

# THE HEATON-ELLIS TRUST

Working to cure Motor Neurone Disease

**NEWSLETTER**

Spring Update 2013

Dear Supporters

This year has been a very exciting one for the Trust, both in terms of the monies raised and the developments made in the research.

## Exciting News

In June 2012 another mutated gene was discovered, responsible for 2% of familial MND cases. This, with the other discoveries to date, means that we now know the causes of two-thirds of familial MND cases, and most of these discoveries have occurred since 2011.

Professor Shaw and his team at King's College London have been assisted in their endeavours by massive leaps in gene sequencing technology. They are now able to capture more DNA more quickly. The team have been able to assess more MND samples as a result, which basically means that the speed of gene capture has effectively been doubled. Professor Shaw recruited two additional staff members to assist him, which is a reflection of the advances being made.

## GENEROSITY ABOUNDS

The Heaton-Ellis Trust has reached its £1 million target.

We would like to say a big **THANK YOU** to all of our supporters, who have been so generous, committed and loyal to the cause.

In 2012 alone, the Trust received donations of **£262,000**, an impressive amount given the tough economic situation we are in.

## Where Are We Now?

Huge optimism is felt by all in MND research that within the next four years the causes of over 95% of familial MND will be known. The Heaton-Ellis Trust and its supporters should be extremely proud of the contribution their funding has made. Finding a cure for MND is now seen as an achievable goal.



Professor Chris Shaw

Prior to 2009, only two genes responsible for MND had been discovered. By 2012 this had increased to seven genes.

The research funded by the HET has been a trigger for other organisations to get involved in funding. A major US-based drug company is, for example, funding the whole genome sequencing of 1000 MND DNA samples. This decision was directly influenced by Professor Shaw's research.

Professor Shaw's team was the first in the world to develop models of MND in cells so that pathological features of the disease could be replicated and observed. These have been made available to the international research community by our research team.



## What Next?

The Trustees have decided that this is too exciting a time to leave Professor Shaw's team without Heaton-Ellis Trust funding, when a cure for MND is so tantalisingly close.

The Trust will continue in a less prominent form.

It is very much hoped that our supporters will continue to see the Trust as a worthwhile cause to back should they be undertaking any fundraising.

The annual Opus Energy Shooting Challenge will continue, as much as a memorial to David Heaton-Ellis as a fundraising opportunity.

We hope you will see why we have taken this decision.

If you no longer wish to be kept updated about the Heaton-Ellis Trust and the research developments please email us and let us know.

We would like to re-iterate our sincere thanks for all of your support over the years. You have made a huge difference !

## Dates of Interest

- Champagne Afternoon Tea at the Royal Park Hotel 9th May 2013
- Luton Hoo Golf Day 2013 19th July 2013
- Opus Energy Shooting Challenge at the Royal Berkshire Shooting School 27th September 2013



Some participants from last years' Luton Hoo Golf Day.



## Heaton-Ellis Trust Afternoon Tea

The Heaton Ellis Trust has teamed up with luxury, four star, boutique hotel, The Royal Park ([www.theroyalpark.com](http://www.theroyalpark.com)).

The hotel has chosen the Heaton-Ellis Trust as its preferred charity for 2013 and to celebrate this wonderful collaboration, The Royal Park will be hosting a Champagne Afternoon Tea on Thursday 9th May from 3.00pm to 6.00pm. Tickets are £35 per person and include a drinks reception and afternoon tea.

To book tickets please contact Laurent Boutonne, General Manager at The Royal Park on 0207 479 6602 or email [lboutonne@theroyalpark.com](mailto:lboutonne@theroyalpark.com).

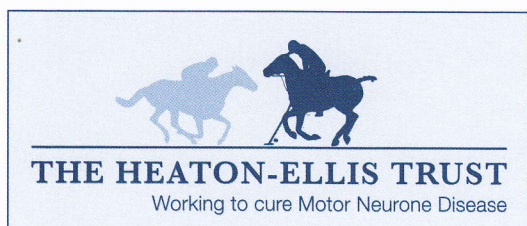
The event will also announce the launch of The Royal Park's charity month, taking place in June.

Throughout the month of June, the hotel will be releasing a limited number of rooms per night for just £100! Guests are encouraged to pay what they think their stay is worth. If a guest thinks their stay was worth £175, the remaining monies (£75) will be donated to the Heaton-Ellis Trust.

In addition to this fabulous offer, The Royal Park is offering Heaton-Ellis Trust supporters a 10% discount on all rooms booked throughout June – perfect for those attending Polo in the Park!

To book, simply call 020 7479 6600 and quote Heaton-Ellis Trust Polo 10% at time of booking or email: [reservations@theroyalpark.com](mailto:reservations@theroyalpark.com) and put Heaton-Ellis Trust Polo 10% in the subject line to claim your discount.

**Thank you, and please continue to support The Heaton-Ellis Trust.**



Registered Charity No: 1126534

**Trustees:** Simon Arber, Charlie Crossley-Cooke, Tim Roupell, Sophie Heaton-Ellis

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