



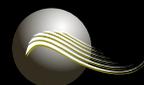
## BRITISH ASSOCIATION OF CHARTERED PHYSIOTHERAPISTS IN AMPUTEE REHABILITATION

# 1993

Britain comes out of a three-year recession • First high speed train through the Channel Tunnel • Hospital waiting lists reach 1 million for the first time • Bill Clinton becomes President of USA • Buckingham Palace opens to the public for the first time • Both England and Wales fail to qualify for the 1994 World Cup • Bank of England lowers interest rates to 6% (lowest figure since 1978) • Prince Charles and Diana Princess of Wales announce separation • Stephen Lawrence stabbed to death • Ford replace the Sierra with the Mondeo and Vauxhall launch the Corsa • Czechoslovakia is dissolved and Vaclav Havel is elected President of the Czech Republic • Niamh Kavanagh wins Eurovision Song Contest for Ireland with "In Your Eyes" • Ravenscraig Steelworks close ending steel making in Scotland • Andrew Wiles presents proof of Fermat's Last Theorem which has remained unsolved for over 300 years • Maastricht Treaty takes effect formally establishing the EU • Biosphere 2 mission 1 ends after 2 years • John Wayne Bobbitt became infamous • UKIP is formed and BNP win their first council seat in Tower Hamlets • Women's Royal Navy Service is disbanded and becomes part of The Royal Navy • Microsoft Windows NT is launched and IBM announces biggest single year corporate loss America has seen (\$4.97 billion) • Waco siege lasts 51 days and ends in a fire killing 76 people including David Koresh • Russian troops withdraw from Poland and a democratic parliament is elected • A false start causes the Grand National to be cancelled • IRA attacks Warrington and City of London • United States selects its first female Attorney General (Janet Reno) and Canada elects its first female PM (Kim Campbell) • Thames Water Ring Main is completed in London • George Bush and Boris Yeltsin sign 2nd Strategic Arms Reduction Treaty • James Bulger is murdered • MI5 reveals its operations and duties and the identity and photos of its Director General (Stella Rimington) • Yasser Arafat makes his first official visit to Britain • UK and Irish governments sign the Downing Street Declaration providing a joint vision for the future of Northern Ireland...

...and BACPAR is formed

## The Journal Issue 39, Autumn 2013



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## Guidelines for Journal Article Submission

- Please send the article as a Word or PDF file.
- If your article includes pictures please also send these as separate files (JPEG, BMP, GIF, PNG etc format) at the highest quality you have. It would really help if you could put your name on them so they link to the article please!!
- If your article includes graphs please also send these as separate Excel files and name these the same as your article followed by a number in the sequence that they appear in the article (as with pictures). If all the graphs are in one Excel file this is fine.
- Finally, if there is anyone out there who would like to advertise in The Journal, or if you know anyone who you think would like to, please let me know.

Please email [bacpar@flutefamily.me.uk](mailto:bacpar@flutefamily.me.uk) with your submissions and any queries

**DEADLINE for Spring 2014: 14 February 2014**

## Hello readers

I think we should start with a chorus of:

Happy Birthday to you

Happy Birthday to you

Happy Birthday to BACPAR

Happy Birthday to you

Yes BACPAR is 20 years young this year and at the time of writing this letter the 20th Anniversary Conference organisers; Julia Earle, Penny Broomhead and Clare Singh are busy finalising arrangements for the Conference and AGM in Wolverhampton. With plans for a celebratory dinner and a programme that reflects on BACPAR's history whilst continuing to ensure an awareness of the importance of Physiotherapists within the Amputee Rehabilitation MDT. Did you know that Penny Broomhead was one of the organisers of the first BACPAR conference?



I will present, as part of the AGM, BACPAR's achievements against the 2013 Work Plan. The work plan is found within the Service Portfolio available to members on the BACPAR website.

Achievements of the BACPAR year so far:

The publication of the following updates; the Prosthetic Guidelines, the Guidance for the Education of Pre-Registration Physiotherapy Students and Resources for audit and research document.

Bursary support for BACPAR members' attendance and presentations at ISPO India.

Involvement in the Consultation process and in on-going projects around the Service Specification Complex Disability equipment – prosthetics.

The Executive Committee will also be seeking your views on items for discussion in the AGM which will include the outline of a Research Bursary, initially proposed in 2012.

As ever CPD has been supported at a regional level, for the organisation of which we are grateful to the Regional representatives, and nationally through the availability of SAGE articles on the BACPAR website. Whilst there is not a great deal of evidence of any discussions about the selected articles on the website, we hope that they have been useful, on an individual basis, to your professional development. Let us know at the AGM.

A big thank you is extended to BACPAR's committee members for their commitment to projects carried out on behalf of the membership in the last year. To anyone out there who is interested in being part of the team, there are again opportunities to be part of the committee this year. It's always good to get new people on the committee but equally as joyous to get the old ones back again.

Thank you to the Flutes as ever for producing this journal.

And finally if you wish to make any comments about BACPAR's current projects and ideas of what we should be involved in in the future please contact me at [Louise.Tisdale@nhs.net](mailto:Louise.Tisdale@nhs.net).

**Louise Tisdale - BACPAR Chair 2013**

## Secretary's Report

Autumn again but at least this year we can say we had a summer! And Autumn means its nearly time for the BACPAR AGM and elections. This year the profile of physiotherapists working in amputee rehabilitation has risen hugely thanks to the Paralympics last September and more recently the Anniversary Games. BACPAR now more than ever is helping drive forward our area of physiotherapy expertise, and this is especially important in the current climate

So, why not think about becoming more involved in the day to day running of BACPAR? I've now been a member of the BACPAR committee for nearly 10 years and have enjoyed it all, deadlines and all! I would encourage you to think about taking on a committee role. We have 3 executive officer posts up for election this November; Treasurer, Diversity officer and iCSP Co-ordinator. You will already have received an email with job descriptions for these posts as well as a nomination form. Voting for the posts will take place at the BACPAR AGM which is being held during this years BACPAR conference being held at Wolverhampton Science Park on the 14th-15th November 2013.

For more information you can contact me or the current post holders. Our details are at the back of this journal. Nominations will be accepted right up until the start of the elections. You don't need to attend the AGM to be nominated.

So don't hold back, take on a new challenge. Actually challenge is the wrong word, maybe I should say opportunity. Either way go for it!

Hopefully see you in November.

**Lucy Holt Secretary**

## Editorial

This journal wrote itself I have been very lucky this time with people contributing without the usual prodding and reminding that I have to do.

So a massive thank you to everyone, there was only one late entrant past the deadline for a change!

A big thank you to our advertisers for all getting there on time both old friends and the acquisition of a new sponsor which is great, all of your support is much appreciated.

Lots of things to read and don't forget the BACPAR conference on 14th-15th November.

Just one thing, I have included some guidelines about submitting to the journal, I would appreciate anyone who is submitting to have a read through as it would just make my life easier, if the articles came in a format that I could access, rather than spending more time than I have in my life trying to extract them. Then I could just process them. So be warned I intend to look at them and bounce them back if they aren't in the correct format! This is not to put people off submitting articles it is to try and streamline my life as unless you have edited the journal sometimes (and only sometimes Lou) for the love of BACPAR doesn't do it for me!

Thank you Mr Flute for technical support.

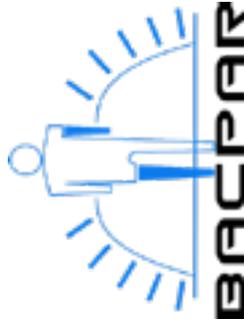
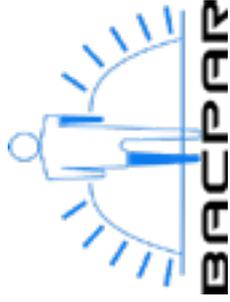
**Sue Flute**

# BACPAR 20<sup>th</sup> Anniversary Conference

14<sup>th</sup> -15<sup>th</sup> November 2013

Wolverhampton

*Come and join us for a great 2 days ...Sessions include;*



## Day 1

### Acute care

- Hypoglycaemic control in amputees participating in prosthetic rehabilitation
- Oblique abdominals training pre and post-op stage
- The Roehampton Stump Score – assessing the perfect stump
- Physiotherapist approaches to phantom limb pain

### Service provision

- Key note speech by Karen Middleton
- Reconsidering evidence based practice in prosthetic rehabilitation
- How can we engage with NICE?

## Day 2

### Prosthetic rehab

- Influence of posture & movement control in prosthetic rehabilitation
- Outcome measures for amputees
- Self-management and living with a long term condition

### Sport

- Supporting paralympic team GB
- Amputees and recreational running
- Amputee Football
- Leisure pursuits following lower limb amputation – the reality
- Getting into Sport – Paraspport



For registration form go to  
[www.bacpar.csp.org.uk/studydays](http://www.bacpar.csp.org.uk/studydays)

*...and cake*

# International Society of Prosthetic and Orthotics World Congress

## Hyderabad, India 4-7 February 2013

### Incredible India - the Land of Spice, Beaches and Backwaters

#### My First International Amputee Conference Experience

#### Where do I sign up?

Through attendance at previous BACPAR conferences I discovered that the February 2013 ISPO conference was being held in Hyderabad. Brilliant, I thought to myself, not only had I always wanted to go to an international conference but I've always wanted to go to India. Where do I sign up? What can/ should I present?...and (very importantly!) who might want to help fund this trip?

#### Pre conference organisation

Abstracts for the conference had to be submitted by April 2012. Reflecting on the increased awareness and importance of patient feedback and current drivers to evidence collection and analysis of this data, I decided to submit an abstract relating to our Amputee Patient Experience Questionnaire findings. Furthermore, as I was already planning on presenting this topic at the Sheffield BACPAR/ ISPO conference in September 2012 I had already started collating the information, excellent!

In early September, following submission of my abstract, I was informed that the ISPO committee wanted me to provide a poster presentation on the information, which would be displayed on the Wednesday and Thursday of the conference....so the stand-up scary moment in front of an international audience was avoided, phew! With the help of our medical illustrations I duly knocked up an AO sized poster, neatly rolled it into a cardboard tube and to ensure it didn't get left behind in the unclaimed airport baggage department, submerged it into the depths of my rucksack...I was on my way.

#### Conference organisation

The conference was held in the Hyderabad International Convention Centre, which was excellently equipped with three large halls set up for the prosthetic and orthotic exhibitions, keynote lectures and the poster presentation boards. They were then numerous smaller break out rooms for the instructional course, exhibitor workshops and free paper presentations. On registration on the Sunday morning we were given a congress technical programme (a sturdy volume detailing every presentation/ exhibition/ abstract submitted) and a congress quick finder, which was a slightly more user friendly and less daunting guide....all I had to do now was work out what I wanted to attend.



## Conference Highlights

My aim from the conference was gain updated evidence on current practise in the developed as well as developing world. Furthermore, although I wanted to attend presentations that were relevant to my daily practise with lower limb dysvascular amputees, I was also particularly keen to gain greater insight into upper limb prosthetics, Osseo-integration developments and psychological interventions relating to amputation.

Here are some of the presentations I attended and a few of my concluding points.

### Free papers

- The Experience of Multiple Limb Loss following Meningococcal Septicaemia. There is a need for more information and training of health care professionals and a need for greater continuity of care especially when patients are transferred between healthcare settings (M Donovan Hall).
- Guidance on the Management of Post-Operative Residuum Oedema in Lower Limb Amputees. Rigid dressings should be used in clinical practise when expertise, time and clinical resources allow (M. Cole)
- The Amputee Mobility Predictor for People with Bilateral Lower-Limb Loss. Minor modifications in scoring of the AMP does not alter total score and allows clinicians to determine the functional mobility of those with bilateral TFA and TFA/TTA (B. Gailey)
- The use of Focus Groups to Aid in the Development of a Mobility Outcome Measure. Focus groups provided valuable information about environmental conditions encountered by persons with limb loss and facilitated development of a comprehensive instrument to measure prosthetic mobility (D. Amtmann)
- Effects of Diabetes on Postoperative Ambulation Following Below Knee Amputation. Diabetes Mellitus is an independent factor which has an adverse effect on the functional outcome (reduced ambulatory level) of patients following below knee amputation (A. Saraf)
- Roehampton Stump Score – A Method of Estimating Quality of Stump For Prosthetic Rehabilitation. The scoring method offers an objective assessment of stump quality and there is a plan to validate the measure (S. Sooriakumaran)
- Development of the Transfemoral Fitting Predictor – A Functional Measure to predict prosthetic potential in TFA. The measure is simple, valid and reliable and should be used as an adjunct to therapy. Work is being completed to identify whether a specific score could determine prosthetic potential (L. Whitehead)
- Energy expenditure of Transfemoral Amputees Walking with different speeds on different surfaces. Oxygen uptake is not influenced by walking surface, but solely on walking speed (I. Starholm)
- The Use of Multiple Sensors in the Control of Prosthetic Arms. Microprocessor controllers and cheap sensor technology can be combined to give prosthetic arms more autonomy (P. Kyberd)

- Bone Anchored Prostheses in Upper Arm Amputees: Radiologic Outcomes. Bone anchored prostheses in the upper arm amputee work satisfactorily with few implant failures (R. Branemark)
- Is there a difference in the characteristics of an amputee population when divided into outcome? Dysvascular amputations occur more commonly in men with a 1:1 ration of those with or without diabetes (F. Smith)

### Instructional courses

- Essential Physiotherapy – What all prosthetists should know. The multi-disciplinary approach following amputation is well known. If prosthetists can assess and correct posture at the prosthetic fitting stage, the alignment can be optimised, reducing the number of appointments with the prosthetist once physiotherapy training commences (C. Hirons, L. Burgess)
- Microprocessor Knees, How to maximise Functional Ability. Exercises designed to increase hip strength in a closed chain environment of the socket can intensify the speed and power



of the muscle contractions for improved single limb stance control (R. Gailey, S. Moeller)

### Symposium: Developing Countries

- Experiences in Disaster Management and rehabilitation. Multiple challenges present when making orthotics and prosthetic devices when nothing is available. Early mobilisation of patients with orthotic and prosthetic devices simplifies rehabilitation management (L Gada, M. Prabhakar, M. Doshi, V. Shandilya)
- Haiti 2010 Earthquake: Lessons learned after 3 years. One of the largest humanitarian responses in record history. Disproportionate influx of international aid brought further difficulties.

### Reflections on my conference experience

Overall the four day conference was intense but really enjoyable. At times, because the programme was so jam packed with topics and presentations of interest it can be quite overwhelming initially to work out what you actually want to go and see. Although you could pop in and out of sessions there were invariably time when presentations which I was keen to attend ran simultaneously and other times where I chose to review the exhibition stands rather than listen to presentations that were of less interest.

In general I thought the quality of presentations and presenters were very high, however there were times where I was disappointed with the content and delivery of the material. I guess the positive to this is that I now know what is expected from speakers at an international conference level and I would feel slightly less daunted about potentially completing a podium rather than poster presentation in the future... maybe I should steady myself down now!

The conference was also really good chance to network with UK therapists and prosthetists and Hyderabad provided us with the perfect cultural backdrop to enjoy a Indian night of curry, and traditional Bollywood dancing on the last evening.

### Beaches and backwaters

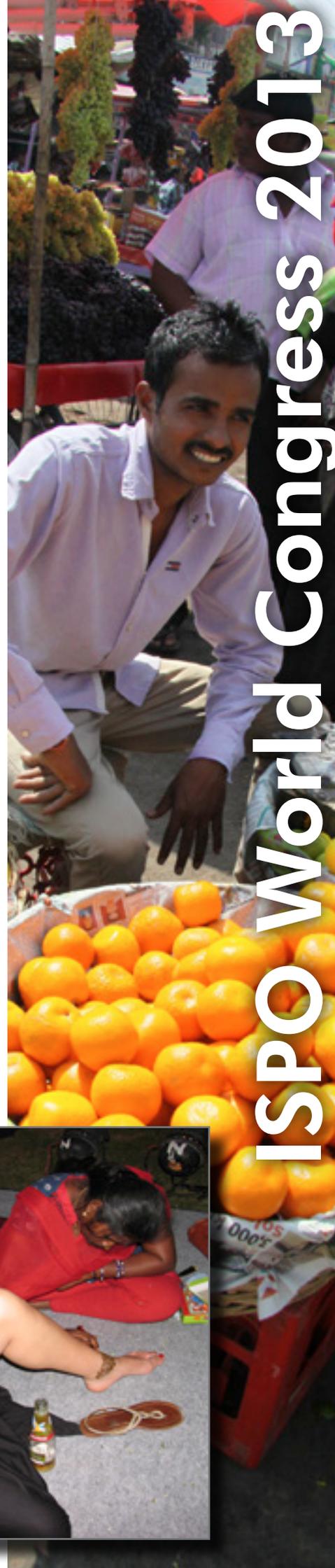
....seeing as I had flown all the way out to India it would obviously have seemed rude not to explore the country so after the conference I tagged on a ten day holiday travelling through the Kerala backwaters to southern beaches. India was truly spectacular, the people were very friendly, the climate was steamy hot and I tried my best to eat curries hotter than a korma.

If you are thinking of attending an international conference I would definitely recommend it. Although the pre-conference funding applications and presentation organisations are often timely, the rewards are well worth it....especially if it is in a country you always wanted to visit!

### Final thank yous

Following a number of letters and application forms and the promise of written articles I was extremely lucky to be supported by my therapy and vascular department at the Royal Free Hospital and by BACPAR. Both of whom I would formally like to thank....so thank you very much!

**Kate Primett**



## Inclusion, Participation & Empowerment

### Essential Physiotherapy – what all prosthetists' should know?

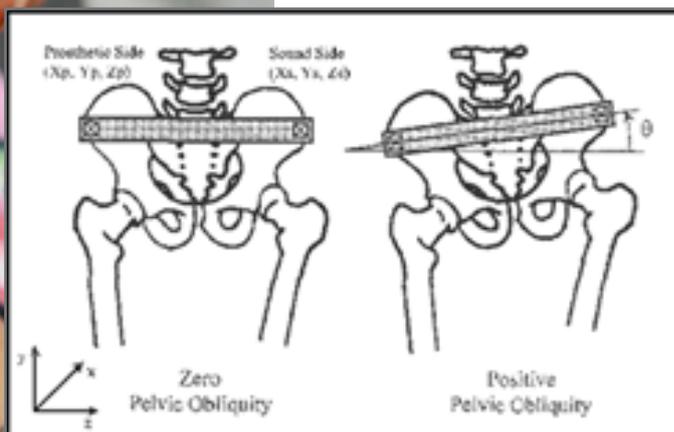
In February 2013, I presented a basic instructional course with my NHS colleague Laura Burgess. We are both clinical specialist physiotherapists in amputee rehabilitation. I work for an independent private practice, Pace Rehabilitation and Laura works for Charing Cross Hospital. The course was initially aimed at prosthetists who do not have a physiotherapist available to them at fitting stage and at any clinician new to the field of prosthetic rehabilitation.

The instructional course content included:

- Basic theory of how we move, stabilise and mobilise muscles.
- Outline of normal posture and how we control it.
- Secondary anatomical faults common to prosthetic limb wearers (posture changes and muscle imbalances) and their impact on the prosthesis.
- The influence of posture on prosthetic alignment and that of prosthetic alignment on posture, and the resultant overall influence that this has on the user's everyday function.

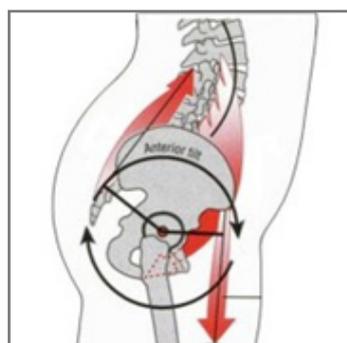
We know from the paper by Gailey et al, there are known postural asymmetries in transfemoral amputees: Leg length discrepancies (88%), pelvic inclination, innominate asymmetry, increased lordosis, limited lateral trunk flexion and limited hip extension (Gaunaud I, Gailey R, Hafner B, Gomez-Marín O & Kirk-Sanchez N (2011) *Pros & Orthot Int* 35 (2) 171-180)

This change in inclination PSIS to ASIS, leads to short hip flexors and back extensors and as a consequence long weak abdominals, hamstrings & gluteals. Our prosthetic provision and rehabilitation programmes must address these issues. Prosthetic alignment must accommodate these postural changes and optimise user movement, and yet be realigned as users change their strength and postural set.



### Why did we go to ISPO Hyderabad?

ISPO world congress is the ideal stage for this instructional course due to the multi-disciplinary nature of the delegates. The goal was to teach newly qualified prosthetists AND physiotherapists to look above the prosthesis and understand how the prosthesis impacts on the skeletal frame, and thus on movement and function; for the more experienced, who have a wealth of understanding, the goal was to address how prosthetic functions can be enhanced by user posture control, and for those in the developing world, this session provided invaluable skills in teaching basic movement, where physiotherapy input is scarce and limited.



### A summary of my learning action points

Over 2000 people attended from all over the world. There were 6 streams of presentations over 4 days; upper and lower limb prosthetics, orthotics, the developing world, education & wheelchairs. I chose topics relevant to my work

and but also those that interested me and that I would not hear in the UK.

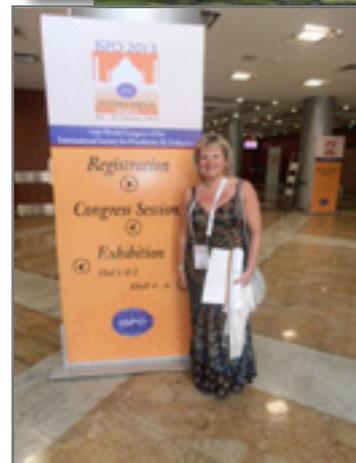
- Outcome measures PEQ (12 item mobility subscale) and ABC (5 level response scale); shorter valid versions are now available as shown to be easier to administer (B Hafner)
- Uncertainty causes anxiety; people need better understanding of & more responsibility in their rehabilitation programmes (C Ostler)
- Use problem solving as part of a rehabilitation package by involving the counsellor to help people develop strategies in line with motor training. This is to prevent deterioration in mobility and socialising skills after discharge (S. Van Twillert)
- New outcome tools: B-AMP; this is development of the Pro-Amp scale, used currently with the military bilateral amputees whereby a few items have been modified. It was noteworthy that hip extensor strength was the greatest predictor of being able to walk a certain distance (R Gailey), Transfemoral Predictor for determining the prosthetic success of elderly transfemoral amputees, a 9 item questionnaire used 3 weeks post op prior to and with an early walking aid (L Whitehead, published in Arch Phys Med 2011), Physical Function Performance Index- 10 (J Kahle) <http://www.physther.org/content/85/4/323.abstract>
- Educate patients about the influence of diet and activity on stump volume fluctuation (E Brannigan)
- Teach the use of prosthetic stance flexion more, particularly in starting and stopping gait strategies (M Nederhand), practise target stepping & avoidance stepping for gait adaptability skills, this study used patterns projected onto a treadmill (K Schenkeveld)
- Pay more attention to the sound leg due to its adaptation strategies when stopping and starting movement. Aim for better muscle symmetry. (E Prinsen)
- Osseo integration symposium – better vibratory sensory feedback & bone density through direct bone anchoring. In general, better walking variables result in better walking function but OI cannot guarantee this compared with socket fit.
- Treadmill is good for conditioning & fitness training (Inga Starholm)
- Increased arm use in sitting to standing on amputated side causes secondary problems long term in lower limb amputees. Long term management of upper limb issues should be considered (M Stalin)

## My memories of India – a country of contrasts

I must thank Laura for steering me around this amazing country as she is far more travelled than I. We enjoyed a 5-star view of this interesting and exciting place, a thoroughly wonderful experience despite neither of us managing to eat the curry!

**Carolyn Hirons - [www.pacerehab.com](http://www.pacerehab.com)**

**With thanks to: BACPAR bursary, Private Physiotherapy Educational Fund, CSP International Lecture Fund award**



## Memories from India, 2013

Amid tight security – frisked and bag search to enter hotel / conference centre, we (well most of us) survived Dehli Belly free, and enjoyed our experience travelling to ISPO World Congress in Hyderabad, India in February.



**So was it the cut flower water (don't ask!) or the chicken which made Laura poorly??!**

The exhibition was well represented by the main prosthetic and orthotic companies, along with NGO's and other charities. Unfortunately all the "freebies" were confiscated at customs so we came home empty handed – not even a pen was snaffled!

I gave my report on the Transfemoral Fitting Predictor (TFP) – it seemed to be well received with questions regarding future developments and whether a score could predict whether someone will proceed to fitting or not. Unfortunately there are so many other factors which influence a transfemoral amputee's ability to use a prosthesis that the TFP should continue to be used as an adjunct to assessment for fitting and not as a stand-alone measure. On discussion with many others who are using the TFP assessment tool, one of the main uses has been found to be in helping those not for fitting to come to terms with this fact.

We met lots of interesting people and learnt about diabetic foot screening in the slums of Mumbai where people moving from rural areas to the city are developing diabetes at an alarming rate – this may be due to the change in diet – it was impossible to get non sugary drinks and they even eat deep fried sugar (and who says the Scot's have a bad diet – well I suppose we do offer deep fried Mars Bars!)

**"Mmmm – reminds me of home"**

**Fiona, Glasgow, munching on deep fried sugar!**



The conference was very stimulating as always, and gave us new ideas for further research, audit and through networking with colleagues, comparing current practise across different sites, and looking at standards / protocols of management related to outcome.

ISPO World Congress will now be every 2 years – Lyon, France in 2015; and Cape Town, South Africa in 2017 – I can thoroughly recommend attendance so lets get more research completed and see you there!

**Louise Whitehead, Vascular Physio Team Leader, Dundee, Scotland**

# Finally...

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do what moves you



# The Prosthetic Aesthetic: The Role of Prosthetic Appearance in the Rehabilitation and Satisfaction of Lower Limb Wearers Aged 21-30

## User-limb relationships

The psychological and sociological impact of amputation can become a hindrance to the effective rehabilitation and satisfaction of a wearer. The development of these satisfaction-related issues can become initiators that lead to the prosthetic wearer not developing a relationship with the new limb that is consistent with that of the one removed.

Atherton & Robertson (2006) found that the occurrence of these issues could allow a user to resent the limb or situation thus reducing the quality of their rehabilitation. This is further recognised by Desmond & MacLachlan (2002) who found rehabilitation quality as being determined by the psychological adjustment of the user to their situation. Particularly, it is the ability of the lower limb design to address wearer psychological adjustment amongst other issues which can help dictate the rate and standard of wearer rehabilitation. Novotny (1991) notes, "...Health professionals must be aware of the importance of the amputees' relationship with their prosthesis as a physically and psychically invested aspect of the self and its potential to symbolise how they relate to the world".

Consequently there is a requirement for any prosthetic limb design to reflect upon the psychological need that wearers place within their limb and understand how this need can portray how they link with their environment or situation. However, the potential to achieve the balance between the aesthetic appearance, comfort and functionality of a limb can be difficult. As Desmond & MacLachlan (2002) found, an amputee may experience post-traumatic stress disorder (PTSD) leading to 'hyper-arousal' of sensitivities related to the new limb. As a result any emotional investment placed within the limb by the wearer would further emphasise sensitivities if it does not meet wearer expectations. This sensitivity to limb limitations could hinder the development of an effective user-limb relationship and impede rehabilitation quality.

It is clear that the wearer's perception of their limb is very indicative of their relationship with it and for younger users a positive perception is extremely valuable to their future independence and rehabilitation. MacLachlan (2004) suggests that increased aesthetic value could provide the wearer with a stronger 'emotional attachment' to their limb like that of wearing a wedding ring. An increase in limb aesthetic appeal could become easier to implement when compared to comfort and functional issues; for example a reduced level of variability between individuals can be achieved through use of standardised cosmesis coverings. It could therefore be determined that if a stronger form of emotional attachment could be produced between the wearer and limb through increased aesthetic appeal, it would be more likely to be incorporated into body image and positive perception.

There is a growing trend for individuals to choose to embrace their amputation and use their prosthesis as a method to show their individuality through means such as limb decoration and socket impregnation. An increased emphasis on aesthetic appeal such as this could become of value when facilitating an emotional attachment between the wearer and limb. With many factors contributing to wearer perception and satisfaction, providing better limb aesthetic value could facilitate improved user satisfaction particularly for those younger users for which appearance is increasingly important.

## Prosthetic design limitations

Although a rising number of prosthetic wearers seek a higher level of appearance choice in their prescribed limbs, this has become increasingly under-represented in favour of over-arching requirements such as comfort and function due to financial limitations of many healthcare budgets. Schaffalitzky et al. (2009) argue that prosthetic choice must be seen as a main tool in facilitation of increased limb use, even when governed by financial constraints. However, it is clear that these financial implications have an impact on the type of artificial limb that a particular individual will receive. Furthermore, it is clear that there is a lack of literature surrounding the effect that limb aesthetic appearance choice may have on the psychological rehabilitation of the wearer post amputation. Existing literature does suggest that improving this choice and allowing greater wearer input into prosthetic equipment design could aid development of positive perceptions, in turn creating greater relationships between user and limb.

## Methodology

This study recognised the amount of variables inherent with the subject area and endeavoured to provide initial research into the importance of limb appearance. The research took the form of 6 semi-structured interviews with two main stakeholders in prosthetic limb design: prosthetic wearers and healthcare practitioners. The methodology aimed to highlight and investigate user-limb relationship issues and the importance of limb aesthetic choice to those users.

Literature analysis showed age and gender to be indicative of user-limb relationship and limb requirements. NASDAB (2009) indicated that in 2006/07, 71% of all cases referred were male. Of these males, both 16-54 and 75+ age ranges include the majority of referrals. This study was conducted with a purposeful sample of 3 male transfemoral amputees aged between 21 and 30. The rationale for this selection was that male users were less likely to be influenced by additional factors i.e. fashion and trends. In addition, the age range was less likely to be impaired by poor health compared to that of older individuals and would allow for a more psychologically developed sample than that of younger users. Within this sample, only trauma-related lower limb amputations were included; poor health and further dexterity issues would less impair these users.

Three semi-structured interviews were also conducted with practitioners; 2 prosthetists and 1 physiotherapist. This sample was reflective of those practitioners who provide prosthetic limbs and aid user rehabilitation at different stages of the prescription process.

	<b>Age</b>	<b>Amputation Date</b>	<b>Amputation Level</b>
Participant A	23	2006	Upper Right
Participant B	24	2000	Upper Left
Participant C	24	1997	Upper Bilateral

**Table 1 - Amputee Participant Overview (source: Author)**

## Main findings

### Amputee input:

- When asked to rate the importance of appearance, comfort and function from 1-100 (100 = most important) in the design of their prosthetic limb, it was found that all participants consider the aesthetic value of the limb to be of equal or greater importance to comfort and function.
- All three participants indicated that through having greater input and choice in the design of their limbs, their satisfaction with them would be greater increased. One user indicated that choice to adapt or stylise his limb would have made him "more comfortable with it" and he believed that this would allow him to wear it on a regular basis.
- All three participants believed that their own and healthcare financial constraints greatly reduced their perception and satisfaction with their limb.
- Participants A and B both required foam coverings, however they felt that the limited number of stocking colours did not reflect their own skin tone causing greater awareness of them in public and social situations.
- Participant B noted that after receiving an updated cosmesis covering with greater muscle definition from his prosthetists, his perception of the limb significantly improved and allowed him 'comfort' in using it more regularly.
- It was found that participant A had refused to wear his limb regularly. He argued that his limb made him "feel uncomfortable as a person in social situations" due to the fact he "didn't think it was discrete". Additionally he believed that its look, plus comfort issues, negatively affected his perception of it "...the addition of look made it unbearable".

### Practitioner input:

- All three practitioners recognised aesthetic appearance as of some importance in producing good limb relationships for users, however they indicated that financial constraints would restrict the extent to which they would be able to provide choice of cosmesis coverings to prosthetic wearers.
- The physiotherapist cited reference to a patient who felt uncomfortable wearing a limb until it was personalised with graphics. As a result this patient felt more socially able to display and wear the limb.

- All three practitioners indicated issues relating to weight, comfort and functionality also contributed to the quality of user-limb relationship in addition to appearance quality.
- Both prosthetists found that for younger wearers requiring higher activity prostheses, there is a greater financial requirement for this than for older wearers requiring lower specification limbs. As a result the appearance of the limb may be affected in favour of reaching functional necessities.

## Conclusion

It was found that choice of aesthetic appearance in prosthetic limbs could improve user rehabilitation for certain individuals, however this was based not only on personal preference, but also that of age and gender. The results suggest that comfort, functionality and aesthetic appearance of prosthetic limbs all contribute to the rehabilitation of a prosthetic user. Nevertheless, research indicates that practitioners can be restricted in what they can provide to users in terms of cosmetic coverings due to financial constraints. As a result, practitioners tend to focus on over-arching independence requirements such as comfort and function.

It emerged from wearer interviews that for younger individuals, appearance could be rated as important as comfort or function of the limb. It was found that good quality limb appearance could foster a strong relationship with the user through improved user perceptions of the limb and increase limb use through a reduction in limb resentment or social factors. These results provide weight to the argument of Gallagher (2004) who indicated that both psychological and physical factors have to be combined into limb design to ensure user acceptance, but it also confirmed that it was important to consider personal preferences of the wearer within the prosthetic limb design. It was apparent that appearance value may become increasingly significant for younger individuals in the future.

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# Knowledge and Understanding of Vascular Disease and Health Risk Factor Modification in Peripheral Arterial Disease Amputee Patients

## Abstract

The aim of this study was to evaluate the knowledge and understanding of peripheral arterial disease (PAD), and the subsequent health behaviours in patients with a lower extremity amputation. Research in cardiovascular patients indicates incomplete or flawed understanding in risk factor modification which impacts effective disease management. There has been little research specific to the PAD patient population.

Qualitative data was gathered through semi-structured interviews via telephone, in an urban centre in Scotland. Interview questions were developed from previous research and consultation with specialist vascular clinicians. Demographic data such as postcode, gender, age and level of amputation along with aetiology were also collected.

Nine PAD amputees (5 male, 4 female) mean age 66.7 years ( $\pm 19$ ) provided the sample. Six themes were revealed which highlighted a lack of disease knowledge in the dysvascular patient population. Those of a lower socioeconomic status had more disease knowledge than those of a higher socioeconomic status, but were more likely to continue risky lifestyle behaviours. Lack of understanding of PAD potentially will be a barrier to changing and sustaining healthy behaviours.

Key words: Peripheral artery disease, knowledge, health risk factors, amputee patients

## Background

Chronic diseases are a major cause of poor quality of life, disability, (Widener, 2011) health care spending (Doherty, 2012) and premature death, representing 63% of worldwide mortality (WHO, 2012a). Among them, peripheral arterial disease (PAD) remains under-diagnosed and poorly managed (Brazziel et al, 2011; Cambou et al, 2010; Jaffrey et al, 2009; Vaartjes et al, 2009; Welten et al, 2009; Rosamond et al, 2007). The process of PAD is known as atherosclerosis, and primarily affects arteries of the lower limbs, causing pain, tissue damage, and in some cases amputation (Lawrence et al, 2011; Gardner et al, 2010; Welten et al, 2009). Welten et al, (2009) concluded that patients diagnosed with stage II PAD have a 25% risk of symptoms worsening, and 5% risk of amputation (Welten et al, 2009). Compounding this is that one third of patients with PAD concurrently have type II diabetes (Welten et al, 2009; Marso & Hyatt, 2006). While these outcomes have significant implications for quality of life and disability, it is crucial to note that atherosclerosis is systemic, and therefore PAD is strongly associated with higher rates of cardiovascular mortality from myocardial infarction and stroke (NICE, 2012; Brazziel et al, 2011; Mendis et al, 2011; Ergova et al, 2010; Lakshmanan et al, 2010; Welten et al, 2009; Criqui et al, 2008; Rosamond et al, 2007).

Approximately 30 million people worldwide have PAD (Rosamond et al, 2007), but limited disease awareness leads to under-diagnosis, making actual numbers difficult to estimate (Becker et al, 2011; Widener, 2011; Villablanca et al, 2010; Vaartjes et al, 2009; Welten et al, 2009). Interventions for PAD present a "unique financial burden" to the health system due to re-admissions from unsuccessful revascularization attempts and inadequate primary amputations (Becker et al, 2011; Fry et al, 2011; Sachs et al, 2011; Bradbury et al, 2010). In a study of PAD patients undergoing revascularization surgeries, 31% were re-admitted for follow-up revascularization, and 15% required subsequent lower limb amputation (Sachs et al, 2011; Bradbury et al, 2010).

Minimisation of risk factors such as smoking and alcohol is the most effective way to prevent and manage existing PAD (Doherty, 2012; NICE, 2012a; Brazziel et al, 2011; Lawrence et al, 2011; Mendis et al, 2011; Yohannes et al, 2010; Chummum, 2009; Welten et al, 2009; SIGN, 2006). Risk factors for cardiovascular disease (CVD) have been part of public health campaigns across the UK for many years (BHF, 2013; ScotPHO, 2012b; ScotGov, 2009). However, while there is awareness about how these behaviours link to heart disease (SIGN, 2002) and cerebrovascular disease (stroke), awareness about the links to PAD is strikingly low (Lovell et al, 2009; Aboyans et al, 2007). Arguably, this is because education about symptoms and outcomes of PAD is absent from public health campaigns (ScotGov, 2009). Research to date in heart and cerebrovascular disease populations has investigated patient perspectives on various CVD risk factors and disease management, and identifies recurring issues around information provision, understanding, and expectations

(Parks et al, 2011; Roaldsen et al, 2011; Senra et al, 2011; Zhu et al, 2011; Sol et al, 2008; Smith&& Liles, 2007). Effective chronic disease management is achieved through behaviour change which according to Bandura's Social Cognitive Theory (Bandura, 2004) requires the key component of knowledge.

There is minimal literature within the Scottish PAD population specifically that assesses service-user perspectives on knowledge and behavioural change (Gallagher et al, 2012; NICE, 2012; Parks et al, 2011). The majority of the existing literature focuses on patients with heart disease or stroke, and while the common diagnosis of atherosclerosis suggests an extent of comparability to the PAD population, the experience of these diagnoses differ greatly.

## Methods

### Design

A telephone semi-structured interview was used (Patton, 2002) to accommodate the mobility difficulties of the participants. Ethical approval for the research was granted by the host University Research Ethics Committee (HLS id: B11/39)

### Subjects

Subjects were included if they had undergone a minimum of one surgical intervention in the previous year, and had been discharged from rehabilitation. The subjects were in a transitional phase in life following their respective vascular intervention (Senra et al, 2011). A convenience sample of nine subjects were recruited. All subjects completed informed consent.

### Question development

Questions were developed from the literature, revised following consultation with two vascular specialist physiotherapists, and refined after a pilot study with three subjects.

### Analysis

Preliminary analysis of data was carried out by identifying noteworthy responses during transcription. Secondary descriptive analysis used an inductive thematic approach to identify patterns and categories (Patton, 2002). A selection of quotations was triangulated by two assistant researchers to ensure accuracy and validity of the pattern descriptions and minimize researcher bias (Patton, 2002). The tertiary stage of analysis consisted of interpretation and consolidation of results into substantially significant themes (Patton, 2002). Lastly, a deductive approach was used to discuss and explain themes and their interconnections in the context (Patton, 2002).

## Results

Nine participant interviews (5 male, 4 female) were carried out. The mean age of participants was 66.7 years ( $\pm 19$ ). All participants had a diagnosis of PAD, and had consequently undergone a major lower limb amputation (8 TTA, 2 TFA) within the past 12 months. A Scottish Index of Multiple Deprivation (SIMD) ranking was determined by postcode to ascertain socioeconomic status, with rank 1 being the most deprived area and rank 6505 being least deprived area within all of Scotland (ScotGov, 2012). Table 1 shows the demographics of the subjects.

P	M/F	Age	SIMD	Previous vascular surgeries	Amputation level	Time since amputation (at interview)	Co-morbidities
P4	F	69	649	Toe amputation	Lt. TTA	8 months	D, S
P9	M	63	791	Multiple toe amputations, previous Lt. TTA	Rt. TTA	7 months	D
P7	M	63	1398	Angioplasty x1 Bypass x 3	Lt. TFA	9 months	Mlx3, S
P6	F	48	1774	Bypass x 3	Lt. TTA	8 months	N
P5	F	75	2416	Bypass x1	Rt. TTA	9 months	N
P3	M	73	3105	N	Rt. TTA	10 months	D, MI
P2	M	69	3172	Bypass x 3, toe amputation, LL amputation modification	Rt. TTA	10 months	N
P8	M	54	6213	N	Rt. TTA	9 months	D, MI, S
P1	F	86	6288	Bypass x1	Rt. TFA	6 months	N

**Table 1: Participant demographics, ordered by low-high rank on SIMD (1 most deprived, 6505 least)**

**LL = lower limb, TFA = trans-femoral amputation, TTA = trans-tibial amputation, N = none D= diabetes, MI= myocardial infarction, S= stroke P= participant**

## Patterns, categories and themes

Six major themes emerged:

- Limited PAD awareness in the general public;
- Insufficient knowledge about PAD and its pathophysiology;
- Inconsistencies on being informed about causes of PAD and or changes to behaviour;
- PAD has a high functional and economic impact;
- Positive attitudes towards behaviour change;
- Ill-advised attitudes towards behaviour change.

### Limited peripheral arterial disease awareness in the general public

Most participants stated they had not heard of PAD prior to being diagnosed, and commented that there is not enough awareness in the general public:

'I mean, I'd never heard of this vascular disease... I didn't know what they were talking about.' Participant 5, SIMD 2416, p.63.

Most stated that had they known that certain behaviours could lead to an amputation, they would have made changes earlier, or not started the behaviour in the first place. The majority of the participants eagerly demonstrated a desire to pass their knowledge on:

'There must be some... coherent way of getting through to young diabetics, that, their condition is serious, and has long term effects if you don't treat it well, early on in life.' Participant 8, SIMD 6213, p.100.

### Insufficient knowledge about peripheral arterial disease and its pathophysiology

All participants had heard of PAD at the time of the interview, but despite the fact that all participants had a diagnosis of PAD in their medical records, one third made statements which suggested they did not know they had the disease. While participants had varying degrees of disease understanding, all participants made statements indicating limited disease knowledge :

Does the term 'peripheral vascular disease' ring a bell at all?

'Yes, I've heard that mentioned'

Has anyone told you if you have it or not?

'No... what is it, how does that affect you?' Participant 3, SIMD 3105, p.31.

It was clear that participants were not aware that their condition was systemic. Most participants believed that their amputation and their MI or stroke were mutually exclusive.

Two participants believed that the problem had been fixed with the amputation:

'Do you feel that there's a connection between the heart attack you had and your amputation?'

'No... I was going to get the leg off before the heart attack anyway. ...it made [the amputation] less important to me, 'cause obviously your heart is more important than anything else...'

Participant 3, SIMD 3105, p.37.

A couple participants linked high risk behaviours to their MI or stroke, but did not believe the same behaviours were responsible for the amputation:

'It's just been, the blood...not flowing', and I think the stroke was caused by smoking'. ' Participant 7, SIMD 1398, p.90.

Of special note is the pattern that emerged suggesting there is a period of time during the experience of acute PAD that may result in decreased comprehension:

'Before you had the operation, at least at my stage... I really couldn't get concentrating on anything else because the pain was so intense. ' Participant 1, SIMD 6288, p.9.

### **Inconsistencies on being informed about causes of PAD and or changes to behaviour**

Some participants were told explicitly about risk factors for PAD, or encouraged to make behaviour changes, while others stated they were not informed about any such things:

'They never told us an awful lot about it. They never, they were not very explicit they just told' me what the problem was, and how they were going to rectify it, and that was with, what do you call it, bypass. ' Participant 2, SIMD 3172, p.18.

'I think my practice nurse took on a number of occasions sayin' "You've got to really watch... the diabetes... you've gotta keep yourself controlled.' Participant 9, SIMD 791, p.111.

### **Peripheral arterial disease has a high functional and economic impact**

The high functional and economic impacts of PAD were clearly demonstrated across all interviews, expressed as debilitating pain prior to the amputation, multiple hospital admissions, and challenges associated with prosthetic rehabilitation:

'I was lying in bed with my leg out the bed and walking' about the floor about 2, 3 in the morning, it was just awful, you know.' Participant 6, SIMD 1774, p.69.

There was evidence of multiple costly encounters with the health service:

'I lost three toes, 1, 2, 3, yes, 3, 3 or 4 toes from 2007, April 2007, eventually I had to get my leg amputated for the cellulitis was all down my legs... in the meantime me losing' my leg on my left foot, I lost 3 toes on my right foot. ' Participant 9, SIMD 791, p.105.

Those who had experienced an MI or stroke felt that the amputation had a greater impact on their lives:

'[The stroke] was very mild, it was just... basically I 'had 99% of my, my senses, reflexes, everything back within a week, so...I was using' the leg every day, till this ulcer just got a wee bit, worse..., my transfers from the chair to anywhere is quite good... and my wife, she's 68 now, and she's got to push me up this ramp' Participant 7, SIMD 1398, p.86.

Half the participants were experiencing ongoing vascular complications at the time of interview. Six participants made statements indicating how PAD negatively affected their mental health:

'But [there are] days when I'm really down. But you just say well, 'I'll have another day and things might be better tomorrow'. [The amputation is] really hard, it changes your life completely.' Participant 5, SIMD 2416, p.62.

### **Positive attitudes towards behaviour change**

Six participants stated they thought differently about their health following their amputation:

'I certainly got a different outlook on it now, ya know, a wee bit late maybe but I do... I think a lot about my

health.' Participant 4, SIMD 649, p.49.

Six participants demonstrated predominately good insight into what healthy behaviours were and were not:

'I assume that if I keep, if I try and stick to, you know, a fairly positive diet and stay healthy, the circulation will not get any worse.' Participant 8, SIMD 6213, p.98.

Approximately half of the participants had made behaviour changes, mostly following amputation, and believed the changes had made a difference to their health:

'Oh my diet was dreadful with a capital 'D'. And I have tried to improve it. And I was a smoker but I quit... [I quit because] I was frightened that something would happen to my other leg. ' Participant 6, SIMD 1774, p.70.

### **Ill-advised attitudes towards behaviour change**

In contrast, three participants stated they did not feel differently about their health following the amputation:

'No, I don't think much about my health now, I still, apart from the leg missing' I still feel quite healthy. Participant 2, SIMD 3172, p.19.

They also demonstrated predominately poor insight into what healthy behaviours were and were not:

'I says 'oh I better smoke', cause I feel ok than taking' these tablets and feeling' lousy day in and day out.' Participant 2, SIMD 3172, p.19.

Many participants continued the high risk health behaviours that they had prior to their vascular symptoms. A couple did not believe a behaviour change would make a difference:

'I think if I didn't smoke, didn't drink, didn't, eat fatty foods or whatever, I think it'd still, you know, I think I was, just unlucky.' Participant 7, SIMD 1398, p.87.

Accordingly, many participants demonstrated low levels of self-efficacy with relation to making behaviour changes:

'I always look at this foot and... it's not getting worse, well not just now anyway. But other than that, I mean, what can you do?' Participant 5, SIMD 2416, p.60.

These themes represent the most common concepts that emerged when considering all nine participants equally. However, there are secondary outcomes in the context of SES comparisons.

### **Socioeconomic trends**

Those subjects of a lower SES more consistently demonstrated good awareness of PAD pathophysiology, symptomology, connections between CVD risk factors and outcomes, and believed that behaviour changes would make a difference to their health than those of a higher SES.

Notably, staff were more consistently reported to have explained the causation of poor CVD outcomes to the lower SES group than to the higher SES group. However, the participants of the lower SES continued demonstrating unhealthy behaviours after the intervention, and were experiencing ongoing vascular problems at the time of the interview despite inconsistent concern for their vascular future. Those in the higher SES voiced concerns about developing vascular complications in the future despite demonstrating more examples of positive behavioural changes and only one participant having ongoing vascular problems at the time of the interview.

## **Discussion**

The current study identified a serious lack of frequency, quality, and comprehension of disease specific information that is either delivered to or taken on by this cohort of dysvascular patients throughout their experience with the disease. A sufficient knowledge base is cited as a key element of behaviour change within Bandura's SCT (1991) and by not having this knowledge PAD sufferers are less likely to be successful with behaviour change and therefore adequate management of the disease. Parks et al (2011) similarly showed that cardiovascular participants valued prevention, but did not value self-care behaviours, lacking the awareness that self-care behaviours are integral to prevention. This finding was further confirmed by Smith & Liles (2007), where information to prevent complications was valued, but PAD symptom information was ranked least important showing decreased awareness for the systemic nature of CVD. Zhu et al (2011) identified patients' desire for information on self-management, but that there was either a lack of or incorrect information provided to the cardiovascular patients in their study.

The findings from this research suggest that there is a need for more health information and public campaigns to highlight the systemic nature of cardiovascular disease that includes development and symptoms of PAD. Furthermore, findings from this study indicated many barriers to comprehension in the PAD population, such as the impact of pain and

cerebrovascular complications (Phillips & Mate-Cole, 1997). This should be acknowledged by clinicians, recognising many PAD patients have cognition problems, and educational approaches adjusted accordingly. In this way, PAD patients will be better able to acquire information and understanding of their condition effectively.

From the current study it can be suggested that a more streamlined and thorough approach to education and advice is required across all PAD patient groups regardless of background and SES. More structured education provision which is standard in other cardiovascular conditions should be considered. Structured educational support is the norm in cardiac rehabilitation which is delivered by a multi-professional team including nurses, physiotherapists, dieticians and other health care professionals (SIGN, 2002). Consideration should also be made to include information about PAD symptom recognition and associated risks in future public health campaigns associated with CHD. This is one of the first studies to investigate using qualitative approaches the knowledge and understanding of vascular disease and health risk factor modification in peripheral arterial disease amputee patients. Limitations include the interview medium and sample size. As interviews were conducted by phone, there are positive aspects such as omitting visual judgements, but also negative aspects potentially impacting rapport and honesty of responses. As is the case with any study of a small sample size in a single geographic location, there is a limit to generalizability of this research.

## Conclusion

In summary, this study has highlights a lack of understanding and knowledge among a sample of vascular amputee patients. This lack of knowledge can hinder participation in long term health behaviour. A more structured education and behaviour change approach as used in cardiac rehabilitation may improve the way vascular and amputee patients manage their cardiovascular risks.

Conflict of interest: none.

## Key points

- Peripheral vascular disease is an increasing problem worldwide, but awareness is limited
- Vascular disease amputee sufferers appear to have poor understanding of their condition and risk factor modification associated with the development of the condition
- There should be more emphasis on the education and behaviour change components of care for vascular patients

**Holly D. Higgins, Morag Thow, Fiona Smith, Joanne Heberton**

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# Patient Experience in Acute Amputee Rehabilitation



Kate Primett (Bsc (Hons), PGc) – Acting Msk Inpatient Clinical Lead, Royal Free Hospital  
Email: kate.primett@nhs.net

Royal Free London NHS Foundation Trust

## Introduction

Patient feedback is increasingly being seen as a key component for 1) monitoring and improving healthcare quality (1), 2) benchmarking of services and 3) demonstrating accountability for the public and taxpayers (2).

In line with government initiatives the amputee steering group at the Royal Free Hospital collected patient satisfaction questionnaire (PSQ) throughout 2010/2011. In 2012 the questionnaire format was altered to capture information on patient experience rather than satisfaction.

This was because evidence highlighted that:

- 1) Experience rather than satisfaction style questions provide greater specific insight into where the potential problems actually lie and how to improve particular elements of patient care (3).
- 2) Satisfaction style questions are likely to have an increased potential bias associated with the subjective nature of satisfaction style questioning (4).

## Study Aims

This study aims to;

- 1) Summarise the method of collecting patient satisfaction and experience feedback
- 2) Evaluate data collected between 2010 and 2012
- 3) Reflect on the change in questionnaire format and areas for future development

## Method

### Questionnaire Design

- A bespoke questionnaire was designed by an expert panel consisted of two physiotherapists, a matron, vascular clinical nurse specialist, occupational therapist, pain team nurse, patient pathway co-ordinator and a psychologist.
- Questionnaire content and format were reviewed by the amputee team in a focus group aimed at reviewing comprehensibility, clarity and face validity.
- A pilot study was completed over a one month period, to run through the process of distribution, collection and data inputting.
- The questionnaire was limited to one double sided sheet to increase response rates.
- The questionnaire comprised of 21 closed questions relating to 'Rehabilitation', 'Discharge', 'Ward Experience', 'Information Received' and 'Pain management'. A section was available at the end of the questionnaire for open comments.
- The questionnaire was distributed to all patients who were deemed able to accurately complete the survey. Patients who had cognitive deficit or did not consent were not asked to complete the questionnaire. Assistance from volunteers or relatives was encouraged as required.

### Questionnaire format

- In 2010/2011 a six scale likert system was chosen to provide a wide range of responses for patient to select from. See response options below.

#### PSQ – Six option likert scale (2010/ 2011)

	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Agree Strongly
I felt the reason for my amputation was explained to me						

- In 2012 the likert system was reduced to four option responses. Use of the 'N/A' option and alterations in order of response options were included to try and reduce missing values and use of the middle category response. See response options below.

#### PEQ – Four option likert scale (2012)

	N/A	No	Yes, to some extent	Yes
Were the reasons for your amputation fully explained to you?				

## Results

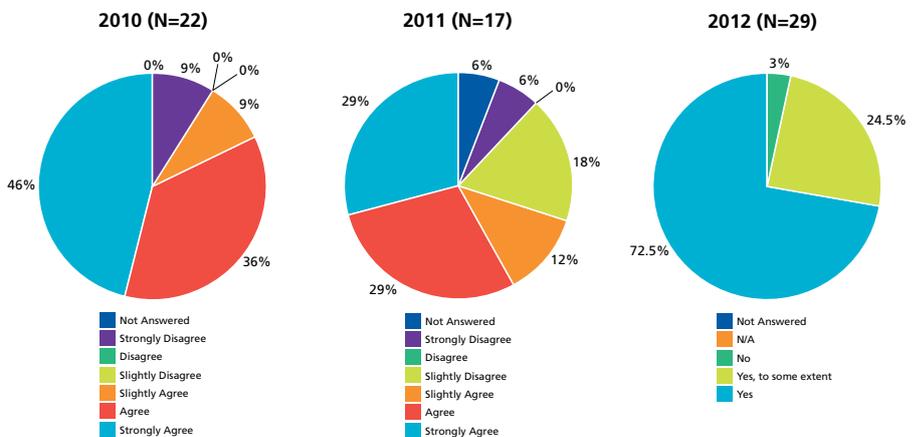
### Data Collected

Year	2010	2011	2012
No. of amputees (primary and established)	56	55	56
No of questionnaires collected	22 (39%)	17 (31%)	29 (52%)
No. of missing questionnaires 2012 (N=29)	34 (61%)	38 (69%)	27 (48%)

### Summary Findings (2010-2012)

- Overall satisfaction/ experience with nursing care, information given, pain management and therapy input was good.
- Levels of overall dissatisfaction were generally low (8% reporting a poor experience)
- Counselling/ psychological input satisfaction/ experience was generally poor.

### Responses to Question 21: I felt satisfied with my overall experience at the RFH before, during and after my amputation.



## Discussion

- Missing question data has been attributed to the following reasons;
  - 1) Patients had cognitive deficit
  - 2) Patients did not give consent
  - 3) Patients failed to complete or return the postal questionnaire.
- Although the same questions were used it is difficult to make a direct comparison between the 2010/2011 – 2012, due to a change in questionnaire format.
- There was no statistical analysis completed therefore it is impossible to determine the significance of the yearly changes and overall findings.
- Feedback is from a relatively small sample size and only related to amputee patients within our service, so data collection cannot be generalised nationally.
- As the questionnaires are anonymous we are unable to identify patient characteristics. This limits our ability to;
  - 1) Implement future targeted strategies and increase response number from specific patient groups and,
  - 2) Make potential alterations required to improve questionnaire acceptability and utility.

## Future Developments

- In the future we plan to;
  - 1) Properly validate the questionnaire by linking with UCL.
  - 2) Complete statistical analysis to quantify significance of the findings.
  - 3) Ensure provision of the questionnaire is available in alternative languages.

## On going challenges

- Positive patient experience may be affected by time constraints imposed on staff members with expanding caseloads, resultant from implementation of the vascular hub.
- Continued high multidisciplinary staff turnover within all departments may affect overall patient experience as new staff are being trained. It also increases the likelihood of missing questionnaire data.
- High level of patient exclusion rates due to cognitive deficit experienced by vascular caseload.

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# Contralateral Foot Audit of Patients Admitted to Sutherland Ward, Astley Ainslie Hospital, Edinburgh

## Introduction

At the BACPAR conference in 2010 new guidelines were presented relating to “Risks to the Contra-lateral Foot of Unilateral Lower Limb Amputees: A Therapist’s Guide to identification and Management”. This was based on a systematic review of literature narrowed down to 34 included articles and guidelines. The scope of the guidelines is to “recommend that care of the remaining / contralateral limb is included in therapeutic practice” and that they are “intended to be a practical resource for therapists working with lower limb amputees and should be used alongside other current published guidelines”.

Amputee patients admitted to Sutherland Ward in Astley Ainslie Hospital for pre-prosthetic and/or prosthetic rehabilitation are largely representative of the general amputee population with regards to age, level, aetiology of amputation and percentage of bilateral amputations. It was felt relevant and appropriate to complete an audit with the same inclusion criteria as an information gathering exercise in order to highlight to the physiotherapy, and wider multidisciplinary team, any issues with the patients’ contralateral leg/foot and, if required, any changes in practice that may be thought necessary to ensure optimal care for this group of patients.

## Methodology

From a certain date the subsequent 100 patients admitted to the ward were included in the study. The main cohort were primary amputees being transferred from the acute hospital setting but there were a few patients admitted for other reasons – transferred in from other areas 2 years post spinal injury and amputation for pre-prosthetic rehabilitation, readmission following completion of wound healing for pre-prosthetic rehabilitation, residuum breakdown not able to be managed in community setting, admission for prosthetic rehabilitation and medical admission directly from clinic.

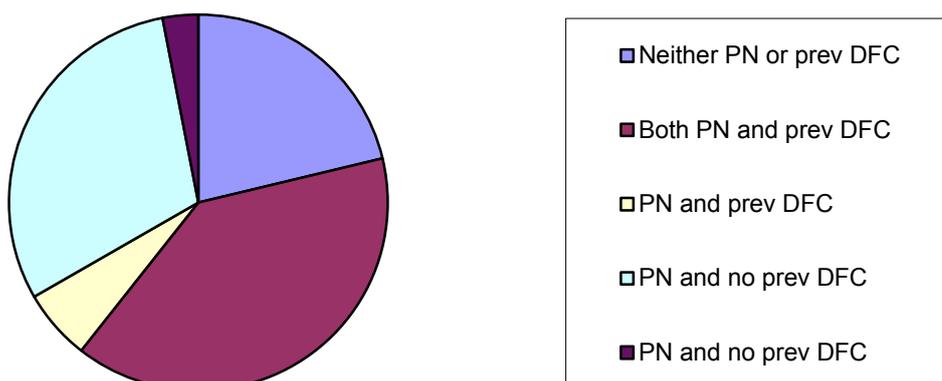
Data from medical, nursing and therapy notes and assessment were used to complete an audit form for each patient. The form had three sections: “Diabetic status”, “Contralateral foot” and “Other referrals made” and was made up of yes/no tick boxes. The data was collected and initially analysed by two therapists with the final analysis by one therapist.

## Results

There were 40 diabetic and 60 non-diabetic amputees with the male to female ratio being 72:28. 14 were bilateral (7 diabetic:7 non-diabetic, and 12 male:2 female) and were excluded from the audit. 86 were included in the final analysis, with 53 non-diabetics and 33 diabetics.

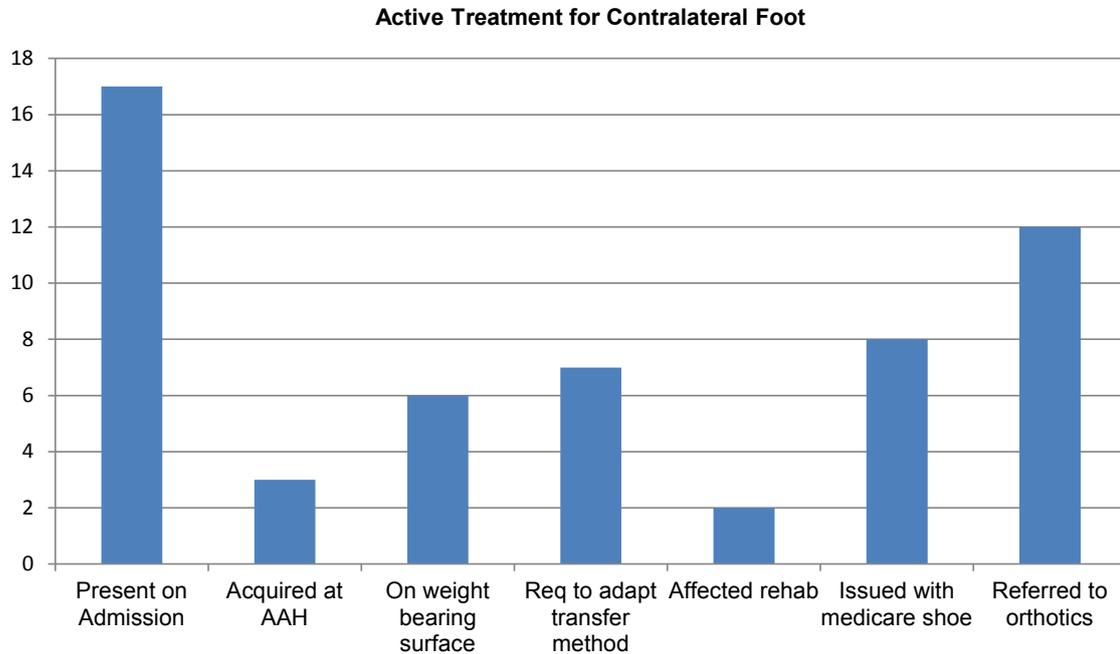
Within the 33 diabetic patients there was wide variation in whether there had been previous attendance to a diabetic foot clinic (DFC) and also as to presence of peripheral neuropathy. 23 had attended a DFC and 16 had peripheral neuropathy. 7 had neither peripheral neuropathy nor attended a DFC. 13 had both peripheral neuropathy and had attended previous DFC.

### Presence of Peripheral Neuropathy and If Attended a Diabetic Foot Clinic Previously



### Treatment of the contralateral foot

20 (23%) out of 86 received active treatment for the contralateral foot, see table below. 17 were receiving treatment on admission, 3 were acquired during their admission, 6 were affected on the weight bearing surface and 7 had to adapt their transfer technique. For 2 patients their rehabilitation was affected and they were prevented from using an EWA or prosthesis. 8 received medicare shoes and 12 were referred to orthotics.



### Provision of Medicare shoe

18 (21%) of the 86 patients receive a blue medicare shoe. 8 of these were receiving treatment on the contralateral foot but 10 were not. One patient had a previous spinal cord injury with resultant foot problems, one had not other footwear available, 2 were due to swelling of the foot and 6 others were not recorded as to why.

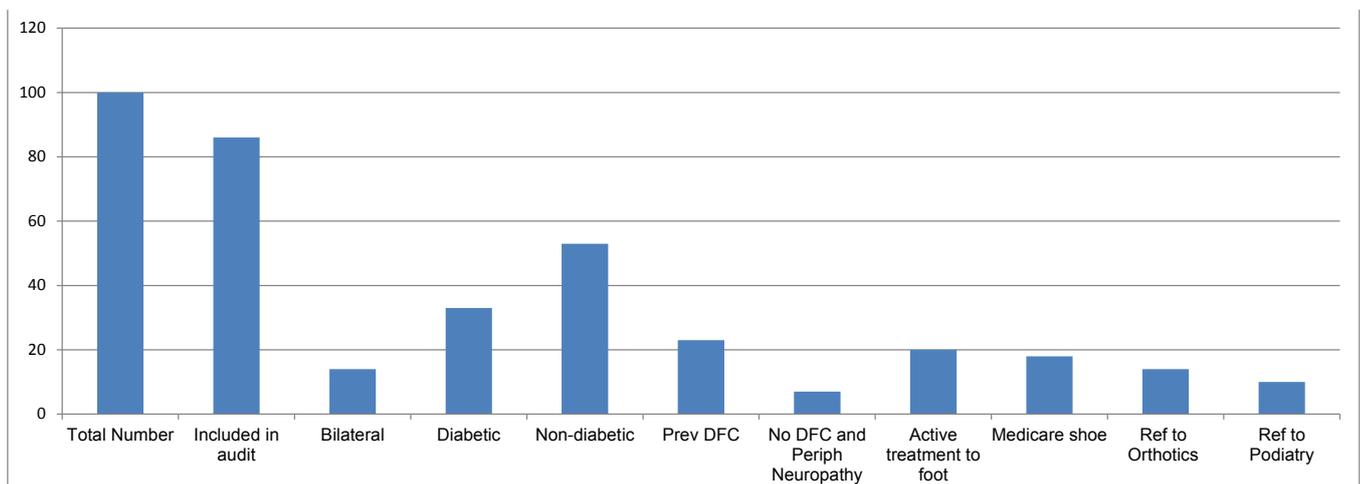
### Onward referrals

Orthotics - 14 (16%) of the 86

12 were for contralateral foot issues, 1 for previous spinal injury patient with foot abnormalities and 1 for previous foot surgery issues.

Podiatry - 10 (12%) of the 86

### Summary of audit findings



## Discussions Points

Having completed the audit and presented the findings to the immediate MDT (physiotherapy/nursing/OT/prosthetics/medics), various points have been raised:

- In this particular sample the percentage of patients who were diabetic was lower than expected.
- That 21% of the diabetics had no previous diabetic foot clinic appointments was surprising
- There was lack of clarity as to when and why provision of a medicare shoe occurred and members of the MDT agreed that given that 21% of patients received such a shoe it was worth further audit
- There was lack of clarity as to the exact role of orthotics and podiatry and when was optimal to refer to either service
- Since the audit took place there have been changes in how the orthotic service is delivered locally (it is now onsite) and it was felt by the wider MDT that it would be helpful to establish if there was an increase in referrals as a result.
- With regard to the above points it was noted that the MDT team were unsure whether physically this patient group would be capable of managing their own footcare (reaching their foot) and if they could, how well would they know what to do.
- There has been discussion as to the need for a comprehensive leaflet for the patients on discharge to give clarity as to the maintenance of good foot care and hygiene.

## Conclusions:

A further audit will be carried out. It will be simpler than the original with focus being on the following:

- Only primary amputees
- Diabetic or not?
- Aetiology of amputation (vascular or non-vascular)
- Percentage undergoing active treatment of the contralateral foot
- Medicare shoe provided – and why?
- Onward referrals to orthotics and prosthetics
- Patient capability to manage own footcare and knowledge to do so effectively

Orthotics and podiatry will be contacted by the authors with the aim of:

1. Raising awareness within the immediate MDT as to the role of orthotics and podiatry
2. Promoting education to the MDT as to when most appropriate to refer
3. Optimising access to their services for this patient group.

**Catriona Mawdsley**

## References

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## Appendix 1

### **Contralateral Limb Audit 2010**

To be completed for all unilateral patients admitted to Sutherland Ward, AAH.

Patient Name: \_\_\_\_\_

Diabetic Status:

Is the patient Diabetic?	Y / N	Peripheral neuropathy	Y / N
Prev Diabetic Clinic appointments	Y / N		

Contralateral foot:			
Are they undergoing active treatment for the contralateral foot? e.g. dressings, antibiotics			Y / N
If yes,	Present on admission?	Y / N	Acquired at AAH
			Y / N
Location of skin breakdown (circle):			
Toes	Fore/Midfoot	Heel	Ankle
Weightbearing Surface	Y / N	Adapted transfer technique due to foot	Y / N
Prevented EWA/prosthetics due to foot	Y / N	Medi-Shoe Provided	Y / N
Other Referrals made:			
Orthotic Referral Made		Y / N	
Date of Ref:	/	/	
Date Seen:	/	/	
Orthotic Supplied and Date:	/	/	
Podiatry Referral Made		Y / N	

## GOOD NEWS!

Working as a physiotherapist for over ten years I felt I needed more of a challenge and stupidly applied to do my MSc not really thinking too much about it. I didn't think I would get the bursary I needed to do the course but as it happened I did and so the following month I started my course whilst working full time. Little did I know that this would be a steep learning curve but one that I thoroughly enjoyed. I focused my dissertation on looking at SPARG data relating to amputee outcomes, as most people know when you start any project it throws up more questions than answers, so after writing up my dissertation I was already thinking about how to answer the question, what influences the ability to limb fit with a prosthesis, is it aetiology, age, gender or socio-demographics? A mere passing suggestion by my supervisor about applying to do my doctorate led me to applying for the Sir George Alberti Fellowship with Diabetes UK. I really hadn't considered the process as the first stage was applying for an application form! In hindsight I think it went in my favour how naïve I was to fellowship funding and the competition and work involved, had I known I may not have started the process!

After clearing the first hurdle of getting an application form, it was a lengthy process to write a proposal (about 40 pages long!). Then there was the waiting....4 months later I found out I had been shortlisted for an interview. It was all becoming very real and now there was only one more terrifying hurdle and 3 months to prepare for the unknown! At this stage it seemed that all my colleagues thought it was in the bag but my supervisors and consultants were much less optimistic filling me with dread and a reality check. The interview was nothing like anything I have experienced, eight people on the panel all asking questions about how I would manage the project and what it would do for those with diabetes. It was over in twenty minutes and then total relief that the process was over, no matter the result, well not exactly, obviously I really wanted the fellowship!

I only had to wait about 5 days to find out that I had been awarded the fellowship, total disbelief ensued not only by myself but also my supervisors and more unusually my husband, whose quote was "anyone can get a masters but not everyone can get money out of people!", praise indeed!

Well with only two weeks of clinical work to go I am getting nervous with anticipation of what may lie ahead for the next 3 years, I know I have to get the work done but more importantly it has to answer the question which I have been wondering for over 3 years now: What influence does diabetes have on amputation outcome and why? I will keep you all posted.....

**Fiona Smith**





Charlotte aged 5:  
Quadrilateral amputee

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# Clinical Management in Acute Amputee Rehabilitation

This course will be of interest to Physiotherapists, Occupational Therapists and Rehabilitation Assistants who treat amputees in the acute surgical setting.

Date: Friday 29th November 2013

Time: 8.30 – 4.45pm

Venue: Sheila Sherlock Medical Centre, Royal Free London NHS Foundation Trust, Pond Street, Hampstead Heath, London, NW3 2QG.

Cost: £50

Early Bird Rate (Pre 30th September 2013): £40

BACPAR members will be issued a £5 discount on all costings.

(Please make cheques payable to G305 Fund, RFH Therapies)

Drink refreshments will be provided.

Please contact Kate Primett (Msk Inpt Team Lead) for more details/ application form.

Address: Physiotherapy Department, Royal Free London NHS Foundation Trust, Hampstead Heath, NW3 2QG

Email: [kate.primett@nhs.net](mailto:kate.primett@nhs.net)

Tele: 02077940500, Blp 2368

## Provisional Programme

08 30	Registration and welcome
09 00	Surgical Amputation Intervention/ Causes/ Investigations (Vascular Consultant)
09 30	Pain Management following major amputation (Pain Team)
09 50	Care of the diabetic foot (Podiatry)
10 20	Refreshments
10 40	Wound management following amputation (TVN)
11 00	Influencing behaviour change/ health promotion (Wellness Team)
11 15	PT/OT input – pre/post op intervention
12 15	Morning Round up
12 30	Lunch
13 30	Practical Sessions: <ul style="list-style-type: none"> <li>Station 1: Exercise Prescription</li> <li>Station 2: PPam aid Intervention</li> <li>Station 3: Femurett Intervention</li> <li>Station 4: Patient transfers</li> </ul>
15 30	Refreshments
15.45	Gait Analysis
16 30	Questions/ Discussion
16 45	CLOSE



## Pushing the Boundaries Life Beyond Childhood Limb Loss Due to Septicaemia

Organised by the Meningitis Research Foundation was held at Alder Hey Children's Hospital Liverpool on the 31 May 2013

I had a wonderful day at this event, which was well organised by the Meningitis volunteers. My role was to chat to children and parents giving advice or simply listen to their individual stories. The children are always inspiring and I also learnt lots from both parents and professionals. Our very own Kathleen Hawkins who originally attended the Leeds centre and is also an ambassador for the Meningitis trust, was the local reporter for the day.

Paralympian wheelchair rugby player Aaron Phipps and Linda Roberts, mother of Gold Paralympian medal winner Jonnie Peacock, met children who have lost limbs as a result of bacterial meningitis and septicaemia at Meningitis Research Foundation's first ever childhood amputee day in May 2013. The charity hosted the event, in conjunction with Alder Hey Children's NHS Foundation Trust in Liverpool and 18 families from across the UK attended the day.

Everton FC's Community team provided activities for the children whilst parents shared inspirational stories, heard presentations from a panel of experts and asked questions on a range of amputee related topics from the management of scarring to effects on bone growth and the types of prosthetics available on the NHS.

Vicky Travers from Merseyside attended the day with her daughter Amber who contracted meningococcal septicaemia in November 2010 when she was two. The disease spread so rapidly doctors had to take drastic action to save her life. Amber had her left arm amputated at the shoulder and her right arm removed above the wrist. She also lost her right leg above the knee and the left leg below the knee.

Vicky said: "It was a fantastic event because Amber has only ever seen pictures of other children with amputations but never actually came face to face with children the same as her. It was also really nice for me to be able to sit and talk to other families who have gone through the same terrible experiences as us."

Shirley Gieron, Head of Membership & Support at Meningitis Research Foundation said: "We organised our Amputees' Day to help families to feel informed and positive about the future. This was a fun day for the children and many made new friends whilst the parents got to add to their knowledge about amputations by talking to the professionals and meeting other families who know what they have been through."

Sian Falder, Consultant Burns and Plastic Surgeon at Alder Hey Hospital said: "We were delighted to work with the Meningitis Research Foundation to help them organise this day for their members and have recommended some of our own families to come along. It can be very helpful for patients and parents to share their experiences of this terrible disease and to be able to talk to professionals about their concerns in an informal setting. It was a really successful day." A video of presentations from the day is available at [www.meningitis.org/pushingboundaries](http://www.meningitis.org/pushingboundaries)

The Meningitis trust have also produced "Your guide" (an information resource for parents of children recovering from meningitis and septicaemia). There is a journal which accompanies this resource and parents can get hold of this by contacting ourselves (we will send out copies free of charge). There is more information about the guide and journal on our website at [www.meningitis.org/recovery](http://www.meningitis.org/recovery).

The event was sponsored by the following organisations: Novartis Vaccines & Diagnostics, Dorset Orthopaedics, Ossur, Ottobock and RSL Steeper.

**Lynn Hirst - Specialist Prosthetics Physiotherapist Seacroft Hospital Leeds and Claire Wright - Medical Information Officer Meningitis Research Foundation**

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## **BACPAR West Midlands - An Introduction to Amputee Rehabilitation**

The Maltings, Wolverhampton 12 March 2013

When Louise Tisdale and I were deciding on a date for this year's study day we felt that holding it in March would be better than last time when we held it in January. The thinking being that the weather would be better; that worked then. It was a bitterly cold day although very sunny and it was touch and go whether the snow would return.

We were expecting 10 participants which was a low number compared to the last study day in 2011 when we squeezed 20 in and could have had more. It is just a sign of the times; very little movement in personnel and people having difficulty in taking time out of work. Eight of the expected ten people attended, so we were a nice select few which made for a more informal atmosphere.

The morning session was kicked off by Dr. Rajeev Singha, Associate Specialist in Rehabilitation Medicine who is the Medical Officer at Stoke Limb Fitting Centre. He gave an overview of amputee rehabilitation including complementary gory pictures and a comprehensive description of what to assess in a person who wishes to pursue prosthetic rehabilitation. Next up was me, who was in charge of explaining pre-prosthetic rehabilitation including live demonstrations of application and use of the Ppam aid and Femurett. A big thank you has to go to Dennis and Ray who kindly gave up most of their Tuesday to make the demonstrations real and being excellent interactive models.

Judy Moule, Counsellor at the Maltings, then gave comprehensive insight into the impact of amputation on a person and their families and how we can help people to overcome the difficulties which in turn help to improve the outcome of their rehabilitation.

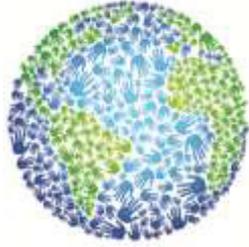
The last presentation of the morning was by the Maltings' Occupational Therapist, Sue Hayes. Sue gave a well explained description of the role of the Occupational Therapy during discharge planning and her role as the Centre O.T post discharge.

After quite a fully packed morning, lunch was very welcome. I certainly recommend Sainsbury's chocolate crispy cakes which had marshmallow in the middle.

The afternoon was taken up with Louise Tisdale and Rachel Neilson, Prosthetist explaining prosthetic rehabilitation including more live demos by Dennis and Ray. We were also made to think about certain gait deviations and to be able to recognise these gait deviations in our patients and be able to assess whether they are caused by imbalance of muscles and which muscles or prosthetic reasons.

Certificates were given out on return of a completed evaluation sheet. The evaluation of the day was that it was well received and gave good clear information which was useful to the participants and which they will be able to adopt into their practice. In fact one participant has contacted Louise requesting if he could spend more time with her to learn more, as amputee rehabilitation is an area where he would like to work in in the future; so the day inspired someone which is the best evaluation there is. The only major criticism was that the venue was a bit cold. Unfortunately the rooms did have floor to ceiling glass windows and as one participant commented 'it was freakishly cold weather'.

**Ruth Woodruff - Physiotherapist, Specialised Mobility Centre, Stoke-on-Trent**



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The easy-to-follow interactive teaching programme will remain with the communities after the physio has left, guiding them through anatomy, physiology, pathology, assessment, differential diagnosis and treatment. Other physios can then return and continue teaching where the last left off.



We are specifically looking for physiotherapists with a special interest in amputee rehabilitation as this is an area of priority to many NGOs. If you are interested in helping us write an amputee rehabilitation teaching programme, we would love to hear from you. You can contribute as much time as you feel comfortable, even an hour can make a real difference.

We are a non-political, non-religious and non-profit organisation aiming to empower individuals, their families and their communities, regardless of cast, colour, creed, religion, gender, age, type and cause of disability.

80% of disabled people live in developing countries and 62 countries have no rehabilitation. With your help, we can change this. Please get in touch.

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