

30 Years - and Going from Strength to Strength

In 2015 we celebrated the Silver Jubilee of LUPUS UK. To commemorate that, the winter issue of News & Views magazine had a special supplement detailing the history of our charity and what had gone before. This article will summarise that history and set out what the last five years have brought. For more information on the earlier years you can read the winter 2015 issue on the LUPUS UK website at www.lupusuk.org.uk/silver-jubilee



Prior to 1990, the story is very much about one woman, Cheryl Marcus, and her herculean efforts, supported by husband Martin. Shortly after

their wedding in 1971, the symptoms Cheryl had been experiencing worsened. Her father, Benjamin Green, was a GP, and his knowledge led to a diagnosis of lupus, initially discoid then systemic. For the next few years Cheryl's life was very difficult, with periods in hospital; one ray of sunshine was the birth of son Daniel. In 1976 a new chapter began when Cheryl met Dr Graham Hughes; together they formed a partnership that was to change both their lives and indeed the lives of many more.



Cheryl contacted BBC Radio London and that was the start of her campaign to gain recognition and support for people with similar symptoms to hers. Letters poured in and Cheryl realised she was not alone. Gradually a network of patients and supporters developed across the UK and a link was made with The British Rheumatism and Arthritis Association (later 'Arthritis Care' and now 'Versus Arthritis'). In December 1978, the British SLE Aid Group held its first meeting, with Dr (now Professor) Hughes as guest lecturer. Cheryl and Joyce Cross became Joint Presidents. Cheryl produced a newsletter, a duplicated sheet sent to a few people; in time this became our News & Views magazine. Cheryl met Princess Diana at Dr Hughes' clinic in Hammersmith Hospital in 1983, when the Princess met several lupus

patients. Later Dr Hughes' new clinic at St Thomas' was opened by singer and actress Elaine Paige (who has lupus).



Dr Hughes remained a source of encouragement for Cheryl and on 10th November 1990 he chaired the inaugural meeting of the National Committee, which adopted the name LUPUS UK, with over thirty representatives from across the UK; one of whom was Peter Norton, who brought apologies from Yvonne as she was unable to attend. At this meeting Dr Hughes was elected as Chairman and Cheryl was made an Honorary Life Member. An office was opened in Romford (in the same road as our current office!), staffed by volunteers, including Geraldine Leonard. A constitution was established, officers elected and financial arrangements made. In 1992, Ronnie Gourley was elected as Chair, Yvonne Norton as Vice-Chair, with Brian Hanner (pictured) becoming Director, and there was a small, paid staff, supported by volunteers. In December 1995, LUPUS UK was registered as a charity. Current staff members Janine Hirsch (1994) and Mary Phillips (1996) were employed, to be joined later by Christine Watkins (1997). Their loyalty and experience continues to be greatly valued.



In 1997, the first LUPUS UK video was produced. Janet Dean MP (whose mother and husband had lupus) set up the All-Party Parliamentary Group for Lupus. When Janet left Parliament in 2010 the Group ceased and to date no MP has taken on the task of re-establishing it. In 2000, 'A GP Guide to Diagnosis' was published. Compiled by Yvonne Norton, this was launched at a reception at the Houses



Janet Dean, Chair of the All Party Parliamentary Group for Lupus, addressing the Reception.

of Parliament. LUPUS UK sent a copy to every GP practice in the country. Later, in 2009, the revised version was published.



In 2000, a new member joined the staff, Chris Maker. Initially Deputy Director, he became Director in 2004. In 2011, Paul Howard came on board. Chris (now titled Chief Executive Officer) remained in post until March 2020, when Paul took on the role. Geraldine Leonard retired at the end of 2015, having served the charity initially as a volunteer and then as a member of staff. Geraldine's service to LUPUS UK cannot be over-praised.

'Longevity' pops up repeatedly in LUPUS UK. No-one epitomises this more than Yvonne and Peter Norton. Both were there at the very start of LUPUS UK; Yvonne became the first Vice-President (a post she holds today!) and she and Peter have given outstanding service. In 2015, Peter was made an Honorary Member and Yvonne Honorary Vice-President as a mark of the regard in which they are held. Yvonne's roles have been many and various, including her work



at an international level. Yvonne has been the guiding influence behind the three editions of the text-book for health professionals, the latest edition now waiting in boxes to be distributed once we can move more freely. In addition to this outstanding book, LUPUS UK has a wide range of booklets and leaflets covering many aspects of lupus and related matters.

Financially, LUPUS UK has always sought to be prudent. In 2001, Director Chris Maker reported that income had topped £500,000 for the third successive year, allowing for increased grants to be made. That year, the official website was set up and in October 2002 'Lupus Awareness Month' was launched. An 'early day motion' commending LUPUS UK and calling on the government to raise awareness and invest in research into effective treatment was signed by 322 MPs. There were receptions at the House in 2000 and 2003 and also in 2003 the LUPUS UK Light Sensitivity Support Group (now Eclipse) was set up.



The charity is governed by its Trustees. Over the years, many have served, for varying periods, with great distinction. Whilst our amazing staff run the charity on a day-to-day basis, the Trustees direct and oversee all aspects of its work, under the terms of our Constitution. The Constitution was amended at the AGM in 2017, when members overwhelmingly agreed the new format, which brought in elections for the Officers and Trustees, bringing full democracy and accountability. Our AGMs started in 1993, with a day event that incorporated the business session with a series of talks, lunch and the opportunity to meet old and new friends from all over the UK. In 2013, we held the last of this style of AGM and now have two Information Days each year, one linked with the AGM, which move across the UK giving more people the opportunity to attend the AGM and listen to leading lupus specialists.

One of the most rewarding developments has been the growing number of LUPUS UK Centres of Excellence. This award is made



by the Trustee only after careful inspection of the facilities at the applying centre. When the required standards are met, the award is presented and the hospital can place it on display. Regular inspections are carried out to ensure that these standards are maintained. This work forms part of the Trustees commitment to the lupus family; this 'family' aspect having great on-going relevance in the work of the charity.

Social media now forms an important part of the work of LUPUS UK. A great deal of information is presented on various platforms and the website is also a valuable source of knowledge.



Our HealthUnlocked online community forum provides opportunities to raise issues and gain the advice and experience of many with lupus. Regular updates during the current COVID-19 pandemic have been issued, and local Groups have passed these on to members. LUPUS UK has its Contacts who are able to respond personally, bringing a friendly and understanding voice, and, as important, an ear of someone who understands. We remain committed to work for all affected by lupus; all are seen as part of our family.



Recent years have seen some changes in the staff. Chanpreet Walia joined the Romford team and is now Social Media and Projects Officer. Her most recent task was to set up our e-newsletter. John Braybrook (who has lupus) is our Membership Officer. Our most recent addition is Rebecca Wilby. Rebecca came on board as Trust Fundraising Officer, starting work in March 2020, only to have to work from home after just three weeks! This was not a reflection of her but the result of lockdown! These new rules also affected the change-over of CEO. Chris Maker finished his term on 31st March. We were not able to give him the send-off we had planned and which he so richly deserved. Fortunately, Chris remains a part of the team, working part-time as Finance

Manager. Chris left big shoes to be filled. Paul Howard has stepped into those shoes and done an outstanding job. Just a week into lockdown, he took on his new role - truly a baptism of fire! Paul, with the support of Chris, kept the office functioning, with other staff working from home for months. It is to the credit of LUPUS UK that all the staff remain employed, and to the credit of the staff that so much was still done in this difficult period.



During this time, the Trustees set up the COVID-19 Emergency Assistance Fund. This provides cash grants to lupus patients in particular need. The assistance given has proved to be greatly valued by recipients. This was a new initiative for the charity but shows its commitment to provide support for those affected by lupus.

Small research grants (up to £25,000) are provided for specific projects, with larger grants enabling the appointment of Lupus Specialist Nurses in numerous health authorities. Currently we support one new Nurse per year, with that goal to change to support three every two years. A five-year commitment for a full-time nurse involves an 'investment' of around £250,000 for LUPUS UK. This will, of course, mean that new sources of income will have to be established, whilst the contributions of members and supporters will remain invaluable. (Pictured Jane Hollis who has been a Lupus Nurse Specialist since 2011)

In the last few years we have seen more attention being paid to lupus in the media, as we have had many articles and stories appearing in



national and local newspapers and journals, and on radio and TV, with CEO Paul Howard very active in leading our publicity drive. Some of the items have followed reports related to well-known people having lupus or associated conditions, and whilst we express concern and support for these individuals it has helped us spread the word and raise awareness.

LUPUS UK also realises the importance of working with other groups whose purposes are similar. Our involvement with the Rare Autoimmune Rheumatic Diseases Alliance (RAIRDA) allows us to be in a better position to lobby authorities. Getting our voice heard has been difficult as a small body but working in combination helps raise the profile of the charity and our work.



In 2020, many of our income streams were reduced, with the cancellation of marathons and other activities. Some could be replaced to a limited degree and members

have rallied around with new ways of helping. We remain confident that future years will see us in a better financial position, as marathons and walks, coffee mornings and lunches, parachute jumps and all the other things members and friends do to help support the work of LUPUS UK are re-established.



Of course, this difficult year has affected local groups. Not only has fundraising almost dried up, the personal aspects of local work have been curtailed. Friendships shared at Coffee & Chat meetings and other group events have been lost, and we



know how important this aspect is. The Trustees, too, have not been able to get together, enjoying the usual camaraderie, with meetings being online and no chance to share each other's company. Yes, 2020 has been a year we will all be glad to see the back of. There will be many shouts of joy as midnight strikes on 31st December!

Despite current problems, the Trustees feel the charity is in a strong position to move forward into 2021 and beyond, with a strong and competent Board and the backing of a membership that values our work and our aims, and shows its support in many, many ways.

We would have hoped that our thirtieth anniversary could have been far more upbeat, but must do the best we can in the circumstances. As we reach this anniversary

we are also about to reach another major milestone. We will shortly reach the point where we can say that LUPUS UK, through the work of its members, staff and supporters, will have committed £10m (yes, ten million pounds!) in grants for Specialist Lupus Nurses and research! I'm sure you will agree that this is an achievement of which we can feel justifiably proud.

Let us take that pride with us as we move into the future, not to rest on the laurels of what has already been done but to inspire us to move forward and achieve even more. All this, of course, depends on our members, our greatest asset, our greatest strength and the base from which we can build a better future. Together we can do so much!

David Hopkins

£10,000,000

LUPUS UK's 30th Anniversary - Cheryl writes...

How the years have flown since 1990 and my great excitement and delight that we were formally now LUPUS UK, we would basically be able to stand on our own two feet and make our own decisions.

This would not have happened without the great support of so many, but to name just a few Prof Graham Hughes, Eric Howard, Brian Hanner, Geraldine Leonard, Ronnie Gourley, Yvonne Norton and Martin Marcus. But there are so many great volunteers who put hours and dedication into supporting us and our endeavours and indeed continue now.

Paul Howard as our new CEO is following brilliantly in Chris Maker's footsteps, and I would like to thank him and our National Office staff for keeping LUPUS UK well and thriving despite this awful COVID-19 time.

I now look forward to great progress for LUPUS UK in its aim to help lupus sufferers far and wide.

My great thanks to you all and please keep safe and well.

Cheryl Marcus - Founder

