

THE HIBBS LUPUS TRUST

TRUSTEES' ANNAL REPORT

31 OCTOBER 2016

Company number: 7805005

Charity number: 1147783

## **Chairman's statement**

This year has yet again been fulfilling and inspiring as the Trust has worked with many new patients and their families to grow the charity and widen its reach. The challenges faced last year continue; the decision with regard to the Mid Staffordshire NHS Trust's future were made dictating that Cannock Hospital would be controlled by the Royal Wolverhampton NHS Trust, which means changes to leadership and some personnel for some key figures within the rheumatology team. In spite of these changes, donations have been pledged this year to the Rheumatology department at Cannock Hospital; the benefits of which will be experienced by lupus patients in Staffordshire. However, a decision on the final use for the donations was yet to be made in 2016.

The lupus patient helpline, manned solely by volunteers and aiming to be an initial port of call for anyone looking for help or support with lupus, has been accessed by a number of patients and their families from across the U.K. The helpline complements the Trust's website and offers a link that can make the difference when people require it.

The Trust has seen further development with the recruitment of more Ambassadors. Located across the UK, the work of the Ambassadors is proving vital in raising awareness whilst also supporting them in their own lupus journeys. The latest Ambassadors are family members of patients too, which serves as evidence for the benefit of this role to patients and those affected by this illness. Excitingly, an Ambassador based in the USA has come on board as a key advocate for international links in the world of lupus awareness.

Our work in the community continues to grow. The number of support meetings we have held has been maintained and attendance figures continue to grow. The role of guest speakers along with patient participation has further helped to strengthen the meetings' value. Key areas of discussion are prompted by patients and responded to by professionals. Feedback continues to be healthy and the support given during these meetings will continue into 2017.

In addition to local community work, the role of the Ambassador has grown. One group in particular, Team Alice, have led the way in extending the reach of the Trust as they campaign and trail blaze with some tremendous fund raising activities. With an inflatable Alice always on board, challenges are fought from mud running to mega running, Team Alice leads the way in raising awareness and having fun whilst doing it. Providing a model of what it means to be Ambassadors.

In May 2016, the Trust held its annual lupus walk based on Cannock Chase. Patient friendly, this challenge encourages a rally of walkers to step forward in aid of lupus awareness. A virtual walk also proved to be a great success allowing those further afield or in poorer health to participate. This proved to be a great family day with patients and their networks joining in the fun.

Perhaps most significantly to us in 2016, the Trust launch the Rhys Parker Memorial Award. In memory of Rhys, a patient of lupus but most importantly an awareness raiser too, the award seeks to recognise and celebrate a person or group who has made a substantial contribution to the lupus community exemplifying the character of Rhys Parker. Nominations for the award were invited and a winner chosen. The inaugural award was given to Nathan Bridger who has taken on tremendous challenges in the name of lupus and in memory of his friend, Rhys. Nathan is a shining example of what it means to advocate for those who face lupus and his hard work and efforts, we felt, were rewarded with his receipt of this award.

The team at the Trust work tirelessly to make the lives of lupus patients better and I'd like to say thank you to all of them for their invaluable contribution.

**John Hibbs**  
Chairman

## **HIBBS LUPUS TRUST 2015-2016 AT A GLANCE**

- The Hibbs Lupus Trust held the U.K's annual World Lupus Day Walk which was a big success
- We attended UK Parliament for the Giving Tuesday reception to highlight and raise awareness of lupus and the Trust
- Introduced the Rhys Parker Memorial Award. In memory of Rhys, the award seeks to recognise and celebrate a person or group who has made a substantial contribution to the lupus community that exemplifies the character of Rhys Parker.
- We held quarterly support meetings where experts from the medical profession joined the meetings to provide detailed information and advice on how to manage lupus which had an increased attendance on last year
- Our Twitter account grew to 14,500 followers
- Our Facebook page now has 3250 likes
- The Trust website, which provides information and support, has seen an increase of 3.24% in unique visitors taking it to 100,112
- We distributed approximately 4,000 lupus leaflets at events to hospitals and GP practices throughout Staffordshire
- In addition, we have distributed 10,000 Lupus Support posters to targeted GP practices across the U.K.
- The Hibbs Lupus Trust continued and leads the 'L Hand Sign' campaign in the U.K.

## **WHERE THE MONEY CAME FROM**

The Hibbs Lupus Trust raised £37,672 through fundraising events, donations and corporate support. A 70.2% increase on the previous year.

When the proposals for the Mid Staffordshire NHS Foundation Trust have been finalised, we will be purchasing a Nailfold Videocapillaroscope for Cannock Hospital at a cost of approximately £20,000. This equipment will help in the early diagnosis of lupus as well as other connective tissue diseases. This purchase has been delayed as we await the merger between Cannock Hospital and the Royal Wolverhampton NHS Trust. This was reported last year but final requests from the Royal Wolverhampton NHS Trust have not been finalised. We await final decisions.

## **MISSION**

The Hibbs Lupus Trust works to improve the lives of people affected by lupus and to raise awareness of the condition.

## **OBJECTIVES**

- To provide support and information to anybody affected by or concerned about lupus
- To raise awareness of the symptoms of lupus to encourage early diagnosis and reduce life threatening complications associated with the condition.
- To raise funds to provide facilities, equipment and services for NHS hospitals and foundation trusts for the benefit of lupus patients.

## **MEETING THE CHALLENGE**

How we met our objectives in 2015/16

### **Providing support and information to anybody affected by or concerned about lupus**

#### Patient support group

We continued to hold patient support groups in Staffordshire. The group meets quarterly and provides the opportunity for people living with lupus to meet, share experiences and support each other. Experts from the medical profession were invited to join us providing detailed information and advice on how to manage lupus and its effects.

*"@HibbsLupusTrust @RWT NHS its a pleasure to take part in the work done by you for raising awareness of #lupus" - Consultant James Bateman following his talk at the support meeting.*

*"Just back from @HibbsLupusTrust support meeting. Full of useful info about my next drug Rituximab. Just need the flare to happen. #lupus"*

### Information advice line

The information advice line continues to provide support and information to those affected by lupus, their family and friends. The information advice line is open from Monday to Friday from 9am – 5pm. Outside of these hours, we offer support via email and social media.

*“Thank you for everything you do to make sure the awareness for lupus is out there for us fighters.”*

### Online community

Through our online community, Twitter, Facebook and Instagram and now snapchat, we provide support and information to lupus patients and put them in touch with others who find themselves in a similar situation. We have seen an increase of followers on Twitter and we have doubled our number of Facebook likes. The Trust has also increased its use of Instagram, which now has in excess of 1,000 followers.

### Hibbs Lupus Trust Website

Our website continues to feature as a key platform for providing information to our supporters and patients of lupus. It is updated frequently with information and is noted to be easy for people to navigate; the Hibbs Lupus Trust site is also optimised for mobile use. Unique visitors to our website have increased by 3.24% from last year.

### **Raising awareness of the symptoms of lupus**

#### Information days and talks

We have run information days in the local community. These provide the opportunity for us to raise awareness of the symptoms of lupus and promote earlier diagnosis. They also increase the awareness of our work. During 2015/16, we have held a number of information days. Our Ambassadors now also promote the work of the charity further afield.

#### Leaflets

During 2015/16, we distributed 4,000 lupus leaflets at hospitals, GP practices and at events. The Trust has also distributed 10,000 more Support Posters to targeted GP practices across the U.K.

#### The LHand Sign campaign

The LHandSign campaign encourages everybody to get involved and raise awareness of the symptoms of lupus by submitting a photo of themselves raising their right hand in the shape of an L. We share these photos through our social media community and on our website. The Hibbs Lupus Trust is the leading charity in the U.K. to promote the campaign, which is an international movement to raise awareness supported by patients and celebrities.

#### World Lupus Day

World Lupus day aims to raise awareness of lupus. In 2016, Sarah Brown contributed to our efforts by tweeting a message to over 1 million followers:

*“A shout out to [@HibbsLupusTrust](#) campaigning for better awareness on [#WorldLupusDay](#)  
<https://www.hibbslupustrust.org/go-purple/> “*

#### Trust Ambassadors

This year, we have recruited more Trust Ambassadors from across the UK to help promote and support the work of the Trust and to help increase the reach of our work. The Ambassadors are working to distribute information leaflets and posters as well as using social media to publicise our events and our support network.

### **FUNDRAISING**

Despite a continuing difficult economic climate, our supporters, event participants and corporate partners have raised over £37,672 to help the Trust to continue our work.

## Raising funds

A number of local community groups have provided donations following events held locally. The sale of Christmas cards has also generated funds for the charity this year. These have been sold in local venues and online to a wider customer base.

## Events

Over 150 people participated our annual walk to celebrate World Lupus Day.

A Team of 10 took part in the Mud Run, West Midlands.

2 runners travelled from the USA to take part in the Race to the Stones, a non-stop 100km run along the oldest path in Britain. Members of the Trust travelled to welcome our fundraisers to the UK and support their fantastic efforts during the run.

7 runners took part in the Birmingham Half Marathon as well as 3yr old Xanthe who took part in the Mini Great Run.

We had a number of runners taking part in the Stafford Half Marathon.

B&M Cannock continued their support hosting a tombola as well as collection tins located at the checkouts.

## **POLICY, PERFORMANCE AND ORGANISATION INFORMATION**

### Reserve Policy

The charity operates a 6 month reserve policy

### Financial review

The results of this year show a year on increase in income of £15,537, from £22,135 in 2015-2016 to £37,672 in 2015-2016. Resources expended increased from £15,641 to £21,178 in the same period.

### Staff

The Hibbs Lupus Trust is run entirely by volunteers. It is aware of its health and safety responsibilities towards volunteers and all users of its services. It maintains a Health and Safety Policy and Equal Opportunities Policy.

### Structure, Governance and Management

The board meets quarterly and delegates day-to-day running of the charity to the Chairman who works on a voluntary basis with a team of volunteers. The charity does not employ any paid members of staff.

### Recruitment Induction and Training of Trustees

From time to time, the Trustees may advertise for new members to join the Board. They may review their own contacts and those of the charity in order to identify suitable candidates and also advertise on the charity's website. All candidates are interviewed before being appointed. The board aims to maintain a diverse mix of skills and backgrounds.

As part of their induction, new Trustees are given financial and other documents and encouraged to review the charity's website and social media activity to familiarise themselves with the work of the charity.

**Approved and signed on behalf of the trustees by:**

John Hibbs  
Chairman

Date: 28<sup>th</sup> June 2017

## LEGAL AND ADMINISTRATIVE DETAILS FOR THE YEAR ENDED 31 OCTOBER 2016

### Status

The organisation is a charitable company limited by guarantee. It was incorporated on 11 October 2011. Members of the charitable company guarantee to contribute an amount not exceeding £1 to the assets of the charitable company in the event of winding up. The total number of such guarantees at 31 October 2013 was 3.

### Governing document

The company was founded under a memorandum of association which established the objects and powers of the charitable company and is governed under its articles of association. These were last updated 24 April 2013.

### Company number

Registered with Companies House under 7805005

### Charity Commission

Registered in England and Wales under charity number 1147783

### Registered office

15 Bakers Way  
Hednesford  
Cannock  
Staffordshire  
WS12 4SX

### Board of Trustees

Chairman - John Hibbs

Board Members

Viki Hibbs – Trustee  
Steve Hibbs – Trustee  
Kate Hibbs – Director  
Carol Hibbs – Secretary

### Accountants

CMS Associates  
St Thomas House  
83 Wolverhampton Road  
Cannock  
Staffordshire  
WS11 1A

## **STATEMENT OF TRUSTEE'S RESPONSIBILITIES**

The Trustees (who are also Directors of The Hibbs Lupus Trust for the purpose of company law) are responsible for preparing the Trustee's report and the Financial Statements in accordance with the applicable law and UK Accounting Standards (UK Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare the financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company as at the balance sheet date and of its incoming resources and application of resources, including income and expenditure, for the year then ended.

In preparing these financial statements the Trustees should follow best practice and:

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Charities Statement of Recommended Practice (SORP)
- Make judgements and estimates that are reasonable and prudent
- State whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements.
- Prepare the financial statements on the going concern basis unless it is inappropriate to assume that the charitable company will continue in business.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time that financial position of the company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- There is no relevant audit information of which the company's auditors are unaware; and
- The Directors have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.