

NATIONAL ADVISORY COUNCIL
TO
The Thalidomide Trust

Newsletter

Spring 2018

Welcome to the NAC's Newsletter.

The format I follow, for our newsletter, is to focus on what we've been up to as a group, and to intersperse this with news from both the Trust and from individual beneficiaries.

In this issue we introduce you to Cheryl Pinkney, who takes up the role of Health & Wellbeing Team Administrator and Wellbeing Adviser.

I was so inspired by the excellent fitness article by Ramesh in our last edition, who has devised some ingenious fitness exercises, I allowed myself to be persuaded to write an article myself, with my Personal Trainer, Lotti Klatt.

Our second Fit for the Future event has taken place, and Carolyn reports on a symposium on pain.

Also read about:

- Campaign update
- Nigel Richards – a beneficiary living in Jamaica
- News on the Trust's website



If you wish to receive campaign updates by email, please contact the Trust office (email hello@thalidomidetrust.org) so that you are included in their distributions.

Thank you to all who have contributed information for this edition, and to Simone who has, again, been instrumental in sourcing articles for inclusion.

Please enjoy reading..... AND if you've something you'd like to contribute to the next newsletter please contact me.

Karl Davies – Newsletter Editor
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Chair's Update

Firstly, many thanks to Simone and Karl for compiling this edition with the usual variety of information.

You will have seen the announcement of the NAC election results. We say goodbye to Kim Fenton and we thank her for the valuable contributions she made to the NAC's work over the last two years. I would like to thank all the other candidates who stood (with congratulations to those who were successful and thanks to those who were not) giving us a wide choice to select from.

I would also like to thank all who voted – the selection of NAC members by democratic election is a very important process which gives the NAC a mandate in *representing* you.



Looking ahead, there is much work for the NAC:

- Myself and Nick Dobrik will be meeting up with Diageo in April as the first of the annual review meetings that was agreed as part of the last Covenant Review meetings in 2016 – this meeting gives the NAC (along with Trustees and Director) an opportunity to update Diageo on all that is happening as an example in *representing* you;
- We have two NAC meetings in April and November with Trustees and staff present. Again, the agenda will be made available to you in advance if you have opted to receive information from the NAC and comments will be welcomed to guide us in *representing* you;
- We have the Trustee Health & Wellbeing (and Research) / Finance sub-committees at various times during the year at which NAC members are present *representing* you; and
- We have our Awayday in June – this is not a 'jolly' but a day in which the NAC members work together with the aim of better *representing* you.

If you have read the above carefully, you will have noticed that I used the words '**representing you**' repeatedly and whilst this might be irritatingly bad English, this was deliberately so. Representation is the core purpose of the NAC, it is important not to lose sight of this. All the changes/improvements in the recent past that we have made in the way that the NAC works is driven by a focus on '*representing you*' and must continue to be a driver for all of the NAC's activities. Over the last two years as Chair, this has been my focus and as I am about to start serving a third year (and the last before I step down) as Chair, this will continue to be my focus and I, with my NAC colleagues, will continue to strive for representation as being at the *core* of all the NAC does for you.

As ever, I wish you well.

Rowland Bareham, Chair of NAC.

Fit for the Future Weekend: 6 – 8 October 2017

By Simone Illger

This was another successful event, held in the Radisson Blu Hotel, Liverpool.

Liverpool was considered a good venue because of the number of beneficiaries living within a short travelling distance. The event was attended by 18 beneficiaries, 6 of whom attended the previous Fit for the Future. However, very few of these came from the local vicinity (only about 4- 6).



Participation in the event was originally open only to those beneficiaries who had not attended the first event. Due to low take-up, 6 weeks before the event registration was opened up to

those who had attended the first event and were on a “standby list”.



Although the size of the group was smaller (the previous Fit for the Future was attended by 27 beneficiaries) this event felt more intimate, allowing every participant to engage fully over the course of the weekend. The positive aspect of the

smaller event that was evident was how caring and supportive everyone was of one another.

The structure of the weekend broadly followed the first held in April 2016, but was slightly tweaked to take account of feedback received – fewer presentations and more time to take part in interactive workshop sessions.

Two general personal assistants supported participant over the weekend and their presence and hard work really helped to contribute towards the success of the event and ensured that every participant was to participate fully in all sessions. Having practical support to position, get on and off the floor and being assisted / directed in the use items of equipment was essential to the wellbeing and participation of everyone, particularly in the Pilates and the exercise sessions.

Three NAC members (Geoff, Simone, Carolyn) were involved in delivering the event. Sue Kent was unfortunately unable to attend due to illness. Three Trust staff members (Katy, Michelle and Dee) were also there to provide invaluable support and assistance.

Two short films of the event have been produced and can be viewed here:

https://youtu.be/v2Tt_s5sO-M

<https://youtu.be/lz92kSoribY>

And a film is also available on the Trust's website here:

[Fit for the Future - Thalidomide Trust](#)

A Facebook group was set up following the first event, and now has 46 members, which includes thalidomiders, the professionals who delivered sessions, and one of the general personal carers (who is also an experienced masseur and personal trainer).



We have a monthly weigh-in and share information on diet, well-being and exercise.

A future Fit for the Future?

There is a small but keen cohort of beneficiaries who have embraced some long-term life-style changes. There is no doubt that their involvement in the second event was invaluable - sharing their experiences and the positive changes they've enjoyed as a result and this definitely added to the success of the weekend. They were able to share ideas for exercises and lifestyle changes as well as their weight loss success.

During the final session of the event, many participants gave positive feedback about their plans to make changes to their lifestyle.

There is a danger if a third event is planned, the same small cohort will wish to attend. In terms of the cost and the planning, the viability of organising another event needs careful consideration with perhaps some thoughts to alternative ways of delivering or financing.

Many of the professionals who were involved in delivering this event have reported that they would be keen to assist at any future events the Thalidomide Trust organises.

Attendee feedback – by Marie Pearse

FRIDAY: We arrived that evening to a Welcome reception and Registration. Then we joined together for buffet dinner, socialising, meeting friends we knew, and made new ones too.

SATURDAY: Began with a morning of stretching and exercising to make a positive and good start to the day.

During the introduction led by Carolyn Desforges, we explored our individual hopes for the weekend, and what needs to happen for change to take place, and this gave us an opportunity to get to know other participants.

The speakers were Dr Anthony Papathomas – speaking on Sports and Exercise Psychology and Dr Chrisof Leicht who spoke on Exercise Physiology. They both Lecture at Loughborough University, and between them they spoke about the science of sport and exercise in psychology and the physiology of health and wellbeing, and the impact of what this means for our bodies. They demonstrated a great understanding of these issues with people with disabilities and benefits of improved health and reducing risk heart attacks, strokes and type II diabetes.



Workshops

Mindfulness and Meditation: with David Spencer

Mindfulness, meditation is about isolating yourself into a moment away from your surroundings. Learning how to breathe. This is seen to be very helpful when feeling very stressed in certain situations. A method which may be able to help with our health and wellbeing.

Pilates: with Victoria Downland Cosasine and Jane Hall; Physiotherapy: Carol Adkins

We explored and tried out various floor exercises and physiotherapy being able to have a greater understanding of the wide range of our disabilities and fitness levels. I do believe through positivity, whatever your disability it is possible to improve your fitness level to achieve a greater sense of wellbeing. I believe everyone realised there was something they could do towards improving their fitness, health and wellbeing.

Personal Trainer: with Emma Medus and Catherine Bradazon

We were given an opportunity to experience the possibility of having a Personal Trainer, and were shown equipment and exercises.

Food and Weight: with Christine Kenny

This session was not about diet but about nutrition, health and wellbeing, to promote the adoption and control of good, healthy, eating habits.

Hydrotherapy session

I think this was very enjoyable for all, doing a range of aqua exercises in the hotel pool.

EVENING: Dinner – An opportunity for socialising.

SUNDAY: Also began with a stretch – with Yvette Ford, and was followed by the closing session “Planning your change”, led by Carolyn Desforges.

Planning Team Members and roles: Simone Illger – Chair of Health & Wellbeing (Chairing the weekend), Geoff Adams-Spink (Technology, Presentations & overseeing filming), Carolyn Desforges (Introductory and Final Sessions).

Trust Staff: Katy Sagoe – Director of Health & Wellbeing; Dee Morrison – Medical Advisor to the Thalidomide Trust; Michelle Robinson – Health & Wellbeing Team Administrator.

Personal Assistants: Yvette Ford and Rachel Webster – Excellent, who assisted, encouraged and supported attendees.

Filming: Harvey and crew filming only on Saturday.

SUMMARY:

I thoroughly enjoyed the weekend, the workshops and obtained very useful information. This is a great credit to all professionals and Personal Assistants who were there, with their knowledge, expertise, awareness, and understanding of the wide range of disabilities. Credit is owed to all participants of Fit for the Future and Trust Staff.



Campaign update

UK

By Mikey Argy – on behalf of the Campaign Team

We have written to all the new MPs and many of you have forwarded on your letters so thank you. If you haven't then please do so.



It is also getting harder for me to see a beneficiary's MP when they haven't given permission for their details to be shared with the Campaign Team.

If this is the case for you, please consider allowing the Trust to share your details (or even just your name) with us as it could really help us build cross-party support.

We are still getting great support in parliament and are making sure the name thalidomide is not being forgotten.

Any questions please email us on email@thalidomidecampaigners.com

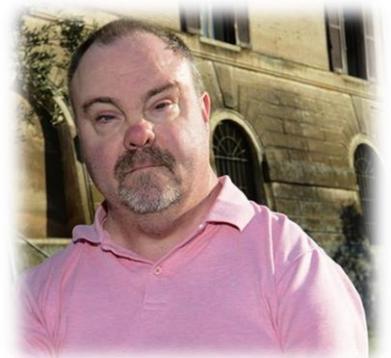
Or call Mikey Argy on: 07875 084320

EU

By Craig Millward – on behalf of the Campaign Team

We mentioned in our last newsletter and in an email update that there was a positive meeting with the German Government's Families Ministry in September, which was followed by another meeting in Berlin in December. We also indicated that the SPD partner in the previous German Government has acknowledged that there should be some sort of recognition of thalidomide survivors outside Germany.

In the meantime all the effort in Germany has been in trying to form a government. This was concluded earlier this month and the good news for us is that the SPD are sharing power with the centre-right once again. Our efforts are now being focused on persuading the CDU and CSU that they should take the same stance as the SPD. We are doing that through our relationships with Germans in Brussels.



The fact that Germany was without a government for six months has meant we have been forced to wait to discover what tactics are needed for the next step of the campaign. We have been preparing the ground since the EU parliament opened for the New Year in January and are now stepping up our efforts once more. We are extremely positive about the progress we have made and the possibilities of an eventual breakthrough

Thank you all for your continued support.

Symposium: Mobility & Thalidomide Embryopathy

By Carolyn Desforges

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Key messages from the Symposium: Mobility Maintenance of People with Thalidomide Embryopathy – Prevention, Pain Therapy and Alternative Therapeutic Procedures, 22-24 October 2017 Hamburg

I stepped into Sue Kent's shoes with trepidation when asked to attend the symposium when Sue was unable to travel. Her knowledge and experience in the field of physiotherapy, and ability to communicate this effectively to our thalidomide community is skilled – I do hope these key messages are clear – please contact me should you have any questions....

I attended with Dr Dee Morrison, and Liz Newbronner (Researcher). Dee and Liz will be using knowledge gained to inform planned research and also ensure key information leaflets are developed as appropriate. The conference was hosted by Dr Rudi Beyer who runs a specialist clinic for Thalidomiders in Hamburg. It was well attended with about 200 attendees and a full 2 day programme of speakers from medical, physiotherapy and alternative therapies backgrounds. The conference was in German and we were grateful for the simultaneous translation provided by the organisers. There were also attendees from Italy, Sweden and Australia.

There was an emphasis on how we can manage our health, and for me the central message that we all have health preserving strategies within ourselves – we CAN influence our health at any time, was key. I have brought together the information into key points – I have written up notes from the whole conference – please email me should you wish to have a copy.

Managing Health - Is sitting the new smoking?

The general population used to be very active and it was estimated (in Germany) that people walked 20km daily with 90% muscular activity used for economic activity. Now, however, people often sit for 9 hours a day and in the US for 12 hours a day. We sit for breakfast, sit to drive to work, sit for lunch, sit for work, sit to drive home, sit to watch TV and to relax.



We know that being sedentary **and** working out is not enough. We need to be more active in the work place and at home. (I.e. sport alone does not compensate for a sedentary lifestyle). Studies have shown that if someone forced to be bedridden by illness, they lose power and muscle quickly. There is reduced immunity, increased resting heart rate, loss bone density, once thrombosis, pneumonia and reduced IQ.

There is an issue using mobile phones which can cause “widow” back (i.e. head sits forward on the spine). A head weighs 5 kg, if tilted forward it gives a dangerous load equivalent to 25kg load on the spine.

What can we do?

- **Sit up straight**, get up every hour- minimum 1 minute every hour.
- Have a **dynamic work station**, put phone etc. out of reach so you have to move to answer it.
- Do small **exercises when seated**, roll shoulders forward then roll them back. Set a reminder to do them.
- **Take the stairs** rather than a lift if you are able – otherwise ensure you have to move to different rooms
- If you stand and are at work, think about having a **standing desk**.
- Try out some sort of **sport or power training**
- Stretch arm, knee bend, sit down, get up without using arms, stand on one leg, walk/ jog.
- Use balls to massage back.
- If you have arthritis - important to improve **quality** of movement- optimise joint function, load/ reload the spine. Movement can eliminate pain so remain as active as possible
- Managing your weight is very important

Other key messages for managing health

- **Don't wait** until you are “sick” or have a problem or pain to start looking after one’s health
- **Talk** about your issues – this makes them easier to manage and put a plan in place – no “wall of silence’
- Developing understanding and **self-awareness** is all important. We need to have an idea of one's own limits, be able to explain our own circumstances, and understand the resources available to ourselves
- We need to use all types of “resources” to **help ourselves** – physical, psychological (positive thinking, motivation) and social (friends, family etc.)
- Seek **support** – a personal trainer will work with you to develop an appropriate programme for you and help us set realistic objectives
- Ensure you have a trainer who is willing to take time to understand you and your “**different**” situation.
- We need to **understand** why certain activity / exercise is beneficial – once we understand ourselves and what can help, we are able to evaluate the outcomes of action, and we are more likely to maintain motivation. This is so important as we need the motivation to be able to work on the programme EVERY day
- A **trainer can help** problem solve every day obstacles. Our bodies may have limitations but we can substitute different movements to work around our difficulties
- “**Alternative**” may be useful for you – e.g. Qigong, different massage approaches, mindfulness etc. Look around
- We need to be able to develop a persistent and long lasting feeling of being confident in ourselves

Managing pain

The symposium also covered some important aspects about pain management, it is important to have support from professionals as well as those in your everyday life - key messages to manage it are as follows :-

- **There is a difference between acute pain and chronic pain** and these need different pain management strategies. Think about where and why it hurts. You need to act - do you need a diagnosis? (NB. ensure you have ruled out all acute causes)

- **All pain has the potential to become chronic** – need to ensure this does not happen
- **Be aware** of the long-term side effects of drugs – alternative therapies (e.g. massage, mindfulness etc.) and psychological therapies can be very helpful
- **Take time to understand yourself** - How you perceive pain may vary on different days. Other negative influences in life can affect pain perception.
- **It takes time to get it better** 1-2 years - need to train the brain as well as the muscles – both have memories.
- **Know pain boosters** and be aware – stress, emotional upset, too much quiet, mindset
- **Know pain relievers** and use them- relaxation techniques, positive body awareness can reduce body tension, move around, activities you like to do
- **Monitor** your pain – perhaps keep a pain journal. Use of a pain scale (i.e. scale 1 – 10 where 1 = no pain, and 10 = worst pain)
- **Stay active whatever** – if one gives up, pain is harder to manage. Pain management can be improved by active strategies. Being passive does not work. Do activities you like to do but do remain active. Use relaxation, mindfulness etc.
- **Strengthen your own personal situation** – get support in place, investigate how to develop resilience
- **Train your memory/brain away from the pain.** This is by focusing on what you "can" do.
- **If you feel you are “falling back” - don't give up.** Take stock, start again, take small steps. Muscles are smaller when we don't use them, we need to gradually develop the muscles. Gradually increase your therapy. Your brain needs to say "you can do it".
- **Need to be brave** to face the pain
- **Be creative** when finding solutions. Have trust/confidence in yourself
- **Use positive language** to help yourself. Use all your senses to notice/ be aware of changes by seeing, feeling, tasting, touching, smelling.
- If you can manage the pain sensation, then you can **focus on what you enjoy**



On our way home... Dr Dee, Liz Newbronner and myself!

My Cancer Story

By Heather Clark

Hi, I'm Heather Clark. I was diagnosed with incurable Stage 4 Ovarian Cancer on 1 February 2017. I'm 56 years old. I just thought I was going through the menopause. My condition is managed by treatment; I'm currently undergoing chemotherapy. Long-term sick leave from work is allowing me time to raise awareness of the illness.



I was born with thalidomide related impairments but have overcome obstacles and challenges, enjoying a successful career working in television news for ITV Calendar. I'm also a qualified Clinical Hypnotherapist.

I loved singing and drama at school. I was good at English, French and German with thoughts of becoming an interpreter. Never understood maths and still don't! I left with disappointing results, eventually going to college aged 30 to study journalism. In the interim I worked in an office, jumped out of an aeroplane and fell in (and out) of love!



My passion (bordering on obsession) is horses. I rode for many years as a child but lost my nerve when balance in the saddle became harder as my artificial legs were made longer as I grew, meaning I spent more time hanging underneath the

pony than sitting on top! With a few adaptations, an amazing pony and a lot of support, my hobby became carriage driving. Competing in Horse Driving Trials on a level playing field against more physically able competitors, I've also represented GB at Para World Championships three times.

I am hugely grateful for all the support I have received from Ovacom - a charity founded by women with ovarian cancer. I am hosting a coffee morning in March which is Ovarian Cancer Awareness Month and Heather's Ball in September in Leeds, both of which are being held to raise funds for Ovacom.

Ovarian cancer is totally indiscriminate and it is my mission to make members of the public and the medical profession more aware of the symptoms. Often referred to as the 'silent killer' ovarian cancer is the sixth most common cancer in women in the UK. There are too many misdiagnoses. One of the



main symptoms is bloating and women are often mistakenly diagnosed with IBS. There is a misconception that ovarian cancer can be detected through the routine cervical smear. It cannot!

I want people to know about the symptoms, changes to look out for, not being afraid to go to your GP and not being afraid to ask for a second opinion!

Should anyone wish to help me to raise funds for the vital work carried out by Ovacome by making a donation, then please go to:

<https://www.justgiving.com/fundraising/HeathersOvacomeAppeal>

Heather has written a blog about her cancer journey:

<https://wheelsofsteelblog.wordpress.com/blog/>

In closing, I'm holding a charity ball for Ovacome who've been so supportive following my ovarian cancer diagnosis but I need your support!

All tickets to the ball have now been sold, however if you would like to make a donation please go to:

<https://www.justgiving.com/fundraising/HeathersOvacomeAppeal>

Ovacome Registered Charity Number 1159682

My Gym Workout

By Karl Davies, and Lotti Klatt

I have been working out with Lotti as my Personal Trainer for a number of years now. She is particularly qualified in using sports as a strength and rehabilitation therapy, and I think that she has achieved remarkable results with me.

I have lost 10 kilos since we began (from 90Kg, I'm now just over 80Kg and reducing), and my life has improved physically in many ways I couldn't have thought of. Take a simple example – after coming out of the bathroom having showered, my body temperature control used to be such that I had to sit still in as cool a temperature as possible to stop myself sweating so that I could get dressed. *Now* – this has totally changed, and the time I need has massively dropped –reducing from 20 to just 5 minutes.

I remember that my first time on a treadmill – it took me 15 minutes to run (OK mainly fast walk) 0.5 kilometres; now I can run 1.0Km in around 7 minutes and ran 5kms outside in the summer which would have been unthinkable before. Bending to reach things is now normal.

My flexibility is coming back, and my shape and posture is improving, OK – slowly, but I literally feel younger and other people have begun to comment on how well I look. I have never been so strong and my seemingly permanent knee and other joint problems which I have always been told will only get worse, have gone, and I have muscles across my shoulders too, as Lotti has created exercises to reach parts of me that never had muscles before.



My confidence has increased dramatically both in the gym and by extension into everyday life. Doing lunges on alternating legs, and single leg exercises such as leg press, and hopping, has built up strength evenly, such that now I have much greater confidence when standing on either leg to reach things, without fear of falling. Having equal strength on each side means that I have much less fear of being incapacitated by an injury to one side and reduces the risk of injury from ordinary activities due to greater stability and better balance.

My workout generally consists of 3 x 1 hour sessions per week, with a selection of cardio, strength, and power exercises. In the gym, Lotti sets the machines for me such as weights on the leg press, and treadmill speed.

We are seeking to create a series of exercise publications, based on all disability types, and abilities. We'll put these on the trust website too,



including videos, so that both you and a personal trainer can get an idea of what is feasible, and we invite contributions from individuals across the disability spectrum.



THAT MEANS YOU PLEASE.

Lotti has helpfully created the below table which lists the range of exercises from which she selects what we do, to maintain progress.

Exercise	What it works	Why we do it
Treadmill Run/Walk	Cardio & joint strength Great for glutes and legs Increase heart and lung strength and endurance	Confidence. Unilateral and bilateral work – strengthens both hips and increases stability
Incline leg press	Glutes, hamstrings, quads (thighs and bum) great for core strength	Incline is less weight through the knees and emphasises glutes more than thighs
Single leg incline leg press	Bilateral work focuses on the stability so stops knees from coming in	Hip stability and strength, more confidence
Dorsal/back raises	Lower back, glutes and hamstrings, erector spinae.	Strengthen lower back, and core, and therefore we can also work on posture – no curves or hunch.
Step ups onto high box, and jumps	Glutes and hamstrings in the thigh, and also quads, and glute adductors – (wider).	Strength through range and endurance. Hip dominant exercise. Higher to focus more on hamstrings, and increase strength through range of movement. The jump adds cardio but also works on power.
TRX lunge. Drop lunges off edge of box.	Quads, calves, glutes, hamstrings, core. Single leg work and a lot more core for balance.	Strength and stability. A lot more muscles are involved as need to stabilise. Single leg focuses on the strength of the muscles

Exercise	What it works	Why we do it
	One leg static, rather than having to stabilise with the TRX.	around the one hip, allowing more strength and therefore confidence standing bilaterally.
Curtsey – Forward Curtsey – Backward	Adductors, glutes, quads, hamstring, and calf.	Focuses on stabilisers. Rotation on the hip in a loaded state helps stability through range of movement.
Box jumps with squat – NO hard landing from start to finish.	Quads, hamstrings, glutes, core, cardio.	For strength and power in the legs. Turns strength into power, shows control of strength in the joints. The stronger you get the easier this becomes.
Single leg hops.	Calf, and hamstring primarily. The hamstring works to decelerate and control landing; glutes stabilise, and calf allows jump.	Promotes stability (glutes) and symmetry on bilateral work. One leg is always more powerful and movement becomes more controlled.
Sit up with leg raise. Sit up with VIPR.	Abdominals, obliques, rectus femoris (hip flexors)	Strengthens the core and allows us to get up without using one side only, and without using arms. Improves balance and posture, and grip.
TRX chest fly	Pectorals major and minor (chest muscles), and anterior deltoids.	Strengthens, and allows for more control in movement.
Leg extensions, and squat thrusts.	Quads (and hip flexors in Karl's case too.)	Strengthens the muscles around the knee, it's vital to keep the joint strong.
Leg curls.	Hamstrings, and glutes.	Strengthens the muscles around the knee, it's vital to keep the joint strong.
Assisted squats.	Glutes, hamstrings, quads, and core.	Strengthens core as well as all leg muscles – this is a great whole lower limb exercise.

Welcome, Cheryl Pinkney

Health & Wellbeing Team Administrator and Wellbeing Adviser

Cheryl joined the Thalidomide Trust on 6 November 2017 to take up the role of Health & Wellbeing Team Administrator and Wellbeing Adviser.



Tell us about yourself - family, previous employment

I live in Cambridgeshire and am married with two children. I've held administrative positions within the private, public and charity sectors, and have worked with young people and adults, supporting them with welfare issues, such as mental health, wellbeing, education, training and rehabilitation.

What is your role in the Trust?

My role as Health and Wellbeing Administrator and Wellbeing Adviser is the first point of contact for the Health and Wellbeing Team. I assist our Medical Adviser, Dee, with the support she offers beneficiaries with health issues, access to healthcare and with new claims to the Trust. I'm involved in the administration of research projects, and one big piece of work I'm looking forward to get started is the Cardiovascular Risk research project in conjunction with RNOH. I visit beneficiaries to carry out Holistic Needs Assessments, identifying any needs that are not being met and directing them to the right support, either within the Trust or externally.

What attracted you to the position?

The position is varied and challenging, offering the opportunity to work as part of a committed team in supporting beneficiaries, both as a group, and on a one-to-one basis.

First impressions about the work and your role?

When I was told that "no two days are the same" working at the Trust I wasn't being misled! I speak and meet with people all over, about a whole variety of issues and experiences. I've been able to learn some of the things that have worked really well for beneficiaries and share their successful ideas/approaches with others who have been struggling, as well as being able to offer other kinds of support. I thoroughly enjoy working in a team who have such a high level of dedication and wide-ranging skills.

What kind of things have you been doing in the first months of work?

In my first week I attended the Health and Wellbeing committee which gave me an early opportunity to meet some beneficiaries. Based in the office, I've been supporting beneficiaries by phone and email. However, I consider the best aspect of my role is to be able to visit beneficiaries in their own homes - this has given me a chance to get to know individuals and get a real sense of their differing needs and how the Trust can help, both now and for the future.

Can you tell us what sort of things you have managed to achieve (within the confines of confidentiality) to support some of our beneficiaries?

In my first three months at the Trust I've been able to assist with not only the big things: such as health concerns; following up referrals; and support around medical issues; but also the smaller things which can really make a difference to daily living.

I've provided administrative support to the team which has resulted in a number of beneficiaries securing good outcomes with their PIP applications.

I've researched aids and adaptations to make particular daily living tasks easier for beneficiaries, looked into specialist holidays and equipment, and identified appropriate local services to help with more complex emotional issues. I've also been able to put beneficiaries in contact with volunteers who have been able to offer guidance or provide emotional support.

Living in Jamaica

By Nigel Richards

Nigel is a beneficiary of the UK Thalidomide Trust, and he shares his experiences with us in this article.

Can you tell us a little about yourself?

My name is Nigel Richards and I am a Thalidomide beneficiary living in Kingston, Jamaica where I have lived for most of my life. I am a beneficiary of the UK Trust as I was born here in Kingston; Jamaica was a former British Colony and a member of the Commonwealth.

I was born with my left arm shorter than right arm, with four fingers on my left hand and five fingers on right. My right leg is shorter (by about 1"1/4' inches) than my left leg; my right hip joint is abnormal; my right leg faces outwards, not straight like my left leg. I had numerous corrective surgeries on both my hand and right leg, which have enabled me to have better mobility and function.

For my Primary education I went to St. Andrew Prep School after which I continued into secondary education at Priory High School in Jamaica. As my father worked as a Medical Consultant for the Malaysian Government for three years, I went on to finish my last two years of High School at the International School of Kuala Lumpur in Malaysia.



I did my tertiary education at St. Leo University in St. Leo, which is a small town just outside of Tampa, Florida, where I graduated with a Bachelor of Arts in Marketing and Finance.

After my graduation, I went on to work at the Bank of Nova Scotia Jamaica Ltd. for eight years, after which I decided to go work at the Sir. John Golding Rehabilitation Centre (a rehab centre for persons with disabilities) to set up an Orthotic Shop, which made and repaired wheelchairs, leg callipers, crutches, and artificial (prosthetic) arms and legs. It also provided persons with disabilities training skills and employment at the Orthotic Shop.

After my tenure at the Sir. John Golding Rehabilitation Centre, I worked for twelve years in the manufacturing sector at J. Wray & Nephew Ltd. who are the blenders and bottlers of the Appleton Rum Brand. I currently work as a Consultant for a small company.

Can you tell us what it's like living as a person with a disability in Jamaica?

Living in Jamaica and/or the West Indies as a person with a disability, I come across different levels of discrimination, as is probably the case in most other countries. In the West Indies the discrimination is possibly compounded by lack of awareness and the lack of programs ensuring inclusion of people with disabilities; thereby perpetuating the stigma for disabled people. However, this has not stopped me from living a normal life as I as I participate in several social activities. I was part of running club (1996- 2002), play tennis and go to the gym, so I do not let the stigma against persons with disabilities prevent me from doing what I set out to do.



As I have been having a lot of discomfort in both hips, I will be getting a double hip replacement in April this year. Mainly because of this, I have attended the gym regularly, two – three times a week (see embedded photos) and I take a Pilates class twice a week to maintain the mobility of my joints. My personal motto is to live my life with positive vibes.

Do you ever feel isolated in Jamaica and wish you had more contact with other Thalidomiders?

Most of my life was spent around mostly able-bodied people, and some of them or most of them have treated me with a lot of love and respect. I therefore don't feel that isolated, but at the same time I do wish that I could attend some of the activities and events that the UK Thalidomide Trust has been organising and perhaps access specialist services in the never future.



When I was younger I can only remember meeting one other Thalidomider - both our fathers were medical doctors. There is another Thalidomider who has told me that he remembers me at the Rehab Centre where we both attended when we were younger for rehabilitation.

I attended the 50th Anniversary Symposium in London 2015, and this was my first time amongst such large number of Thalidomide Survivors. Being able to see so many moving forward with their lives in a positive way which was both interesting and very inspiring.

What's New? The Trust Website

By Charlotte McCawley

Charlotte McCawley, Administrative Officer at the Trust has been working hard on updating and adding content to the Trust website.

She shares some of the recent additions to the website that readers might be interested to hear about:



Falls and Balance Awareness

In the 2015 Health & Wellbeing Survey, you told us that, although some of you have had falls [...]

[Read on](#)

The last 6-8 months has seen a lot of work being put into the new website to further improve the usability as well as the content we have for you. One thing we added last year are the new **“Beneficiary Articles”** which can be found under **“My Account”**. The Trust are currently writing the next one but we would like people to start engaging with these. They are different from regular articles because they give beneficiaries the ability to comment on the article beneath it and share their advice or experiences. The current one is on falls and balance which we know (from Holistic Needs Assessments) a lot of beneficiaries are experiencing problems with:

<https://www.thalidomidetrust.org/falls-balance-awareness/>

Another recent new area of the website being further developed is the **“Beneficiary Stories”** section which is really growing as we get more of your stories to share.

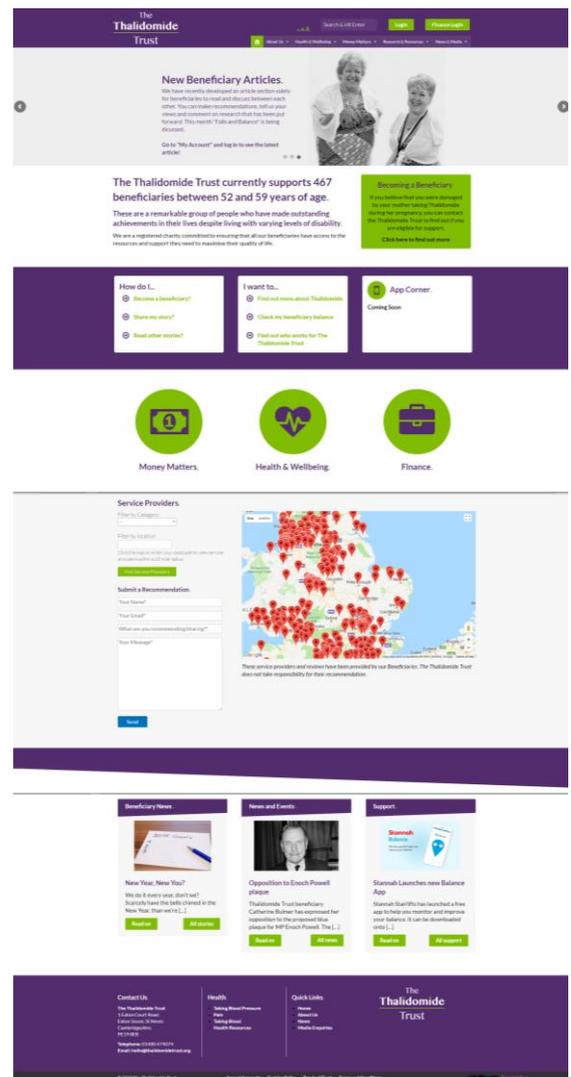
<https://www.thalidomidetrust.org/professional-resources-research/beneficiary-stories/>

The stories are split into categories and further stories are in the process of being added. Have you got a story to share with other beneficiaries? If so, please contact Charlotte:

charlotte.mccawley@thalidomidetrust.org

Some larger pieces of work are happening around a **“Beneficiary Community”** area which will eventually have forums and blogs (including guest bloggers) but may take a little longer to get up and running since it has to be trialled first. The development of this section of the website will make it much more interactive allowing beneficiaries to engage with the Trust (and each other) via the website rather than just providing a one-way conversation.

If you haven't visited the Trust's website for a while, why not pay it a visit? There is a new look Home Page too! www.thalidomidetrust.org



The screenshot shows the Thalidomide Trust website home page. At the top, there's a navigation bar with 'Home', 'About Us', 'Services', 'News & Events', and 'Support'. Below this, a banner for 'New Beneficiary Articles' features two elderly women. A central section states 'The Thalidomide Trust currently supports 467 beneficiaries between 52 and 59 years of age.' Below this are three circular icons for 'Money Matters', 'Health & Wellbeing', and 'Finance'. A 'Service Providers' section includes a map of the UK with red location pins and a form to 'Submit a Recommendation'. At the bottom, there are three columns for 'Beneficiary News', 'News and Events', and 'Support', each with a featured article and 'Read More' buttons. The footer contains 'Contact Us', 'Health', and 'Quick Links' information.

Contact Us

We do hope that you've enjoyed reading this newsletter.

The next edition will be published in the Autumn of 2018. If you've any feedback from this newsletter or would like to contribute to the next edition, please contact the newsletter editor, Karl Davies. DaviesKB@aol.com

Tel: 07790 492 967

If you need assistance to get your thoughts for an article into writing, then help can be provided!

Mission Statement

"The NAC is a user led group that exists to represent the beneficiaries of the Thalidomide Trust by working in partnership with the trustees and the staff.

Our aim is to give the beneficiaries the resources to meet their increasing financial, health and other needs.

Its work is underpinned by a belief in justice, dignity and equality."