



**KIDNEYS FORLIFE**

Fundraising for the MRI Renal Units

# Spring 2011 Whispers

[www.kidneysforlife.org](http://www.kidneysforlife.org)

## IN THIS ISSUE

Reflection on Sacrifice



A memoir from the 1000<sup>th</sup> transplant patient...

Help us get to the British Transplant Games



Jack and Riley are on a fundraising journey...

**...AND MUCH MORE**

**Kidneys for Life  
fundraising for MINT**

Charity number 505256

## An 80km Skating Adventure

In February, Muir Morton (Senior Registrar) took part in the Vikingarannet 80km ice skating race in Sweden...



Muir Morton (Senior Registrar) who I am sure many of you know took part in the Vikingarannet on the 13th February which is an 80 km ice skating race in Sweden across the frozen freshwater lakes that surround Stockholm. It is an old viking route. Muir mentioned that if you could skate competently that was cheating and the ice was thick enough! Muir and his team managed to do the race in 5 hours and came about half way down the field of skaters.

Above: **Muir Morton and fellow racers**  
Below: **The Vikingarannet 80km**



**Thanks to Muir and everyone who supported him in this mad adventure.**

## Accounts: 2009-2010



### Income £72,355

Voluntary income	£49,028
Investment income	£23,327



### Expenditure £101,941

Cost of generating voluntary income	£33,077
Charitable activities	£50,431
Governance costs	£15,687
Depreciation	£2,746

This is summary of the charitable accounts for Kidneys for Life fundraising for MINT for the year ending 30 April 2010.

A full copy of the accounts can be found on the charity commission website: [www.charitycommission.gov.uk](http://www.charitycommission.gov.uk) and searching on our charity number 505256.

## 2010 Transplant Figures

During 2010 the MRI Renal Transplant Unit carried out 212 transplants which is a 22.5% increase on 2009.

**113** deceased donor kidney transplants

Of the living donor transplants, over a third came from unrelated donors of which six were paired/pooled transplants and there were also two altruistic donors.

**78** living donor kidney transplants (increase of 33.9% on last year)

At the end of 2010 there were 621 active patients on the transplant list (this number changes on a day to day basis).

**20** simultaneous pancreas & kidney transplants

Well done to the transplant team

The Unit in conjunction with Manchester University also did their first Islet transplant in 2010 - Mr Leslie Jones, the first islet transplant patient, said: "This treatment has been fantastic! Before my transplant, I was always eating to avoid "hypos", and now, it's like the clock has been turned back to when my diabetes was easy, though, at the moment, I still have to take a small amount of insulin. This will bring new hope for patients with diabetes. For me it was like turning the clock back to 1979 before diabetes affected my life".



Above: Leslie Jones

## With Thanks To...

Whilst we recognise the help of all patients and volunteers who have supported Kidneys for Life in the past, we have highlighted just a few from the last six months.

### Horses at Halloween



Karen Part donated a kidney to her daughter in 2001 and as a thank you Keira (aged 12), Joanne's daughter along with friends Marcus & Ellis decided that they would like to have a charity day to raise money for Kidneys for Life and what better day to have it than on Halloween. Jo & Andrew Callwood (Marcus & Ellie's parents) offered the use of their showjumping area free of charge and on the day there was a fancy dress competition and clear round showjumping together with a homemade cakes, witches brew soup and hot fruit punch which all went down very well indeed.



All of the prizes were donated and everyone went home with something. Our thanks go to everyone involved who raised over £175.

### Superfast Superhero

Five "Super Hero Runners" took part in a 5km run in Heaton Park on 26 Sep 10, the runners were David Peat, Anne Lewis, Gail Woods, Stephanie Raabe & Irene Chambers. The group raised just over £1,400 so well done.



### First Impressions

Gail Cox & Gill Bussey organised a fashion show at the White Hart at Lydgate with all proceeds going to Kidneys for Life on Thursday, 21 October. Over 90 attended on the day for lunch followed by a fantastic fashion show featuring clothes and accessories available from First Impressions of Staylbridge and modelled by customers and friends. There was also a raffle and auction for which we thank everyone concerned for their donation of the prizes. £2,000 was raised on the day so thank you to everyone who attended for helping to raise such a fantastic sum for Kidneys for Life. [www.firstimpressionsbygail.com](http://www.firstimpressionsbygail.com)

### Manchester High School for Girls



A number of fundraising activities have taken place at Manchester High School for Girls and in total during the past twelve months they have raised £1,150 including Christmas card sales as Hattie Dufton a pupil at the school submitted the winning design for our Christmas card design competition in 2010.

### Christmas Gifts

We would like again to thank Boots Rochdale for their help and support which enabled each of our Renal Patients to receive a small gift at Christmas.

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**Once again, thanks to everyone who has helped support Kidneys for Life.**



## Reflection on sacrifice... ...a memoir

Left: Kay Knowles

**Kay Knowles who many of you may know passed away in September 2008 just after her 69th birthday. Kay was the 1,000th transplant patient here at the MRI in March 1988. We would like to thank Peter, her husband who was recently looking through Kay's papers and sent us this memoir which Kay had written in 1993 about her experience as a dialysis and transplant patient and reflecting on the sacrifice made by the person who donated their kidney.**



"This week I've been watching the Coronation again. Forty years! Then I was a thirteen year old school girl, full of the optimism of the age and my own youthful expectations. Forty years on, I have a comfortable domestic existence as wife, mother of two daughters and doting grandma to our new grandson.

So what has this to do with sacrifice? Perhaps I had to leave school prematurely to help the family finances? No, I went on to College and became a teacher. Did I lose the love of my life to my best friend? Not so, I met Peter shortly after leaving college and we celebrate our thirty first wedding anniversary this year. Well, maybe I had to give up a glowing career for the sake of the family? Hardly! I was only too happy to exchange teaching for the joy of bringing up my own family.

To my mind, a real sacrifice requires at least some element of regret, if not real pain, either physical or emotional, on the part of the person concerned. The fact that I am here now, able to enjoy my life and family and the nostalgia of that occasion forty years ago, owes very little to any sacrifice on my part.

Having said that, not all my life has been untroubled serenity. For forty years I regarded myself as a physically able person, seldom afflicted by any but the most trivial illnesses. Then I was discovered to be suffering from a hereditary and progressive kidney disease. My complacency was somewhat shaken, but life continued much as before. The disease took its inevitable course, until I reached the stage I had secretly feared – I required renal dialysis. Even here

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I was lucky; the reality was much less terrifying than I had imagined, and I was only on dialysis for a few weeks before I received the most momentous telephone call of my life.

This is where sacrifice enters the story, and even now I cannot claim it for my own. I am here now as a testament to the skill of the medical profession and the sacrifice of one anonymous person. That telephone call was to tell me, in the words of the night-sister, "We have a kidney for you."

I can now say that in the euphoria of the next hours, the excitement of a new life opening, the apprehension of the operation to be undergone, you never quite forget that it has only happened for you because

someone else has had to make the greatest sacrifice – to give up life.

I know very little about the donor of the kidney. She was a woman younger than me, but by her sacrifice and that of her family, at least two people have been given the chance of life.

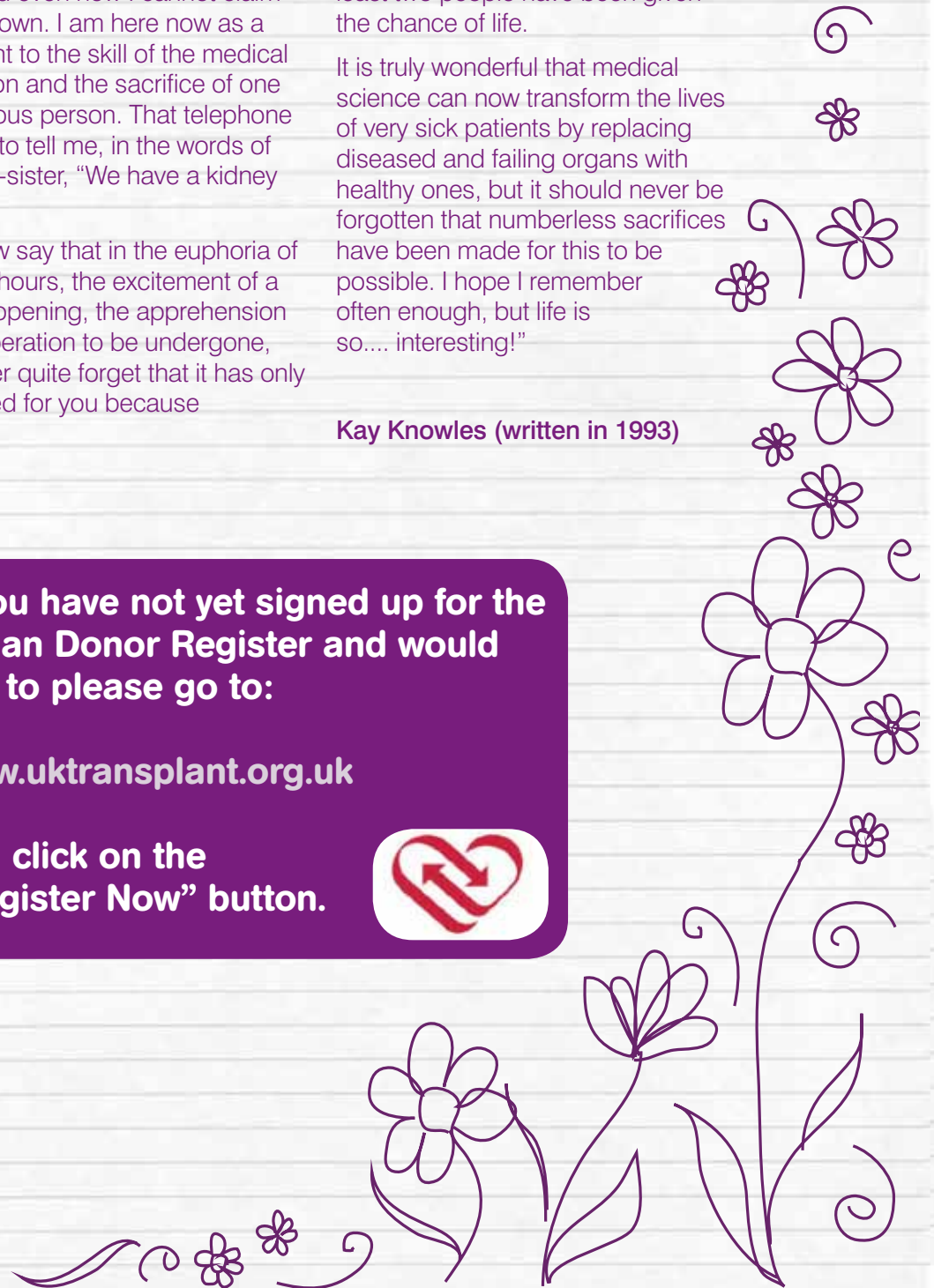
It is truly wonderful that medical science can now transform the lives of very sick patients by replacing diseased and failing organs with healthy ones, but it should never be forgotten that numberless sacrifices have been made for this to be possible. I hope I remember often enough, but life is so.... interesting!"

Kay Knowles (written in 1993)

**If you have not yet signed up for the Organ Donor Register and would like to please go to:**

**[www.uktransplant.org.uk](http://www.uktransplant.org.uk)**

**and click on the "Register Now" button.**





## Help the Manchester Children's Transplant Team get to Belfast

**Jack and Riley are just two of the brave children that we are hoping to take to the British Transplant Games later this year...**

Left: **Riley Greenwood**  
Below: **Jack and his stepdad George take part in the Static Bike Ride**

**Jack has had a number of TV appearances over the last couple of years, first appearing on the first series of Children's Hospital and then went on to appear on Granada Reports and GMTV. He is also appearing in the current series of Children's Hospital.**

Jack was born weighing just 2lb 15oz at week 36 of the pregnancy and spent his first three months in a special care unit at Wythenshawe hospital. He was diagnosed with intra-uterine growth retardation, glaucoma, underactive thyroid and pancreatic insufficiency. He was allowed home at 3 months weighing just 5lb 14oz and then spent the next few years seeing a number of consultants and had a number of operations and having found that he has faulty chromosomes, Perthes disease, diabetes and an enlarged liver & spleen to add to his health issues.

His mum, Jeni Spilsbury, describes him as: 'An inspiration, Jack is what keeps me going, to him, he's just Jack; he just gets on with it, and I wouldn't have him any other way.'

In 2006 he was referred to the Royal Manchester Children's Hospital at Pendlebury under the care of Dr Nick Webb. In June 2007 Jack's kidneys were removed and he tried peritoneal dialysis but that wasn't successful so went on to haemodialysis three times a week at the hospital, "he comes here happily as he

loves the attention and never complains," says Jack's mum Jeni Spilsbury. Jack was then put on the kidney transplant waiting list.

In July 2009 the Royal Manchester Children's Hospital moved to its new site here on Oxford Road and Jack came too.

In October 2009 he had an operation to repair his hip which has been flattened by disease; the operation was a success he doesn't need to rely on his wheelchair as much. Jack said at the time:



"I just want to be normal – and eat bananas".

The family then received the "phone call" and on 23 January 2011 Jack received his kidney transplant and was at home after two weeks, his comment on receiving the kidney was "now I can pee up a wall like the big boys!"

**His mum, describes her little boy as: 'An inspiration... I wouldn't have him any other way.'**

Riley Greenwood was born with a genetic condition called Atypical Haemolytic Uraemic Syndrome which is a rare disease among children causing kidney failure and high blood pressure and also had a Factor H deficiency. However, it was not diagnosed until June 2009 when Riley was 2½ years.

In simple terms this meant that Riley needed both a kidney and liver transplant as although a kidney transplant would help in the short term the liver itself would cause the condition to reoccur so both the kidney and the liver needed to be transplanted at the same time. At the end of November last year suitable organs were found to be a good match and the transplant took place at Birmingham. Riley who is

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from Rochdale then had his follow up treatment in the Children's Hospital and is well on the road to recovery.

Stacey, Riley's Mum and family and friends organised a party for Riley on 5th March and raised over £400 to help get the team to Belfast so thanks to everyone concerned.

Above: **Children's Transplant Games 2010**

Left: **Riley and Jack supporting their favourite football team.**



There are a number of events taking place to help raise funds including:

### **Static cycle ride from Manchester to Belfast**

A team of staff and patient's family members did a static cycle ride from Manchester to Belfast in the foyer of the Royal Manchester Children's Hospital on 31 March. We would like to thank Edinburgh Bicycle Co-op for the loan of the bike and equipment to enable us to do this. Over £274 was raised on the day.

### **'My Super Sweet Transplant' charity evening**

Teresa Starkey has organised this event which will take place on Saturday, 30 April at Swinton Park Golf Club. Tickets are £15 for adults and £6 for children and include a buffet and disco and there will be an auction and raffle on the night. For more information please contact: Denise Roberts on 0161 701 7708 or email [denise.roberts@cmft.nhs.uk](mailto:denise.roberts@cmft.nhs.uk)

**If you would like to help Jack, Riley and the rest of the Manchester Children's Transplant Games Team get to Belfast this year please help by making a donation online by going to [www.kidneysforlife.org](http://www.kidneysforlife.org) and following the link on the home page or use the slip provided at the back of this copy of Whispers.**



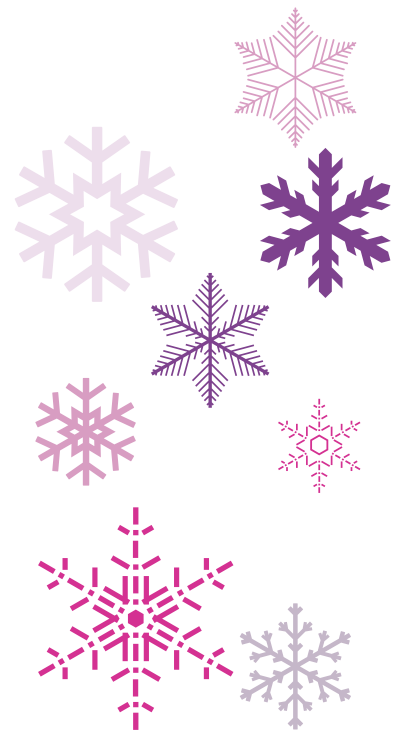
# Great Manchester Run 2011

Would you like to join our team?

Kidneys for Life had 45 runners in last year's Great Manchester Run who raised a fantastic £6,500. We are looking for runners for the Great Manchester Run 2011 which takes place on Sunday, 15 May and if you are interested in taking part on behalf of Kidneys for Life all we ask is that you pledge to raise a minimum of £100 (which includes the registration fee) and we will provide a T-shirt or running vest and a sponsorship pack.

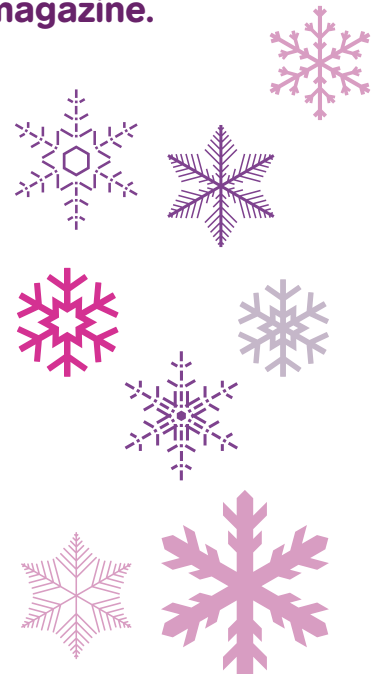
If you are interested please do get in touch with Irene Chambers either on 0161 276 6671 or email: [fundraiser@kidneysforlife.org](mailto:fundraiser@kidneysforlife.org)

**DEADLINE FOR REGISTRATION**  
**29 APRIL 2011**



## Christmas Card Sales

Our Christmas Card sales in 2010 raised over £7,100 last year for Kidneys for Life, so to everyone who purchased our cards can we please say a big thank you. The cards will again be available from around September this year, so look out for them online and via the next Whispers magazine.





## Research Grants Awarded by Kidneys for Life 2011

Kidneys for Life launched a new round of funding for small research projects and has awarded £40,000 in the following areas:

### Recurrence of Idiopathic Membranous Nephropathy (IMN) post transplantation.

IMN is the commonest cause of nephrotic syndrome in adults and this study will look at how we can prevent the recurrence of IMN post transplant with the use of auto-antigens to ensure the maximum life of a transplanted kidney and should offer further clues about the mechanism of the disease in the original native kidney.

### The use of retinal imaging to identify calcification of the retinal blood vessels in patients who have vascular calcification due to chronic kidney disease.

This study will attempt to identify vascular calcification in its early stages, as vascular calcification is associated with greatly increased mortality in patients with chronic kidney disease.

### Sensitisation to MICA in renal patients.

This study will look at the identification of tissue antigens such as the MHC Class I like Antigen A (MICA). Identifying the cause of sensitivity to antibodies such as MICA which have previously been undetected will help to influence kidney transplant survival

### Improving outcomes in acute kidney injury in paediatric intensive care patients.

This study will look at the identification of biomarkers to identify potential acute kidney injury before the rise in serum creatinine and will help to improve clinical management of Paediatric Acute Kidney Injury.



# Manchester Renal Patient BioBank (MRPB)

**Recently we have set up the Manchester Renal Patient BioBank which has been supported by Kidneys for Life and University Hospital of South Manchester (UHSM) Endowment Fund.**

The East sector of the Greater Manchester Renal Network includes dialysis centres in South Manchester (UHSM), Tameside, Prestwich, North Manchester and Central Manchester (Manchester Royal Infirmary). Central Manchester acts as the centre for acute nephrology, fistula services, transplantation and house the renal research labs which act as the focus for renal research across the sector.

We have established with ethical permission, a BioBank to collect and store samples (blood, DNA, serum & urine) from patients having renal disease, chronic kidney disease (stages 3-5), on dialysis and post

transplantation. The intention is to recruit both existing patients and newly diagnosed patient which together will comprise several thousand patients at all stages of the renal pathway with follow up for a minimum of 5 years.

A clinical set of data will be established at the time of the initial banking of the samples. An annual blood sample and clinical follow up data will be added for each patient who consents. The samples will be used for genetic, proteomic & metabolomic screening and biomarker assays where appropriate. This will let us investigate the following:

- **The causes, epidemiology and outcomes of kidney disease**
- **The reasons some patients progress to renal failure and others don't**
- **The reasons why some patients are better off with a particular dialysis modality**
- **The reasons why the vascular access site or peritoneal membrane function fails**
- **The causes of co-morbidity in uremia (eg. Cardiovascular disease)**
- **The damaging pathologies associated with kidney transplantation (eg. Ischaemia reperfusion injury, acute and chronic rejection)**
- **The links between complications experienced by an individual patient at different stages in the renal replacement pathway (with chronic kidney disease, on dialysis and post transplantation)**
- **Designing the optimum therapies to preserve renal function**



## Renal Remembrance Service

**A Remembrance Service will be held at The Lowry Theatre in July 2011 to remember those renal patients who have passed away in 2010. If you would like to attend or require further information please contact Noel Hurley on 0161 276 4652.**



## Pin badges

Help support Kidneys for Life by buying one or more of our new pin badges. The badges are £1.50 each and post & packaging is just £1 for up to 5 badges. Please get in touch with Irene Chambers if you would like to place an order or visit our website "shop".

[www.kidneysforlife.org/products-page/pin-badge/](http://www.kidneysforlife.org/products-page/pin-badge/)



## How can you help us to fundraise?



There are a number of ways in which you can help raise funds for Kidneys for Life one way in which you can do this is to take part in a fundraising event in your local area such as cycle rides, walks, runs, triathlons and for the more adventurous 250m zip slide from the Imperial War Museum in Salford across to the Lowry Theatre at a height of 30m. More information on such events can be found on our website under our "own place in an event section".

Left: Zip slide

# Get in Touch...

If you would like further information on any of the articles in this edition of Whispers or you would like help with fundraising ideas do please contact Irene Chambers.

**Irene Chambers**  
Fundraising Manager

**Tel:** 0161 276 6671

**Email:** fundraiser@kidneysforlife.org

Kidneys for Life fundraising for MINT,  
The Renal Unit,  
Manchester Royal Infirmary,  
Oxford Road,  
Manchester M13 9WL

## Donations

When making donations to Kidneys for Life or collecting sponsorship for events such as runs, walks etc please don't forget to:

*giftaid it*

Using Gift Aid means that for every pound you give, the charity you are supporting will receive an extra 25 pence from the Inland Revenue, helping your donation go further.

This means that £10 can be turned into £12.50 just so long as donations are made through Gift Aid. Imagine what a difference that could make, and it doesn't cost you a thing.

**Donate online at:**  
[www.kidneysforlife.org](http://www.kidneysforlife.org)



# Make a Donation and Help Make a Difference...

MINT has a proud history of being at the forefront of many acclaimed scientific discoveries and internationally celebrated successes. The research work undertaken by the team working in MINT offers real hope for patients both now and in the future. Please help us by making a donation...

To make your donation please fill in your name and address below and return to Irene Chambers, Kidneys for Life fundraising for MINT, The Renal Unit, Manchester Royal Infirmary, Oxford Road, Manchester M13 9WL

**Don't forget to giftaid to make your donation worth more (see above).**

Name .....

Address .....

..... Postcode .....

Signature ..... Date .....

- I enclose a cheque made payable to Kidneys for Life for £ .....
- I want my donation to go towards the Children's Transplant Games
- I want to giftaid my donation\*

\* To qualify for Gift Aid what you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year.

