

## MURRAY FOUNDATION CONFERENCE DAY IBROX STADIUM FRIDAY 28<sup>TH</sup> NOVEMBER

Open to all of those with limb loss, their carers and rehabilitation professionals, this one day conference boasts a comprehensive programme covering many aspects of amputee rehabilitation. There will be a number of presentations on Paediatric Rehabilitation, Phantom Limb Pain, up dates on new prosthetic technology and techniques and an open forum discussion on the way the prosthetic service is delivered in Scotland. More details of the conference are available inside this magazine.



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## PAEDIATRIC REHABILITATION

*It is important for those working in paediatric rehabilitation to remember that children are not just smaller versions of adults - the differences are more than just size and maturity. The physiological and psychological differences are considerable and the rehabilitation process needs to be altered accordingly to reflect this fact. This includes factors such as periods of rapid growth and development, an increased level of physical activity and the active involvement of the family. For this reason the team approach needs to be employed to ensure that every area of care is provided.*

### Upper Limb / Lower Limb Prosthetics

In their presentations, the two prosthetists will be looking at the reasons why children are prescribed, or not prescribed as the case may be, specific prosthetic devices. They will also give an overview of the prosthetic products for children with emphasis on limited range available.

**Mark Broomfield**, SR prosthetist and lecturer at the National for Prosthetics & Orthotics, has worked with children with upper limb loss/absence for over 15 years. He is a regular contributor to the REACH (The Association for Children with Hand or Arm Deficiency) publications and was instrumental in the setting up their web site.

**Alison Morton** is a SR prosthetist and has worked at both Belvidere LFC and now WestMARC for a number of years. Alison has been involved in the paediatric clinic at WestMARC since it began and will be drawing on her experiences of dealing with children of all ages.

### The Role of the Physiotherapist

It is often the case with children who have received artificial limbs that little or no physical therapy is offered; although with upper limb cases there will usually be significant input from the occupational therapist.

**Melissa Berry** is part of the paediatric team at the Selly Oak Hospital in the West Midlands who have recently been awarded the Limbless Association Prize for Best Rehabilitation Team. Melissa has worked extensively with children who have lost limbs as a result of meningitis and will be presenting the programme of therapy offered to these children.

### Emotional Impact on Family & Child

From an early age children with limb loss or absence can be aware of people's reaction to their appearance and as a result, these children can grow up with an awareness of being "different". It is also well recognised that the attitudes and behaviour of the family will affect how the child thinks about themselves and how they look. Because of the pivotal role that parents play within the rehabilitation process, their needs are as important as those of the child.

**Terry Daly** has been involved with the counselling & support services offered by the Foundation since 1996. He

is a lecturer in counselling at the University of Strathclyde, has his own private practice and is also the counselling co-ordinator for the Murray Foundation. From his work with the parents who are part of the MF Family Contact Group, he will be looking at how having a child with a limb loss or absence can impact on the rest of family and the emotional support that can be offered as they go through the necessary process of adjustment and change.

## PAIN

### Pain after Amputation

Many amputee's suffer from some degree of chronic pain, whether it is pain in the actual stump itself or some level of phantom pain or sensation. **Dr Bill Macrae**, a consultant anaesthetist at the pain clinic in Dundee, will be looking at the mechanism of pain i.e. how and why we feel pain and also looking at the possible causes of phantom pain & sensation and how it might be reduced or managed.

### Phantom Limbs - Diversity & Impact

**Dr Anne Whyte**, who is herself an amputee, has spent many years researching the possible causes and treatments for phantom pain and sensation. This presentation will look at the different ways in which individuals can experience this type of pain and also the impact it can have upon their lives. She will also be covering some of her recent work into the use of exercise to reduce the effects of this condition.

### Hypnotherapy - The whole issue of "not"

Hypnosis does not cure anything but it can be used to assist the subconscious mind to take on board any suggestions that are for the individuals' benefit, **without** the interference of the conscious mind. Some long-term pain can be controlled by hypnosis, which is obviously of great benefit as it allows clients to reduce their need for analgesics and thereby the side effects of the various pain relieving drugs. This in turn can boost both the morale and immune system, allowing the individual to enjoy a better quality of life.

**Dr Hetty MacKinnon** is a General Practitioner and a Registered Hypnotherapist, who regularly uses hypnotherapy in her practice. She will be looking at the role of the subconscious mind in accepting the loss of a limb and how this might be used to our advantage when considering the treatment of phantom pain & sensation.

## OPEN FORUM ON SERVICE PROVISION

*Representatives from different sectors of the amputee population in Scotland will be asked to talk for a few minutes and give details/opinions on a number of issues. It has been emphasized to the users how important it is not to focus too much on personal issues, such as non-provision of specific prosthetic components, but to try and look at the bigger picture.*

The representatives on the service providers panel will then be asked to respond to the issues and concerns raised (they will have been given prior notice about the main areas of concern) and also given the opportunity to ask the users what is important to them.

The ultimate goal of the open forum is to identify ways in which the service providers and the users might work together to improve the services offered. We are hoping that this part of the conference day will provide a lively and informative discussion, which will be useful for all concerned.

## TRANS FEMORAL (ABOVE KNEE) PROSTHETICS

*There are two presentations within this session, which will then be followed by a tea/coffee break and a small exhibition of the products/techniques discussed*

### Osseointegration - an up date

Osseointegration is a method by which the prosthesis is suspended directly onto the residual limb by means of an abutment, which in turn is surgically attached to the bone at the end of the stump.

Both **John Sullivan** (SR prosthetist) and **Maggie Uden** (Senior Physiotherapist) have been involved with the osseointegration study since it started at Roehampton over 5 years ago and to date, eleven patients having been assessed and entered onto the trial. This presentation is an opportunity to be up-dated on the assessment procedure, including candidate suitability, and also the prosthetic and physiotherapy intervention required at each stage of rehabilitation. The first person to enter the programme has now been using an osseointegrated prosthesis for over 5 years. This user will be attending the presentation to demonstrate the osseointegrated device and also to answer any questions you may have about his experience. There will also be an opportunity to discuss the future prospects for osseointegration and how it maybe applied to other amputation levels.

### Otto Bock C-Leg

The C-Leg is one of a number of microprocessor controlled prosthetic knees and readjusts to both different walking speeds and uneven terrain to produce a more natural and efficient gait.

**John Mortimer**, SR Prosthetist and Education & Training Manager for Otto Bock UK, has worked with the C-Leg for a number of years now. During the course of his presentation he will be demonstrating, with a double (A/K & B/K) amputee, the features of the C-Leg and also discussing how the prosthesis can be set to fit the individual's optimal gait pattern. He will also detail how the user themselves is trained and observed while walking on both level and uneven terrain, and how a 2nd set of settings can be used for a



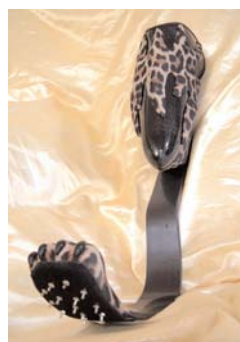
different activity. John will look at how to assess individual users suitability for this type of device and discuss the situations where it might be considered inappropriate to prescribe this type of component.

## TRANS TIBIAL (BELOW KNEE) PROSTHETICS

*There are two presentations within this session, which will then be followed by a tea/coffee break and a small exhibition of the products/techniques discussed*

### Flex Foot up-date

Flex Foot was first introduced in the USA and is one of a number of "Dynamic Response" feet available in lower limb prosthetics. Each step you take starts with heel strike and so the heel motion is the lifeline of a natural gait i.e. a smooth, flowing movement of the limb over the foot without having to "push" or feel as if you are



climbing up hill with each step. With a dynamic response foot, the effort or force put into the heel strike is then returned to help you over the foot and then to push off with the toe.

There are now a number of different flex foot products available ranging from the original "Flex-Foot" through to those designed for special activities such as sports.

**Richard Hirons**, SR Prosthetist with Ossur UK, will be taking you through the various products and outlining their features and suitability for particular users. He will also demonstrate some of the products discussed with the help of a user.



### Special Activity Limbs

Artificial limbs that can be used for recreational or special activities have been available for some time. One such limb is a Water Activity Limb (WAL) for which there are a great number of requests.

As a SR Prosthetist with Chas Blatchfords, **Richard Niveen** was recently involved in a study to identify the criteria for prescribing such limbs and also to recommend the best practices and procedures that should be involved. Richard's presentations will look at some of the findings of this study and the implications for the future prescribing of such limbs. He will also look at the prescription guidelines and availability of other special activity limbs.

## BRITISH AMPUTEE GOLF OPEN 2003 WESTERWOOD, SCOTLAND

Donnie McDiarmid

*This year's tournament attracted the largest field ever with 75 amputee golfers registering from all over the U.K. Germany, Denmark, South Africa, Republic of Ireland, Tasmania & Australia. The fact that this Championship was being held in Scotland (the home of golf) for the first time, helped account for the high numbers.*



The weather held out well and the support from the Hotel and our sponsors was overwhelming. The event started on 26th with a practice day, 27th was sponsors and guests day and 28th 29th and 30th were the three days of the championship proper.

As the championship was over a full week, a number of competitors brought their families along. Outings were arranged for them to the Trossachs, the Falkirk Wheel, Edinburgh, Glasgow and Stirling. Entertainment was also arranged in the evenings. Tuesday was The Scottish Trio. On Wednesday, Sponsors day, the Kilsyth Thistle Pipe Band marched over the 1st tee after the last 4-ball team finished and in the evening prizes were presented by our own Susan Shaw (Murray Foundation Director). Wednesday evening's entertainment was a full Scottish floorshow, consisting of highland dancers, sword dancers, fiddlers, a piper, a Ceilidh band and a dram. A Civic Reception was held on Thursday night, followed by a wonderful firework display. Friday night was more Scottish entertainment and the Saturday Gala and prize-giving Night was a Glen Miller style band.

The Gala night prize giving was the grand finale with prizes being well scattered about the globe for category winners. I am happy to report that the Champion is from the U.K. and is:

**Duncan Hamilton Martin**  
**British Amputee Open Champion 2003.**

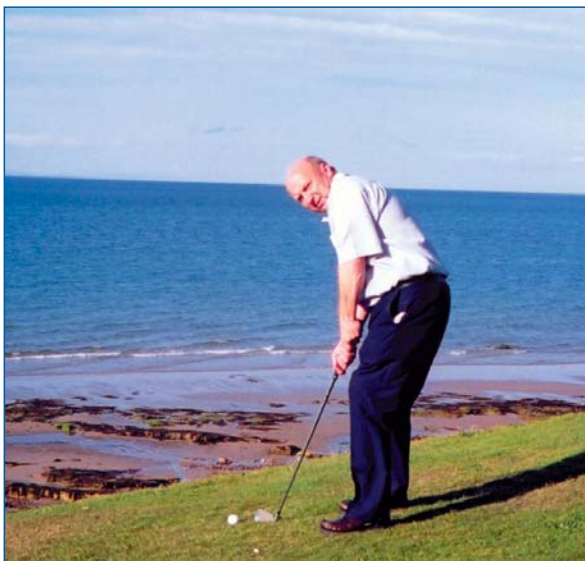
Gross (par 72)	1st round 81	2nd round 73	3rd round 74	Total	228
Net	78	70	71	Total	219

The feed back on the tournament has been fantastic with cards, letters and e-mails using words such as "first class", "brilliant", "fantastic", "well done", and "best week ever". This certainly gives us encouragement for any future event. The Americans, South Africans and Australians went on to play the Canadian and the American Amputee Open.

These guys are fortunate enough to have individual sponsorship and in some cases receive grants from their Government.

Australia will be holding their Inaugural Open Championship in March 2004 and commented that if their Championship was half as good as Westerwood they would be delighted. Hopefully I will be able to attend the Australian Open. At the moment I am halfway there with sponsorship for my entry fee and accommodation.

Summing up, I was talking to a chap from South Africa who is blind and he said to me "Donnie since a small boy I have travelled with my father to golf tournaments all over the world and this one at Westerwood has been the most professional and best ever." I asked him (as he is blind) "How do you know Peter"? His comment was "It just feels good". That really summed up the tournament for me. Thanks Peter.



Donnie McDiarmid  
Tournament Director  
MF Hospital Visitor

## SARCOMA STUDY DAY

Dawn Currie

*In August of this year Susan Shaw and Marjorie Dodds of the Murray Foundation were invited along to a study day on Sarcomas at the Western Infirmary, Glasgow. We were invited to exhibit our stand, which highlights the work of the Foundation, and take part in the day itself. It was a very informative session and we asked Dawn Currie the Sarcoma Clinical Nurse Specialist, who was instrumental in organising the day, to write a short report for Foundations.*

As part of my role as Sarcoma Clinical Nurse Specialist is to educate other professionals, I felt it was important to have a study day on sarcomas, particularly as there had never been one before. Also, bone and soft tissues are very rare cancers accounting for less than 1% of all malignancies and I hoped the day would increase awareness of them.

The morning session provided a broad overview of sarcomas and their treatment, both surgical and non-surgical. The afternoon session concentrated on pain control and also care of adolescents. I included these topics as I felt they were both important to the care of sarcomas.

With pain control, I know from my own experience that surgical and oncology pain control can be two different

entities - doses of opioids are usually smaller in surgical patients than in oncology patients and I felt it was important to highlight the importance of effectively controlling cancer pain and how one type of analgesia can be converted to another.

I also included a couple of talks specifically addressing the needs of adolescents. As certain types of sarcomas are more common in the children and young adult age group, I felt it would be beneficial to have these talks as most health professionals have had experience of looking after adolescents and it is generally acknowledged that most staff find this group difficult to look after as they are neither adult or child. Sue Morgan, Macmillan Nurse Specialist for Teenagers and Young Adults in Leeds gave a fantastic talk about the award winning Adolescent Unit in St James University Hospital, Leeds and made looking after adolescents sound easy! Shona Robertson (Sargent Social Worker for Young People) and Dr Susie Porteous (Clinical Psychologist) gave an interesting talk about psychosocial needs of adolescents, focusing first on normal adolescence and then on adolescents affected by cancer.

The whole day was evaluated well by all the delegates and it is hoped to hold another one next year.

## PHANTOM LIMB AND WHEELCHAIRS - ASSESSMENT & SUPPLY FACT SHEETS

### PHANTOM LIMB

This fact sheet was compiled in response to requests from both amputees and rehabilitation staff, to offer reassurances to those experiencing the symptoms. It gives a brief and simple explanation as to why phantom sensation may occur, how it may feel, what might trigger it and also some alternative treatment options. We are also currently working on more detailed fact sheet in this area, for those who may wish to know a little more about the underlying neurology of the condition.

### WHEELCHAIRS - ASSESSMENT & SUPPLY

Since the Foundation began in 1996, support, information and activities have been focused very much on those amputee's who have been limb fitted. However, nearly 50% of all patients who undergo an amputation are **NOT** limb fitted and while these patients are rehabilitated to lead an independent life in a wheelchair, very little information or support is offered to them. Over the course of 2002 the Foundation began to look at the procedures for wheelchair supply, with a view to providing guidelines/information on how to achieve the best result. The resulting document has now been distributed throughout Scotland and has proved extremely useful for those wanting to source their wheelchair from out with the NHS.

**IF YOU WOULD LIKE COPIES OF THE ABOVE FACT SHEETS  
PLEASE CONTACT THE FOUNDATION OFFICE 0141 580 8564**

## CHANGES IN PROVISION AT THE PROSTHETIC CENTRES ACROSS SCOTLAND

David Gow

*The previous situation of the prosthetic services being provided to the NHS by a private company has changed in some centres across Scotland over the past few years. The services have been taken "in-house" i.e. within the NHS, in the Aberdeen and Dundee Centres, while Inverness and Glasgow centres remain with the private contractor. Now the Centre in Edinburgh is experiencing the change to "in house" and the following report by the Director of Rehabilitation Services, David Gow, outlines the process.*

### EDINBURGH PROSTHETIC SERVICES

The prosthetic service currently provided by RSL/Steeper Ltd at the Eastern General Hospital in Edinburgh transfers to the National Health Service on 1st October 2003. All staff will transfer to Lothian Primary Care Trust and work within the existing Rehabilitation Engineering Services.

This will bring to an end many years of service from RSL/Steeper in Edinburgh but David Gow, Director of Rehabilitation Engineering Services believes it will set the tone for the future development of the service both locally and in Scotland as a whole.

"Competitive tendering for clinical services such as these is wholly inappropriate", said Gow. "No-one wants to see highly skilled staff have their services bought and sold like this. All it does is create staff anxiety and I believe disadvantages the service in that it is seen as a commodity. As a centre we have a track record of user involvement. Not only did we have the first prosthetic user group in Scotland, but were the only centre to invite user representation on the last tender evaluation panel in 1998".

"Before embarking on this in-house move we conducted a patient survey in the Edinburgh centre and the results confirmed our decision to move the service in-house. If nothing else we will be able to spend all the service budget

on the patients and will attempt to improve the service by investing in it, in a way not possible under the previous set up."

"I acknowledge the many years of prosthetic provision given by firstly, Hugh Steeper Ltd and then latterly by RSL/Steeper Ltd. Their contribution and professionalism over the years is a credit to them. The in-house service move is, however, I believe the way forward for Scottish prosthetics as is evidenced by the fact that Aberdeen, Dundee and now Edinburgh have made this move"

RES is due to merge with its sister services in the Mobility Centre at Astley Ainslie in 2005, forming what will be known as **S**outheast **M**obility **A**nd **R**ehabilitation **T**echnology services. A new centre similar to Westmarc in Glasgow is well on the way to commencing construction around March 2004. This will bring Wheelchairs, Prosthetics, Driving Assessment, Disabled Living Centre and other Rehabilitation Technology Services together under the same roof and management for the first time. One of the features of the new building will be the inclusion of a user resource room to allow user groups to operate from the centre and utilise its resources to help make the services provided more patient centred.

### WESTMARC GLASGOW

The current situation at the Glasgow Centre was explained by Roderick Ross the Prosthetics/Orthotics Manager:

"Thank you for asking me to provide an update on the current position regarding the method of providing the prosthetic service. As you are aware the current contract with RSL Steeper expires at the end of September. To date the Trust has agreed to extend the current contract. The length of the extension is subject to negotiations with RSL Steeper, which we hope to have approved by the Trust in the near future. I hope to be in a position by the publication of the next 'Foundations' to provide the readers with more complete information."

## MURRAY FOUNDATION COMPLEMENTARY THERAPY DAY SATURDAY 18TH OCTOBER 2003



### IT IS WITH REGRET THAT WE ANNOUNCE THE **CANCELLATION** OF THIS EVENT.

*The required number of applications to enable us to proceed with the arrangements for the Complementary Therapy Day have not been forthcoming. This is not a cost issue since the day is heavily subsidised by the Murray Foundation but we do require a certain level of support to make the event viable.*

***This we have unfortunately not received.***

## THE GREAT SCOTTISH RUN

Wallace Currie

It was during an Executive meeting of the Murray Foundation that I first decided to take part in the Great Scottish Run. At the meeting there was a discussion on ideas to raise money to help fund social events. In a moment of madness I volunteered my services - "I've got an idea, I'll compete in the Great Scottish Run." Everyone thought it was a great idea and from that moment on there was no turning back!

I used to be a long distance runner before my accident and amputation. I've done it all before, so it was going to be relatively easy. I would just ease myself back in, it would be a dawdle. Wrong! I will not bore you with the details but let's just say it wasn't as easy as I first thought, not only had I lost a leg but I was eleven years older and I think the latter was more debilitating than the amputation.

I started the long 'road' to getting fit enough to complete 13 miles with three mile training runs, building up to six and then eight miles. I didn't do any further than 8 miles although maybe I should have. In between my road runs I would visit my local gym, sticking mostly to cardiovascular stuff e.g. an hour on the treadmill and exercise bike, and I would visit my local swimming pool because I think swimming is an excellent way to exercise (you use all your muscles without putting any weight on the limbs) - a great way for any amputee to exercise.

After getting myself reasonably fit I took part in a couple of 10k road races organised by the Kilmarnock Harriers as part of my build up to the half marathon. One was in May and the other in August and both of them were over very hilly courses. The August 10k was my final push before the big event on September 7th. Everything was going fine until I came to the final run in. At about a quarter of a mile from the finish a bunch of young lads were standing all wanting to do 'high fives'. Well I joined in the fun all along the line but when I got to the last one I tripped over my prosthetic foot and landed spread eagle on the cycle track I was running on! My hands, arm and shoulder were shredded and my suspension sleeve was damaged - sorry Rhona, but I wasn't going to stop just a quarter of a mile from the end so I stumbled tired and bleeding to the finishing line. What a hero - I think some would say what a mug! As this was only 11 days from the Great Scottish Run all sorts of things were going through my mind. Would I be O.K. for the half marathon? Luckily I am a quick healer and everything was all right, but if I learned one thing from this it was to leave the 'high fives' until after you finish!

**Sunday September 7th** - my big day had arrived. It started very early, as I had to get up at 6am to get to the High Street car park to be sure of a parking space.

**10.15am** - the muster time before the start. For anyone who is not familiar with the event, the elite runners start at the front and then the rest of us take our places at the time marker for our estimated finishing time. There was a buzz of excitement and expectation around with most people running to raise money for various charities. It is their big day too!

**10.30am** - we are off and running. This for everyone was the end of the training; this was what we had been building up to. This was the real thing.

The weather and conditions were first class, as was the route. If it wasn't for the fact that we were running a half marathon we could have taken in the wonderful scenery around us. We started at the Gallowgate and ran through such beautiful places as Bellahouston and Pollock Parks.

**Position 5798**  
**Time 2.44.07**



I decided that I would wear my sensible head and start out reasonably slowly, maybe easing past some runners and then, if I had anything left in the closing miles, I'd go for it. What a joke! The further the race went the harder it seemed to get, in fact in the latter stages the miles seemed to be getting longer. You try to think of anything to keep your mind off the race. One of the things that my mind wandered to at about three miles from the end was a pub I was passing that offered a three-course lunch for £3.80, if anyone from Glasgow knows the pub I mean, I'd be very grateful if they would point me in the right direction!

The last mile seemed like six. Then there it was the Finish! All the training I had done now seemed worthwhile even although I was very tired and sore. Well everything was sore except my stump; my Tec prosthesis had done an excellent job.

I would like to thank a couple of people if I may. Rhona Wilkie from Otto Bock who produced the Tec and Kevin Murray my prosthetist from WestMARC who tried everything possible over a number of years to find a leg that I could run on. Without these two people all of this would not be possible. I would also like to thank all of my friends in the amputee support groups who sponsored me. Raising money is not just done by one person, it is a joint effort. Thank you all.

*If you have an article  
for FOUNDATIONS,  
please contact:*

Marjorie Dodds,  
The Murray Foundation,  
Argyle House,  
Ibrox Stadium,  
Glasgow G51 2XD,  
Tel: 0141 580 8564

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## Amputee Support Groups

<b>ALF</b> Fife	Gillian Cosgrove	01383 726135
<b>AYR</b> Ayrshire	Archie Bennie	01294 215208
<b>DUNDEE</b> Tayside	Iain Spence	01828 650677
<b>ELGIN</b> Elgin & Morray	John Barclay	01343 820899
<b>HISAG</b> Highlands & Islands	Anne Driver	01463 793584
<b>IN STEP</b> Falkirk & Forth Valley	Donnie McDiarmid	01786 824282
<b>LAWSTEP</b> Lanark	John McNeil	01555 770730
<b>LOONS</b> Aberdeen & North East	Dave Macdonald	01224 644749
<b>PAGE</b> Glasgow (Central & East)	Norman McCallum	01236 873459
<b>PUSH</b> Edinburgh	David Wraight	0131 258 9555
<b>RAMP</b> Inverclyde	Agnes Lang	01475 742723
<b>SCAFFOLD</b> Glasgow (North East)	Jim Caldwell	01236 601970
<b>SWAGGER</b> Glasgow (South West)	Johan Graham	01389 730012
<b>TULIP</b> Glasgow (North West)	David Lang	0141 576 0565

RETURNED COPIES: Murray Foundation, 2nd Floor, Argyle House, Ibrox Stadium, Glasgow. G51 2XD,  
T: **0141 580 8564** F: **0141 427 7241**

Email: [info@murray-foundation.org.uk](mailto:info@murray-foundation.org.uk) [www.murray-foundation.org.uk](http://www.murray-foundation.org.uk)