

# Newsletter

Winter 2011



## *The Voice of Lincolnshire Kidney Patients*



Lincolnshire  
Kidney  
Patients  
Association  
[www.lincs-kpa.org](http://www.lincs-kpa.org)



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**A independent Association Run by Patients and Carers**

## **CHAIRMAN'S MESSAGE**

**It doesn't seem a year since the last Christmas message, how time flies! I hope that the last year has been a happy and enjoyable one for you. The LKPA has been busy, we have made changes to the grants and allowances we make, and the Counselling service has proven to be successful.**

**We've held social evenings, visited the units in the County and generally given help to those who have needed it.**

**Our AGM in November was very poorly attended, in addition to the committee only three members attended in spite of the meeting being advertised to each member and at the units.**

**Please remember that we, like you are patients and for us to help you, we need you to help us and to let us know what you expect from us. Our Committee badly needs members and a treasurer. We meet 6 to 8 times per year for approx. an hour and a half and the meetings are informal. If you can help please let either myself know or Mick Walker our Secretary.**

**I was recently invited to speak on Lincoln City Radio (LCR) about the Lincolnshire Kidney Patients Association.**

**This is good for us, it advertises who we are and what we do, hopefully we will be invited again.**

**LCR is a fairly new station, it aims at the 50+ ages and broadcasts on 103.6FM tune in, it's worth a listen.**

**On December 11th we had our first Christmas dinner at the Carholme Golf Club. 54 attended and enjoyed the evening. The meal was excellent, cooked for us kidney patients. After the meal we were entertained by singer Martin Goodson .**

**If you didn't come, think about the next one, possibly at Easter time. We thank those who have supported us through the year and the various organisations who have donated to our funds. Without the donations we could not do what we do.**

**Our thanks also to the staffs at the units, as always the help and support they give is excellent , so a big thank you for all you do.**

**Christmas is just round the corner and I wish you and your families a Very Happy Christmas and that the New Year brings all that you wish for.**

**Tony Perry**

## Secretary report

Dear member hope things are going well for you and your family members. It's been a busy few months doing things for Lincs -kpa, If you have changed your name or changed your address could you contact the Secretary so I can keep up to date on our database so that the Lincs-kpa can send the newsletter and Kidney life to the right address, thankyou,

Articles for the newsletter please if you could put a few words together about anything on your experiences of you going on holiday. Or your experiences of been a pre-dialysis, CAPD/ APD, Haemodialysis, Transplant,

Something for the APD members, talking to other kidney patients in others parts of the uk, what nickname do you call your APD machine, please get in touch.

Merry Christmas everyone,

## Thankyou for all Donations

<b>Donation</b>	<b>amount</b>
Donation	£58.50
NKF ( raffle ticket)	£21
Cranwell (Post Office and Shop	£9.36
Gainsborough Christmas Charity Market	£85.50
Hundleby Social group	£602
Donation	£58.50
Donation	£75
New Provincial Benevolent Fund	£500
Donation	£15
Cranwell post office and shop	£16

## Holidays Away – by Tony - Shirley Sims

"Since having to become an APD patient at the end of July this year, my wife and I were dubious about having a holiday break. On speaking to our renal nurse and several other people in the same situation, we decided to make a short "trial" trip with, of course, Sidney (our nickname for the machine). We booked a short break of three nights only a couple of hours drive from home - just in case we encountered any problems and had to return quickly home - we duly loaded the car with all the necessary accoutrements and set off for our destination.

We are very pleased to say and also to reassure other new comers to APD, that everything was just fine. So life doesn't grind to a halt after all. Just get up and go!

After speaking with several members who have been away on cruises and have had no problems we're now considering trying a coach holiday first, for a longer period.

**From The Secretary** It's nearly that time of year again, deciding on where to book holidays in this Country or abroad, PD patients or Haemodialysis patients there are things you have take into account off,

Haemodialysis patients,

- Ask your Renal Consultant if you are fit to go on Holiday,
- Decide on a unit (please have a another unit in mind because they might not have room at your first choice
- Please don't book your accommodation before you have booked your Dialysis sessions,
- Tell your holiday organiser or a renal nurse where you have booked so they can sort things out,

PD Patients

- Ask your Renal Consultant if you are fit to go on Holiday,
- Ask the Home Care team Nurse if you can have a form so that they can organise the PD dialysis Fluid be sent to the accommodation if you are stopping a week, (Baxter will deliver the fluid, but please take your connections and hand wash and any other items,

Ask the Lincs-KPA secretary for a holiday Grant form,

After all that Have Lovely Holiday

## Lincolnshire Kidney Patients Association Annual General Meeting

The Secretary read the notice to convene the meeting, then the Chairman then talked about what the KPA has been doing in the last year organizing social evenings, meetings with the unit managers, and a meeting with Clinical staff with the other KPA's under the umbrella of Leicester, this meeting was for Leicester to give info as to what is happening with renal in Lincolnshire then the Chairman resigned as required,

The Secretary gave his report he said the things he had been doing through the year such Holiday grants, Travel Grants, doing the database, giving leaflets out, talking to patients, and many other things, the Secretary resigned as required. The Vice Treasurer gave her report on finances,

Any other Business, The secretary asked if we could set up a young persons group for Lincolnshire, Chairman, Tony Perry was voted in as Chairman Secretary Mick Walker was voted in as Secretary Then the meeting closed.

### Lincolnshire Kidney patients Association NEEDS YOUR HELP

The Lincs-KPA committee more help to continue with work we do, if you are able to give a few hours of your time per year your help will be appreciated please contact the secretary on,

tele 01427 880125.

e-mail Secretary [secretary@lincs-KPA](mailto:secretary@lincs-KPA).

**Young Group** The Lincs-KPA is considering setting up a young persons group for ages 18 to 40, if you are interested in joining the group and be part of a committee for it, please let the Secretary know on 01427 880125.

The group would consider problems that younger members have and hopefully help with them.



## Try this Quiz is from the Lincs-KPA

The Answers will be in the Newsletter or on the boards at the Units,  
or on the Lincs-kpa website [www.kidney-kpa.org](http://www.kidney-kpa.org)

- 1 What date is St Stephen's Day?
- 2 In Charles Dickens' novel A Christmas Carol, who was Scrooge's dead business partner?
- 3 The song White Christmas was first performed in which 1942 film?
- 4 London's Trafalgar Square Christmas tree is traditionally given by which country?
- 5 In the song The Twelve Days of Christmas, '...my true love brought to me nine...' what?
- 6 Name the original eight reindeer from the 'Twas the night Before Christmas' poem.
- 7 Which Christmas carol includes the lyrics '...To save us all from Satan's power, when we were gone astray..'?
- 8 The character Jack Skellington appears in which 1993 Tim Burton film?
- 9 What colour are the berries of the mistletoe plant?

- 10 In the inspirational 1946 film, *It's a Wonderful Life*, what's the name of George Bailey's guardian angel?
- 11 What are the names of the three wise men said to have brought gifts to the baby Jesus?
- 12 What is New Year's Eve called in Scotland?
- 13 What Christmas item was invented by London baker and wedding-cake specialist Tom Smith in 1847?
- 14 In what year was Band-Aid's *Do They Know It's Christmas* the UK Christmas chart-topping record 1?
- 15 Which country did St Nicholas come from?
- 16 Who wrote *How the Grinch Stole Christmas*?
- 17 From which country does the poinsettia plant originate?
- 18 Who wrote *Auld Lange Syne*?
- 19 How many points does a snowflake have?
- 20 What is the name of the cake traditionally eaten in Italy at Christmas time?

# Christmas Cake Recipe

225g plain flour  
75g caster sugar  
1 level teaspoon of baking powder  
½ level teaspoon cinnamon  
½ level teaspoon of nutmeg  
120ml oil (polyunsaturated e.g. sunflower oil)  
60ml pineapple juice  
2 eggs (separated)  
2 tablespoons treacle  
120g glace cherries  
120g mixed dried fruit (pineapple or apricots chopped)



**Method:** Pre heat the oven to gas mark 2 (275F. 125oC.). Grease a small cake tin and line with greaseproof paper. Mix the flour with the baking powder, cinnamon and nutmeg. Cream the sugar with the egg yolks until pale yellow and fluffy. Add the flour mixture to the oil, pineapple juice and treacle, and mix until smooth. Whisk the egg whites until firm and fold into the cake mixture together with the fruit. Pour the cake mixture into the lined cake tin and bake for 2 ½ - 3 hours, or until knitting needle inserted into the centre comes out clean. If necessary cover with aluminium foil or greaseproof paper for the last half an hour to prevent excess browning. Remove cake from the tin and cool completely on a rack. Sprinkle liberally with brandy or rum. Wrap the cake in aluminium foil and store in a cool place.

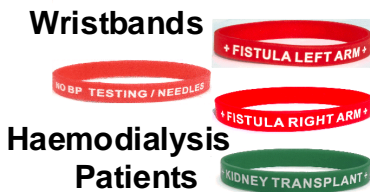
## Christmas Cake

The Christmas cake is good warmed and served with brandy cream or butter.

## Mock Marzipan

120g unsalted butter  
250g caster sugar  
100ml water  
250g semolina  
4 teaspoons almond essence  
Grated rind of 2 lemons

Heat the water and let the butter melt in it. Add the sugar and the grated lemon rind. Heat until the sugar has dissolved, add semolina and stir over a gentle heat for 5 minutes or until the semolina is cooked. Stir in the essence. pour into a dish and chill until firm enough for rolling out. Cover the sides with the marzipan and ice the top.



We can get wristbands specially made up for Haemodialysis and Transplant patients, in large and small sizes,  
Wear one to protect yourself in a Emergency.

Please be aware the no testing of bp, is on each of the Fistula right and left wristbands not as a separate wristband  
Please contact the Secretary of the Lincs-KPA if you require a wristband and say the size,

<b>Fistula Right Arm</b>	Large__ Small__
<b>Fistula Left Arm</b>	Large__ Small__
<b>Transplant</b>	Large__ Small__

### Information corner

#### Seasonal Flu- why you should have the Vaccination,

There is a booklet or on the internet, if any one wants a copy of the booklet please ring the Lincs-KPA secretary,

Website address

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_105356.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_105356.pdf)

**Renal Patient View**  **Providing up-to-date medication information for patient and Health Care.**

*See your blood results on renal patient view, even your GP can look at them so it helps them too, the web address is*

<https://www.renalphatientview.org/>

*If you want to join the renal patient view have a word with the renal team and they will give you a form and they send it of for you.*

#### **For Sale – Bag for Transporting and warming Peritoneal Dialysis solution**

The bag is good for capd patients that are going out for day, it warms up the fluid ready to use, it holds 2 full bags of fluid and all the items needed to Dialyse,

The Original cost was £200, it`s open to offers, the bag is the size of a computer bag

Please send your offers into the secretary with your name and address on the paper. Never been used.



## **Our next ADPKD Patient Information Day will be:**

**Date: Saturday, 28 January 2012**

**Time: 10.00 am — 4.30 pm**

**Place: Leicester General Hospital**

### **Morning Presentations.**

- Management of PKD,
- Genetics of PKD,
- Research Update,
- PKD Patient's Story

### **Afternoon Workshops**

- Pre-Dialysis Options,
- Coping with a Long Term Illness,
- Dietary Advice,
- The PKD Patients Health & Social Care Pathway,

No charge for attending but a donation is always welcome  
To help cover costs.

Register online

<http://pkd-charity-patient-info-day.eventbrite.com/>

Or

Phone Justina 01246 823468

E-mail: [justina@pkdcharity.org.uk](mailto:justina@pkdcharity.org.uk)

**Recipe Book** I have put a few Renal recipes for Christmas. or they can be made any time of the year too, The Recipes are for renal Patients,

The Dietician has given permission to use these recipes

Please contact mick for one of booklets, [secretary@lincs-kpa.org](mailto:secretary@lincs-kpa.org)



We want to get people talking about renal failure to show we are here to help with Issues that young patients have.

<http://www.kidney.org.uk/young@NKF/>



### Help for Kidney Patients and Carers

**Tel: (0845) 601 02 09** (charged at LOCAL CALL RATE, UK only)

E-mail [helpline@kidney.org.uk](mailto:helpline@kidney.org.uk)

The NKF Helpline provides assistance to patients, carers, family, friends and medical professionals. Seek advice, obtain literature, get help, all from the one Helpline number (details below). It is open for calls from 9am to 5pm, Monday to Friday.

### NKF ROADSHOW AT BLACKPOOL



The NKF was held in Blackpool on the 7<sup>th</sup> to 9<sup>th</sup> October, the programme included: Stem Cell Research, Genetics, Home Dialysis, Transplant, Living Well, Integrative Health, Anyone wishing to listen to any of the speakers on the web address <http://www.kidney.org.uk/roadshow11>,  
**A full report will be in the Kidney Life**

## **Officers of the Lincs-kpa**

**Chairman – Tony Perry** (01522 792395 [chairman@lincs-kpa.org](mailto:chairman@lincs-kpa.org))

**Secretary – Mick Walker** (01427 880125 [secretary@lincs-kpa.org](mailto:secretary@lincs-kpa.org))

Contact address – Hideaway, Fingle Street, N.Leverton, Retford,  
Notts, DN22 0AE

**Treasurer –** ([treasurer@lincs-kpa.org](mailto:treasurer@lincs-kpa.org))

Website of the Lincolnshire Kidney Patients Association is

**[www.lincs-kpa.org](http://www.lincs-kpa.org)**

For information and advice 01427 880125

## **The National Kidney Federation**

For information and advice

**08456010209**

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

**E-mail**

**[helpline@kidney.org.uk](mailto:helpline@kidney.org.uk)**

**Address:- The Point, Coach Road, Shireoaks,  
Worksop, S81 8BW**

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### **Websites:-**

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

**[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)**

**[www.nhs.uk/](http://www.nhs.uk/)**

**[www.renalpatientview.org](http://www.renalpatientview.org)**

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

**[www.pkdcharity.co.uk](http://www.pkdcharity.co.uk)**

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

**East Midlands Renal Network**

**NHS Direct**

**NHS Choices**

**see your results on line**

**polycystic kidney disease**