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Peer review relaunch

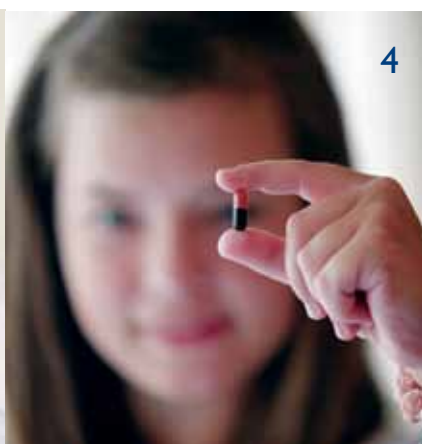
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The primary purpose of *CF Today* is to provide for its readers a reliable source of medical, research and other information relevant to Cystic Fibrosis and to play a supportive role for CF families. Opinions expressed in articles do not necessarily express the official policy of the Cystic Fibrosis Trust. The editor reserves the right to edit and otherwise alter articles or letters submitted to the magazine for publication.

Some pictures used in this publication may be posed by models or taken from library images.

Medical information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment regimen.

Cystic Fibrosis Trust
11 London Road, Bromley, Kent BR1 1BY.
Tel: 020 8464 7211 Fax: 020 8313 0472
www.cftrust.org.uk

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Editor: Jacqueline Ali

All communications should be sent to Editor, *CF Today*, Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY or email cftoday@cftrust.org.uk

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The CF Trust believes that everyone living with Cystic Fibrosis deserves the best possible care and real hope for the future. Median predicted survival for people with CF in the UK is now amongst the highest in the world and my amazing team and I look forward to working with you to continue to push this higher. Also in 2012 we hope that the first of the new generation of CFTR modulators – drugs which tackle the basic defect in CF – will herald a new and exciting era in the fight against Cystic Fibrosis in the UK.

At the end of the last year the board of the CF Trust signed off on our new strategy, *Living Longer, Living Better*. The direction is based on input from a large number of families, people living with CF, clinicians and researchers so thank you very much for all the input we have received in this review period. *Living Longer, Living Better* defines the impact that we seek to have on CF over the next five years based on an analysis of what must be got right in CF if we are to continue to push higher life expectancy and quality of life. There is more about *Living Longer, Living Better* in this edition of *CF Today*; in the next edition there will be further information and an introduction to the CF Trust's new research strategy, designed to make real advances in Cystic Fibrosis care and treatment.

Dr Jim Littlewood is a man who knows a little about making advances in Cystic Fibrosis. It was in 1975 that Jim started a small CF clinic in Leeds. In 1983 he became a member of the CF Trust Research and Medical Advisory Committee (RAMAC) and was chair from 1995. From 2003 through to his retirement in September 2011 Jim has been Chair of the Board at the CF Trust. Jim's distinguished career in CF and tenacious aspiration that children and adults should have the best possible care and treatment has guided the work of the CF Trust for more than half of its 50-year history. The board and staff gathered in Bromley in December to thank Jim and his wife Ann for the enormous contribution they have both made to the CF Trust. I am delighted that Jim has accepted the board's invitation to be the new Honorary President of the CF Trust and we wish him all the very best in this new role.

The process for selecting and appointing a new Chair is now underway and more details will be available on our website. If you know someone of the right calibre who should be approached for this role or encouraged to apply then please let me know.



Matthew Reed

Through 2011 we sought to address the significant funding gap in the gene therapy programme. Our focus has been on funding the Wave 1 product through to a phase 2 clinical study to test the efficacy of multiple dosing. Thank you for the huge effort and generosity to close the funding gap during our Gene Therapy Appeal. At the time of writing the great news is that along with the grant commitment from the CF Trust through to the end of 2014, the National Institute for Health Research has made an 'in principle' decision to fund the clinical element of the trial. This is fantastic, and we hope therefore that the phase 2 study will now start this year. Thanks again for all you have done to make this possible. If the trial data is positive we hope that a pharmaceutical company will bring the extra capital and expertise required to fund the next round of trials, development and production so this can be brought to patients as rapidly as possible.

On behalf of all of us at the Trust thanks again for all your support over the last 12 months, and we are looking forward to all we will do together in 2012 to continue our fight against Cystic Fibrosis.

Kind regards,

Matthew

Matthew Reed
Chief Executive

TOBI Podhaler launches in UK

TOBI Podhaler (tobramycin inhalation powder), a fast and simple antibiotic inhaler aimed at reducing the treatment burden in people with CF, has launched in the UK.

The new dry powder form of the established antibiotic tobramycin (TOBI) comes in a hand-held inhaler called the Podhaler. The treatment suppresses chronic *Pseudomonas aeruginosa* lung infection in people with Cystic Fibrosis aged six years and older.

Data show the Podhaler decreases treatment time by 72% compared with nebulised TOBI. This is the first ever antibiotic podhaler and is a development the CF Trust welcomes.

Treatment for G551D mutation a step closer

A new drug to correct the G551D mutation in Cystic Fibrosis has been submitted to the European Medicines Agency (EMA) for approval.

Phase 3 trials of Kalydeco (VX-770), which is designed to be taken as a single tablet twice daily, showed significant improvements in lung function in those with the G551D mutation – around 4% of the UK CF population.

In 48 weeks of testing, Kalydeco improved lung function by 17% and increased weight by an average of 7lb. It works by targeting the basic defect in CF – the faulty CFTR protein. In those with G551D – known as a gating mutation – CFTR is produced but doesn't follow instructions from the cell to allow chloride ions out. Kalydeco works by helping open the gate at the cell surface, allowing chloride ions to flow through.

The EMA has accepted Vertex's request for accelerated assessment, which shortens the review time from 210 days to 150 days. It is anticipated that Kalydeco could be approved for marketing in Europe within six months.

Another treatment from Vertex aimed at those with the more common F508del mutation is in clinical trials. Treatment with VX-809 in combination with Kalydeco has shown small but significant reductions in sweat chloride, which is considered to be a marker of improved CFTR function. The second part of the phase 2 clinical trial commences this year.

For more on Vertex, see our conference review on pages 6–9.



The treatment burden in CF could be reduced by the new wave of treatments

CF Trust publishes new standards of care

In December, the Cystic Fibrosis Trust published an updated version of the Standards of Care consensus document, which provides a detailed overview of the optimal clinical care and treatment of people with Cystic Fibrosis.

The Standards of Care will help to ensure all patients have equal access to the highest level of multidisciplinary specialist care, that is adequately resourced and encompasses the latest evidence-based theories.

The document was produced and reviewed by expert CF clinicians in the UK. Dr Ian Balfour-Lynn, consultant respiratory paediatrician at the Royal Brompton Hospital in London, who together with Dr Su Madge, nurse consultant at the Royal Brompton Hospital, led the revision of the document, said: "This document sets out the recommended clinical care and treatment someone with CF should expect throughout their lives. It will help CF services to assess and improve the care they offer to their patients, and can also be used as the basis for peer review and designation of CF services."

Although primarily aimed at clinicians and those involved in commissioning CF care, the Standards of Care and other CF Trust consensus documents are available to all and will help parents and carers of children with CF, and adults with CF, understand what level of care they should expect.

Available at www.cftrust.org.uk/aboutcf/publications.

Concerted effort to correct the F508del mutation

Genzyme, now part of Sanofi, has announced a new programme with the US CF Foundation to develop small molecule approaches to correct the most commonly occurring mutation in Cystic Fibrosis. Genzyme, which also produces the lipid used in the current gene therapy trials, will be testing millions of molecules using a technique called high throughput screening to see if the F508del mutation can be corrected through a molecular approach.

Professor Stuart Elborn, chair of the CF Trust's Research Advisory Committee, said: "This new programme is very good news for people with CF who have the F508del mutation. It comes on the back of the breakthroughs from Vertex with Kalydeco with the less common gating mutations. We wish Genzyme all the best with their new programme."



The new Standards of Care document will help improve care of CF patients in the UK

Bronchitol approved in Europe

A treatment that reduces mucus build up in the lungs is to be made available to CF patients in Europe. Bronchitol, a dry powder that will be administered using an inhaler, has been approved by the Committee for Medicinal Products for Human Use (CHMP) as an “add-on therapy for adult Cystic Fibrosis patients”.

The CHMP initially rejected pharmaceutical company Pharmaxis’ application to market the product in Europe, however reversed its decision last autumn and Pharmaxis intends to begin marketing the treatment in Europe early this year.

Jo Osmond, Director of Clinical Care & Commissioning for the Cystic Fibrosis Trust, said: “The CHMP’s approval of Bronchitol is very welcome for the CF adult community in Europe. We hope that ongoing trials in the younger CF population will have a similar positive outcome so that children can also enjoy the benefits of this new treatment. The CF Trust is always keen to support development of new treatments which help to improve the quality of life for people living with Cystic Fibrosis.”



Bronchitol will help prevent mucus build up in the lungs

Royal Brompton uncertainty remains

A decision on the closure of children’s cardiac surgery at the Royal Brompton Hospital in London has been delayed after a High Court ruled the consultation exercise ‘unlawful’.

The Brompton provides care to 330 children with Cystic Fibrosis and is Europe’s biggest CF service. The NHS ‘Safe and Sustainable’ review recommended closure of the cardiac surgery unit as a part of a reconfiguration which would see fewer paediatric cardiac surgery units around the UK each with higher patient numbers. However without cardiac surgery other critical services at the Brompton such as the paediatric intensive care unit would be unlikely to remain open, putting at risk other specialist services in the hospital – including Cystic Fibrosis.

Cystic Fibrosis Trust CEO Matthew Reed said: “The Royal Brompton hospital is a leading national and international CF Specialist Centre for adults and children. The proposed withdrawal of children’s cardiac surgery from the Royal Brompton Hospital will have a knock-on effect and we believe that this could make this world-leading children’s CF service unviable.”

The CF Trust supports the campaign to retain the current high quality specialist CF care provided for children at RBH, and therefore to keep all services open. We have written to the commissioners, the Secretary of State for Health, and other organisations involved in this review to ensure that the best possible outcome for families living with CF is achieved. Our primary concern is that safe and appropriate care for all CF patients remains of a high quality and that specialist CF services are fit for purpose.

The consultation will continue in the New Year.



The future of the Brompton’s CF service remains uncertain

EME gives green light to gene therapy



Phase 2 gene therapy trials are due to begin this year

The Efficacy and Mechanism Evaluation (EME) programme has made an “in principle” decision to fund phase 2 of the gene therapy trial.

Thank you to everyone who supported our Gene Therapy Appeal in the latter half of last year. In total over £1.6million was raised. This is a fantastic achievement in such a short time period and the funds raised enabled vital preparations for the trial to continue.

For more on gene therapy, read our update from Professor Eric Alton on page 6. You can also read a Q&A which answers some of the questions we’ve received on the CF Trust website – see www.cftrust.org.uk.

NEWSFLASH

Dr Jim Littlewood accepts Honorary Presidency

In September 2011, Dr Jim Littlewood OBE resigned from his role as Chairman of the Cystic Fibrosis Trust, a post he had held since 2003. We are delighted however that Jim has accepted an invitation to become the Trust’s Honorary President.

Please look out for our tribute to Jim, who has been instrumental in many developments and improvements in CF care and treatment during his long and distinguished career in Cystic Fibrosis, in the April edition of *CF Today*.



Dr Jim Littlewood OBE, Honorary President of the Cystic Fibrosis Trust

“Informative, positive and inspiring...”

Parents Conference 2011



The Cystic Fibrosis Trust Parents Conference was held in Manchester on 19 November 2011. Over 400 parents and carers from across the UK came to the University of Manchester to hear talks about clinical trials and new treatments in the pipeline, the impact of living with CF on families, ways to get involved in fundraising and other ways of supporting the CF Trust, the CF Trust's strategy for the next four years and to close, a talk from a very special guest speaker. As one parent commented, it was “a really informative, positive and inspiring day.”

In this review each of the speakers has summarised the key points of their talks, which we hope will be helpful for those who were unable to attend and as a reminder to those who were present. We are conscious of the fact that many adults with CF would like to be kept up to date as well as parents and we regret that restrictions posed by cross-infection risks mean we cannot open these conferences to all people living with and affected by CF; however, we are looking into ways in which we can make future conferences more inclusive, whether by video link or by recording the footage for later viewing, so that everyone affected by CF has a chance to hear the latest news and developments. Meanwhile we hope those who were not able to attend the November event find this summary useful.

Improving clinical care

Joanne Osmond, Director of Clinical Care and Commissioning at the Cystic Fibrosis Trust, provided an update on what the Cystic Fibrosis Trust is doing to help CF services improve the level of care they can offer their patients, and the challenges in clinical care that lie ahead.

To provide some context, Jo provided some details about CF care in the UK and the changing UK population. There

are 50 Specialist CF Centres in the UK; 25 paediatric and 25 adult. 43 are in England, two are in Northern Ireland, three are in Scotland and two in Wales. In addition there are 120 CF Network/Shared Care Clinics. In total, these Centres and Clinics provide care to over 9,000 children and adults with Cystic Fibrosis.

“The CF Trust is working hard to ensure fair, safe care for everyone with Cystic Fibrosis in the UK.”

Jo outlined the care that someone with CF should expect from their Centre or Clinic as set out in the CF Trust Standards of Care 2011 (see page four for more details); specifically:

- An expert, multidisciplinary team
- Easy access to all aspects of care and treatments

It is encouraging to note that data from the UK CF Registry shows there are now more adults (55%) than children (45%) with CF and the number of adults is increasing year on year. However with these increasing numbers come new challenges, which the Trust is actively planning for.

The CF Trust is working hard to ensure fair, safe care for everyone with Cystic Fibrosis in the UK. Initiatives such as the peer review programme, which has leveraged almost £20million in NHS funding for the services visited (see page 12 for more details) and tools such as the UK CF Registry are making a real difference in ensuring CF services are adequately resourced, and increasing understanding of CF and improving the level of care and treatment available.

Campaigning, lobbying and advocacy are also key to improving clinical care. From 2012, the Department of Health has agreed to work towards implementation of nationally agreed service specification and standards of care which will ensure appropriate and sustainable funding for Cystic Fibrosis. As part of the CF Trust's 2016 strategy, we will also be aiming to increase the number of trained CF professionals, and expanding the capacity of Specialist CF Centres to deal with the increasing numbers of adult patients. In terms of social care and welfare rights, the Trust will be lobbying for equal access to social worker input and campaigning for fair and appropriate welfare rights. And we will be working with pharmaceutical companies and the Department of Health to advise on new treatments in development, ensure pricing is realistic and that eligible patients receive new treatments as soon as they are available, and generally working towards reducing the burden of treatment and improving adherence in Cystic Fibrosis.

In summary, it is encouraging to note that there has been a continued improvement in clinical outcomes and survival over the last decade. But while these are exciting times in terms of the care and treatment of people with Cystic Fibrosis, in terms of increasing survival and patient numbers, national commissioning for CF services due to be implemented and new treatments in the pipeline, these developments present new challenges of their own. The Cystic Fibrosis Trust will be doing all it can to ensure it is prepared to meet these challenges and to meet the needs of the growing CF population in the UK.

Making clinical trials work for you

Professor Alan Smyth is Professor of Child Health at the University of Nottingham. Professor Smyth explained why clinical trials are important, the benefits of being involved in a clinical trial for someone with CF and advised on some options for those interested in taking part in a trial.

Clinical trials are a vital tool to enable CF teams, patients and parents to make informed decisions about CF care. In 2009, 10% of all UK CF patients participated in one or more clinical trial. Taking part in a trial leads to better outcomes irrespective of which of the randomised treatments a patient receives. Recent trials, funded by the CF Trust, such as the TOPIC trial (once daily tobramycin), CF WISE (inhaled steroid stopping trial) and CALICO (oral calorie supplements) have allowed significant improvements in care. In some cases the findings of these trials have allowed standard treatment to be simplified or ineffective treatment to be stopped.

“Clinical trials are a vital tool to enable CF teams, patients and parents to make informed decisions about CF care.”

The Cochrane CF and Genetic Disorders Group (www.cfgd.cochrane.org) is an international group of volunteers (including CF professionals and patients with CF) who summarise and combine the results of clinical trials to help with day-to-day decision making about CF care.

The results are open to all on the Cochrane Library (www.thecochranelibrary.com).

A number of key trials are currently enrolling at UK CF patients. These can be found on the CF Trust website. www.cfftrust.org.uk/research/clinicaltrials/ukclinicaltrials.

In particular, the TORPEDO trial (www.torpedo-cf.org.uk) compares intravenous with oral therapy to eradicate *Pseudomonas* in patients who acquire the germ having been free for at least a year (both groups receive nebulised therapy). We would ask patients who are currently free of *Pseudomonas*, and who develop *Pseudomonas* infection, to give careful consideration to taking part in the TORPEDO trial.

Drugs in the pipeline

Dr Jane Davies is a Reader & Honorary Consultant in Gene Therapy and Paediatric Respiratory Medicine at Imperial College London and Royal Brompton & Harefield NHS Foundation Trust. Dr Davies updated the audience on some key drugs that are in the pipeline and show promise in treating Cystic Fibrosis.

Currently, all therapies for patients with Cystic Fibrosis are targeted at downstream effects rather than the basic defect itself. Examples of this are physiotherapy and drugs which break down mucus, antibiotics and anti-inflammatory agents. A focus further upstream on the lack of normal function of the chloride channel, CFTR, and the resulting dehydration of the airway surface, has become a reality only in the last couple of years.

The lecture focussed on the drugs which were in phase 3 clinical trials, that is, being tested for clinical improvements in large, multicentre studies once the proposed mechanism of action had been confirmed. Two such drugs target the CFTR defect: Ataluren (PTC124) is designed to target class 1 mutations, as a result of which, no full length CFTR protein is produced. Early phase studies produced conflicting data, but seemed promising enough that the company, PTC Therapeutics, has embarked on a phase 3 global study; in this trial, patients were randomised to receive the active drug or placebo, by mouth three times a day for 48 weeks. Data should be available some time in 2012. As many other genetic diseases are caused by class 1 mutations, such a drug may have wider applicability.

Class 3 mutations lead to protein being made which is incapable of opening and allowing chloride molecules out of the cell. Ivacaftor (trade name Kalydeco) (VX-770) is another oral drug, which has recently been reported to lead to significant improvements in lung function, weight, quality of life and respiratory exacerbations in patients with the commonest class 3 mutation, G551D. Vertex has applied for marketing approval in the US and Europe. Sadly, this mutation occurs in only 4-5% of the CF population, but these results are encouraging other groups trying to design drugs for commoner mutations such as deltaF508.

For further information see www.cff.org/research/DrugDevelopmentPipeline.

Gene therapy update

Professor Eric Alton is Professor of Gene Therapy and Respiratory Medicine, National Heart & Lung Institute, Imperial College London and Honorary Consultant Physician, Royal Brompton Hospital, and Coordinator of the UK CF Gene Therapy Consortium. Professor Alton updated delegates on the progress of the gene therapy trial to date and plans for 2012 onwards.

Gene therapy for Cystic Fibrosis is simple in theory; replace a copy of the faulty CF gene with a healthy one. Unfortunately however, the body has evolved to try to get rid of foreign bodies – therefore getting a gene therapy product into the lungs is not as simple as it sounds.

After ten years of research, the UK CF Gene Therapy Consortium is now at a crucial stage in its world-leading trial of gene therapy for Cystic Fibrosis. The wave 1 gene therapy product comprising a lipid (fat) carrier to get the product into the cells, and DNA containing the correct copy of the CF gene, is ready to proceed to a Phase 2 Multi-dose trial. One hundred and thirty patients are already largely recruited for the study at the trial sites in London and Edinburgh. They will each be given the gene therapy product or a placebo, once a month for a year. The start times will be staggered for practical reasons, so the trial will take around 18 months to complete.

“After ten years of research, the UK CF Gene Therapy Consortium is now at a crucial stage in its world-leading trial.”

In preparation for the Multi-dose trial the Consortium completed the ‘Run-in study’ which assessed ~150 CF patients for two years to find a) the optimal tests by which the efficacy of the gene therapy product can be monitored, and b) the optimal patients for this first study. In addition we finished the ‘Pilot study’ in which 36 CF patients received one dose of gene therapy. The study identified the safe dose for the Multi-dose trial, as well as for the first time, showing that in some patients we could replace all the missing CF protein. Finally, and very encouragingly, 11 out of 14 patients we tested showed an improvement in their lung function even after only one dose of gene therapy.

2011 has been a difficult year for the gene therapy programme, due to funding restrictions in part related to the economic climate in the UK. However the outlook for the future of the trial now looks more positive. The Consortium applied for funding from the Efficacy and Mechanism Evaluation (EME) programme, which has made an “in principle” decision to fund the trial subject to further discussions. In addition the Cystic Fibrosis Trust launched an appeal to raise the funds needed to enable preparations for the trial to continue until this grant can start; it is hoped that the trial will proceed in the spring of 2012.

Living Longer, Living Better: Developing the Trust’s new strategy

A charity’s strategy is a bit like a route map. For the Trust, its new strategy, a draft of which was presented to delegates at the Parents Conference by Jo Tanner, Strategy Development Manager, will be its ‘sat nav’ for the coming years taking it from Point A to Point B via the most effective possible route.

As part of her presentation, Jo explained why a strategy is useful for organisations like the Trust. She explained that it defines what the Trust will be working toward over the next four years but, just as importantly, it will also be a yardstick for the CF community, researchers, clinicians and our supporters to measure us by.

Developing the strategy has been a year-long project and has been shaped throughout by the CF community. We have listened to what you want to see from the Trust and what you want us to achieve on your behalf. From discussions at branch events and on the Forum to online surveys and focus groups, you have helped us develop the new strategy.

So what does the strategy look like? Well, over the next four years, the Trust will be focusing on four key areas: Living Longer; Living Better; Becoming Stronger, and; Shouting Louder.

In practice, this means we will be investing in research to extend length of life for people with CF, building on the work that we are already funding. We will develop ways of improving quality of life for people with CF, including advice on education and employment. We will work with our partners to increase capacity in clinical care and research, and we will shout louder to increase awareness and understanding of Cystic Fibrosis.

Implementation of the new strategy will begin in April 2012, and there will be more detail in the next issue of *CF Today*.

Living well with CF in the family

Dr Kate Russo, Clinical Psychologist, has spent the past ten years working with the Belfast Paediatric CF Centre, and is also an academic at Queens University Belfast. She provided an overview of what stress is and how it affects us – many people do not realise that it affects our thoughts, our body; our behaviours and our emotions.

Everyone feels stress, but living with CF in the family introduces so many more challenges, on top of the usual stressors that everybody has to manage in their daily lives.

“Many people do not realise that stress affects our thoughts, our body; our behaviours and our emotions.”

Everyone can manage quite a bit of stress before it becomes overwhelming – some can manage more than others, but nobody can continue with lots of stress occurring over a long

period of time without it having a negative impact. Kate provided a metaphor for this – daily stress is like water dripping into a container (the container is you). Sometimes the drips are slow; sometimes the water gushes out of the tap. When the container is full, it has nowhere else to go and so just overflows. Learning to manage stress is like trying to prevent the water from overflowing. We can actually learn to manage the way stress impacts upon our thoughts, our body, our behaviours and our emotions. Three take-home points were highlighted:

1. Increase the size of your container – that is, try to use the support network that you have around you in order to feel that you are not alone. Let people help; delegate tasks, share the burden, talk to your CF team. No one has to manage completely on their own.
2. Strengthen the container – that is, look after your body and your health, so that you can deal with the challenges that living with CF throws at you. Get enough sleep; eat well; and do some exercise to ensure that you keep yourself healthy. It is tempting when things are really difficult, like during a hospital admission, to not even think about yourself, but it actually helps you manage better if you do take time to look after yourself physically.
3. Reduce the flow – that is, there are some things we can control, and some things that we cannot. So control what you can, but learn to accept what you cannot and let those things go. Worrying about things that you have absolutely no control over is exhausting.

We couldn't do it without you

Nikki Samsa is Senior Regional Fundraising Manager at the Cystic Fibrosis Trust, responsible for managing the team of Regional Fundraising Managers covering the south of the UK. Nikki gave a comprehensive overview of the myriad ways in which parents and families can lend their support to the CF Trust.

I'm Nikki Samsa and I have three children; my daughter was diagnosed with Cystic Fibrosis in August 2000. I work in the Marketing Department supporting fundraising for the CF Trust. Many of our supporters wish to fundraise, raise awareness and campaign for improvements in CF care and research. The CF Trust works on behalf of everyone living with Cystic Fibrosis and we are very grateful for the huge support and honest input many of you provide. Thank you.

We can only do this by working alongside you to raise funds and there are many ways you can help us to do this, whether through direct fundraising, through your networks or by sharing your skills.

Campaigning can be undertaken through contact with MPs, writing letters or working on petitions and increasing support. Campaigns will be well publicised via all Cystic Fibrosis Trust media channels. Our expert patient advisors can be contacted to comment on local and national issues.

If you would like to take part in fundraising, support can be found from Regional Fundraising Managers, the corporate, donations and legacy teams; we can help make fundraising as easy as possible. We would be delighted if you could share your

story with your networks and if you want to help raise public awareness we can help with press releases. **Cystic Fibrosis Week** is the ideal opportunity to get involved, **29 April–5 May 2012**. See *Inspired!* in this issue for more details.

Special guest speaker with CF – Rob Law

The highlight of the day for many was listening to the special guest speaker Rob Law MBE (also known as 'Trunki Daddy!') talking about his highly successful career as an entrepreneur and company director, and living with Cystic Fibrosis.

Rob, creator of the Trunki suitcases familiar to many parents of small children, has won 24 consumer and industry awards (including those granted by Nickelodeon, Practical Pre School, Mother and Baby and Design Week) and was awarded an MBE for 'Services to Business' in the New Year's Honours List 2011.

As Rob explained, he first came up with the concept for a ride-on suitcase in 1997 whilst studying at university, and despite being turned down by the infamous dragons on the BBC's *Dragon's Den*, and suffering a number of other setbacks, still managed to get his idea off the ground and into production.

Trunki products are now distributed to 60 countries worldwide and Rob's company Magmatic currently sells a Trunki every two minutes!

As well as talking about his amazing career to date, Rob also spoke movingly about his own life with Cystic Fibrosis and the personal hurdles he has had to overcome. Many of those present were inspired to hear how Rob has not let CF stand in the way of achieving his goals in life; from being director of his own company, to living and working abroad, to meeting his own considerable health and fitness challenges (this year Rob will take on a triathlon in 2012 and the Iron Man Challenge in 2013!). As one delegate commented: "The talk from Rob was a real inspiration." A great way to end the day.

Details of the CF Trust's conference programme for 2012 will be available shortly. Thank you to everyone who attended the Parents Conference 2011 and also to our speakers for their presentations and summaries for this article.



Rob Law MBE

In the lab with...

Professor Eshwar Mahenthiralingam



Last year, the Cystic Fibrosis Trust awarded a grant of over £45,000 to the research group of Eshwar Mahenthiralingam, Professor of Molecular Microbiology at the University of Cardiff, to study a little-known species of bacteria. *Burkholderia multivorans* – part of the *Burkholderia cepacia* complex – is emerging as the dominant infection-causing species of *Burkholderia* seen in Cystic Fibrosis where it can cause serious problems in the lungs. We caught up with Professor Mahenthiralingam and researcher Dr Andrea Sass at their Cardiff laboratory, where they explained what is known so far about this pathogen, and how research is leading to new methods of prevention and treatment.

I've heard of *Burkholderia cepacia* but not *Burkholderia multivorans* – why is it so significant?

Burkholderia multivorans is one species in the group known as the *Burkholderia cepacia* complex (*Bcc*), which also includes *B. cepacia* and *B. cenocepacia*. Until recently we knew very little about *B. multivorans* – most studies have been focussed on better-known species, particularly *B. cenocepacia*. But in the past couple of years *B. cenocepacia* diagnoses have dropped off – possibly due in part to increasingly strict cross-infection procedures – and *B. multivorans* has emerged as a significant pathogen in terms of the numbers of infected individuals, hence the need for this research.

The *Burkholderia cepacia* complex

The *Burkholderia cepacia* complex (*Bcc*) is a group of several distinct but closely-related species of *Burkholderia cepacia* bacteria. These different species were known as genomovars until researchers found ways to differentiate and name them. To date, there are 17 formally named species in the complex, with *B. cenocepacia* and *B. multivorans* most commonly seen in Cystic Fibrosis.

How common is infection with *B. multivorans*?

It is estimated that between 3–5% of CF patients in the UK are infected with *Burkholderia* species (compared to around 70% who have *Pseudomonas* infection). Until recently it was thought that *B. multivorans* and *B. cenocepacia* each caused around half of all infections. However it now looks as though up to 70% of *Burkholderia* infections are caused by *B. multivorans*. We do not fully understand why infection with *B. multivorans* has increased despite improving infection control practices.

Where is *Burkholderia multivorans* found?

We still don't know a great deal about where *B. multivorans* comes from. However it is thought that it is quite common in the natural environment, possibly even to the same extent as *Pseudomonas aeruginosa*. We know that it is found in river water and in soil – several *Bcc* species interact with plant roots and can have beneficial effects on plant growth by secreting antibiotics that kill fungi.

Who is at risk from *B. multivorans* infection?

It seems that certain people with CF, particularly older individuals and those with poor health, are most vulnerable. Thankfully people with CF do not seem to be as susceptible to infection with *Burkholderia* as they are with *Pseudomonas*. Unfortunately however the smaller number of people with CF that do contract *Burkholderia* infection tend to suffer quite severe effects. Some people with *Bcc* infection though do remain stable for many years.

Why is *Burkholderia* so difficult to eradicate?

Burkholderia (and indeed *Pseudomonas*) infections are so difficult to treat because they are resistant to multiple antibiotics and also oxidative stress – the body's antimicrobial mechanism for getting rid of pathogens it encounters. They have mechanisms

such as pumps in their cells which expel antibiotics or enzymes which destroy administered antibiotics. They are also very good at growing in biofilms – large clumps of bacteria held together with slime – which allows them to resist attack. Treatment therefore usually involves combinations of antibiotics.

It used to be the case that infection by any of the *Burkholderia* species was virtually impossible to eradicate. This is not so much the case any more; however, *Burkholderia* infection can return even if successfully treated initially, and in some cases does become chronic and cause serious damage to the lungs.

What did your research involve?

We want to discover more about how *Burkholderia* bacteria are so resistant. If we can map these pathways, we can identify drugs which may inhibit them and use them as new antibiotics. *Burkholderia cepacia* complex bacteria are quite difficult to study because they have a large DNA content – over eight million bases of DNA. This means they encode over 7,000 genes (humans have 25,000 genes), with hundreds potentially involved in resistant and virulence. So where to do you start to look for pathways you can block?

“We want to discover more about how *Burkholderia* bacteria are so resistant.”

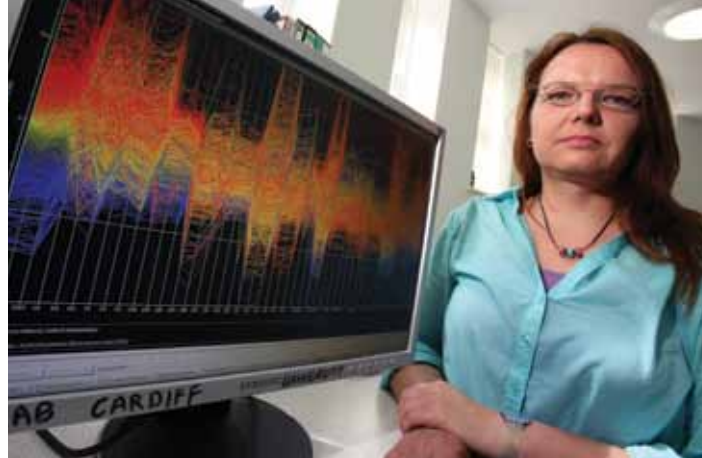
Using a genomic approach – where we could examine all the information encoded by a bacterium – was the obvious way forward. We used a DNA microarray, in which every single gene in a bacterium is patched out in a minute grid on a glass slide. From this we can see when each of the 7,000 genes in *B. multivorans* is switched on or off. By growing the bacteria under conditions which mimic Cystic Fibrosis infection or antibiotic action, we can then discover the genes specific for these disease-specific pathways.

What have been the most significant findings of your research?

Our research has thrown up a few surprises and some new avenues for further study. Using the same microarray approach as for *B. multivorans*, we recently completed a study on *B. cenocepacia*, and pinpointed several key antibiotic resistant genes in the bacteria which can now be targeted to improve success with the current antibiotics we have.

One pathway we were not expecting to discover in antibiotic resistance of *B. cenocepacia* was that it switches on genes required to grow on complex carbohydrates. If we fed the bacteria simple carbohydrates, i.e. glucose, it switched off pathways for degrading complex carbohydrates and at the same time reduced the level of resistance towards antibiotics. This could mean that something as simple as glucose could be used as a pharmaceutical additive to improve antibiotic action against *Burkholderia* infection. Though very speculative at the moment, it would be great to think that in future “a spoonful of sugar” could really help the medicine go down in terms of treating *Burkholderia* infections.

Another finding related to oxygen levels. Within CF sputum O₂ concentration is highly depleted, and research has now shown that it contains very high numbers of anaerobic bacteria



Dr Andrea Sass next to a microarray, which shows when each of the 7,000 genes in *B. multivorans* is switched on or off.

(bacteria which thrive in the absence of oxygen). *Burkholderia* are aerobic bacteria, meaning they need oxygen to thrive, however we were surprised to see that *B. multivorans* was able to thrive in a low oxygen environment as found in sputum. When we mapped the genes involved, we discovered a novel cluster of ‘low oxygen survival’ genes were switched on at a very high level, suggesting they are essential for growth in these conditions. By targeting these genes in the future, we may be able to prevent *B. multivorans* from growing in sputum and other body tissues where oxygen levels are low.

Finally, we discovered an antibiotic which looks to be very potent against *B. multivorans*, which is actually produced by another species – *Burkholderia ambifaria*. We discovered it by screening *Bac* strains recovered from CF patients for antimicrobial activity, in a very similar way as Sir Alexander Fleming did when he discovered penicillin. We have now patented this antibiotic, called Enacyloxin, and are in the early stages of talks with pharmaceutical companies to see whether we can get funding to test if the antibiotic is suitable for clinical trials.

How could this research benefit people with Cystic Fibrosis?

Learning more about *Burkholderia multivorans* gives us ways ahead to develop novel therapies as described above. One year of research has given us and others in the field much more to study, because we have mapped so many interesting gene pathways in this bacterium. We already have a couple of leads which could help us to develop therapeutic strategies based on combining glucose with antibiotics or preventing *Burkholderia* from growing at low oxygen conditions.

Overall, we now have a much better understanding of how *Burkholderia* bacteria resist antibiotics and grow during Cystic Fibrosis infection. This will help us improve treatments and prevent future infections in people with CF with these problematic bacteria.

References

Sass, A., A. Marchbank, E. Tullis, J. J. Lipuma, and E. Mahenthalingam. 2011. Spontaneous and evolutionary changes in the antibiotic resistance of *Burkholderia cenocepacia* observed by global gene expression analysis. *BMC Genomics* 12:373.

This is an Open Access paper that the public can access at <http://www.biomedcentral.com/1471-2164/12/373>

Mahenthalingam, E., L. Song, A. Sass, J. White, C. Wilmot, A. Marchbank, O. Boaisa, J. Paine, D. Knight, and G. L. Challis. 2011. Enacyloxins Are products of an unusual hybrid modular polyketide synthase encoded by a cryptic *Burkholderia ambifaria* Genomic Island. *Chemistry & Biology* 18:665-677. <http://www.cell.com/chemistry-biology/archive>

New and improved peer review of CF services

The formal launch of the new peer review programme took place at the British Thoracic Society in December. Peer review is an important process initiated by the Cystic Fibrosis Trust whereby NHS services dedicated to the provision of CF clinical care are reviewed by fellow CF clinicians.

The project to improve the peer review process has been underway since early 2011 and, after national consultation with clinicians, parents, patients, managers and commissioners, two peer review pilots were launched.

For the first pilot in October we visited the Liverpool Heart and Chest Hospital to review their Adult CF Centre. The visit went extremely well and positive feedback was received. A report of the Liverpool CF Service was produced following the visit to see how the CF Trust can best support any service improvements agreed with the team. We are currently completing the Great Ormond Street Hospital network review for the second pilot project which has peer reviewed four shared care clinics and the specialist centre. The report for this review will be available shortly.

“The visit went extremely well and positive feedback was received.”

The new peer review process aims to use a partnership approach to deliver improved quality in the use of the CF Trust and NHS resources to improve clinical outcomes, to increase the impact of these outcomes on quality and length of life for people with CF, and ensure that the reports generated meet the needs of key stakeholders in driving up standards of care.



The new peer review process will use a partnership approach to drive up standards

Manifesto for better CF care on the Isle of Man

There are a number of families living on the Isle of Man who have children with Cystic Fibrosis and encouragingly there are also a growing number of adult patients residing on the Island, which is testament to the advances in the treatment and care of people with Cystic Fibrosis.

Notwithstanding this, people with CF living on the Island continue to struggle with care issues that may not necessarily be a problem in other parts of the UK. The CF Trust has worked closely with managers at Nobles Hospital on the Island, and the CF clinical team at Liverpool Heart and Chest Hospital who provide their specialist expertise, to address these issues and ensure that the needs of the growing Isle of Man CF population are being met.

To highlight these issues we created an Isle of Man CF Manifesto in preparation for the 2011 Isle of Man elections, which we distributed to parents, patients and of course, the candidates seeking election to the House of Keys.

The CF Trust wrote to all candidates to ask for their commitment to champion CF care on the Isle of Man if they were elected at the end of September 2011 and we have received many letters of support from the candidates, which is hugely encouraging.

The Manifesto called upon candidates to champion the following aims:

1. Every Island resident with CF will have parity of care with those on the mainland
2. Every Island resident with CF will have access to the medication and equipment they need, delivered in a safe, clean environment
3. Every Island resident with CF for whom it is appropriate will have the best possible chance of receiving a life-saving transplant

The third aim of having the best possible chance of receiving a transplant will become ever more crucial in the future of CF care, both on the Island and in the UK. Dr Van Der Merwe, paediatric consultant at Nobles Hospital, is supportive of the Manifesto, saying: “The work of the CF Trust is integral to the success of treatment for patients with CF in the UK. In a genuinely remote and rural location such as ours where the total number of patients with CF is relatively small, where the challenges to delivering specialist care can be significant, and where the health needs of this group of patients are not widely known or understood, the role of the CF Trust in advocating on behalf of patients and supporting clinical teams is critical.”

We will continue to work towards equality of care throughout the UK, including for those resident on the Isle of Man.

Opt-out comes under scrutiny in Wales

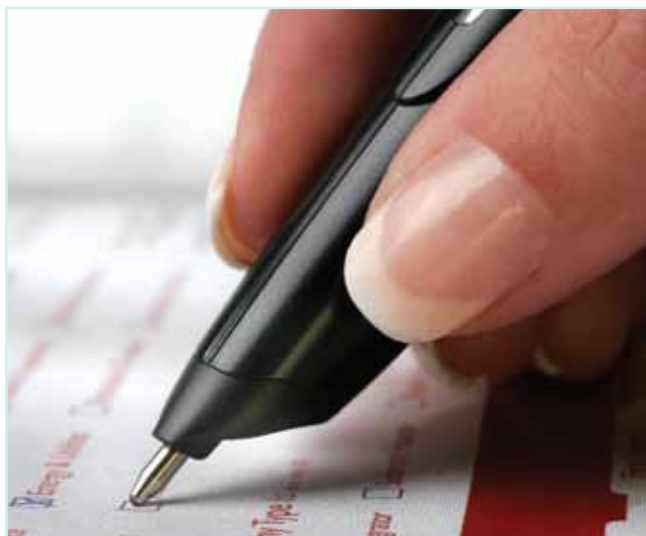


Photo credit: Flickr/Anoto AB

Wales is considering introducing an opt-out system for organ donation

In November 2011, the Welsh Government published the White Paper 'Proposals for Legislation on Organ and Tissue Donation', in which it set out plans to introduce a 'soft' opt-out system for organ donation in the country.

The opt-out system means that the use of organs and tissues is permissible unless the deceased objected during his or her lifetime, and procedures would be in place for individuals to opt-out of the system. However unlike a hard opt-out system where only the wishes of the deceased are considered, bereaved relatives will be involved in the decision making process and their wishes taken into consideration in a soft system.

“Around 300 people at any one time are on the active waiting list for a transplant in the UK.”

The Paper states: “The Welsh Government’s aim is to increase the number of organs available for transplantation after death, in order to improve the health and quality of life for people who need a transplant. We will do this through implementing our manifesto commitment to bring forward an Assembly Bill to introduce an opt-out system.”

However a number of high-profile Welsh figures have raised questions over the legality of the proposed move.

Around 300 people at any one time are on the active waiting list for a transplant in the UK. In Wales, one person dies each week whilst waiting for organs. The Paper has been under a consultation period since November and a Bill will be brought to the National Assembly this year.

For more information, see <http://wales.gov.uk/docs/dhss/consultation/111107orgdonwpen.pdf>.

Campaigning against cuts to CF services

News headlines have recently been dominated by stories of ‘efficiency savings’ and financial pressures on the NHS. There has also been extensive coverage of the Government’s proposals for reforming the health service and plenty of people and organisations campaigning against the parliamentary legislation. Although the financial pressures and the NHS reorganisation are not directly linked they are both having a significant impact on how services are delivered and this impact will continue to be felt in years to come. You may be wondering how all these changes will affect the service that you or your family receive. You may also have noticed problems with your local service yourself.

“We are receiving reports of issues affecting CF services.”

The CF Trust has been watching these national developments closely and, since the launch of the ‘Don’t turn back the clock’ campaign, has continued to monitor services to look for trends that indicate real-time cuts to CF services. Across the country, we are still receiving reports of specialist nurses having to take on general ward work away from their CF work, physiotherapy posts being shrunk so physiotherapists have less time to spend with patients, physiotherapy posts being left vacant when someone leaves and no cover for maternity leave for physiotherapists, amongst many other issues.

Many thanks to those of you that have taken part in the campaign so far by contacting your local MP to ask them to sign parliamentary petition EDM 2033. At the time of going to press the petition had 58 signatures. If you haven’t taken part, there is still time. To add your name, please visit www.cftrust.org.uk/aboutus/what_we_do/campaigns/nhscuts.



Physiotherapy services are among those which may be compromised by NHS cuts

Why I'm leaving a legacy to the CF Trust

Rose is a CF grandmother and in May last year she updated her will as part of the CF Week will promotion scheme. Rose tells us why she has made the decision to leave a legacy to the CF Trust in her will.

"There are several reasons why I came to the conclusion that as a CF grandparent I must include the CF Trust in my will.

Firstly, Cystic Fibrosis is very much a family affair. My granddaughter, aged 11, has inherited Cystic Fibrosis partly through my family and for this reason I feel it is a family responsibility to help share the burden in some way. My mother died four years ago at the age of 95 leaving a small legacy and I felt that having reluctantly crept into my late 60s I should reciprocate. Before putting pen to paper, I discussed the details with my children who were both very happy for me to leave a legacy to the Trust. Whilst the CF Week promotion was an additional incentive, changing my will was on the list of 'things to do'.

Secondly, whilst raising funds for gene therapy trials has, for many, become the foremost issue, there will always be a need for funding of the Trust's day to day activities and I believe that legacies could provide a steady stream of valuable income in this respect. My legacy on its own won't amount to much but collectively if everyone directly involved leaves something, however small, it will make a difference and after all... every little helps.

Finally, the tax rules regarding legacies to charities will change this year, as announced in the 2011 budget. Where 10% or more of a net estate is left to charity, the rate of Inheritance Tax will be reduced to 36% from 6 April 2012. This won't make a huge difference to my beneficiaries as I don't have a vast estate but it might be an additional encouragement for those who are thinking about leaving a legacy. Better to leave to charity than to the tax man."

To find out more about including a gift to the CF Trust in your will or to request a copy of our legacy booklet (pictured), please contact Sue Whitehead at whitehead@cftrust.org.uk or telephone 020 8290 8051.



CF CYSTIC FIBROSIS TRUST

Rosie's
LASTING LEGACY

Supporting the Cystic Fibrosis Trust through a gift in your will

Ask the expert under review

Our Ask the Expert service is currently under review. You can still view an archive of past questions on the CF Trust website at www.cftrust.org.uk/aboutcf/asktheexpert/archivequestion but general queries about CF should be sent to enquiries@cftrust.org.uk until further notice. You can also contact our confidential helpline for advice, support and information on any aspect of Cystic Fibrosis on **0300 373 1000**.



An archive of Ask the Expert questions is available on the CF Trust website

Congratulations Jennifer and David

Pictured is CF Trust Expert Patient Adviser Jennifer Wederell (née Grannell) with husband David who she married in September 2011. Jennifer received a lung transplant in April last year after over two years on the waiting list. Huge congratulations to Jennifer and David from all at the Cystic Fibrosis Trust.



Jennifer and David Wederell on their wedding day

Big Yellow discounts for CF Today readers!

Big Yellow is supporting the Cystic Fibrosis Trust and offering readers of *CF Today* an extra 10% off their storage charges plus 15% off any packaging materials upon production of this article. For more information please call Scott at **Big Yellow** on **020 8313 0854** for details of your local store.



TORPEDO-CF trial seeking participants

The Cystic Fibrosis Trust supports research that has the potential to improve and lengthen the lives of people with Cystic Fibrosis.

TORPEDO-CF is a clinical trial looking at the best way to eradicate *Pseudomonas* infection, in its early stages, comparing intravenous with oral antibiotic treatment. TORPEDO-CF is already open in 35 CF centres in the UK, with many more to follow over the coming months. If you or your child has a new *Pseudomonas* infection, diagnosed in your CF clinic, please consider asking your doctor about the option of taking part in TORPEDO-CF.



Clinical trials such as TORPEDO-CF are helping to improve the treatments available for children and adults with CF

Patients need to have been free from *Pseudomonas aeruginosa* for the preceding 12 months and the trial treatment must start within 21 days of the microbiology report of a new infection. Ages from 28 days upwards are eligible.

If you would like to know more about TORPEDO-CF here are some ways you can get more information:

- Visit the TORPEDO-CF website: www.torpedo-cf.org.uk
- There are more details and inclusion criteria at www.controlled-trials.com/ISRCTN02734162/
- Contact the Clinical Trials Unit in Liverpool on 0151 282 4714 or torpedo@liverpool.ac.uk.

Medical Conference 2012

The Cystic Fibrosis Trust Medical Conference is taking place on **Thursday 8 March** at Aston Business School Conference Centre, Aston University, Birmingham.

This one day event is open to those involved in the clinical care of people with Cystic Fibrosis in the UK, including hospital managers and ward staff.

The theme of this year's Conference is Improving Standards in the New Healthcare Environment. The programme includes plenary sessions on newborn screening and planning for the growing adult CF population, and an update on current research. Delegates can also attend two of the following workshops:

- How to develop your CF website
- Port CF 4 years on – Review and Consolidation: A hands-on workshop
- Engaging patients and parents
- CF care issues in ethnic communities in the UK
- Developing and strengthening multidisciplinary paediatric CF Networks
- New NHS UK commissioning process

Parents / guardians: would you like to take part in a UK-wide research study?

Who: Parents or guardians of children and young people aged less than 18 years with Cystic Fibrosis in the UK.

What: Online questionnaire survey.

Why: To find out more about parent / guardian beliefs about treatments used in Cystic Fibrosis and how children and young people use treatments on a daily basis.

When: If you would like to complete the survey please do so by 31 March 2012.

How: By typing or copying and pasting this link <http://edu.surveymzmo.com/s3/562650/cf> into your computer browser or by visiting the CF Trust Facebook page or web forum and clicking on the link.

This study is being conducted by the University of Belfast.



Photo credit: Flickr/CTSIatUCSF

The Conference will start at 10.15am (registration from 9.30 am) and finish by 4.30pm. A non-refundable registration fee of £24 per delegate (£20 + VAT) will be charged.

For further details and to book online visit www.cftrust.org.uk/aboutus/what_we_do/conferences/medconf2012.



The Cystic Fibrosis Trust Medical Conference

Happy New Year and welcome to the January edition of *Inspired!* which will now be included in *CF Today* rather than published separately. A lot of the stories that used to be included in *Inspired!* can now be found online at www.cftrust.org.uk/help including many of the fantastic activities of our supporters and fundraisers. But in these pages you will still be able to read about great events and campaigns taking place across the UK and other ways you can support the CF Trust. We hope you'll find something to inspire you!

For more fundraising news, events and stories visit www.cftrust.org.uk/help.

CF Week 2012

It seems like CF Week 2011 has only just finished, but CF Week 2012 is fast approaching and we hope lots of you will get involved and help make this year even bigger and better! If you haven't already made a note of the date then please add it to your diaries now: **29 April–5 May 2012!** Our special CF Week website www.cfweek.org.uk will be live soon with details of all the events and other goings-on that week. We'll be raising awareness of the difficulties posed by cross-infection and have some great case studies lined up. If you'd like to get involved in **CF Week**, or have any ideas or suggestions, please email cfweek@cftrust.org.uk – we'd love to hear from you.



Walk

Will you take Great Strides for CF this year?

Great Strides 65 is our brand new event which invites teams of four to six people to take part in a 65km sponsored walk from Newlands Corner near Guildford to Shoreham by Sea along the Downs Link on **Saturday 19 May 2012**.

The route will take you to a maximum height of 133 metres with a total ascent of just over 500 metres in under 16 hours.

This is a team event costing £50 per team with a minimum sponsorship of £1,000 per team. Walkers must be 16 years or older on the day of the event. Each team will arrange to be supported by its own vehicle, which will meet up with their team at regular

checkpoints along the route to provide food, water and spare clothes.

Online entry is now open – please visit www.greatstrides65.org.uk to register your team or find out more.

For something slightly shorter, the sixth annual **Great Strides Birmingham Botanical Garden Walk** is set to take place on **Sunday 27 May 2012**. Join us for a 9km walk which will take you through a children's discovery garden, a rock garden and pool, a woodland walk and a sensory garden.

As if that's not enough, we're giving you the chance to walk on water! Why not get our CF Week ball rolling by taking part in our popular walk over the **Severn Bridge** on **Sunday 29 April 2012**? Walkers can choose whether to start on the English side of the Bridge at Aust or the



Welsh side of the Bridge at Chepstow. It's an 8km walk in total – or you can just walk to the middle and back. Either way you'll be in for a treat because the views are spectacular! You can see all the way from the islands of Steepholm and Flatholm to the Wye Valley Area of Outstanding Natural Beauty. Don't forget your cameras!

Finally our increasingly popular **Ashridge Forest Bluebell Walk** will be taking place on **29 April**. Come and join us for this family

friendly 10km walk through the Bluebell woods in the historic Ashridge Forest. Well behaved dogs are welcome but please bring your lead as some of the route crosses farmers fields. For details of all Great Strides walks and entry details visit www.cftrust.org.uk/help/nationalcampaigns/greatstrides.

To find out about events in your region visit www.cftrust.org.uk/help/whatsoninyourarea

Run

Tata Steel Cardiff Bay 5, Monday 7 May

Ten years ago we organised our first 5-mile run around Cardiff Bay. In that decade the Bay has been completely transformed into a vibrant hub for locals and visitors alike to shop, visit the many attractions and enjoy the beautiful surroundings.

Our 5-mile route takes you over the Barrage with the sea kept inline on one side, whilst the Rivers Taff and Ely create a massive fresh water lake on the other.

The 2k Fun Run is open to anyone of every age to come on down and join the fun.

With medals to all finishers, a prize fund and chip timing in

the 5-mile event, spot prizes and great facilities, it's a perfect way to start your May Day Bank Holiday.

Great City Runs

To burn off those extra festive pounds and keep that New Years resolution, sign up to a 2012 Great Run! These expertly-organised events are open to elite athletes or novices; the energy and enthusiasm from fellow runners and crowds lining the route will carry you across the finish line.

The **Great Manchester Run** 10k kicks off the series on **20 May** and the 13.1 miles of the **Great North Run** takes over Newcastle upon Tyne come **16 September**. The **Great Birmingham Run** half marathon route leads you through this city



Photo credit: I H Dixon

centre on **21 October** and the 10-mile nautical, flat route of the **Great South Run** finishes off the year in style in Portsmouth on **28 October**.

Make a marathon effort this spring!

Burn rubber in the treads of motor racing legends at the **Silverstone Half Marathon** on **11 March** or run arms aloft around the Madejski Stadium on **1 April** as you finish the **Reading Half** or how about entering the fastest growing run in the UK – the **Brighton Marathon** on **15 April**.

The **Virgin London Marathon** takes place on **22 April**; if you have a place, please use it to run with us! The **2013 Virgin London Marathon** ballot will open on **30 April** so put the date in your diary now or you may miss the boat.

The **Edinburgh Marathon, Half and 10k** on **27 May** round off these spring challenges. Voted the 3rd

best city marathon in the world, above London, join the tartan army and see what all the fuss is about.

Other runs for your diary

Bath Half Marathon, 11 March – Golden Bond places available!
www.cftrust.org.uk/help/events/bath

Yorkshire 10k, Newby Hall, 20 May
www.cftrust.org.uk/help/events/y10k2012

Dulwich Park Fun Run (London), 26 May – 10k, 5k or 1k route
www.cftrust.org.uk/help/events/dulwich

STOP PRESS

Murrayfield Abseil, Sunday 15 April

Take on this free-air abseil with Glasgow Warriors! – www.cftrust.org.uk for details



Cycle

Callander to Balquidder Cycle

Come and join us on **19 May** for our annual family friendly level cycle ride around Loch Lubnaig. Starting at 10.30am we will be stopping in Strathyre for refreshments then carrying on back to Callander; a total of 28 miles. Alternatively if you prefer something a little shorter you can turn around at Strathyre (15 miles) or for a longer cycle you can carry on to Killin (50 miles). For more details see www.cftrust.org.uk/help/events/callanderQR.

Nightrider

Embark on an exciting 100km moonlit bike ride through London. Starting at Crystal Palace or Alexandra Palace 11pm on **9 June**, the route will be fully sign-posted so you can cycle at your own pace taking a short rest at each of the four snack stops.

Along the way you will take in some of London's most famous streets and landmarks including Smithfield Market, Arsenal Football Club, Brick Lane, Canary Wharf, Hampstead Heath, London Zoo, Regent's Park, Covent Garden, Big Ben, Buckingham Palace, Downing Street and many more. The ride will finish where you started in time for some well-earned breakfast.

There are two options for entry:-

Charity Place Participant:
Pay £39 registration fee and commit to raise £350 sponsorship money. Charity places for this event are limited.

Own Place Participant:
Pay the £99 event cost then raise sponsorship – this fee will be broken down into a £39 registration fee and a final payment of £60 due eight weeks before the event.



STOP PRESS

Reach for the skies

Join **Team 100** for a mass skydive on **28–29 April** at Langar, Nottinghamshire. We aim to have 100 people taking part in a tandem skydive for **CF Week 2012**. Contact **Stephanie Henderson-Barrett** on 0300 373 1026 or shenderson-barrett@cftrust.org.uk.



Unless otherwise stated, for more details or to register for any of the events listed visit www.cftrust.org.uk/help/events or contact us on 0300 373 1100 or events@cftrust.org.uk



Swim

Splash for cash!

Open-water swims are perfect for novice or serious swimmers – why not dive in to the Royal Victoria Dock, London on **26 May** or the enter the **Great North Swim** in the picture perfect Lake Windermere on **22–24 June**? Swims are also taking place in Strathclyde Country Park,

Alton Water Park Ipswich and Salford Quays.

We are also thrilled to have our own Grasmere Channel Swim too, taking place on **6–7 July** including 1km and 2km swims with B&Bs and a campsite nearby come on in and help make a huge splash, raise a lot of cash and have good clean fun!



STOP PRESS Humber Bridge Bounce

Join us to kick- (or rather bounce!)-start CF Week on **29 April** by bouncing a mile across the Humber Bridge

– the world's third largest suspension bridge! With the help of sponsors GGP Consult in Hull, we're aiming to raise £10,000 on the day. Contact Regional Fundraising Manager **Christina Gabbittas** on **0300 373 1024** or cgabbittas@cftrust.org.uk.



Raise funds by recycling

There are lots of different and easy ways to support us through recycling requiring very little effort and at no expense to you too.

You will find enclosed in this publication an envelope to forward your used printer cartridges and old mobile phones. The CF Trust receives up to £1 per ink cartridge successfully recycled and reused and up to £150 for your old phone too.

Plus there's an opportunity to enter into the fantastic free prize draw at www.eachonecounts.co.uk.

Here are some other items you can also easily recycle:

Jewellery (gold, silver, costume jewellery, watches – even if broken)

CDs, DVDs and games

Printer cartridges and mobile phones.

Plus our textile banks and door to door collections may well be in your area soon

So time for a full 'spring clean' to help support the Cystic Fibrosis Trust. You can be assured that all your recycling efforts translate into vital funds.

You may also wish to consider having a recycling box perhaps at your work, school, club or maybe gym? We will happily co-ordinate delivery and collection.

If you would like any further bags or more details of any of our recycling schemes please contact the **Corporate Team** on **020 8290 8043/6** or email company@cftrust.org.uk.



Founded in 1964, the Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis.

Our objectives are to:

- Fund medical and scientific research to develop a cure and provide effective treatments for Cystic Fibrosis.
- Ensure appropriate clinical care for those with Cystic Fibrosis.
- Provide information, advice, support and, where appropriate, financial assistance to anyone affected by Cystic Fibrosis.

Cystic Fibrosis Trust

11 London Road, Bromley, Kent BR1 1BY

Tel: 020 8464 7211 Fax: 020 8313 0472

www.cftrust.org.uk

You can view CF Today online and download our extensive range of factsheets and booklets providing further information about Cystic Fibrosis at www.cftrust.org.uk/aboutcf/publications



Cystic Fibrosis Trust Helplines

Our Support Service has three Helplines offering the following services:

For information and advice about benefits and how to apply for them.



Benefits Advice
0300 373 1010

For a *confidential* service that enables anyone to obtain information, advice and support on any aspect of Cystic Fibrosis.



CF Helpline
0300 373 1000

For information and advice on how to access small grants from the Cystic Fibrosis Trust and other organisations.



Welfare Grants
0300 373 1020

Our Helplines operate from 9am – 5pm weekdays. An answer machine is available during busy periods and outside these hours.

You can also access our website www.cftrust.org.uk to find out more about CF Trust Helplines and to download various forms and factsheets relating to these services.