



Connections

Volume 8 issue 3 Winter 2005

Welcome to Connections News and notes for donor families

Spotlight on the DFN Trustees – David & Jane Nix

David Nix is the Chairman of DFN and co-founder with his wife Jane. David is 57 years old and retired in 1997 from the West Midlands Police Force after serving 30 years. Most of that time David was a career detective, involved in investigating major crime and latterly he worked as a member of the drug squad. David now runs his own fleet logistics company with fellow director Pete who is also a retired police officer.

Jane is 55 years old and has worked her entire career with people with learning disabilities. She trained as a nurse and now works as Service Improvement and Quality Manager for a Primary Care Trust in the Learning Disabilities Directorate.

David and Jane founded the DFN in 1997 following the death of their 21 year-old daughter Rebecca in a road traffic accident in Connecticut USA in 1996. Rebecca became a multi-tissue donor. They also have a son Stuart who is an electrician. David & Jane have been involved in charity work for many years, mainly taking aid to countries in crisis for Siloam Christian Ministries. Trips made include those to Romania, Ukraine, Belarus, Croatia, Bosnia, Albania, Russia and Kosova

This year they were very proud to go to Buckingham Palace where David received the MBE for charity work in Europe and the UK

Watch out for the spotlight on other Trustees in future newsletters



Patron Lady Heather Mills McCartney
Registered Charity 1078981

Please send any questions,
articles or tributes to;

Donor Family Network (DFN)
9 Fairfield Avenue
Great Barr
Birmingham B43 6AG

Tel/Fax 0121 357 7271

donorfamilynetwork@btinternet.com

Stop Press

Don't forget to keep an eye on our new website in the New Year. It will be interactive and you will be able to 'adopt' a butterfly in memory of your loved one.

It is very easy to keep in touch if you are on e-mail and many families find this contact supportive. If we have not had your e-mail address send an e-mail to Jane Nix at donorfamilynetwork@btinternet.com to be put on the mailing list.

Are tissue donors treated differently to organ donors?

Two years ago my husband, Graham Fisher, suffered a heart attack and died at the wheel of his car on his way home from work, aged 47. At the time the police came to tell me what had happened I didn't want to ask about organ donation in front of my daughter but the next day when we went to identify him the police who met us at the hospital just said, "He carried a donor card" (as the rest of the family do). They told me that tissue, bone and eyes could be taken if we so wished and when I agreed they said that I would receive a phone call from the Blood Transfusion Service later that afternoon. Sure enough a very nice lady phoned and I was asked a whole series of questions and I agreed to tissue and bone donation but not the eyes because poor Graham had a "thing" about eyes and I felt I could not do that to him, even though his feeling would probably have been that they were not much use to him now! I was told that provided all was OK tissue from the back and bone from the thighs would be taken for use in bone grafts, burns, etc, and I gave permission for either or both to be used in pharmaceutical research if they could not be used on living recipients. I received a phone call the next morning to say that the procedures had been successfully carried out and thanking me for granting permission and a few days later I received a letter of thanks which, from memory, was a standard letter. That was it.

Having read the articles in Connections has just made me realise that everything was all arranged by phone, there was no face-to-face contact and we received no follow-up support whatsoever. I never even thought about support at the time (I thought that would just be for recipients of major organs) but having read the articles has just made me realise that yes, even a phone call to see how we were coping would have been nice. We have, after all, still lost a loved one and it would have been nice to know if the donation had been of use.

Having read the article about the donor family care policy it seems like there could be a two-tier system or it could just be how the system works here. It would be interesting to hear if other families of tissue/bone donors have received support.

Marion Fisher

GIFT AID

The Donor Family Network (DFN) is now registered with the Inland Revenue to claim back tax for donations received. For every £1 donated we can claim back 28p as long as the person donating is a taxpayer (this includes works or private pensions!).

Attached to the newsletter is a Gift Aid certificate. This information is required by the Inland Revenue If you would like to donate money to DFN or receive donations from others for DFN please complete the form and return to us. If you regularly donate you will only need to complete one form and tick the box relating to future donations.

As you are aware we are a small charity and this is one way we can make the most of money we receive

The Donor Family Quilt

At the Gathering this year we had 9 patches made by children. These will be made up into a panel especially commemorating the event. We would like to extend an invitation to children to make a patch in memory of a family member to go into the First National Children's Donor Family Quilt. The Quilt template is attached for guidance.

Links

Transplant Sports Association of Great Britain (TSAGB)

www.tsagb.org

Transplants in Mind (T.I.M.E.)

www.transplantsinmind.co.uk

Organ Donor Line

www.uktransplant.org.uk

British Organ Donor Society (BODY)

www.body.orpheusweb.co.uk

Donor Family Network

www.donorfamilynetwork.co.uk

Family Cluster Support Leaders

We now have over 150 families in the Donor Family Network and we are all spread across England, Scotland, Wales and Northern Ireland. Much as we would like to keep in regular contact with you all it is an impossible task.

For those of you using e-mail please could we have your address, as it is much easier to keep in contact via e-mail. We are looking for Family Cluster Support Leaders who are willing to keep in contact with families in their area. You would be representing the Donor Family Network and we would support you with the cost of telephone calls and postage costs.

The commitment would be as much or as little as you feel able to give. This may be telephone, e-mail or letter contact. It may be an occasional visit to someone living near to you. There are so many families who would enjoy having the contact from someone who has been through a similar tragedy.

For all our families to be part of a cluster is purely optional. When we have the leaders in place we will contact you individually to confirm the level of support, if any, you would like. There is absolutely no pressure but we would like our families to feel a special part of our network.

We already have a donor mom in Scotland who is willing to keep in touch with families there. We can do so much more for our families and support them in whatever way they wish if there are enough people to share the work. We are all volunteers and helping others can be very therapeutic in the healing process.

We hope this idea will be acceptable and look forward to hearing your opinions.

Jane Nix Secretary DFN

DONOR BUS

Torch Relay

This year's relay leading up to the Transplant Games started in Norwich and ended at Loughborough. The route, registrations and details of sales and donations is attached.

Donor families, recipients and their families and co-ordinators, supported the bus along the route. We are most grateful for all their efforts which resulted in us achieving 2 relay records – In Nottingham we broke the record for the most completed registrations in one day with a grand total of 704. Overall the total for the relay was 4119 again a relay record!

We were visited in most venues by a Mayoral party and in York received the Mayor and Sheriff. We have to thank the stalwarts of the relay including Peter Lawson who gives up 2 weeks annual leave each year to travel with the bus, his wife Rebecca who is a kidney recipient and celebrated her 13th birthday of her donation while we were away. Rebecca also gave up annual leave to join us. Regular crew members from DFN who give up annual leave to travel the roads of England include David Nix Chairman, Jane Nix Secretary, Eddy Crouth Vice-Chairman and Karen Crouth Treasurer. We would like especially to thank Sue Johnstone, Administrator for TIME for organising the venues and Mayors and joining us for part of the trip.

Donor families were welcomed at the Transplant Games and next year we hope to be included in the opening ceremony and parade of athletes. The games will be in Bath and the opening ceremony will be on Thursday evening 17th August. We do hope as many of you as possible will join us either for the opening ceremony or at the athletics on Sunday 20th August at the University of Bath. The athletes enjoy coming to the bus to see what new sale items we have and to view the donor family quilt. We have made many new friends over the years and seeing people who were desperately ill now; having had a transplant, able to achieve athletic recognition makes us feel very humble.

On a final note the ownership of the donor bus has now transferred to TIME. DFN is a small charity and the costs of maintaining the bus have meant we are unable to sustain this activity. We will of course retain the Transplant Torch Relay and David Nix will continue to drive the bus for the 2-week relay.

Gary Steven Westwood
(03.01.84 to 02.11.01)

In memory of our precious son and brother who was taken from his family so tragically. Gary lived his life to the full and loved sport of every kind, especially golf. Gary will always be remembered for his warmth, his kind, gentle ways and the love and compassion he gave to his family and friends, enriching our lives. Our bond of love can never be broken and his gift of life continues to give us the strength and inspiration to carry on. Loved and missed so very much by his mum and dad and sister Carla.



Brenda Powers 10.10.1947 – 02.10.2005

An Ode to Brenda

(An ode to Brenda? We all owed Brenda)

Brenda was friend to me and a mum to you,
She was a mum to me and a friend to you,
Daughter, wife, grandmother, colleague too,
She was an aunt to me and to you
A sister to all of us – she was everything – successfully too.

There were 9 of us and 4 of you, but into each others arms (and hoses) we flew, getting the door, putting the kettle on, hunting for little Sue or chasing after John.

Bren, can we borrow flour for cooking, glue for homework, a tea-bag, a pin for me dress, the answer was always yes, 'cause she'd never let us get in a mess.

Christmas, weddings, birthdays, funerals, Bren was always there, doing what she could – mothering us, coddling us, making sure we had something to wear.

Celebrations, partying, festivities, we think of Bren with our antiquities, altruistic, noble and good she did it 'cause she wanted to not because she should. Complete, organised, not always prepared, she did it though because she cared.

She was always so ready to lend a hand, but always staying in the background, quietly cooking, sewing, doing whatever was needed, giving advice – her sensible words were always needed and heeded.

Dress-up, painting, gardening, sewing, didn't matter where you were going, knitting, drilling, baking or make-up – on cue, it was Bren to the rescue, bricklaying, paving, wallpapering too – was there anything Bren couldn't do?

A dress for this, a cake for that, a quiche for this, a brick wall for that! She made you the sun and then the moon and everyone else the stars, her constant selfless acts endeared her to all our hearts.

Brenda, with half your wit, your talent and years, we should be so blessed to possess just an ounce of your flair. Let not sorrow, pain or despair at our loss of one so lovely, wise and fair, 'cause no doubt, mum was laying in wait, at heavens gate, then pair off they'll go, re-designing heavens estate.

So take away these sorrowful tears, and before it grows too late, let's celebrate, for today she was 58 years.



When tomorrow starts without me, and I'm not there to see.
If the sun should rise and find your eyes, all filled with tears for me;
I wish so much you wouldn't cry, the way you did today,
While thinking of the many things we didn't get to say.

I know how much you love me, as much as I love you.
And each time that you think of me, I know you'll miss me too.

But when tomorrow starts without me, please try to understand,
That an angel came and called my name and took me by the hand.
She said my place was ready, in Heaven far above,
That I'd have to leave behind all those I dearly love.

But as I turned to walk away, a tear fell from my eye.
For all my life, I'd always thought, I didn't want to die.
I had so much to live for, so much yet to do.
It seemed almost impossible, that I was leaving you.

But when I fully realised, that this could never be,
For emptiness and memories, would take the place of me.
And when I thought of worldly things, I might miss come tomorrow,
I thought of you, and when I did, my heart was filled with sorrow.

But when I walked through Heaven's gates, I felt so much at home,
When God looked down and smiled at me, from his great golden throne,
He said, "This is Eternity, and all I've promised you."
Today for life on earth is past, but here it starts anew.

So when tomorrow starts without me, don't think we're far apart,
For every time you think of me, I'm right here, in your heart.