

Spring
2019

Valerie Taylor Trust

Supporting the work of Valerie Taylor in Bangladesh

Chairman's Report

An important part of Valerie's vision for CRP has been that it should develop Centres outside Dhaka and Savar, and particularly Centres in the Divisional Headquarters outside Dhaka Division. So in the course of an 18 day visit in January 2019, I welcomed the opportunity to spend 2 days each at the CRP Centres in Chittagong and Rajshahi, which have now been running for several years.

Shortly after arriving at the Chittagong Centre, we saw a Rohingya boy taking his first unassisted steps outside on his new prosthetic leg, and his smile tells it all.

The Prosthetics and Orthotics Department at CRP-Chittagong is now well established, with help from ICRC. It is good that the Government now permits Rohingya amputees to stay there for several days, while their prostheses are being made and fitted and adjusted, before returning to their camps.

Later I sat in on a meeting of current patients at which they were asked to say what they felt about the treatment they were getting. There followed a number of contributions, most of them very appreciative, but the one that struck me most was a forceful intervention from a man who was having physiotherapy for stroke rehabilitation. His stroke had occurred at Feni, and he complained that when he was discharged from hospital there, and he asked the doctors what further treatment he could get, they hadn't even mentioned CRP. After that he wasted a lot of money on useless treatment before he finally found CRP-Chittagong. He felt CRP should advertise more, particularly with doctors. Maybe so, but in a similar feedback meeting at CRP-Rajshahi later that week, we heard a different view forcefully articulated by an ex-patient. He said that, since his treatment there, he had



Enjoying his first steps outside

personally recommended CRP to 11 people, and he felt that CRP was much more effectively publicised by patient recommendations than expensive advertisements. In any case, if patients complain that CRP's services are not well enough known, it shows they think the services are worth knowing about. That should reassure us that the quality of service for which CRP is internationally known has not been compromised by extending its offering outside Dhaka and Savar.

I felt slightly overawed by the warmth of my reception at CRP but of course the appreciation expressed was really for all VTT supporters who by their contributions either of money or as Volunteers help CRP to continue to offer high quality services to people with various disabilities.

Ben Clackson Chairman, Valerie Taylor Trust

Generous Bequest Received from John Lanzer

John Lanzer died in February 2018, but it was only later that it emerged that he had bequeathed £309,000 to VTT. A few of those who read this may remember meeting him at CRP, but others will be curious to know something about the man behind this extraordinary generosity.

John was born in 1927. After leaving the RAF in 1956 he worked as props master in musicals such as *My Fair Lady* and *West Side Story* but moved on to become a production buyer in a long list of films: *Morgan – A Suitable Case for Treatment*, *If, Charge of the Light Brigade*, *Blow-Up*, *Moonraker*, *The Mummy*, *Superman*, *Gorillas in the Mist*, *Oh What a Lovely War*, *A Bridge Too Far*, *Batman* and *Charlie and the Chocolate Factory*.



John Lanzer

A colleague Dave Balfour described what it was like working with him: *“The sound of his typewriter, it was like hearing George Gershwin playing Rhapsody in Blue. I looked round the door and there he was, cigarette in his mouth, the ash precariously balanced over a perfectly composed purchase order then the warm greeting, followed by his infectious laugh, right there and then I knew I had met a very special man. He was never intimidated or discouraged by difficulty, danger or disappointment. He did everything with elegance and style but with a fierce determination.”*

He also gave us some insight into what drew John to CRP: *“He was selfless and he cared more for the needs of people less fortunate than himself. He was a philanthropist who worked tirelessly under the radar for the underprivileged and the lost souls.”*

Two reminiscences printed in *“Reaching Higher”* add to the picture: *“I must mention one volunteer, John Lanzer. I often wondered during my short stay if CRP would fold without him. Well, of course it wouldn't, but he knew how to get things done like no-one else, keeping us laughing, but in order. The Bangladeshis do love celebrations and John really knew how to conjure up drapes, banners, garlands of*

flowers, to give every event a magic touch ... and when it was all set up, there he was, in the background with his camera.” Wendy Best

“We all went to CRP for Valerie's birthday. Her sisters were both there, and CRP made such a thing of it. They borrowed a cart which John Lanzer decorated (he was such a clever man). Valerie and her sisters and Poppy and Joyti were taken to a coffee stall just outside the gate. Then this

multicoloured wagon drew up. Valerie was put on it with her sisters and the children, and pulled along inside and outside the Centre to the great delight of all the onlookers.” Patience Holt

We also asked Valerie for some of her own recollections: *“John had a special name for the bus station at Gabtoli. He called it “Hell”. One day on his way to CRP, having been collected from the airport, he was sitting in our vehicle in Hell. He had brought a box of chocolates for us but as he sat in Hell they were quietly and gradually eaten by John, leaving just the empty box! On another occasion he was teaching Shemol, paraplegic carpenter at CRP, to drive the three wheeler “tempo”. They had been down to Old Dhaka from the centre when based at Farmgate. I remarked that John looked so cool and unruffled on his return, to which he replied that he had taken no notice of Shemol on the journey but had sat next to him, filing his nails!*

In the early days, John would spend time with patients on bed rest trimming beards and cutting hair. I remember the day he came into Mohua's office in the hot season, his shirt wet with perspiration, and said he was like “Widow Twankie in the laundry scene”! But my overriding memory was how John would throw

*his arms around the most lonely,
unhappy male patient sitting on his
bed in the ward and make them
feel so important and valued.”*

These memories of John speak of his sense of humour, his imagination and his generosity, but there still seems to have been something elusive about John, as suggested by his great friend Peter Young:

Epitaph

It is not what you did or did not do
But the memory that you left behind.
You were a solitary moon that could not find
a planet to go round
We loved you for your secret ways
And search our souls for what you were.
We never knew the object of your gaze
It has to be where you are now.

Volunteers develop skills in SLT Department

Volunteer Speech and Language Therapists Emily Danvers, Jessica Miles and Savannah Senior tell of their time at CRP.

We left London with a very small suitcase packed with a few essentials, including South African tea bags and our Bangla phrase book. As first-time visitors we had no expectations – we were blown away by the business of the streets, the fantastic colours and the warm welcomes we were given. Navigating the busy streets by foot or by rickshaw soon becomes second nature but getting used to the bus system may take a few more years of practice.

The Speech Therapy department really impressed us. For a relatively new department and profession in Bangladesh, they have collected many resources and used them within their various settings well. Everyone was very open to learning, eager to share their concerns and discuss therapy techniques/ideas. During our time at CRP, we worked together with the in- and out-patient therapists, discussing patient cases and evidence-based practice. Together with the school's therapist, we provided education to the hostel carers and implemented an alternative communication device for Foyez, a student living in the school hostel. We were also involved with teaching the 3rd year Speech Therapy students who were eager to learn and develop their knowledge. Without the support of the Speech Therapy Department, our visit would not have been as fruitful as it turned out.

We were pleasantly surprised with the possibilities available at CRP, for the patients as well as the volunteers. One of our favourite things about CRP is the celebrations (and the lights of course!) The CRP community love celebrating things – big and small – we think a lot can be learnt from this.

Thank you, CRP, for accepting us with open arms and your big heart. We will miss the CRP community and our tummies will grumble for our 10am Puri and Cha.



*Foyez practicing with his
new communications device*

Boost for Wheelchair Basketball in Bangladesh

Last year, CRP was honoured to host Jess Markt, a wheelchair basketball coach and Disability Sports and Integration Advisor for the International Committee for the Red Cross (ICRC). He tells of his time at CRP:

In April 2018, I had the opportunity to coach in Bangladesh for the first time. I knew that the ICRC had been supporting a fledgling wheelchair basketball program in Bangladesh for the past couple years, so I was excited to meet them for the first time and see what kind of progress we could all make in a week together.

The training took place at the main campus of CRP. At the center of the campus was a full-size, nicely appointed outdoor basketball court. On that court – already playing despite the sweltering heat and the fact that the beginning of the official training session was still over an hour away – were 22 smiling, shouting male and female wheelchair basketball players.

From the first moment of introducing myself to the players, I could tell they were a special group. They had a vitality and excitement about them that was a bit different than what I'm used to experiencing when meeting a new group for the first time. Normally it takes me a day or two to establish a connection with new players, but the group in Bangladesh was 100 percent ready to go from minute one, warmly welcoming me, volleying questions, and asking to get started as soon as possible.

I soon learned one of the reasons why they were so enthusiastic and confident. They'd had the advantage of working with a coach – a young staff member at the CRP named Nahid Tonmay – who had dedicated himself to learning as much about wheelchair basketball as possible over the last two years and passing that information on to the players. I knew of Tonmay from emails and messages he'd posted on my blog over the past year asking for information about coaching and wheelchair basketball strategy as well as any insights that would help him build a sustainable program in Bangladesh.

I was already excited that a young coach would reach out to me of his own volition, but once I got a chance to meet him in person, I found out that he'd also been sending similar requests to



*Chatting with coach
Nahid Tonmay*

coaches all over the world in an attempt to gain knowledge from as many sources as possible. What a go-getter! He told me that of all the messages he sent out, I was one of the only people who responded, yet he refused to give up and kept up his outreach to learn to be the best coach he could.

Tonmay's dedication has already had a clear impact on the players in Bangladesh, and I was impressed by the level of knowledge he (and they) already had about the game. He is exactly the kind of coach I've hoped to develop in all the countries in which I've worked – intellectually curious, self-motivated, and interested in both creating opportunities for as many people as possible and helping those who show promise and interest develop into high-level athletes. He'll be a very important leader for the program as it moves forward.

The other participants who joined Tonmay for three-day classroom courses on coaching, refereeing and classification were equally interested, even though it was the first time most of them were learning about wheelchair basketball. Many of the students were either experienced coaches or former players from Bangladesh's able-bodied basketball federation. The head coach of the Bangladesh

men's national basketball team even took part, as did the coaches of the military and police teams. Despite their strong backgrounds in running basketball, all of them were extremely respectful, focused and curious throughout the courses. It was great also that everyone, no matter what their primary area of focus, decided to participate in all three courses. Without me even telling them, they understood that having a broader understanding of all the technical aspects of wheelchair basketball would give them a better foundation from which to grow in their chosen disciplines.

The one briefly unpleasant moment of the classes was when, partway through the final morning, Tonmay stopped me in mid-sentence to calmly-but-urgently point out a spider that was right behind my wheelchair. I casually turned around to look at it, assuming it would be like most spiders I've seen before. When I saw that it was almost as big as my hand, I let slip a few words of... um... alarm. Apologies to the class for my temporary lack of professionalism, but seriously, it was huge!

The rest of the week with the players was fantastic. They're all still relatively new to the game, but Tonmay's work with them had given them a nice jump start. Their fundamentals were a lot better than most new players I work with as a result. By the time we played an ad hoc tournament between three teams on the last day, they were scoring, defending, and setting picks like old pros. It was a ton of



Discussing tactics before a game

progress in a very short amount of time and, seeing how focused they and their coaches were throughout the week, I'm excited to watch their growth in the coming years.

The newly-formed Bangladesh men's and women's national teams travelled to Indonesia for the 2018 Bali Cup tournament in July – the first time both male and female teams have represented Bangladesh. I know the teams will continue to develop and I will be back to support them again next year. With Coach Tonmay on their bench and the players' can-do attitudes, I have a feeling they'll surprise people.

New Law Focused on Improving Therapy Standards

After years of campaigning by CRP and other therapy organisations across Bangladesh, the Bangladesh Rehabilitation Council Bill was passed in October 2018.

The newly formed Bangladesh Rehabilitation Council (BRC) is a government regulatory body for all rehabilitation professionals including Physiotherapists, Speech Therapists, Occupational Therapists, Psychologists and Special Educators.

The body will improve professional recognition, promote the role of rehabilitation professionals and work to improve education standards.

This in turn will result in better services for those in need. A great outcome for staff and patients alike.

Crowdfunding: a new way of raising money

Laura Bennett reports on how she used a less familiar fundraising method to help a young boy in Bangladesh:

Upon hearing about the heart-breaking predicament of a Bangladeshi boy with cerebral palsy called Shawon, who could not afford to live near to his family, I decided to learn about 'crowdfunding' to see if I could help. Crowdfunding is a fairly new method of raising money, involving collecting donations from as many people as possible. This is mainly done online; through social media sites, or crowdfunding platforms, where high numbers of people can be reached. Crowdfunds can be small-scale, and just ask for donations with no strings attached, or they can be larger scale, where an element of 'giving something back' to the donator is used as enticement.

Perhaps some of the most popular crowdfunds are the charitable ones, and there are crowdfunding sites specifically for this, which are often 'not for profit'. I settled, however, on a 'for-profit' site called 'gofundme', which takes a small percentage of any money raised. I was confident that they were a reputable and well-known company and felt that this was a fair price to pay for this security.

Creating your crowdfunding site on gofundme is free, and involves a basic to moderate knowledge of computers. Creating a crowdfund

page involves writing your story, adding pictures, and stating your goal amount. If you have access to the internet, then feel free to have a look at mine. It's by no means perfect, but it raised £1760 out of a goal amount of £2000, which I was happy with: <https://www.gofundme.com/reunitewithhisfamily>

In order to get donations you need to present your page in an way that the reader can instantly feel something, just by looking at it. It therefore makes sense to use emotive language. Too much detail, facts, figures etc will likely have someone scrolling right past and onto the next thing. A punchy, emotive title, complete with a good picture is essential.

How you share your crowdfund page around is up to you; but without a doubt, the more effort you put into this the better the result you will get. It is you who needs to advertise it. This could be by contacting organisations similar to the one you are raising money for, and asking them to advertise the page on their websites, putting a poster up in the library, contacting your local paper to have them put the page up on their website or posting fliers through the doors of people in your town. I also posted in various charitable facebook groups. With the benefit of hindsight, I would have spoken directly to these charities, rather than through facebook as I imagine they are inundated with requests. I didn't reach my target amount for the second crowdfund I tried, and I think that this was through a combination of factors including having already asked friends and family to donate to my previous one, having a slightly less emotive title, lower quality pictures, and of course many factors which I don't know, but would like to find out!

I believe that crowdfunding is a fundraising avenue with significant potential, but perhaps only for a certain type of situation. I imagine that with the right knowledge of campaign-advertising, and/or the right imagination and free time to spread the word, it may well be one of the better, new methods of fundraising out there.



Shawon having fun at CRP

Pressure Ulcer Conference A Great Success

Jan Varney reports:

It was in February 2018 on visiting CRP that I did some work on the wards looking at clinical governance indicators. It was then that I noticed that 46% of patients transferred to CRP from other hospitals were being admitted with grade 3-4 (severe) pressure ulcers. Patients with severe pressure ulcers can die due to sepsis and often have a longer stay at CRP meaning other patients wait longer for a bed. Due to this information we decided to organise a conference and invite nurses from all over Bangladesh to attend. This conference wasn't about blame but to learn from these findings and put processes in place to prevent this happening. It took a year to organise the conference entitled "Together we can work to STOP THE PRESSURE". 116 nurses attend from the government hospitals all over

Bangladesh. We looked at the key messages to prevent pressure ulcers: keep moving, bladder and bowel management and the role of nutrition in prevention. It was a very successful day with delegates commenting on the evaluation form "Thank you CRP for holding this conference, we have learnt so much from today, it should have been over a longer period!"

For me it was so encouraging that delegates said that they were going to go back to their work place and tell colleagues what they had learnt but also inform their hospital leaders. 95% of pressure ulcers are preventable and by adhering to these key messages and embedding them into every day practice we can save patients' lives. Thank you to the conference committee in CRP for their cooperation, Skype calls and encouragement in putting on this conference.



Jan with some of the participants

Expanding Mental Health Services in Bangladesh

Ben Clackson received updates on the Mental Health Services at CRP during his recent visit. He reports:

There are now several locations at which CRP provides mental health services. At Gonokbari the Kadoorie Foundation funds an occupational therapy day centre for people with mental health needs and a counsellor has now been added to the staff at the Mirpur Centre. However I was particularly struck by a therapy group for mothers and autistic children which I joined in with at CRP-Rajshahi.

An occupational therapist led the group through a variety of activities with the aim of eliciting active participation, or at least eye contact, from the children, and the mothers gently encouraged their children. We sang “Twinkle, twinkle little star” in English(!), and a Bengali version of “Old Macdonald had a farm”, giving the children an opportunity to imitate animal sounds. Of course each autistic child is different, and they varied in their degree of engagement, though most seemed pleased when they were handed a big inflated ball to play with before passing it on to the next child.

After the session the mothers were remarkably keen to talk with me, some in excellent English. Many had been coming to the group for more than a year, and spoke of the progress their children were making, gradually, with the help of the therapy. I was moved by their persistence. Many of them were clearly well educated and probably not poor, but the options for day therapy of this sort in Bangladesh are very limited, so CRP is meeting a desperate need.

I was also taken to the home of a woman living in a very poor area of Rajshahi who had come to CRP-Rajshahi with a different mental health problem after trying twice to kill herself. In the course of occupational therapy at the Centre, staff realised that she was completely deaf in her right ear and partially deaf in her left ear. CRP bought her a hearing aid for Tk10,000 (£100 at current rates) and after the 6 month tailoring training she is now working as a tailor at home with a sewing machine supplied by



Autistic children's group

CRP and earns enough to support herself. She said she was now happy, and looked it. It made me realise that, living in the UK, I take for granted the provision for free of at least a basic level of hearing aid.

Michael Willi, Psychologist, recently volunteered at the Mental Health Project at Gonokhbari:

The project at Gonokhbari treats around 15 patients suffering from schizophrenia or bipolar disorders at a time. The staff include one psychologist, three occupational therapists, some assistants and caregivers with a psychiatrist visiting the project every few weeks. It is an out-patient facility with patients brought via bus. There are a number of different therapies on offer. Patients get single coaching lessons from the psychologist or occupational therapists, psychological group therapy or occupational group therapy like singing, painting, playing music. They can also enjoy a lot of different social activities like playing chess, darts and other board games. Some patients work in the wheelchair factory, the woodwork factory or other offers of the CRP Gonokhbari. Because of the high language barrier my part was to function more or less like a supervisor or assistant. I took part in group or single therapy units and discussed patients problems with the psychologist. Of course I joined the singing or painting sessions, which was quite fun and a great way to get more in contact with the patients. Not to forget the endless chess matches I played (and lost).



Michael with staff and a patient

My aim was to implement a new group therapy called metacognitive therapy, for schizophrenia patients. It comes from the behavioural approach and teaches patients to handle and improve their way of thinking and acting in daily life. We managed to start this therapy in the last weeks of my stay and I really enjoyed the possibility to contribute a little bit of my

knowledge to this project. This project is a lovely relaxing place and is well set up for the treatment it provides. I really hope it can raise more awareness of mental health in Bangladesh and improve the availability of treatment for mental health conditions. I miss the people there a lot and I am looking forward to coming back!

Brief Update on the P+O Department

Regular volunteer Glen McGhee is back at CRP currently. He reports:

The Prosthetics and Orthotics department continues to go from strength to strength with increasing locations, staff and patients. Ten more new graduates passed ISPO (international) exams last week and they will all start work in CRP centres in the next few weeks.

The department has a new machine which takes the waste produce of limb sockets and remoulds it into the arm support for elbow crutches. These are stronger and cheaper than the ones you can buy here. The department has also expanded into making custom footwear for misshaped feet, for example for those with club feet or polio. On top of all of this, a new P+O department will open in Barisal by the end of the year.



Making crutches

Making Friends at CRP

General volunteer Daisy Daniel reports on her experience at CRP.

As an aspiring medical student, when my friend Tom Pendry told me about CRP and his family's link to Valerie's incredible work in Bangladesh, I was desperate to get out to Savar and see the centre myself. Tom and I travelled to CRP in July 2018 as General Volunteers, and I can safely say that it was the most challenging and rewarding experience of my life so far. As two 17-year-olds visiting Bangladesh for the first time, I at least, struggled initially with culture shock and the weather, mainly as we arrived in the full throws of the monsoon. But the staff at CRP were so helpful and accommodating, allowing us to decide where to volunteer and where we felt we could most make a difference.



Learning new skills

We spent much of our time at the William and Marie Taylor School helping children learn their first numbers and letters as well as assisting with hydro-therapy trips to the pool and hippotherapy (horse-riding) sessions. This was eye-opening as despite many of the children struggling to hold a pencil many possessed an insatiable desire for learning with some even writing with their feet. Tom and I also spent time playing wheelchair basketball, in my case playing it poorly, much to the amusement of patients. The sports team at CRP are in my view relatively unsung heroes, the activities they run and the tournaments the patients can attend often become the reason some get up in the morning, as well as providing an excellent opportunity to make friends.



*Fun and laughter
in hydrotherapy*

Tom and I bonded with two people in particular. Both were the same age as us but facing very different challenges. One was learning to walk again after falling from a fruit tree, and the other was sleeping under her father's bed in the ward as he recovered from injury. Seeing both of them move from the medical wards, into the halfway house and then back home during our time there was an emotional experience and served to cement in my heart what incredible work CRP does. It is thanks to CRP that our friends are back at school and living as close to normal teenage lives as is possible.

After my time at CRP, I am even more determined to study medicine and return when qualified, to help contribute to the life-changing work being done tirelessly every day by the doctors, therapists and teachers that make up the staff at CRP.

WAYS YOU CAN HELP

The disabled poor in Bangladesh continue to need help. The Valerie Taylor Trust supports the Centre for the Rehabilitation of the Paralysed. This is the only place in the country where the paralysed are given specialist treatment – free of charge for the very poorest.

Support our work by:

- Regular donations by completing the back page of this newsletter – our preferred method.
- Donate on-line to our bank, details overleaf, or via www.valerietaylortrust.org, www.paypal.co.uk or www.justgiving.com.
- Please register your donations for Gift Aid if this is applicable.
- Use a VTT Collection Box in the home and outdoors – obtained from the Administrator.
- Make a legacy. All sizes of donations are valuable and are tax-free. Please ask for our leaflet.

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Helping the Disabled Poor and their Families

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Tel: 01622 743011 **Email:** admin@valerietaylortrust.org **Web:** www.valerietaylortrust.org

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- I enclose a cheque for £..... made payable to **Valerie Taylor Trust**
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In order to become a member, at least £25 per year, or £2 per month, must be given as a donation. You do not need to be a member to donate to the Valerie Taylor Trust, but being a member entitles you to regular updates on news and information, voting rights at the Annual General Meeting and ensures VTT continuity.

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Name (Mr/Mrs/Miss/Ms)

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Account Name (usually your own name)

Account No Bank Sort Code -

To the Manager: Please pay to HSBC for the credit of **Valerie Taylor Trust**, Account Number 3122 5227, Sort Code 40-28-29. IBAN (International Banking Account Number) GB59MIDL40282931225227 the sum of

£..... starting on (date) and on the same date each **month / year**

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- I wish all future donations to VTT to be under the Gift Aid Scheme until I notify you otherwise.

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