

THE HIBBS LUPUS TRUST

TRUSTEES' ANNAL REPORT

31 OCTOBER 2013

Company number: 7805005

Charity number: 1147783

### **Chairman's statement**

This year has been both fulfilling and inspiring as we have worked with many new patients and their families whilst the Trust has gone from strength to strength. The challenges however continue; perhaps most significantly has been the wait for the decision of the future of the Mid Staffordshire NHS Foundation Trust. The delay in the verdict has led to a postponement in the donation of funds, which will be used to support lupus patients in Staffordshire.

We have launched our lupus patient helpline, manned solely by volunteers, which aims to be an initial port of call for anyone looking for help or support. Complementing the Trust's website, the helpline offers the link that can make the difference.

We've had success with volunteer recruitment, as the Trust has seen the development of Ambassadors. Located across the UK, their work is proving vital in raising awareness whilst also supporting their own lupus journeys.

The year has seen our website receive 99,668 visitors of which 85,674 were unique visitors thus indicating its impact is significant and wide reaching.

Our work in the community continues to grow. The number of support meetings held have increased and attendance figures are also growing healthily. The role of guest speakers along with patient participation has further helped to strengthen the meeting's value.

International links for the Trust continue to develop and donations are being received from across the world suggesting the impact of the Trust and highlighting the need for our work to further grow as we reach new audiences in need of help.

The work of the Trust was recognised in January of this year when chair, John Hibbs, was short listed for Staffordshire Volunteer of the Year.

Sadly, Trust Ambassador Rhys Parker, passed away on 28<sup>th</sup> September 2013. Aged just 36 years old, Rhys had fought heart & kidney problems for 13 years in his battle with lupus. Our thoughts are with Rhys' family.

The team at the Trust work tirelessly to make the lives of lupus patients better and, as we press forward in the forthcoming year, we keenly anticipate the next developments to raise awareness of lupus.

John Hibbs  
Chairman

## **HIBBS LUPUS TRUST 2012-2013 AT A GLANCE**

- We launched a Freephone helpline for patients and their families.
- We held 4 support meetings. Experts from the medical profession joined our meetings to provide detailed information and advice.
- We gave 5 talks to local groups and organisations to promote our work and raise awareness of lupus.
- We held 15 information days at hospitals and in the wider community.
- Our Twitter account now has 10,900 followers (an increase of 24% from last year).
- Our Facebook page has grown by 1000 likes in the past 12 months.
- Our website, which provides information and support, has received 85,674 unique visitors (up 418% from last year).
- We distributed 10,000 lupus leaflets at events, hospitals and GP practices throughout Staffordshire

## **WHERE THE MONEY CAME FROM**

The Hibbs Lupus Trust raised £28,188 through fundraising events, donations and corporate support.

Once the final 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 £20,000. This equipment will help in the early diagnosis of lupus as well as other connective tissue diseases.

## **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 2012/13

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

#### Patient support group

We set up our first lupus patient support group in Staffordshire. The group meets regularly and provides the opportunity for people living with lupus to meet, share experiences and support each. This year we invited experts from the medical profession to join our meetings to provide detailed information and advice.

*“Just been to Hibbs Lupus Trust support meeting, thanks guys got some good tips and glad to know I am not alone”*

#### Information advice line

In September 2013, we launched our information advice line 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 email support. Since its launch, we have supported over 50 people.

#### Online community

Through our online community, Twitter and Facebook, we provide support and information to lupus patients and put them in touch with others who find themselves in a similar situation. In the last year, our Facebook community has grown by 1000 likes and our Twitter followers have increased to over 2,500 followers.

*“Always grateful @HibbsLupusTrust will always listen no matter what time of day”*

*“@HibbsLupusTrust Thank you for always supporting me and listening to me when I need someone to understand I appreciate & you care”*

#### Hibbs Lupus Trust Website

This year, we redesigned our website making it easier for people to find what they are looking for and optimised the site for mobile use. We reviewed and re-wrote some of our patient content. Visitors to our website have increased by 418% over the last year.

*“My younger sister was diagnosed with lupus and your website was a big help when she needed information and support she couldn't find elsewhere”*

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

#### Information days and talks

We 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 2012/13, we held 15 information days.

We regularly provide talks to local groups and organisations to promote our work and raise awareness of lupus. This year we have given 5 talks.

#### Leaflets

During 2012/13, we distributed 10,000 lupus leaflets at hospitals, GP practices and at events.

#### 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 them raising their right hand in the shape of an L. We share these photos through our social media and on our website.

## World Lupus Day

World Lupus day aims to raise awareness of lupus and in 2013 Stephen Fry took part by tweeting our message to over 3 million followers:

*"For the volunteers @HibbsLupusTrust raising awareness is a way of life. Visit <http://hibbslupustrust.org/> to find out more about [#WorldLupusDay](#)"*

## Trust Ambassadors

This year, we have recruited four 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 £28,000 to help us to continue our work.

### Raising funds in the community

In November 2012, 500 people including Stafford MP Jeremy Lefroy joined us for the Stafford Santa Dash to raise both funds and awareness of lupus.

Public Services students from South Staffordshire College raised £1115 recently by running for lupus. Set a challenge by their lecturer, Carl Edwards, to create a fund raising event, the students quickly set to work. After selecting The Hibbs Lupus Trust as their charity, the students designed a range of challenges from 3 – 10 mile runs around Cannock Chase to test their fitness whilst raising awareness and money. The project, which formed part of their studies, was a great success and the team of learners hit a grand total of £1,115.

### Events

In January, over 200 riders joined the LUPUS 50/50 Cycle Sportive completing either 50km or 50mile courses around the Cannock Chase countryside to raise awareness of lupus. Over £1,400 was raised. Cyclists travelled from across the UK and from as far afield as London to take part.

In April, over 100 guests joined us for a fashion show hosted by The Fashion Factory Cannock. Smooth Radio's Emma B compered the event. The fashion show raised over £500.

On Saturday 16th June 2012, a team of 4 cyclists including trust chairman John Hibbs, cycled the 200 miles from Lupus Way in Ellesmere Port to Lupus Street in London raising over £3,000.

### Corporate Support & relationships with local groups

In June, our 12 month partnership with Sainsbury's Cannock came to a close. We held lots of events throughout the year involving both staff and customers which saw £6,000 raised and presented to The Hibbs Lupus Trust.

The store has hosted information stands to highlight the effects of lupus and the work of the charity along with bag packing events where volunteers from the Trust have been able to help customers whilst sharing knowledge about the charity. In store, the staff have been busy supporting us too as departments were challenged to raise funds. The checkouts have been host to the Hibbs Lupus Trust collection buckets whilst the information desk has offered our jute shopping bags for sale. As well as the opportunity to raise funds, an information board was maintained by the staff at the store which helped promote other events held by the Trust.

We continue to build and grow partnerships with local businesses: The Lewis Partnership, Verso Creative, Run & Ride, Stuart James Photography, CJM Associates, First Choice Catering Spares and B&M Cannock

August also saw us forge new relationships with local groups when we took part in the 'Hednesford It's A Knockout' competition. We entered two teams thanks to the support of Cannock Hockey Club with whom we continue to build our relationship to raise awareness and funds.

## **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 £11,640, from £16,548 in 2011-2012 to £28,188 in 2012-2013. Administrative expenses increased from £3,530 to £7,910 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: 23<sup>rd</sup> March 2014

## **LEGAL AND ADMINISTRATIVE DETAILS FOR THE YEAR ENDED 31 OCTOBER 2013**

### 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.