



Providing support and friendship for patients, carers and families in transplantation

Registered Charity Number - 1052328

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NEWS

A number of exciting things have happened since the last newsletter

- On January 28th we became Registered Charity 1052328. We can now bid and beg for funds with some degree of official status. So if any of you are enthusiastic in that regard, get out there and see what you can do.
- We had a number of media engagements promoting the aims of the TSN, which brought forward a significant number of enquiries.
- We have applied for membership of *TIME*, an umbrella organisation which includes most other groups involved in transplantation.
- Our first pilot course establishing the needs of the network, took place at the network base. A further course is planned for May.

Here are some details of our progress.

MEDIA EVENTS

Jo has been involved in a number of publicity events during the last few months.

In December she was interviewed for *VIVA* radio, a women's programme put out in the London area.

On Boxing Day there was a full page article with colour photographs, discussing her life and how she had come to set up the Transplant Support Network.

In January there was a similar double page spread in *YES* magazine in the *Sunday People*.

In January we both appeared on the *GOOD MORNING* show.

All of these events produced a good deal of publicity for the network. It is

THE BREATH OF LIFE

NEWCASTLE'S ROLE IN LUNG TRANSPLANTATION AND RESEARCH.

Sam Hamilton.

Based on recent interviews with: Mr John Dark, director of the heart and lung transplantation unit at Newcastle's Freeman hospital and senior lecturer in cardiothoracic surgery in the medical school's department of surgery; Dr Anne Cunningham, research scientist in the department of surgery at Newcastle medical school & transplant patients, Jackie Babiczuk and Grant Armstrong

New lungs save Jackie

Jackie Babiczuk serves with grace and power for her volleyball team. As the ball is hammered back in her direction over the net, she leaps to return it. Like any sportswoman, she exudes enthusiasm and energy, but for Jackie, life was once very different. Jackie, 44, of Hebburn, was born with a hole in her heart and subsequently developed pulmonary hypertension, her lungs eventually deteriorating to the point where a combined heart lung transplant was necessary. Jackie was only the third heart-lung recipient to be transplanted by the Freeman Hospital's lung transplant team led by Mr John Dark, in June 1988, at a time when she had been given just 6 months to live. Jackie was bedridden and required a continuous supply of oxygen merely to survive. The operation turned her life around to the point where, after an initial recovery period, Jackie began participating in sporting events at the European and British transplant games. Hard won medals in shotput, badminton and long jump were tangible proof of her soaring quality of life since the operation.

Rejection setback

However, in early 1994, Jackie began to experience chronic rejection. This is where the body's white blood cells or immune cells, normally responsible for fighting infection (and therefore having a protective role), become "confused". These immune cells recognise the new organ as being a foreign body and therefore attack, or reject it as if they were fighting an infection. Until recently, Jackie received the usual courses of conventional treatment for rejection, which had unpleasant side effects, so it has taken almost two years for her to begin to feel well enough to participate again in competitive sport.

Kidney patients - a smoother ride?

Jackie's story is something of a contrast to that of Grant Armstrong's, 42, of Ouston. Grant suffered from kidney failure from the age of 10 and now, 15 years on from his kidney transplant, performed at the RVI, he has been a regular participant in the many events of the transplant sporting calendar over the years. Like all organ transplant patients, he takes a daily cocktail of pills to keep him well, but Grant is the first to admit "It hasn't stopped me from doing anything".

Lung versus other organ transplants

Bridging the survival gap Grant's story is typical of many kidney and heart transplant patients who have a good quality of life post transplant. They are susceptible to rejection, like anyone in receipt of a new organ, but patients with new lungs, like Jackie are more likely to have rejection-related problems, and therefore often have a poorer overall quality of life and reduced survival. Newcastle-based experts are striving to bridge the gap between the more common types of organ transplant and lung transplant.

Patients unite at local sporting event

The British transplant volleyball championships, held at Gateshead in November 1995, provided the venue for Jackie's sporting comeback. Jackie, joined the Freeman team while Grant captained the RVI team. Both teams originating from the hospitals where the patients had their operations: The "RVI Newcastle" team made up of the "kids" or kidney transplant patients, and the "Freeman" team made up largely of heart transplant patients and two heart-lung patients, one of whom was Jackie, represented the city's great history of transplantation. Heart and kidney transplants are the commonest and most successful type of organ transplants in the UK at present, whereas lung and heart-lung (pulmonary) transplants are less commonplace and still have some way to go before they approach a similar success rate in terms of longevity and quality of life. However, surgical techniques developed by Newcastle University staff, supported by research carried out in the Medical School are currently being applied with success on increasing numbers of lung transplant patients. This fuels the hope that in years to come, more of them will be well enough to join the Freeman volleyball team. Jackie speaks for all the players when she says "None of us are great sportsmen! It doesn't matter how good you are, just that you can play at all".

Pulmonary transplant

Newcastle's pioneering efforts in surgery Heart and lung transplants have been taking place in Newcastle for the past 10 years at the Freeman Hospital, one of the UK's three centres of excellence for pulmonary transplantation. John Dark, who, as well as being the director of the Freeman's heart lung transplant unit, is senior lecturer in cardiothoracic surgery in Newcastle Medical School's Department of Surgery. He explained that such operations are becoming safer all the time, although there is still room for improvement. The first heart transplant took place in 1985 and now 8 out of 10 heart patients are still alive and well 5 years after their operation. The first lung transplant followed two years later and since these tentative steps into the unknown, over 500 patients have received new hearts and/or lungs to the present date. The success rate for lungs has yet to approach that of the hearts but it is improving all the time. New surgical techniques developed in Newcastle, have helped to improve the chances for certain types of lung transplant patients. John's surgical team pioneered a special form of lung transplant - the bilateral lung transplant - in the UK. He explained " This operation involves supplying the patient with two new lungs but leaving their own heart in place. There is a major advantage in this for sufferers of cystic fibrosis (CF). With this disease, the lungs eventually become useless bags of pus, but the heart is usually still in good working order. By transplanting new lungs but leaving the patient's heart in place, this operation is more successful than the old style heart/lung transplant as the patient's own heart has a good nerve and blood supply which helps speed recovery following major surgery." Excellent survival rates for young CF patients and the fact that the operation is now routinely performed worldwide are testament to the standards set by the team at the Freeman Hospital.

Science and surgery: joint ventures help lung patients' chances Although such surgical techniques have gone a long way to improving the chances for some populations of lung transplant patients, experts recognise the need to support innovations in surgery with laboratory-based research, to directly attack the problem of rejection, as experienced by 30 to 50% of all lung transplant patients. As rejection slows the process of recovery from surgery and current regimes for treating it have unpleasant side effects for so many, the search is now on for newer and more "patient-friendly" treatments. These could eventually help reduce the suffering Jackie experienced for two years, as a result of rejection.

Fighting rejection the scientific way Dr Anne Cunningham, a research scientist based, like John, in the Department of Surgery at Newcastle University, and working collaboratively with him, is attempting to address the problem of lung transplant rejection, which affects the whole spectrum of patients with transplanted lungs, including those with bilateral lung transplants. Anne is currently interested in a group of delicate airway cells which line the lungs and form the barrier between the blood and air allowing oxygen to pass through these cells and into the lungs. In many lung diseases, these cells are damaged and breathing is therefore made more difficult. Just how these vital "breathing cells" become damaged is a mystery, but Anne says "I am certain that the same immune cells responsible for rejecting transplanted lungs, are somehow involved". Anne is investigating her theory that the donor's airway cells are able to activate the recipient's immune cells, resulting in damage to the transplanted lung. In particular, she hopes to discover more about how this damaging immune response can be stopped. Anne was keen to explain that by investigating the process of lung damage through her research into inflammatory lung diseases such as pulmonary fibrosis, asthma and, of course, transplant rejection, damage to the lungs could eventually be halted, reducing the need for transplants in the first place and, secondly, if transplant was necessary, better treatment for lung rejection than is currently available could be a real possibility.

Moral support for all

Grant and Jackie both agree that the doctors and scientists fulfill their roles in providing the best levels of clinical care and the newest scientific innovations but do not also provide the crucial third factor of moral support. The Transplant Support Network or TSN, founded by Jo Hatton, one of the UK's longest living heart/lung transplants, is a new national organization recently awarded charitable status. It offers emotional support to transplant patients and their carers whose "normal" lives prior to transplant were spent coping with illnesses that frequently took them in and out of hospital. The TSN helps these people before transplant, during recovery and afterwards when they are advised to "go away and live a normal life" and serves as a reminder that an individual's emotional well-being is as important an aspect of organ transplantation as their clinical health.

This article was written by Sam Hamilton (Ph D), for the University of Newcastle. She has kindly given us permission to print it in our newsletter.