

Nail Patella Syndrome (UK) is a charity that provides information and support to those whose lives are affected by this condition and also for the use of the medical profession.



*Issue 10
January 2006*

**An introduction from the Chair
Submitted by Carol Dobbins**

NPS(UK) would like to wish you a very happy, healthy and prosperous New Year.

“It has been such an exciting few months and to be honest, it feels like this is going to be a very daunting task to try and condense it all into this Newsletter! So much has happened that I would never have thought possible. I can only hope that it proves to be very positive for each and every one of us.”

NPS(UK) Annual 5-a-side football tournament

On the 17th September 2005 the weather was a little unpredictable, as usual. It started to pour down when I was in the middle of preparing the buffet for the football tournament. I had a great wee helper in Nicola who made an entire loaf of cheese sandwiches, a loaf of meat sandwiches and a loaf of egg sandwiches. I made all the usual stuff, sausage rolls, chicken bites, chicken legs, cocktail sausages etc....

Thankfully the sky cleared a little and some of our friends arrived in preparation for the big day.

We arrived just after 11.30am as loads of other cars came too and we waited patiently for all the teams to arrive. Unfortunately, one team, just simply never arrived!! It proved to be a problem, but we quickly solved it with some help from the staff members who created a new fixture list! Originally, we had 15/16 teams..... But 11 teams was still a great show! The official referees arrived and got themselves ready and the tournament began, rain free!!

The official team looked just brilliant! I was so proud of them all. They won convincingly in all their qualifying matches!! This meant that they entered the final stages of the tournament. They faced a great team in the semi finals, and my nerves were off the scale!! They won! This meant that for the first time since the tournament started in 2003, NPS United entered the finals! They played their hearts out and, believe me, there were some injuries and a lot of pain at the end, but sadly, they were beaten by the most incredible team we have ever had in the tournament. The winning team were formidable and won their matches, 9 – 0, 9 – 0, 7 – 0 and 5 – 0. We have never had a team who has won every match so convincingly and not even concede a single goal. It was great to watch, and I was filled with such pride as I watched our guys take the defeat with such grace. Poor Trevor's NPS shirt was splattered with blood, Jim had a very painful groin strain, and Eddie, damaged his ankle!! Keith had a load of bruises and cuts, but was proud of their overall performance on the day. Keith scored a barrel load of goals and I had to stifle my excitement on many occasions!!

The East Kilbride News arrived and took a photo for the paper again. On the 21st September, the article went to print and NPS made the papers again!

I laid out all the buffet for the hungry, exhausted guys, who all met one another in the bar afterwards and shared their stories of the day. Believe me, there are so many stories that I think I will start a wee diary of events in the future. You would not believe how competitive some of these guys are!!



The presentation went so well again and as usual they gave me their full attention when I explained a little about the charity. I also presented Jim Alexander with a lovely gift and explained that BOC gases would match all that we made on the day. I told them all to dig deep for raffle tickets as our prizes were brilliant!

In Glasgow, nearly everyone supports Rangers or Celtic, so was very lucky to receive gifts from both teams. I had a Celtic Raffle box and a Rangers raffle box. The Rangers prize was a tour for 4

around the stadium and the Celtic prize was a huge life size picture of Bobo Balde, (Celtic player) signed by the man himself and a Celtic Top!

On this occasion, I also organised my first NPS auction! It was really a lot of fun and so exciting! A family member donated an incredible prize of a day at Celtic Park in one of the private boxes. The winners would have a champagne reception, receive a beautiful meal and basically be spoilt rotten for the whole day!!

The winning team, the Usual Suspects, returned their £50 prize money to the charity and I was very grateful to them for this. After much protest from me, they assured me that they wanted to do this.

My mother in law, Sheila arrived with the second buffet for the evening fundraiser. It was time to set the second one out and remove the first one! I got a lot of help from the staff who actually TOLD me to get a rest and go home for a wee while to get ready for the night! I managed to get about half an hour to get a very speedy wash and get changed for the night.



So what's inside?

NPS(UK) 5 A SIDE TOURNAMENT	1
NPS(UK) 5 A SIDE FOOTBALL—NIGHT EVENT.	2
DELICIA AWARDS BBC ITV GIG	3
STEPHEN'S STORY	4
BBC REPORT	5
CONTACT DETAILS WHAT'S NEXT? ACKNOWLEDGEMENTS	6

I jumped in a taxi with my friends, laden with bags and boxes of raffle prizes! Of course, as I very gracefully....NOT...climb out of the taxi, I dropped a bottle of red wine and smashed it all over the road!! What a start!

I went inside to find Keith, Jim and Richard slightly inebriated as they decided to stay all afternoon and planned on remaining until the end!! I set out the raffle prizes, met the staff, met the D J, who were all brilliant and waited on the people to arrive.

I received a call from a cousin of mine who wanted to make a donation! Joe wanted me to do an auction on the night and originally wanted to get a signed top for us from Celtic, but he worked out a better plan! He decided to donate his corporate box at Celtic park for the day to two lucky winners, who will receive a champagne reception, Five course meal, and basically free food and drink all day with a great deal of attention being lavished on you! The prize is worth a phenomenal amount of money and the bidding began. I loved doing this and I would love to do it again. It was a lot of fun, until Keith started bidding high!!! My friend shouted £100, another shout came for £130 then it crept up to £190 and I was asking for the nice rounded number of £200...then Keith shouted £210!!! I nearly collapsed and told the person sitting next to him to kick him in the ankles to shut him up!! This voice came from no where and shouted £220 which was the winning bid! I am so grateful to Joe for donating this and he is heading to Celtic this week to talk to them about our charity and what we do, so as they will hopefully get in touch and support us in the future.

We handed out the raffle prizes, then we ate from the buffet and then later in the evening we threw the coins to the bottle of malt whisky, the nearest wins! It was brilliant and I laughed until I was sore at the competitiveness, once again, between these grown men! They were hysterical!!

The DJ was just brilliant and played everything we asked for, we danced the night away and then he suddenly stopped! He said that he loved to see the women all up dancing, but he felt that it was the men's turn now!! He got all the men up on the stage and then he put on the "Full Monty" music!! I tell you what folks, I have no idea how I never literally hurt myself laughing!!! They all had to take off their shirts in succession and dance to the music as they done it! I took lots of photos in between shouting, grabbing shirts that were being thrown to all the women and trying to control the fit of laughing! Yes....Keith done it too and all shapes and sizes were appearing from underneath their clothes!! One boy thought he would take it upon himself to start break dancing on the wooden floor!! That just about killed me as I tried to get photos without falling to the ground from laughing so much! Once they were all bearing their torsos, the DJ got them all to do a Greek dance!! He then showed them how to do this Russian step and asked them all to try it out and I am happy to announce to the nation, Keith can do it!!! Almost thirteen years married to a man who I never knew could Russian Dance!!



The night continued like this and it was almost a sad feeling when the clock drew nearer to the one o'clock deadline.

This was when I paid out all our expenses for the day and got home to tally up the end result of the most memorable day in our fundraising calendar yet!

We aimed to beat our target from last year (£1,410)...and we did!!! Overall, we received £930 cash which will be doubled by BOC gases to make the grand total of £1,860!!!!!!

Next year, I am determined to break the £2,000 barrier and I have some ideas already what I can add to make this happen.

If you or your family members are willing to give the "gift of life" then you will need to register your intention, and carry the donor card at all times.

Phone the Organ Donation Literature line on 0845 60 60 400

Or write to The NHS Organ Donor Register

PO Box 14

FREEPOST

Patchway

Bristol BS 34 8ZZ





On the 20th September 2005, I received an unusual call. I thought it was another sales call and wasn't paying a lot of attention until I heard that Vanessa Feltz would be picking the winner!! I realised that I needed to ask a few questions and

it turns out that our family had been nominated as "Family of the year" in a competition sponsored by Goodfellas pizza.

We are all very honoured to have received this nomination and I would like to thank those of you who voted for us in the competition. We were told at a later date that we had made it through to the final 18, so I would like to thank those of you who voted for us in this competition. We are all very honoured to have your support with this and throughout the year.

The final 10 are to be announced this month and the winner will be selected by Vanessa Feltz.

If you would like to learn more about this, please visit <http://www.goodfellas-pizzas.co.uk/family/>

The local newspapers and the national press became very interested and NPS has received a lot more interest as a result.

The East Kilbride News and the East Kilbride Mail have been wonderfully supportive on this and have included our story in their newspapers. The Glasgow Evening Times and the Daily Mail have also included stories recently.



On the 26th September 2005, I received a phone call from Candida Harris, who is the BBC journalist who came to my home in April 2005 and recorded an interview with me on Nail Patella Syndrome for BBC Radio 4. The programme highlighted the decisions that often have to be made when having a child with a rare genetic condition and aired on the 2nd June.

As a result a decision was made that it would be a good idea to put this whole issue on screen in the form of a documentary, highlighting a few families in the UK who live with rare genetic disorders. Candida decided that it would be nice to include our family in this programme.

It is a wonderful opportunity for Nail Patella Syndrome to become more recognised and hopefully the blank faces at the hospital clinics will become a thing of the past!!

More on this story on Page 5.....

You may remember in the last issue that I had been contacted by the producer of ITV'S "This morning" hosted by Philip Scholfield and Fern Britten. They were planning on seeking out potential case studies for This Morning's "Living With Extreme Medical Conditions" strand. Unfortunately, the email was sent to me when I had a computer crash, which happened just before our conference. As I was delayed in responding, we lost out on this occasion, but all is not lost as I received a very touching letter from him. He asked that, with my permission, he would like to keep our details on a database as they are discussing a second series of medical films.





One of the wonderful parts of working to highlight our rare genetic condition is getting the chance to work with some very special people. I have had the opportunity to work with Melissa Winter at GIG recently and write another article for their Newsletter. This will go to print in January and you will be able to read it online very soon. It will describe my experiences of working with the BBC as they followed myself and my family around for 3 days to film the documentary. You will be able to view it if you visit www.gig.co.uk and click on publications.

Just before Christmas I received a phone call from the producers from the Richard Hammond 5'O'clock show who asked if Stephen, my NPS affected son, and I would like to go on their new programme which would start on January 3rd 2006.. This came as another huge shock! I accepted the invitation, replaced the handset and panicked!!



I was told that we would be on the show in their first week of screening. We would be flown down to London, stay overnight and travel home the following day.

They had heard all about the story of Stephen and his remarkable courage that he displayed recently in the Tae-Kwon Do championships. (You can read all about this on page 4.)

I chatted to the producers on many occasions, discussing plans for the show, making arrangements for the family, but unfortunately the date had to be re-scheduled. I was told that it would be likely on the 11th or the 19th. Stephen and I became avid watchers of the new programme as I was keen to get Stephen used to the two presenters, Richard Hammond and Mel Giedroyc.

As I started typing up this Newsletter yesterday, I received a phone call from the researchers and they said that it would have to be postponed once again. They are now planning on sending a VT crew up to East Kilbride and they would like to film Stephen at his class again. They will interview me at the class also and hopefully it can all be completed in a day. I should hear from them very soon as they would like to do this as soon as possible.

It will be shown on ITV sometime in the future.

Stephen's story

On Sunday, 27th November 2005, the British Tae-Kwon Do Coloured belt Championships took place at the Time Capsule in Glasgow. Stephen had prepared himself for this event for some time and was training hard at his classes, twice a week in East Kilbride with his instructor, Mr Brian Leckie. At home, he was practicing regularly and learning all he could for the day.

Stephen is my eight year old son. He has NPS and has always had a positive outlook on life. He has had major surgery when he was just under the age of three to rebuild his leg as he was unable to walk more than a few steps without his leg dislocating at the knee area. It was a very difficult time for us all as a family as there was such limited knowledge on the condition. Thankfully, we had a wonderful orthopaedic surgeon, Mr Duncan who works in Yorkhill Hospital who was willing to try everything he could to help. The story was a huge success as the surgery proved to correct the problem and Stephen not only walks without dislocation, but he does almost everything any other child of his age should do. The negative side is that he suffers a great deal of pain, but he has learned that this just comes with the package. It doesn't have to be a bad thing, we accept it is part of who we are and get on with it.



I made a promise to myself and also to Stephen that I would never wrap him up in cotton wool and I would allow him to do anything he wanted in life. I didn't really expect him to come to me just after his 7th birthday and say that he was going to do Tae-kwon Do!! I suppose I was hoping for something slightly less physical, such as drama or art classes!!

Anyway, the rest is history, for the past year and a half, Stephen has taken part in three competitions and has taken two gold medals and one silver medal. He has worked himself through the grading system from a white belt to a red tag and each time he achieves something I am so grateful to those professionals who have worked with him in the past and I am overawed by his courage. His attitude is just simply, "This is me!"

On the Thursday, just three days before the British tournament, Stephen felt a crack at school in his right leg. When he got home, he was in a great deal of pain, so we ran through our routine to try and ease it a little....hot baths and massage!

I looked at his leg and I was shocked to see that it had obviously changed in appearance. The leg I was looking at was almost exactly like the one I looked at many years ago when he needed surgery to rebuild it.

Like so many others with NPS, Stephen has tiny patellae that basically move around inside the knee area. They do not sit where they should be, so therefore his leg has a dent in the middle when bent. This dent had become larger and the bones on either side had move outwards slightly. He noticed the difference himself.



On the Friday, we visited Yorkhill Accident and Emergency as he was having intermittent pain that was really troubling him. He was unable to get up the stairs and was very upset when he climbed the hill from the car to the hospital door. The staff who looked at him had no case history and as his condition is so rare, it was difficult for them to say what we could do. They advised him to be very careful and come back to the fracture clinic the following Wednesday. I explained everything we had gone through in the past with him and that we were all very concerned that his leg was very unstable and could dislocate at any time. We were advised to try and keep him away from anything that could cause him pain i.e. stairs, hills, etc...

On returning home, I gently approached the subject of Tae-Kwon Do. Stephen became very upset and yelled at me that he was still going to take part. I just could not bear the thought of him going there and his leg dislocating in such a public place. I was also so scared for the opponent and also

his instructor who had always treated him the same as every other child. It was, nevertheless, a sleepless night.

The following day, Stephen attended his class and I explained it all thoroughly to Mr Leckie. It was such a dilemma for him too as he had to do the right thing. It seemed wrong to allow him to do it for so many reasons, but when we looked at him working so hard in the class that morning, it also seemed wrong to say no.



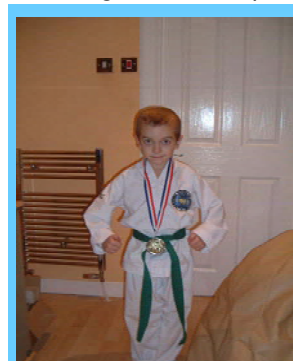
The day of the competition came and I was never in my life so scared. Stephen on the other hand was getting ready for what he had trained for. I tried in vain to talk him out of it, but I just knew that it was never going to work anyway. He is such a determined young man and I am proud of him for that. He promised me that the pain was gone and that he was capable of participating. We drove to the Time Capsule and I felt physically sick. He was still adamant, and for the first time in my life I wanted to hear the words, "I am too sore." They didn't come!

Stephen warmed up and was ready. Stephen was more determined that day than ever before and became the Coloured belt British Champion for his height division at sparring! When he was handed the trophy, I felt that I could burst with pride. If I could bottle it, no price could

be put on such a moment!

His story is courageous and shows such determination in life. However, I know there are others out there who have stories that they could share with us. Please send me your story, or the story of your child, who battles against the odds and just refuses to give in. I would love to add your story to the next edition of the Newsletter in May 2006!

Stephen and I live with our motto in life :-



*Grant me
The serenity to
accept the things
I cannot change,*

*Courage to
change the things
I can.....and*

*Wisdom to know
the difference.*



As previously mentioned, I had met Candida Harris, the BBC journalist who came to my home in April of last year. Since that time, we have remained in contact with one another. She is such a wonderfully inspirational woman and I am proud to be her friend.



The idea of producing a programme on the same subject matter as the Radio show seemed a very interesting one and I was absolutely in favour of going ahead with it all. Candida told me that the Current Affairs Producer/ Director would like to come and speak to me at my home first.

On the 30th September, Dickon Le Marchant arrived at my home and we discussed all the details on the proposed documentary. It would case study 4 or 5 families who live with genetic conditions and hopefully give an account of the many decisions that have to be made. I knew instantly he was the type of person I knew instantly that I would not have a problem working with and the initial fears of the intrusiveness were slowly disappearing from my mind. He explained a little about the programme and that he would be coming with one other person, Lucy, who would help with the sound control amongst many other jobs. This was a great relief as I am sure you can imagine, I had visions of cameras all over the place and the house swamped with people for a few days. He explained that they would film over the period of 3 or 4 days and that we should start to think about what we would like to see on camera. I had some ideas immediately and we discussed these and agreed that it should be shown. Over the next few weeks, we planned out what was needed very easily by email and telephone conversations, all the time building up a trusting relationship.



On the 1st November, 2005, Dickon, Candida and Lucy arrived at my house at 9.30 am. I have to say that I was a lot more excited, nervous to see them as I hadn't seen Candida for a few months! It was very calm and we all settled in before the decisions being made as to where the "Main interview" should take place. We decided at my dining room table, and I am glad that I had a good clean beforehand! The camera was set up, my mike was put in place and Candida and I chatted naturally, all the time with the camera focussing on our conversation. It wasn't difficult at all as it was completely natural to discuss the subject matter, but at one stage, I completely welled up and the tears began to flow! I had no idea that this would happen and I had no idea how to deal with it, but Dickon, very compassionately, switched the camera off. I didn't feel uncomfortable as these people had become "friends" and knew how emotional this was to talk about. The interview lasted approximately 90 minutes.

After the interview, we planned on picking up my son, Stephen, from school. From school, we were to go to Yorkhill Children's Hospital where he had an appointment with the Renal specialist, Dr. Heather Maxwell, followed by an ultrasound scan of his kidneys.

We left the house at 12.20 pm and picked up Stephen from School. It was quite bizarre in many ways as I was still wearing the radio mike, but became very natural over the course of time. We drove from the school to McDonalds for a quick bite in motion as we continued on to the hospital. As we arrived at the Hospital, we were met by the Press Officer for the Greater Glasgow Health Board. She is the one who clears all the presence of the cameras with the people concerned. We then met up with Dr. Maxwell, who has been caring for Stephen since he was a year old! We discussed what would be nice to be filmed and then we were asked to do a re-take on entering the clinic. They filmed it all and then we were asked to go to the ultrasound scan room where he would get his scan of his kidneys. It was all well organised with very little waiting time and no hitches at all. It wasn't too intrusive for Stephen and all he wanted to do was to get outside to play in the little park!

We returned home and Dickon filmed little scenes of general family life. Nicola, my daughter was home from High School by this time and was introduced to everyone. We basically carried on as normal, I made dinner, Nicola started her homework and Stephen went outside to play with his friends. Dickon and Lucy followed Stephen and filmed him playing football and then followed him to a little park close to our home. They came back to the house afterwards and filmed us moving around at home and then decided that the day should come to an end. It had been a very full day and we should start afresh in the morning. Unfortunately, Keith, my husband, was working late, so it meant that the interview with Candida would need to be postponed as she needed to go home to London to her family. It was emotional for me to say goodbye to this incredible woman who I will always maintain, is a true inspiration. I am sure that we will keep in touch regularly now.

The following day, 2nd November, started a little later, approximately 12 noon. I was on the phone to Stephen's TaeKwon-Do instructor Mr. Brian Leckie, when they arrived. We were discussing what would happen at the class later in the day as this would show the inspirational side of Stephen's character. This was the bit I was looking forward to as the students were all well informed and I had worked on permission slips for them to sign and hand back to say that they were comfortable about being filmed.

Dickon explained to me that he would like to film me walking in a park somewhere locally. We drove to a little park and I brought some bread for the ducks and swans. We waited for the rain to stop and grabbed our opportunity. He told me to walk towards the camera and stop at a point where I was to feed the swans. I am sure that we provided some entertainment for an elderly couple who were parked next to us!!! Dickon was filming me leaning towards a beautiful swan who had come right out of the water for the bread when another came up behind him and hissed loudly at him and suddenly bit him in the nether regions!!! I have to say he was so professional about it and continued filming!

We then left the park and drove to Stephen's school where we planned on filming Stephen coming out of school. The school had all been informed and were a great support to us on this. He came out swamped between two of his classmates, who I think were happy to be Stephen's friend on that day! We then returned home and filmed a little more at home and then it was time to go to the Taekwon-Do class.

We left just after 5 pm and introductions were made by Mr. Leckie and the BBC crew. They spoke about what would happen and Mr Leckie was wonderful and so accommodating. He was asked if he would wear a radio mike for the filming and he agreed. As the students arrived, I have to say I was becoming a little overwhelmed at the support shown. They were all immaculately groomed and were fine examples of the discipline taught to them throughout the years. The class numbers were immense and I had to gather myself on more than one occasion by leaving the room for some fresh air. It was just amazing to see. Stephen worked so hard and was very keen to show off his talents!

We returned home and I was totally elated at what had just happened. I will never forget that hour as long as I live and breathe. It was simply magical! When we arrived home, Keith was home from work and he finally got the chance to meet with Dickon and Lucy. The difficult part was always going to be for Keith to talk on camera as he is such a private person and as Candida had to leave to be with her family, I would be the one who would have to "interview" him on camera! I was anxious about this as Keith is not a great conversationalist, but he knew how important this was to all of us. We quickly grabbed the opportunity as Stephen and Nicola disappeared upstairs. Keith was miked up and initiated the conversation. At first it was a little uncomfortable, but as the time passed it became quite natural and the conversation flowed. It was an incredible few minutes as we were sitting there being filmed as we discussed something that was very emotional for us both. I realised during that time just how much Keith loves and accepts his family. He just accepts the fact that his wife and son both share a rare genetic disorder and views his life as normal. He knows the implications, but he has adjusted his life to suit.

After the filming, we decided that we probably would need no more. I was asked to find a few photos and make a little picture story of our experiences together. I will send these to the BBC and Dickon will keep in touch regarding the screening of the programme. It is likely to be seen on BBC 4 first in January and should be then transferred to BBC2 at a later date.

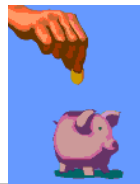
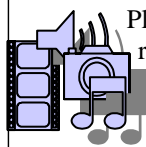
It has been a wonderful opportunity to raise awareness for our rare genetic condition, Nail Patella Syndrome. I know that I could never refuse this chance as this platform does not come around every day. I hope that we are able to find many others in the UK with this condition and are able to help them. I hope that we are able to prevent many of them from losing their eyesight and encourage them to attend renal units to prevent kidney damage. I hope that we make many medical professionals sit up and listen to us and realise that even though statistically we are 1/50,000, we are ALL important and need medical care.

None of this would have been possible without the incredible support from the Genetic Interest Group. I am indebted to them now and will never forget the love and support they have shown us over the past couple of years.



Collecting tins

I am happy to say that recently we purchased many more collecting tins as we were in need for some new ones. If anyone feels that they may be able to help by taking some of these and placing them in local shops, clubs, pubs or wherever you feel may gain interest, please get in touch and I will post them out

**Photos**

Please remember to send me any of your conference photos and I will make up a disc of our "NPS family" for the 2007 Conference!

Financial assistance

Many of you have asked about help with benefits that you may be entitled to. It is always something that causes a great deal of confusion and I also have first hand experience of this in my own life.

Thanks to one of our members, she has found a website that is very useful in providing some guidelines in where to go.

<http://www.bhas.org.uk/dla/index.shtml>

<http://www.youareable.com/forums/forum.jspa?forumID=1>

The sites are particularly useful for people who are looking for information on DLA.

Another useful site is <http://www.dwp.gov.uk/medical/med-prac.pdf>

What's happening next?

Many thanks to so many of you for all your recent offers of help in relation to raising awareness and helping with the funds. So many names to mention on this occasion.

We received a request from one of our NPS friends who is happy to try and ask for a donation of some sort from a company in his area.

We have received a letter from another NPS friend who is going to ask if her work would like to participate in a "dressing down" day to help raise some funds and awareness for our cause. This same lady has also talked her friend into donating up to 50% of the money raised when she runs in the London Marathon next year! If anyone knows of any fit people who are willing to do this for us, please let me know as these events can generate a great deal of interest and funds for our charity.

I am working with a researcher who is working on one of the research programmes for the North West Genetics Knowledge Park (NOWGEN) I have received an invitation to take part in the Delphi process to identify outcome measures for clinical genetics services. I will keep you informed on the outcome.

If you are interested in learning more on the work being carried out, please visit www.nowgen.org.uk



Many thanks go out to so many people. The past four months have been incredibly exciting for our charity and on a personal level, I never knew that it was possible to be so scared!!! However, it is all for a great cause and I can't thank you all so much for your amazing support.

Colin and Karen Clarke—Thank you so much for going to your local newspaper and gaining more publicity.

Bill and Anne Sneddon—The collecting tin donations are so important to us and your ongoing support on this is invaluable.

Donations from Elders Pub, Joseph Woods from "Quality Ceilings", Thomas Woods, friends and neighbours who wish to remain anonymous all make life much easier when it comes to this time of the year. The Newsletter is a major expense to us and these donations make it possible for me to print these all out without causing too much damage to our existing funds in the charity account! So, thank you all from the bottom of my heart!

Special thanks must also go to the staff at the East Kilbride Mail Newspaper, the East Kilbride News, the Glasgow Evening Times, the Daily Mail, Rod Mills, Gerry McHarg, Dickon Le Marchant and Lucy, Candida Harris, Dr. Heather Maxwell, Brian Leckie, UKTC students and many, many more for all the support in our publicity campaign.

Contact details and useful sites

For more information on Nail Patella Syndrome, please check out the following websites.
www.npsuk.org
www.nailpatella.org



Alternatively email me, Carol Dobbins on :-
dobbinsek@btinternet.com
Phone me on 01355 241277

Look out for our next edition of the Newsletter which will be issued in May 2006!

Page 5 of our Newsletter is normally given over to our treasurer, Shirley Raynor who works tirelessly on our behalf.

In this edition, I would like to take a moment to offer our deepest condolences to her and her family on the loss of her mother who sadly passed away recently. Our thoughts and prayers are with you all.

Copyright May 2005

