responding to all the points raised by a complainant; and
- consider making its annual report available to donors directly on its website.

## The Complaint

1. Mr S and Ms T complained to us about Brain Tumour Research (the charity). They told us that *“through numerous false statements on its website”, the charity may have “gained money by deception from traumatised, vulnerable bereaved family members of brain tumour patients, and has not applied that money in the way that it has described.”*

## Our Role

2. The Fundraising Regulator is the independent regulator of charitable fundraising. Part of our role is to investigate complaints from members of the public about fundraising practice where these cannot be resolved by the fundraising organisations themselves. We do so by considering whether the fundraising organisation has complied with the Code of Fundraising Practice (the Code), which outlines the legal requirements and best practice expected of all charitable fundraising organisations across the UK. Where poor fundraising practice is judged to have taken place, we can make recommendations for remedy and implement changes to the Code.

## Key Facts

3. Mr S and Ms T told us that sadly both of their spouses had passed away as the result of a glioblastoma, which is a *“high grade primary brain tumour and the most common in adults.”* Mr S and Ms T said that this condition is always fatal and that *“over 70% of patients do not survive for twelve months after diagnosis.”*
4. Mr S and Ms T told us that this is one of the *“most horrific diseases known to mankind...The limited chemotherapy options available, and other medications, cause enormous collateral damage to the patient. The effect on the family of the patient, during the illness and after bereavement, is highly traumatic, distressing and psychologically scarring. In other words, they are truly vulnerable after such an awful experience. Bereaved family members often suffer from traumatic depression and require counselling.”*
5. Mr S and Ms T said that they know that many patients and families affected are motivated to donate funds for research to try to *“prevent others having to endure this dreadful disease.”*
6. Mr S and Ms T told us they were *“dismayed and disgusted”* to realise that the charity’s annual report and accounts submitted to the Charity Commission showed that for 2015/16 the funds it granted to research were only 46% of its

annual expenditure. They also said that similar amounts were spent on research in the three preceding years.

7. Mr S and Ms T told us that their fear is donors are being “*badly misled into giving*” on the assumption that all of their donations would be used for research into brain tumours. They said that the charity’s 2016/17 accounts show that “*£426,132 was spent on ‘Campaigning and Raising Awareness’ – which is not mentioned in the charity’s declared objectives*”.
8. Mr S and Ms T told us that they believed Brain Tumour Research had breached the Code in making the following statements:
  - “*We are the only national charity in the UK that is dedicated to granting all available funds to continuous and sustainable research into brain tumours.*” (Charity’s JustGiving Page)
  - “*We are the only national brain tumour charity dedicated purely to funding scientific research into all types of brain tumour.*” (Charity’s website, May 2017)
  - “*To sustain the long term peer-reviewed research at our Centres of Excellence we need to **continue** to provide £1m a year in funds per centre.*” (Charity’s website)
  - “*Advancements in research (are) made every day.*” (Charity’s website)
  - “*all funds raised will help sustain long-term, life-saving research*” (Facebook, 20 June 2017 )
  - “*Like Brain Tumour Research, some of our members focus solely on fundraising for research.*” (Entry on website for Association of Medical Research Charities (AMRC)<sup>1</sup>)
  - “*dedicated to granting 100% of its funds to continuous and sustainable scientific research into brain tumours.*” (Removed from AMRC’s website in Summer 2017 but still on charity’s Facebook ‘About’ page.
9. Mr S and Ms T said that the statement “*We are the only national charity in the UK funding sustainable and continuous research into brain tumours.*” was

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<sup>1</sup> The Association of Medical Research Charities (AMRC) is a national membership organisation of leading medical and health research charities. [www.amrc.org.uk](http://www.amrc.org.uk)

incorrect as *“The Brain Tumour Charity is also a national UK charity funding such research – and invests at least twice as much p.a. in research grants.”*

10. Mr S and Ms T said that the statement made regarding the need to continue funding each centre with £1 million implies that Brain Tumour Research is currently providing funding of £1 million *per centre*. However, the submitted accounts for 2015/16 show the total research grants awarded last year were £1,439,674 and which equals an average award of only £359,919 for each of the four centres.
11. Mr S and Ms T also said that the statement regarding medical advancements was *“a gross exaggeration”*. They said that *“no evidence is offered to substantiate such a claim. Patients and families reading this may take very cruel, false hope from this statement.”*
12. Mr S and Ms T told us that the charity’s entry on the AMRC’s website states *“Like Brain Tumour Research, some of our members focus solely on fundraising for research. Our members all recognise that funding research is of vital importance so that we can advance treatments and ultimately one day, find a cure. Whilst we fundraise for vital research, some of our member charities are busily supporting patients and their families where and when they need it”*. They said that this suggests to them that the charity claims to *“focus solely on research.”*
13. Mr S and Ms T said that their own personal experience has given them an *“accurate perspective on the need for more research into this dreadful disease. However, in [their] view, any charity using public voluntary funds should operate with integrity, respect, dignity and – above all – honesty – and follow the Code.”* They told us that they do not know *“why this charity would claim that it grants all available funds to research, when it is only 46%.”*
14. After assessing Mr S and Ms T's concerns we contacted the charity and asked that they provide a response directly to the complainants. We explained to Mr S and Ms T that on receipt of the charity’s response they could come back to us if they remained dissatisfied.
15. Mr S and Ms T subsequently contacted us to say that they had received a response from the charity and that it did not fully address their concerns and they remained dissatisfied.
16. Mr S and Ms T provided us with a copy of the charity’s response. The response briefly sets out the concerns Mr S had previously raised with the charity about the *“fragmentation”* of the charity sector and the

possibility of merging charities with common aims and objectives. In this response, the Director of Fundraising stated that Brain Tumour Research was *“born out of the grief of [its] Chief Executive, and her family”* after the death of a close relative at a young age, as well as that of its Chairman and President who had both had immediate family members die as a result of the disease. He explained that the charity’s vision of the future is one *“where increased scientific knowledge means that this devastating disease can be treated, and ultimately cured, thus preventing the suffering of patients and their loved ones”*.

17. The Director of Fundraising explained that the charity disagreed that there is something misleading about its *“communications to supporters and the public.”* He told Mr S and Ms T that as an organisation, Brain Tumour Research made a *“strategic choice to focus on research.”* He said that it does not fund patient support services, and instead *“signpost[s] to those of its member charities who focus on support such as Brainstrust.”*
  
18. The Director of Fundraising told Mr S and Ms T that the *“amount of admin expenditure for the financial year 2015-16 was 8%.”* And that *“all of its non-admin expenditure was related to its core mission,”* whether:
  - *direct grants to its Research Centres of Excellence;*
  - *direct grants to other organisations (such as the brain tissue bank in Southampton);*
  - *money spent on campaigning as one voice with its member charities to government and larger charities with a laser focus on growing the market for research spend; and*
  - *money spent as the cost of generating funds.”*
  
19. The Director of Fundraising told Mr S and Ms T that in its Article of Association dated 14 June 2013, the charity’s objects are detailed as to *“assist in the relief of sickness and distress of persons suffering from brain tumours, particularly by supporting research projects into the causes and treatments of brain tumours and disseminating the useful results of such research.”* The Director of Fundraising said that this statement is publically available and listed in its 2016 Annual Reports and Financial Statements. He said that this, therefore, *“permits the Charity to engage in activities such as campaigning and awareness.”*
  
20. The Director of Fundraising also explained that *“these activities have been conducted with the ultimate aim of increasing the amount of funding put into brain tumour research, not only through the generosity of the public through the charity sector, but crucially from Government too. We certainly take the view that if we can make brain tumour research a Governmental priority, we can substantially change the change the research landscape for good.”*

21. The Director of Fundraising explained that the reference to available funds, *“must be taken in context. In an ideal world, all our all of our income would simply arrive in our bank account; unfortunately, this is not the case.”* He said that in order to raise funds the charity must engage in fundraising activities and must also, in line with Charity Commission guidance, hold reserves. The Director of Fundraising said that *“available funds must therefore exclude the cost of raising funds and building reasonable reserves.”*
22. The Director of Fundraising explained to Mr S and Ms T that he did not consider the charity’s statement that it is *“the only national charity in the UK that is purely dedicated to raising funds for continuous and sustainable scientific research into brain tumours”* to be misleading.
23. The Director of Fundraising also explained that whilst the charity’s mission is to fund seven £1 million centres it does not claim to be spending £7 million a year in grant funding and that this can be evidenced by its publically available accounts.
24. The Director of Fundraising concluded his response to Mr S and Ms T by stating that the charity does *“indeed state that we focus solely on research .... By employing staff and a professional approach, we have been able to invest in growth and raising awareness. Even with the cost of generating funds, we are now able to invest £2,000,000 a year into research and our plans are for this figure to continue to rise year on year.”*
25. Mr S and Ms T explained that they remained dissatisfied that the charity’s response did not explain how donors would be aware of the *“context of available funds”* and that it excludes money spent on campaigning and awareness. They told us that this goes to the heart of their concerns and that *“traumatised terminally ill patients, and their subsequently bereaved families, may not be thinking about context and will take the statement at face value.”*
26. Mr S and Ms T also told us that they were pleased to see that since their initial contact with the charity about this matter it had amended some of its statements online. They said that they were also pleased to see that the charity had amended its statement on the AMRC’s website which previously said it was, *“dedicated to granting 100% of its funds to continuous and sustainable scientific research into brain tumours”*. However, they also said that this statement had not been amended on the charity’s Facebook page. Mr S and Ms T said that they remained dissatisfied as they did not feel that their concerns were fully addressed.

### **What Brain Tumour Research told us**

27. We contacted the charity to inform it of our investigation and to ask if it would like to make any further comment. The charity replied to advise that, whilst it is committed to resolving this matter,

its final response “provides a robust rejection of the claim that [it] mislead[s its] supporters.”

28. Brain Tumour Research said that it “refutes” the claim that “it might have gained money by deception.” It said that it can evidence its transparency to donors in a number of ways including:

- *its regular supporters’ magazine Believe which is available online and in hard copy and which features detailed reporting on projects that it funds. It pointed out that within the Autumn 2017 edition its Chief Executive “Sets out in detail the funding journey and the relationship between [its] income levels and [its] research.”; and*
- *its mission which is clearly defined on the most prominent part of its website, stating that it is dedicated to “raising funds for continuous and sustainable scientific research into brain tumours” and that it is a leading “voice calling for greater support and action for research into what scientists are calling the last battleground against cancer.”*

29. Brain Tumour Research also told us that since receiving this complaint it has reviewed its website and Facebook page to remove any “unintentional ambiguity.” It said that it is also currently in the process of reviewing third party websites to remove any historic wording.

#### **Other evidence we have considered**

30. During our investigation we looked at Brain Tumour Research’s website, paying particular attention to its ‘Donate’ page. This page is separated into three sections. The first section explains ways it is possible to help fund its cause including leaving a legacy, online fundraising and Gift Aid.

31. The next section explains that the charity is “striving to fund a network of seven dedicated research centres” and that its “mission is to build a network of experts in sustainable brain tumour research”, with a link to a page which discusses its research centres of excellence. This page then explains that its “funding strategy means that we’re investing in long-term research, building the ‘critical mass’ of expertise needed to accelerate the journey to find a cure. In turn, this facilitates increased research investment from other sources.”

32. The final section is entitled ‘Make a Difference’ and states “We are striving to fund a network of seven dedicated research centres. Help us fund the fight. Together we will find a cure.” It is in this section that the reader can make a single donation or set up a regular one. Below this section is a link to its

'Research' page which provides links to details about its Research Centre of Excellence, Research Strategy and Research News. At the bottom of this page there is, again, an option for people to donate.

33. Additionally should a visitor to the charity's website click on the Research Strategy link they are taken to a page that details the charity's aims which are as follows:

- *"Helping develop the next generation of researchers ultimately focusing on all types of brain tumour;*
- *significantly accelerate the progress of brain tumour research within the UK in order to make a real clinical difference, through the funding of our dedicated Brain Tumour Research Centres of Excellence;*
- *raise at least £7 million per year in order to provide long-term, continuous and sustainable funding and support to the seven centres;*
- *increase awareness of the lack of funding for brain tumour research in order to stimulate a greater investment by the Government and other cancer charities; and*
- *improve the clinical outcomes for brain tumour patients."*

34. At the bottom of every page on Brain Tumour Research's website there is the statement *"We are striving to fund a network of seven dedicated research centres. Help us fund the fight. Together we will find a cure"* along with a request for a donation and a link to how is the money spent.

35. We have also considered the charity's Facebook Page which on its 'About' sections contains a brief outline of the charity's history and objectives along with a link to its main website and a donate button.

## **Our Findings**

36. We have set out below our findings. We have identified which areas of the Code we consider to be relevant and whether there have been breaches.

### ***Section 1 of the Code – Key Principles and Behaviours***

37. Section 1 of the Code sets out the key principles and behaviours that we expect charities to adhere to when fundraising.

38. Section 1.2 (a) states that *"A legal principle underpinning fundraising is that all funds raised for a particular cause **MUST\*** be used for that particular cause."*

39. Section 1.4 (c) states that *“Fundraising organisations **MUST\*** ensure that accepted donations are used to support the cause in accordance with the conditions attached to the donation, which may arise from donors’ stipulations or representations made by the charity as to the uses of the funds.”*
40. We understand that based on the statement made on the charity’s website that *“Brain Tumour Research is the only national charity in the UK dedicated to funding continuous and sustainable scientific research into brain tumours”* it could appear to donors that donations would go directly to research into the illness. However, we have seen evidence that before making a donation the donor is provided with a link to how the money is spent and this in turn links to the charity’s aims. We also note that the charity states that its objectives are to *“Increase awareness of the lack of funding for brain tumour research in order to stimulate a greater investment by the Government and other cancer charities”* and *“Raise at least £7 million per year in order to provide long-term, continuous and sustainable funding and support to the seven centres.”* Therefore, we consider that donors are provided with sufficient information prior making a donation to allow them to make an informed decision.
41. Whilst we acknowledge Mr S’s and Ms T’s concerns about the proportion of the charity’s income that is used to directly fund research, we have seen no evidence to suggest that the additional funds raised would not ultimately go towards the stated charitable objectives. By carrying out campaigning and fundraising the charity are in turn increasing the profile of the illness and ultimately working towards increasing research funding. Furthermore, the charity’s charitable objectives do not simply refer to funding research. **On this basis we do not consider Brain Tumour Research to have breached sections 1.2 (a) and 1.4 (c) of the Code.**
42. Section 1.2(c) of the Code states that *‘Organisations **MUST NOT** exaggerate facts relating to the potential beneficiary’*. Mr S and Ms T have raised concerns that the statement *“Advancements in research (are) made every day”* is a *“gross exaggeration”* and would give families and patients false hope. We acknowledge their concern, however it appears to us that this statement is intended to reflect the gradual and cumulative benefit of research, rather than claiming that new treatments or breakthroughs occur every day.
43. **We, therefore, do not consider that the charity has breached the Code in making this statement.** However, we do consider it may be helpful for the charity to reflect on the wording they have used given the sensitivity around this issue.

44. Section 1.6 (b) of the Code states *“Organisations MUST respond to any complaints from donors, beneficiaries or other parties in timely, respectful, open and honest way”*.
45. We note that the charity replied promptly to Mr S and Ms T and that within the response the Director of Fundraising attempts to explain why he does not believe that the charity is misleading donors. However, whilst the charity believes that it has provided a *“robust rejection of the claims that it mislead[s its] supporters”*, we do not consider that response fully addresses the concerns raised by Mr S and Ms T. In particular it does not address their concerns about the statements *“Advancements in research [are] made every day”* and *“all funds raised will help sustain long-term, life-saving research.”*
46. We note that whilst the statement made on the charity’s website in May 2017 that *“To sustain the long term peer-reviewed research at our Centres of Excellence we need to continue to provide £1m a year in funds per centre,”* has been removed, we do not feel that pointing the complainant in the direction of the charity’s accounts was an adequate response.
47. We also do not consider that the charity’s statement advising that all available funds *“must be taken in context. In an ideal world, all of our income would simply arrive in our bank account; unfortunately, this is not the case”* was a helpful response. It does not explain how the donor would/should be aware of this context and could also read as dismissive of the specific points the complainants were making.
48. In not fully addressing all of Mr S's and Ms T's complaint, we do not consider that the charity has been sufficiently open. **On this basis we have found that Brain Tumour Research has breached Section 1.6(b) of the Code.**

### ***Section 5 of the Code – Fundraising Communications and Techniques***

49. Section 5 of the Code outlines the legal and best practice requirements of all fundraising organisations who engage directly with the public through a variety of channels to raise money for their work. Topics covered include basic data protection requirements along with stipulations that prohibit fundraisers from distributing shocking, misleading or offensive communications.
50. Mr S and Ms T have expressed concerns about statements made by the charity on a number of online platforms including the charity’s website, JustGiving page, Facebook page and its entry on the AMRC’s website. We have considered the statements made on these platforms and whether they are designed to encourage the reader to make a donation. We note that while the charity’s website and Facebook page are designed to educate the reader about the charity

and its objectives they are also used as a fundraising tool and are therefore considered to be fundraising communications.

51. Section 5.2(e) states *“Organisations MUST\* ensure that materials do not imply money is for a restricted purpose (such as buying a goat, or helping a particular child) when it may be used for different purposes or for general funds.”*
52. After reviewing the charity’s online platforms we have seen no evidence that it claims that the donations given would be directed solely to research projects. We consider that when referring to donations going towards *“continuous and sustainable scientific research”* the charity are making a broad statement about how the funds raised will be used to meet its charitable objects. **On this basis we do not consider that the charity have breached Section 5.2 (e) of the Code.**
53. Section 5.2(h) states *“Fundraising communications MUST NOT mislead, or be clearly likely to mislead, by inaccuracy, ambiguity, exaggeration, omission or otherwise.”*
54. Mr S and Ms T have concerns about the accuracy of the statement that *“Brain Tumour Research is the only national charity in the UK dedicated to funding continuous and sustainable scientific research into brain tumours”* considering there are other charities which raises funds for brain tumour research. We do not consider Brain Tumour Research are using this statement to assert that they are the only charity raising funds for research but rather that funding research is its primary objective which separates it from other national organisations which also provide care and support for sufferers and their families.
55. As explained in paragraph 41 we have seen no evidence that the funds raised are not being used to achieve the charity’s stated objectives. However, we understand why potential donors visiting the charity’s JustGiving page and reading the statement that Brain Tumour Research is *“the only national charity in the UK that is dedicated to granting all available funds to continuous and sustainable research into brain tumours”* or the statement on its Facebook page that it is *“dedicated to granting 100% of its funds to continuous and sustainable scientific research into brain tumours”* could make the assumption that their donation would be directed towards research only. We note that this statement has been amended on the AMRC’s website.
56. We are also concerned that Brain Tumour Research advised Mr S and Ms B that statements such as these need to be taken *“in context”* but do not provide the readers with the information to understand this context. At no point does it make potential donors visiting its JustGiving or its Facebook page aware that *“all available funds”* and *“100% of funds”* means what is left after the deduction of fundraising and staffing costs. Given that potential donors may view the statements on these platforms in isolation without the more detailed context

provided on the charity's website, the charity should have taken more care to ensure that there was no potential for the wording used to be misunderstood.

57. We also note that Brain Tumour Research has removed the statement *"To sustain the long term peer-reviewed research at our Centres of Excellence we need to continue to provide £1m a year in funds per centre"* from its website. We are encouraged by this as we agree with the complainants that the use of the word *"continue"* could be understood as implying that the charity already provides £1m to each centre which it has confirmed is not the case.
58. We do not consider that the charity intentionally set out to mislead potential donors with these specific statements. We also recognise the steps the charity has taken since first receiving Mr S's and Ms T's complaint to amend the statements complained about and to remove any potentially ambiguous statements from its online platform. However, we consider that the charity should have taken greater care in the first instance to make sure that the wording could not be misunderstood. **On this basis we consider that the charity has breached Section 5.2(h) of the Code.**

### Recommendations

59. We are encouraged to note that Brain Tumour Research have now undertaken a review of its online platforms to amend potentially ambiguous statements therefore, have no further recommendations to make in this regard.
60. We recommend that Brain Tumour Research considers the learning from this complaint when describing how it uses funds raised.
61. We recommend that when dealing with complaints of this nature Brain Tumour Research considers the learning from this complaint and the importance of responding to all the points raised by a complainant.
62. Whilst we note that Brain Tumour Research's annual report is available on the Charity Commission Website, we would ask that it considers making this available to donors directly on its website.

### Conclusion

63. We have seen no evidence to conclude that the money raised by Brain Tumour Research is not being used to achieve its charitable objectives.
64. We have also concluded that the charity did not intentionally set out to deceive potential donors. However, in order to be compliant with the Code it should have taken greater care to ensure that all messages to possible donors did not have the potential to mislead. Our investigation also found that the charity did not address the complainants' concerns appropriately.

