



# THE DISABILITY FOUNDATION NEWSLETTER

The Disability Foundation is a Registered Charity Number 1076761

ISSUE NO. 5, SUMMER 2003

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**NEWS ROUND UP**  
The TDF AGM:  
Minutes now avail-  
able.

## Events for the European Year of Disabled People.

You'd never know it, but the European Year of Disabled People is now well under way.

It may come as no surprise that whereas some European countries have set up individual, well-made websites (fully accessible of course) with more activities to attend in the year than you could possibly overcome, the UK has only managed a rather basic website with about 67 events and activities. This may sound grand, but considering the UK has approx. 60 mill. people (with 8.3 of those being disabled) it really is not much.

In London, the total count come to a staggering 12 events - with ten of these having already taken place. That only leaves 2 (two) for us to advertise in this issue:

### **Disability Rights Exhibition** September 2003

The Disability Rights Commission is planning to launch a touring arts exhibition on the theme of disability rights. The Greater London Authority is co-funder and also hosting the exhibition. It will then tour other cities around Great

Britain. A consortium of disabled people, led by arts organisation Shape and photographer David Hevey, are creating the exhibition. Place: The GLA building, City Hall, London

### **Xposure Disability Arts Festival 2003**

30 Oct - 30 Nov 2003

London's largest annual festival of international, national, regional and local work by leading professional and emerging deaf and disabled artists.

Place: Different venues all over London. Call [0208 340 5226](tel:02083405226) for information.

Of course, more events may crop up as the year comes to an end and people decide to jump on the bandwagon. If this is the case, we will strive to advertise these either by poster at the centre or in the next newsletter.



The European Year of Disabled People

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# chairman's letter

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Summer seems to have flown by, and given the amount of weather changes we experienced, I still don't know what season we are actually in. So, where to begin with our news?

The Wendy Lewis Ladies' Luncheon mentioned in our last Newsletter was extremely successful. It was held in May, at The Berkeley Hotel in Knightsbridge, where 100 well-dressed ladies had a delicious lunch and bought loads of raffle tickets to support the charity. Wendy Lewis, who consults with Hollywood celebrities and mere mortals alike, gave us the low down on cosmetic surgery and I don't know whether she gave me courage to do something or put me off for life!!!  
We raised in excess of £12,500...

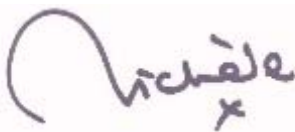
My daughter Nicky came home from her Atlantic crossing full of her adventures. The four weeks sped by and with wind direction constantly changing, they could never be quite sure how long it would take to reach their destination. Watching the ship sailing into the port, and seeing the frantically waving little outline of my daughter as they sailed closer was one of the proudest moments of my life. She raised lots of money for TDF and can now tie a perfect reef knot. The money she raised paid for a much needed state of the art therapy bed.

We have taken on Eve to replace Mario and Charles with Thai massage. Nicky also offers one-on-one yoga sessions. Charles is now concentrating on craniosacral therapy. All therapists are extremely busy. Anne, our Disability Information Officer, and Emma Jane, one of our therapists, were invited to speak at a local back care group in Harrow. If you would like TDF to speak at your local group, please do let us know.

I am planning another Ladies' Beauty Lunch before Christmas as well as taking over The New End Theatre at the beginning of December to see a production of "Take a Chance", which is about 6 people meeting at a specially devised dinner party event for singles. Tickets will be reasonably priced including refreshments - for any further information please do give us a ring.

We have more than 1,200 clients now - reaching at least one new person every day. The thrilling part of it all is that word of mouth seems to be our main pulling power. We greatly appreciate that once you have been here, you recommend us to your friends and family. The ever-growing bond between us is stretching out and encompassing, empowering and healing.

We always look forward to seeing you, sharing your special moments and your not-so-special ones. Keep on coming and once again, thanks for your support. We couldn't do it without you!!



Michele Freedman  
Chairman

# appeals

## Flora Light Challenge

Here at TDF we are neither complete couch potatoes nor top tuned athletes so it is with equal parts of trepidation and excitement that we are looking forward to the Flora Light Challenge.

On September 14th, 7 TDF admin staff and therapists will walk and/or run 5 miles in Hyde Park to raise money for the charity.

The Flora Light Challenge is an annual event and we are very happy to be taking part this year. Now all we need are lots of spon-

sors so that we can raise lots of money.

If you would like to support us you can find out how by calling us on:

**0208 954 7373**



## Equipment available for loan

TDF has been donated an almost unused manual wheelchair.

We felt that it would be put to best use by being available on loan for our members.

Also, we have a set of bed guards that we will be happy to loan out to

whoever might need them.

The loan service is without charge, but a donation will always be welcome.

If you are interested please contact us on:

**0208 954 7373**

## TDF Wish List

TDF always needs office equipment and other little bits and pieces.

Once again, we have a small wish list in the newsletter and hope that some of our readers might have just one of these items sitting at home in a storeroom or an attic, and would be willing to donate it to us.

The items we are looking for are:

- 2 small drawer units (height max. 68 cm/27 inch)

- An office chair
- A book case
- A shelving unit
- A small folding table

If you (or anyone you know) have any of these items sitting unused at home and would like to donate them to TDF, please call **Julia** or **Ruth** on:

**0208 954 7373**

## TDF NEEDS YOU

**TDF is always on the hunt for good volunteers.**

Duties can include helping to update our database, assisting clients or therapists and general duties. So if either you, yourself, are interested or you know a warm, caring person with many talents and time on his/her hands, who would like to make a difference to our clients and staff, please contact

**Julia Henry or Ruth Vickers on 020 8954 7373.**



**Do you know anyone who would like to do a sky dive to raise money for TDF, or would you like to do one yourself?**

**If so please contact us on: 0208 954 7373 for further details.**

# body, mind and soul

## Between Heaven & Hell

"On the third of August 2001 my son was born. He did not look like a Nathaniel, as planned, because of his golden hair, so it took us a few days to decide on his name. I think the nurses thought we were rejecting him. Less than two weeks later a neurosurgeon at Alder Hey was drilling a hole in his head.

Nathaniel Austin was born with obstructive hydrocephalus. The doctors had never seen anything like it. The extent of the cysts inside his head caused by the build up of cerebral spinal fluid was phenomenal. I asked the paediatrician the day after he was born to be completely honest. I told her I used to go to Stanmore RNOH. That my mother was a play specialist. I had worked with disabled kids. But it is different when the 'differently abled' kid is yours. She told me that he would never speak, perhaps he could learn sign language, and he would be paralysed down one side of his body, the opposite side to the major cysts. She drew a picture of his brain on a napkin.

We had only found out the day before his birth that anything was wrong and were in complete shock. With a 'normal' birth, you are totally amazed anyway, add this into the equation and it just blows your mind. In a shabby room in a Preston hospital, with the men in white coats hovering over us, the look of fear on their faces palpable, seconds before the birth, this was the worst moment of my life. The actual birth was the best moment of my existence. Nathaniel and I were left alone for twenty minutes

while they sewed Rebecca up. He just stared up at me with his beautiful big brown eyes. The love I felt and feel now is indescribable. If something had shown up early on in the pregnancy, perhaps an abortion would have been suggested. I love Nathaniel as he is, but obviously wish he had not had to go through two operations and have a life that is 'challenged'. He will be two soon. I often thought he would not get this far. He is talking now. Just his movement is limited.

Nobody really knows anything about the brain; someone with a completely normal brain scan can have really abnormal behaviour. Most of us like to fit in. We long for people to approve of us, to accept us. What happens when we are different? I am still grappling with the question 'what is normal?' Being a father feels the most normal thing in the world. Nathaniel in many ways is normal, whatever that means. Obviously I worry about his future, more so I suppose than parents of 'normal' children. The fact that he is alive is amazing but this could be said about each and every one of us."

Charles Jason Lee



In this issue we have dedicated this section to a wonderful piece written by one of our members, Jason Lee, about the turmoil of emotions a parent faces when told that his newborn child might end up severely disabled.

But the love for a child will see past all disabilities, and Jason's definition of his son as 'differently abled' rather than 'disabled' sums this up in the most beautiful way.

Here at The Disability Foundation we strongly believe in supporting children like Nathaniel through therapies and play in order for them to acquire the tools they need to function as independently as possible in today's world.

To ensure this, we set up the children's sensory room, and offer a range of therapies adapted to children's needs and are in the process of finding and employing a paediatric OT.

If you wish to know more about these services, or have any input on this issue please contact us on **0208 954 737**

# body, mind and soul

## REIKI COURSE AT TDF

**Our wonderful Reiki therapist, Rebecca Lowrie, is now offering a Reiki Level 1 course on the premises of TDF.**

**Reiki is an ancient hands-on healing method that can be used on yourself, friends, family and even animals. Reiki is pure healing energy. It is very powerful yet gentle. As well as dealing with specific issues and ailments, Reiki is useful as a preventative measure against illness, stress and fatigue.**

**If you feel that you have come to a time in your life where you are ready to heal and love yourself, Reiki Level 1 may be for you.**

**Please contact TDF for more information or call Rebecca directly on 020 8959 8589**



## Fact File: Yoga One-on-One

TDF has recently started offering 'Yoga: One-on-One' sessions and our fact file in this issue introduces our Yoga teacher as well as explains some of the principles of Yoga.

Our Yoga teacher is Nicola Smith. She has studied and practiced Yoga for 10 years with various teachers and has been a practising massage therapist for over 5 years. She has worked with people of all ages and needs, covering a multitude of different abilities and experiences. Nicky's approach to teaching is about making the student feel more integrated during the yoga practice. Working in a slow and quiet way gives students the opportunity to release deeply held tension and is ideal for all levels of flexibility, ability and experience.

### Posture:

Hatha yoga practice works the muscles and the joints, creating space within the body's structure to help increase circulation & improve flexibility. Thus our physical functioning becomes more integrated - the body is re-educated toward a less stressful and healthier way of functioning.

### Breathing:

Regular yoga practice also increases the lung capacity so that the body can maximize its use of oxygen, making breathing more physically efficient. Good breathing can also help release deeply held physical and emotional tension within the body.

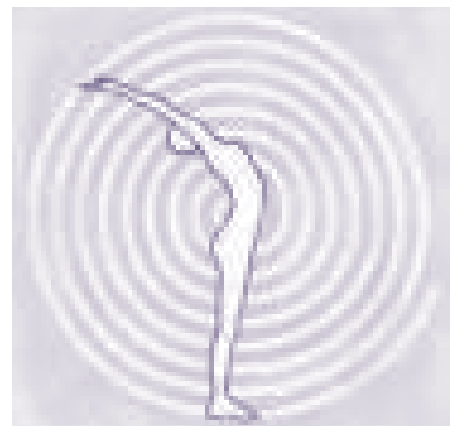
### Relaxation:

The relaxation that occurs during yoga practice can be physical, mental & emotional. When we are completely relaxed we consume very little energy or 'prana', and more energy is preserved within the body to help maintain its healthy functioning. Only when there is an absence of tension in the body can positive change occur.

### Meditation:

As we pay close attention to the breath whilst we are doing our yoga practice, this can help steady and focus the mind into a state of meditation. As the mind becomes more focused, concentration improves as do a sense of mental balance.

Practice of yoga is as much about the way in which we do the postures or breathing exercises as it is about what we are doing. We always aim to work with the body, - allowing the posture to unfold from within. It is this respect for working honestly with our bodies that distinguish it from other forms of physical exercise. The benefits of Hatha yoga is to unite the body, the mind and the breath: Creating a state of balance within the whole self.



# community

## Parenthood and Pregnancy

Jason Lee's story on page 4 about his son Nathaniel, highlights some of the issues that arise when you have a disabled child. A whole different set of issues arises when the tables are turned and a person with a disability becomes a parent.

"Will I be able to go full term?" – "Will I have to get a caesarean?" – "Will I be able to play with my child and stimulate it enough?" - "Will my child be teased for having a disabled parent?"

These and many others questions face people with disabilities who are about to become parents. As the happy event (because it *is* a happy event) actually occurs, there are even more questions.

As a disabled parent you might feel that you are on trial and have to prove yourself; prove that you can 'cope' and that your disability doesn't prevent you from being a good parent. Accessing regular parent support may not always be possible and finding information on being a disabled parent, specialist equipment or specialist support may seem almost impossible.

You are not alone. There are many other disabled parents in similar situations and there are networks you can use for support and information.

Disabled Parents Network is a national organisation of and for disabled people who are parents or who hope to become parents, and their families, friends and supporters. They aim to provide support

and information for people with all types of disabilities and have a range of services including a help line and a quarterly newsletter. You can contact them on:

National Centre for Disabled Parents,  
Unit F9  
89/93 Fonthill Road  
London N4 3JH

Tel: **08702 410 450**

Email: [information@disabledparentsnetwork.org.uk](mailto:information@disabledparentsnetwork.org.uk)

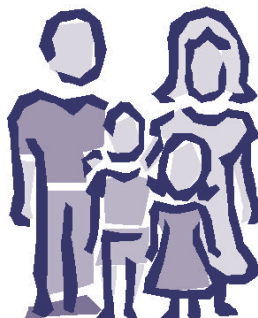
Web: [www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)

Disability, Pregnancy & Parenthood International is a UK based charity, run by disabled parents, that aims to promote better awareness and support for disabled people during pregnancy and as parents. They publish an international quarterly journal, run a UK information service and are joint partners with the Disabled Parents Network at the National Centre for Disabled Parents. Their address is the same as above and you can also contact them on:

Tel: 0800 018 4730

Email: [info@dppi.org.uk](mailto:info@dppi.org.uk)

Web: [www.dppi.org.uk](http://www.dppi.org.uk)



## TDF working with ESL

Many of our clients call with questions on equipment and adaptations.

As an extra service to our clients we can offer to facilitate contact with a company that does bathroom adaptations.

ESL (previously known as Goodhearts) is a reputable company that has provided excellent and consistent service to both private and public contractors for more than ten years

They provide an initial free, no-obligation survey, work out a quote and undertake the full installation and service of any bathroom adaptation you need.

Through TDF, clients can access this service and get a small discount on the final cost of the work. We can also assist with advice on how to apply for a Disabled Facilities Grant to finance the work.

For more information please call Anne on:

**0208 954 7373**

# benefits & advice

## Did you know..

...that if you pay for 14 or more prescriptions in one year, you can save money with a Prepayment Certificate(PPC). Phone: **0845 850 0030** for more information.

... about the **Independent Living Exhibition**. It is a yearly exhibition held in **Wembley, London** with almost every type of equipment for the disabled on display. The exhibition takes place on the **23rd & 24th September** and it is free to attend. Call **0870 429 4372** or visit [www.independentlivingevents.co.uk](http://www.independentlivingevents.co.uk) to get a ticket and more information.

## Permitted Work on Incapacity Benefit

Incapacity Benefit is given on the grounds that you are not able to work, however there are some cases in which certain types of work are allowed:

- Any work as a local councillor
- Any work as a member of an appeal tribunal or the DLA Advisory Board
- 'Permitted work' - you must inform social services of this and is work of any kind which you can do:

**Either:** for an unlimited period as long as you do not earn over £20 a week. This is called permitted work lower limit.

**Or:** for up to 26 weeks, as long as you work on average for less than 16 hours a week and do not earn more than £67,50 a week. This is called permitted work higher limit. You can have a 26-week extension to this work straight away, if there is evidence that extending the period will improve your capacity to undertake full-time work.

## Free Advice Clinic

If you need to talk to somebody in person about any issue regarding disabilities, The Disability Foundation now offer a free advice clinic once a week.

Apart from general information we also now offer benefits advice. If you need help calculating your entitlements or your circumstances change and you are not sure how

this will affect your benefits, make an appointment.

The advice clinic is open **Thursdays between 14.00-17.00** and it is **by appointment only**.

If you would like an appointment, contact our information officer Anne, on **0208 954 7373**



## Accessible Houses

A new web-site specialises in accessible and adapted properties for sale and rent.

The Accessible Property Register accepts adverts from individuals, businesses and organisations and advertising is currently free.

[www.accessible-property.org.uk](http://www.accessible-property.org.uk)

# news round up

## Project Coordinator Leaves

TDF has had to say goodbye to our Project Coordinator Suzanne Rymer, who has decided to return to social work.

Suzanne has been a great asset, helping TDF to take the next steps in expanding the charity and its services. We thank

her for her efforts.

TDF is now on the hunt for a new Project Coordinator who can continue her good work and give his or her very own contribution to the special place that TDF is.

## Do you have a good pen?

Then what are you doing idling your time away?! Get straight to your desk and start composing a good piece for the next TDF Newsletter.

Write about your personal experiences, about life with a disability, or caring for a loved one, or even about a good holiday experience. The deadline for the next issue will be October 2nd. Please contact Anne Dvinge ahead of this date if you wish to contribute.

### Harrow Shopmobility

Registered Charity No.1044173

OPEN MONDAY - SATURDAY 10am - 4pm

37 St George's Centre, Harrow

020 8427 1200

**FREE** use of electric scooters, powerchairs & wheelchairs daily, or up to 2 weeks' loan of a wheelchair for anyone **with limited mobility** – temporary or permanent

**VOLUNTEERS  
NEEDED**



**CAN YOU SPARE  
3 HOURS A WEEK?**

## Newsletter by Email

For those of you who are logged onto the information highway, we can now send the Newsletter to you by email. It will go out in PDF format, so Adobe Acrobat Reader is necessary.

If you wish to join our email mailing list please email Anne Dvinge on [anne@tdf.org.uk](mailto:anne@tdf.org.uk)

## TDF AGM

The AGM for The Disability Foundation was held on May 12th 2003. We had hoped to see many of our members there, but are sorry to report that only a small number managed to attend on the day.

If you could not make it but would like a copy of the minutes, they are available on request. To receive a copy, please ring the admin team on 0208 954 7373.

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