



MDS UK Patient Support Group NEWSLETTER

VOLUME 1

ISSUE 1 - SEPTEMBER 2010

Petition to No.10 Downing Street

In May a petition with more than 680 signatures went to the Prime Minister asking him to ensure that MDS patients in the UK receive care comparable with that available in most European countries, following the NICE final recommendation not to make Azacitidine available through the NHS.

(L-R) Janet Hayden, Myeloid Clinical Nurse Specialist; Professor Rodney Taylor, Deputy Chair, MDS UK Patient Support Group; Sophie Wintrich, Patient Liaison, MDS Foundation and Dr Samir Agrawal, Senior Lecturer & Honorary Consultant in Haematology, Barts and the London NHS Trust present the petition at 10 Downing Street.



Chairman's Introduction Getting Better Acquainted

Perhaps, like me, you choose to spend as little time as possible glued to a computer screen. Maybe, browsing for you is the pleasant, tactile comfort of a favourite book, relaxing in an easy chair. You may even find it difficult to absorb, fully, the content of email, particularly the long, badly composed copy that characterises so much of modern day communication.

The majority of MDS patients are well into later life and probably still value traditional standards. Even those of you with computers may not always feel inclined to enter the mesmerising world of web sites for information.

MDS, too, is a complex, ever changing scene, as consultants and researchers strive in search of a cure, rather than simply a new treatment. It is also a field of pain and discomfort, one where only fellow sufferers are able to empathise. Often, the reassurance that others are experiencing the same intrusion into the quality of life as

you lessens the feeling of isolation and reduces the common feeling that 'I seem to be the only one with this problem'.

Your discomfort is compounded by an NHS service which seems unable, or unwilling, to recognise the particular needs of MDS patients and others suffering from rare diseases. The NHS talks glibly about improving quality of life, yet refuses to release into UK new, life prolonging, highly efficacious medication, already available in many other countries of the western world.

Our Committee has decided to try and produce a, twice yearly, patient newsletter. This will be an amalgam of the several facets of the MDS experience, combining contributions from many of the 'good and the great' from -

continued overleaf...



the treatment front, with letters from patients willing to offer and share their individual experiences with MDS for the common good. There will be news from specialist MDS nurses, consultants, treatment and research centres.

Fund raising, together with other news from within the MDS circle, will hopefully add interest and appeal. This is your publication. Your feedback, particularly your views on the reluctance of government to address the very real problems we all face in the access of the

Dr Dominic Culligan An Overview of MDS

MDS is an umbrella term for a group of blood diseases which share important characteristics. Firstly, these diseases predominantly affect elderly people. Secondly, they are malignant diseases of the bone marrow leading to ineffective production of blood cells. Patients commonly present with symptoms of anaemia including fatigue and poor exercise tolerance. Other problems include increased infections because of low white cell counts and occasionally bleeding because of low platelet counts.

When MDS is suspected a haematologist will carry out a thorough assessment aiming to exclude other causes of anaemia and low blood counts. A key test is a bone marrow sample. This allows the 'dysplasia', which means 'funny looking cells', to be identified and also allows other important tests such as an analysis of the chromosomes to be carried out. A well recognised feature of MDS is a tendency for the condition to progress to acute leukaemia in some patients. The most important risk factor for this is the percentage of leukaemia (blast) cells identified in the bone marrow sample. Once MDS is confirmed the risk of developing leukaemia or of the blood counts quickly worsening can be estimated by the International Prognostic Scoring System (IPSS). In general patients are classified into 'low risk MDS' or 'high risk MDS.'

The aims of treatment for MDS vary depending on whether the disease is low risk or high risk. In low risk patients anaemia is most often the major problem. The commonest way of treating anaemia is with blood transfusions. Blood transfusions are good at relieving the symptoms of anaemia and on the whole are very safe. However, after many transfusions the benefit may wane and patients can accumulate excess iron. Some patients with low risk MDS may benefit from receiving drugs to remove this

best, most appropriate treatments, will serve to help our continuous, insistent efforts with all major political parties, NICE and NHS to address these serious deficiencies.

We welcome your involvement in producing, regularly, a document which will serve as a source of relevant information, comfort and inspiration.



David R. Hall
Chairman –
MDS UK Patient Support Group



excess iron. Other ways of improving the anaemia include the use of growth factors like erythropoietin, which stimulate the bone marrow to produce more red cells. For patients with a particular type of MDS called '5q minus syndrome' the drug lenalidomide can lead to transfusion independence. However, lenalidomide is not currently licensed for use in the United Kingdom.

For high risk MDS the main problems are severe bone marrow failure and the development of acute leukaemia. Some patients who are relatively young and fit can be cured of high risk MDS by a stem cell transplant from another person. For the majority of patients who cannot have a stem cell transplant for whatever reason then the drug azacitidine is the treatment of choice. Azacitidine prolongs survival, delays the onset of acute leukaemia and reduces the need for transfusions. Unfortunately, despite acknowledging these clinical benefits, NICE and The Scottish Medicines Consortium have not recommended azacitidine for use in the NHS because of its perceived poor cost effectiveness. It is hoped that these decisions will be reversed.

Despite a significant improvement in treatments over the last few years, MDS remains a serious and life threatening group of diseases for many patients. It is important that we continue to improve our scientific understanding of MDS and that new and better treatments are developed. Patients should feel free to enquire about participation in studies which contribute to these goals.

Dr Dominic Culligan
Consultant Haematologist,
Aberdeen Royal Infirmary, UK.



Dr Rodney Taylor

NICE and the MDS Patient



NHS

National Institute for Health and Clinical Excellence

NICE is the National Institute for Health and Clinical Excellence – the ‘H’ is silent. NICE’s purpose is to be “an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health”. Though it is independent – a so-called arm’s length body from the Government – it is responsible to the Department of Health, and that department determines its terms of reference and how it operates. So NICE recommends what is available in the NHS for patients and, most importantly, what is not. This really matters both to patients, especially those with less common diseases, and to their carers.

The remit of NICE is to provide guidance to healthcare providers. NICE says that its guidance is produced by the people affected by their work, including health and social care professionals, patients and the public; based on the best evidence; transparent in its development, consistent, reliable and based on a rigorous development process; good value for money, weighing up the cost and benefits of treatments, and internationally recognised for its excellence. These are very challenging standards to work to. The guidance falls into a number of categories, the most important of which in the context of MDS are the technology appraisals, which are about the evaluation of new treatments.

These examine not only the clinical effectiveness of treatments, but also their cost-effectiveness, so, in weighing this up, the clinical effectiveness has to be balanced against their cost and value for money to the taxpayer. In order to achieve this NICE applies some very complex mathematical modelling in assessing cost-effectiveness, based on the Quality Adjusted Life Year (QALY) which is a measure of the quality of life determined by a number of factors. In simple terms, NICE’s standards reckon that a year of good quality, totally independent life is costed at around £30,000, so if a new treatment will provide that it must not cost more than this amount.

NICE gathers all the information that can be found about a new treatment in order to appraise it. That includes the evidence from clinical trials about benefits and outcomes, and also the information about costs. For a new treatment, much of this is provided by the manufacturer. Azacitidine, which is of great value to some patients with higher risk MDS, is the most recent NICE technology appraisal relevant to MDS

UK. The evidence submitted was evaluated by an Evidence Review Group, to be condensed into a form to be presented to the Technology Appraisal Committee for discussion at its meetings. In Azacitidine’s case, in March 2010, the committee decided that, after three hearings, though Azacitidine was considered to be an effective treatment, it was too costly, so that NICE could not recommend it for use in this country, even though available throughout Europe and North America. Therefore PCTs are not required to pay for it. This is yet another in a series of clinically effective drugs intended for patients with uncommon conditions, mostly cancers, which has not been recommended by NICE. Other examples have had wide coverage in the press. MDS UK, supported by three other patient support groups, along with three professional bodies and the manufacturer, appealed against this decision at a hearing on 1st June. NICE’s decision was announced on 26th July 2010 with an announcement that the appeal was successful and a recommendation that Azacitidine should be referred back to the Appraisal Committee for further consideration. It specified that comparison should be made with chemotherapy, as well as with best supportive care, and that consideration should be given to the quality of life data provided by MDS UK Patient Support Group.

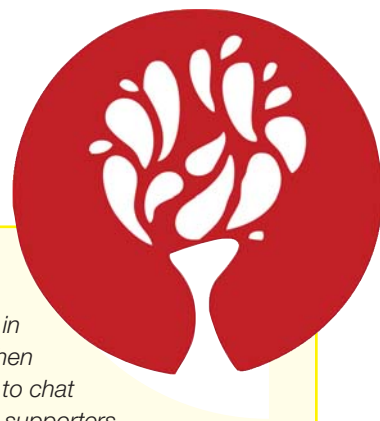
Another issue currently being considered by NICE is whether it should review iron chelation treatments, which is particularly relevant to those with MDS who are transfusion-dependent. This is the start of the process and NICE will decide, on the basis of the evidence provided, whether to appraise these treatments. The MDS UK Patient Support Group is having an active input.

So does NICE matter to us? Yes, it certainly does. Please take an active interest. NICE has the power to control the availability of treatments and is not particularly sensitive to the needs of those with uncommon diseases that require specialised treatments. Find out more from <http://www.nice.org.uk> about what NICE does and have your input there, or through the Discussion Forum on our website at <http://www.mdspatientsupport.org.uk>. As a patient group we have the power to make a difference through the media, by lobbying, through our MPs, and in whatever way we can.

Dr Rodney Taylor
Deputy Chairman –
MDS UK Patient Support Group



What our patients say:



I was diagnosed with MDS in August 2009 and was in a very frightened and depressed state when I chanced upon the MDS Patient Support Forum website.

I found that there was a Forum planned for Cambridge the following November and it was really easy to book in, after which we received a helpful email from Sophie Wintrich (a great source of information) with the agenda for the event and directions.

My husband and I went to the Forum together, as he too was feeling a bit isolated and in need of support and information. I felt a bit apprehensive as I was expecting to see a lot of really sick, elderly people and I felt a bit of a fraud for being so worried and upset when I was actually still relatively young and feeling pretty fit and healthy. I was relieved therefore to find that everybody looked OK and were around my own age – some were even younger. In fact it was difficult in most cases to know who was the MDS sufferer and who was their partner/supporter.

The day started with an overview from the Chairman, David Hall, who is a really inspirational person, and was followed by a session with all the MDS patients and their supporters talking

about their experiences of MDS. Two specialist nurses also contributed and were very kind, supportive and helpful in their comments and responses. We then had a lovely lunch with an opportunity to chat informally with other patients and their supporters.

The afternoon sessions were led by Professor Alan Warren from Addenbrooke's and we were lucky enough to have an informal talk with him at the end of the event which made us aware that there are quite varied approaches to drug trials, stem cell transplant and other treatments for MDS.

Driving home afterwards, we both felt immeasurably better: knowing quite a bit more about MDS and feeling that we weren't the only ones really did help.

I would urge anybody who is newly diagnosed to make contact and join the MDS Forum.

Christine Dugmore

Thank you for persuading me that I should seek referral from my county hospital to the MDS Centre of Excellence at King's College Hospital.

We didn't know that the diagnosis of MDS made at my county hospital was made on the basis of some pretty poor evidence and although I was regarded as being at low risk in the first intermediate group, I now know that I could well be re-categorised as being at very low risk.

Professor Mufti and his staff could not have been kinder nor more attentive; a refreshing change from the attitude of our local

medics. Professor Mufti even spoke positively regarding the prospect of treatment, should it be necessary. Had you not stuck to your guns about my going to see Professor Mufti, I would still have been feeling distinctly nervous about my future. As it is, my morale has soared and my wife has sent away for a wide selection of holiday brochures.

If any of your members are concerned about seeking a referral to King's, tell them there's nothing to it. Their GP's have no option but to oblige and no possible grounds for refusing.

T

When I told someone recently that I had MDS he replied that he'd got some somewhere too – probably at the back of his garage. It took a little time to work out that he thought I had said I'd got some MDF (Medium Density Fibreboard). The misunderstanding made us both laugh.

Some might say however that MDS is no laughing matter. That's true: it isn't. But spending the rest of one's life being miserable isn't an option. I find that if I can make people laugh, I laugh too – and the more I laugh, the better I feel. I also feel better when I count my blessings.

All MDS sufferers have "an elephant in their room" with the letters MDS writ large along its flanks. It never entirely disappears, but it can be made to fade considerably if one puts one's mind to it. For instance: the way to achieve inner peace is

to finish all the things you have started and never finished.

So look around your house to see what needs to be done and, before you procrastinate any more:-

- finish off that bottle of White Zinfandel or that bottle of Tequila
- eat the last of that still crusty and fresh French loaf and that really cold butter
- finish off those ginger biscuits; the rest of the cheesecake; that cold pork chop; your old Prozac prescription and your grandchildren's box of chocolates

*.... You have no idea how good you'll feel, MDS or no b*** MDS!*

T.F.



The MDS UK Support Group is doing a great job: thank you so much for encouraging me to make the move and insist on a referral.

I went to King's College Hospital on Monday and actually had a consultation with Professor Mufti himself: I did not really think I would be seen by the top man himself, so I was delighted. I can understand why anyone who has been seen by him is impressed, and would recommend others to do likewise. Professor Mufti asked me about my experience just before

diagnosis and since; he then explained what MDS was all about, where I fitted in and how he and his colleagues could help me.

I was pleased to learn that I was in a fairly low risk category and when I asked how I could maintain my existing level of relative well being, Professor Mufti said that he and his colleagues would look after that. He was so reassuring and I left feeling as though a weight had been lifted from my shoulders.

I.

The meeting near Cambridge towards the end of 2009 was helpful for me personally since there was considerable input from fellow sufferers and useful exchange of experiences. I felt great sympathy for those who had been very recently diagnosed and were in a state of shock, as I suppose I must have been at a similar stage.

The fact that there were many partners/carers present at the meeting with my fellow patients brought home to me the huge impact that an MDS diagnosis is likely to have on a partner. I had not appreciated this in my own case, no doubt because of a desire to keep it to myself rather than burden my wife, but now I have come to understand I need to involve my wife regarding my condition.

Attending the meeting made me realise how fortunate I am that my local hospital, Addenbrooke's, is an MDS Centre of Excellence, and it was good to renew contact with the specialist nursing staff present at the meeting and to know that I could always pick up the phone when necessary to seek advice. I also appreciated the opportunity to put questions to the experts at the meeting. I have always felt welcome at meetings and there is nothing stressful about attending them.

I would certainly recommend to any newly diagnosed patient the benefits of making contact with the MDS UK Support Group.

John Heywood

Janet Hayden

The Role of the Clinical Nurse Specialist



I have been working at King's College Hospital for 6 years and have cared for many patients with MDS. This is Professor Mufti's specialist interest so we receive approximately 20 new referrals per month from both the South East and all over the country.

The main reason that patients with MDS are referred to King's can be for diagnosis or reassessment of disease, consideration for blood stem cell transplantation, novel therapies and clinical trials. Patients may be referred from their GP or local haematology consultants. Some patients may also request a second opinion regarding management.



When patients are first referred to King's it is my responsibility to make sure that all the necessary investigations are completed. All new patients are reassessed to include bone marrow

investigations for diagnostics and more sophisticated research tests that may not be done in patients' local hospitals. At this stage, I can also discuss with the patient what potential treatments might be available to them pending the results.

An important part of my role is to ensure that patients have all the relevant written/verbal information they need and the relevant contact phone numbers. Patients often have lots of questions and will call me with follow up queries and questions after they leave the hospital. This is especially relevant after the patient has had an initial consultation with the consultant where complex discussions may have taken place regarding their disease or proposed treatment. I can help patients understand the information and put it into context with their own lives. I may be able to offer help regarding benefits, travel and other practical issues.

The clinical nurse specialist has an important role in always being able to offer support throughout the patient's treatment journey.

Janet Hayden RN, BSc (Hons), MSc
Myeloid Clinical Nurse Specialist,
King's College NHS Foundation Trust, London



We need your help...



Westminster awareness Post Election Update

Prior to the election, MDS UK Patient Support Group had been actively involved in making contact with MPs and Peers to make them aware of the needs of MDS patients and their families. In May this year, we also delivered the Downing Street petition. Many of you also wrote to your MP's using our template letters - this work definitely had some impact.

Since the General Election there are many new MPs in the House of Commons, and the Coalition Government has been very busy creating much new Parliamentary business, especially around the organisation and funding of the NHS.

It is now vitally important that we continue to maintain this high profile for MDS in the 'corridors of power'. If you have contact with anyone in Parliament or in public life who might be able to provide support for those affected by MDS, please contact us so that we can coordinate action for MDS UK on this front.

Alternatively, please attend the London MDS Forum Event on the 24th September, where we shall discuss further political awareness work for MDS.

Your assistance in writing or in person could make an enormous difference.

Become a member of the MDS UK Patient Support Make a Donation

Simply complete, tear off and mail respective forms.

Membership

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.

An MDS UK Membership Card will be sent to all applicants.

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.

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.

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

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

Our Patient Support Group is active throughout the year and conducts Forum Meetings and their carers and experts in MDS and its effects on patients.

It is also upon request available upon request with _____

Making a donation
Funds are urgently needed to enable us to expand 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 writing.

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

I enclose a donation of: £ _____
If you are a UK taxpayer, the value of your donation can increase by nearly a third under the Gift Aid Scheme.

Please tick this box to join the scheme

Signature: _____

Please return to:
The Treasurer
MDS UK Patient Support Group
The Rayne Institute
Kings College Hospital
123 Coldharbour Lane
LONDON, SE5 9NU



visit our website

www.mdspatientsupport.org.uk

Fundraising

We are dedicated to bringing awareness of each and every aspect of an MDS patient condition. Diagnosis of MDS brings both suffering and anxiety to patients, their carers and families. There often follow feelings of fear, isolation and depression as patients enter a virtual black hole of uncertainty, aggravated by the physical symptoms of extreme tiredness and fatigue which characterise MDS.

Anxiety is often rooted in lack of understanding and we have undertaken a major role in assisting patients to come to terms with the reality of their illness by bringing together sources of expertise from treatment centres, consultants and patients themselves and distributing this expertise and experience over the entire patient spectrum – transfusion dependence, iron chelation, chemotherapy, medication, stem cell transplants...

Patient Forum meetings are conducted throughout the UK, at which experts in MDS present patient friendly talks on a wide variety of MDS related topics, which are later developed in open discussion with specialist MDS nurses.

The MDS Patient Support Group distributes patient friendly information through its web site (www.mdspatients.org) and via publications, press releases, research updates and visit reports, all aimed at improving patient capacity to live with MDS and enjoy the best possible quality of life in the circumstances.

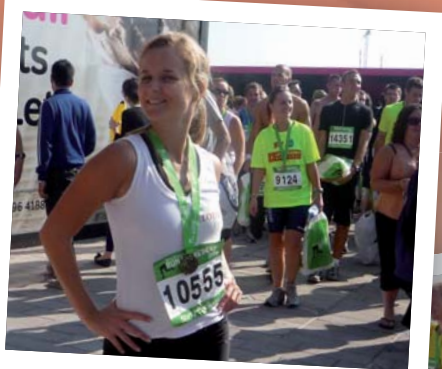
Our activities are frequent and the need for daily attention to urgent patient needs requires resources to guarantee both quality and quantity of response. Our support group has already benefited from generous donations. Patients, carers, relatives, sponsors and others have undertaken challenges to enlist public financial support, including marathon runs, charity events, collections and raffles from which valuable funds have accrued to our group.

We urgently need to increase this flow of funds. A regular newsletter, with our website, will become prime vehicles for this purpose and readers are encouraged to take any opportunity to organise and/or participate in an initiative which is capable of generating income to support our work. Our group is able to supply posters, T shirts and other accessories to advertise and highlight our cause. **BUT YOUR PERSONAL SUPPORT IS CRITICAL.**

Would you like to become a fundraiser? If you are able to raise funds from organised events, or simply make a contribution yourself, please complete the attached 'Making a Donation' form.

If you are a UK taxpayer, please be sure to complete the detail required in order to benefit from the Gift Aid Scheme.

Thank you.



**Elodie Miranda -
London's Music
Half-Marathon,
September 2009**



**David Paterson -
Edinburgh
Marathon,
May 2009**

...and we need your help!

MDS UK PATIENT SUPPORT GROUP



Committee:

Chairman	David R Hall
Deputy Chairman	Dr Rodney Taylor
Treasurer	Sharon Berger
Secretary	Fiona Pirilla
Member	Lin Ewart
Member	Kay Melmoth

(all the above are MDS Patients)

Patient Liaison Sophie Wintrich

Clinical Nurse Specialists Janet Hayden
(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 2010-2011

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

London MDS Patient and Family Forum

Friday 24th September, 2010
– 10.00 to 16.30

This FREE event will be held at the Royal Lancaster Hotel, Lancaster Terrace, London W2 2TY

Cambridge MDS Patient and Family Forum

Friday 12th November, 2010
– 10.30am to 16.30

This FREE event will be held at the Imperial War Museum Duxford, AirSpace Conference Centre, Cambridgeshire CB22 4QR

Further forum events for 2010/2011

Bournemouth, Exeter, Glasgow, Dublin, Oxford

Dates to be confirmed

Local MDS Meeting Groups

Essex, Exeter, Hastings, Kent

Please contact us for details.

Want to start your own local informal group?

Please let us know – we will help.



Find us online

MDS Foundation website
www.mds-foundation.org



MDS Support website
www.mdspatientsupport.org.uk



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

MDS Foundation Facebook:
MDS Foundation, Inc.

MDS UK Patient Support Group (Charity No. 1122780)
c/o The MDS Foundation, Inc
The Rayne Institute, King's College Hospital
123 Coldharbour Lane, London SE5 9NU, UK

Telephone: 020 7733 7558 **Email:** mds-uk@mds-foundation.org