

# Let's Do It For ME!



The Let's do it for ME campaign was launched by a small group of people with severe ME in July 2011 in support of the proposal by innovative and forward-thinking UK-based charity Invest in ME to establish a centre of excellence for ME based in East Anglia and the first of its kind in UK/Europe, combining translational biomedical research with patient care and education and training for medical professionals, in collaboration with international researchers and like-minded ME organisations across the world.

We are keen to help progress research and treatment, not only to benefit ourselves as patients, but also to avoid losing another generation to the ravages of this disease. We have no more time to lose.

We wished to assist in a practical way by raising the £100k needed to fund the foundation project to get the research strategy underway in Norwich.

We were delighted to receive supportive comments for our Guest book or by other means, from some of our MPs, the Countess of Mar and Jane Colby, Executive Director of The Young ME Sufferers Trust.

## ***BRMEC & IIMEC8 London 2013***

At the 8th annual Invest in ME international conference in May, Dr. Ian Gibson announced that we had reached our initial fund-raising target, which means that we had raised £100k in under two years.

This is no mean feat, starting from scratch from our homes and beds, with no campaign budget or publicity.

We could not have achieved this without the tremendous efforts of a wide range of supporters, from very severely ill survivors to wonderful willing wellies.



We are genuinely delighted and appreciative of any types and all levels of support, and there have been too many ingenious, innovative, creative, generous, courageous and inspiring ideas, events and contributions to mention them all individually here, some are featured in our blogs and main websites and please do let us know if you'd like yours added.

Our supporters hail from all corners of the UK, Europe, Canada, USA, Australia, NZ, and over 3500 votes in April won Invest in ME 1st prize of £2000 in The Big Break contest run by Direct Debit.



Everyone involved is a volunteer and every penny raised goes to the Biomedical ME Research.

Any competition prizes or similar resources are donated.

Members of the planning group run the campaign websites and on-line shops, organise ME Awareness events such as The Big Sleep for ME, designed to be accessible to people of all ages and levels of illness severity and launched in 2012, ongoing fundraisers such as the 1st of each month One Day-One Pound and Small Change to Change M.E, the Christmas card competition, calendars, summer quizzes, card sales, stalls, supermarket and church collections. We also proactively help to organise or support other patient initiatives that include Invest in ME, such The Big Shave 2013 and Walk for ME.



This is all done painstakingly between us over the course of days, weeks, months as and when illness allows and we are ever grateful for all help and support.

Writer Jacqueline Rayner is a founder member of our planning group. She had been planning with her friends and colleagues at Big Finish Productions to produce a charity audio play for download in aid of Invest in ME, based on the character of Bernice Summerfield: Many Happy Returns.

Not content with that, producer Scott ran the Edinburgh Marathon for Invest in ME, writer Simon donated funds from his choir, and others working on the project have done more besides.

You can see some of these lovely people in our Bear Meets gallery on the main Let's do it for ME website.





At the same time, planning group member and writer Barnaby Eaton-Jones reworked his play, Running To Stand Still, in aid of our cause and again, everyone involved gave generously of their time and talent.



Music artist Mama Chill decided to proactively support Invest in ME in her awareness raising and by donating proceeds of downloads and joining the team.



Her ME Awareness track is based on the original "I Can't Stand The Rain", and her new track, "Don't Say Nuthin If It Ain't Worthwhile" was released for May Awareness.

There are various other artists, writers, musicians, photographers, supporting the charity.

Make ME Crafts exploded onto the scene last year and is proving hugely popular, with an everexpanding team producing an impressive range of arts and crafts available all year round.



Katie summed it up with this comment:

"Big thank you to Jon because you have brought the community together, its really positive, everyone is happy making and doing things they enjoy and its all going to hopefully find what is going on with our bodies !! Sooo happy to be a part of this XD xx"

Another member of our planning group featured alongside an advert placed by IIME to raise awareness of the foundation research project.

Rosa had previously crocheted soft wool blue awareness wristbands for IIME and her grandparents hosted a coffee morning in aid of our cause.



Following a decline in her health, Rosa was moved to a nursing home, and fed by nasojejunal tube.

She chose to mark her 21st birthday by raising awareness and funds for our cause. The staff at the nursing home joined in with a pyjama day with all proceeds to Rosa's appeal. Goodwill messages were posted across the social networking sites and some people used Rosa's



photo as their profile picture for the day. Her mother said that the appeal passed all their expectations. Having contracted ME at 8 years of age, Rosa's story epitomises the indomitable spirit of the majority of people of all ages with ME, as well as the spirit of our campaign.

Empowerment is a key element driving the campaign and it has been very rewarding to see children and young people in particular, as well as the very severely affected, able to play a role in speaking out about their disabling illness and how it is viewed and treated by society and the medical profession, whilst taking such positive steps to raise funds for the translational biomedical research required to bring realistic hope for their recovery, with support of well friends and family members.

13-year old Harri wrote:

“Although it has been a year since I was in hospital due to M.E. I am still struggling with this awful misunderstood illness. I am still not in school and I want my life back as I knew it. I know many other children who are suffering with this illness too and I am in touch with them. They are also missing out on so many things like me. This is such a great cause, raising money to find a cure!!”

We have clearly all been very busy over the past two years, so what's next?

The £100k raised has enabled the translational biomedical research strategy to get underway at the University of East Anglia by fully funding the foundation project on gut microbiota in ME patients.



ME is classified by the World Health Organisation as a neurological disease, but a body of research points to it as primarily a disease of the immune system with downstream effects on other systems and organs in the body and this is consistent with "encephalomyelitis" as that means inflammation of the brain and spinal cord and inflammation is an immune system response.

This could also help to account for the often fluctuating nature and variable severity of symptoms, as inflammation tends to flare and subside.

Poliomyelitis is caused by a virus that multiplies in the intestine and ME has been described as atypical or non-paralytic polio. When Jane Colby contracted ME she



was referred to microbiologist, the late Dr. Betty Dowsett, and was found to have a virus similar to the polio virus. The majority of the immune system is in the gut and so it makes sense for a strategy aimed at finding reliable biomarkers for early and accurate diagnosis and effective treatment options to begin by looking at the gut and gut microbiota and this is an approach being taken by researchers in other countries to ME and to other diseases that affect the immune system.

A week after the hugely successful and productive 2013 conference, Invest in ME announced plans for a UK clinical treatment trial of Rituximab, an immune modulating monoclonal antibody used in treatment for autoimmune diseases and non-Hodgkin's lymphoma and found to result in major or overall improvement in all ME symptoms in 67% of patients in research in Norway.

This research points to ME as an autoimmune disease and even better results have been achieved in follow up studies by increasing doses to create a more prolonged effect.

Researchers in other countries now need to replicate and validate this important research, which has huge potential to increase understanding of the disease, by studying those who respond well to the drug as well as the nonresponders.



Rituximab helps about 70% of patients with rheumatoid arthritis.

We are delighted that Professor Jonathan Edwards is acting in an official capacity as Advisor to Invest in ME on all aspects of the trial as there is no-one better placed to do this, and we are now helping Invest in ME to raise the funds required for the dedicated Rituximab Research Fund, which stands at £15,000 at the time of writing.

Invest in ME has other biomedical research and related projects in the pipeline to be supported from the main Biomedical Research Fund and we will keep you posted when we have news of these to share.

The charity does a lot more besides organise and fund biomedical research and if you wish to support the other aspects of the charity's work - their campaigning, advocacy, education and awareness materials and the excellent conference events, there is a general fund you can donate to.

Details and donation options are on the Invest in ME and Let's do it for ME websites.

The charity's wonderful trustees perform their work for free, ceaselessly all year round, sometimes around the clock and often under challenging circumstances, as ME sufferers or parents/carers themselves, working hard to make progress in ME research and treatment and to bring wider understanding of ME in UK into the 21st



century. What they have achieved since they formed as a group in 2005 and as a registered charity since 2006 is nothing short of miraculous. They have done much to galvanise biomedical research into ME and we are proud to support their efforts.

We are immensely grateful to Invest in ME and to all those who support them in their international drive to instigate, fund, and conduct the kind of high quality scientific biomedical research that may be translated into reliable diagnostic biomarkers and long-awaited effective treatment options for this organic disease and we are also extremely appreciative of everyone who supports our campaign by raising awareness in such a variety of ways.

Wherever you are based and whatever role you play, be it front of stage or behind the scenes - we thank you for your support.

See more - See more here - <http://blog.ldifme.org/2013/07/happy-birthday-to-us.html>.



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