

## December '15 weekend

Although it rained for most of the December *Living Proof* weekend, the inclement weather did not dampen the spirits of those who attended. Of the 29 guests, 7 were newcomers. Our facilitators were Jenny Read and Peter Jones; George, Josie, Lyn and Simone offered a wide range of complementary therapies.



Shallowford House kitchen staff, Sara and Jake excelled themselves in preparing a splendid Christmas dinner on Saturday evening...they richly deserved the standing ovation offered as a token of everyone's appreciation. The meal was preceded with aperitifs in the Lounge which encouraged social interaction and development of the warm friendly atmosphere that pervaded the weekend.

Thanks to Carl and Shaun for running the raffle which raised £215. A big thank you as well to all who donated prizes and bought tickets.

Tom Matthews, a founder member of the group, was awarded the first Fellowship of NLTSG for outstanding dedication and commitment to the group since its formation.

## September AGMs

At the AGM in September, there were 17 members present with 3 postal/email votes. To comply with Charity Commission guidelines, we held two AGMs; the last one of the old charity at which the final annual report was accepted, and the first of the new CIO that included a resolution on Membership and the election of a new Board of Trustees.

The resolution (below) proposed by the Board was passed by a large majority: 14 for, 2 against with 4 abstentions.

*The membership of NLTSG should comprise a group of Members who wish to be actively involved in planning and running NLTSG and a group of Associates who wish to attend weekends but play no other active role in the group. Additionally, there should be membership levels of Fellow and Honorary Member that the Board can award.*

All candidates for trusteeship were elected: Andy Hilton (Chair), Roland Chesters (Vice Chair), Gary Burns (Treasurer), Maurice Greenham (Secretary), Tremain Cornish (Bookings Secretary).

## Members' Survey

As part of the planning for NLTSG's future, the Board recently asked those who have chosen to become Members to complete a survey about their skills, future plans for the organisation and the level of support for a number of possible changes. The good news is that these Members have a broad range of skills and can assist the Board with a whole range of plans. In addition to this, Members are willing and able to support with a variety of tasks at the weekends. The survey also gave some resounding messages; the "Living Proof" weekends work well as they are, there is support for a

mixed weekend once a year with long-term survivors and recently diagnosed people coming together, and there is an appetite for NLTSG to promote and get involved in campaigns which support those who are living with HIV. One significant highlight was that there is strong support for the option of people paying more to secure a single room. All in all, the responses were very positive, and the new structure will certainly help us secure the future viability of NLTSG.

## Single rooms

Shallowford House has a mixture of single and twin rooms and we want to make the best use of all space available. However, we are getting more and more requests for single rooms. The Board have therefore decided to put a new policy in place from the March 2016 weekend onwards:

- There will be an additional charge of £25 if you request a single room at the time of booking. These requests will be taken on a first-come-first-served basis and no more than 12 single rooms will be guaranteed. After 12 single rooms have been allocated then we will only accept bookings from people who are willing to share.
- If you require a single room for medical reasons you will need to get a confirmation letter from your doctor and the £25 single room fee will be waived.

This policy will apply to everyone attending the weekend including first-timers and those applying to the 1992 fund for a fully funded place (i.e. the 1992 fund will not cover the single supplement).

## Group finances

The Board is always looking at ways to make the weekends more cost-effective so that we can support as many people as possible. Now that statutory funding has all but disappeared, we are wholly reliant on what we charge people to attend the

weekends, any money that we can raise through *ad hoc* fundraising, and by applying for grants. We also need carefully to consider our costs and how these can be reduced. As a consequence of this, the Board has decided that from March 2016, we will no longer be ordering sandwiches for the evening, which cost us almost £100 per weekend. Cooked breakfasts cost us around £200 per weekend and we are currently investigating ways to reduce this. None of these decisions is taken lightly.

We are always looking for new funding opportunities so do let us know if you have any great ideas. In the past people have held events, run sponsored walks, filled collecting tins and left bequests in their wills. We applaud member John who has responded to our recent request for members to help with fund raising by collecting £66 at venues in his locality.

If you wish to make a donation, or know anyone who does, please visit the donations page on our website [www.nltsg.org.uk/donations](http://www.nltsg.org.uk/donations)



## Going paperless

Virtually all of our bookings and payments are now made electronically and from the July 2016 Living Proof weekend onwards we will stop accepting paper bookings and payments by cheque. People who do not have access to online banking can always pay us by cash or cheque at any branch of HSBC. Further details nearer the time...

## Database clean-up

Our database of Members and Associates contains hundreds of people many of whom have not attended a weekend for many years and possibly no longer wish to be in contact with NLTSG. In line with good personal data management principles, we are going to start removing entries from our database who we have not heard from for over 3 years. If you are one of these people who has not attended for some time but do want to stay in touch with us, please send an email to [Tremaine@nltsg.org.uk](mailto:Tremaine@nltsg.org.uk) saying that you would like to stay on the database.

## Payments and cancellations

Regularly, we get very late cancellations or people simply don't turn up for a weekend and a disproportionately high number of these is people who have a fully funded place (e.g. via 1992 funding). This is very wasteful of the organisations resources. From the March 2016 weekend onwards we will be asking people who are applying for a fully funded place to pay a deposit of £10 before their place is confirmed. This is a relatively small amount of money but it will help to demonstrate the person's commitment to attending. If they wish to claim it back we can refund it in cash at the weekend.

As a reminder of our cancellation policy: If you cancel more than 7 days before any weekend we will refund all money that you have paid. Within 7 days of the weekend (when we have to confirm final numbers to Shallowford House), if you let us know that you are unable to attend due to illness then we will refund your payment. For any other reason, or if you do not turn up for the weekend without letting us know, we will not refund any payments.

## Travel expenses

We are still in the fortunate position that we are able to offer to refund travel expenses for those that wish to claim. This is a very significant cost of running the weekend (on one weekend it was over £800) but the Board feel that it is important to offer travel expenses to make the weekends as inclusive and accessible as possible.

From the March 2016 weekend onwards we will be changing the way that we refund travel expenses. All payments will be made by BACS rather than cheque. At the weekend you will be asked to complete an expenses claim form as usual but you will need to provide your bank account number and sort code unless you have previously done so. The payment will be made directly to your bank shortly after the weekend. In exceptional circumstances, for people who don't have a bank account for example, we will pay expenses by cash.

## Getting funding from social services - a few notes

*Thanks to Welsh Steve for sending this useful advice...*

Social services departments have a statutory duty to provide respite care, and attending a Living Proof weekend can easily be considered as such. It helps to be already known to your local social services department, rather than a request for funding to be your first contact with them. Results will vary from council to council.

Firstly, be aware of the extremely obvious: no way can you make an application for funding without disclosing your HIV status. Make contact with the social worker with responsibility for HIV (if there is one). Lay it on thick about the stress you're under and the help you expect to receive from Living

Proof weekends. The pattern seems to be the council matching a charitable grant, so if the council turn your application down, the next step is to ask for a social worker's help in obtaining funding entirely from charitable sources (these sources won't make grants to individuals).

They're going to want proof of your HIV status, so get your clinic to write you a letter of diagnosis (for good measure ask them to include date of diagnosis). Unless they absolutely insist on seeing the original, give them a photocopy (if you have a scanner, make a picture file of it). Respite is usually considered to be the major part of a week, if not longer, so try to get funding for an entire year (it can be done, though some councils are sufficiently cash-strapped that they won't be able to help at all, in which case try for a travel grant)

## Ways of keeping in touch

- Send us a comment for the newsletter to [maurice@nltsg.org.uk](mailto:maurice@nltsg.org.uk)
- Follow us on Twitter @NLTSG – We are now following 1,818 twitter accounts and have over 600 followers
- Visit our website: [www.nltsg.org.uk](http://www.nltsg.org.uk)
- Like us on Facebook: 'National Long Term Survivors Group'.

*Please note that we have closed the NLTSG Yahoo Group because lack of use. People appear to prefer other means of social media contact.*

## Weekend Dates

### 2016

**Mar 11 – 13\***

**July 8 – 10**

**Sept 23 – 25**

**Dec 9 – 11**

*\*Please note that the March Weekend will be open to anyone who has attended one of our Recently Diagnosed weekends as well as those with a 5 year+ diagnosis.*

Invitations to weekends will be sent out 6-7 weeks before each weekend. If it is less than 6 weeks to the next weekend and you have not had an invitation then please contact us on [bookings@nltsg.org.uk](mailto:bookings@nltsg.org.uk) .

Invitations to the March 2016 weekend will go out before the first of February.