


# East Midlands

Lupus Group

Volume 2 Issue 1  
Autumn/Winter 2009

## Chair's Notes



**Hi Everyone and welcome to our end of the year group newsletter. The festive season is upon us and everyone will have seen what  has brought them this year.**

**We offer a very warm welcome to our membership friends in Leicestershire and Derbyshire who have recently been re-located to our East Midlands Lupus Group. We also welcome on board two new Lupus UK members who also reside in the East Midlands Area.**

**Since our last newsletter, and more recently a committee meeting, we have had the opportunity to discuss, consult and review the group strategy. We realise that very few people have any interest in attending group meeting or functions and therefore with the exception of the AGM and our group committee meetings to be held before the AGM, the committee feel that they would serve better by adopting a reactive approach to member needs, rather than a proactive approach as we have attempted to do in the past.**

**Changes to the newsletter and its content was felt to be a positive step forward especially for those members who have mobility difficulties and/or very little interest in using or owning a computer. For those members who are computer and internet friendly then our web sites are worth a visit and contain many links to other recommended lupus sites.**

**It is my intention over the early part of next year to make improvements to our web sites and add topics that lupus sufferers may find useful.**

**The committee have agreed the venue and location for the groups AGM in 2010. The AGM will be held at the Holiday Inn Nottingham on Sunday 11th April 2010 commencing at 2.00pm. Mr Chris Maker Director of Lupus UK has agreed to attend the meeting and will be available to answer questions from members immediately following the main business of the AGM. We look forward to seeing as many of our members as possible at our AGM. More details regarding this event can be found inside this newsletter.**

**Please spare a thought at this festive season for those friends and colleagues who have been affected by the abnormally heavy rains and high winds., and other traumas.**





A Letter from a Lupus sufferer to the Cambridgeshire Lupus Group is most worthy of a place in our newsletter. We thank the Cambridgeshire Group for sharing this information and especially the author of this excellent description of living with Lupus

## Dear Friends

My illness is a difficult one to understand, even for me. Many of the problems it causes are invisible and difficult to anticipate. I need you to understand that my life is always subject to change because of the unpredictable nature of the illness.

First, let me explain the depth of this illness:-

- My joints and muscles are under constant attack and can be very sore and painful.
- My skin is very sensitive to touch, heat or cold and even sunlight.
- My vision, hearing, sense of smell and sense of taste all can be affected.
- The fatigue I get can be overwhelming and on some days simply walking two feet can seem like a marathon.
- My skin, brain, kidneys, lung, heart and liver can all be damaged by the illness and its treatment.
- There are emotional side effects as well like depression, memory loss and difficulty with concentrating.
- The medication I take has side effects and may make gain or lose weight making a change to my appearance.
- I may need to use walking aids or sometimes even a wheelchair, other times I may need no Help.
- I might not be able to drink alcohol or eat certain foods because of my medication or illness.
- The illness is here for the rest of my life, sometimes I may seem well and other times I could be very ill.

This is all because my immune system doesn't work correctly anymore. It has turned against my own cells and tissues instead of protecting me from infection. Sometimes I will go into remission and do pretty well for a while and at other times I will have flares and things will get very bad. I can't tell when a remission or a flare will happen.

There are some things you can do which would make it much easier for us and I would be grateful if you would take the time to read this and try to understand. I will have good and bad days and many days in between. I can't always tell from one day to the next, or even one hour to the next, how well I will be, so please be forgiving when I must change plans suddenly. Some days I will have all the energy in the world and the next day I will be half-dead. Its just the way things are so please don't say, "you were okay to do this yesterday". I just can't help it.

Please don't judge me as a complainer or a person making more of their illness than seems necessary. Many of these problems are invisible so please be patient, understanding and compassionate. I try to be happy and enjoy myself. This doesn't mean I am physically better but that I am coping. My health will never be "back to normal", as "healthy" and "better" will always be relative terms for me. Remember me, call me and most of all visit me. Please don't try to tell me that I need more exercise, or to get out and about. A simple illness or virus can be quite devastating so please let me know if you have a contagious illness like a cold or flu.

Please don't belittle my pain and fatigue as it upsets me. I often wish that I could have pain as a result of doing something that I enjoy. Please don't tell me that I need to lose weight. The medication that I take makes me gain weight, increases my appetite, and changes the way that my body stores fat. I don't choose to be down and miserable but depression is part of this illness. It is common in this illness to have moments when your memory is poor or it is difficult to think clearly. These moments will pass and if it is important then please get me to write it down as I feel terrible when I forget.

Little things like keeping in touch can make a huge difference. Friendship is the most important therapy I have. All in all, I need you to realise that I am the same person I have always been. My heart, soul, hobbies, interests, sense of humour are all still there. Please accept me the way I am, please forgive me for the things that have changed. Try to accept that I am not in control of what the illness is doing to me. Please forgive me if I forget things or let you down in any way. I know these changes are hard on everyone and I wish it could be different for us all. With time, compassion and love, things will eventually settle down..

Lots of Love  
from a Lupus Sufferer.





## LOCAL NEWS UPDATE

### Our Local news Update

It was sad to see that nine of our members failed to pay their subscriptions to Lupus Uk by the closing date of the end of September. Fortunately the news was not all bad and we are pleased to welcome into our fold two new members who have joined Lupus UK during the year.

Would all our members please note that the membership year is January to December regardless of which month you joined the organisation. For example, all the new members who have joined Lupus UK in the past few months will need to renew their subscription in January for the year 2010.

In September we were invited to stand at a charity function held in the Civic rooms at Mansfield District Council. Sixty one organisations mainly based in Nottinghamshire were represented at the function. The afternoon held something for everyone from healthy eating to computer based exercises, suitable for all categories of disability and using the latest technology and software. The stands offered a wealth of information covering a wide range of diseases, infirmities, and helpful advice to those people seeking financial or material aids.

October was Lupus awareness month. Our secretary Gill Woodford concentrated her efforts at the QMC in Nottingham and during the month restocked the leaflets on a regular basis.

At the beginning of October my wife and I held an information stand at the entrance to the rheumatology department at Kings Mill hospital. Later on in the month we ran a information stand and fund raising stall for the Kings Mill open day.

Mrs S Spencer from Sutton in Ashfield organised a fund raising event at her home and presented the group with a cheque during the Kings Mill open day. We thank Mrs Spencer for her contribution and any other members who have done similar that we are unaware of.

In November Mr & Mrs Woodford (on the behalf of the East Midlands Group ) attended a dinner/dance fund raising event held in Nottingham. The request for assistance was initiated by Charmaine Brown, a Lupus sufferer from Nottingham, who approached Lupus Uk. Gill gave a short talk about lupus and is in regular touch with Charmaine. We are hoping that Charmaine will join Lupus UK as she is very interested in becoming a telephone contact.

Following up on a request from Radio Derby Linda and I were invited to a staff meeting to give a short talk about lupus. One of the staff had recently been diagnosed with lupus and it was a request from Radio Derby to Lupus UK to provide someone to speak on the topic. We were made welcome by the editor of Radio Derby and had a short meeting in his office prior to the staff meeting, which included the lupus sufferer. We opened the staff meeting with the short talk, distribution of posters and information, and left the meeting immediately after. I received an email of thanks later in the day and the feedback from the editor after discussion with his staff was encouraging and positive. We were happy to do this because it opens doors to an important media that can raise awareness of our condition to thousands of people.

Nothing further is planned by the committee before the AGM in April. We are always available to our members and local hospitals for providing information and stands on request.

Please visit our websites which often contain alternative information to that contained in the newsletter. This newsletter will be available on the web sites after all our members have received theirs. Our websites can be found at:-

Web address

[www.emlupus.com](http://www.emlupus.com)  
[www.emlupus.co.uk](http://www.emlupus.co.uk)

[www.emlupusgroup.co.uk](http://www.emlupusgroup.co.uk) (under reconstruction)

Two of the Three sites are normally available (unless the server is down temporarily)

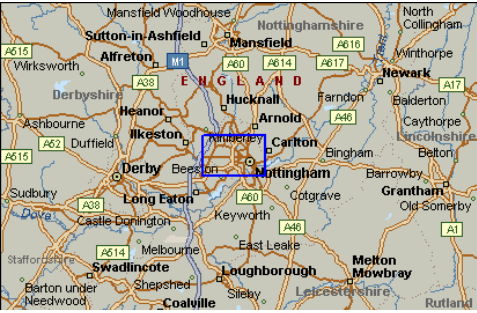




# East Midlands Group AGM April 2010

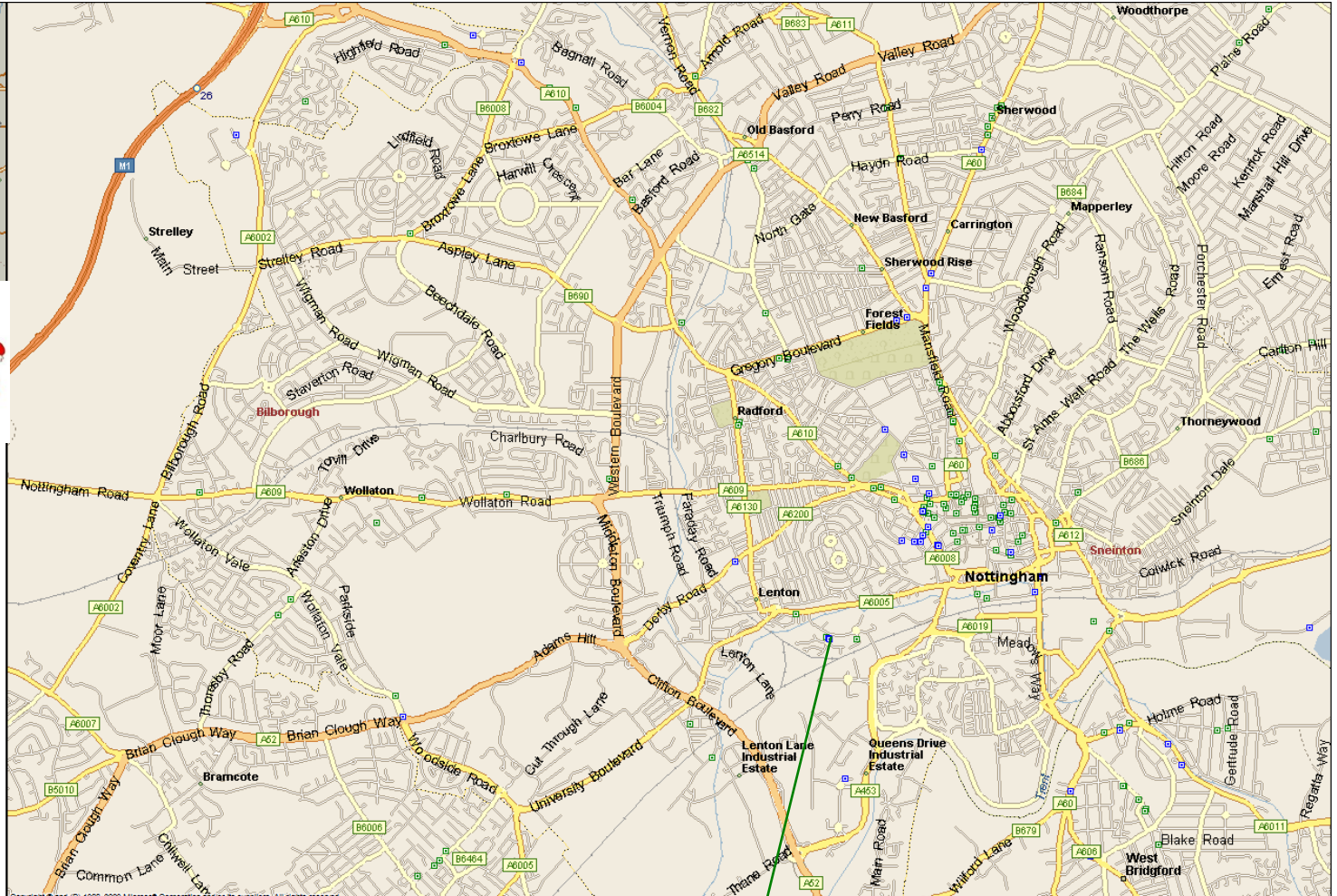


The AGM will be held on Sunday 11th APRIL 2010 at the Holiday Inn, Castle Bridge Road, Nottingham, commencing 2.00pm



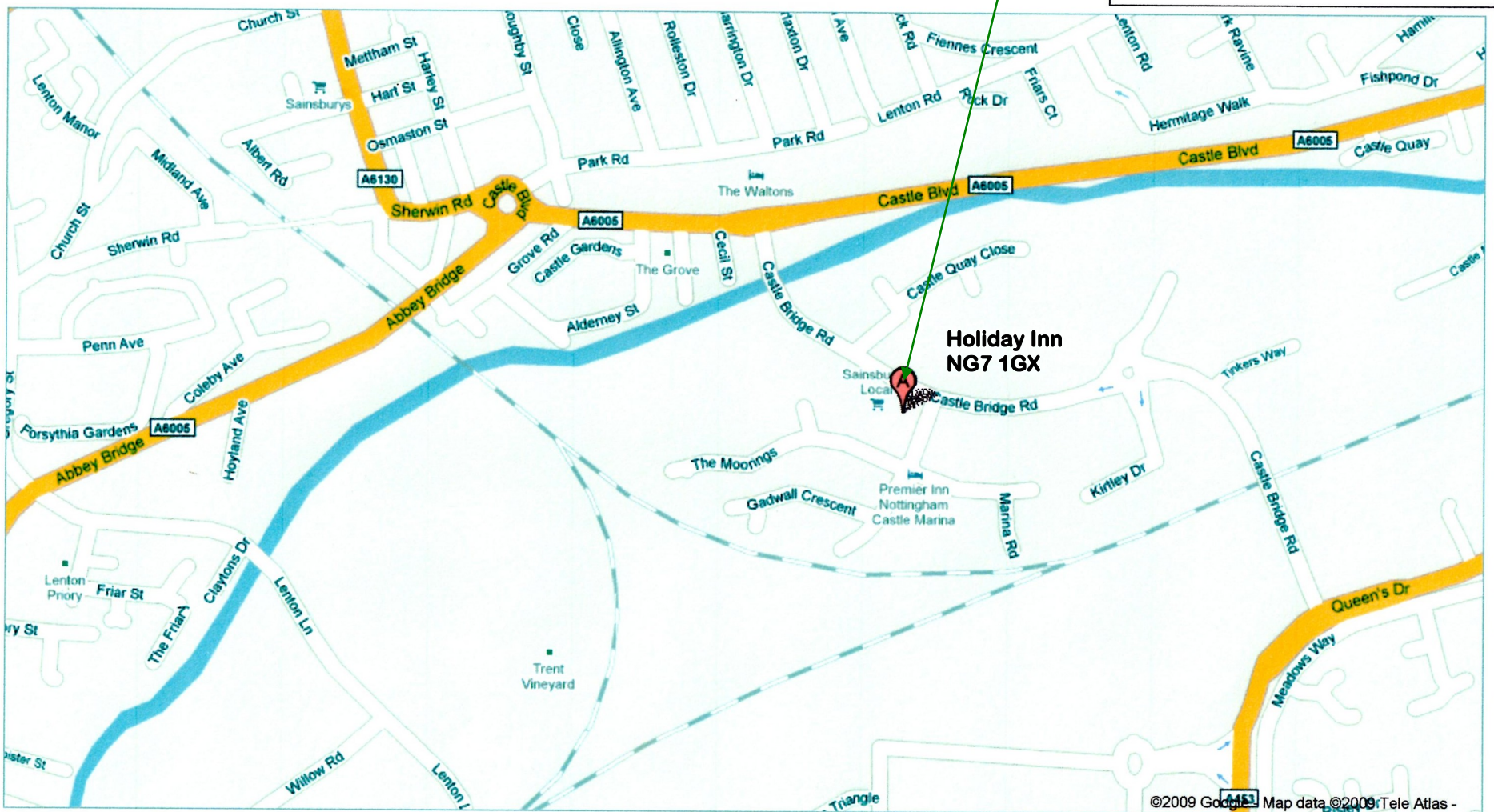
We would like to extend a warm welcome to all our members at your 2010 AGM.

Mr Chris Maker, director of lupus UK has accepted our invitation to attend and will be available to comment on any queries that the membership would like to ask after the conclusion of the main business of the AGM



Google maps Address

To see all the details that are visible on the screen, use the "Print" link next to the map.



The directions to the AGM venue can be found from the maps shown above. For those travelling by car the hotel has good parking facilities at the rear. The venue is approximately 1 mile from the train and tram station. Tea and coffee will be provided to guests as they assemble for the meeting. Please make that extra effort and support your committee who spend many hours of voluntary work to raise funding for lupus UK as well as providing information and support to other fund raising ventures.

For more detailed maps with direction visit Google Maps and enter NG7 1GX and click search.

Take this opportunity to have your say, influence how we operate or even join our team.



## Extracts of interest from our Lupus colleges in Europe

**Prof.med Matthias Schneider**

### **OUR MEDICAL ADVISOR WRITES**

#### **BENLYSTA™**

##### **Successful in Second Pivotal Clinical Trial**

Human Genome Sciences (HGS) and GlaxoSmithKline(GSK) today announced positive results from BLISS-76, the second of two large-scale phase III clinical trials of BENLYSTA™ (belimumab) for treating systemic lupus. A full presentation of results from BLISS-52 was recently shared at the 73rd Annual Scientific meeting of the American College of Rheumatology. Both trials succeeded in meeting their primary endpoints, which should make BENLYSTA eligible for approval by the U.S. Food and Drug Administration (FDA).

Both trials demonstrate that treatment with BENLYSTA plus standard of care was superior to that of placebo (inactive agent) plus standard of care. BENLYSTA significantly reduced disease activity. If approved by the FDA, BENLYSTA would be the first drug ever developed and approved specifically for the treatment of lupus. Sandra C. Raymond, President and Chief Executive Officer of the Lupus Foundation of America (LFA) issued the following statement.

"We are truly excited to receive this groundbreaking news! Individuals with lupus and their families have waited more than 50 years to hear that it is possible to develop therapies that control the disease. We believe that this is a significant first step in developing the full arsenal of therapies and personalized treatment lupus requires. "Conducting clinical trials in lupus has been extremely difficult due to many factors including the heterogeneity of the disease, the selection of appropriate clinical trial endpoints, and the confounding role of required background medications given to clinical trial participants. Human Genome Sciences and GlaxoSmithKline have proven that these barriers, while formidable, can be overcome. "For decades the entire lupus research community has worked hard to better understand the causes and consequences of the disease. The fruits of that labour are starting to emerge. However, now is not the time for complacency. We must band together for lupus and continue to capitalize on the decades of research made possible through the efforts of the many dedicated researchers, physicians, people with lupus, and advocates.

"This announcement by HGS and GSK and the *Overcoming Barriers to Drug Development in Lupus* report, commissioned by the Lupus Foundation of America to outline recommendations on ways to overcome the barriers to lupus research, combine to serve as a call to action for a national coordinated effort to accelerate the pace of discovery, to develop more tolerable and effective treatments, and to ultimately find a cure for this perilous disease. "We congratulate HGS and GSK on reaching this important milestone in lupus research and in the development of new therapies for lupus. We also extend our appreciation to the researchers and study volunteers who made this achievement possible: the physicians who have passionately committed to researching this disease, and the companies that continue to invest in finding new and necessary treatments for this devastating disease."

The next step in the process is for HGS and GSK to submit marketing applications in the United States, Europe and other regions during the first half of 2010. The LFA will closely follow this process, and continue to keep its constituents apprised of developments.

**With acknowledgement to  
LUPUS FOUNDATION OF AMERICA**

#### **Vaccination**

During the last weeks the most often asked question in my office and on the phone was "Should I, as a patient with lupus, get a swine flu vaccination?" I do not know whether all European countries had the same campaign for swine flu vaccination, a hype with tendency to hysteria. Without better knowledge, I referred to the recommendation of the German official agency (STIKO) who advise a vaccination against H1N1 influenza for all people with chronic diseases that may affect immune system function. In parallel, one of my patients, a lady in the end of her 50's with a history of more than 20 years of lupus treated with 10 mg methotrexate weekly and 200 mg hydroxychloroquine daily, developed septicaemia from pneumococcal pneumonia. By early detection and luck she survived from the multi-organ failure. Vaccination in lupus has several pathophysiological aspects and also plenty of rumours. Vaccination is the administration of antigenic material (the vaccine) to produce immunity to a disease.



## Extracts of interest from our Lupus colleges in Europe

Vaccines can prevent or ameliorate the effects of infection by a pathogen. Vaccination is generally considered to be the most effective and cost-effective method of preventing infectious disease and we know that - due to the often necessary immunosuppression - infectious diseases are under the major risk factors for death in lupus patients. From this perspective, every patient with lupus should be vaccinated at least according to recommendation for healthy people (Tetanus, Diphtheria and Poliomyelitis; for adults over 60 years Pneumococci and Influenza). The EULAR recommends in addition a vaccination against Hepatitis B. In patients without spleen or with asplenic syndrome (a rare manifestation of lupus) vaccination against Pneumococci, Haemophilus influenzae and Meningococci are suggested. We also recommend this triple vaccination for lupus patients that are going to be treated with rituximab. This brings us to another aspect of vaccination in lupus patients: do patients with lupus benefit from vaccination? It is obvious that in a situation with complete B cell depletion, as under rituximab and/or cyclophosphamide, the response of the immune system that is necessary in active vaccination for a successful protection against the target virus/bacteria is insufficient. That makes a prior vaccination before therapy mandatory. There is data showing that under other immunosuppressive medication like azathioprin or methotrexate the overall success of vaccination may be reduced compared to healthy people but the studies indicate that there is overall no higher risk for side effects due to vaccination in lupus patients. The fear for more side effects in lupus is based on the immune system stimulating effect that is inherent in active vaccination that may also boost the existing pathologic autoimmune reaction of lupus. We also asked our patients in Germany for the vaccination status and their reactions to vaccine application. These data also indicate that the recommended vaccinations are safe in lupus patients, but they also show us that the vaccination status in our patients is poor. The vaccine used in Germany for H1N1 Influenza contains a booster substance that unspecificly stimulates the immune system. The effect of this booster is not investigated in autoimmune patients and, therefore, this vaccination has to be evaluated carefully.

Some vaccines contain live, attenuated virus microorganisms. Examples include yellow fever, measles, rubella and mumps. These are live micro-organisms that have been cultivated under conditions that disable their virulent properties. They typically provoke more durable immunological responses and are the preferred type for healthy adults. These vaccines with live microorganisms are contraindicated in patients under immunosuppression. There is one other aspect of vaccination that may, hopefully, come up for lupus patients sometime. The ultimate goal in the treatment of autoimmune diseases is to re-establish tolerance to self antigens. One strategy to induce tolerance is to express the target autoantigen by DNA vaccination. This is tried already in experimental autoimmune encephalomyelitis, unfortunately, with the opposed results: the animals exhibited a disease exacerbation. This shows us that there is lot to learn for us to understand the human immune system completely.

For today, the recommendation for patients suffering from lupus is that they all should pick up their vaccines record card and discuss with their primary doctors and their lupologists their vaccination status and its improvement. Protection is far better than suffering from infections that may activate your lupus or may be lifethreatening.

**Prof.med Matthias Schneider (author)**

### Fact Sheets

Did you know that Lupus UK provides a wide range of fact sheets which are available to all members on request. These fact sheets cover the following topics:

Lupus— Incidence within the community	Lupus—& The Feet
Lupus—A guide for Patients	Lupus—Fatigue & Your Lifestyle
Lupus—Systems & Diagnosis	Lupus—& Men
Lupus—The heart and Lungs	Lupus—& Light Sensitivity
Lupus—& the Brain	Lupus—& Pregnancy
Lupus—& the Kidneys	Lupus—& Blood Disorders
Lupus—The Joints & Muscles	Lupus—& Laboratory Tests
Lupus—The Skin & Hair	Lupus—& Medication
Lupus—The Mouth, Nose & Eyes	Lupus—& Mixed Connective Tissue Disease
Lupus—& Associated Conditions	

Apply to: Lupus UK, St James House, Eastern Road, Romford, Essex. (RM1 3NH) Tel 01708 732251



## Miscellany (Sundry Items)

### BANANA BREAD

4 brown bananas  
 210g caster sugar  
 1 tspn of vanilla essence  
 1 tspn of cinnamon  
 1.25 tspn of baking powder  
 0.25 tspn of bicarb soda  
 2 eggs  
 50g butter  
 300g plain flower

Pre-heat the oven to 350F/180C  
 Mash the bananas in a large mixing bowl until smooth and then combine all the other ingredients again mixing until smooth.  
 Pour contents into a large greased loaf tin.  
 Bake for approximately 1 hour. Stick a skewer into the centre of the cake to check if it is cooked. When the skewer comes out clean then the cake is ready. Eat and enjoy.

 *What do you call two robbers?*  
 A pair of Knickers

### THE LIGHTER SIDE OF LIFE

Sign on a garden gate: "All salespersons welcome! Dog food is becoming too expensive!"

Sign on a plumbers truck: "We repair what your husband fixed"

Sign on a plumbers truck: "Don't sleep with a drip. Call your plumber."

Sign on a septic tank truck: "Yesterdays meals on wheels."


Vet's waiting room: "Back in 5 minutes. SIT! STAY!"

### The thoughts of 7 year olds

"If you are surrounded by sea, you are an island. If you don't have sea round you then you are incontinent."

"When ships had sails, they used the trade winds to cross the ocean. Sometimes when the wind didn't blow, the sailors would whistle to make the wind come. My brother said they would have been better eating beans."

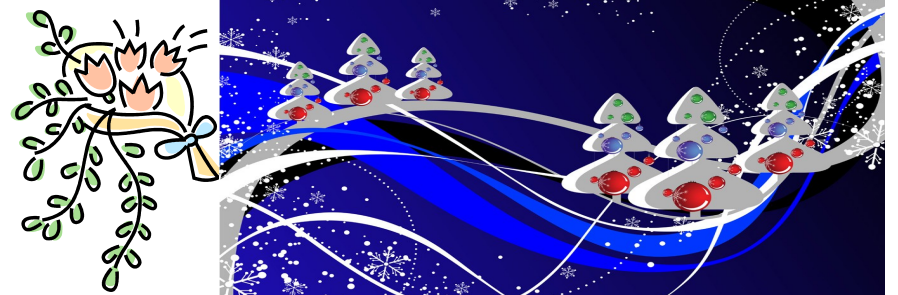
"Divers have to be safe when they go under the water. Two divers can't go down alone. They have to go down on each other."

 *What do you get if you cross a fish and two elephants?*  
 Swimming trunks.



We would like to inform our members that your treasurer for the East Midlands Group (formerly Linda Skinner) and her partner Mike married in December. We wish them both a long and happy life together.

Congratulations Mr & Mrs Herbert



### The East Midlands Committee

Chair	Brian Kimberley	chair@emlupus.com	01623 552834
Secretary	Gillian Woodford	secretary@emlupus.com	0115 9374168
Treasurer	Linda Herbert	treasurer@emlupus.com	0115 9253807
Membership Secretary	Linda Kimberley		01623 552834

### Committee Members

Kathleen Baker

Sharon Mousley

Correspondence address 9 Saville Road, Skegby, Sutton-in-Ashfield, Notts. (NG17 3DF)

### HERBS

#### The "Green First Aid Kit

Aloe:	Apply the gel from inside the plant to treat minor burns, sunburn and rashes.
Goldenseal Powder:	Sprinkle onto an infected cut
Witch Hazel:	protects broken skin from infection. Cleans wounds and aids healing.
Arnica:	Eases pain, swelling and discolouration of bruises. Do not use on broken skin.
Dried chamomile flower:	Chamomile tea eases digestive discomforts, calms anxiety, relieves insomnia, and eye infections.
Gingerroot:	For nausea or motion sickness.
Echinacea:	For treating colds, flu and infections.
Tea tree:	Dilute the tea tree oil with vegetable oil to fight fungal and bacterial infections in cuts, athlete's foot.

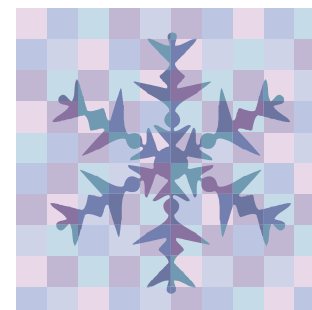
## East Midlands Group Contacts



Gill Woodford	(Keyworth Notts.)	01159 374168
Linda Kimberley	(Sutt-in-Ash Notts,)	01623 552834
Sylvia Massey	(Loughborough Leics.)	01509 266389
Margaret Lawrence	Markfield Leics.)	01530 242837
Chris Neville	(Loughborough Leics)	01509 260631

### National Young Contacts

Helen Salter	01283 544407
Stephanie Matthews	01912 645634



### Internet sites for Useful Information

LupusUK <http://www.lupusuk.org.uk> (raise funds for lupus by using this as your home page & search engine). You can earn our charity up to £50 pounds a year.

British Sjogrens Syndrome Association (BSSA) [www.bssa.uk.net](http://www.bssa.uk.net)

Hughes Syndrome Foundation [www.hughes-syndrome.org](http://www.hughes-syndrome.org)

Lancashire & Cheshire Lupus Group [www.lclupus.co.uk](http://www.lclupus.co.uk) (Light sensitivity Information)

West Midlands Lupus Group [www.westmidlandslupus.co.uk](http://www.westmidlandslupus.co.uk) ( our nearest neighbour )

The lupus group sites shown above have links to other Lupus groups. Please visit all our sister lupus group sites as they cover a wealth of information that I am sure all our members will find useful.

Other useful sites will be included in our next newsletter (Spring Addition).



## General Information



*Don't forget that the new Lupus Membership Rates are (Single £10.00 and £15.00 per couple). With your help we can continue to improve the quality of life for lupus sufferers.*

*Are you proficient with using a computer? If anyone would like hints, tips, or basic advice then please email or phone me (chair) as I will be very happy to assist.*

*The National Convention/AGM will take place in Harrogate ,Yorkshire on Sunday 9th May 2010. I look forward to possibly seeing some of our members at this event. If you have never been to a National Convention then please make the effort as you will not regret this day out.*

*As I have previously stated and truly believe, the internet will continue to increase its influence as the major source for communication and information to lupus members. I would therefore like to request our new members, or any member, to provide me with their email addresses. This information will be kept strictly private and not shared with anyone.*

*Can we please persuade any of our Derbyshire and Lincolnshire members to consider becoming a telephone contact. It entails a short weekend residential course conducted by Lupus UK. We would also be delighted if any of our younger members would be interested as young people who are diagnosed would often prefer to talk with people in their own age bracket. Anyone wishing to discuss the contacts course can gain more information by ringing Linda Kimberley.*

*Some of the material in this newsletter has been re-cycled from our lupus family. My sincere thanks go to our sister groups who kindly allow the use of material from their group newsletters.*

***We would like to wish a happy new year to our members and lupus sufferers everywhere***