Re-imagining Rehabilitation for Survivors of Brain and Spinal Injury

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“You may have to operate out of your own comfort zone and will learn from doing so.”
Winston Churchill Memorial Trust website

This was way out of my comfort zone!

Would someone like me find within himself the courage to travel abroad alone for several weeks, meeting perfect strangers in unfamiliar places, returning with the confidence to inspire and influence others?

Thanks to my Churchill Fellowship changing me,
the answer was yes.

Winston Churchill Fellowship in 50 Words
by Andy Golightly

Re-imagining Rehabilitation for Survivors of Brain and Spinal Injury
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www.wcmt.org.uk

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BACKGROUND

My background includes working as a primary school teacher, community relations advisor for Manchester Airport and travel trainer for people with brain injury, before spending the last seven years as fundraiser at BASIC, the Brain And Spinal Injury Centre in Salford.

When Derek Gaskell brought his wife, Dorothy, home after life saving brain surgery at Hope Hospital, Salford, she was unable to do anything for herself. She could not walk or talk and suffered a deep depression. After many years she recovered but the unexpected horror of this experience prompted Derek to establish ‘Neurosurgical Research’ in 1986, now called BASIC. Our mission is to support when medical treatment has ended and families are left to cope largely on their own with the consequence of brain injury in the family.

The story of BASIC is one of inspiration, sheer hard work and grim determination to meet glaring gaps in the provision of neuro-rehabilitation. It is also the story of 28 years of innovation, of pushing back the boundaries of established rehabilitation practice.

Large gaps in provision exist for physical and cognitive rehabilitation for people with neurological conditions. Neurological rehabilitation in the UK remains patchy, inequitable and under-resourced according to Government reports such as “Access to Rehabilitation ‘A Life More Ordinary’, Findings from the Long-Term Neurological Conditions Research Initiative”, March 2012, The National Stroke Strategy (2009) and the National Service Framework for Long Term Neurological Conditions (Dept. of Health 2005).

Research shows that Virtual Reality (VR) has great potential in speeding up brain injury rehabilitation, reducing the impact of brain damage. BASIC has ordered a Computer Assisted Rehabilitation Environment, or CAREN VR system for Spring 2015 to help our 700 brain-injured clients. This innovative technology enables the patient to practice real life situations in a safe and controlled environment.

Captain Pauline Godsell, Rehabilitation Physiotherapy Coordinator, Canadian Forces: “The CAREN system (pictured above) is an amalgamation of virtual reality and robotic systems designed to create an immersive and flexible rehabilitation environment; challenging patients harnessed into a safe simulation of worldly challenges and hazards.

“The CAREN utilizes a complex combination of elements including a moveable platform, an instrumented treadmill incorporating force plates, full motion capture, a virtual reality screen, advanced sound system, external sensors and advanced software. Room-sized 3D graphics, a platform that moves with the person as they explore the 3D world, a dual-treat remote controlled treadmill and world-class motion analysis technology sums up CAREN.

“ Its use has been researched in lower limb amputation, mild traumatic brain injury and neurorehab clients to name a few. It has the potential to be used in pain management, anxiety disorders and PTSD. It is both a clinical and research tool, offering the analysis of motion and the flexibility of increasing the complexity of tasks through combining physical challenges, mental effort and visual or auditory stimuli.”

The CAREN at BASIC would be the first in the UK to be located in a community rehabilitation setting, continuing our proud history of innovative community neuro-rehabilitation.
FELLOWSHIP AIMS & ITINERARY

• To gain first hand knowledge of piloting VR in the UK by visiting those already using CAREN in a clinical rehabilitation setting. The experience of staff and patients over there would be invaluable in helping BASIC set up a highly efficient, successful and effective therapy for our clients here in the UK.

• To gain a clear understanding of staffing skills required, measuring and evidencing patient progress, marketing to potential funders, business models used abroad and exploring opportunities for generating additional income.

• To look at how CAREN is used abroad by the army with amputees, a group that may benefit in the UK.

8-9 Sept  Chicago, USA: closest city to Lansing (see below) served by a direct flight from Manchester.
10-12 Sept  Lansing, USA: Brain Injury Association of Michigan two-day conference.
13-19 Sept  Ottawa, Canada: visiting CAREN at The Ottawa Hospital Rehabilitation Centre.
20-22 Sept  The Canadian: a cross-Canada train from Ottawa to Edmonton via Toronto, a time for restoration and reflection.
23-28 Sept  Edmonton, Canada: visiting CAREN at the Courage in Motion Centre at Glenrose Rehabilitation Hospital.
29-7 Oct  Pittsburgh, USA: visiting CAREN at the Human Engineering Research Laboratory
8-14 Oct  Washington DC, USA: visiting CAREN installations at Walter Reed National Military Medical Center.
17-23 Oct  New York, USA: visiting CAREN at the Dynamic Neuromuscular Rehabilitation Center.

I was very excited and felt extremely lucky at this amazing opportunity to travel and learn. Having never been abroad on my own before, I did feel a bit nervous and as a bit of a home-bird, this trip was way outside my comfort zone, but that’s an important aspect of a Churchill Fellowship: “Travel to learn, return to inspire.” It is as much about learning about oneself in unfamiliar circumstances as anything else. It was safe to say that as a wheelchair user, I would literally be pushing myself to the limit!
After a couple of days in Chicago to recover from jetlag, I took an Amtrak east to Lansing, state capital of Michigan and home to the largest brain injury rehabilitation conference in N America. It provides state-of-the-art information about brain injury treatment and therapies. Into its 34th year, this was an event I was looking forward to as it brought together top speakers, over 300 rehabilitation service providers and 1500 attendees, many of whom were surviving brain injury.

BIAMI tirelessly campaign for the rights of people surviving brain injury and are a force to be reckoned with at legislative level. The first thing I learnt was that people in BIAMI didn’t say, “I am a survivor of brain injury,” they preferred to say, “I am surviving brain injury”, emphasising the fact that it was very much an ongoing process throughout their life.

I heard so many inspirational speakers, like Lee Woodruff, wife of journalist husband Bob who was brain injured whilst reporting in Iraq. Her talk In an Instant emphasised how Bob’s injury had affected the whole family and that hope had to be allowed to be a key ingredient in such a horrendous situation. She now works tirelessly with Bob in raising the awareness of brain injury to the same level as breast cancer awareness at a national level in the US. As she says, “We are going to do it!”

Another excellent session was Meet Me Where I Am: Working with TBI Veterans by Michael J Bruns, a veteran himself. He talked about Moral Injury as a kind of brain injury and how this can have a devastating effect on a soldier’s ability to adapt to civilian life.

Having spoken with a number of attendees and rehabilitation providers at the conference, it seemed that in the USA, if you were not insured you did not receive rehabilitation. I could not help thinking: what happens to those that can’t pay? It made me feel very proud of BASIC, that with a relatively small budget, a small workforce and a group of dedicated volunteers, we offered largely free of charge rehabilitation that was literally a lifesaver for many.

Other sessions attended over the two days included:

*Brain Injury: an introduction by Mary Jo Hall, Special Tree Rehabilitation System.
*Care for Yourself, Too: Journaling for Family Caregivers by Barbara Stahura, Journal Facilitator.
*Aquatic Therapy: Beyond the Pool by Chad Boprie, Hope Network Rehabilitation Service.
*Love Your Brain by Kevin & Adam Pearce, ex-US Olympic snowboarders.
*When You Can’t "Just Get Over It" by Barbara Barton, Western Michigan University.
*Emotional Changes Following Brain Injury by Stephen Vangel, Rehabilitation Institute of Michigan.
*Michigan Sports Concussion Law Resources and Update by Laura Rowen, Michigan Department of Community Health and Michael F Dabbs, BIAMI.
At lunch one day, I met Laura who worked in upstate Michigan in a small Native American community of 500 people. As a Native American herself and surviving a traumatic brain injury (TBI), she started a vocational project for people with TBI, many of whom had no health insurance. I was lucky to hear many interesting speakers at the conference, but this person working alone in an isolated community was truly inspirational, refusing to allow lack of funding and open opposition to her work deter her from helping those that had no where else to go. Humbling.

It had been a week of getting used to travelling around by myself on planes, trains and automobiles, of finding places with addresses comprising lots of numbers and of acclimatising to life in two different countries. So much seen and learnt and not just about brain injury, but also about myself and how I could cope with travelling independently. I was beginning to relish this whole wonderful opportunity! The next part of the trip would be largely spent at The Ottawa Hospital Rehabilitation Centre, home to a computer Assisted Rehabilitation Environment, or CAREN for short. It would be when Andy met CAREN for the first time on my Churchill Fellowship.

The Ottawa Hospital Rehabilitation Centre (TOHRC), Ottawa 15-19 September

My hosts for the week were Patricia O’Neill, Research Engineer and Courtney Bridgewater, CAREN Operator. Sean Gehring at TOHRC was also instrumental in organising my visit but was out of the country on a scholarship during the week I was there.

The Ottawa Hospital is a very large medical complex with over 10,000 employees, including 400 that work at TOHRC. Facilities include a cancer centre, a large children's hospital, and there were close ties with the University of Ottawa, which was very useful for research and expertise purposes, for example, computer programming for CAREN.

The CAREN was paid for by Canadian Forces and the hospital paid for building renovations to house the CAREN in the Virtual Reality Lab. Time allocation is generally a 60:40 split in favour of the hospital and the military tend to book chunks of time for bursts of rehabilitation or research. The hospital pay for CAREN staff but the military send their own physiotherapist with personnel. Any issues with maintenance have to be sanctioned by Canadian Forces as the equipment technically belongs to them.

CAREN installation

There were several problems with installation and TOHRC staff say it would have helped if someone had been in overall charge of the project with a clear understanding of the CAREN from inception through installation to completion. The pit in which the CAREN sits needed to be bigger than minimum specification to accommodate full movement of the platform mechanism. Also, ceiling clearance needs to be such that the projector gantry can be correctly positioned. Existing pipework meant this did not happen and a further investment of an extra projector was needed because the three supplied could not be positioned correctly due to pipework. The CAREN at BASIC has three cameras and given the ceiling height, this should be enough.

Re-imagining Rehabilitation for Survivors of Brain and Spinal Injury
Installation began in December 2010 with the first patients using CAREN in May 2011. There were numerous glitches with software and hardware, e.g. positioning of projectors. The overall message for BASIC was: take it one day at a time because it will not go smoothly at first. CAREN operator Courtney Bridgewater was hired as installation began and this was essential as she could get to know the system as it was being configured. There were also serious problems with the treadmill belt and in the first three years, it had to be replaced four times. The CAREN was not completely glitch-free for 12-18 months.

**CAREN Operator, Courtney Bridgewater**

Courtney has a Bachelor in Aerospace Engineering, a Masters in Kinaesthiology, has done research into sensory motion science and has a sports background. Her engineering and software expertise meant she was capable of carrying out tweaks and repairs to the physical machinery.

She regularly liaised with medical staff to ensure patients had appropriate therapy sessions, but also to ask what the therapist needed from the CAREN in terms of performance. She then developed software that delivered a tailored therapy session that met physiotherapy goals for a patient. Motek could provide the starter applications that have one or two variables for a physiotherapist, but to develop individualised applications, a programmer was needed.

Courtney thought the operator had to be good at psychology and reading patients, because, for example, a fear of the platform/dark could hamper therapy progress on the CAREN.

Schedules of patients on the CAREN were organised by Courtney and all staff involved could see the calendar online. She worked full time, 8.30 to 4.30, Monday to Friday, and needed time to sort out inevitable computer and engineering glitches in the system as and when they happened.

Two other staff were trained as operators to allow Courtney time off, but they did not have Courtney’s experience or technical background to correct the same range of glitches.

**CAREN use**

Initially, an hour was given to each patient, including the fitting of safety harnesses, but it was felt that 4/5 patients per day at 45 mins each gave Courtney a better space between patients. A patient would use multiple treatment programs (applications) in their 45-minute session, depending on the rehabilitation goals set by the physiotherapist and a common use of CAREN was for balance re-training. Patient fatigue is a big factor that could affect sessions, but it could also affect choice of transport to/from a session (tired patient unable to drive home) and time of day for a session.

If the patient used a wheelchair it was with a static treadmill, as it was felt too dangerous to allow someone to push on the treadmill during a session (contrast this with the work at HERL in Pittsburgh – see later chapter in report). It is possible that in the future, a set of rollers would be developed for a wheelchair on the CAREN in conjunction with an application.

The computers to operate the CAREN had no connection to the internet to avoid viral infections. Every modification to an application was fed into the system only after the datastick had been thoroughly cleansed of viruses.
TOHRC staff & the CAREN

Sandy MacLeod, Physiotherapy Lead, said, “Patients using CAREN have some trunk control. It is used episodically to increase the challenge for patients when needed. It’s chosen as a specific intervention, not because all else has failed. It’s an adjunct, part of the whole gamut of therapies we offer. It doesn’t suit some patients and depends on their ability to cope with dark, noise, heights, visual perception, cognitive overload.

“The physio must balance the time spent taking the patient down to the VR Lab with time that could be spent in a traditional physio setting, ie. is it worth it? There’s also a question of time cost, a physio being around $120 per hour and discussions around the subject of charging for certain patients are beginning to happen.

“CAREN is very engaging for patients and I believe the next step in developing the service will be offering Virtual Reality to children from the adjoining children’s hospital.”

Janine Szarbo, Occupational Therapy Lead, firmly supported the CAREN: “I believe the CAREN is good for developing fine motor skills and technology is very motivational for all ages. From an OT perspective, CAREN can be developed to recreate real life situations, for example, a kitchen, and would be good for hazard awareness in traumatic brain injury patients before they go home. Another possible application is a driving simulator to be used by the driving rehabilitation staff.”

Ed Lemaire, Head of Research, felt a background in biomechanics was essential for the CAREN operator role but not necessarily a programmer, as programming could be done by using students. Wheelchair research using the CAREN was a possible future development, especially in identifying the right chair and specification for a user.

Dorothyann Curran, Research Coordinator, approves CAREN research approaches after consulting with Courtney and other staff and takes into consideration the impact on patients, staff and resources at TOHRC. She also decides whether the research is valid and any costs to be charged to the researcher.

“Research usually involves university students but sometimes it is the military and involves ex-patients, but not always. Commercial research can demand fees of $500 per hour. The existing relationship with Ottawa University means they get a better rate.”

Emily, Research Projects, showed how motion capture on the CAREN using the sensors enabled data to be collected and processed. She emphasised that it is critical for researchers to ask the right question and also that the operator had motion capture experience.

Kerrie Ritchie, Psychologist, explained that VR trauma therapy was being planned on the CAREN and her role would be responsibility for the welfare of hospital staff, including Courtney, as prolonged exposure to disturbing images could be damaging to staff.

“Overcoming anxiety and phobias using the CAREN is something we are about to offer patients as a graded exposure. Examples include a virtual supermarket and city centre for people anxious about crowds. EMDR could also be offered using the CAREN.”
During my week in Ottawa, I was invited to observe patients using CAREN.

TOHRC Case Study One:

Stroke survivor Amy, a 72-yr old female inpatient, had right side weakness and Guillain Barre Syndrome (GBS), a viral attack on the nervous system that takes away movement, sensation and strength. This was her second session on CAREN to work on her walking.

Amy arrived in a wheelchair and was helped to her feet by a physiotherapist, Ashley. Courtney attached the safety harness and Amy walked onto the CAREN and asked to use the detachable sidebars for stability. At numerous points in the 45-minute session, Courtney asked Amy if she was ok, gave plenty of encouragement and conversed with Ashley to check the work going on.

“I liked the CAREN from the start with patients that had a high level of physical ability, but had doubts as to its effectiveness with low ability patients” said Ashley, “BUT results with patients of low ability and low motivation, particularly large tall men where physio opportunities in a gym with a petite therapist are limited, have been amazing and those patients love it!”

Amy worked on a number of applications, including:

- **STEER THE BOAT** - adjusting her feet position to steer and alter the virtual boat’s speed.
- **FOREST WALK** - walking on the moving treadmill along the virtual forest path. She took a rest after 8 mins of walking and couldn't believe what she had achieved and was on a real high!
- **PADDLE BOARD** - balancing on a virtual board in the virtual water. Instant performance feedback provided by the force plates under the treadmill meant Ashley could see that Amy was standing too much on her left foot.
- **MAZE** - steering a ball through a maze by altering the weight from one foot to the other. The % of use for each foot was displayed at the bottom of the screen and clearly illustrated Amy’s right side weakness, so was asked to increase the right side %.
- **CHRISTMAS TREE** - moving a virtual Christmas tree from side to side by altering weight from one foot to the other to capture falling decorations.

This was 45 minutes pretty much non-stop activity and Amy was very tired, but commented: "That was good, eh. Awesome! I couldn’t do that stuff before. I didn’t realise what I could do until I came on the CAREN."

TOHRC Case Study Two:

Mark, a male from Canadian Forces in his late 20’s. He was a single amputee below his left knee after being wounded in action four years ago and used a prosthetic. He was about to finish traditional rehabilitation at TOHRC when CAREN was offered as a greater challenge. Successful therapy using CAREN largely depends on personal goals set by patients and Mark was clearly very motivated and always aimed to push himself to his physical limits. This session was one of a series over a week for Mark, a burst of VR rehabilitation during a military block booking.
Applications worked on included:

- **STANDING and BALANCE EXERCISE** - legs side by side with physio calling out instructions, e.g. tandem stance (one foot behind the other) whilst the platform shifted position. Exercises done with eyes open, then repeated with closed eyes to increase challenge.

- **WALK THROUGH FIELD ON PATH** - sudden fast jerky platform movements forced Mark into making adjustments to his walking, the parameters of the jerks being chosen by the physiotherapist. Surprising how quickly the platform can move and it really threw Mark around!

- **WALKING WITH BLANK SCREEN IN THE DARK** - quick walking with tilting platform in all degrees of movement, again throwing Mark around to really challenge him. The physiotherapist and operator tried to throw him off balance with steep 15-degree tilts.

- **STEERING CAR** - Mark steered a car by adjusting weight from one foot to the other to avoid other cars, needing a great deal of agility.

Mark had clearly pushed himself and worked hard in his 45-minute session, his aim eventually being a return to active duty. “Sessions on the CAREN have been great for finding out what I can and can’t do with my prosthetic. Confidence-wise, it gives me a boost.”

**TOHRC Case Study Three:**

Canadian Forces member Bee Nielsen, a 30-year-old male, was injured on active duty in Afghanistan in 2010:

Sgt Bjarne ‘Bee’ Nielsen of the Royal Canadian Regiment was leading a foot patrol around an Afghan village looking for hidden bombs. He was mid-stride when they found one. The explosion blew him 17 metres, right over an eight-foot mud wall. He was still conscious but couldn’t move; he knew one arm and leg were useless. The bones of his left leg were still there and the boot was attached, “but all the flesh was stripped away.” His upper left arm bone was broken twice and his elbow destroyed.

If you meet him today, he has a quick smile, a firm handshake, and a desire to push ahead with difficult rehab. “There’re two ways you can do things. You can lie down and have everyone take care of you, or you can decide you’re going to take care of your own life. Just because I have a physical change, why does that limit me in what I have the potential to do? I plan on getting tired,” he said. “Life’s about work.”

_Ottawa Citizen, Friday 17 June 2011_

Bee’s rehabilitation included doing exercises to strengthen his trunk, extend his endurance, rediscover his centre of gravity (which shifted when one leg disappeared) and improve his balance. He was now looking forward to re-entering active service and sessions on the CAREN were designed to test his ability to use a prosthetic leg.

Applications worked on included:

- **FOREST WALK** - inclines, declines, varying speed to increase challenge.
- **WALKING WITH BLANK SCREEN IN THE DARK** - very steep walk downhill but keeping speed constant, then sudden jerks left/right, pitch forward/back.
STEER THE BOAT - this brought out the competitive side of Bee as he tried to beat his previous time. He was encouraged not to touch sidebars to increase the challenge.

THE BRIDGE - cross the bridge by walking with one foot in front of the other as a balance challenge (like walking a tightrope). Then walking backwards facing away from the screen, both exercises with added platform movements.

WALKING THROUGH FIELD ON PATH – platform pitched forwards to throw Bee off balance. Then an added cognitive ingredient: pictures of single training shoes randomly appearing at different positions on screen and Bee had to identify if it was a left or right shoe. This was to help distract him to overcome phantom pain and was part of a pain research programme designed to help rewire the brain. Cognitive ingredients like this are called flash cards and can be programmed in by the operator according to the therapist's needs.

CAREN offered unique opportunities to test Bee’s prosthetic in a safe secure environment. The applications were chosen to push Bee to the limit of his endurance

TOHRC Case Study Four:

Michelin, a 55 year-old lady, was unable to walk two months before due to disc problems. Conventional physiotherapy had helped her regain the ability to walk a few steps and stand unaided, but she still used a wheelchair.

The CAREN offered further challenge and improvements in walking, but only four sessions had been funded. Unless Michelin paid herself, the next session would be her last. This is a shame, as the physiotherapist would like to have continued to work on Michelin's confidence before the winter set in.

Courtney, the CAREN Operator, said, “Snow and ice are very common in Canada during winter and make walking outside difficult. The CAREN can help a patient practice compensating their walking for trips and slips that occur. The CAREN gives excellent physio opportunities in winter and all year round as it provides a safe environment to try things and push abilities.”

It was interesting to observe a number of very different patients during the week, each with different needs and from different spheres of life, but all with something in common: they were all highly motivated by CAREN and according to both the patient themselves and hospital staff, were making remarkable progress in their rehabilitation. It was also interesting to meet a range of hospital staff and learn of other services and therapies offered to patients:

• Patsy McNamara, Acquired Brain Injury Stream Lead, was able to provide information on the care pathway for those with a brain injury.
• Caryn Johnston, Therapeutic Recreation, organised activities designed to encourage an active lifestyle, eg. canoeing, climbing, cycling and gliding, in partnership with local organisations.
• Sherry Daigle, Ward A Locomotor Stream, dealt with acute care and the rehabilitation of amputees, a group that could benefit from the CAREN at BASIC. She was interested to hear about BASIC’s commitment to caregivers and felt this was an area in which they could develop their services.
• Serge Falardeau, Disability Awareness Coordinator, ensured the hospital met Ottawa Province’s aim of becoming fully accessible by 2025, including accommodating the needs of those with brain injury.
• David Nielan, Prosthetics and Orthotics Lead, demonstrated the whole process of creating an artificial limb and explained the difficulties faced by those requiring a prosthetic.
There were so many things I learnt about CAREN that week, including the fact that CAREN is used to complement traditional therapies, not replace as the be-all and end-all solution to therapeutic needs.

I also learnt why Sir Winston Churchill’s photograph was hanging in the corridor at TOHRC:
Canadian photographer Yousef Karsh was responsible for this famous portrait of Sir Winston Churchill. He donated this picture to Ottawa Hospital after they treated his wife. Thanks to the generosity of the Winston Churchill Memorial Trust, I could visit the fantastic place where this picture now hung.

The week came to a close and TOHRC’s Therapeutic Recreation department kindly arranged a gliding experience at a local club that encourages people with a disability to experience this unique pastime. Despite a fear of heights and my reluctance to let go of the sides of the cockpit seat, I did enjoy the flight and would definitely recommend the experience to anyone.

Rather than take the easier option of flying to Edmonton for my second CAREN visit at Glenrose Rehabilitation Hospital, I opted for a cross-Canada train journey that would take the best part of three days. With no wi-fi on board and confined to a sleeper cabin for the entire journey due to inaccessible rolling stock from the 1950’s (when “wheelchairs didn’t exist”, according to the VIA Rail Canada lady), I smiled and settled down for a time of reflection, writing and thinking.

Glenrose Rehabilitation Hospital, Edmonton
23-26 September

After reacquainting myself with fresh air and sunlight, it was straight from the station to Glenrose Rehabilitation Hospital in Edmonton. Jim Raso from their research department would be my host and, after meeting Jim, we headed straight to the CAREN.

Glenrose has 140 inpatient beds for children, adults and the elderly offering a wide range of rehabilitation services. Each year, it hosts thousands of outpatient appointments for the city of Edmonton and the wider province of Alberta. The CAREN is located in the Courage in Motion Centre, an area of Glenrose previously part of the car park. In a similar way to TOHRC, it was paid for by Canadian Forces and time was split between military and hospital use.

**CAREN installation**

The electrically driven platform installed at the start delivered a sluggish performance for staff and patients, with slow laboured movement. Within just six months of initial installation Glenrose requested a switch to hydraulic pistons, incurring extra cost for conversion, but do not regret the switch: now the platform was able to respond instantaneously according to staff demands, with quick jerky movements if required, offering patients greater challenge in their rehabilitation. One drawback of this was that the compressors that power the hydraulic system can be noisy, but Glenrose housed these outside the lab, minimising disturbance.
Unlike TOHRC, Glenrose had no problems with the recommended pit width for full movement of the platform. Encouraging news for BASIC was that there were also no problems with treadmill belts as reported by TOHRC.

**CAREN Operator, Darrell Goertzen**

Darrell has a mechanical engineering background and had worked in medical biomechanics. He felt some programming experience was useful for tweaking applications supplied by Motek and experience of motion-capture for understanding how CAREN records and stores information.

Motek, the Dutch manufacturers of CAREN, host a users group conference every year. Darrell felt the group was useful to belong to but was unnecessary to attend every annual get together. Rather, it was the collaboration sheet circulated by Motek to all CAREN users that had proved useful. This sheet gave an overview of what each CAREN facility was working on and promoted an approach to another site if working on similar projects.

Darrell allocated up to one hour per patient, but precise session duration depended on the individual, as some did not like conditions in the CAREN (dark, sounds, moving platform etc.). His work included a short ten-minute weekly maintenance check and once a month, completed a longer series of checks on the CAREN.

One of the differences between Glenrose and Ottawa was that Glenrose chose to put four sensor cameras at leg level rather than all on the overhead gantry. Darrell would ideally like to have put more at this level as the above cameras can have problems picking up movement of a patient's body if another body part obscures the line of sight.

**Glenrose staff & the CAREN**

Don Simoneau, Occupational Therapy, said, “I was sceptical about CAREN but won over by patient reaction and motivation. The problem in general is getting staff to try technology, but having a CAREN operator means they don’t have to operate it themselves.”

Gary Faulkner, Rehabilitation Research, provided information about research fees for using the CAREN: “Typical charges would be $50 per hour or for a block of time, say an afternoon per week for three months, would be $5000. We don’t currently market CAREN time for research as there is no need.”

He went on to advise that: “…it is essential to recruit students from universities and technical colleges for CAREN technical support.”

When asked about evidence of effectiveness for CAREN as a therapy, staff said that there was anecdotal evidence but no conclusive study had ever been done.

**Glenrose Case Study One:**

Before the patient arrived, Darrell explained: “Sue is 19 years old and a CVA bleed to the brain has given her walking and balance difficulties. She’s missed several physio appointments and is totally unmotivated by rehabilitation.”

STEER A CAR – by transferring body weight from side to side, Sue steered a car down a virtual street. Challenge was increased by adding ‘bumps’ (sudden movements of the platform). Sue had problems anticipating the position of and avoiding other cars, suggesting a cognitive difficulty.
STEER A BOAT: Sue had difficulty steering the boat with her body weight past the 'correct' side of the buoys, even though Darrell had added a white guideline to the course to help patients identify the correct route around each buoy; another suggestion of cognitive difficulty.

FOREST WALK TO HUT: as Sue walked along the virtual path, the platform became tilted, recreating an uphill slope. When completed, the physiotherapist asked Sue if she would like to try the walk again and she said yes, very much(!), suggesting she was highly motivated by the CAREN experience.

Afterwards, Darrell commented: “This was Sue's first CAREN session and (did you notice that) at the end she was highly motivated by the CAREN experience and had a huge smile on her face and wanted another session.”

He illustrated how for some patients he added cognitive elements to the forest walk application by making simple mathematical sums appear on screen for the patient to call out the answer (flash cards), for example, 11 + 2. The flash cards can be made to appear in random places, at varying speeds and in a variety of colours to help readability against different backgrounds.

**Glenrose Case Study Two:**

David, a male aged 40, sustained a traumatic brain injury when the car he was driving was hit by another vehicle. This left him with right-sided weakness, walking and cognitive difficulties. As an in-patient at Glenrose, he was receiving traditional therapies complemented by a series of virtual reality therapy sessions on the CAREN.

When David arrived it was clear he had difficulty walking and was helped onto the platform by his physiotherapist, who remained at his side for support throughout the session. He began by practising basic weight shifting with an application that came as part of the start-up package with the CAREN. The physiotherapist helped David put equal weight through each foot on the dual treadmill. Pressure plates under the treadmill measure how much force is being exerted on each side and the results expressed as a % bar on the screen in front. In this way, the CAREN gave instant performance feedback to the physiotherapist and patient and the data stored for comparison with the next session to measure improvement.

A key part of a CAREN session is understanding and following instructions. Although this was David’s fifth CAREN session, his cognitive difficulties were apparent as he had problems understanding what to do with each application even though he had done them before.

With the car steering application, the physiotherapist had to help David steer the car down the street as he found it hard to steer right. When steering the boat he also had problems steering right. It struck me that the physiotherapist has to know the range of CAREN applications and needs time to explore what is available in order to choose what is appropriate for patients.

Once again and in a similar way to TOHRC, patients and staff seemed highly motivated by CAREN with patients making remarkable progress in their rehabilitation.
Additional meetings were organised, including the opportunity for me to give a 30-minute presentation about BASIC to Glenrose Tech Forum, a collection of health professionals including physiotherapists, occupational therapists and researchers. I also met with:

- Wendy Dugas, CEO Glenrose Foundation, raises $2.2 million CAD per year to support projects across the hospital. We were able to swap fundraising ideas!
- Quentin Ranson, Children's Adaptive Technology, gave a tour of the children's rehabilitation department to look at technologies for the physical and cognitive rehabilitation of children.
- Claudia Berwald, Social Worker TBI Patients, is the link between hospital and community resources available. Support for physical problems was good but not so great for cognitive difficulties.
- Karen Slater, Director of The Steadward Centre at Alberta University that encourages disabled people to get involved in sports and fitness.
- Andrea Papriny, The Brain Care Centre, a community-based organisation providing rehabilitation services to those discharged from hospital in a not dissimilar way to BASIC.

A few days prior to leaving the UK, Jim had emailed asking if I would like to join him and his wife, Jane, for a weekend in Jasper in the mountains. After approximately two seconds of thinking time, I said yes and was so glad I did. It was simply stunning and added to my Return Visits list.

Canada had been a fantastic time of learning about the CAREN, with so much invaluable knowledge gained that would help BASIC begin to establish a highly effective brain injury therapy for our clients. It had been such a fabulous mix of lovely generous people, inspiring patients and amazing natural wonders.

What would the next phase of this wonderful journey have in store for this highly fortunate individual? This was a question I pondered as I sat at Ottawa Airport waiting for a flight that would take me to Chicago for a connection to Pittsburgh, home of the Pittsburgh Steelers, Pittsburgh Penguins and Pittsburgh Pirates. And also home to the CAREN at a unique establishment called the Human Engineering Research Laboratory, or HERL for short.

**Human Engineering Research Laboratory (HERL), Pittsburgh**

29 September - 7 October

The CAREN in Pittsburgh is located at HERL, a research facility rather than a clinical setting, so this part of the trip involved no patient observations, a real difference in context to the other two CAREN locations visited.

The Human Engineering Research Laboratory (or HERL for short) was founded by Dr Rory Cooper in 1994 to research ways to make life easier for people with disabilities using assistive technologies. It is funded by the Department for Veterans Affairs (known as the VA), a government organisation that looks after a wide range of needs of soldiers returning from active duty, including those injured in action. Additional funding arrives in the form of research grants and HERL were considering the option of offering clinical time on CAREN to health professionals.
My contact was Deepan Kamaraj, Research Associate. Deepan is one of six trained CAREN operators at HERL. He has a biomechanical and medical background with some experience of motion capture techniques, which seemed to be a common theme amongst CAREN operators I met. In addition to completing a PhD, he supervised research projects and oversaw CAREN time. He was the lead for the installation process that presented a number of unique problems!

**CAREN installation**

Bakery Square is an old mill converted for modern industrial use and HERL occupied the 4th floor, comprising a number of offices and a very large research space about the size of a small football field. The CAREN was located at the far end of the space and, unlike other CAREN facilities visited, installed at floor level rather than in a pit.

Potential vibration problems stemming from when the CAREN was in use were minimised by using foam and wooden plates at the point where gantry legs entered the floor because vibration is a serious problem that can affect projectors and motion sensor cameras. Power lines also needed to be adapted as vibration kept tripping safety switches.

Access to the CAREN platform was via stairs or a small lift to a purpose built wooden staging area containing the operator’s desk. Things were designed this way because the floor wasn’t thick enough to accommodate the usual pit configuration. Although this is unusual, it gave the operator easy maintenance access to the platform mechanism and hydraulic pistons underneath the platform. Once again, the hydraulic system was chosen for its superior performance over the electric system. After every use, the platform was cleaned using a damp cloth to prevent dust entering delicate parts of the mechanism.

Chemical anchors and bolts were used to secure CAREN in place. Some drilling, pouring of concrete and the addition of steel plates gave CAREN a secure home surrounded by the stage.

**Special adaptations**

This CAREN had a number of special adaptations to accommodate static and moving wheelchairs, including an extra wide treadmill. In addition, eight sunken eyehooks were placed around the treadmill: one front, one back and three either side. These eyehooks, combined with straps, served to anchor a wheelchair safely on the treadmill. The wheelchair user could still push when the treadmill was in motion, but straps ensured the wheelchair stayed in position.

Close to the back of the treadmill were two small red raised blocks, one on each side. When the treadmill is in motion, a laser beam is transmitted between the blocks. If the patient went too far back on the treadmill and broke the beam, the treadmill stopped. The rear anchor strap created a problem in that it broke the safety beam. Researchers at HERL designed a special strap configuration whereby the beam was avoided and also used a Y-strap at the front for better uninterrupted wheelchair motion.
**The ideal operator**

According to Deepan, an ideal operator would run the system, collect data and programme applications. They would have game designing experience with virtual landscapes and a biomechanical background; also, some motion capture experience. The system used MATLAB and LABVIEW, two common biomechanical and programming software packages.

**Contracts & after-service from CAREN manufacturer Motek**

Deepan offered advice on contracts based on his experiences of dealing with Motek:

1) Installation contract and logistics - the wording of the installation contract should indicate: how many days Motek would be on site; how many people would be involved; when would Motek’s responsibilities end and at what point would we be left on our own. The contract should also cover installation logistics in terms of access to the room, width of doors and how packages would get from point of drop into the room.

2) Service contract and add-on costs for maintenance and support - the warranty at HERL was for one year only and included the 'hard' licence and 'soft end' licence. The ‘soft end’ licence covered software and an extra payment was made to keep this licence current, otherwise software may not have worked after a year. The licence included annual software upgrades but HERL argued they did not want upgrades every year because a research project taking several months needed the same software for all data collection to keep conditions the same and upgrades would negate the research results. HERL now received upgrades every two years.

3) Motek’s response to problems was very prompt, often within 24 hours of reporting. Motek charged to attend and diagnose what was wrong, then HERL would pay for replacement parts. A recommendation was made to check how much we would pay for phone support because this may not be included in the contract.

4) Once installed, operator training took a few days and was included in the price.

**CAREN research projects**

HERL has carried out numerous research projects and has a world-renowned reputation for their work in creating and testing products and devices designed to ease the life of disabled people. A number of devices developed at HERL had gone on to be successful commercial products adopted by large companies.

Biomechanical researchers at HERL had used the motion-capture abilities of CAREN to analyse pushing techniques in new wheelchair users, working out force and pressure points. This data was then used to predict potential injury problems in later life and the long-term health costs of using an inappropriate chair for a patient. Health insurers had been known to opt for a cheaper wheelchair for a patient, but research can be used to show that in actual fact, a more expensive chair is the cheaper long-term option.

All these research projects gave me plenty to think about in terms of how effective, unique and versatile a research tool the CAREN can be. When the CAREN at BASIC is not being used to provide rehabilitation therapy for our clients, could we offer it to researchers as a unique research tool? Visiting HERL had given me an exciting new perspective on the CAREN.
Whilst in Pittsburgh, I had the opportunity to visit the Center for Assistive Technology (CAT) at the School of Health and Rehabilitation Sciences. Located in the university part of the city, this is the place that would help students that needed special equipment adapt to campus life. It also served other members of the community that needed help adapting to life with a disability.

Staff included wheelchair experts, a speech and language therapist with in depth knowledge of the latest hearing equipment, a computer equipment specialist and CAT Director Rosemarie Cooper, who liaised between wheelchair manufacturers and customers, ensuring products were high in quality and service. In a similar way that BASIC is a one-stop shop of help for people with brain injury, CAT were a one-stop shop for people requiring assistive technology.

Before leaving Pittsburgh, Deepan arranged a meeting with Bryan McCormick, Vocational Rehabilitation Counsellor and President of the National Spinal Cord Injury Association, Pittsburgh. He worked with people with a wide variety of disabilities, including acquired brain injury, and we were able to identify similarities between his work and the work of BASIC’s own vocational project.

As a fellow wheelchair user and sports enthusiast, Bryan invited me to see some of the adaptive sports on offer to wheelchair users in Pittsburgh and invited me to a hand cycling ride to experience some of Pittsburgh’s many cycle paths. Just like the gliding experience in Ottawa, this was great fun but thankfully came with less fear and white knuckles!

Once again, this was a memorable few days full of learning and eye-opening experiences.

I had really taken to Pittsburgh and added it to my growing list of places I was sad to leave but to which I wanted to return at the earliest opportunity. Next stop on this trip would be Washington DC, location of not one but two CAREN installations, both at Walter Reed National Military Medical Center.

Walter Reed National Military Medical Center (WRNMMC), Washington DC
8-14 October

Walter Reed National Military Medical Center was “Where the Nation Heals its Heroes”, the hospital that took care of military personnel but also served the White House. I was visiting two CAREN installations in separate departments of the hospital, namely the National Intrepid Center of Excellence and the Military Advanced Training Center.

National Intrepid Center of Excellence (NICoE)

This department at Walter Reed was located in a purpose-built stand-alone building and had been designed to create a relaxing environment for soldiers by using soft colours and lighting, water features and used curved walls to minimise dark corners that could spook soldiers traumatised by war.

NICoE had twenty beds and offered four weeks of intensive help to soldiers on active duty that were experiencing problems adapting to either military or personal life following a tour of duty; problems included substance abuse, anger issues, anxiety when walking down a street or using a lift. Everything suggested a soldier was physically fit for active duty but problems in service or personal life suggested an ‘invisible’ problem. NICoE also offered therapy and facilities to family members in order to strengthen the patient’s support network, something we firmly believe in at BASIC. The raft of help and professionals available at NICoE included counselling,
physiotherapy, occupational therapy, speech therapy, podiatry, psychology, art and music therapy, yoga, relaxation and virtual reality therapy on CAREN.

Engraved on a plaque in the entrance hall were the words, “A place to heal the invisible wounds of war”. NICoE’s work was with soldiers that had possibly sustained brain injury or psychological damage. This is where their work had strong connections with our work at BASIC.

The four-week course began with a thorough assessment of need and patients underwent a series of tests to help identify problems. Scans, coupled with other cognitive assessments gave staff an all round picture of what was going on in the brain of a patient and included:

MEG = Magnetoencephalography (very few places in the world have this equipment)
MRI = Magnetic Resonance Imaging
CAT = Computerised Tomography

Magnetoencephalography (MEG) is a non-invasive neurophysiological technique that measures magnetic fields generated by neuronal activity of the brain. Locations of the sources of brain activity are superimposed on anatomical images, such as MRI, to provide information about both the structure and function of the brain. This can help both patient and family ‘see’ for the first time that there is a problem and that they are not making things up.

It has been shown that art and music therapy can help the brain bypass blockages in verbal communication, so patients undergoing these therapies can find for the first time, they are able to express feelings and emotions. Art therapy is part of the rehabilitation programme at Walter Reed. One of the first art tasks for soldiers is to decorate a plain white mask in whatever way they choose to reflect something about their lives.

One soldier chose to depict her deployment to Iraq in a series of detailed drawings. It was only afterwards that she noticed she had drawn her family last of all, just under the chin of the mask. She realised that subconsciously, she was acknowledging she had put them last in life and that they had taken so much on the chin, including her anger, her frustration, her fear.

When soldiers leave NICoE, a programme is in place whereby NICoE staff liaise with the soldier’s home base staff to continue support and monitoring.

**CAREN installation**

This began in June 2010 and took six months to iron out glitches before a patient received therapy. The bars on either side of the treadmill were removed at the request of staff to encourage patients to work harder.

An electric system was installed and staff thought platform performance was on a par with a hydraulic system. A separate generator powered the CAREN, so if power got cut in the building the CAREN did not suddenly revert to default position (immediately moving down and stationary), which could be dangerous if a patient was on the platform.
**CAREN operator, Sarah Kruger**

Sarah had a biomechanical and biomedical background and spent some time as a nurse. She also had experience in motion capture techniques and programming and said that 50% of her job was trouble shooting either the hardware or software running on the CAREN.

“Applications should be made as busy or as plain as required for the patient,” she advised, hence the need for the operator to have programming experience. “It's all about what the patient needs to get out of the session. If a patient has had trouble in an elevator, which application reproduces or practices that? If there isn’t one, create one.” She also recommended dimmable lights in the room to adapt conditions for individual patients.

**Usage**

NICOE’s CAREN was used exclusively by military patients, not civilian. It was used for research with volunteer patients, a symbiotic relationship whereby NICOE collected research data using patients and in return, patients received rehabilitation on the CAREN.

At their first CAREN session, patients were assessed using a quick simple application designed to test:
- Static balance using weight shift left/right on still platform
- Stepping using weight shift forward/backward on static platform
- Straight walking on moving platform

This simple assessment gave Sarah an idea on the patient's ability to balance, move and importantly from a safety point of view, to listen to instructions.

**Military Advanced Training Center (MATC)**

The second CAREN was at MATC. This department was located in the main hospital building and like the CAREN at NICOE, was used for research. A wider treadmill was installed on a wider than usual platform (3.5m) to accommodate greater sideways movement from patients.

**CAREN operator, Vanessa Gatmaitan**

Vanessa had an engineering background with a little programming but thought motion capture experience was not essential. She used the same simple initial assessment application with patients as a prelude to their first full CAREN session. This simple application was also a great way to familiarise older people who were not used to technology.

**Walter Reed staff & the CAREN**

I met with Sarah Kruger, Carla Alexis (neurological physiotherapist - vestibular therapy), Vanessa Gatmaitan and research lead, Erik Wolf. They were able to offer very useful advice based on their experience of using the two CAREN at Walter Reed:

- Neither CAREN was used for trauma therapy or combat simulations.
- Carla would not use the CAREN with attention disorders as she believed some would ‘play to an audience’ rather than concentrating on the therapy.
- Interestingly, staff here found that patients faking illness had been 'outed' by a session on the CAREN because it had the ability to bring out the competitive side of someone's nature and they 'forgot' they were ill or injured!
Motek User's Group was ‘a great way for Motek to act as Big Brother and control the flow of information between users’.

Sarah and Vanessa organised in-service training for staff on the CAREN to show them the possibilities and developments.

If there was a problem with the CAREN:
1. they tried to fix it themselves
2. they consulted with other CAREN facilities
3. they sought help from Motek only as a last resort because it was expensive to deal with Motek.

Some staff found the thought of using CAREN purely for commercial gain 'frightening' as they thought profit would be put above patient need.

Some of the soldiers were very competitive and classed as ‘high end users’ of the CAREN, so basic applications provided insufficient challenge. Sometimes you had to have a much higher, more challenging starting point to therapy with these sorts of people.

Cognitive additions to applications (flash cards) were well developed at Walter Reed in the form of maths problems, TV character names, military ranks or anything that engaged a patient’s interest.

When asked if much work had been done with memory rehabilitation, the response was that the supermarket application had a memory element, but not much work had been done in this field.

It is a virtual supermarket that requires a patient to remember a short shopping list that appears for a few seconds then disappears from the centre of the screen. The patient then has to touch the virtual list items on the shelves in the right order.

Case studies were the evidence that CAREN worked as a therapy tool.

An interesting case involved a patient that had passed cognitive testing as a step to re-entering active service. When he encountered motor applications with a cognitive element on the CAREN, he could not do the cognitive element, indicating undiagnosed problems.

**Walter Reed Case Study One:**

A soldier's hearing is well protected in battle but impaired the ability to locate the source of gunfire, so soldiers took off their ear protectors. As a result, they could sustain inner ear damage (vestibular problems) due to being in close proximity to explosions. Common after-effects were dizziness, headaches, nausea and inner ear pain and such soldiers are known as ‘blast patients’.

The first blast patient I observed, a male in his 30’s, had inner ear and balance problems. He was undergoing sessions on the CAREN to improve his scanning abilities and his responses to light and sound stimuli. Two sensors were placed on his face, so the CAREN cameras could record where he was scanning and looking.

NICOE had a rig built behind the CAREN screen with 64 speakers attached to accommodate sessions that require a precise sound element. The speakers were wired up to a computer that connected to the CAREN computer.

There were two components to the session:
Sight test - rows and rows of dots on the screen, either in clusters of two or four together. The patient had to find the only cluster of three dots on the whole screen.
Hearing test - a sound played through a randomly selected speaker behind the screen, with the patient having to identify from where the sound came.
The patient would press a button on an adapted X-Box controller to indicate a find and the computer would record where the patient was looking when the find was made. Different scanning combinations were tested: sight only; sight and sound; sound only; treadmill still; treadmill moving. During the tests using a moving treadmill, it became clear that the patient had balance problems as he kept veering to one side or the other.

**Walter Reed Case Study Two:**

Mr P, a 60-70 year old ex-serviceman, was undergoing therapy on the CAREN to help with his vestibular problems and knee/back pain.

“My problems are like having a gyroscope in my ear that has stopped working, so I keel over if I lean forwards and I suffer from dizziness.”

The session began with a series of exercises taking around a minute each:
- **Exercise 1:** patient had two markers placed on his back and he transferred his weight left, right, forwards, backwards to steer one shape on top of another. The platform was moving randomly and the treadmill was still.
- **Exercise 2:** same exercise repeated with a rolling/rotating platform.
- **Exercise 3:** same as 1 but the shapes disappeared more quickly.
- **Exercise 4:** same as 3 but with a rolling/rotating platform.
- **Exercise 5:** same as 4 but with maths problems added. Sums appeared in random places and Mr P called out the answers.
- **Exercise 6:** by shifting his weight, the patient steered a marble around a maze to ‘collect’ other coloured marbles, with the treadmill still and the platform randomly moving. Maths problems were added in random places on the screen and in different font sizes. The task ended when all coloured marbles had been ‘collected’.
- **Exercise 7:** same as 6 but with more ‘lean’ needed by the patient to guide the marble left or right.
- **Exercise 8:** using weight shift to steer a boat on a lake to ‘catch’ sharks. The water was ‘moving’ and sharks had a green balloon to indicate their position. There were also seagulls flying in small groups across the screen, sometimes directly at the patient, to act as a distraction and islands had to be avoided. Flash cards appeared with military ranks that Mr P had to identify, illustrating how this cognitive element to applications can be tailored for individual patients to reflect something with which they are familiar.

The on-screen background for any of these exercises could be changed in terms of colour or movement to see if it affected the patient’s performance.

This was a 50-minute session in total and the patient felt very tired by the end. He said that CAREN sessions had helped with walking up/down stairs. The staff said that Mr P travelled a lot, sometimes for 3 or 4 months at a time, and breaks in his CAREN therapy did not help!

Barri Schnall, Physiotherapist, commented: “I can’t do in the gym what I do on the CAREN. It enables me to be much more creative, flexible and responsive with a patient. The CAREN is invaluable in my work.”
Walter Reed Case Study Three:

The third observation at Walter Reed was of a female soldier, 20-30 years old, who was injured on active duty in Iraq. She was having vestibular problems, including dizziness and inner ear pain due to blast damage and had been receiving CAREN sessions once a week for two months.

The patient completed similar exercises to Mr P but needed the full width of the extra-wide treadmill due greater difficulties with balance and she almost stumbled sideways several times.

Some exercises incorporated flying coloured balls on the screen that came towards the patient. The physiotherapist asked the patient to follow the ball with her eyes (she had sensors placed on her forehead) to practise scanning, as this was a problem for the patient.

Her final exercise was walking down a virtual street. The treadmill moved but the platform remained still. City sounds like traffic played on the sound system, cars drove past on the road and virtual pedestrians stood still or walked past. Maths problems were added to the walk. The physiotherapist wanted to look at the patient's position on the treadmill to check her positional sense (left, right, forwards, backwards). This went on for a couple of minutes until the patient reported feeling anxious as the exercise evoked memories of her time on street patrol in Iraq.

Despite the anxiety, the patient said, “I’m very tired physically and mentally but can’t wait for the next session. Bring it on!”

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Once more, it was a privilege to meet such inspiring staff and patients and to see this remarkable technology in action. I found Walter Reed both inspiring and moving, the way soldiers were cared for and appropriate rehabilitation provided. Here, they had a place where they were listened to, understood, believed and helped, more echoes of BASIC.

My visit to Washington had coincided with a weekend and Columbus Day, a Federal holiday, so there was time to see some of the sights of DC.

The Freedom Wall is part of the World War Two memorial in the National Mall. There are 4,048 gold stars, each representing 100 American soldiers killed in WW2, a very sobering thought.

Not unconnected to the WW2 memorial was an experience at the National Holocaust Museum. The exhibits and eyewitness accounts on display were moving enough as they told the story of Hitler’s rise to power in Germany. It was when the exhibits began to describe the systematic discrimination and eventual genocide of different groups in society that really got to me. First group to suffer were the disabled, both young and old, non-Jewish and Jewish. A small black and white photograph of a little five-year old girl, naked and terrified, being held in the air at arms length by a ‘doctor’, taken moments before she was lethally injected, simply because she was born disabled.

My tears were for that little girl, for the millions of other disabled and non-disabled men, women and small children that were murdered. And this wheelchair user also cried tears of thanks that he was at that place in Washington DC at that moment, thanks in no small part to the man that gave his name to the organisation that made my trip possible.
It had been yet another memorable time of meeting incredible people, making valuable contacts, witnessing remarkable work and being challenged. Would there be any more to learn as my final ten days away began and I travelled to New York to visit the last CAREN installation on my list?

Dynamic Neuromuscular Rehabilitation (DNR), New York
20-24 October

The Dynamic Neuromuscular Rehabilitation Center is a private facility run by Clinical Director, Dr Lev Kalika. Unlike other CAREns visited, this one was stand alone and not part of a larger organisation like a hospital or university.

Although the DNR had seen a number of neurological patients, they mainly treated orthopaedic patients from the community with a range of therapies, including:

- Physical Therapy
- Chiropractic
- Computer Assisted Rehabilitation Environment
- Extracorporeal Shockwave Therapy ESWT
- Neurorehab
- Gait Analysis LAB
- Vojta Therapy
- Dynamic Neuromuscular Stabilization
- Diagnostic Ultrasonography

This particular CAREN was installed three years ago and like other CAREn locations, it was used alongside, rather than as a replacement for, more traditional therapies. Patients paid $250 for a 45min CAREN session and this was usually paid by themselves as insurers seemed reluctant to fund sessions on the CAREN. Dr Kalika tried to get the medical fraternity interested by holding open days etc, but there seemed to be opposition to the DNR from hospitals (the DNR was somehow seen as competition to the establishment), so to date, no referrals had come via local hospitals.

This CAREN was installed where space was at a premium: there was no safety barrier guarding the pit or a bridge across the gap to the CAREN platform. Interestingly, there was also no treadmill on the platform, so the physiotherapist enhanced CAREN therapy session with traditional equipment, eg. a balance board.

Dr Kalika was very interested to hear about the CAREN on order at BASIC and recognised that the DNR and BASIC were similar because we would be the only CAREN installations without large organisational support. He suggested some exciting collaborations: creating new applications is difficult because of the expense involved, so Dr Kalika had tweaked the basic applications supplied on installation. Collaboratively, new applications could be developed as costs would be shared. He was also working on a Wikipedia entry for CAREN and thought BASIC could play a part in this.

Nick Yakolev, the CAREN Operator at DNR, had programming and physiotherapy experience. He suggested an operator should be part engineer, part programmer and have a knowledge of biometrics and motion capture. In addition, there was a need to have a person with no fear of handling patients as this was an integral part of the job.
**DNR Case Study:**

Whilst at the DNR, I was able to observe a patient with Cerebral Palsy using the CAREN. This young man, 25-30 years old, had problems standing and walking, but by receiving a range of therapies including sessions on the CAREN, he was now able to walk more freely and sustain employment.

Observed applications included the patient using weight transference to steer a boat on a lake. Another exercise had the patient moving a tower of blocks to keep his on-screen figure superimposed on a silhouette on top of the tower. A squawking parrot also flies across the screen acting as a distraction.

When specifically asked about the benefits of the CAREN, he said, “The CAREN has helped with my balance and core strength” and he was highly motivated to attend rehabilitation sessions.

Dr Kalika added, “We had another neuro patient with a spastic foot who had received lots of conventional physio without much result. Three sessions on CAREN and it helped the spasticity enormously.”

Another fantastic week had come to an end, another set of inspiring memories. Time to up sticks once again and move on to a different place, but this time it would be different, because after almost seven weeks away, it was finally time to come home. There were many things to think about, many experiences to reflect upon, many lessons to absorb.

Where could I begin to sort through everything I was so lucky to have seen and heard? What were the most important lessons to learn? Had I been changed at all professionally and personally and would I approach my work at BASIC in a different way? Which things could help BASIC set up an effective virtual reality therapy service in the UK in the community? Questions, questions, questions! Time to think and reflect on what had been an amazing, awesome experience.
FOOD FOR THOUGHT

The following bullet points are food for thought as BASIC seeks to develop virtual reality therapy using the CAREN for those surviving brain and spinal injury. Where appropriate, reference is made to the source of the information (TOHRC, Glenrose etc):

1. **How is the CAREN used?**
   - CAREN was used to complement traditional therapies, not replace as the be-all and end-all solution to therapeutic needs.
   - It seems that most places gave patients 45-minute sessions depending on the patient. Any shorter and things seemed rushed, any longer and tiredness became a factor.
   - Starting time for the first session of the day varied from 7am to 9am. Finishing times were around 5pm. The operator needed a small break between clients and a longer break at lunchtime.
   - The average number of patients seen per day varied between 5 and 7.
   - Those patients observed on CAREN had one or more of the following conditions: amputated limbs, cerebral palsy, brain injury, stroke, vestibular problems. All benefitted from using CAREN.
   - CAREN did not suit every patient. A fear of the dark, loud noises, technology, heights, visual perception problems, a propensity for cognitive overload are all conditions that might render a patient unsuitable (TOHRC). Patients with attention disorders could be unsuitable as they might ‘play to an audience’ rather than concentrating on the therapy (Walter Reed).
   - If BASIC is to offer rehabilitation to military personnel using CAREN, we may have to offer additional therapy to treat Moral Injury (BIAMI conference, Walter Reed).
   - Interestingly, staff at Walter Reed found that patients faking illness had been ‘outed’ by a session on the CAREN because it had the ability to bring out the competitive side of someone’s nature and the patient ‘forgot’ they were ill or injured!
   - Competitiveness is very important to military personnel in rehabilitation (TOHRC). This was reinforced by observations at Walter Reed, where some of the soldiers were very competitive and classed as ‘high end users’ of the CAREN, so basic applications provided insufficient challenge. Sometimes a much higher, more challenging starting point to therapy was needed with these sorts of people.
   - Cognitive flash cards were widely used in applications. These were well developed at Walter Reed in the form of maths problems, television character names, military ranks and anything else that engaged a patient’s interest.
   - When asked if much work had been done with memory rehabilitation, the response was that the supermarket application had a memory element, but not much work had been done in this field (Walter Reed). Could BASIC lead the way in this field?
   - Integrate the use of other physiotherapy equipment into CAREN sessions to enhance the experience for clients (DNR).
   - Raising awareness of CAREN, and the patient possibilities that exist, with external organisations was a factor in its success and occupancy rates. (Glenrose)
   - Research using CAREN can bring in significant revenue but must be managed in the context of the whole organisation. (Glenrose)
   - If we intend to offer wheelchair users rehabilitation opportunities, special adaptions may need to be ordered at the manufacturing stage. (HERL)

2. **How many weeks of VR therapy do patients receive?**
   - Military patients received short bursts of 3 or 4 sessions per week for 2-4 weeks. It varied for civilian patients from 4 – 8 weeks, once a week. Inpatients received CAREN sessions a little more often.
3. What are the charges for different groups to use CAREN?

- DNR charged $250 for a 45-minute session. Other locations (HERL, TOHRC, Glenrose, Walter Reed) offered it as ‘all part of the service’ and it was difficult to find out if there was a charge, how much it was and who was responsible for invoicing. Some locations did not offer appointments to external organisations, but were thinking about doing so and charging in the future (TOHRC). Some people had insurance that covered CAREN sessions, whilst some were funded by the health authority.
- It was also difficult finding information about running costs. What was clear was that apart from the privately funded DNR, CAREN running costs were met by the parent organisation.

4. CAREN operator

- This was key to the smooth running and success of CAREN in locations visited and extended much further than simply pressing buttons and saying, "Go". S/he worked very closely with physiotherapists to deliver tailored therapy sessions for patients and enabled the patient to get the most out of CAREN time.
- The operators I met were all in agreement that experience in the following was needed for the operator: biomechanics; motion capture techniques and data collection; computer programming. If possible, a medical or sporting background was also useful. What was also needed was to be at ease handling patients.
- Duties included regular maintenance of the platform and keeping the treadmill clean.
- Each location had at least one main operator and several others trained as back up.

5. Staffing

- Staff involved with patients using CAREN needed to be fully supportive of VR therapy and have a depth of knowledge of available applications in order to plan appropriate activities for patients (Glenrose).
- Operators regularly organised in-service training for hospital staff on the CAREN to show the possibilities and developments (Walter Reed).
- BASIC staff were welcome to contact staff in N America for advice regarding CAREN.

6. Marketing

- No organisation visited had marketed CAREN as a separate entity and actively solicited business from outside agencies. TOHRC were considering this for the future (see below), but for the moment, people tended to hear of the CAREN by word of mouth and approach the hospital. DNR included CAREN on their website as one of a number of therapies offered, but again, not separately from other services.
- A relationship with the military was an avenue well worth pursuing for BASIC (TOHRC).
- Regarding block time bookings, manufacturers of prosthetics, Ottobot, had asked to hire CAREN for product testing at Ottawa.
- TOHRC were thinking about more involvement from business, professional sports teams and the adjacent children’s hospital, but this would mean opening after-hours and at the weekend, which had insurance and staffing implications.

7. Evidence

- When asked how to answer someone that cast doubt on the validity of CAREN as a therapy, staff visited answered in a similar way, that case studies were the evidence (see patient observations and staff quotes from each location).
8. Problems

- Installation practicalities needed to be thought through to avoid delivery delays (HERL).
- The delivery, installation and after-service contract wording required careful scrutiny. Explicitly ask: “What are we getting for our money?” (HERL)
- If there was a problem with the CAREN, staff at Walter Reed:
  1) tried to fix it themselves.
  2) consulted with other CAREN facilities.
  3) sought help from Motek as a last resort because it was “expensive to deal with Motek”.
- When contacting Motek about any problems, their response times were excellent. (HERL)
- Vibration from the platform can cause problems with camera and projector positions, the tripping of safety systems and damage to equipment. (HERL)
- In the beginning, take it one day at a time and don't expect too much. (Glenrose)
- Glenrose thought the pneumatic system of controlling the platform gave a far superior performance over the electric system, so they ‘upgraded’ to pneumatic. Walter Reed, however, disagreed and said there was no loss of performance with their electric system.
- TOHRC initially had problems with treadmill belts, whereas other locations did not.

9. Software

- Capturing Christmas decorations, steering a boat, walking the forest path and crossing the rope bridge were all part of the starting package of applications. Staff at individual locations decided specific make up of packages.
- The operator, at the very least, tweaked software to suit certain clients. Depending on qualifications and experience, they also wrote applications from scratch or could at least heavily adapt existing applications.
- Ed Lemaire at TOHRC mentioned Laurence Kenney in Rehabilitation Technologies at Salford University as a possible source of help for our programming needs.
- Collaborative projects were a great way to develop applications at a lower cost. (DNR)
- As far as the future goes, HERL wanted to further develop their wheelchair prescription project, using the CAREN for biomechanical analysis to recommend an appropriate wheelchair. DNR had limited resources to create their own applications, so chose to tweak what was provided on delivery.

10. Motek Users Group

- It was generally felt that belonging to the group was useful for exchanging ideas and instigating collaborative projects, but it was unnecessary to attend the annual conference every year. When things went wrong, fellow CAREN users were a valuable source of help.
DISSEMINATION

It is December 2014, two months after returning from N America and excitingly, three weeks before BASIC takes delivery of its own CAREN. Part of our marketing plan is to issue press releases and will include reference to my fellowship.

To date, several meetings have taken place with colleagues, including a 45-minute presentation on my fellowship. These meetings served as an opportunity for questions to be answered about how CAREN might be used at BASIC.

Information collected regarding the role of the operator has proved useful when advertising for the operator post at BASIC.

Case studies and observations made during travels are being used in preparing materials designed to raise the profile of BASIC’s CAREN with different client groups.

Contact details for staff in N America have been passed to relevant staff at BASIC to open lines of communication between BASIC and existing CAREN locations. Having help from other organisations will, I am sure, prove invaluable to us as we seek to get the best out of this remarkable technology.

Presentations to community groups and commercial organisations about my fellowship and BASIC’s VR therapy are being organised. These will be a great opportunity to not only talk about CAREN, but also raise the profile of BASIC and the Winston Churchill Memorial Trust.

PERSONAL REFLECTIONS & RECOMMENDATIONS

The main purpose of my fellowship was to ascertain as much information as possible about CAREN from those that were already using this technology. This information could then help BASIC deliver a UK-first, namely VR therapy in a community setting.

There was also another strand to my fellowship, one of personal growth and development. Before travelling, a friend said to me that I would return changed in some way. And I think they were right because I now feel more confident in unfamiliar situations, better able to meet challenges when things go differently to expectations, a greater confidence in taking risks and embracing change.

I travelled 13,000 miles in seven weeks, took six flights and rode endless trains and buses. I stayed in eight apartments in unfamiliar places, cooked meals and did laundry. I only had one small rucksack and a small suitcase. I met strangers that became friends. I navigated around unfamiliar cities. I discarded one pair of jeans and a pair of shoes and gained luggage space for memories in the form of a handful of fridge magnets, two small books and three CD’s from the Andy Warhol Museum in Pittsburgh.

I didn’t get mugged, accosted or bothered in any way by strangers, apart from being shouted at by a rather angry intoxicated gentleman whilst having a quiet coffee sat outside Starbucks in Chicago. I survived inaccessible buildings, bathrooms and train carriages.
I learnt that I like to travel, that I’m able to hold conversations with strangers in cafes and on trains and planes. I learnt that people are generally the same everywhere and strengthened my view that 95% of people are helpful and generous with their time and respond positively to a smile. Setting aside the moral arguments for and against war, I discovered a new found respect for men and women that choose to serve in the military that were being treated at Walter Reed.

Whilst away, many people asked what was the best part of the trip. The answer was always the same: yesterday! This was because every day brought fresh new experiences to relish and treasure for the rest of my life. It also brought personal lessons, so to finish my report, here are some reminders from my trip for me to put into practice every day and one recommendation for everyone else:

1) **Welcome strangers**: you may be one yourself some day.
   (thank you to all my hosts, but especially Jim and Jane Raso)

2) **Embrace things that go differently with a smile**: you’ll live, find the positive, move on.
   (thank you Canadian trains, the Ottawa apartment and the buses that never turned up)

3) **Take risks**: don’t miss out on the excitement of life.
   (thank you gliding, handcycling, Jasper, the people I met on planes, trains and in cafes)

4) **Travel on public transport. Or walk**: discover those gems that are off the beaten track.
   (thank you every place I visited)

5) **Try [www.airbnb.com](http://www.airbnb.com) instead of hotels**: it’s cheaper and much more like living than visiting.
   (the apartments were lovely, apart from the scene from CSI that greeted me in Ottawa!)

And finally, a recommendation for anyone with a passion for their subject, a willingness to travel and learn and the courage to return and inspire…

6) **Apply for a Churchill Fellowship**: but beware, it could mean your life will change forever.
   (thank you Wendy at BASIC and the Winston Churchill Memorial Trust)

   “You may have to operate out of your own comfort zone and will learn from doing so.”
   **Winston Churchill Memorial Trust website**

   **This was way out of my comfort zone!**

Would someone like me find within himself the courage to travel abroad alone for several weeks, meeting perfect strangers in unfamiliar places, returning with the confidence to inspire and influence others?

   **Thanks to my Churchill Fellowship changing me,**
   the answer was yes.

   **Winston Churchill Fellowship in 50 Words**
   **by Andy Golightly**

Re-imagining Rehabilitation for Survivors of Brain and Spinal Injury