



Myotubular Trust Reception The House Of Commons

KINDLY HOSTED BY PETER AINSWORTH, MP

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Myotubular Trust Charity Event The House of Commons 5th November 2009

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Thank You

WELCOME

Welcome to this very special Myotubular Trust event in the beautiful House of Commons Terrace Rooms. We are delighted to be here and honoured to have you join us for this evening.

The purpose of tonight's event is to raise funds for a cure to save the lives of children born with the devastating condition, myotubular myopathy.

But tonight is also about you. We are very grateful to have you here with us, to celebrate our new journey as we begin to fund new and exciting research that has the potential to change lives. By being here tonight, you are giving great hope to families and a real chance of life for affected children.

We are very grateful to Professor Francesco Muntoni, Head of the Dubowitz Neuromuscular Centre at Great Ormond Street Hospital and Chair of our Scientific Advisory Board, for coming along tonight, and to Mark Damazer for once again kindly offering to introduce this evening's programme.

Our reception here in the beautiful Terrace Rooms is being hosted by Peter Ainsworth MP, and we thank him for his kindness. We are certain that this venue is the perfect setting for a spectacular evening!

And finally, a huge thank you to those of you who have given so generously in so many ways to make this evening a success – you know who you are! We would not be here without you.

We hope you have a sparkling night!

With thanks,

Anne Lennox and Wendy Hughes
Parents and Trustees

MENU

Canape - House of Commons Mini British Classics

Prawn cocktail with crisp lettuce on brown bread and butter

Smoked Scottish salmon with macerated leeks and pumpernickel bread

Roast corn-fed chicken breast with watercress on sour dough bread

Devils on horseback - prunes wrapped in British bacon

Marmalade of red onion and Ragstone goat's cheese cream on a savoury scone (V)

Fish and chips with tartar sauce and lemon

Toad in the hole with Cumberland sausage

Root vegetable 'Shepherd's pie' with Quicke's cheddar cheese mash (V)

SCHEDULE

6.00pm

Pre-Booked Tours Commence

7.00pm

Terrace Rooms, Main Reception Starts

9.00pm

Raffle Prizes Announced

9.15pm

Auction Closes

9.30pm

Close

Speakers:

Mark Damazer

Controller of BBC Radio 4

Stephen Pollard

Journalist, columnist and political commentator

Professor Francesco Muntoni

Professor of Paediatrics, Imperial College
and Head of Dubowitz Neuromuscular Centre,
Institute of Child Health,
Great Ormond Street Hospital

SILENT AUCTION

01. The English Cotswolds

A weekend break in a beautiful private 18th Century cottage in the charming Cotswolds town of Burford. Days and dates very flexible. Sleeps 4 (including one child).

Donated by Filippo and Silvia Gori

02. Nutcracker Rehearsal at the Royal Opera House

A chance for two people to attend a morning stage rehearsal of the world famous Royal Opera House Christmas performance of The Nutcracker, followed by a private behind the scenes tour of the Opera House guided by Andrea de Flammineis, first bassoon of the orchestra.

Donated by Andrea and Marion DeFlammineis

03. The French Riviera

A week's holiday for up to 6 people in a beautiful traditional style French villa on the Cote d'Azur, designed by the internationally renowned architect Robert Dallas. Located in the stunning village of Chateauneuf de Grasse with unrestricted views to the Mediterranean Sea from Antibes to the Massif de l'Esteral mountain range. Available any dates in April and May (including Easter).

Donated by Barry and Anna Sheffield

04. Disneyland* Paris

A magical 2-night family holiday for four at a Disneyland* Resort Paris hotel, including 3-Day Disney Park tickets with Fast Pass, Continental breakfast ...and even 4 Eurostar tickets to get you there!

Donated by Andrea Tartaglia and the Disney Group

05. This is the BBC

An offer for two people to spend an afternoon at the BBC's News Centre in West London - the heart of its worldwide news operation. You'll meet some of the BBC's best known presenters, tour the newsroom and visit World News. You'll be able to see the news put together, how scripts are written and reports edited. Your afternoon will end with seats in the programme gallery as the Six O Clock News goes on air and is broadcast live to four million viewers.

Donated by Marek Pruszewicz

06. Make over with Kylie Minogue's Make up artist

A one-to-one personal make over and lesson with Caroline Barnes, the internationally renowned make up artist who has worked with Kylie Minogue, Naomi Campbell and Charlotte Church and for Vogue, Tatler, Red and Harpers & Queen.

Donated by Caroline Barnes

07. Sunday morning with Andrew Marr

Come to watch the award-winning Andrew Marr show broadcast live from BBC Television Centre, just before Christmas. The programme always has an array of interesting and influential guests, and is considered one of the most important political programmes on British television. You will be part of the live audience while Rory Bremner does his famous political impersonations, and you will then meet the guests and presenters at an after-show breakfast in the BBC cafe. For two people.

Donated by Susanna Reid

01



02



03



04



05



06



07



SILENT AUCTION

08. An original signed MAC cartoon

A rare opportunity to have your very own original, and signed, cartoon by one of Fleet Street's most famous cartoonists - MAC, of the Daily Mail.

Donated by MAC (Stan McMurty) and Elizabeth Vaughan

09. Nice One Cyril!

A special edition Tottenham Hotspurs Shirt from their 125th anniversary season – signed by the team. ...plus a signed ball.

Donated by Matthew Collecott

10. Fly-Fishing for Trout

A day's flyfishing for trout for 1 person on a private stretch of a famous Southern England river - the Test or the Kennett. All tackle and tuition provided on the day with the opportunity to take home the catch. (between May-Sept 2010 - No prior fly fishing experience necessary.)

Donated by Jeremy Bourke

11. Original Ceramic Collection

Beautiful set of three ceramic pots by the highly talented Georgina Fowler, a third year art student at Hereford College of Arts. An opportunity to buy this up-and-coming artist's work early in her career! Georgina who herself has the rare recessive form of myotubular myopathy, has won several awards for her art.

Donated by Georgina Fowler

12. Formula One Exclusive

A unique tour of the Williams Formula One factory in Oxfordshire where you will get the inside track on how the cars are made followed by a visit to the Williams World Championship museum where you will see Mansell's, Hill's and Piquet's winning cars, ...and a pub lunch to follow!

Your host for the day will be Formula One commentator and writer James Allen. James presented ITV's Formula One coverage alongside Murray Walker and Martin Brundle and has written Nigel Mansell's and Michael Schumacher's autobiographies.

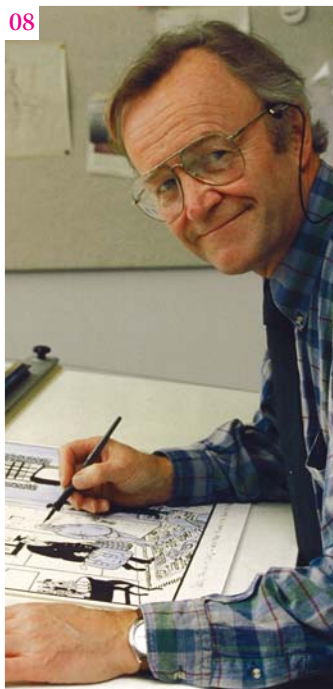
Donated by James Allen

13. Come Cook with Me

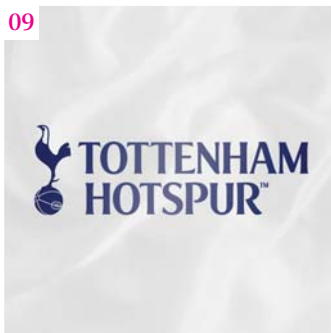
An all day cookery class for two. Enjoy a full day class at this unique, central London cookery school. Choose from Flavours of Italy, Morocco, Thailand, Southern India... You'll prepare a culinary feast under expert tuition from John Benbow and then get to eat it in convivial company! And later, when you try your new skills on your friends, we have 4 waiting staff for 4-6 hours to serve up (and clear up!) your culinary genius while you relax and enjoy your party!

Donated by John Benbow of Food at 52 Cookery School (www.foodat52.co.uk), and Fergus Seccombe O'Loghlen of High Society Staffing (www.high-society.co.uk)

08



09



10



11



12



13



RAFFLE

Black and white photo of the Houses of Parliament by award winning photographer Mark Anderson

Donated by Mark Anderson

A night in a junior suite at the beautiful English country hotel, Chewton Glen,
including breakfast and dinner

Donated by Daniel Poser and Chewton Glen



18 carat yellow gold amethyst bead necklace

Donated by d'Arcy Jewels

Spa day and lunch for two at Pennyhill Park, Tunbridge Wells

Donated by Danny Pecorelli

3 tickets to the sell out Miley Cyrus, aka Hannah Montana, concert at the O2 Arena, 14th December

Donated by Andrea Tartaglia

Video Camera

Donated by John Lewis and Chris May

Bottle of House of Commons Whiskey...with some added signatures for posterity!

Donated by Chrysoulla Kyprianou

Burberry Handbag

Donated by Ilaria Gregotti

4 tickets to Madame Tussaud's Waxworks

Donated by Madame Tussaud's

Original print by Aardman Animations

Donated by Toni Abrams

2 tickets to the West End show Legally Blonde

Donated by Ambassador Theatre Group

Gift basket from Kiehls

Donated by Kiehls, Northcote Road

DVD and book signed by James May

Donated by James May

Cath Kidston Holiday Bag

Donated by Cath Kidston, Northcote Road

FINDING STRENGTH

Myotubular myopathy is a rare genetic condition, mainly affecting boys, which causes profound muscle weakness. In the baby with myotubular myopathy, the myotubularin protein is missing, which means that the muscles remain in a very early stage of development. So as well as causing general muscle weakness, many sufferers need mechanical ventilation to stay alive and need to be fed straight into the stomach via a gastrostomy. Many are medically very fragile and need nursing care 24/7 for at least the first few years of life. Myotubular myopathy is life threatening in the extreme - 8 out of 10 of these boys die before their first birthday and only 1 in 100 makes it to 10 years old. These children are so frail that even a simple childhood cold can be fatal, simply because their muscles are so weak that they can't even cough effectively.

There are currently great advances in the field of muscle disease but rare diseases like myotubular myopathy find it exceptionally hard to attract mainstream funds. Treatments or a cure can lag literally years behind the medical possibilities when a child suffers from a rare disease. Hence the Myotubular Trust was created - its goal being to fund research that would simply 'find strength' for these children.

Raising funds serves two purposes:- first, it pays for the actual research; second, the very existence of a specific fund where once there was little possibility of research being paid for, inspires new academic thinking..



Tom Lennox
21st July 2003 – 29th May 2007

Indeed, from this September we are funding two new and exciting research projects and we have just put out our second Call for Grants amongst the neuromuscular scientific community.

We are so confident that with your help, our goal of finding a treatment or cure is within reach. So one day soon, a diagnosis of myotubular myopathy will not mean nearly certain death for a child.

We look forward to that day with great joy.

THANK YOU

Auction Committee:

Lizzie Geffen, Ilaria and Marco Gregotti, Anne and Andrew Lennox, Johanna Martin, Chrysoulla and James Rosling, Melanie Spring and Andy Wilson-Smith

Helpers on the night:

Annie Thompson, Jenni Gordon, Caroline Cook, Helen Sharp & Jess Childs

We would like to thank:

Lynn Alleway, Emily Ash, Sarah Bourke, Linda Fowler, Rebecca Fraser, Deborah and Simon Gurney, Catherine James, Guy Martin, Noni and Oliver Needs, Daniel Poser, Martin Rowland, Veronica Ruddle, ...and all of you who have so generously given us the wonderful gifts for the auction and raffle

With very special thanks:

Peter Ainsworth, Melanie Spring and Mark Damazer

Without whom this evening would have been a pale imitation of itself!

Richard and Tracey at Nightingale Austen Designs who have helped us with all our design from day one, and present the charity so beautifully.

www.naduk.com

Wendy and Anne

myotubular trust 
FINDING STRENGTH

Founding Patron: Professor Victor Dubowitz Emeritus Professor of Paediatrics, University of London and President, World Muscle Society
Scientific Advisor: Professor Francesco Muntoni, Professor of Paediatric Neurology, Imperial College, London
Trustees: Wendy Hughes, Ian Hunter, Anne Lennox, James Rosling Charity number 1113809