

# Silver Jubilee 1990-2015



LUPUS UK - A Personal Retrospective  
*by David Hopkins*





**When I took on the position of Secretary of LUPUS UK I was handed a large and heavy file; this contained the minutes of all the meetings of LUPUS UK. On**

**looking through, I saw that the first meeting was held in late 1990 – meaning that this year of 2015 marks our Silver Jubilee. The Trustees agreed that this milestone should not go unmarked. It fitted with plans to review our 'corporate' image and the constitution. So 2015 marks an end to one chapter in our history and the beginning of the next phase of our growth.**

But let's not jump too far ahead. In fact, I feel it is important to look back and see what has brought us to the point at which we now find ourselves.

In November 1990, LUPUS UK opened the doors of its National Office for the very first time. This was clearly an event of great importance for all involved at the time and in subsequent years but it is important to realise that this was not something that just 'happened'. The creation of the only national charitable organisation dedicated specifically to supporting lupus patients was a development of something that had begun a dozen years earlier, when one woman, having been diagnosed with SLE, felt she needed to meet with, seek support from and offer support to others in a similar situation.

Imagine the situation - it was 1971 and a young woman had just enjoyed one of the most important and happiest days of her life, her wedding, to Martin. On her 'honeymoon in the sun', the symptoms she had had for some time became far more pronounced. Not the start of a 'new life' any of us would want. The young woman was Cheryl Marcus and her father was GP Benjamin Green. His knowledge led to her diagnosis (initially of discoid lupus, later of systemic lupus) and the beginning of a long story of struggle and of achievement, one that is worthy of far more space than this article can offer. So I shall pick up on a few points, based on correspondence, articles and photographs that Cheryl has kindly shared with me. For these I am immensely grateful, as I am for her time, help and patience. Reading through the material has given me hours of fascinated interest. This applies, too, to Professor Graham Hughes, who shared with me some of his very valuable time and his memories. Others have also added to my 'source

material' and my thanks go to all of them.

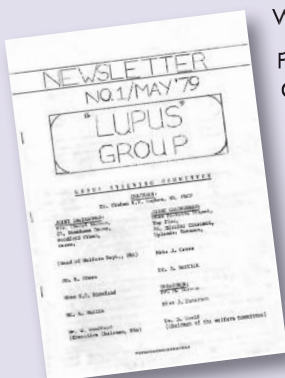
Years of misery followed for Cheryl, including many months in hospital, though the arrival of son Daniel was a huge boon. Then, in 1976, Cheryl met Graham Hughes and, as she put it, 'a new chapter in my life began'. This was later to include a two-and-a-half pound baby boy, Jonathan; he eventually grew to be six feet three! But I digress. During her illness, Cheryl began to wonder if there were others with this condition with whom she could communicate. So early in 1978 she contacted BBC Radio London; this led to an interview and her appeal for others with lupus to contact her. That's where the story of 'lupus support' really begins, for little could Cheryl have realised what she had started. Letters and other contacts were received and Cheryl realised she was not alone. 'I felt like Robinson Crusoe finding Man Friday' was how she described it.

Gradually, Cheryl began to build up a group of lupus patients and supporters and a link was made with The British Rheumatism & Arthritis Association (now 'Arthritis Care'). On 1st December 1978, the inaugural meeting of the British SLE Aid Group (BSLEAG) was held in Langham Place, London, where the guest lecturer was Dr Hughes, and the Joint Presidents were Cheryl and Joyce Cross. In April 1979, the first fundraising event, a Spring Fayre, raised £4,000 - quite a sum in those days! This was followed by a supper at the Westcliff Marina (financially successful but which attracted too many people!) and then a dinner/dance in April 1980. In 1981 the Group became a registered charity.

Some years later, it was felt that the next step (and it was quite a big step!) was to form a charity that would be solely for lupus patients and their families, rather than be linked with a charity with a much broader base. After a series of meetings, LUPUS UK came into being in November 1990 and in December 1995 became a registered charity.

On Friday 5th April 1991, there was an official 'launch' of LUPUS UK with a reception at the Royal Court Hotel, Sloane Square, London, hosted by the first Chairman, Dr Graham Hughes, at the commencement of Lupus Awareness Week 1991.

From the outset, Cheryl had produced a 'newsletter.' This started in 1979 as a simple duplicated sheet, sent out to 20 lupus penfriends. Over the



period until she retired as Editor in 2002, Cheryl was to make this into the publication we now know as 'News & Views,' which reaches thousands. Another remarkable achievement in her personal lupus story!

In 1983, Cheryl had the pleasure of meeting Diana, Princess of Wales, when the Princess visited Dr Hughes and his team at Hammersmith Hospital. Princess Diana chatted informally to staff and then to



patients. The visit received extensive media coverage, raising awareness about lupus amongst the general public. Cheryl's youngest son Jonathan was referred to in the media as a 'miracle baby' as Mum had spent five years confined to a wheelchair. After presenting his bouquet, Jonathan also gave the Princess his bottle and teddy bear! Cheryl apologised to Princess Diana for the 'boisterous' behaviour; her reported response was: 'He certainly looks a bundle of fun. I understand perfectly – Prince William is a mini-tornado!' A comment we may remember at a coronation of the future!



**Nora Vanday fulfilled her dream to meet Diana. Diana unexpectedly visited the ward meeting other lupus patients.**

In 1994, Cheryl was nominated to attend the Savoy Hotel as one of 500 women



recognised that year for their work for charity, the economy or the country. In 2005 she and Martin were invited to 'Number 10' by Cherie Booth, wife of then



Prime Minister Tony Blair, and in 2009 she again went to Number 10 for the LUPUS UK reception hosted by Sarah Brown.



A key figure in the pre-LUPUS UK history and through its development is Doctor, now Professor, Graham Hughes. Professor Hughes is a very important figure in the study and treatment of lupus. After training in London and New York, in 1971 he set up



a lupus clinic and lupus pregnancy clinic at Hammersmith Hospital, London. In 1985 he moved his team to St Thomas' where he established the Louise Coote Lupus Unit,



described as Europe's first 'dedicated' lupus clinic. This was opened by singing star Elaine Paige, herself a lupus patient.

In 1983 Dr Hughes described 'antiphospholipid syndrome', (APS) often called 'Hughes Syndrome'. (Not many people have a health condition named after them!) Many of our members will be only too aware of this condition and its effects. In 1991 Dr Hughes became Editor of a new journal, which published its first issue in November of that year. 'LUPUS' is the only fully peer-reviewed international journal devoted exclusively to lupus (and related disease) research. Professor Hughes remains Editor. He is also on the board of many journals, a member of the American Lupus Hall of Fame and Doctor Honoris of the Universities of Marseilles and Barcelona and Master of the American College of Rheumatology. He and his team have many awards and honours. He currently heads the private London Lupus Centre.

Dr Hughes encouraged Cheryl to link with other lupus patients and actively supported the establishment and growth of the BSLEAG. When this moved on to become LUPUS UK, Dr Hughes chaired the inaugural meeting of the National Committee of LUPUS UK at the Drury Lane Moat House on Saturday 10th November 1990. This is where the LUPUS UK story truly begins.

On that afternoon, a group of more than thirty came together. Amongst the group were Cheryl and Martin Marcus, Ronnie Gourley and Peter Norton. There were apologies from wife Yvonne. At this November meeting it was agreed that a new unified Society be formed which combined research and welfare. It was made clear that the Trustees of BSLEAG (a registered charity) had no desire to interfere with the new body or with the regional groups, of which there were now quite a few. Through his company, Martin Marcus offered the use of a free office and telephone in Eastern Road, Romford. (Our current office is just along the same road!) BSLEAG member Eric Howard had recently retired and offered to run the office. The staff would all be volunteers. Initially the Trustees would provide £10,000 to run the organisation for the first year but after that the costs would be met by LUPUS UK through its own activities and those of the groups. Up to this time, all money raised had gone to research. Now running costs of the organisation and 'welfare' were factors.

It was at this meeting that the name 'LUPUS UK' was adopted.

Up to 31st October 1990, all money held had belonged to Arthritis Care (later, Arthritis Care said that groups could retain their funds); from November, any money

collected went to LUPUS UK directly or was part of local funds. Dr Hughes was elected Chairman and the meeting unanimously agreed that Cheryl Marcus be made a Life Member of LUPUS UK.



When the Executive met, in January, 1991, it was confirmed that those working as volunteers at Head Office were Eric Howard (pictured) and three part-time staff, including Geraldine Leonard. Several others

worked from home. A constitution was under consideration and officers were elected - Vice-Chairman: Ronnie Gourley, Treasurer: Martin Marcus, Secretary: Doreen Milner. A programme for 'Lupus Awareness Week' was considered for 6th-13th April. It was suggested that the AGM alternate on a three-yearly basis between London, Birmingham and Glasgow/Edinburgh. (Later, in 1994, it was decided to move the AGM around the country.

The next meeting was held in September, when there were representatives from:

Avon, Central England, East Midlands, Essex, Fife/Lothian/Borders, Greater Manchester, Hampshire, Herts & Beds, Kent, Merseyside, North East, Northern Ireland, South Wales, Strathclyde, South London/Surrey, West Midlands and Yorkshire. This was the first 'representational' meeting of LUPUS UK. Gerald Ansell became Secretary. A 'Young Group,' for 16 to 30s, had been started in the March. Eric Howard was given the courtesy title of Director. In April, 1992, the Third International SLE Conference was to be held, in the UK, in London. The LUPUS UK AGM would be held during the Conference on one of the days.

In April, 1992, Ronnie Gourley was elected Chairperson, Gerald Ansell and Martin Marcus were re-elected as Secretary and Treasurer respectively and a new Vice-Chair was elected: Yvonne Norton; she stills holds this position. Eric left the role of Director and Brian Hanner, who was initially engaged as a fundraiser, took on the role. The small staff was now paid, with support supplied by volunteers.



Left to Right: Brian Hanner (Director Lupus UK), Martin Marcus (Treasurer), Neil Buchanan - Consultant Royal Hampshire - Rheumatologist, Ronnie Gourley (Chairman)

The next milestone was when LUPUS UK became a registered charity. This happened on 29th December 1995. The assets of BSLEAG were officially transferred to the new charity. By 1996 there were three full-time staff, including then Director Brian Hanner and Geraldine Leonard, with three part-time staff, including Janine Hirsch and Mary Phillips. Geraldine, Janine and Mary remain valued members of staff.

In 1997 the first LUPUS UK video was produced, in conjunction with Dr David d'Cruz; Janet Dean was elected an MP and in November, 1999, she held a reception in the House to launch the All-Party Parliamentary Group for Lupus. Janet's mother had had lupus, as had her husband, Alan, who had died in 1994. These events gave her a personal and passionate interest in promoting awareness of the condition. (Unfortunately we have not been able to see the re-establishment of the APPG after Janet left Parliament in 2010 - but we keep hoping!)

In 2000, the book *A GP Guide to Diagnosis* (compiled by Yvonne Norton) was launched at a reception at the House, attended by MPs, peers, members of the medical profession, representatives of regional groups and other guests.



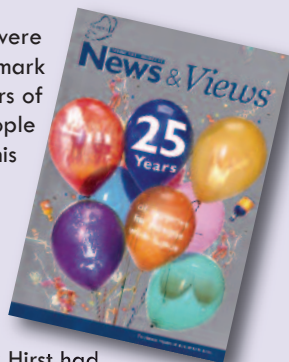
Subsequently LUPUS UK sent a copy to every GP practice in the country – a lot of work for our small staff! (In 2009, the revised version, *Lupus – Diagnosis and Treatment* - compiled and edited by Yvonne Norton (now MBE!) - was published.

In 2001 the Director reported that for the third successive year, income had topped £500,000 and grants awarded were higher than ever. Also that year, in March, LUPUS UK took a leading role in managing a successful 4th International Patients Conference in Barcelona. In October the official website was launched.

In 2002, 'Lupus Awareness' became a Month and was moved to October, in line, at the time, with the USA, Canada and Australia. Also in 2002, Vice-Chair Yvonne Norton presented Janet Dean with a LUPUS UK Certificate of Appreciation, whilst Janet

introduced an Early Day Motion in Parliament commending LUPUS UK for its work and calling on the government to raise awareness of lupus and invest in research into effective treatment of the disease. 322 MPs signed the EDM – half the House!

In 2003, there were celebrations to mark twenty-five years of 'support for people with lupus.' At this time Ronnie Gourley and Yvonne Norton were still in place as



Chairman and Vice Chair, Jack Hirst had become Secretary and Tony Rance was Treasurer. There were thirty-four regional groups on the list, with some 7,500 members. Group patrons included well-known personalities Max Bygraves (Dorset), Faith Brown (Herts & Beds), Ken Dodd (Merseyside - where else?), Su Pollard and Liza Goddard (Norfolk), Gareth Hunt (South London) and Sir Patrick Moore (Western). There were several MPs - John Gummer, David Jamieson, Liz Blackman and Joan Ryan.



**Actor Norman Bowler at the Reception with Janet Dean and Prof. Graham Hughes**

In October 2003 the second reception at the House of Commons was held (the first was in 2000) with representatives from groups joining MPs, peers and others. In 2003 and 2004, the Retief Goosen's Golf Challenge raised many thousands of pounds at golf clubs across the country and, of course, awareness. In 2003 the LUPUS UK Light Sensitivity Support Group was set up, with Brenda Ryder as co-ordinator. Janet Dean accepted an invitation to become a National Patron. Her



**l-r Paul, Mary, Geraldine, Chris, Christine, Janine and Hayley**

efforts did a great deal to raise the profile of lupus at the highest level, for which LUPUS UK remains extremely grateful.

At the centre of LUPUS UK's work is 'Romford,' home of our 'National Office.' Mention has



already been made of staff in the past so let's look at the staff we have now.

Janine Hirsch joined the staff in 1994, Mary Phillips in 1996 and Christine Watkins in 1997. In 2000 Chris Maker came on to the scene, initially as Deputy Director and then Director when Brian Hanner retired in 2004. So there is a wealth of experience amongst this group to create a strong foundation for all that we do. In 2011 Paul Howard joined the team; he has helped move us into the IT and social media age. Most recent member of the team is Hayley Winter. The word 'team' is important, because not only do all our staff have their 'specialist skills,' they all show that you can be a 'Jack (and Jill!) of all trades' and be a master of some. They are prepared to 'muck in' and do whatever happens to be needed at the time.

There is one name to be added to the list, that of Geraldine Leonard. November marks twenty-five years of service by Geraldine to LUPUS UK. She is one of a few people who were involved from Day One and who remain active in the organisation. You may know that Geraldine has decided that at the end of 2015 she is going to take early retirement and leave LUPUS UK. Of course, it is true that no-one is irreplaceable but when Geraldine leaves we will lose a wealth of knowledge, not just of the operations of LUPUS UK but of people, inside and outside the charity, with whom Geraldine has contacts and of whom she knows so much. She will be missed but we wish her well with her new 'job' as full-time grandmother and trust that she will get plenty of opportunity to share quality

time and experience with those dear to her. Though we know that ours is a small charity it is not unusual for surprise to be expressed when people learn just how few paid staff we have. This speaks volumes for their dedication and hard work. Many of us feel that LUPUS UK 'punches above its weight' and that much of this is due to the quality of our staff. So to all of them, an enormous 'thank you'. Not many may still be in place when the Golden Jubilee comes around but we know that their commitment will continue well into the future.

Two names that keep appearing in the LUPUS UK story are Yvonne and Peter Norton. Yvonne's role at the forefront of the charity is clear for all to see. She works tirelessly for her regional group as well as nationally and internationally. We marvel at her energy as she travels all over Europe, representing LUPUS UK and striving to take the best of what we in the UK can offer to groups who hold LUPUS UK in high esteem. Some may not realise the depth of Peter's role. Whilst he is there to support Yvonne (not just push her wheelchair!), the time, effort and expertise that he supplies is outstanding. Together these two make a



great team, a credit to themselves and to LUPUS UK. You may be aware that at the 2015 AGM Yvonne was made Honorary Life Vice-President of LUPUS UK and Peter an Honorary Life Member, both awards extremely well deserved. The importance of their work in and for LUPUS UK cannot be overemphasised.



As 2015 draws to a close, so does a period of nine years (three electoral periods) during which we have been led by Jane Dunnage as our Chair. Few know just how much time, effort and commitment

Jane has put into her role during those years or how much sacrifice she has had to make to carry out the tasks and objectives she has set herself. Despite the severity of her health problems Jane has represented LUPUS UK, lupus patients and the cause of advancing awareness of lupus with great diligence and fortitude, bringing awareness of the condition and the charity to a wide range of organisations and individuals. To

Jane, too, we send our thanks and best wishes for her future health and happiness in all she does. Jane will be succeeded as Chair by an existing Trustee, Kevin Weston from North Wales. Kevin has a wealth of experience in business and the voluntary sector and his expertise will help LUPUS UK over the next three years as it considers its future direction, its policies and its organisation at all levels.

Over the years, LUPUS UK has been well served by its Trustees. The Director and the staff run the 'organisation' and the day-to-day activities but it is the responsibility of



**Jane Dunnage, Yvonne Norton MBE, David Hopkins, Tina Stemp, Jan Roberts, Karen Newby, Kevin Weston and Janet McComiskey**

the Trustees to decide on the overall direction of the charity. The Trustees also make the decisions on grant applications, carefully weighing up each one and being guided by the advice of the Specialist Medical Panel. Recent events have made us all aware that things can go wrong with charities. However, members can be assured that our Treasurer and Trustees take a considered long-term view and always err on the side of caution. LUPUS UK 'reserves' are maintained at a level where we can fulfil all agreed grant applications and have enough 'in the kitty' to cover a full year's running costs. With the Director's financial background you can be sure that 'prudence' will always be present at meetings! Our fund-raising policy is ethical and transparent and beyond reproach: no mail-shots, no telephone calls or e-mails, no pressure. The trustees regularly and frequently monitor the activities of the charity to uphold the highest standards.

Birmingham hosted the AGM in 1993, after which we went to Renfrew, Shepperton, Harrogate and Cardiff, moving around the country until Chester hosted our final 'old style' AGM Day in 2013: a lovely city in which to end a tradition. We now have the



AGM followed by an 'Information Day.' With proxy voting, members can register their views on motions etc. However, the AGM can be more than just a vote-casting exercise. It is the chance to comment on what has been done and share your vision of the future. It is also the chance to meet trustees and staff (and vice versa) and 'meet and greet' other members.

Having two Information Days a year (one linked with the AGM) spread across the country, makes more financial sense. Hopefully this will bring together more people in an area than in the past and make people aware of the work of LUPUS UK. Since adopting this new method we have held these 'Days' in London, Devon, and Birmingham, with Northern Ireland and Scotland next on the list. Be sure your area gets included!

The Silver Jubilee will be celebrated by numerous groups, with a variety of events, including dinners and dances (in at least one famous football stadium and a hotel called a castle!), lunches, talks and more. Well done to groups able to take on board one or more celebratory activity.

LUPUS UK (that means us!) can take great pride in what has been achieved over the last twenty-five years. We fund small and specialist research projects which may lead to advances that will attract other funding for larger-scale research.

In 1992, LUPUS UK agreed grants totalling just over £80,000. From 1992 to 2000, grants agreed totalled £1.7 million and from 2001 to 2010 (inclusive) this figure was over £3.26 million. In the four years 2011 to 2014, we agreed £1.56 million. So from LUPUS UK Day One to the end of 2014, over six and a half million pounds (£6.5 million!) has been committed in grants!! Our grants programme already, late in 2015, commits us to funding projects until the end of the decade and every year we take on more projects and provide more financial assistance. For the four years from 2011 to 2014 the average annual commitment has been £445,000, so it is not unreasonable to expect to add another £2+ million by the end of the decade.

Not bad for a small, specialist health charity that does not draw the publicity given to many other charities and where

many members are far from healthy, mobile or able to fund-raise! I think that it is a record of which every member can be immensely proud. A bit of mutual back-patting is very much in order!

In recent years, great emphasis has been placed on funding specialist lupus nurses. Reactions indicate that where there are such specialist lupus nurses they are of great advantage to lupus patients and patient welfare is considerably directly enhanced.

LUPUS UK's group of 'Contacts' has been of great assistance to many people. We don't know how many have been in touch over the years but can be certain that the help and advice received has been of immense value. In expressing thanks to all those who have taken on this task we need to add the names of Geraldine Leonard, Jan Roberts and Linda Rumbles for the training they have prepared and presented in more recent years, drawing on their knowledge and skills to enhance the abilities of our Contacts. This training will of necessity change as greater use is made of the internet and social media and less emphasis placed on telephone calls. Times and needs change and we move forward with changes in practices.



**Cheryl Marcus surrounded by balloons at the launch of Lupus Awareness Day in 1988 at St Thomas' Hospital**

1990 doesn't seem that long ago but just think of the enormous developments we have seen in these twenty-five years. The



**Participants at a LUPUS UK Contacts' Course**

rate of change is likely to escalate not diminish; if our charity is to survive and our ambitions reach further success we cannot let the grass grow under our feet! This concept will need to be applied throughout LUPUS UK, through our Trustees, our staff and our regional and local structure. In the next ten years we are likely to see changes in charities and voluntary organisations we cannot imagine today.

LUPUS UK will not sit back on its laurels and just congratulate itself on what has been achieved, as there is still much to do. A major task is to raise awareness amongst health professionals. I know that I still hear 'horror stories' about the way in which lupus patients, and possible patients, are treated by health professionals. Some of these still have the 'it's all in your mind attitude' and people, even today, get referred to psychiatrists! Many cannot get a diagnosis. Whilst some people speak with great affection and appreciation of their GP or consultant (not often both!), many are left frustrated and confused. For me, one major issue is that so few health professionals tell lupus patients, particularly those newly-diagnosed, that there is national and local support. Is that their fault or ours? So we have identified one challenge – to seek to ensure that many more health professionals know about us and endeavour to get them to pass on information to those who might benefit!

In this article I deliberately chose to write about those 'pre-LUPUS UK' days as I felt it important (as well as interesting) that our members have some knowledge of the history of 'lupus patient support' in the UK. As members get older and new members come on board I would not want our 'past' to be overlooked or ever forgotten. Over the years we have established an organisation that is the envy of countries across the globe, showing a level of expertise and professionalism unmatched even in larger countries and organisations. The quality



**Prof Ian Bruce (left) receiving the Centre of Excellence plaque given to The Kellgren Centre for Rheumatology Manchester**

and variety of the literature we provide is outstanding, our 'Contacts' system is unique and the concept of 'Centres of Excellence' draws admiration.

Voluntary organisations throughout the country face similar challenges, as demands increase and there are fewer people prepared to give their time and energy to help. Only our staff at Romford are paid. Trustees, local committees and co-ordinators and everyone who works to organise events, raise funds or spread awareness – all are volunteers! Add to that the fact that nearly all have lupus themselves, often impacting very severely on their lives, and the enormity of the challenge can be seen. It is sometimes easy to say 'why doesn't someone...' and suggest an idea or activity; finding that 'someone' is far more difficult.

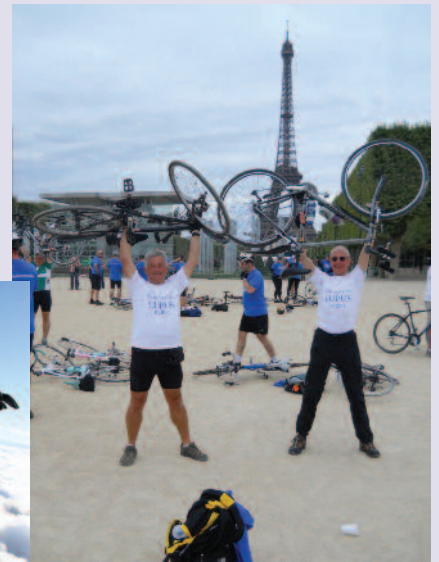


**National Patron Paul Moriarty helps the Sussex Lupus Group volunteers with a bedpush to raise awareness and funds for the Group**



**Essex Group members and friends regularly helped mail News & Views from National Office in Romford**

Thousands of people have been part of the LUPUS UK story over the last twenty-five years; each one has her or his own special story. It would take volumes to record all that has been shared and achieved. A few individuals have been mentioned in this article but no-one is forgotten! The history of LUPUS UK is the sum total of the parts



played by everyone. No record of that history would be complete without acknowledging all of you.

If the past inspires you, then think what you can do to inspire the future. Some of you will be doing as much as you possibly can but there will be some who may be able to offer to do a little more so that the burden is more widely spread. Ours is a self-help group! In those very early days, Cheryl Marcus felt alone and sought to bring together those with similar problems. In many ways, little has changed. Across the country there are people being told that they have lupus and wondering what that

will mean for their lives, how they will cope, who can they talk to, who will understand how they feel, who will be there to give encouragement, experience, knowledge and support. For twenty-five years LUPUS UK has been there to be the 'who' able to offer assistance and guidance. But remember that LUPUS UK is not only its trustees or its small dedicated staff in Romford - it is every one of us, the members.

As we remember the past with thanks for its inspiration, we consider the present and the opportunities it presents so that we can face the challenges of the future. You don't

have to start planning for the Golden Jubilee just yet but these are the moments to plan for today, tomorrow, next month and next year, and to think how much LUPUS UK has given to you and how much you can give to LUPUS UK and lupus patients in the days ahead.

**For lupus patients everywhere, known and unknown, diagnosed and undiagnosed, current and future - long may the work continue.**

**Happy Silver Jubilee!**

*David Hopkins  
November 2015*

# Past & Present



Sussex Group with Patron Paul Moriarty



Past contact Fiona Moore with National Patron Gwyneth Strong and Cheryl Marcus



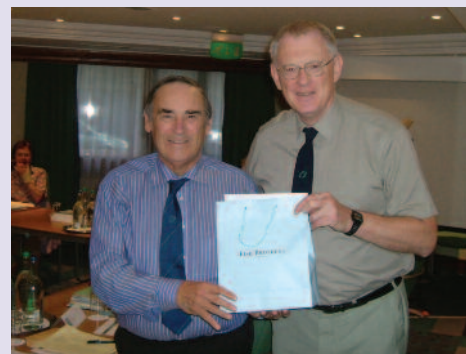
Celebrating the 50th Edition of News & Views



An early National Council Meeting



Epic walk - Lands End to John O'Groats



Ronnie Gourley retires



Martin and Cheryl Marcus with Rae Gourley



Brian Hanner's retirement gift from Fife, Lothian and Borders Group



West Midlands Butterfly Ball



Centre of Excellence Award at Queen Elizabeth Hospital Birmingham



Kent Patron John Sandon



Regular fundraisers, The Stort Folk Music Club



A regular Lunch4lupus event hosted by Linda Streeter



Lancashire Go The Extra Mile Event



Geraldine and Janine meet Lady Carnarvon at Highclere Castle