

**Delivering positive health outcomes free for all  
sufferers of myalgic encephalomyelitis/chronic  
fatigue syndrome (ME/CFS)**

**The case for a pilot project**



THE  
OPTIMUM HEALTH CLINIC  
FOUNDATION

# Delivering positive health outcomes free for all sufferers of ME/CFS

## The case for a pilot project

### Summary of key points:

- There are an estimated 250,000 ME/CFS sufferers in this country
- Of those 250,000, it is estimated that only 8,000 are diagnosed, assessed and treated by the NHS
- Conventional treatments from the NHS offer very little hope of recovery
- There is a significant need for an alternative treatment option for ME/CFS sufferers
- Our integrative medicine approach offers a unique combination of nutritional therapy including a functional medicine approach and a range of psychological therapies
- Of the 6,000 ME/CFS sufferers we have treated over the last 11 years, we know from our own surveys that 93% have benefited from our integrative medicine approach to treatment and many have fully recovered
- If we can help 93% of the individuals we see, it follows that we could help 93% of all 250,000 ME/CFS sufferers
- We believe that our integrative medicine treatments should therefore be offered as a treatment choice by the NHS to all 250,000 ME/CFS sufferers
- In order to achieve that objective, we need first to produce the evidence that our treatments are safe and effective
- We will conduct a 'pilot project' for 136 ME/CFS sufferers in order to deliver positive health outcomes free for these individuals and produce the evidence based results required by the NHS
- We will then seek to persuade the NHS to offer integrative medicine as a treatment choice to all sufferers of ME/CFS.

# **Delivering positive health outcomes free for all ME/CFS sufferers**

## **The case for a pilot project**

The objective of this document is to seek your support for our pilot project to deliver positive health outcomes free for 136 ME/CFS sufferers.

### **Who are we?**

We are the Optimum Health Clinic Foundation (registered charity no. 1131664), an award winning charity incorporating our private clinic, the Optimum Health Clinic.

We exist in order to promote optimal healing and physical and mental wellbeing to sufferers of ME/CFS by offering them integrative medicine as a treatment. Our clinic has treated more than 6,000 ME/CFS patients over the last 11 years.

Details of our charity are set out in the attached appendix.

### **What is our mission?**

Our mission is to make our integrative medicine approach to treating ME/CFS freely available to every one of the 250,000 sufferers of ME/CFS in this country.

To achieve that objective we need to provide the NHS with the evidence based results that our approach to integrative medicine treatments for ME/CFS sufferers is safe and effective.

To produce the required evidence based results we propose to run a pilot project with 136 ME/CFS who will receive our integrative medicine treatments free.

### **What are the objectives of our pilot project?**

The objectives are to:

- Deliver positive health outcomes to 136 ME/CFS sufferers;
- Provide the evidence-based results as required by the NHS to demonstrate that our approach to integrative medicine is safe, effective and produces positive outcomes.

We will record and evaluate the results of the project using the gold standard methodologies approved by the NHS.

We will then discuss with the NHS the offer of integrative medicine as a treatment option for all ME/CFS sufferers.

## What is ME/CFS?

ME/CFS is a very real physical illness (World Health Organisation's International Classification of Disease 10:G93.3). It is a serious and complex illness characterised by a prolonged and debilitating fatigue.

ME/CFS can shatter lives, and often for many years. As well as appalling fatigue, sufferers often experience sleep difficulties, muscle and joint pain and cognitive dysfunction. Whilst the severity of symptoms differs considerably from patient to patient, many are bedridden or confined to the house for years and are no longer able to work.

## What is the need?

Our own experience with people suffering from ME/CFS is that they invariably feel isolated and abandoned by the NHS:

- Many sufferers are misdiagnosed with depression; whilst depression can play a part in ME/CFS it is not the cause;
- Many patients are never correctly diagnosed and those that are still have to suffer for 6 months before they are diagnosed;
- ME/CFS sufferers experience a sense of detachment and isolation from their friends and families who are as perplexed by the illness as they are;
- The cumulative effect of this sense of isolation has a profoundly damaging effect on the lives of individual sufferers, their sense of self and their standing in their communities;
- Continued suffering leads to loss of employment, an increase in anxiety over finances, loss of education and loss of quality of life in every sense.

It is estimated that ME/CFS affects around 250,000 people in the UK each year ([www.nhs.uk/conditions/pages/hub.aspx](http://www.nhs.uk/conditions/pages/hub.aspx)). Because this illness is often misdiagnosed as depression, we believe that there are far more than the official figure of 250,000 sufferers.

ME/CFS affects men and women, the young and old, and is one of the most misunderstood, poorly supported, under diagnosed and misdiagnosed conditions of our generation.

Compared to other chronic illnesses such as Multiple Sclerosis (100,000 patients in the UK), and Parkinson's disease (130,000 patients in the UK), ME/CFS is much less widely understood, supported and publicised.

## How many ME/CFS sufferers currently receive treatment?

Recent studies have shown that of the estimated 250,000 ME/CFS sufferers, only 8,000 are assessed and treated at specialist NHS facilities every year. The guidelines from the National Institute for Health and Care Excellence (NICE) for those who are correctly assessed, are based on one year of treatment sessions in NHS facilities despite the fact that patients suffer from this illness for an average of more than six years.

There is, therefore, a significant need for a more effective treatment to be made available to each and every one of the 250,000 sufferers of ME/CFS in this country and throughout the duration of each patient's illness.

### **Is there a need for an alternative approach to treating ME/CFS?**

We believe there is a need for an alternative approach because conventional treatments for ME/CFS offer very little hope of recovery. Treatments such as Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET), as recommended by NICE, have been shown to be effective in some cases.

However, in our experience, many ME/CFS sufferers have difficulty engaging with these therapies. CBT is invariably seen to be blaming the patient for his or her thought patterns, and GET can be physically damaging if implemented at the wrong time, which is invariably the case. There are several different stages to this illness and a treatment that works at one stage will not necessarily be appropriate at another stage of the illness.

### **What is integrative medicine?**

Integrative medicine is a combination of practices and methods of complementary and alternative medicine with conventional biomedicine and functional medicine designed to achieve optimum health and wellbeing.

Integrative medicine is a holistic approach to medicine because it focuses on the whole person rather than the illness itself. Integrative medicine identifies and treats the underlying causes of the condition – the imbalances and dysfunctions in our bodily systems including the mitochondria, the adrenal glands, the thyroid gland, the digestive system, the immune system and the nervous system.

It is the sub-optimal functioning of one or more of these systems which can produce the symptoms of ME/CFS. This is what our integrative medicine approach identifies and treats for each individual patient.

### **What will our integrative medicine approach be for these ME/CFS sufferers?**

Our integrative medicine approach puts the individual sufferer at the centre of the treatment process by:

- Recognising the physical and psychological complexity of ME/CFS;

- Embracing the biochemical individuality of each person using a functional medicine approach;
- Applying a unique combination of nutritional therapy incorporating functional medicine together with a range of psychological therapies including a special 90 day programme;
- Recognising that there are different stages to the illness and that different treatment strategies are required for each stage.

Our 11 years experience in treating ME/CFS shows that this patient approach centred on the individual sufferer is critically important in helping people recover from this awful illness.

### **What treatments will each ME/CFS sufferer receive?**

The objective of our treatments for the 136 ME/CFS sufferers is to deliver positive health outcomes compared to the standard NHS treatments.

In order to measure accurately the effectiveness of our treatments, we shall give:

- 6 hours of one to one nutritional therapy sessions incorporating a functional medicine approach to 36 individuals; healthy eating guides, personalised dietary suggestions and natural supplement recommendation sheets will be provided to each individual;
- 5 hours of one to one sessions of psychological therapies to a further 34 individual sufferers along with our 90 Day Programme which is a workshop for groups of 4-8 individuals; in addition each sufferer will receive our “Psychology Foundation Pack” consisting of four audio downloads each for “Learn to relax” and “The Sleep Inducer”, and a book and DVD called “Beat Fatigue with Yoga”;
- 6 hours of one to one sessions for a further 34 individuals combining both nutritional therapy and psychological therapies.

The remaining 34 sufferers will receive the NICE recommended treatments from the NHS comprising CBT and GET over 9 sessions. This will enable us to compare and contrast very accurately the effect of our treatments as compared to those offered by the NHS.

### **What further support will be each individual sufferer receive?**

ME/CFS is a lonely and isolating illness and in our experience patients benefit considerably from emotional support as well as the integrative medicine treatments themselves. We will, therefore, offer the following support to all 136 ME/CFS sufferers:

- A network of websites providing a huge amount of information and support, which together receive 300,000 unique visits a year ([www.freedomfromeme.co.uk](http://www.freedomfromeme.co.uk)) and ([www.secretstorecovery.com](http://www.secretstorecovery.com));
- Over 100 hours of audio and video support;

- A huge archive of inspirational recovery stories from our clients;
- A social network through our websites and Facebook site to help support each other;
- Consultations via telephone or skype for those individuals who are too ill to travel;
- A monthly newsletter sent to over 15,000 people.

### **How long will this support be available to each patient?**

The above support will be available for the duration of each patient's recovery.

### **What outcomes do we expect?**

We expect to see the following outcomes at the end of the pilot project:

1. An improvement in the health and wellbeing of sufferers with some being able to start working again and play a role in their community again.
2. A clear roadmap to continued recovery for those individuals who will need more time to recover after the end of the pilot project.
3. The tools learned from both nutritional and psychological therapies to take ownership of the condition and self manage the balance of their recovery.
4. An improved understanding of the illness, how it came about and how to manage any future symptoms.
5. A greatly reduced sense of isolation and loneliness with families and friends having a better understanding of the illness and the individual's road to full recovery.

### **Why do we believe that the outcomes will have a positive impact on the health of these ME/CFS sufferers?**

We believe that our treatments will deliver positive and lasting health outcomes because:

- We have already carried out a preliminary pilot project on 138 of our own patients which produced statistically significant improvements over a 3 month period and these results were published in the British Medical Journal Open (<http://bmjopen.com/content/2/6/e001079.full>);
- We know from our own surveys that 93% of people whom we have treated have been helped by our treatments, and many have fully recovered and are leading active lives again;
- Our founder and CEO, our chairman, one of our patrons, one of our trustees and eleven of our practitioners have fully recovered from ME/CFS after receiving the benefit of our integrative medicine treatments.

In recognition of our treatment approach and track record, we won the Complementary and Alternative Medicine Award (CAM magazine) in 2009 and in September 2015 we were featured in the Private Health Care edition of the Parliamentary Review as a model of best practice in our field.

## **Will this be an equal opportunities project?**

Yes. Our pilot project will be available to all ME/CFS sufferers irrespective of age, gender and social class. Our project will embrace a diverse group of ME/CFS sufferers from all walks of life from all parts of the country.

The 136 ME/CFS sufferers will be recruited randomly from the 40 specialist NHS treatment centres around the country which currently treat ME/CFS patients.

## **Who will manage this pilot project?**

Our partner in this project is the internationally recognised Faculty of Health and Medical Science at the University of Surrey (UOS). The UOS team will be our independent project manager.

## **How will UOS manage this project?**

The team at UOS will independently manage, analyse and evaluate the results of this project. The UOS project team will be responsible for the:

- design of protocols including the methods of recruiting individual sufferers the number of sufferers, statistics assessments, safety procedures and individual consent literature;
- collection and analysis of data;
- producing a report of the results of the project for publication;
- producing monthly reports for us throughout the pilot project, measuring and evaluating our progress and identifying any areas where corrective action needs to be taken in order to ensure the overall success of the project.

## **What outcome are we seeking?**

The outcome we are seeking is to show that our integrative medicine treatment protocols have a significantly positive influence on the recovery of ME/CFS sufferers and that this recovery is sustainable.

## **How will we measure and track progress towards achieving our outcomes?**

UOS, our independent project manager, will track and measure our ability to:

- recruit and retain individual ME/CFS sufferers;
- implement our treatment protocols in line with our project documentation;
- produce monthly reports measuring all aspects of the project;
- analyse and assess the results of our treatments at the end of the project.

## **How will we evaluate our project?**



The key to evaluating our project will be obtaining feedback from each individual sufferer. We will evaluate the effectiveness of our treatments individually with each of our 136 ME/CFS sufferers in one to one sessions of feedback and observation.

We will review this feedback:

- monthly in our meetings with the UOS team and our own management meetings;
- quarterly in our meetings of the board of trustees.

Our practitioners will email patient feedback and our own observations to our patients at the end of the treatment sessions.

When all the ME/CFS sufferers in the pilot project have completed the treatment regime, UOS will produce a report which will show exactly how successful we have been in recruiting individual sufferers from the NHS and how much their health and wellbeing have improved after 12 months of treatments using our protocols.

We have been refining our treatment protocols in the light of our clinical experience over the past 11 years and will continue to do so with this project. If the results of our treatments are as positive as we expect, we may then expand the project to a larger number of ME/CFS sufferers as part of our strategy to develop an evidence base for our treatments.

### **How much will the treatments cost?**

The cost of our treatments for each individual will be £1,000.

The costs of analysis, assessment and evaluation of the study by UOS are not included in the above costs per sufferer. We seek to fundraise only the costs of the treatments themselves.

The cost of the NHS treatments will be £1,073.

### **What will the total cost of the pilot project be?**

The total cost of the project to deliver a positive health outcomes for 136 ME/CFS sufferers will be £136,000.

### **Is it possible to sponsor treatments for say 20 or 40 or any number of ME/CFS sufferers?**

Yes, any number of your choice appropriate to your objectives and budget.

### **Is our motivation to make profits from the NHS when our integrative medicine approach to treatment is made available?**

No. We are a charity and any and all profits we make through our private clinic go directly to our charity to fund future research into the causes of and treatment for ME/CFS.

### **Will we have the help of any volunteers with this project?**

Yes. Our Head of Research and Medicine, his team of 6 practitioners and our chairman will, in various roles, all give their time voluntarily and freely to this project.

### **Why is this pilot project so important?**

This project is extremely important because it will:

- deliver positive and sustainable health outcomes for 136 sufferers of ME/CFS within 12 months;
- provide us with the evidence based results which will enable us to discuss with the NHS the opportunity to make these treatments available to all 250,000 ME/CFS sufferers.

We further believe that this pilot project has the potential to benefit the country.

### **What direct impact will our project have on the country as a whole?**

We believe that ME/CFS represents a substantial cost to this country. That 'macroeconomic' cost can be measured in terms of lost employment, lost tax, the costs of absenteeism and presenteeism, and the cost burden to the NHS of treatments that have limited success for the majority of ME/CFS sufferers.

We have, therefore, separately commissioned a think tank to assess the macroeconomic costs of ME/CFS to the country. When this study has been published we intend to engage with policymakers and media to change the public debate about ME/CFS in order to raise awareness of the illness and to argue for greater research funding into both the causes of and treatments for ME/CFS.

We have already fundraised the full cost of this macroeconomic study and our own trustees have donated generously towards this cost.

### **What will be the long term impact of our pilot project?**

To summarise, we believe that the long term impact of this project will be:

- 250,000 ME/CFS sufferers will have an alternative and proven treatment available to them giving them the opportunity for optimal healing and wellbeing, and ending the suffering, depression and despair which is the experience of so many ME/CFS sufferers;
- the costs of ME/CFS to the country could potentially be substantially reduced with a corresponding benefit to the UK economy.

## Why the Optimum Health Clinic Foundation?

We believe we are the right organisation to deliver integrative medicine treatments to all ME/CFS sufferers starting with this pilot project:

- through our clinic, the Optimum Health Clinic, we have 11 years clinical experience of treating ME/CFS patients;
- we have developed a highly effective approach to integrative medicine treatments;
- from our own surveys we know that 93% of our patients have benefited from our treatments, and many have fully recovered and gone on to lead very active lives again;
- we are the only organisation in the ME/CFS world with so much personal experience of ME/CFS and an unrivalled experience of recovering fully from this terrible illness;
- in recognition of our approach and our achievements, we won the Complementary and Alternative Medicine Award (CAM Magazine) in 2009 and we were selected for the Private Health Care Edition of the Parliamentary Review in September 2015 as a model of best practice in our field;
- our Trustees have donated their own money to the macroeconomic study referred to above which will assess the total costs of ME/CFS to the country as a whole;
- we are the only ME/CFS organisation with a strategy to make integrative medicine treatments available to all of the 250,000 ME/CFS sufferers;
- we are the only ME/CFS charity with a strategy to demonstrate to government how much ME/CFS costs the country and to show how our integrative medicine approach can not only be an effective treatment for ME/CFS but can also provide the opportunity to reduce the costs of ME/CFS to this country.

## We need your support for our pilot project now

We now seek your support to raise the £136,000 required for this vitally important pilot project for 136 ME/CFS sufferers.

**The Optimum Health Clinic Foundation**

## APPENDIX

### The Optimum Health Clinic Foundation

(registered charity number 1131664)

#### Patrons

**Shirley Conran** – international bestselling author, founder President of the Work Life Balance Trust

**Claire Jones** – classical musician, formerly the official harpist to the Prince of Wales and a former patient

#### Trustees

**David Butcher BA (Hons)** (Chairman) – former chief executive in financial services and former patient.

**Ian Hatton BSc** – pharmacist, research specialist and father of current patient.

**Tim Bichara** – technology entrepreneur and former patient.

#### Company Secretary **Gillian Farrier**

#### Senior Team

**Alex Howard BSc (Hons)** – Founder and CEO

**Glynn Gratrix** – Director of Finance and Operations

**Linda Jones** – Director of Fundraising

**Helen Lynam BSc, mBant, NTCC** – Director of Nutrition

**Jess Thompson BSc, Dip Counselling, PGCE, Dip.Clin.Hyp.NLP.Coach EFT** – Director of Psychology



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