

## **EX-EMPLOYEE v BIOGEN**

### **Conduct of ex-local senior leader**

**An anonymous, non-contactable complainant who described themselves as an ex-employee of Biogen Idec Limited complained about the behaviour of a local senior leader in 2018 who had since left Biogen.**

**The complainant alleged that, at the time in question, Biogen was looking to secure a positive decision from the National Institute for Health and Care Excellence (NICE) for its Spinal Muscular Atrophy (SMA) medicine Spinraza (nusinersen sodium) after it had been rejected. The complainant provided a copy of an email that was sent by the local senior leader in question to the site wide team and alleged that he/she asked them to contribute to the SMA charity so that it would have a positive impression and thus it would curry favour and increase the pressure on NICE to reverse the decision.**

**Following this email, the complainant alleged that contributions to this charity increased significantly.**

**The detailed response from Biogen is given below.**

**The Panel noted that the email in question sent by the local senior leader in 2018 was headed 'Important – Please read: We can do better than this!' and was addressed to the 'site team'. It stated, *inter alia*:**

**'With a week to go before Biogen staff have a great day out, walking 10 kms, 22kms or a massive 100kms at Henley with a family picnic afterwards, I wanted to ask a small favour of you and encourage all of us to go deeper with your giving. Our official fund raising event is our Henley walk where we are raising money for these UK and Ireland SMA charities. These SMA charities are doing some amazing work as we partner with them to put pressure on the NHS to release funding for nusinersen and avoid parents whose children could die from this dreadful disease, not having access to our breakthrough drug Spinraza. This week alone we were on Sky news and ITV news. Please see link below [links provided].**

**As the leaders in SMA, to be absolutely frank, I would be embarrassed going to charities and splitting £66 as a gift from Biogen. Please help to turn this around.**

**Without putting any of you under any pressure (as I know how generous you all are), please could you dig a little deeper and see if we could at least raise £2000 for these charities. It would mean each of us giving £10. Thanks for your understanding.**

**You can still donate on the JustGiving page [link provided] ...'**

**The Panel noted that one of the links in the email was to an article titled ‘SMA Groups Outraged Over UK Rejection of Spinraza Coverage as Too Expensive’.**

**A snippet of a news article from the Sunday Independent titled ‘Power to the Kids’ and which referred to SMA and Spinraza was attached to the email. Below the article heading it referred to the hope a family had that HSE would ‘relent and agree to fund a drug that could be a life-saver ...’.**

**The Panel disagreed with Biogen’s submission that the activity was not within the scope of the Code. In the Panel’s view, although the activity in question appeared to be taking place over a weekend on employees’ own time, and it appeared that the money being donated was from personal funds rather than Biogen, the multiple references to Biogen Idec on the JustGiving page and the facilitation by the company in relation to raising the funds meant that, in the Panel’s view, the fundraising activity fell within the scope of the Code.**

**The Panel considered, regardless of whether or not the fundraising activity itself was within the scope of the Code, the allegation was that a local senior leader asked employees to contribute to the charity so that it would have a positive impression of Biogen and thus curry favour and increase pressure on NICE to reverse its decision in relation to Biogen’s medicine.**

**In this regard, the Panel noted that the email in question appeared to link the fundraising activity to the NICE decision by stating, ‘These SMA charities are doing some amazing work as we partner with them to put pressure on the NHS to release funding for nusinersen and avoid parents whose children could die from this dreadful disease, not having access to our breakthrough drug Spinraza’, and by including references to articles which referred to the NICE decision.**

**In the Panel’s view, the email implied that employees should donate to these charities as these charities were working with Biogen to put pressure on the NHS to release funding for nusinersen. The Panel noted the seniority of the local leader who sent the email and the wide internal audience it was sent to and considered that in linking the fundraising activity to the work that these charities were doing in relation to Biogen’s medicine was wholly inappropriate. The Panel considered that Biogen had failed to maintain high standards in that regard and a breach of the 2016 Code was ruled.**

**The Panel considered that, on balance, the email in question, sent by a local senior leader to a broad internal audience, linking a fundraising activity with the work that the recipient charities were doing to ‘partner’ with Biogen to ‘put pressure on the NHS to release funding for nusinersen’, was such that Biogen had brought discredit upon and reduced confidence in the pharmaceutical industry and a breach of Clause 2 of the 2016 Code was ruled.**

**An anonymous, non-contactable complainant who described themselves as an ex-employee of Biogen Idec Limited complained about the behaviour of a local senior leader in 2018 who had since left Biogen.**

## COMPLAINT

The complainant alleged that at the time in question, Biogen was looking to secure a positive decision from the National Institute for Health and Care Excellence (NICE) for its Spinal Muscular Atrophy (SMA) medicine Spinraza (nusinersen sodium) after it had been rejected. The complainant provided a copy of an email that was sent by the local senior leader in question to the site wide team and alleged that he/she asked them to contribute to the SMA charity so that it would have a positive impression and thus it would curry favour and increase the pressure on NICE to reverse the decision. The SMA charities were disappointed in the negative NICE decision.

The complainant alleged that this was totally inappropriate for the local senior leader to ask site wide for all Biogen employees to contribute to a charity associated with its expensive medicine in order that a negative NICE approval decision could be revisited and reversed. Following this email to the site wide team, the contributions to this charity increased significantly.

The complainant stated that unfortunately, this was one of several incidences of the local senior leader acting inappropriately but the only one where the complainant could supply evidence. The local senior leader had since left Biogen.

The email provided by the complainant stated:

'Dear site team

With a week to go before Biogen staff have a great day out, walking 10 kms, 22kms or a massive 100kms at Henley with a family picnic afterwards, I wanted to ask a small favour of you and encourage all of us to go deeper with your giving. Our official fundraising event is our Henley walk where we are raising money for these UK and Ireland SMA charities. These SMA charities are doing some amazing work as we partner with them to put pressure on the NHS to release funding for nusinersen and avoid parents whose children could die from this dreadful disease, not having access to our breakthrough drug Spinraza. This week alone we were on Sky news and ITV news. Please see link below...[details provided].

As the leaders in SMA, to be absolutely frank, I would be embarrassed going to charities and splitting £66 as a gift from Biogen. Please help to turn this around.

Without putting any of you under any pressure (as I know how generous you all are), please could you dig a little deeper and see if we could at least raise £2000 for these charities. It would mean each of us giving £10. Thanks for your understanding.

You can still donate on the JustGiving page [link provided]:

Thanks team

The headlines to hit the papers over the last 2 weeks:

Biogen's big breakthrough drug Spinraza runs into a barrier as NICE turns.'

When writing to Biogen, the Authority asked it to consider the requirements of Clauses 2 and 9.1 of the 2016 Code.

## **RESPONSE**

Biogen submitted that it would like to assure the PMCPA of its full commitment to the Code which it took very seriously and invested in compliance with comprehensive procedures and policies, regular internal and external training, and staff support and speak-up processes. Biogen stated that it strictly followed its company policies and procedures for company grants, donations and sponsorships to all external organisations, including patient organisations.

Biogen submitted that the matter in question happened over three years ago and context could be lost with the passage of time. Biogen provided the full email sent at the time by the local senior leader in question who was no longer with Biogen. Biogen also provided below further background context to the fundraising activity by the employees at that time.

Biogen believed that this matter fell outside the scope of the Code for the reasons set out below.

## **Background**

Biogen UK submitted that it fully supported its employees to engage in socially responsible behaviour, including fund raising for charity in a private capacity. Each year, employees selected a different charity that they wished to support personally and were involved in various fund-raising activities. Biogen did not initiate this activity, did not have any say in the charity selected, nor did it make any donations or matching contributions to the employees' selected charity.

The lead fund raiser for the activity in question was a Biogen employee, who was unconnected with any specific product, and was a regular runner. The employees decided to raise money for Spinal Muscular Atrophy (SMA) charities via a series of sponsored runs and walks, including the 'Thames Path Challenge' and the 'Henley 10k'. Biogen's product Spinraza (nusinersen) was indicated for the treatment of 5q SMA and so SMA was a cause close to the heart of many employees, however, Biogen did not, in any way, influence the choice of charities by the employees.

The employees set up a 'Just Giving' page for their fund-raising efforts. It was not possible to link multiple pages from individual fundraisers so the employee setting up the page labelled it as 'Biogen Thames Path Challenge and Henley 10k' to facilitate the employees' combined efforts. The primary page linked to three SMA charities so that friends and family could choose which organisation would receive their sponsorship donation. Biogen provided screenshots of each individual charity page. In all instances, it could be seen that the donors were individuals and a mix of colleagues, friends and family. The total amount raised was £3,945.24 which was divided between three different SMA charities.

The early stages of the fund-raising were slow, and the employees involved approached the local senior leader in question to ask if he/she would send an email encouraging staff to support their colleagues' efforts. The reference in the email to £66 was the total of the donations raised at the time the email was sent. As a participant in the charitable fund-raising efforts, the local senior leader in question willingly agreed.

The internal email mentioned Spinraza which had just been turned down by NICE. This was the reference made in the email to 'working to put pressure on the NHS'. The email did not say, as alleged by the complainant, that employees should give money to the charities to 'curry favour'. It was unrealistic of the complainant to suggest that Biogen employees' private efforts to raise money for these charities would impact the NHS's budget or outcome of NICE's health technology assessment process. However, Biogen acknowledged that the language chosen for the internal communication should have been considered more carefully in this context.

### **Application of the Code**

Biogen submitted that the activity in question fell outside the scope of the Code for the following reasons:

- The Code applied to relationships between companies and patient organisations – in relation to this fundraising activity, there was no relationship or contact between Biogen UK and the three charities involved.
- The activity in question was not a 'Biogen' activity and the company did not initiate or organise the activity, rather the employees were raising funds for the charities in a private capacity with donations being made only from their friends and family.
- Biogen (company) did not make any donation or other transfer of value to the three charities involved in relation to this specific fundraising activity.
- The purpose of the fundraising activity was for employees to raise money for the named charities, the activity was not initiated with the intention of promoting medicines to health professionals and other relevant decision makers.

Given the above, Biogen believed that this activity fell outside the scope of the Code.

Biogen submitted that it was regrettable that the former local senior leader in question conveyed his/her enthusiastic support for the employees' charitable fundraising activities in the manner expressed in the email, however, Biogen noted that this was an internal email limited to circulation amongst employees.

In the event that the PMCPA's view was that this fundraising activity was within the scope of the Code, Biogen did not believe that the matter breached Clause 9.1 nor was a breach of Clause 2 of the 2016 Code. Biogen submitted that the fundraising activity itself and the interaction between the employees and the charities was well intentioned and maintained high standards. The charities selected were chosen without the company's input, Biogen UK did not make any payment or transfer of value to the charities and the funds raised were not in any way linked to, or conditioned on the promotion of, or support for, Biogen's products and as such this activity would fall outside the scope for Disclosure as per 2016 Code.

### **Conclusion**

Biogen took its commitment to the Code seriously and hoped that the PMCPA agreed that the matter in question was outside the scope of the Code for the reasons set out above.

### **PANEL RULING**

The Panel noted the complainant's allegation that a local senior leader asked employees to contribute to the Spinal Muscular Atrophy charity so that the charity would have a positive

impression of Biogen and thus curry favour and increase pressure on NICE to reverse its decision in relation to Biogen's medicine.

The Panel noted Biogen's submission that there was no relationship or contact between Biogen UK and the three charities involved in relation to this fundraising activity and the company did not consider that it was a Biogen activity. The Panel further noted Biogen's submission that it did not initiate or organise the activity, rather the employees were raising funds for the charities in a private capacity with donations being made only from their friends and family. According to Biogen, it did not make any donation or other transfer of value to the three charities involved in relation to this specific fundraising activity; the purpose of the fundraising activity was for employees to raise money for the named charities and the activity was not initiated with the intention of promoting medicines to health professionals or other relevant decision makers. The Panel noted Biogen's submission that for these reasons Biogen considered that the activity was not within the scope of the Code.

In the Panel's view, it was of course not unacceptable for company employees to perform fundraising activities for charities in a private capacity; the Code would not automatically apply to all such activity. Whether the Code applied would be determined on a case-by-case basis, taking into account all of the circumstances including: the company's role in relation to the activity and whether such activity was facilitated or encouraged by the company; whether the activity occurred during employees' working time; or if the activity overlapped with the employees' professional responsibilities or the interests of the company.

The Panel noted that the email in question sent by the local senior leader on 31 August 2018 was headed 'Important – Please read: We can do better than this!' and was addressed to the 'site team'. It stated:

'Dear site team

With a week to go before Biogen staff have a great day out, walking 10 kms, 22kms or a massive 100kms at Henley with a family picnic afterwards, I wanted to ask a small favour of you and encourage all of us to go deeper with your giving. Our official fundraising event is our Henley walk where we are raising money for these UK and Ireland SMA charities. These SMA charities are doing some amazing work as we partner with them to put pressure on the NHS to release funding for nusinersen and avoid parents whose children could die from this dreadful disease, not having access to our breakthrough drug Spinraza. This week alone we were on Sky news and ITV news. Please see link below [links provided].

As the leaders in SMA, to be absolutely frank, I would be embarrassed going to charities and splitting £66 as a gift from Biogen. Please help to turn this around.

Without putting any of you under any pressure (as I know how generous you all are), please could you dig a little deeper and see if we could at least raise £2000 for these charities. It would mean each of us giving £10. Thanks for your understanding.

You can still donate on the JustGiving page [link provided]:

Thanks team

The headlines to hit the papers over the last 2 weeks:

**Biogen's big breakthrough drug Spinraza runs into a barrier as NICE turns thumbs down on reimbursement**

August 14, 2018 08:44 AM EDT

Once again, UK regulators have proven that they are unwilling to pay a heavy price for the breakthrough drugs that the FDA enjoys hustling through to quick approvals.'

The Panel noted that one of the links in the email was to an article titled 'SMA Groups Outraged Over UK Rejection of Spinraza Coverage as Too Expensive'.

The email included an attached snippet of a news article from the Sunday Independent titled 'Power to the Kids' and referred to SMA and Spinraza. Below the heading it referred to the hope a family had that HSE would 'relent and agree to fund a drug that could be a life-saver ...'.

The Panel noted that the email in question referred to 'a gift from Biogen' and set a target of £2000.

The Panel noted that the email in question was part of a chain of three emails. The first email was dated 29 August and was sent to UK office staff by an employee with a link to the JustGiving page and explained that donations would be collected at 'Month End Lunch tomorrow' via collection tins. This email listed the 40 employees participating in the fundraising activity. The second email was by the same employee, dated 31 August, and stated that they had raised £66 at the Month End Lunch; the email by the local senior leader in question was sent 25 minutes later and to a broader internal audience than the first two emails.

The Panel noted Biogen's submission that the early stages of the fundraising were slow, and the reference in the email to £66 was the total of the donations raised at the time the email in question was sent; the final total amount raised was £3945.24 and was divided between three different SMA charities.

The Panel noted, from the screenshots of the JustGiving page provided by Biogen, that the fundraising activity was titled 'Biogen Thames Path Challenge and Henley 10K' and stated, *inter alia*, 'On the weekend of 8/9<sup>th</sup> September, a number of Biogen employees are participating in walking and running events along the banks of the Thames to raise money for SMA charities'. It further stated, 'We would like to raise money for all three of the different UK SMA charities ...'. The Page named the three charities and stated the amount Biogen Idec had raised for each.

The Panel noted that the team members names were given on the JustGiving page as 'Biogen Idec' and one of the screenshots provided showed that £70.50 was raised by Biogen Idec and was stated as 'Money from UK site month end lunch'.

The Panel noted, contrary to Biogen's submission, that donations were not only made from the employees' family and friends. It appeared that there was great effort made on encouraging employees within the company to donate money.

The Panel disagreed with Biogen's submission that the activity was not within the scope of the Code. In the Panel's view, although the activity in question appeared to be taking place over a weekend on employees' own time, and it appeared that the money being donated was from

personal funds rather than Biogen, the multiple references to Biogen Idec on the JustGiving page and the facilitation by the company in relation to raising the funds meant that, in the Panel's view, the fundraising activity fell within the scope of the Code.

The Panel considered, regardless of whether or not the fundraising activity itself was within the scope of the Code, the allegation was that a local senior leader asked employees to contribute to the Spinal Muscular Atrophy charity so that the charity would have a positive impression of Biogen and thus curry favour and increase pressure on NICE to reverse its decision in relation to Biogen's medicine.

In this regard, the Panel noted that the email in question appeared to link the fundraising activity to the NICE decision by stating, 'These SMA charities are doing some amazing work as we partner with them to put pressure on the NHS to release funding for nusinersen and avoid parents whose children could die from this dreadful disease, not having access to our breakthrough drug Spinraza', and by including references to articles which referred to the NICE decision.

The Panel noted Biogen's submission that it was unrealistic to suggest that Biogen employees' private efforts to raise money for these charities would impact the NHS's budget or outcome of NICE's health technology assessment process. Biogen, however, acknowledged that the language chosen for the internal communication should have been considered more carefully.

In the Panel's view, the email implied that employees should donate to these charities as these charities were working with Biogen to put pressure on the NHS to release funding for nusinersen. The Panel noted the seniority of the local leader who sent the email and the wide internal audience it was sent to and considered that in linking the fundraising activity to the work that these charities were doing in relation to Biogen's medicine was wholly inappropriate. The Panel considered that Biogen had failed to maintain high standards in that regard and a breach of Clause 9.1 of the 2016 Code was ruled.

Clause 2 was a sign of particular censure and was reserved for such use. Examples of activities likely to be in breach of this clause included conduct of company employees that fell short of competent care and unacceptable payments. The Panel considered that, on balance, the email in question, sent by a local senior leader to a broad internal audience, linking a fundraising activity with the work that the recipient charities were doing to 'partner' with Biogen to 'put pressure on the NHS to release funding for nusinersen', was such that Biogen had brought discredit upon and reduced confidence in the pharmaceutical industry and a breach of Clause 2 of the 2016 Code was ruled.

**Complaint received**      **5 November 2021**

**Case completed**        **7 September 2022**