

## SMA FACTS

*SMA affects motor neurons in the spinal cord. This results in muscular weakness, leading to severe disability.*

*It is the leading genetic killer amongst infants and toddlers.*

*In the UK, at any one time, between 5,500 and 6,000 people have SMA.*

## THANK YOU

*Team Benny*

*Team David*

*Team Freddie*

*Team Millie*

*Team Octavia*

*Awards Dinner Committee*

*The Danube Cycle Team*

*Bentley*

*ICAP*

*Keira Knightley*

*David Morrissey*

*Emily Maitlis*

*Imelda Staunton*

*Jim Carter*

*Celia Imrie*

*Jane Cussons*

*Sheffield Haworth*

## HOW CAN YOU HELP?

Do your own **MAD** Challenge – the more **MAD** the better. It can be anything from running, walking, tea parties (**MAD** Hatters Tea Party!), cake sales to car washing; come up with your own ideas. For more inspiration or help contact us on **01608 663415**.

Donate directly to The Trust <http://www.smatrust.org/fundraising> or through our JustGiving page <http://www.justgiving.com/smatrust/Donate>.

## WHAT NEXT?

The Charity is planning a **MAD** walk on The Cotswold way – contact the office on **01608 663415** or email us at [info@smatrust.org](mailto:info@smatrust.org).

# We have reached £1 million of our £2million momentum campaign

We have reached £1 million of our **momentum** campaign. We have had a fantastic fundraising year (2011) with **MAD** challenges coming from all quarters. Headed up by the children with SMA and their families and friends.

## THE MAD CHALLENGE STILL GOING STRONG!

[WWW.MADCHALLENGE.ORG](http://WWW.MADCHALLENGE.ORG)

The **MAD** Challenge is still creating a lot of interest and we have a new team – Team David to add to our list.

**Team Benny** (<http://madchallenge.org/challenges/Team-Benny>) – A group of girls – Chilla Knight, Claire, Emma, India, Jade, Nicky, Tash and Verity - walked from Oxford University to the SMA Trust's HQ near Shipston on Stour, some 40+ miles cross-country in October weather (which was very wet and cold!) to do their bit to help Benny and other children like him. They raised well over £1000, well done girls.

Cas Knight, Benny Knight, Alex Smith and other friends and family did the Athens Classic Marathon with Ben in his manual Wheelchair. Another **MAD** Challenge indeed.

**Team David** (<http://madchallenge.org/challenges/teamsdavid-dee>) – The most recent event from Team David is the Zumbathon, an amazing event held in Manchester with over 220 people attending, they raised well over £6000.

**Team Freddie** (<http://madchallenge.org/challenges/sheffieldteam>) – Sheffield Haworth (London) cycled from London to Paris raising fantastic amounts for The SMA Trust.

Employees of Sheffield Haworth New York hosted 'A New York Minute City Challenge' – a fast paced and interactive scavenger hunt where teams roam the streets of Manhattan, solving clues and earning points.

**Team Millie** (<http://madchallenge.org/challenges/Team-Millie>) – Alex Murray for Team Millie is committed to doing the following races- Silverstone Half Marathon, Man Vs Horse, Spartan Race and Aberystwyth! Thank you **MAD** Murray!



*Danube Cycle Ride*

Following on from Millie's **MAD** challenge she has been voted South Cheshire's Young Person of the Year and was presented her award by Olympic champion Tessa Sanderson.

Her younger brother and sister took up the mantle and persuaded their school to take up their own **MAD** challenge for Team Millie. To tie in with the 2012 Olympics all the children at Tarporley Primary School did something **MAD** and physical for 20 minutes and 12 seconds and some of the mums walked for 2 hours and 12 minutes and raised over £400.

1st Tarporley Brownies held a **MAD** Glitter Disco and raised £150.

Millie's school, The Grange has chosen to support The SMA Trust for their annual charity week which takes place this term with lots of crazy **MAD** events planned. A quiz night is planned, a candle party has taken place, **MAD** school photos raffle etc.

**Team Octavia** (<http://madchallenge.org/challenges/Team-Octavia>) – Tim Woodward took on yet another **MAD** Challenge – Pembroke Coastal Path – 188 miles.

Tim, friends and family also walked the South Downs Way.

Barnaby and Tim Woodward cycled The South Downs Way with dreadful weather conditions to contend with.



The Team



Chris, Stephen and Blake

### Tim Woodward and three old school friends walked part of The South Downs Way.

Chris Norman, Blake Rose and Stephen Marsh decided to do 23 miles of the walk from Buriton to Amberley for the SMA Trust with their families and at short notice Safia, Barnaby, Osborne and Tim Woodward decided to join them for the day.

Tim dubbed 'Action Man' by the office staff, donned his walking boots once again for this new MAD challenge, his energy shows no boundaries.



### R.I.P. Osborne

16th September 2003 to 31st October 2011

Those of you who have followed Tim's Blog and know anything at all about his South West Coastal Path Walk will be familiar with Osborne who walked the entire SWCP, as well as miles in training and the South Downs Way walk with the children. Osborne was a much loved family pet. After suffering from a sudden, unknown and highly aggressive illness the family made a very difficult decision to put him to sleep. He had just turned 8 years old. We all at the SMA Office enjoyed reading about his antics and character on Tim's blog.

# A new team in our MAD Challenge

The Dee family heading up Team David – David Dee, the Captain of Team David, is a brave 14 months old boy with SMA type 2.

## TEAM DAVID'S FIRST EVER ZUMBATHON ON JANUARY 8TH AT THE RITZ RAISED OVER £6,800

£2000 on the day (£2,057.10 to be precise). Additional donations from people who could not attend in person were just over £4,800, bringing the total funds raised in relation to this event to over £6,800!

Over 220 people filled the bouncy dance floor of the Ritz in Manchester on Sunday afternoon. Eight North West top Zumba Instructors took the crowd through some serious moves. Zumba lovers came from all over the region: Manchester, Liverpool, Cumbria, Leeds and some even travelling down from Scotland!

One Zumba dancer said: *"Absolutely amazing event, great atmosphere, fantastic instructors and all for an amazing cause. I am so glad to be here to support Team David and the SMA Trust. I can't wait for the next event."*

Hugely appreciated by the mainly female crowd was a special appearance by Everton footballer Sylvain Distin. He joined Zumba Instructors Patricia and Jo on stage, dancing away to one of the tracks. He did brilliantly! Sylvain has shown an amazing support for Team David and supporting the SMA Trust, a true gentleman.

Patricia Dee, David's mum was delighted. She said; *"We are so grateful for everyone that has come to this event. People seemed to have had such a brilliant time and we raised a lot of money."*

The next Team David Zumbathon will take place in June.

Watch this space for other fundraising by Team David – Charity screening of The Iron Lady, Stockholm Marathon, Wax to the Max, Chicago Marathon, Tesco Collections, Bath and Reading Half Marathons, West Highland Way, Monica's Marathons...

<http://www.teamdavid.co.uk>

## LONDON TO PARIS CYCLE SHEFFIELD HAWORTH STAFF

Staff from the London offices of Sheffield Haworth (Team Freddie) took on the MAD challenge of cycling over 250 miles over 3 days to Paris from our offices in the city.

What was expected to be a 'tough but manageable' tour, turned out to be a baptism of fire for everyone on so many levels (we were soon to learn that northern France wasn't flat!).

On day 1, the team battled the London suburbs before arriving in Faversham for lunch before deciding to skip the Kent countryside and take a 'short cut' via the A2 in order to get an earlier ferry. Anyone who has driven on the A2 will confirm that this pushed the boundaries of our MAD challenge!

Unfortunately on day 2 we lost a team member to a broken arm coupled with the team getting lost almost immediately after departure. After getting back on track and suffering 3 punctures (2 on the support car!), the Sheffield Haworth team fought on and arrived in a desolate Amiens at around midnight!



The final day saw the mercury rise to over 30°C as we peddled the remaining 85 miles through the beautiful country side and into the Parisian suburbs. We arrived at the Arc de'Triomphe at 10.30pm – only to wait for another 3 hours for the support car to find its way to the hotel! A thoroughly enjoyable trip and well worth the cause.

The team list is as follows; James Strover, Paddy Morrissey, Emma Tritton, Matthew Williams, Will North, Tiara Stritzko, Emily Brown, David Stephens, Natasha Marks, Georgia Mahony and Tori Finden.

Our CEO, Tim Sheffield (father to Freddie) bravely joined us for the first day as well.

Written by James Strover

[http://www.sheffieldhaworth.com/corporate\\_responsibility/?s=Fundraising](http://www.sheffieldhaworth.com/corporate_responsibility/?s=Fundraising)



### ICAP Charity Day 7th December 2011

The SMA Trust was selected as one of the beneficiaries of the ICAP Charity Day on 7th December last year, which is the single biggest fund-raising event in the City of London.

On this one day, ICAP, the world's largest inter-dealer broker, gives away its revenues and commissions to charity.

The day was a huge success as all the traders arrived at work in highly imaginative fancy-dress and received a visit from the Duchess of Cornwall. The SMA Trust is hugely grateful to our patron, David Morrissey, and a number of other high profile celebrities – Celia Imrie, Imelda Staunton, Jim Carter and Jon and Dan Snow, who mingled, posed, traded and generally entertained the office staff. They fulfilled their ambassadorial roles with flair and enthusiasm so that a lot more people are aware of the great work the SMA Trust is doing in order to find a cure for SMA.

Altogether a very exciting, uplifting and rewarding day. Thank you ICAP.

<http://www.icap.com/ICAP-Charity-Day/CharityList/SMATrust.aspx>



### Angela Campbell-Noe Runs New York Marathon for The SMA Trust

Angela, as part of Team Octavia ran the New York Marathon and raised over £5000, Angela said;

*"I was absolutely thrilled to finish the New York Marathon on 6th November 2011 in 3 hours and 42 minutes; most importantly, I loved every minute of it and I felt like an athlete at a major sporting event! Perhaps most memorable however were my fellow marathoners who joined me in putting their bodies on the line for causes dear to their hearts; the memories of the day will stay with me forever."*

# The SMA Trust Momentum Awards Dinner

3RD NOVEMBER 2011

### The SMA Trust held their first fund-raising dinner on 3rd November this year at Chelsea FC.

The purpose of the evening was to celebrate all the fantastic achievements that people have accomplished this year, in order to raise money for us. A year previously a number of children with SMA had announced that they were going to challenge themselves to a tough and physical test or a **MAD** Challenge. Some covered miles of inhospitable terrain in their wheelchairs, whilst one brave teenager covered 120 miles in a horse and trap. They then challenged others to follow their example and embark on their own **MAD** Challenge. People took them at their word and hence our evening of celebration.

The venue was chosen for its novelty factor and proved very popular with the football fans who were given access to the floodlit pitch! A large area underneath the stands was transformed into an exquisite, elegant party space and the guests were treated to champagne and a delicious dinner. Emily Maitlis, the BBC Presenter, very kindly hosted the whole evening and interviewed some of the SMA Children about their challenges. With wit and charm the teenagers allowed us into their world, explaining what it is like to live life confined



to a wheelchair, but also demonstrating their grit and determination to achieve great things despite their disability.

Our patrons Keira Knightley and David Morrissey, juggled hectic schedules to be there and we were hugely appreciative of their support, whilst Alistair McGowan entertained the throng with his unique humour and impersonations. The evening finished with a highly competitive auction and the guests departed, feeling entertained but also somewhat wiser.

The SMA Trust would like to thank everyone who contributed to making this evening such an enormous success, in particular Tim Sheffield, the Chairman of the Committee and Atom Events who provided the expertise and flair to make this such a professional and enjoyable event.

## THE DANUBE ODYSSEY

SEPTEMBER 2011

### Have you ever thought of doing a cycle ride for charity?

The London to Brighton ride perhaps (a challenging 50 miles from beginning to end)? A group of our supporters accompanied by 2 trustees – Casimir Knight (Team Benny) and Tessa Rice (Team Millie) wanted to do a cycle ride which would truly qualify as a **MAD** Challenge. They looked to Europe and decided that they would cycle half way along the Danube – the 2nd longest river in Europe – 900 miles in 11 days. Truly **MAD**! They began in the small town of Donaueschingen at the source of the Danube, cycled across Germany and Austria, passing into Slovakia briefly before arriving in Hungary where they ended the ride in Budapest. They endured

the frustration of getting lost, leading to unnecessary lengthy diversions, flat tyres, aching limbs and the occasional fall but they kept up their spirits with the constant sugar highs of apple strudel at every stop, stunning views, tremendous team spirit and the satisfaction that they were raising £1000's for our Momentum Campaign. The Thermal Waters in Budapest were hugely appreciated by all and now there just remains the second half of the river to conquer, culminating at the Black Sea!

We would like to thank David and Rhys Williamson (whose brainchild this was), Anna Williamson, Stephen Spill, Jim Rice, and Bucci Rossi for completing all 900 miles. They were joined along the way by Brady Clough (who joined at Linz), Jan Hruska, Jirka Bonk and Zdenek Bakala who joined us for a couple of days from Prague, and Len Dunne and Stephen Green who did the final leg from Vienna to Budapest.

# 10 minute interview

## Tessa Rice Trustee

### How did you first get involved with The SMA Trust?

My niece, Millie, who is now 15 years old, was diagnosed with SMA Type 2 when she was 15 months old. She wasn't weight bearing on her legs which all toddlers do at that stage, and when my sister took her for tests they found out that Millie would never be able to walk. This was a huge shock to all the family and so we all found different ways of dealing with the news. That was when I found out about the SMA Trust.

### What do you most admire about Millie?

Her positive spirit and her sense of humour. She never complains and she throws herself wholeheartedly into whatever she does.

### How long have you been connected to The SMA Trust?

14 years

### When, how and why did you become a trustee?

I had been a fundraiser for a number of years and had developed a close relationship with some of the Trustees at the SMA Trust. When I was asked to become a Trustee 2 years ago it felt like a natural progression to get more involved in an organisation which could change the lives of families affected by SMA. Most of the Trustees have experience of SMA in their family, and therefore there is a very close bond between us and a huge drive and determination to get closer to finding that cure.

### What has been a high point for you last year (2011)?

There have been a number of highs this year. Notable amongst them was arriving in Budapest having cycled 900 miles to raise money for the SMA Trust. But probably the biggest high was seeing so many of the people who have gone to huge efforts to do their own **MAD** Challenges this year, all gathered together in the exquisite Grand Hall at Chelsea FC for our inaugural Momentum Awards Dinner. It really was a night of celebration and everyone should have felt very proud. I was delighted that our Patrons Keira Knightley and David Morrissey were able to make it despite their hectic schedules. A truly memorable occasion.

---

**“The SMA Trust has such a personal appeal to me that I can't imagine that I would have thrown myself into another job with such enthusiasm.”**



Tessa at ICAP

### You have amazing energy and drive and you have done many amazing challenges, how do you prepare for these events for example the Danube Odyssey cycle?

The key is to start training early. I usually make sure I am thinking about doing the appropriate exercise at least 3 months before the event, whether it be climbing a mountain or doing an endurance cycle ride. I love having a focus when I am exercising - it seems to dull the pain!

### If you were not involved with SMA what would you be doing instead?

I am sure I would be involved with a local charity, but the SMA Trust has such a personal appeal to me that I can't imagine that I would have thrown myself into another job with such enthusiasm.

### With all the hard work you put in for the Trust, how do you relax?

Exercise is still my main means of relaxing and I love tennis and cycling. I am also passionate about the theatre and enjoy supporting the fringe theatres in London. It is so important to support the arts at a time when they are losing so much government funding.

### If you had a Dinner party and you could invite 6 guests, dead or alive, who would they be?

That is such a difficult question. I think I would combine some of my heroes from the world of sport and the arts but who knows if they would work around a dinner table. I would invite Keira Knightley, our Patron, and Jane Austen, so they will work well together, Tom Hanks who is hilarious, Ernest Shackleton, who could teach me a thing or two about endurance events, Nadal, for his amazing tennis ability and Sir Paul McCartney, because he is a legend.

### What is your favourite book?

Atonement by Ian McEwan. We all make mistakes in life and it is how one deals with them which is important.

The charity has donated **£1.6M** to SMA research since its inception.  
Keep up to date with SMA research at [www.smatrust.org/news](http://www.smatrust.org/news)



**Kevin Talbot** (MBBS, DPhil, FRCP) Biography:

*Kevin Talbot qualified in medicine with Distinction from London University in 1990 and trained in Neurology in London and Oxford.*

*He joined the laboratory of Dame Kay Davies in 1995 to work on the childhood motor neuron disorder spinal muscular atrophy, which has remained a major focus of his research ever since. From 1998-2001 he was Clinical Lecturer in Neurology and from 2001-2006 held an MRC Clinician Scientist Fellowship. He leads a multidisciplinary team providing a clinical service for patients with motor neuron disease from all over the South of England.*

## Funding the new **Chair of Motor Neuron Disease** at Oxford University

**The SMA Trust committed £100,000 towards this prestigious post based at the centre of excellence that is Oxford University and the position was awarded to Professor Kevin Talbot.**

The new Professor's main research aim is to overcome the barriers to translational medicine in neurodegenerative diseases by identifying the earliest pathological pathways activated in motor neuron disease in order to define the most therapeutically tractable areas for drug therapy and to apply these findings to clinical studies in patients.

Kevin Talbot gave his inaugural lecture to HRH Princess Royal on 1st November



2011 at the Medical Sciences Teaching Centre at Oxford University. Trustee Casimir Knight and Research Co-ordinator Vanessa Christie-Brown also attended and spoke to Princess Anne.

## DEVELOPING A UK SMA CLINICAL TRIALS INFRASTRUCTURE, IN COLLABORATION WITH UK AND EUROPEAN CENTRES

**The SMA Trust is committed to facilitating the preparation of the UK for clinical trials by leading the way to the creation of the first UK SMA Platform.**

The charity hopes to ensure the UK's readiness for the introduction of clinical trials in the very near future.

As a first step towards this goal, the SMA Trust has engaged Research Physiotherapist, Jessica O'Hagen, who will advise and help to drive clinical trials forward, both in the UK and overseas.

### Travel Awards

**The SMA Trust supports training and career development by granting young scientists Travel Awards to allow them to attend crucial, relevant, worldwide conferences.**

<http://ickl.co/SMAtravel>

**Jessica O'Hagen** (PT, DPT) Biography:

*Jessica O'Hagen is a Research Physiotherapist at Great Ormond Street Hospital.*

*She obtained her Bachelor's degree from the College of Charleston, SC in Biochemistry and both her Master's and Doctorate degrees from Columbia University. As a Columbia student, Jessica took part in the Research and Neurology Specialisation Track. She was a member of a Capstone Research Project studying Motor Neuron Disease and exercise. In 2003, Jessica worked as a physical therapist within the Board of Education of New York City serving district 75 children with multiple physical impairments.*

*Jessica also worked as a clinical evaluator at the Eleanor and Lou Gehrig MDA ALS Research Centre at Columbia University. Her work included evaluating and treating patients with motor neuron disease and co-ordinating their rehabilitative services and durable medical equipment. Following this, Jessica became lead clinical evaluator and co-ordinator at Columbia University's SMA Clinic. Jessica has acted as co-ordinator and/or evaluator for phase I, II and III clinical and observational trials. She has also been involved in several research projects, focusing on children with SMA and paediatric neuromuscular disease. She has written papers and abstracts on outcome measure validation and equipment use in the US. In the past she has worked as a consultant for the SMA Trust and is looking forward to rejoining the team.*



# International research collaboration

**The SMA Trust is a driving force behind international research collaboration and co-ordination.**

The most important development for the charity has been its contribution to SMA Europe of which the SMA Trust is a founder member as well as the most significant financial contributor. The Trust has committed over €1 million to the four annual calls for projects made by SMA Europe so far (around 40% of the total).

The fourth call occurred in October 2011 and the projects will be reviewed and selected by SMA Europe's Scientific Advisory Board in Paris in March 2012. The SMA Trust will be contributing 250,000 Euros (39% of the total commitment).

## ABOUT SMA EUROPE

**SMA Europe is the umbrella coalition of SMA patient organisations in Europe.**

SMA Europe was set up in 2006 in order to provide a framework to stimulate collaboration and accelerate translational research pathways in SMA and promote patient care. Cooperation between European organisations is meant to enhance and support the existing efforts of each association by identifying areas for collaboration that are mutually advantageous.

### Members of SMA Europe

**Spain:** Associació Catalana de Enfermetats Neuromusculars (ASEM Catalunya).

**France:** Association Française contre les Myopathies (AFM).

**Germany:** Deutsche Gesellschaft fuer Muskelkranke (DGM).

**Italy:** Famiglia SMA.

**Spain:** FundAme

**United Kingdom:** Jennifer Trust for SMA.

**United Kingdom:** The SMA Trust.

**The Netherlands:** Vereniging Spierziekten Nederland (VSN).

<http://fundame.net/smaeurope/index.html>

## Some of the funded projects:

### Call 2 (2009)

INSERM, Université de Nantes, France.  
Dr. Béatrice Joussemet: *"Evaluation of new AAV-mediated gene therapy strategies in a feline model of Spinal Muscular Atrophy"*. €32,500 (1 year of a 2 year project).

University of Sheffield: Dr. Ke Ning and Professor Mimoun Azzouz: *"PTEN modulation effects on motor neuron axonal growth and neuromuscular junction size in spinal muscular atrophy"*. £53,561.

Emory University, Atlanta, USA. Dr. Claudia Fallini: *"Analysis of mRNA transport and local protein synthesis in axons of SMA motor neurons"*. €65,000.

Columbia University, New York, USA.  
Professor Umrao Monani: *"Investigating the temporal requirements of the SMN protein in SMA"*. €122,513.

### September 2010

The SMA Foundation, New York, USA: *"Rasch Analysis of Functional Scales used to Assess SMA"*. The SMA Trust contributed €3,000 to SMA Europe's support of this project. This project is part of an international effort to prepare the way for meaningful clinical trials.

### Call 3 (2011)

Manchester University, Professor David Sattelle: *"New drugs and new drug targets for Spinal Muscular Atrophy using chemical and functional genomics"*. A grant of €74,575 was awarded for this one year project.

Ohio State University, USA, Dr. Sandra Duque: *"Delivery and Correction of SMA using AAV Vectors"*. A grant of €51,000 was awarded for this 2 year project, which started in August 2011.

*"Clinical Trials Preparation Project"*. A grant of €74,425 was awarded to build a SMA dedicated clinical trial infrastructure across Europe.

## Researchers' Conferences

**The SMA Trust is deeply committed to facilitating communication between research teams by promoting exchanges of ideas, data, methodology and technology through the organisation and funding of SMA Research Conferences.**

The most important function of these conferences is to provide a forum for presenting cutting-edge research. In addition, they offer attendees the prospect of identifying new research directions or approaches, networking with colleagues and developing collaborations.

Indeed, in its quest for European and International research collaboration and co-ordination, the SMA Trust has been organizing and funding annual research conferences for the past 4 years. All were hosted by prestigious names in medical research, and all heads of department in international centres of academic excellence. Guest speakers were chosen from the SMA Europe grant recipients bringing in news and ideas from other countries.

<http://ickl.co/SMAconf2011>

## THE CONFERENCES:

**Sheffield, November 2008** hosted by Professor Azzouz, Chair of Translational Neuroscience at the University of Sheffield and Head of Gene Therapy Laboratory at the Sheffield Institute for Translational Neuroscience.

**Edinburgh, October 2009** hosted by Professor Gillingwater, Chair of Neuroanatomy at the University of Edinburgh, Editor-in-Chief at Journal of Anatomy and Founder Director, CEO & CTO at NeuroORG Business Consulting Ltd.

**Lake Vyrnwy, Wales, October 2010** hosted by Professor Glen Morris, Chair of Biochemistry, Institute for Science and Technology in Medicine, University of Keele.

**Oxford, October 2011** hosted by Professor Kevin Talbot, Chair of Motor Neuron Biology at the University of Oxford.



**Vanessa Christie-Brown**  
SMA Trust Research Co-ordinator  
[vanessa@smatrust.org](mailto:vanessa@smatrust.org)  
Compton Scorpion  
Shipston-on-Stour  
Warwickshire CV36 4JP

Follow us on Twitter <http://twitter.com/smatrust>  
Like us on Facebook <http://facebook.com/smatrust>