MDS Newsletter

MDS UK Patient Support Group

Supporting Patients with Bone Marrow Failure

VOLUME 2

ISSUE 2 - APRIL 2012

Latest news from ASH 2011

For the second edition of our newsletter, we start with a report about ASH 2011 – the Annual Congress in the USA. The American Society of Hematology (ASH) is the world's largest professional society concerned with the causes and treatments of blood disorders. The mission of the Society is to further the understanding, diagnosis, treatment, and prevention of disorders affecting the blood, bone marrow, and the immunologic, haemostatic and vascular systems, by promoting research, clinical care, education, training, and advocacy in haematology. ASH attracts about 20,000 attendees every year (physicians, scientists, laboratory staff, pharmaceutical representatives). Half of them are international visitors. There the latest research results are presented and it is an opportunity for attendees to discuss and explain their work.

Dr Austin Kulasekararaj, Haematologist Consultant at King's College Hospital, London kindly agreed to summarise the highlights of ASH 2011 for us. He covered progress with existing therapies, promising trial data, new molecular mutations, as well as the revised IPSS (International Prognostic Scoring System).

MDS therapies

Combination therapy approaches both in low and high risk MDS was the focus of many presentations, building on the remarkable results obtained with 5-azacitidine and lenalidomide monotherapy.

A multicentre trial using combination therapy of 5-azacitidine (75 mg/m2 subcutaneously on days 1-5) plus lenalidomide (10 mg daily orally for 21 days out of 28 day cycle) in 'high risk' MDS patients showed response rate of 72%, with complete response seen in 42% and a median response duration of 16 months. The therapy was well tolerated with minimal toxicities (fever and cardiac) and significantly high response rates.

An interesting study from MD Anderson Cancer Centre assessed combination therapy of 5-azacitidine with vorinostat, a histone deactylase (HDAC) inhibitor in MDS and AML patients who were ineligible for another clinical trial or had liver or renal functions or had poor performance status. This combination was well tolerated in this 'poor risk group' of MDS patients with complete response rate of 26%.

Several other combination therapies of were studied in Phase 1 and Phase 2 trials, showing good tolerability and clinical activity

- Panabinostat (HDAC inhibitor) plus 5-azacitidine,
- Belinostat (HDAC inhibitor) and bortezomib (Velcade, proteosomal inhibitor)
- Ezatiostat hydrochloride (Telintra) and lenalidomide (Revlimid)

Interestingly, studies using oral 5-azacitidine show good tolerability, with no drug accumulation, and promising clinical responses were observed, although these data are preliminary but the encouraging results show promise for oral azacitidine. A Phase 1 study also evaluated the safety of oral decitabine (Dacogen) in MDS patients and found to have a similar safety profile to intravenous decitabine.

A retrospective pooled analysis of MDS patients treated with lenalidomide (Revlimid) did not show a clear evidence that lenalidomide is associated with an increased risk of secondary cancers (second primary malignancies, SPMs) in lower risk MDS patients and the rate of development of SPMs was what would be expected for this age group when compared with US epidemiological database (SEER database). In another retrospective analysis of RBC transfusion-dependent patients with lower-risk MDS and del 5q, lenalidomide treatment was not associated with a higher risk of AML progression but led to a survival benefit. Romiplostim (thrombopoietin agonists) showed an

improvement in platelet count in one third of low risk MDS patients enrolled in a Phase 2 extension study, but unfortunately the trial was terminated early in view of transient increase in blast count which resolved when the drug was discontinued.

A few other selected studies presented included

- Home administration of 5-azacitidine (Vidaza) in France – showed feasibility, higher level of patient satisfaction and safety of administration. The home administration was not associated with increased side-effects or hospitalisation.
- Romiplostim (thrombopoietin agonists) to increase platelet counts after stem cell transplant.
- Role of azacitidine in Lenalidomide failure in del 5q MDS patients.
- Low dose clofarabine (5 mg/m2 vs. 7.5 mg/m2,dose finding study)-standard dose(D1 to D5) or alternate dosing (D1,D3,D5,D8 and D10), in patients failing 5-azacitidine therapy

The increased understanding of the molecular biology in MDS will help in future development of targeted therapies as the currently available therapies, although clinically effective, do not have a well-defined mechanism of action.

MDS pathogenesis

2011 has been an exciting year with the discovery of new class of molecular mutations in patients with myeloid neoplasms. The discovery of recurrent somatic mutations in RNA splicing factors in patients with MDS, especially in those with ring sideroblasts was highlighted in several presentations including the presidential symposium. Although the functional consequences of the altered splicing factors are being elucidated, this is a major breakthrough in the understanding of the pathogenesis of MDS with ring sideroblasts.

SF3B1 mutations are detected in 80-85% of patients with MDS associated with ring sideroblasts and is also present in 30% of patients with MDS overall. The mutations of the RNA splicing factors are the most common MDS-associated mutations yet to be described and these were detected as a result of whole genome/exome sequencing projects undertaken by several groups. Although SF3B1 mutations conferred a better prognosis, the prognostic impact of the other splicing factor mutations is not clear.

Prognostic models

IPSS-R

Recently, the provisional Revised International Prognostic Scoring System (IPSS-R) has been formulated for assessing the prognosis of primary MDS patients by the International working group for prognosis in MDS (IWG-PM). In this new system, as discussed by Dr.Greenberg in the MDS foundation symposium, cytogenetics remains the key stratification parameter and karyotypic abnormalities are classified into five prognostic subgroups with inclusion of more uncommon cytogenetic subsets. The depth of cytopenias was also considered and the information was obtained from 7012 patients who had not received any disease altering therapy. The IPSS-R divided MDS patients into 5 prognostic groups, with median overall survival of 8.7 years for very low risk group versus 0.8 years for the very high risk group. The value of incorporating of molecular abnormalities into the prognostic scoring systems was also debated and various groups also validated the impact of mutations on different prognostic scoring systems in MDS.

We are definitely achieving a better understanding of the mutations associated with MDS and refining risk model, but it is difficult to know just how any of these might translate into new therapies.

We thank Austin for his very informative contribution to our newsletter.

Calling all MDS Patients and families

Your support needed for exciting, new nationwide study on MDS treatment

This year we will start an important nationwide survey to assess the needs for patient support in the UK. This will cover four main aspects of MDS treatment (Demographics, Diagnosis, Resources of clinical support and Resources offered by us the Patient Group)

This survey will help to understand better what MDS patients and their families require, what areas need to be improved and how, what services are really useful and appreciated - and absolutely need to be maintained. An anonymised summary of this information will be published and will be shared amongst relevant parties. This will provide further evidence to push for the necessary changes in MDS support. Please help us by filling out the survey as soon as you receive it in the post or if you pick up a copy in the hospital waiting room.

This project will span over three years – 2012 to 2014. We aim to interview 450 patients in total. We have funding for the first year so far. In addition to completing the survey, please also assist by helping us fundraise to make sure we can complete this important project.

Introducing our new patrons

We are delighted that two eminent people have recently agreed to become patrons– Professor Ghulam Mufti, Professor of Haematology at King's College Hospital in London – and Tariq Ahmad, The Lord Ahmad of Wimbledon.

Professor Ghulam Mufti

Professor Mufti – whom many of you already know as his patients – is an internationally renowned specialist in MDS. He is the head of the haematology department at King's College Hospital in London. He commenced his training in haematology at Radcliffe Infirmary, Oxford, and Hammersmith Hospital Royal Postgraduate Medical School. Because of his interest in pre-leukaemic states, in 1981 the Leukaemia Research Fund awarded him a fellowship in Bournemouth, Southampton & Royal Postgraduate Medical School. He was appointed as senior lecturer in haematological medicine and consultant haematologist in May 1985.

He has extensive clinical and research expertise in myelodysplastic syndromes (MDS), leukaemias, and lymphomas. The Unit at King's is one of the leading centres for Bone Marrow Transplantation in MDS. He heads the research groups and works with a team of nine other professors who are experts in various medical fields including gene therapy, stem cell biology, bone marrow transplants, plasma cell dyscrasias and immunotherapy of myeloid malignancies, in particular MDS. Professor Mufti also leads 86 researchers who focus on treating leukaemia. He has published over 400 original papers and chapters in scientific journals and textbooks on leukaemias. He devised the prognostic score (Bournemouth score for MDS) and contributed to the IPSS scoring system. He was a member of the working group that produced national and international guidelines on the treatment and prognosis of MDS. He is a founding member of the Board of the International Myelodysplastic Foundation of which his Department at King's College Hospital is a recognised Centre of Excellence.

Prof Mufti adds: "The MDS Newsletter is an emotional milestone for me, for MDS as a disease has at last come to the forefront of scientific and translational research. I am confident that the research will translate into real therapeutic benefit to all our MDS sufferers not just in the UK but worldwide."

Lord Tariq Ahmad

Tariq Ahmad's career has been in the City of London in corporate banking and marketing and currently serves as Marketing and Strategy Director at a leading commodity and financial futures and options firm, Sucden Financial, where he has been a member of executive team since 2004.

A business graduate, he has extensive experience of financial services and the City spanning over almost 20 years. Joining NatWest in 1991, he spent almost 10 years with the Group in corporate banking and strategy roles before joining the US funds and investment house, Alliance Bernstein.

Lord Ahmad, was Vice Chairman of the Conservative Party (2008-2010), has been active in local government in London, contested Croydon North in 2005 and became a Conservative Life Peer in the House of Lords in 2011. He is a Member of the Institute of Directors and is greatly involved in charity work.

We are very grateful to both for taking on this important role.

Thanks to our volunteers

We'd like to thank all our fantastic volunteers for all their assistance to the MDS UK Patient Support Group – all our committee members, all the patients, family members, physicians and nurses who help out all year round and without whom this group would not exist.

Very special thanks to Rodney Taylor, Janet Hayden, Phyllis Paterson, Geke Ong.

Introduction

Rodney Taylor & Sophie Wintrich

Welcome to this newsletter of the MDS UK Patient Support Group. Our thanks are due to Chris Dugmore and Phyllis Patterson for all their editorial input. There is an enormous amount of work that goes into putting together a newsletter like this. Do not underestimate the effort it takes to chase authors, acquire photographs, check facts and keep the whole thing up to the minute.

Since the last newsletter much has happened in the MDS UK Patient Support Group. Very sadly, as you will read in this newsletter, our Chairman, David Hall passed away. Rodney, as deputy chairman, has therefore been voted in by the committee to take on the chairmanship of MDS UK.

Rodney Taylor himself has MDS, and is currently on his 34th cycle of azacitidine. He is being considered for bone marrow transplantation. Rodney is also a consultant physician, recently retired from clinical medicine. Much of his practice was in the NHS but he also spent time as a doctor in the Royal Navy. His career has included both clinical and basic science research, teaching, medical administration, and he worked briefly in the pharmaceutical industry. He has a great interest in bioethics and still works as a Visiting Professor of Bioethics and tutor in Medical Ethics and Law.

For legal reasons we have become a company limited by guarantee which meant that we had to change our registration with the Charity Commissioners. We now have three Board Directors (Rodney Taylor, our treasurer Sharon Berger and Sophie as Chief Executive).

We have taken on a second member of permanent staff. Alice Murphy joined us in February 2012 to assist on our new nationwide Patient Survey Project: “Assessment for Support in MDS”. Alice will also help Sophie to run the office, manage patient forum events and distribute information to patients. We welcome her most warmly. Our presentations to NICE, along with other stakeholders, through five hearings and an appeal, resulted, after two years, in a recommendation for azacitidine to be prescribed for patients with high risk MDS, CMML (Chronic Myelomonocytic Leukaemia) and AML (Acute Myeloid Leukaemia).

Our website has been improved enormously making it more user-friendly, much easier to update, more informative, and the Online Patient Forum is buzzing.

The Support Group is here for you whether you are a patient, a family member, a carer or affected by MDS in any way. Please continue to let us know what you want and need so that we can continue to improve all that we offer.

Rodney Taylor
Chairman

Sophie Wintrich
Chief Executive

From the Editor

I do hope you have enjoyed reading this newsletter. This is the first one I have ever edited and it has been has been quite a “journey” - as they say!

Chris Dugmore (right) and daughter, Ottilie, at the 2010 MDS London Forum

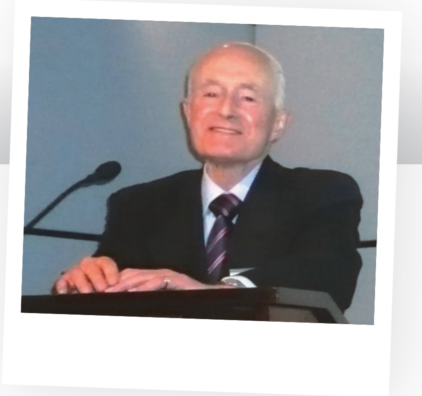
We would appreciate your views on the content, layout and features in this newsletter as well as any ideas for future issues. Please send your responses to me through Sophie Wintrich

Coming up in the next issue:

- Managing fatigue (also available on the website)
- Patient experiences of stem cell transplant
- A patient’s personal view on coping with cancer
- Update following the European Haematology Congress in Amsterdam June 2012
- More news of new regional groups throughout the country

Chris Dugmore
MDS Patient

David Hall 1930-2011



David Hall, chairman of the MDS UK Patient Support Group for three years, died on Thursday 6th October 2011 at the age of 81. In the course of treatment for prostate cancer he had developed MDS. David was vigorous in fighting both the effects of cancer, its gruelling treatment and his MDS for many years and was keen to help others in a similar position. His early career was as a pilot in the Fleet Air Arm during the Korean War. Subsequently he worked in electronics, fibre-optics, video processing and many high-technology areas, initially as a sales engineer, rising to sales manager and eventually managing director. He was on the board of many companies. He was a great believer in people and keen to help their professional and personal development. He retired from this in 1986 but continued to be active in many fields.

In 2008 he had the honour of being appointed an Honorary Fellow of the Society of Cable Telecommunications Engineers in recognition of his contribution to that society. He was described by a colleague as the “perfect English gentleman ... always charming ... elegantly dressed and free with his professional help and advice”.

One of his last wishes was to be driven in his immaculate, spotless Jaguar car to the coast to have oysters and champagne – an ambition which he achieved with great pleasure. We miss his wisdom, generosity and experience greatly.

David was the main driver behind the re-birth of the MDS UK Patient Support Group, following a chance encounter at the EORA international conference on Rare Anaemias in Paris in 2008, where he struck up a conversation with a representative from the pharmaceutical company Novartis Oncology (Elodie Miranda) and Sophie (in her then role of European Patient Liaison for the MDS Foundation). The three of them quickly realised the need and opportunity to set up a formal nationwide support group for MDS in the UK.

Very soon after, another pharma company, Celgene was also offering assistance (via the very knowledgeable Karen Browne). Several meetings later, the leaflet and a website were produced. This UK group followed the tried and tested model started by the MDS Foundation some 15 years ago. The UK group still uses the MDS Foundation patient handbooks. Their experience and assistance has been invaluable, as has that of both pharmaceutical companies Novartis Oncology and Celgene. We thank them all hugely for their continued support.

The group would certainly not have been the same without David’s influence and constant encouragement to all involved. We are planning to have a lecture named after him at the annual UK MDS Forum specialist conference, placing particular emphasis on the patient experience and quality of life issues.

Life Beyond Limits

is a global campaign supported by a coalition of patient advocacy groups and MDS experts that aims to:

- raise awareness of the benefits of equal access to treatment irrespective of chronological age
- improve the standards of treatment for older cancer patients.

The campaign was launched during the international haematology congress (ASH) in tandem with an inspiring photographic essay, Facing MDS: When Every Moment Counts, by internationally acclaimed photojournalist, Ed Kashi. The exhibition features portraits and self-authored stories of six MDS patients from around the world. Each of these patients has benefited from taking a proactive role in their healthcare decisions and is helping to redefine what it means to be an older person living with an uncommon and difficult-to-treat blood disorder. It shows how older people with a chronic disease are continuing to live life to the fullest.

The goal is to inspire and empower other MDS patients to become advocates for their own health.

Facing MDS: When Every Moment Counts will continue to expand with new patient stories and will be featured in different exhibits around the world. For more information about the photographs, upcoming exhibitions and campaign, visit **www.mdslifebeyondlimits.org.**

Dominic Culligan

The 11th International Symposium on Myelodysplastic Syndromes Edinburgh, UK, May 18th-21st, 2011.

Many from around the world with an interest in the causes and treatments of MDS gathered for The Myelodysplastic Syndromes Foundation 11th International Symposium on MDS, held in the wonderful city of Edinburgh during May, 2011. This was the second time that this meeting has been held in the UK, having been to Bournemouth in 1991. The historical timeline of the International Symposia almost exactly matches my own timeline of specialising in haematology with an interest in MDS.

The first meeting was in Innsbruck in 1988 when about 400 determined souls gathered to discuss a group of diseases which were still poorly understood and for which there was little in the way of effective treatment. The focus at that time was very much on improving the diagnosis and classification of MDS. However, the meeting also explored the possible benefits of chemotherapy and bone marrow transplantation and perhaps most notably considered the very early data on the use of erythropoietin to improve anaemia in MDS.

Subsequent Symposia have toured the globe including meetings in Chicago, Barcelona, Prague, Paris, Stockholm, Nagasaki, Florence and most recently prior to Edinburgh, Patras in Greece. These meetings have witnessed a gradual growth in knowledge and expertise and most importantly in effective therapies. In keeping with this the number of delegates in Edinburgh swelled to over 1400, reflecting the determination of specialists from around the world to understand these diseases and provide better treatments for patients suffering from them.

This was an exciting time for UK specialists to be gathering once again with international colleagues to discuss MDS, with the treatment, azacitidine, having just been approved by NICE and with the ongoing successful development of the UK Clinical Trials Group as outlined by Professor David Bowen in this edition of the Newsletter. David was also the Chair of the Scientific Programme Committee and the lead organiser who put together a very stimulating programme for the Edinburgh meeting. In the months since Edinburgh it is fair to say that this meeting has been widely regarded as the most successful of all of the International Symposia, to date. Amongst the many clinical and scientific developments presented, the highlight was the first presentation of the data from Professor Peter Campbell and colleagues describing an important acquired genetic abnormality in a gene called SF3B1. This seems to be especially important in MDS with ring sideroblasts, since abnormalities in this gene occur in about two thirds of such patients. These types of scientific discovery are vital to understanding what causes MDS and to aiding our ability to subsequently design effective treatments.

The UK MDS Patient Support Group was well represented in Edinburgh in its role of supporting the wellbeing of patients with MDS throughout the UK. It subsequently turned out to be touching and very fitting that our late Chairman, David Hall, was afforded the honour of speaking at the opening ceremony about the role of the patient group. This unfortunately was to be David's last public appearance in his role as Chairman and despite his obvious deteriorating health, he gave a typically sharp, focused and very stimulating vision of the purpose of patient support groups. His call for world wide groups to be developed and to form a network of global co-operation was widely welcomed.

Coinciding with the Symposium there was a successful Patient Forum meeting on Friday 20th May. Sophie and Rodney were on hand to help with what turned out to be a Forum meeting with a very international flavour and more patients and carers came from overseas than from Scotland!

I have many memories of past Symposia, including being most expertly relieved of my last 20 dollar bill by a shoe-shiner in Chicago and witnessing a French Connection style police car chase in Paris! There was no such drama in Edinburgh, but plenty of great Scottish culture and hospitality, including a reception at The National Gallery and lessons in whisky tasting at the conference dinner. However, most importantly, there was plenty of useful information about MDS gathered from expert friends and colleagues from around the world. As the meeting came to an end talk already turned to the next gathering, in Berlin, during 2013.

Dominic Culligan
Aberdeen Royal infirmary

Professor David Bowen

The UK NCRI MDS Clinical Trials Group: What is it about and why is it so important?

Although MDS has been recognised as a distinct disease since 1985 with the French American British classification, there has been only limited progress in the treatment,and blood transfusion still remains the mainstay for most patients. Nevertheless several drugs are now licensed for use in MDS in the USA and two are licensed in Europe (azacitidine and deferasirox).

Drug development

Clinical trials are the route to development of new drugs for treatment of MDS, and this development programme must proceed in stages. First a small number of patients receive the drug (phase 1). If the drug is deemed safe, more patients are treated to try to understand if the drug may have a promising effect (phase 2) and finally a promising drug identified in phase 2 is tested against the best available treatment for the disease (phase 3).

The UK clinical trials landscape

In the UK we have established an MDS Trials Group within the government-supported National Cancer Research Institute (NCRI) structure. Clinical trials that are accepted by a government-approved funding organisation can then utilise the clinical research nurses and data managers in all UK hospitals that are funded through this initiative. This is an enviable infrastructure but clinical trials in the UK are still hampered by the length of time taken to obtain funding and to set up the study (minimum of 1 year from the original idea). Pharmaceutical companies also run trials internationally, some of which include UK centres. Such trials can be 'adopted' by the NCRI and thereby use the government infrastructure.

We now have more than 20 members of the NCRI MDS subgroup (Consultants and scientists) which is slowly creating a portfolio of clinical trials. Within this network and outside the NCRI structure the UK has national studies of the disease biology (MDS Bio), the natural history of low-risk MDS (European LeukemiaNet MDS Registry programme), and quality of life in high-risk MDS (with the Italian GIMEMA group) in addition to phase 2 clinical trials. We work closely with the NCRI Acute Myeloid Leukaemia (AML) subgroup and the AML16 and AML17 trials include some MDS patients. We are also developing links with the NCRI Myeloproliferative Disease (MPD) subgroup to develop trials for the rare diseases that overlap with MDS and MPD.

Our main development programme is the establishment of a series of phase 2 studies which together will eventually allow us to test the most promising drugs or combinations of drugs in phase 3 trials for both low-risk and high-risk MDS. We are fortunate to have world class scientists collaborating with our groups, and colleagues from University of Oxford and University of Leeds are studying bone marrow and blood from patients treated in our recent clinical trials with the hope of obtaining more information about how these drugs work and in whom they may be most effective. Finally we are starting to discuss trial collaborations with other countries, initially the Nordic MDS Group.

Is there a clinical trial for me in the UK?

We hope that you and your fellow patients will be interested in participating in UK based research into MDS including clinical trials. Some clinical trials are offered in most UK hospitals (AML 16 and AML17 for example) whilst others may be restricted to specialist centres or a small network. You can identify ongoing clinical trials in MDS from a number of websites including:

CancerHelp UK www.clinicaltrials.gov (international)

Professor David Bowen, Chairman NCRI MDS
Clinical Trials Group and Consultant Haematologist,
St James's Institute of Oncology, Leeds

Note: Since this article was written, Dr Dominic Cullen, Aberdeen Royal Infirmary, has taken on the role of Clinical Trials Co-ordinator.

Fundraising successes 2010-2011

David Bayliss

David Bayliss and co-driver Vikki with Jochen Goller of MINI UK

It is difficult to imagine the trauma of being diagnosed with a disease of which you have never even heard and for which there are no easy cures or quick remedies. My sister had childhood leukaemia, so when my friend said she had been diagnosed with MDS, I could totally understand all the emotions the whole family were going through: the utter shock of having a routine blood test, feeling fine, but suddenly having a diagnosis of a potentially life-shortening illness that turns your life upside down. My sister survived and gave birth to baby Phoebe in November 2010. To celebrate this, I decided to make this trip on behalf of Leukaemia Research and the MDS Patient Support Group.

I love road trips and I wanted it to be the most challenging drive possible so came up with the idea of driving as far North as you can - driving through France, Belgium, The Netherlands, Germany, Denmark, Sweden, Finland & Norway to the Arctic and back. Having already done the trip once before in the Autumn of 2008, I decided to do the same trip but make it even more difficult - by making it longer and in the depths of winter.

The car we took to the Arctic was a newly-released MINI Countryman 4x4 Cooper D which was kindly lent by MINI UK from Arden Mini, in Aylesford, Kent. They also fitted the car with studded tyres and screen wash that wouldn't freeze in the possible -40oC conditions. The coldest temperature we experienced was in Northern Norway when temperatures dropped to -30oC - when we got out the car our nose hairs froze instantly!

Our goal was always to reach the most Northern point drivable in Europe - Nordkapp which sits at over 71degrees north and is marked by a globe monument. Despite the epic challenges , on day 14 we achieved this.

During 25 days we covered over 7,000 miles - most of which were spent driving on ice roads. On December 22nd 2010, my co-driver, Vicki and I completed our 25 day trip that took us to the Arctic (in temperatures as low as -30OC) and back and raising over £3,000 for the MDS UK Patient Support Group and over £3,000 for Leukaemia and Lymphoma Research.

Rachael Foggo

Run to the Beat is a half marathon that starts and finishes at the O2 arena with a route that snakes through Woolwich, Greenwich and Blackheath. With the wind from the north that day, it was Arctic cold and all the runners struggled. I didn't manage to beat my personal best but completed the race in just two hours, 4 minutes and 32 seconds – a very respectable time.

I would like to thank everyone who so kindly sponsored me, and to Celgene who generously agreed to double what I had raised, enabling me to raise £656 for the MDS Patient Support Group. I hope that I have inspired others to take part in their own challenge.

Graham Young

My mother-in-law, Julie, was diagnosed with MDS in 2007 and I wanted to do something to raise money for the support of those with MDS as well as the research into both preventing and finding a cure for the illness. In February 2011, I climbed Mount Kilimanjaro! That was no small feat, as it stands at 5,895 metres above sea level, making it the highest free standing mountain!

The total raised including Gift Aid was £3,204.98 and was split between 2 charities, MDS UK Patient Support Group, and Leukaemia & Lymphoma Research.

Mishcon de Reya

Founded in 1937, Mishcon de Reya is a law firm with offices in London and New York offering a range of legal services. They have a long history of charitable giving. Gloria Brady, a Senior Legal Cashier in our Accounts Department, nominated MDS for the January fund after her Aunt was diagnosed with MDS in August last year. This is typical of the type of charities which are nominated each month, where someone has personal experience of the invaluable assistance charities such as MDS UK offer. We are grateful to the £200 donated to us by Mishcon de Reya.

Mishcon de Reya
www.mishcon.com/about_us/mishcommunity/

Judy Woolfenden


Judy Woolfenden

Judy Woolfenden, MBE is an amazing lady who has undertaken numerous personal challenges, despite suffering from Spinal Muscular Atrophy, a progressive muscle wasting disorder, as well as several other serious medical conditions. She was also recently diagnosed with MDS, which prompted her to contact us. MDS UK is extremely grateful for the kind donation of £236.53 handed over at Judy's annual luncheon at the Stoneleigh Deer Park Golf Club in Warwickshire.

Celgene

The Celgene staff who ran the 2011 Berlin marathon raised an amazing £5,000 for MDS UK – which the Celgene company then matched – donating a further £5,000. Runners were :Tom Mills, Bonnie Doyle, Dawn Thompson, Debbie King, David Payne, Caroline Daintree, Gemma Brookes, Gillian Thomson, Kevin Loth, Liam Quinn, Tracey Davidson, Tim Paget, Rachael Foggo. We are tremendously grateful to all of them – and extremely impressed by the team spirit!!


Celgene at the Berlin Marathon 2011

Dan Crowley - Brighton Marathon and Golf Day

We are grateful to friends and family of the late Dan Crowley for holding these memorial events which raised £1,200 for MDS UK Patient Support.

Ian Denton Memorial Golf Day

The HSBC Liverpool Golf Society chose MDS UK as their charity of the year in 2011. Golf matches, a charity races night and charity auction took place in memory of Ian Denton, organised by family member, Geoff. Generously supported by a matched donation from HSBC, a total of £5,147 was donated to MDS UK.

We would like to send a really big thank you to each and everyone for your hard work and determination to raise funds for MDS UK Patient Support.

Upcoming Fundraisers...

Windsor Walk May 2012

Please come and join us on the 6th Windsor Great Park Walk on Sunday morning,13th May. Enjoy the day out and a picnic lunch with friends and family and get sponsored to walk to raise funds for MDS UK. Walk at your own pace – as little or as much as you'd like. There are options for a 6km, 10km and 16km walk. Optional: wear red, white or purple to denote red/white blood cells and platelets!

AAT (Aplastic Anaemia Trust) organises this event and ask for a small donation of £5 to register and cover their costs. MDS UK Patient Support Group ask you to get sponsored and funds raised by you will come to us. Picnic hampers may also be pre-ordered from AAT. For details, go to the AAT website. Click on Fundraising and the Windsor Great Walk **www.theaat.org.uk**

Laura's Cycling Adventure - October 2012

In October Laura Dover is cycling from Lands End to John O'Groats in memory of her Mum, who loved cycling and passed her passion I to her daughter. This adventure will cover nearly 1000 miles. Please forward the link below to all your contacts to help Laura raise money to support the MDS UK Patient Support Group. Just search for Laura

MDS UK Patient Support Group

What our patients say:

MDS is such a complicated disease; it takes considerable time to begin to understand it once the diagnosis abruptly plunges you in to a whole new world of repeated blood tests, of classification systems and prognoses. Facing the impact on your life and where you might fit on the spectrum of 'how serious is it?' is another journey but this time on an emotional roller coaster.

In our case my husband has MDS and I am cast in the role of advocate/ support system/ minder/interpreter (because I understand the medical terminology etc and he doesn't and would prefer poetry).

'Living with uncertainty' has been a phrase which I have often used in the past, finding some sort of wisdom in it. But living alongside MDS really tests that glib phrase to extremes. In reality it's very difficult to live when you are uncertain what the next few months or years hold in store for you. Uncertainty breeds anxiety and undermines confidence in a very pernicious way. And anxiety for most people with MDS builds as they approach yet another set of monitoring blood tests or a another bone marrow biopsy that may (or may not) clarify what's in store.

So if you know that your time span may be limited, how do you cope ? And how do you explain to friends and family that, although you look pretty normal, you are living with considerable anxiety?

Clearly working with patients with MDS requires a significant specialist expertise from medical and nursing staff. We are relieved to have found one such department. Good departments of haematology will be encouraging patients with MDS to become part of any support mechanism, including the MDS patient forum group. Attending patient forum meetings is also very important for keeping up to date with research and treatment advances both by hearing from and questioning excellent speakers, and by accessing a wide range of patient literature which gives patients the confidence to frame those difficult questions during consultations (It's your disease).

Finally, meetings certainly help us all practise getting our tongues around the language of MDS; we now have the badge of "5Q minus".

Anonymous

The Patient forum we attended at Duxford offered us an opportunity to meet other patients, carers, and clinical specialists, which enabled us to better understand Julie's condition and share experiences. Before our contact with the group we felt alone and anxious about what the future held for us, Julie having only been diagnosed 3 months prior to the forum. After the patient forum we felt informed, reassured, and enlightened as to what MDS is and how to live with it and cope with the implications of treatment etc. Less anxious to a point, but still scared about what lay ahead. Thanks again for an excellent seminar.

N and J

I was diagnosed in June 2011 with MDS RAEB II Intermediate 2 - failed cytogenetics resulting from a blood test ordered by my GP for an unrelated problem. Had it not been for this blood test I would remain blissfully unaware of MDS.

1. The main benefit I find with belonging to a patient support group is that I know I do not suffer alone the medical terminology which confuses the layman. I now know that there are many others like, or worse off, than me. I am also very much aware of how much effort the medical specialists put in on our behalf in respect of this condition. At present my haematological condition remains stable- if I have interpreted the jargon and numbers correctly.

2. Creating a local support group will let others know that they are not alone in the clutches of MDS and gives those who wish to the chance to get together and chat, informally, about matters. It is good that the group is open to carers and relatives of the MDS patients.

Richie Cunnell
Anglian Region MDS Support Group

My husband was diagnosed with MDS last year and it was a complete shock as he is very well and had it not been for a "funny" turn at the gym, resulting in a several blood tests and a referral, we would never have know there was anything wrong.

The annual forum was our very first opportunity to meet others with the same condition. This meeting spurred a group of us to start up a local group so that people have the opportunity to meet, talk and listen to others who are going through similar life- changing experiences. There is a lot of confusing and scary literature around so to talk with real people about it is really helpful.

Whilst we British are sometimes very bad at expressing our feelings, we can hopefully help each other, by listening and supporting each other through the maze of MDS and its complexities.

Chris Cunnell
Anglian Region MDS Support Group

Become a member of the MDS UK Patient Support

Membership (free and open to all)

Membership provides an opportunity for patients, family members and carers to help shape access to treatment; have a say over NHS issues; play a role in the future of MDS patients; lobby politicians; help influence decisions on health made by government.

The voice of the patient now carries substantially more weight than before and greatly helps the work carried out by our Committee members in contesting NICE policies and decisions in the evaluation and adoption of new medication.

Online Access

Why not visit our website, for access to our online discussion forum; contact with fellow patients, details of important events and access to news articles.

Make a Donation

Leaving Money to the MDS UK Patient Support Group

It is important to remember your friends and family when drawing up a Will, and make sure that all loved ones are taken care of. But once you have done this, you may wish to leave a legacy to the MDS UK Patient Support Group. Your contribution could help us save lives and continuously improve the treatment and support of this disease.

Leaving a legacy to the MDS UK Patient Support Group is one of the greatest gifts you can give, Think about it and contact us if you would like us to send you our legacy information sheet.

We need your help!

Does your place of work sponsor charities on a regular basis, maybe monthly or even yearly? Do you know of any company that sponsors charities? If so, please mention the MDS UK. Patient Support Group (Charity 1145214). We need more funds to raise awareness and provide support for MDS patients and their families.

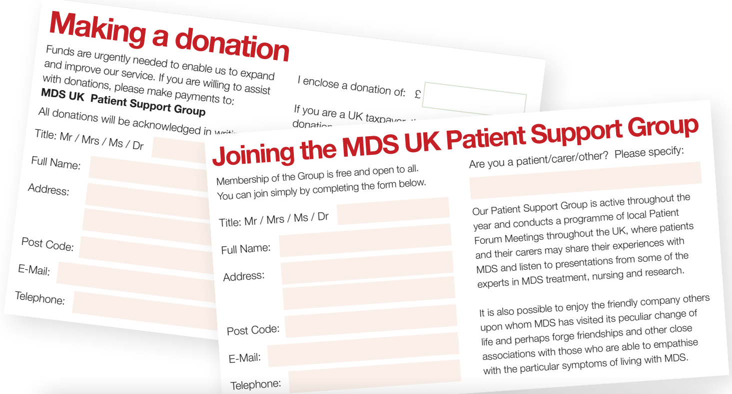
Please download and print off membership and donation forms from our website or contact Sophie Wintrich - details on back page.

Email: **mds-uk@mds-foundation.org**

Donations can be accepted via cheques or online via Virgin Money Giving:

www.uk.virginmoneygiving.com/giving/

Please enquire with our office if you wish to organise bank transfers.



Making a donation

Funds are urgently needed to enable us to expand and improve our service. If you are willing to assist with donations, please make payments to:
MDS UK Patient Support Group
All donations will be acknowledged in writi...

I enclose a donation of: £

If you are a UK taxpayer ...
donation...

Title: Mr / Mrs / Ms / Dr
Full Name:
Address:
Post Code:
E-Mail:
Telephone:

Joining the MDS UK Patient Support Group

Membership of the Group is free and open to all.
You can join simply by completing the form below.

Title: Mr / Mrs / Ms / Dr
Full Name:
Address:
Post Code:
E-Mail:
Telephone:

Are you a patient/carer/other? Please specify:

Our Patient Support Group is active throughout the year and conducts a programme of local Patient Forum Meetings throughout the UK, where patients and their carers may share their experiences with MDS and listen to presentations from some of the experts in MDS treatment, nursing and research.

It is also possible to enjoy the friendly company others upon whom MDS has visited its peculiar change of life and perhaps forge friendships and other close associations with those who are able to empathise with the particular symptoms of living with MDS.

MDS UK Patient Support Group

MDS UK Patient Support Group

Providing continuous support to MDS patients and their carers.
Advancing public education in all aspects of MDS in the UK, through publications and the internet.
Promotes and supports scientific research into the treatment and care of MDS patients.

Have you or a friend recently been diagnosed with MDS?

Thank you all for signing the petition - Check coverage and photos on Events page

Latest News

Patient support group welcomes NICE decision to re-appraise Vidaza
London, 26 July 2010 – The MDS UK Patient Support Group has welcomed the decision announced today by the National Institute for Health and Clinical Excellence (NICE) that it will re-appraise the use of Vidaza (azacitidine) in patients with higher-risk myelodysplastic syndrome (MDS)- a group of debilitating bone marrow diseases. Today's decision by a NICE [...]

Need for Azacitidine featured in Daily Telegraph
'Cancer experts from more than 30 hospitals across Europe have joined a campaign to get an expensive life-extending drug on the NHS', writes Daily Telegraph's medical correspondent Kate Devlin.

Please Support Our NICE Campaign Appeal
On 4th March 2010, NICE published their final decision not to recommend the use of azacitidine (Vidaza) to treat patients with

Latest Events

24 SEPT London MDS Patient and Family Forum
Patient and family MDS Forum day – you can register your place as of now – or contact us for further information

12 NOV Cambridge MDS Patient and Family Forum
Patient and family MDS Forum day – you can register your place as of now – or contact us for further information

Media Coverage
Our campaign to appeal the negative decision NICE decision on Azacitidine has gained media coverage.

Discussion Forums

The discussion forum is open to MDS patients, family, carers, health care professionals and anyone affected by MDS.

Visit the forums now

Follow us for instant news and updates directly through Facebook

MDS UK Patient Support Group

visit our website

www.mdspatientsupport.org.uk

MDS UK PATIENT SUPPORT GROUP

Committee:

Chairman	Prof. Rodney Taylor
Treasurer	Sharon Berger
Secretary	Fiona Pirilla
Fundraiser	Joanne Anderson (all the above are MDS Patients)
Patient Liaison	Sophie Wintrich
Project Worker	Alice Murphy
Clinical Nurse Specialists	Janet Hayden Geke Ong (King's College Hospital, London) Phyllis Paterson (Addenbrooke's Hospital, Cambridge)
Trustee	Stephen Berger

Associates:

Editorial Medical Consultant	Dr Dominic Culligan (Aberdeen Royal Infirmary)
Advisor and Consultant	Professor Ghulam Mufti (King's College Hospital, London)

OUTLINE OF PLANNED FUTURE EVENTS 2012

Please contact Sophie Wintrich on 0207 733 7558 for reservations/enquiries

MDS Patient and Family Forums

- London - September 2012
- Cambridge - November 2012
- Midlands, Bournemouth, Dublin, Oxford, Exeter, Leeds - dates to be confirmed.

See website for details

Local MDS Meeting Groups

Essex, Exeter, Oxford, Cambridge, London

Please contact us for details.

Posters, guidelines and financial assistance available to start your own local group

Find us online

MDS Support website
www.mdspatientsupport.org.uk

MDS Foundation website
www.mds-foundation.org

MDS UK Patient Support Group Facebook:
MDS UK Patient Support Group

MDS Foundation Facebook:
MDS Foundation, Inc.

MDS UK
Supporting Patients with Bone Marrow Failure
www.mdspatientsupport.org.uk
to see how you can get involved

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The publication of this newsletter is supported by unrestricted grants from Novartis Oncology and Celgene UK Limited.

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