

Galanthus

Newsletter of the CLL Support Association



AUGUST 2010

A POCKET FULL OF POSIES

I have been reading 'Injustice' by Daniel Dorling; he quotes 'I gathered a posy of other men's flowers, and only the thread that binds them is my own'. This is what we CLLSA volunteers do. We take the published works on CLL that are out there, sift and select for all the patients and carers. We have to be selective with the information- there is just so much of it, we have to choose what we feel is important. Of course we will make mistakes, your feedback is very very useful so that we know where to concentrate our efforts.

Sometimes it is not possible to help, we had several requests for a new CLL drug described in a national newspaper. The words to look out for when you read press articles on CLL breakthroughs are 'in vitro'. If a study is in vitro it means that it is literally **only been tested** in a test tube. The theory is that it will be effective in humans; it may not be, and it may not be safe, but it will not have been tested in humans. Very few of these drugs ever become proved safe and available for patients, less than 1 in 1,000. This drug we were called about was a promising in vitro test with misleading headlines

But there are effective drugs in the marketplace, we campaign for them to be made available on the NHS. A long, slow and frustrating job. Gradually CLL patients' life expectancies and quality of life are improving. The drugs are still improving.

My dream is that in time, and it will be a long Time, for an increasing proportion of us, CLL will be a manageable, chronic disease, like diabetes, not a life shortening condition.

J. Barnard.



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BRENTFORD MIDDLESEX - MEMBERS MEETING

GSK House, 980 Great West Road,
Brentford, Middlesex, TW8 9GS

21st September 2010, 11.30 - 16.00

You may have already been contacted to inform you that we are holding a members meeting in September which is sponsored by GSK.

If you would like to attend this meeting please email trustees.pa@cllsupport.org.uk or phone the CLLSA Freephone number 0800 977 4396.

FEEDBACK FROM PATIENT MEETINGS

We thought you might like to know some of the feedback we had from you after the following meetings:

Oxford - Tuesday 13th April 2010
Midlands - Thursday 20th May 2010
Newcastle - Thursday 10th June 2010

Here are just a small sample of your thoughts.

“Your positive attitude has rubbed off on me and this week is the happiest I have felt since I was diagnosed. Thank you.”

“It was good to see you and the other trustees at the Hinckley event last week .

I am beginning to get a better understanding of what CLLSA is about now.

It goes, without question, I personally feel that the work done by CLLSA is so unbelievably helpful to all of us struggling to understand and come to terms with this diagnosis.”

“I went with my wife and was slightly nervous – touchy-feely contact groups are definitely not my thing. I needn't have worried. The most wonderful thing about the meeting was that everyone seemed so normal! But equally too, everyone seemed able to talk about their illness, and to listen to others talking about theirs (including me), in a totally open, frank but supportive way. And the chance to do that, without having to explain or be apologetic for oneself or one's condition, was wonderful. The talk was superb: the consultant managed to pitch things at just the right level (for us at least) – not too simplistic, but also making the technical bits intelligible for the lay person. And again, the thing that came across for me was the mixture of being frank and honest (there is no cure) but also 100% supportive and positive about options, present research, future prospects etc.

We found it very reassuring that there is such a committed pressure group working on behalf of people in our situation, especially in these days of funding pressures. We came away feeling really encouraged and I was enthused enough to offer my active support to work for the Association!”



Ann Smoker Left
Dr Ana Schuh right

“Ben Kennedy, whom I had not encountered prior to the meeting certainly pulled no punches in his informative talk, and the hope he passed on of the development of the drugs to alleviate the progress of our illness lifted us all without in any way raising the expectations beyond the bounds of practicality.

This is the third meeting I have attended (including the Norwich meeting). The arrangements and content in each case have been impressive, what more can I say?”

A letter from one of our expert speakers, Ben Kennedy

Dear Tricia,
I greatly enjoyed the meeting. It is a real privileged to be able to speak with such a group outside of the usual limitations of a clinic.

There is a different dynamic which is very interesting and helpful.

Thank you again for the kind invitation.
Best wishes
Ben

B Kennedy
Head of Service
Department of Clinical Haematology
University Hospital of Leicester NHS Trust

AN UPDATE FROM ONE OF OUR TRUSTEES

By Chonette Taylor

Some of you have known me for many years but many of you probably never heard of me before, for the time being I would just like you to know I am an old CLL veteran.

A reason I am putting some thoughts on paper is I am having a short stay in hospital and it feels surreal, perhaps because I am feeling well and I have always felt very safe while being looked after in Hospital.

Why I managed to get something and end up with a high temperature in hospital I do not know but it has given me a chance to reflect.

The last 6-8 weeks have been very busy; we had patient meetings in Oxford, The Midlands and Newcastle.

I took over the membership secretary job from Garry Bisshopp at the end of April. Over the last few years the CLLSA has developed from the original 'kitchen table' stage and we now widely use computer software to manage the membership and other areas. Garry developed both the actual membership and the organisation to run the membership area; he did a wonderful job, thank you Garry.

So as well as other things I have been learning the ropes of the job. I like to think things are now running well, feedback is always very welcome.

I went to Newcastle feeling I was fine but on arriving my temperature was up and went higher in the night so I did not stay for the meeting and arranged to come back direct to Swindon hospital where they were already waiting for me.

This post transplant health setback does not feel real, but it has shown me that I can't take my strength for granted even if I want to do it all.

Over the last year all the trustees have been very busy and have not managed to put together a newsletter. I felt that rather than let the time in hospital pass I would put together a brief update of what we have been doing during the past months.

CLL is part of our lives and one has to live with it. Jane has been through FCR treatment and continued to run things with her health ups and downs during that time.

Andrea went to Australia on a very well deserved holiday and I was able to cover her treasurer's job while she was away.

I am now 16 months post Stem Cell Transplant (SCT) and apart from the present small hiccup of having to go to hospital with a temperature I have been doing very well and I am now back doing my part for CLL Support Association.

I plan to write about my Stem Cell Transplant journey in the near future.

Jaqui Williams Durkin and Garry Bisshopp both also had treatment and have now retired, I would like to take this opportunity to thank them both for their contributions during their time as Trustees. As I write, Jaqui is particularly unwell, and I am sure that you all join me in sending her best wishes for a rapid improvement, and to all those of us who are suffering.

Thank you from the Treasurer

On behalf of the Trustees I would like to thank everyone who has made a donation to the CLLSA. In the past year many of you have through your efforts raised funds through Just Giving by running marathons and skydive jumps to name just a few! Also a big thank you to those of you who support us with regular monthly donations. We are extremely grateful as we wouldn't be able to provide any of the services we do without your help.

Andrea Cockburn (Treasurer CLLSA)

A Long Weekend on the Continent

I am sharing this with you in the hope that you feel free and relaxed to share some of your travel experiences with us.

You would not need to put your name to the experiences if you feel better doing it incognito, but please write to us and tell us how your travels have been.

I have been a keen traveller all my life and I did not stop during my CLL life but after my Stem Cell Transplant 16 months ago now I somehow felt afraid to venture any way outside my comfort zone, even though the transplant consultant encouraged me to try and have a normal life.

So in June this year I organised to visit a friend in Slovenia.

I spent a week in hospital the week before and I was going to cancel the trip but my transplant consultant persuaded me to go ahead.

On the Thursday I thought I was very organised and set off for Stanstead Airport. I was happily waiting on the departure lounge when it was announced there would be 45 minutes delay, soon after some flights were cancelled. Then much later it was announced that my flight cancelled due to air traffic control strike in France.

I was unsure of what to do so I phoned a friend in London, and she said "you can always spend the weekend in London with me", so I took the train back to London and searched the internet for a flight going from Gatwick next morning. Luckily I was able to get a ticket on line.

Being in London it was easy to get to Gatwick so I phoned my friend in Slovenia and told her I would be there at lunch time, she was delighted.

I had such a wonderful weekend, went for long walks in the forest and visited an Arboretum which made me go back through memory lane when I was doing Organic Horticulture back in 1999.

Psychologically it was an important step for me, my fears of going back to travel seemed to have gone, and maybe I can start going to places again as I always did.

Things that I learnt on this important first trip:

I am no longer young, something I sometimes have difficulty accepting as my mind still feels I am strong and fit. I felt tired during the journey, something I do not remember experiencing in the past while flying.

If it had not been for my London friend rescuing me I would have just gone back to Wiltshire and would have cancelled the whole weekend. Having friends in places helps us to cope with unexpected events.

I recently learnt that once we reach the age of 70 travel insurance is higher, so based on that I better plan some more trips before that time comes.

Please send your travel experiences to ch.taylor@cllsupport.org.uk and let us know if you like your name to be printed or remain anonymous.

Thanks you very much in advance for your contributions.
Chonette Taylor



CONFERENCES

Over the last 5 years all of us Trustees have attended many conferences, I had wanted to report on some of them but treatment together with everyday life has put those wishes on the shelf.

I still remember with great excitement the time back in 2008 when Jane and I went to Lugarno for the International Conference on Malignant Lymphoma (*sponsored by Roche*). My consultant in Swindon graciously arranged for me to start treatment for the Stem Cell Transplant after the conference so I was free to go and also gave me some good tips as the place is so huge and there were so many lectures.

As well as attending everything related to CLL during those days, we managed to meet Kanti Rai, Michael Keating from the USA, Michael Hallek from Germany, John G. Gribben from the UK and we talked to many people.



Left Jane Barnard, Centre Dr Kanti Rai, Right Chonette Taylor

After a long gap where every other Trustee has continued to go to conferences, I started to attend some myself.

The one I like to talk about is the User Involvement Annual Conference 2010 that I recently attended in Oxford, since my Stem Cell Transplant I have been asked to be a Haematology User or Patient Representative for Thames Valley Cancer Network and I also go to the Meetings in Swindon where I have learnt a lot about how things are organised in a hospital life.

I found the Annual Conference very productive, listening to the lectures and talking to other Users Representatives informally over coffee and lunch time, I got some DVD's that tell us what a User

Representative is and how we as patients and carers can help put our suggestions and opinions forwards.

All hospitals have patient support groups, I am part of HUG the haematology support group in Swindon, and psychologically the problems we have are very similar in most of the haematology conditions, as well as understanding who to see when needing to talk, clinical nurses, specialist nurses, etc. they are the ones that have a very good listening ear and can explain many things that at first seem so hard to understand. Other CLL Support Association trustees and members are a part of their local groups.

I learnt that there are 28 Cancer Networks in England and some in Scotland and Wales. If you are interested to learn more about User Representatives and maybe to join in your own area, please email me and I will send you a copy of the DVD for you to see how important it is for us to be part of the NHS as patients and carers.

The more CLL involvement we have in our local areas the more influence we will have in the future, you have to understand that compared with solid tumour cancers, haematology conditions are a very small number, so even CLL is the biggest type of leukaemia in adults, it is still a very small part compared with solid tumours. Sadly, almost all the Cancer Networks and even NICE have a very limited idea that haematological cancers are so different in important ways from solid tumours.

For a copy of the DVD and more info email membership@cclsupport.org.uk Subject: User representative



User Members attending the Thames Valley Cancer Network Annual Conference Oxford 2010

MEETING OTHER MEMBERS

Over the years we have had enquiries from members to meet other members, so the patient and carers meetings have been a very good opportunity for you to meet and make contact with each other while at the meetings.

Several people over the years have come forwards to suggest if we could have a “get together” just to talk to each other informally without a conference setting.

I have taken on the suggestion and will try my best to organise a “get together” in the North Wiltshire area, SN postcode, as a test and see how it works and if it can be replicated in other parts of the UK. Please write to ch.taylor@cllsupport.org.uk , subject ‘Get together’

Jane Barnard will run a meeting local to Monmouthshire, NP postcode, please write to jane@cllsupport.org.uk, subject ‘Gathering’

Last Word

If you are into complimentary medicine then use it, but never let go of the message that orthodox medicine can provide for you.

Claire Rayner, the BBC, 16.01.2006.



Our thanks to Roche for funding

Our 24 hour membership telephone numbers are:

0207 644 3052

0800 977 4396



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