The Migraine Trust
Five-Year Strategy 2020-2025
Gail Emmerson
running the London Marathon for The Migraine Trust
Foreword

The Migraine Trust has never been more needed. There are now around 10 million people aged 15-69 across the UK living with migraine. During our charity’s consultation to develop this strategy people affected by migraine told us loudly and clearly that they often feel let down and alone. Whether that’s the poor care and treatment they receive from the NHS, the lack of support they get from their employer, or the fact that they have no one to talk to who truly understands what it is like to live with a complex, painful, debilitating and exhausting brain disease.

Our charity wants to support you. We want to improve awareness and understanding of migraine in our communities across the UK. We want to be your champion, and we want to help you to demand much-needed change in migraine services and care.

The Migraine Trust is also needed to help realise the significant opportunities facing the migraine community over the next decade. We’re living through one of the most exciting periods in new migraine drug treatment development. While the first tranche of these new drugs are slowly making their way into the NHS, there is no doubt that we need to make a more compelling case to decision makers for people living with migraine to have access to the best possible information, care and treatment on the NHS.

Working in partnership with UK migraine researchers we also need to make a more persuasive case for why migraine should receive more research funding, so that we can help more people to live well with migraine, and find a cure, as quickly as possible.

There is also the possibility that the migraine community could go on the kind of journey that the mental health community has been on over the past 20 years – from isolation, ignorance and discrimination to acceptance, new funding and policy reform. As the largest migraine charity in the UK, we think we are best placed to support our community on that journey.

But we also can’t hide from the fact that our charity has found it difficult at times to raise enough money to deliver on our ambitions. The past three years have been more successful, and we are now in the best financial position we have ever been. Over the next five years we need to put in place stronger, more sustainable economic foundations to ensure our charity has the best chance of being here for the foreseeable future. In setting out an ambitious agenda to grow our charity – based closely on what people affected by migraine are telling us they most want and need – we are going to have to earn the trust and financial support of far more of the migraine community in order to deliver it.

We hope that when you read this strategy you will see the passion and determination our charity has to reach more people, help more people and improve more people’s lives, and you will want to get more involved. With your help, we can build a charity fit for the next decade and the many challenges and huge opportunities ahead.

Michelle Walder  Gus Baldwin
Chair of board of trustees  Chief Executive
28 February 2020
Our journey to here

This year marks The Migraine Trust’s 55th birthday. We are incredibly proud of our charity’s long history. We have been championing migraine research, supporting people affected by this horrible brain disease, and campaigning for change since 1965.

During that time we have funded over 130 medical research projects, leading to a far greater understanding of the causes of migraine, the mechanics of migraine, and what happens in the brain during an attack. Through this work we’ve been able to support the next generation of migraine researchers and the development of new management and treatment options for migraine patients.

As part of our commitment to advancing migraine research, since 1966 we have also organised regular gatherings of scientists. We are extremely proud that the 18th Migraine Trust International Symposium (MTIS) will take place in London in September 2020, bringing together the world’s leading experts on migraine and headache to share the latest research findings and to discuss current trends in treatment and prevention.

We started providing information and support for people affected by migraine in the early 1990s. In 2011, we added another helpline providing help for people to access healthcare and those struggling at work or in education. We now support more than 2,300 people affected by migraine through our helplines every year.

Our online presence has also grown significantly over the past decade. Last year, over two million people came to our website for evidence-based migraine information and support. By the end of January 2020, more than 24,000 people had signed up to our monthly ebulletin with many thousands more following us on Twitter and Facebook.

In September 2018, the charity Migraine Action closed down and The Migraine Trust became ‘the’ research and support charity for people affected by migraine across the UK.

In February 2019, Michelle Walder joined as our new Chair and in March 2019, Gus Baldwin joined as our new Chief Executive, taking over from Wendy Thomas. In October 2019 we asked two former Migraine Action trustees, Mike Wakefield and Gary George, to join our Trustee Board and asked another former Migraine Action trustee, Ann Harrison, to be one of our new charity ‘Ambassadors’.
Our three new strategic goals

Following the closure of Migraine Action and the arrival of our Chief Executive, Gus Baldwin, we decided to broaden our charity’s agenda to better meet our new responsibilities as the largest migraine research and support charity in the UK. Following a public consultation, in September 2019 we finalised three new strategic goals for our charity:

i. Help find a cure – play a major role in encouraging new research and treatment to alleviate the symptoms and impairment caused by migraine and ultimately to find a cure.

ii. Ensure every single person with migraine – no matter who they are or where they come from – gets an accurate, timely diagnosis and access to the best possible information, care and treatment and has the same legal protections as other disabled people.

iii. Build an active and supportive community of people affected by migraine (PABM) – this community would act as both a source of support and a movement for change.

We believe these three new goals are sufficiently ambitious and aspirational to set the direction of travel for our organisation for at least the next 30 years, while still feeling real and achievable enough for the whole migraine community to get behind and to direct our charity’s day-to-day work. We can also ‘dial up’ or ‘dial down’ different aspects of this portfolio of goals as opportunities arise. But it is worth stressing that all three goals are equally important to us.
The importance of our charity’s values

Alongside our three new strategic goals, our organisational values are the most important thing to us. All our decisions and actions are guided by our values, which are:

- **Integrity** – we are trustworthy, transparent, honest and impartial
- **Inspiring** – we make things happen, we are forward thinking and are leaders in our field
- **Knowledgeable** – we use and share evidence and up to date research findings
- **Listening** – everything we do is based on the experiences of people affected by migraine
- **Ambition** – we are committed and demand better
- **Community** – we bring the migraine community together

Our trustees, ambassadors and staff

Our trustees

- **Michelle Walder (Chair)** – is Chief Executive of TXG Ltd, a leadership development firm she co-founded in 2004, and Non-Executive Director at both the Hay Festival of Literature and the Arts and Brighton and Hove Albion Football Club, where she also chairs the Women’s Football Club.
- **Dr Shazia Afridi** – is a Consultant Neurologist at Guy’s and St Thomas’ NHS Trust. She set up and runs the headache service in the neurology department.
- **Dr Fayyaz Ahmed** – is a Consultant Neurologist and Hon. Senior Lecturer at Hull University Teaching Hospitals NHS Trust and Hull York Medical School, and a trustee of the International Headache Society.
- **David Cubitt** – is a Partner at international law firm Osborne Clarke, where he leads its employment law team specialising in advising businesses on the impact of rules, regulations and employment law strategies.
- **Sir Denis O’Connor (Treasurer)** – is the former Chief Constable of Surrey Police and Chief Inspector of Constabulary for England and Wales.
- **Dr Brendan Davies** – is a Consultant Neurologist at the University Hospital of North Staffordshire, Stoke-on-Trent, and the clinical lead for the North Midlands Regional Headache Clinic.
- **Gary George** – spent over 40 years working in banking and fund management. He is the Deputy Chair of the trustee board at the Bank Workers Charity and was a Migraine Action trustee.
- **Sir Nicholas Stadlen** – is a former Queen’s Counsel and High Court Judge and Visiting Fellow at St Antony’s College, Oxford. He’s currently a documentary film-maker.
- **Mike Wakefield** – spent his career within blue chip companies including Pan Am, United Biscuits and Anheuser-Busch. Following early retirement, Mike joined several trustee boards and was the chair of Migraine Action.

Our ambassadors

- **Ann Harrison** – spent 30 years in the pensions industry. Since taking early retirement she has been involved in a number of roles in the third sector and was a Migraine Action trustee.
- **Jenny Mills** – is a former trustee and treasurer of The Migraine Trust and former chair of Circle Housing Merton Priory Homes.
- **Ian Watmore** – is a former chair of The Migraine Trust and is the current First Civil Service Commissioner.
How have we developed this strategy?

We have taken a deliberately collaborative approach to the development of this strategy. As a charity we don’t have all the answers to what are often complex challenges, so we’re not going to pretend we do. We also believe that our answers will be better, gain more support, and be more likely to lead to real change if we develop them in close collaboration with others. Most importantly, we believe passionately in the importance of putting people affected by migraine at the heart of our charity.

With this in mind, between May and June 2019 we undertook an initial consultation of people affected by migraine on social media. We wanted to do two things. Firstly, to seek people’s feedback on our three new draft strategic goals. Secondly, to see what people thought we should prioritise over the next five years in seeking to deliver these goals.

Over 300 people took part in the consultation. As well as helping us to further refine our goals, they also gave us a clear steer about the kinds of activities on which they wanted us to focus our efforts. We set out the results of this consultation on our website.

We turned this feedback into a ‘long list’ of 11 different possible projects which we could deliver as part of our next five-year strategy. Between September and November, we undertook further activities to consult with the migraine community to see which projects and activities people most wanted us to deliver.

We ran workshop events at our London ‘Meet up’ event; the Chronic Headache and Migraine Patient Support Group (CHAMPS) in Manchester; the British Association for the Study of Headache (BASH) ‘GPs with a Special Interest’ group meeting; our Managing Your Migraine event in Cardiff; and at our Volunteer Forum meeting. Through these meetings we consulted over 150 people across the UK.

Most significantly, we undertook the largest survey of the UK migraine community in our history, consulting over 1,900 people. Some of the key headline results are set out next and we hope they help to explain the strategic decisions we have now taken.

It is also important to stress that in the delivery of this strategy we will continue with our deliberately collaborative approach. We will seek to build stronger partnerships with professional bodies and charities, such as BASH, and seek to foster more collaborative relationships with key stakeholders, such as the UK migraine research community.
What the migraine community told us in our survey that they most want and need from our charity

Overall, our charity and the services we provide are rated highly:

People were asked whether they agreed or disagreed with the following statements (with 1 being definitely disagree and 10 being definitely agree):

- The Migraine Trust is effective: 8.2
- The Migraine Trust is a leader for the migraine community: 8.5
- The Migraine Trust is ethical: 8.6
- The information provided by The Migraine Trust is impartial: 8.2
- The information provided by The Migraine Trust is trustworthy: 8.8
- The information provided by The Migraine Trust is clearly informed by the views of people affected by migraine: 8.3
People want us to do the following five new projects as part of our five-year strategy:

- Supporting the development of the NHS migraine workforce
- Building a more ambitious migraine research agenda
- Piloting new ways to deliver NHS services to increase the number of people diagnosed with migraine
- A new Workplace Outreach Programme
- Growing our Managing Your Migraine events

We think we need to do more to involve people affected by migraine in the work of our charity:

People were asked how involved they think people affected by migraine are in the following aspects of our work (with 1 being not at all involved and 10 being extremely involved)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Average Score</th>
</tr>
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<tbody>
<tr>
<td>Our strategic aims and decision-making</td>
<td>6.0</td>
</tr>
<tr>
<td>Our research priorities</td>
<td>6.7</td>
</tr>
<tr>
<td>Our policy and campaigning work</td>
<td>6.6</td>
</tr>
<tr>
<td>Our comms activity</td>
<td>6.6</td>
</tr>
<tr>
<td>Our information content</td>
<td>7.2</td>
</tr>
<tr>
<td>Our events</td>
<td>6.8</td>
</tr>
</tbody>
</table>
We also think we need to do more to reach and help different communities and sub-groups within the UK migraine community – notably children and younger people; people from Black, Asian and Minority Ethnic (BAME) communities; men; and people from lower socio-economic backgrounds:

**How old are you?**

- 3% are 16-25
- 11% are 26-35
- 21% are 36-45
- 27% are 46-55
- 22% are 56-65
- 15% are 65 plus

- 21% are under 18
- 29% are between 18-39
- 27% are between 40-59
- 22% are 60 or over

**Which gender do you identify as?**

- Female: 86%
- Male: 11%
- Non-binary: 0.5%
- Other: 2.5%

- Female: 51%
- Male: 49%
- Non-binary: no data

**What is your ethnic group?**

- White: 95%
- Asian: 1%
- Black: 0.5%
- Mixed / multiple ethnic groups: 1.3%
- Other: 2.2%

- White: 86%
- Asian: 7.5%
- Black: 3.3%
- Mixed / multiple ethnic groups: 2.2%

**What is the highest level of education you have completed?**

- University undergraduate programme: 29%
- University post-graduate programme: 27%
- A-levels or equivalent: 19%
- GCSEs or equivalent: 16%
- Doctoral degree: 4%
- Primary school: 0.5%
- Prefer not to say: 5%

Comparable census data unavailable

ONS reports that **27.2%** of the UK national population has a university degree (compared to **60%** of our supporter base)
Our website and digital presence is crucial to our ability to reach and help more people:

How did you find or hear about The Migraine Trust?

60% Internet search

8% From another person who has migraine or headache

14% From a healthcare professional

The top five pieces of content people want to see more of on our website are:

1. More resources to help people self-manage migraine better
2. More information about the new drug treatments becoming available
3. A section that brings to life what living with migraine is really like
4. More information about the latest research trials
5. Commentary from expert health professionals

And they also want us to provide the following on our website (top six):

1. Interactive discussion forum to speak with healthcare professionals
2. More downloadable / shareable resources
3. Interactive discussion forum to speak with other people with migraine
4. Infographics
5. Email alerts for new activity
6. A blogsite
A significant proportion of people would be willing to leave us a gift in their will:

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>I don’t know</th>
<th>Prefer not to say</th>
</tr>
</thead>
<tbody>
<tr>
<td>40%</td>
<td>20%</td>
<td>25%</td>
<td>15%</td>
</tr>
</tbody>
</table>

But people are asking us to do more of the following if we want them to donate or raise funds for us (summary of top answers from a free text box):

1. Be more visible and engage more
2. Hold more local events
3. Show me or tell me the difference my donation would make to people living with migraine
4. Make it easy for me to donate
Migraine patients across the UK feel they are receiving poor NHS care and treatment for their migraine:*  

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am able to access care whenever I feel I need it</td>
<td>7%</td>
<td>25%</td>
<td>18%</td>
<td>29%</td>
<td>18%</td>
</tr>
<tr>
<td>I am satisfied with the care I receive</td>
<td>7%</td>
<td>25%</td>
<td>26%</td>
<td>26%</td>
<td>14%</td>
</tr>
<tr>
<td>Health professionals understand migraine</td>
<td>4%</td>
<td>19%</td>
<td>26%</td>
<td>28%</td>
<td>18%</td>
</tr>
<tr>
<td>The NHS is able to manage migraine well</td>
<td>4%</td>
<td>12%</td>
<td>23%</td>
<td>30%</td>
<td>26%</td>
</tr>
</tbody>
</table>

*of applicable respondents
People with migraine were asked whether they agreed or disagreed about the following statements – with 1 being definitely disagree and 10 being definitely agree.

- Migraine has had a significant impact on my life overall: 8.8
- Migraine has had a significant impact on my social life: 8.3
- Migraine has had a significant impact on my career: 7.6
- Migraine has had a significant impact on my mental health: 7.3
- Migraine has had a significant impact on my relationship with my partner/spouse: 6.8

Migraine is having a major impact on all aspects of people’s lives:

And too many people feel isolated and alone:

How often do you currently engage with other people who have migraine?

Never: 61%
Our finances now and where we hope to be by 2025

We want to be open in saying that The Migraine Trust has faced many financial ups and downs during our long history. In 2012, following the global recession, we came within a few weeks of closing our charity. It is a moment in our history that drives our determination to reach much safer financial ground during the course of our next five-year strategy and beyond. We are also acutely aware that the economic situation in the UK over the next decade is uncertain.

Following the nadir of 2012, between 2016 and now we have received more than £2.4 million in legacy gifts. This wonderful generosity from so many people has enabled us to build charity unrestricted reserves of approximately £1.3 million, of which we have set aside a closure and contingency provision of around £0.6 million. These new reserves give us a small window to put in place much stronger foundations on which to build a more sustainable charity for the long-term.

We hope many more people will be inspired by our charity’s ambition set out in this strategy and decide to leave us a gift in their will. We will implement a new legacies strategy in 2020 to explain how important these gifts are to our charity’s future and to make the process of giving a gift as simple as possible.

However, legacy gifts are difficult to predict and plan for and if we remain overly reliant on them we will continue to ‘yo-yo’ as a charity, i.e. investing in people and projects when we have the funds in one year and then having to cut back again when we don’t the next year.

For our charity to grow sustainably year on year, alongside asking more people to leave us a gift in their will, we will need to grow a number of other income streams so that the balance of what we call ‘controllable income’ to overall annual expenditure goes from where it is now, at around 40%, to somewhere closer to 67% (i.e. our controllable income brings in two thirds of what we spend with legacy gifts providing the other third).

Controllable income – particularly regular and one-off donations, trusts and foundations income and corporate donations – is more predictable and growing these income streams significantly will enable our charity to plan our activities over a number of years more effectively.

Every month around 580 people give us a regular donation. In total around 1,100 people gave us a regular or one-off donation over the last 12 months. We think our donors are heroes and we are extremely grateful to every single one of them. Our task over the next five years and beyond is to not only maintain their trust and support, but to build the trust and support of several thousand more people as well. We recognise that part of this will be about demonstrating more clearly how people’s donations are impacting positively on the lives of people affected by migraine.

To assist in this goal, we plan to invest prudently in the modernisation of our charity and activities which we feel will give us the best chance of getting to safer financial ground and to sustainable growth. In year 1 we will invest approximately £155,000 of our reserves including by making all three posts in the Fundraising Team full-time to bolster our charity’s fundraising capacity. We will also launch a new fundraising strategy in 2020. As well as supporting this five-year strategy, our new fundraising strategy will seek to raise the funds for a major public awareness campaign for our 60th anniversary celebrations in 2025-26.

If we are to deliver all of what we would like to do in this strategy, we will need to move from raising approximately £750k per year currently to raising just over £1 million per year by 2025. This is extremely ambitious and we will need to assess progress and review our strategy at the end of each financial year. To ensure all growth is sustainable, we will only start new projects and programmes of work when we feel confident that we have the funding streams in place not only to fund ‘year 1’ of new projects but to fund the project for its whole lifetime.

Taking significant steps towards financial sustainability and sustainable growth is the most important action our charity must take over the next five years because it is this action that will ensure we are around to help and support people affected by migraine across the UK for the long-term.
What do we hope our five-year strategy will deliver?

Our five-year strategy will focus on taking five years’ worth of steps towards four key priorities for our charity:

1. The delivery of our three new strategic goals

2. Financial sustainability and sustainable growth

3. Ensuring people affected by migraine are at the heart of our organisation

4. Producing a staff team that is the envy of the charity world
Given that so much of our strategy is reliant on the raising of new funding and the delivery of new projects, it is difficult to put ‘SMART’ goals and targets for the whole five-year period against all of these priorities. Every year we will need to undertake a formal assessment of the progress we’ve made and make a sensible plan for what the following year should look like based on our expected income and resources. We hope to do the following:

**What are we seeking to do?**

Help find a cure – play a major role in encouraging new research and treatment to alleviate the symptoms and impairment caused by migraine and ultimately to find a cure

**What will progress in year 1 look like?**

- We will have delivered a highly successful and profitable MTIS in September 2020.
- We will have put in place the ‘building blocks’ to launch a new more ambitious research strategy in 2021, including fostering a stronger relationship with members of the UK migraine research community.
- We will have identified initial migraine research priorities through our ‘State of the Migraine Nation’ report.
- We will have given our first annual bursary – in memory of our former colleague Susan Haydon – to a Masters student studying headache.

**What do we hope progress will look like by the end of our five-year strategy?**

- We will have strengthened The Migraine Trust position as a thought leader in migraine research across the UK and globally.
- We will have in place a stronger and more sustainable ‘pipeline’ of funding to support our research agenda and strategy.
- We will have awarded at least one Fellowship grant, one PhD grant and five bursaries.
- We will have delivered three MTIS conferences.
- We will have in place a new ‘alumni’ programme for the current and former recipients of our research grants.
<table>
<thead>
<tr>
<th>What are we seeking to do?</th>
<th>What will progress in year 1 look like?</th>
<th>What do we hope progress will look like by the end of our five-year strategy?</th>
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</table>
| Ensure every single person with migraine – no matter who they are or where they come from – gets an accurate, timely diagnosis and access to the best possible information, care and treatment and has the same legal protections as other disabled people. | • We will have helped over 2,000 people through our two helplines while maintaining the high quality of the service we provide.  
• We will have launched our ‘State of the Migraine Nation’ report at MTIS in September 2020.  
• We will have launched our new Information and Support Services strategy.  
• We will have launched our refreshed website and monthly ebulletin and new Comms strategy.  
• We will have hired a permanent nurse specialist. | • We will be reaching, helping and improving the lives of significantly more people every year.  
• Our Workplace Outreach Programme will be delivering positive change in workplaces across the UK and more people living with migraine will be recognised as having a disability and be protected under the Equality Act from discrimination.  
• We will have a new diagnostic support tool on our website to help improve levels of diagnosis across the UK.  
• We will be leading at least one policy-influencing project, and lobbying decision-makers across all four countries for change.  
• We will have seen a clear and positive shift in engagement with, and levels of support for BAME groups, lower socio-economic groups, men and children and younger people. |
### What are we seeking to do?

**Build an active and supportive community of people affected by migraine (PABM) – this community would act as both a source of support and a movement for change**

**Deliver financial sustainability and sustainable growth**

### What will progress in year 1 look like?

- The number of ebulletin subscribers will have reached 26,000, we will have reached 14,000 Twitter followers and 23,000 Facebook Likes.
- Five people will have become ‘ambassadors’ for us, helping us to reach new communities and supporting our awareness-raising and fundraising activities.
- We will have delivered three ‘Managing Your Migraine’ events.
- We will have considered if and how to encourage the setting up of new support groups for people affected by migraine across the UK, as part of our new Information and Support Services strategy.

### What do we hope progress will look like by the end of our five-year strategy?

- 36,000 people will be subscribing to our monthly ebulletin.
- We will be running five ‘Managing Your Migraine’ events a year by 2025 and hosting a new online community for people affected by migraine.
- Several thousand people will be supporting our charity and we will have established a number of new fundraising income streams, meaning that the balance of ‘controllable income’ to overall expenditure is at least 55%.
- We will be raising enough money to support the agenda set out in this five-year strategy.
### What are we seeking to do?

Ensure people affected by migraine are at the heart of everything we do, including ensuring we better represent, engage with, and support the whole migraine population across the UK

### What will progress in year 1 look like?

- We will have grown our Volunteer Forum membership to 120 people and established a new agenda for the group’s close involvement in the work of our charity.
- We will have involved at least 60 people in our informal Policy and Research ‘sounding board’.
- We will have grown the number of ‘case studies’ we have to 40 and be better reflecting the experiences of people in different communities.

### What do we hope progress will look like by the end of our five-year strategy?

- The number of people involved in our Volunteer Forum will have reached 300.
- We will have 12 charity Ambassadors supporting our agenda and helping us to reach, engage with and help different communities across the UK.
- We will have seen a clear and positive shift in the levels of involvement of people affected by migraine in all aspects of our charity’s work, in particular amongst BAME groups, lower socio-economic groups, men, and children and younger people.

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### What are we seeking to do?

Build a team and organisational culture that is the envy of the charity world

### What will progress in year 1 look like?

- We will have made progress in the delivery of our team’s development priorities and in key metrics such as staff happiness, empowerment and retention.
- Every member of staff will be actively supported with their own personal development plan, including through a new staff-wide training and development budget.
- We will have refreshed key staff policies, in part based on an assessment of what ‘great’ looks like in charities of a similar size to ours.

### What do we hope progress will look like by the end of our five-year strategy?

- We will have made significant progress towards our strategic goal of making The Migraine Trust “the best, most ethical, most progressive, most innovative, most enjoyable, most challenging (in a good way), most rewarding, most inspiring place any of us ever works”.
- We will have been recognised as a great place to work and other similar sized charities will see us as a leader in building progressive organisational cultures and workplaces.
How will we do it?

First and foremost, we need to refresh and modernise our charity’s ‘core services’ and invest in our staff. Our focus will be:

i. Disease on people and society; preventing attacks; better treatments (and access to treatments) to manage the condition, symptoms, and the different phases of a migraine attack; improving people’s mental wellbeing and (ideally) living well with migraine; and tackling the impairments caused by migraine.

ii. A clearer commitment to supporting the growth and development of the migraine research community. In particular, our charity has a vital role in encouraging and supporting the next generation of migraine researchers to flourish as well as in bringing the research community more closely together around a shared and focused agenda. We plan to invest in at least one new Fellowship grant and one new PhD grant during the next five years. We will also provide a bursary every year to someone studying headache as part of a Masters degree, in memory of Susan Haydon, our former Information and Support Services Manager who died in 2019.

2. New Information and Support Services and Communications strategies

The way people consume information, and want and need support, is changing rapidly. Unless we re-invest in how we do what we already do, the quality of the information and support services we provide, and the number of people we will be able to reach, will decline significantly over the course of the next five years. We will launch new plans for our Information and Support Services and Communications functions in the first year of our new five-year strategy, covering a number of shared themes:

i. Modernising our website content so that it is fully mobile-optimised and the journey we take visitors on encourages them to be a part of our growing migraine community. We will also ensure that content is up to date, accessible and easy to find, and encourage even more people to use the website when seeking our help, so that our helpline team can focus most of their effort on the most complex cases.

ii. Providing new information and support content in different ways – in particular with new sections on our website for children and younger people, living well...
with migraine (including mental health and wellbeing and self-management) and access to good care and treatment; refreshing our monthly ebulletin and encouraging even more people to sign up; promoting our new blogsite and commissioning new and compelling content that reflects all aspects of our agenda and our whole community; and producing more ‘shareable’ content (infographics and short films) and downloadable resources.

iii. Reaching more people and especially those in new and different communities – our consultation told us that we have significantly more to do to reach and help people in BAME communities; men; people from lower socio-economic groups; and children and younger people. We will need to consider how we can best reach and engage with these groups. Once more of these groups are part of our community, we will then need to explore their migraine experience in more detail, and find out what they most want and need from our charity as well.

iv. Raising new awareness and understanding about migraine, the latest migraine research, and the services our charity provides – as well as significant activity to promote new research at our MTIS in September 2020, there will be a new focus on providing support for patients and health professionals at key moments in their migraine journey, and through the creation of new infographics and more shareable digital content.

In addition, the new Information and Support Services strategy will seek to grow our Volunteer Forum, so that it can play a bigger role in our patient empowerment and patient voice agenda, and in enabling volunteers to play various new roles within the organisation (e.g. leading aspects of the Workplace Outreach Programme). It will also introduce more ‘Managing Your Migraine’ events across the UK and consider if and how to encourage the setting up of more support groups for people affected by migraine across the UK, to further our goal of reaching more people from different communities and fostering an active and supportive migraine community.

Our Communications strategy will also look at how to make the charity’s tone of voice more impactful, based on the thinking we’ve done so far, and actively promote new partnerships our charity is able to build and secure with other corporates and charities. With this in mind, we are delighted to have been named Barts Choir’s ‘Charity of the Year’ for 2020, the first time we have received such an honour. We hope it is the first of many new partnerships over the coming years. To support all this new effort, we are adding a new part-time Communications Officer to our staff team in 2020.

3. Delivering our ‘State of the Migraine Nation’ programme and using it as the launch pad for a programme of UK-wide campaigning over the next decade

We will deliver our ‘State of the Migraine Nation’ programme with a report launched at the MTIS Public Day on 13 September 2020. It is clear from the results of our survey that the scale of the migraine challenge, the millions of people that migraine affects, and the hundreds of thousands of lives that are being ruined right now, that this programme is desperately needed. Our report will kick start a new programme of campaigning to improve national policies and practice that will give us the chance to improve the lives of hundreds of thousands of people affected by migraine across the UK.

4. Investing in the development of our team and individuals within it

We believe that small teams of people can do amazing things. We want our staff team to be the envy of the charity world. To do this we will need to retain and attract the highest calibre of people. The Migraine Trust staff would like our charity to become “the best, most ethical, most progressive, most innovative, most enjoyable, most challenging (in a good way), most rewarding, most inspiring place any of us ever works” and we are committed to investing time and resources to move towards this ambition over the next five years.
Alongside the modernisation of these core services we will seek to deliver the following new programmes of work and activities:

1. A permanent nurse specialist role

   We will establish a permanent nurse specialist as part of our Information and Support Services Team in 2020. Over time, we would like the nurse to play four key roles:

   i. Further improve the quality of information and support content we are able to provide people who contact our helpline and come to our website, with the hope of giving more people the confidence to seek better care and treatment from the NHS.

   ii. Help us develop a clearer ‘public identity’ for our Information and Support Services and enable us to communicate latest treatments and best practice more frequently and more effectively to a larger group of people, e.g. through blogging and regular articles in our monthly ebulletin.

   iii. Help us foster and deepen relationships with an informal network of migraine professionals across the NHS.

   iv. Lead on the development of a new headache and migraine module for trainee nurses and GPs so we can play a bigger part in supporting the development of the next generation of the headache professional workforce.

2. A new Workplace Outreach Programme

   Following the success of our programme working with the UK Civil Service in 2019, we would like to launch a broader programme in 2021. We are keen to work with willing employers to raise awareness and understanding about migraine in their workplace, and provide managers and employees with additional support and help. The aim would be to create more ‘migraine positive’ workplaces across the UK and enable more employees with migraine to flourish in their roles. We will also develop new information packs aimed at HR departments and a refreshed ‘migraine in the workplace’ section on our website. Following feedback during our consultation, we have also decided that some of the workplaces could be in NHS settings.

3. A new programme of activity to improve diagnosis rates

   We know that one of the fundamental migraine challenges is how to increase diagnosis rates across the UK. We think that around half of the people living with migraine have never been diagnosed. As a consequence, they are unlikely to have access to the best care, treatments and support. One idea we are particularly keen to pursue is the development of a simple online diagnosis support tool for people who suspect they might have migraine. This new tool – to be launched by 2024 – would sit on our website. By posing a series of questions to the user it would assess the likelihood of that person having migraine. Anyone suspected of having migraine would then be encouraged to go to their GP for a formal diagnosis. We hope to develop the tool in partnership with key stakeholders, e.g. BASH and other professional groups, and people affected by migraine.

4. A new online community

   Our consultation told us that people affected by migraine often feel isolated and the majority never speak to anyone else going through a similar experience to them. We are determined to put an end to the isolation that far too many people affected by migraine feel and replace it with community, kindness and understanding. We would like to set up a moderated online community by 2024 to ensure that everyone has someone to talk to about any aspect of their migraine experience. We would also like our online community to be a place where health professionals can provide additional help and support to people.

Online communities interested in specific health issues and conditions are now far more prevalent on Facebook and elsewhere. We will build our understanding of best practice in advance of our community’s launch and ensure people affected by migraine are closely involved in its design and ongoing role, function, guidelines, rules and moderation.
How much new funding and capacity will we need to deliver this whole strategy?

All new activity will be dependent on raising new funding in addition to the current approximately £750k per year it takes to provide our core services.

<table>
<thead>
<tr>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
<th>Year 4</th>
<th>Year 5</th>
<th>Additional funding per year needed</th>
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<tbody>
<tr>
<td>A new Migraine nurse</td>
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<td>Refreshed website and ebulletin</td>
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<td>MTIS</td>
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<tr>
<td>New Communications, Fundraising and Information and Support Services strategies</td>
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<td>£38k, rising to £69k for a full-time nurse from year 2</td>
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<td>State of the Migraine Nation report launched</td>
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<td>New Workplace Outreach Programme</td>
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<td>New Research Strategy and Fellowship grant</td>
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<td>First policy-influencing project launched</td>
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<td>A more developed programme of activities to support the patient voice agenda</td>
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<td>New awareness-raising about our services</td>
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<td>£198k, plus a one-off cost of £245k</td>
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<td>MTIS</td>
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<td>New sections on our website</td>
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<td>£10k</td>
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<td>New awareness-raising about our services</td>
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<tr>
<td>New programme of activity to improve diagnosis rates, including a new diagnosis support tool on our website</td>
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<td>Additional ‘Managing Your Migraine’ events across the UK</td>
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<td>New online community</td>
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<td>New awareness-raising about our services</td>
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<td>£30k, plus a one-off cost of £200k</td>
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<td>MTIS and new Research PhD grant</td>
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<tr>
<td>New awareness-raising about our services</td>
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<td>One-off cost of £140k</td>
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What would our staff team need to look like to deliver this broader agenda?
Please get involved

We want to encourage and inspire the whole migraine community to get involved in our strategy. We are currently 10 permanent members of staff but there are potentially thousands of people affected by migraine, hundreds of health professionals, and numerous other charities, professional bodies and organisations who could play a vital role in helping to deliver this strategy. We cannot do this without your help and support. If we all push together against the same boulders, we know that over time we will be able to move mountains.

If you only have one minute to help us…

i. Sign-up to our ebulletin so we can provide you with help and support on a monthly basis.

ii. Follow us on social media, ‘Like’ our tweets and Facebook posts and comment.

iii. Ask your friends and family on WhatsApp or Facebook (or however you communicate with them) if they have migraine, tell them about The Migraine Trust and the help and services we provide, and encourage them to sign up to our ebulletin so we can help and support them too.

iv. Set up a ‘Facebook Birthday Fundraiser’.

v. Sign up to give us a regular donation.

vi. Buy our Christmas cards.

vii. If you’re a health professional, tell your migraine patients about us and encourage them to look at our website.

viii. Nominate us for funding grants – we’re always looking for people to vote for us.

ix. Tell your colleagues about The Migraine Trust at your next staff meeting.

If you could spare us an hour or two…

i. Champion The Migraine Trust in your workplace ‘charity of the year’ voting process.

ii. Share your experience with us – we are always looking for new case studies.

iii. Write a short blog for our blogsite on a topic of your choosing to help us raise awareness about all aspects of living with migraine.

iv. Respond to a consultation – the National Institute for Health and Care Excellence and the Scottish Medicines Consortium regularly ask for feedback from people affected by migraine.

v. Help us write a new piece of information and support services content for our website.

vi. Take a campaigning action in support of one of our future policy-influencing activities.

vii. Take part in one of our regular surveys.

viii. Put a collection tin for The Migraine Trust in your workplace or at your social club.

ix. Ask your GP, local library or workplace to put up information about The Migraine Trust.

x. Leave us a gift in your will.

xi. Give us feedback – complete a feedback form or tell us where we’re going right and where you would like us to do things differently.

xii. Recommend us as a payroll-giving charity at your workplace.

xiii. Host or attend a ‘meet up’.

xiv. Read one of our guides or blogs and share what you learn with someone else.

xv. Volunteer, cheer or raise money for us at one of our events.

xvi. Write a letter to your local newspaper telling them about The Migraine Trust and our services.

If you were able to give us 1-2 hours a month…

i. Join our Volunteer Forum.

ii. Join our informal policy-influencing ‘sounding board’.
iii. Fundraise for us – take part in one of our challenge events or run a bake sale in your local community or at work.

iv. Be a social media champion for us and support our agenda online.

v. Volunteer for us – speak on our behalf, get involved in our partnership with Barts Choir, or get involved in one of the many new projects outlined in this strategy.

If you have more time to support our charity…

i. Become an Ambassador for us – we’re particularly looking for representatives from the key groups and communities who we are not reaching at the moment (children and younger people; BAME groups; men; people from lower socio-economic backgrounds).

ii. Set up a support group or raise awareness of migraine and our services in your local area, community or social groups.

iii. Take on a major challenge event – e.g. run a marathon or host a fundraising gala for us.

iv. Train with us – in particular we’re looking for medical and public health registrars who would like to do a major project with us as part of their training programme.

v. Take part in and help raise awareness of a new research trial.

vi. Volunteer to be part of a project group for one of our new programmes of work.

vii. If you’re a health professional, volunteer in our Information and Support Services Team.

And please come along to one of our Managing Your Migraine events when we host one near you and come along to our MTIS Public Day in London on 13 September 2020. Details about all forthcoming events are shared in our ebulletin so please do sign-up.