

# Fightback

MNDA Norwich & Waveney Branch Newsletter  
Issue 57 January 2013

## Celebrating events in aid of the MNDA

Thank you all for helping raise awareness of MND and for the funds raised to help people with MND.

ARCTIC TO THE MED Fred Edwards with friends Fred Martin and Alex Mansbridge, took on the challenge of cycling 3500km for Force Cancer Charity and the Motor Neurone Disease Association in June 2012.



Above is the group just outside the Arctic Circle in a photo posted on their blog on 30 June 2012.



Here they are shown finally in Monte Carlo on 31 July, after 32 days spent cycling 4320 kilometres – rather further than expected! We look forward to hearing how much they have raised.

LINDSEY WILKINS decided to climb Snowdon as a challenge, and to raise sponsorship for the MNDA in memory of her uncle Tony Mulley who died in 2011. Lindsey is a beauty therapist and found people visiting the salon very generous helping her raise £311; a further £190 was raised on her Just Giving Page.



FAMILY BUNGEE JUMP The Keeble family, Ross, Daryl, Meryl and Joel each did a 160 foot bungee jump on 23rd September in aid of the MNDA. Their mother Janet was diagnosed with MND in 2011. This is particularly impressive given that Meryl hates heights and only Ross had jumped before. They raised an amazing £6364 which is to go to research.

ANTHONY BLAKEMORE completed the windiest ever City of Norwich half marathon on 25 November 2012. He ran in memory of Jim



Heal. He is still collecting donations so a final figure is not yet available. He plans to attempt the Three Peaks Challenge on 17 May 2013 and is collecting sponsorship via his Just Giving Page at

<http://uk.virginmoneygiving.com/anthonyblakemore>

**COLNEY WOODLAND BURIALS PARK** It was a cold wet day outside, but there was a warm welcome inside and plenty of Christmas goods on sale at the Christmas Charity Event. The MNDA stall raised £263.20 on the day which will be cash matched by Colney Woodland's parent company Bibbyline Group. The last guess of the day was closest to the weight of the cake at 6lbs and 6oz.

**GEOFF WHITEMAN**, Manager of The Salon has put an MNDA collection box in the salon for several years. The most recent sum collected was £82.64 making a grand total of £409.34 since he began. He has also supported us by selling our Christmas cards. We would like to thank Geoff for his support and wish him well as he begins his retirement in January.

**JASON BECKER: NOT DEAD YET** is a story of dreams, love and the strength of the human spirit. When doctors diagnosed 19-year-old rock star Jason Becker with Lou Gehrig's Disease (MND), they said he would never make music again. 22 years later, without the ability to move or to speak, Jason is alive and making music with his eyes. The film was released in the UK in November but we received the information too late to add it to the October newsletter. However, if you do want to view the movie it is now available to purchase on DVD.

### **Take a Bow** – *thanks to the following for donations received by the branch*

- Mary King, sale of Fruit and Vegetables - £687.50
  - Mary King, sale of Hagstones - £252
  - Dan Georgescu's sponsor money for Iron Man Competition - £217.50
  - Lucie Legg skydive - £492.50
  - Country Dance on 2/12/2012 at Loddon, Eileen & Dick Bloy - £705.80
  - MNDA 2012 Raffle - £50
  - Belton with Browston Parish Council; J.J. Rudrum - £105
  - Norwich Petanque Club in memory of former secretary Norman Guest £150.50
  - Grahame Godsmark sale of 'Mostly Walberswick' - £45
  - Pakefield Wives Group - £500
  - Marion Edwards, Bric-a-Brac, book sale and donation - £105
  - West End Waiters - £800
  - Phillip Laurier Great Yarmouth Marathon - £15
  - The Salon, sale of MNDA Christmas cards - £114.33
    - Proceeds of raffle at Upton Open Meeting - £144
  - Proceeds of raffle at Wortwell Open Meeting - £102
  - Sale of MNDA cards at Wortwell - £376.20
  - Gift aid, bank interest and Charities Trust - £472.54
- Donations in memory of
- John Hathaway – Sue Exley £100.00 and Youngs Funeral Directors £220
  - Mrs Edna May Tinson - £20
  - Barbara Bunting - £205
  - John Francis – £40
  - John Turner – £280.59
  - Geoffrey William Coleby – £377.50
  - Barry Osborne – £50
- Donations
- Janet Shrimpling - £50
  - Mrs. F.A. Martin - £500
  - Thelma Pointer (in lieu of Christmas Cards) - £120
- Collection Boxes
- C.E. Dunger - £30
  - The Salon - £82.64
  - Mrs. Shulver - £5
  - East Anglian Lawn Tennis Club (tennis and squash) - £36.67

## News from Head Office

**Friends of the MNDA:** It is free to become a Friend. The association encourages Friends to sign up to the online community to hear our latest news. Friends can choose the type of content they wish to receive including exclusive research updates, recent activities and campaigns. The majority of communication with Friends will be via email and e-newsletter. We also encourage our Friends to fundraise for us. In contrast to personal members, Friends do not have voting rights and will not receive Thumb Print or an introduction to the branch – so if you are currently a member we hope you will stay as full members; you can receive any or all of the Friends online benefits.

**The MND Charter:** We all know the challenge of low awareness of MND. The MND Charter, with your support, can help to improve the situation. We hope you will sign the charter online if you have not already done so at [www.mndcampaigns.org/mndcharter](http://www.mndcampaigns.org/mndcharter) or on a sign-up form at the next meeting.

The five point MND Charter:

1. People with MND have the right to an early diagnosis and information
2. People with MND have the right to access quality care and treatments
3. People with MND have the right to be treated as individuals and with dignity and respect
4. People with MND have the right to maximise their quality of life
5. Carers of people with MND have the right to be valued, respected, listened to and well-supported

## Branch News

**Next Open Meeting:** 1pm Sunday 3 February 2013 Swanton Morley Village Hall featuring the West End Waiters.

**Open Annual General Meeting:** Advance notice of the date for your diary. Sunday 14 April 2013 at St Andrews Church Hall, Eaton. We are quietly confident that Malcolm has secured Dr. Brian Dickie to give a talk on research developments. Those who have heard Brian speak before know that he makes even the most complex ideas appear easy to follow and understand. He always welcomes our questions.

**Branch Consultation/Review:** On 24 October Suzanne Curtiss, the Volunteer Development Coordinator, met with those of the committee who were available during the day. Among topics discussed was the possibility of holding a get together for carers at some time in the future, or to consider additional and different types of open meetings. Do speak with one of the committee or your association visitor if you have any ideas or think there are things we could be doing better. We would particularly welcome your thoughts on catering at the open meetings and suggestions as to food that you might prefer if you are living with MND.

**Newsletter Editor:** Thank you to all who have sent photos and stories for inclusion in our newsletter. I am sorry it is only possible to advertise events in advance when I have the information before the printing deadline, the end of February for the March edition.

Please consider whether you would be prepared to accept the newsletter as an attachment to an email to help save on the cost of postage. If you would like to receive your newsletter in this format please send me an email. If you still wish to receive the paper version that is fine it will continue to be sent in the normal way.

**Regional Care Development Advisor:** Lindsay Goward, our new RCDA can be contacted on 08453 751829 and by email at [lindsay.goward@mndassociation.org](mailto:lindsay.goward@mndassociation.org). Lindsay works on Tuesday, Wednesday and Thursday as part of a job share arrangement with Liz Cooper.