

# LOOKING FOR SOLUTIONS



for people with Myalgic Encephalomyelitis

**investinmeresearch.org**

Artwork: Wolfgang Stiller

## MYALGIC ENCEPHALOMYELITIS (*ME or ME/CFS*)

Like matchsticks people with ME have often been discarded, no longer worthy of attention.

ME has been a frequently misunderstood disease

- ▶ Underfunded and ignored
- ▶ Poorly researched and lacking any coherent research strategy
- ▶ A cause of hardship and distress for patients and families and difficulties for healthcare staff
- ▶ Misrepresented by ill-informed media
- ▶ Incorrectly described in medical text books
- ▶ Lacking factual information for GPs
- ▶ Subject to flawed or deleterious treatments

There is a better way.

Invest in ME (Research) attempts to change this by raising the standards - via up-to-date educational material and annual international conferences/colloquiums and a research strategy backed up by international researchers.

Our aim – to resolve this

<http://www.investinme.org/matchstick1>

# FOCUSED ON PROGRESS



for people with Myalgic Encephalomyelitis

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## PROGRESS IS A FINE WORD ....BUT CHANGE IS ITS MOTIVATOR

Invest in ME (Research) will address this by -

- ▶ Supporting individuals with ME
- ▶ Changing ways that ME is perceived, treated and funded by providing up-to-date educational material
- ▶ Raising awareness of the effects of the disease
- ▶ Challenging flawed approaches to treating ME
- ▶ Raising standards of research
- ▶ Replacing dependence on establishment policies for research into ME
- ▶ Raising funds to initiate and maintain a strategy of high-quality biomedical research into ME
- ▶ Creating opportunities for European and International collaboration in ME research
- ▶ Organising annual research colloquiums/conferences

<http://www.investinme.org/matchstick2>

# PERSEVERANCE BRINGS SUCCESS



for people with Myalgic Encephalomyelitis

[investinresearch.org](http://www.investinresearch.org)

Artwork: Wolfgang Stiller  
Photographer: Achim Kukulies

## A CAN-DO APPROACH TO CHANGE

### INVEST in ME (RESEARCH)

- ▶ Entering our tenth year as a charity the continued efforts are making a difference
- ▶ Our annual conferences continue to platform biomedical research into ME
- ▶ Our annual research colloquiums bring together international researchers
- ▶ A Proposal for a Centre of Excellence is progressing
- ▶ Crowd-funding to produce opportunities for research
- ▶ Our foundation research project started at IFR/UEA in 2013
- ▶ More high-quality biomedical research is underway at IFR/UEA and UCL with collaboration elsewhere
- ▶ Making a difference by looking for opportunities to improve education, research and treatments for ME

<http://www.investinme.org/matchstick3>

# TOGETHER WE WILL FIND A CURE



for Myalgic Encephalomyelitis

[investinmeresearch.org](http://investinmeresearch.org)

Artwork: Wolfgang Stiller

## A JOINED-UP APPROACH TO CHANGE

INVEST in ME (RESEARCH)

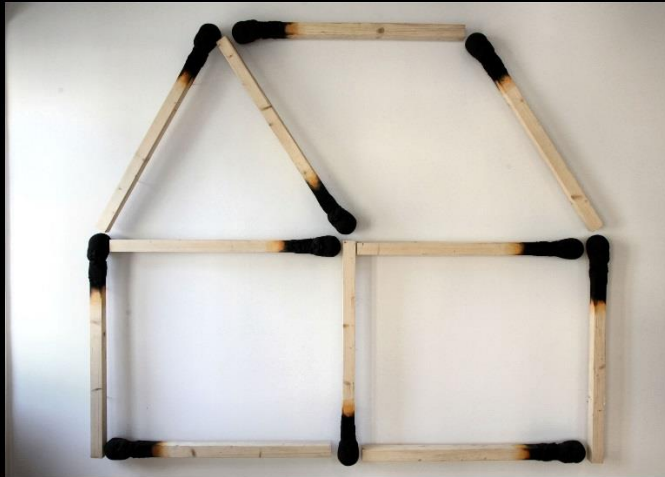
- ▶ International collaboration in biomedical research into ME is occurring and the charity facilitates collaboration between research teams
- ▶ Established an Advisory Board to advise on research
- ▶ Encourages others to join our efforts
- ▶ The '*Let's Do It For ME*' campaign formed by three bed/housebound patients using social media to campaign and fundraise
- ▶ Work on a European level - Invest in ME (Research) are a founder member of the European ME Alliance (EMEA), an umbrella organisation of European national charities/organisations.
- ▶ Our annual international conference regularly attracts delegates from 15 different countries and provides great opportunities for networking

<http://www.investinme.org/matchstick4>

<http://www.ldifme.org>

<http://www.euro-me.org>

# BUILDING A BETTER FUTURE



for people with Myalgic Encephalomyelitis

[investinmeresearch.org](http://investinmeresearch.org)

Artwork: Wolfgang Stiller

## CREATING HOPE OUT OF DESPAIR

INVEST in ME (RESEARCH) is building

- ▶ A research strategy based on high-quality biomedical research into ME
- ▶ A solid and increasing foundation for research
- ▶ Continued international collaboration
- ▶ Support for European ME Alliance (EMEA)
- ▶ Progressing the Invest in ME (Research) proposal for a Centre of Excellence for ME
- ▶ Collaboration with the '*Let's Do It For ME*' team to crowdfund £1 million for biomedical research into ME
- ▶ We have a unique opportunity to make progress for people with ME, their families and doctors treating this disease

Our aim – to resolve this disease – Please Help Us

Let's Do Research – Let's Do It For ME

<http://www.investinme.org/matchstick5>

**Invest in ME Research** (charity nr 1153730), transitioning from **Invest in ME** (charity nr 1114035), was set up by patients, carers and parents of children, suffering from Myalgic Encephalomyelitis (ME).

The charity is run by volunteers with no paid staff. Overheads are kept to a minimum to enable all funds raised to go to promoting education of, and funding biomedical research into, ME.

The charity's objectives are to initiate, maintain and augment a strategy of high-quality biomedical research into ME, to provide education about ME, and to raise awareness of the effects of the disease on patients and families.

The charity organises an annual research colloquium and conference regularly attracting delegates from 15 countries and now funds research at IFR/UEA and UCL as well as influencing collaboration elsewhere.

Invest in ME (Research) are a founder member of the European ME Alliance (EMEA), a collaboration



of European national charities and organisations.

The charity welcomes support for our work. More information from the following links –

Research

<http://www.investinme.org/research>

Centre of Excellence for ME

<http://www.investinme.org/centre>

Fundraising for Invest in ME Research

<http://www.investinme.org/fund>

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