

NAC

Spring 2015

Newsletter of the Thalidomide Trust's National Advisory Council

Hello and welcome to the Spring 2015 Edition of the NAC's Newsletter.

As well as more general news and information items, this edition brings you details about the proposed "Fit for the Future" event that will be taking place this year.

As part of thinking about future fitness and health issues, we have some articles from Thalidomiders about their experiences of losing weight and improving their fitness levels.

Also included is a progress up-date on the Campaign work, what is going on here in the UK as well as in Europe. We've also got an up-date from V-Tag with news on the portable bidet and some very useful information about the new Care Act 2014 that is currently being implemented across England.



There have been many staff changes at the Thalidomide Trust I am pleased to share news of these with you. There's a lot more inside...

In the next edition, we'd really like to share reader's short accounts of what it is like to live a life that has been impacted upon as a result of Thalidomide. These can either be reflections on past events, family relationships or positive stories about the very big difference to your life that the Health Grant has made.

Finally, a BIG thank you to Karl Davies, who has helped me in putting together this edition. It's quite a daunting task, but much easier working alongside someone else. I've done all the nagging and chasing, and Karl's worked behind the scenes to put everything together and make this latest edition look professional!

Please enjoy reading, as ever, if you'd like to contribute to the next newsletter please contact me.

Simone Illger, Newsletter Editor

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Chair's Up-date



Welcome to another packed and informative edition of the NAC newsletter. We hope you find it helpful - and thanks once again to Simone for preparing it with assistance from Karl.

The NAC is a unique beast. It is a collection of twelve individuals all of whom are willing to put themselves forward as unpaid volunteers to serve a large and varied community of beneficiaries to the best of their ability. There is no doubt that it can be very hard work. Putting on an event like NACAC, for example, takes a huge amount of time and effort and Karl has been involved in organising the last three. Thanks Karl.

As proof that we are not resting on our laurels we are now considering whether to host a new event: Fit for the Future. A great deal of time has already been spent considering what we might offer. We have been working closely with Trust staff on this and are now assessing whether there is enough demand from within our community to make the event a success. Thank you to those who returned the feedback form - please take a look at the article on FfF in this newsletter and send us your thoughts.

Thank you too to the hundreds of you who forward our campaign letters to your MPs. It really does make a big difference and we are encouraged by your involvement in our ongoing battle to persuade the German government to do the right thing. Please see the article by Phil Williams if you want more news about how the campaign is going.

Next month we say goodbye to three NAC members whose turn it is to retire. We also extend them our grateful thanks. Phil Williams has brought great skill and vision to the various roles he has taken on over the last eight years. Steve Sinclair has excelled in organising some very effective parliamentary presentations. Both Phil and Steve have served two consecutive terms and are unable to stand again this year. Karl has great organisational ability and has been a great asset for the four years he has served. We are grateful to all three for their hard work.

We are grateful that, despite admitting to you how much work the NAC can be, we have five candidates willing to stand for election to the NAC this year. Thanks to all five who have put themselves forward and we look forward to the unique skills the successful candidates will bring to the team.

If you have any feedback or comments you want to address to the NAC please remember that we are here to serve you and that we do want to listen.

God bless,

Nick Dobrik - Chair
Craig Millward - Deputy Chair.



Farewell to Linda Patching



Q How long have you been working for the Trust?

A 13yrs

Q You'll probably remember your first day at work. Can you share some of your memories of that day?

A I started as a Temp at the Trust when it was at the Shrubbery. I had been made redundant from my previous job so did not have any long term plans of the type of job that I wanted to do. I found everyone very helpful and become interested in what the Trust was doing.

Q What are some of the biggest changes you've seen during your time working for the Trust?

A Was moving to the new building at Colmworth and help implementing new ideas such as HealthLink and new technology.

Q What (if anything!) do you think you'll miss most about the job???

A I will truly miss talking to you all. I have learnt so much from our chats and hope in a small way I have been of some help and support. You have made me laugh and cry.

Q Conversely (if you're happy to share.....), what will you least miss?

A Minutes of meetings and typing them up

Q What are your plans for retirement? (hobbies? Family??)

A To take it easy for a while. Enjoy the 'time' which seems to pass so quickly these days. Spend more valuable time with mum, my 2 daughters and 3 grandchildren - with the 4th one due in August! Enjoy gardening and sitting out with a glass or two. In desperate need of a new bathroom so that will be on top of my agenda. Then I think I will investigate doing some volunteering work just for a couple of hours or one day a week.

Q Any special places you are looking forward to visiting?

A Looking forward to holidays and travel more but nothing booked as yet. I will go with the flow! At least now I can go off at the drop of a hat.

Q How would you like to be remembered by beneficiaries?

A Someone who you could speak to who would listen.

Linda added the following

"I would like to thank everyone for my John Lewis retirement collection and all the lovely gifts, cards and wishes that I have received. I will enjoy spending time looking around John Lewis! I am privileged to have known all you amazing people, many of whom I regard as my friends and will never forget you."

"THANK YOU for the memories that I take away with me. Love to you all – Linda"

Welcome to Fiona Ball - HealthLink Co-ordinator



Q Can you tell us a bit about yourself please?

A I grew up in Northumbria and the Lake District, I moved to London in 1983 to do my Nurse Training and now live in rural Northamptonshire. I have two grown up children, one of whom is disabled, I have a grandson and love to spend time with family or in my garden.

Q What were you doing before you came to work for the Trust?

A I have just finished working on a pilot scheme to help people who have survived cancer get back to full health and before that I have specialised in Multiple Sclerosis, Parkinsons Disease and physical disability.

Q What attracted you to this post?

A I like the idea of being able to help in a holistic way and to be able to use my practical problem solving skills to their fullest.

Q What past experience is relevant to this role?

A My very first job pre nursing was in Holehird Cheshire Home. Following my nurse training and degree I worked for various charities, including Lambeth SHAD, Contact a Family and Parents for Inclusion, before returning to nursing after stint as community development worker for Parkinson's UK. My enthusiasms are many and varied but I'm experienced in chronic pain and chronic fatigue management to name a couple.

Q What are your first impressions since you started work?

A Everyone has been very welcoming so far

Q What are the plans for your first few months in post?

A I would like to get to grips with the main issues that are affecting Beneficiaries and begin to make contact with anyone needing help or advice. I look forward to getting to know as many Beneficiaries as possible.

Welcome Michelle Robinson - Health & Wellbeing Team Co-ordinator



Q Can you tell us a bit about yourself please?

A I have lived in St Neots all my life, all my family live in the same area. I am married with two daughters. Outside work, I enjoy spending time walking my dog and looking after my Dad.

Q What were you doing before you came to work for the Trust?

A I worked for a large housing association, providing care and housing for people aged 55 and over. I thoroughly enjoyed the role as it gave me the opportunity to meet people making sure they were receiving the right level of support and to listen to how we could improve services.

Q What attracted you to this post?

A It looked a very interesting and challenging role and one where I could use my previous skills and experience.

Q What past experience is relevant to this role?

A I have experience of working both in the office environment and being out and about visiting residents in their home to discuss their support needs. I have previous experience of being an office manager and team administrator, where by working with residents and staff we have improved services.

Q What are your first impressions since you started work?

A Everyone has made me welcome. Everyone works hard to provide a good service. I am impressed with staff in the office and the knowledge and understanding they have of individual beneficiaries.

Q What are the plans for your first few months in post?

A I am looking forward to getting to know and speaking to as many Beneficiaries as possible, to see where we can make improvements in the office and within the HealthLink team, to improve our service around communication and the general correspondence we send out.

Communications working group update

By Mikey Argy



Recently we sent out a Communications Survey and we will be following up on those who did not respond. It is important we hear your views.

The Communications Committee currently has its meetings over Skype calls. This is a very easy way to share ideas and saves on travelling time and costs. Terms of reference are still yet to be agreed and when done so we will be inviting a member of the VVs and a non NAC non VV beneficiary to join the Committee so that we have a joined up approach.

We get a lot of interest from the press and the media and we are looking for individuals who would be willing to share their stories. We are conscious that only a small amount of voices get heard, and we believe that more of you may like to share your stories. If you are happy to be one of these people do please let Lynsey (**ed: at the Thalidomide Trust**) know. Generally the press have an angle they are aiming at; and usually we have a message we want to get across; and so we will ensure that you will be briefed about the current status of the campaign at that point and encourage you to weave our message into your story.

It is important that if you want to be kept updated about any subject that you let the Trust know. The Trust will soon be able to make email groups and allow the NAC, the Campaigns Team, and the Communications Committee etc to email you as a group with your email hidden from the NAC (but not the Trust staff). We cannot always rely on Facebook to disseminate our news as we know many beneficiaries do not join in on the groups there.

The Trust is updating its software too which will enable a much easier flow of information.

Extended discounts on Oyster in London

By Phil Williams

Do you use an Oyster card for travel in London? If so, your **1/3 off** with a Disabled Persons Railcard has been extended to **peak pay as you go single fares and peak daily cap**.

Your discount applies for journeys on National Rail, London Underground and DLR services in London. If you already have the Railcard off-peak discount set on your Oyster card, **you will need to have this updated** to get the new discount on all pay as you go single fares and daily caps. You can do this at any London Underground ticket office or National Rail ticket office that issues Oyster cards.

If you don't currently have the Disabled Persons Railcard discount loaded on your Oyster, you can do this at any London Underground ticket office or National Rail ticket office that issues Oyster cards, simply show them your Disabled Persons Railcard and they will apply the discount.

If you're not an Oyster user, you will still benefit from 1/3 off an Off-Peak Day Travelcard, for both you and someone travelling with you.

Please note:

From 17 May 2015 the special concession allowing Disabled Persons Railcard holders using Oyster to buy a Child rate Off-Peak Day Travelcard for an accompanying person will no longer be available. Instead, you can get 1/3 off an adult Off-Peak Day Travelcard for someone travelling with you.

For further information about the discounts offered and about the Disabled Persons Railcard, visit this link

<http://www.disabledpersons-railcard.co.uk/buy-a-railcard/what-discounts-do-i-get>

Telephone

0345 605 0525 (7am to 10pm, Monday to Sunday)

Please have your Railcard and credit/debit card to hand.

Textphone/minicom renewals (for customers with hearing impairments)

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Post

There's no need to fill out the full [application form](#) (PDF format - 113kb), just write your Railcard number in the "Renewals" box, notify us of any address changes then sign your form and send it to:

Disabled Persons Railcard Office

PO Box 11631

Laurencekirk

AB30 9AA

The Care Act 2014

By Simone Illger

If you have a disability or care for someone with a disability, the Care Act 2014 applies to you!

What is the Care Act?

The Care Act is a new law about care and support for adults in England that will come into action in April 2015, making one new law saying what people will be able to get and what councils will have to do.



The main themes of the Care Act are around promoting:

- Wellbeing- giving people greater choice and control to be independent and providing advice and support.
- Carers entitlements and rights: carers will be entitled to their own assessments to see if they are eligible for support and the same rules will apply all over the country.
- A lifetime cap on care costs: there will be a limit to the amount you will have to pay for care in your lifetime (this will not come into force until April 2016).
- Advocacy: the council must find you an independent advocate who will help you and represent your best interests to get the right services if you are unable to do so.
- Keeping adults safe: This is the first time we have had a law telling councils what to do to help keep adults safe from abuse or neglect.

The Bill proposes new rights for carers ...

Assessing needs

The Bill proposes new rights for carers, so that for the first time they will have the same rights to assessment and support as those they care for. This replaces the existing law, which says that the carer must be providing “a substantial amount of care on a regular basis” in order to qualify for an assessment. This right is based on the appearance of needs regardless of financial resources or level of needs for support. This assessment will consider the impact of the caring on the carer.

Crucially the legislation also includes an assessment of the day-to-day life outcomes that the carer wishes to achieve. These include whether the carer is able or willing to carry on caring, whether they work or want to work, whether they want to study or do more socially.

..... the whole family is also now entitled to an assessment

The Care Act relates mostly to adult carers. Young carers and parent carers who care for disabled children can be assessed and supported under the Children and Families Act 2014. However the whole family is also now entitled to an assessment when assessing an adult’s need for care. This has implications for young carers as local authorities will have a duty to consider the needs of children living in households where there is an adult who has a disability or impairment that requires help or care.

The act also enables children to have their own carers' needs assessment carried out, and introduces a new right for young carers aged 16 to 18 who are transitioning to adulthood to have their specific needs assessed in light of how their role might change.

The measures, alongside those introduced in the Children and Families Act 2014, aim to identify child carers and their support needs earlier. Young carers on becoming 18 will then have to request an assessment under adult law.

Eligibility and charging

..... the local authority must decide whether the carer's needs are 'eligible'..

When the assessment is complete, the local authority must decide whether the carer's needs are 'eligible' for support from the local authority, depending on the carer's situation. The Care Act puts in place a national eligibility threshold setting one national level at which needs are great enough to qualify for funded services.

At the moment, each local authority sets its own eligibility threshold based on guidance. This means that the amount – and type – of care that is provided by the council can vary depending on where a person lives.

Where at least some needs meet the criteria the local authority must consider what could be done. If none of the needs meet the criteria the local authority must still provide a written record of advice on what could be done to reduce, prevent and meet needs.

The carer may be entitled to support if:

- They are assessed as having needs that meet the eligibility criteria;
- The person they care for lives in the local authority area

The local authority must then carry out a financial assessment to decide whether the carer can afford to pay. In circumstances where a carer has eligible needs but has assets above the financial thresholds and has asked the local authority to meet those needs, the local authority can charge for these services. They may also charge for putting in place the arrangements. If supporting a carer involves providing care to the person being cared for, and the local authority chooses to charge for that type of care, then the authority must carry out a financial assessment of the person who is being cared for. This is because the care would be provided directly to that adult, and not to the carer.

There could potentially be some ambiguity surrounding whether a service is being provided to the adult with care needs or to the carer. This is important because the person whom the service is provided to is the one that will be charged.

From April 2016, the Care Act will introduce a cap on care costs and will provide new financial protection for those with modest wealth. The cap means that people will be responsible for their care costs as assessed by the local authority, up to the cap if they can afford it.

Additionally, people with modest wealth or around £118,000 worth of assets (savings or property), or less, will start to receive financial support if they need to go to a care home. The amount that the Government will pay towards someone's care and support costs will depend on what assets a person has.

For the first time, there will also be a system by which people may appeal against council decisions on eligibility and funding for care and support.

Support Planning, Personal Budgets and Direct Payments

Where a local authority is under a duty to meet a carer's needs they must prepare a support plan which sets out how they will be met. This might include help with housework, buying a laptop to keep in touch with family and friends, or becoming a member of a gym so that the carer can look after their own health.

Carers should also receive a personal budget, which is a statement showing the cost of meeting their needs, as part of their support plan. If a person is found to have eligible needs but do not receive local authority support (for financial reasons or from choice) they will be given an independent personal budget. This will be equivalent to what the local authority would pay for that person's care and support, if it were meeting their needs. Both budgets will be the rate at which people progress towards the cap.

Carers also have a right to request that the local authority meets some or all of such needs by giving them a direct payment, which will give them control over how their support is provided. Under the Act people who use services, and carers, will now have legal rights to a care and support plan. Previously this only applied to direct payments, with the rest only being set out as guidance.

Continuity of Care

"Continuity" means making sure that there are no gaps in care when an adult who is receiving care moves home from one local authority area to another. This also applies to the needs of any carer moving with the person. The continuity duty continues until the second authority has carried out its own assessment and put in place all necessary care and support.

"Continuity" - no gaps in care when an adult receiving care moves from one local authority area to another.

Provision of information and advice

The Act places a duty on local authorities to establish an information and advice service about how the system operates in their area, the choice and types of care and support available, how to access care and support, how to access independent financial advice on care issues, and how to raise issues of concern. This includes the provision of information and advice to carers.

Advocacy

An improvement from the original Bill is the inclusion of the duty to provide independent advocacy to represent and support an individual if needed to facilitate their involvement in assessments and preparing support plans. This includes advocacy support for carers, carers of children at transition age and young carers at transition age.

If you'd like more detail on the 2014 Care Act and how it might affect you, you can download factsheets covering the following topics:

- Who is entitled to care and support;
- Assessments and eligibility;
- Care and support planning, charging;

- Continuity of care;
- Safeguarding – protecting adults from abuse or neglect.

here: <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets>

Employing my first Personal Assistant (PA)

By Liz Buckle

Some thoughts on my year of admitting I needed regular practical assistance, asking for it, getting it, and becoming an employer in my own home.

Q Did something happen to make you realise you needed more support than you had?

A I'd been relying more on Jeremy (my partner), friends and neighbours to do things for me, for a few years now. But I came to realise my life was shrinking as I wasn't coping – a year ago I realised I had to do something about it. I spoke to my Occupational Therapist, who did a thorough assessment of my needs and set me on the path to receiving Direct Payments from my local council.

... I came to realise my life was shrinking as I wasn't coping

Q How was the experience of having an assessment of your support needs?

A It took 6 months and 4 visits (of OT and Social Worker) to complete my 'needs assessment' and a financial means test, then for the council to make their decision. I was awarded 15 hours a week of assistance, to be paid to PA's employed by me directly. I was anxious about being assessed so intimately, getting dressed and showing how difficult it was to change the bed (someone should film an upper-limb Thalidomider like me changing a duvet some time!!) – but it was an important step to go through in 'accepting' I am not coping, and how that is putting extra strain on my body.

... I decided to split the job two ways into a 'home-based' PA and a 'going-away-from-home PA' to accompany me on longer distance trips.

Q How did you go about finding someone?

A It took a while to work out what I was really looking for, and I discussed this quite widely amongst friends and advisors – I decided to split the job two ways into a 'home-based' PA and a 'going-away-from-home PA' to accompany me on longer distance trips. I recruited by advertising in the local paper, putting up notices locally and word about. I didn't get many applicants who were suitable for interviewing, I live in a very rural area and this kind of social care support in the home hasn't caught on much in rural Argyll. However, I got lucky and several of the people who applied turned out to be keen and willing.

Q Tell me about the experience of having someone helping you in the home?

A Living as we do in a very small house, it has been intrusive for Jeremy to have this extra person bouncing around and doing things round the house, and all the talking that goes with it!

... for me so far it has been brilliant.

He doesn't know where to put himself when my PA is here. Otherwise, for me so far it has been brilliant, but I'm probably still in the 'honeymoon' period. Long may that last.

Q What message would you give to anyone considering getting some support in the home?

A It's quite a complicated process to go through the assessment and setting myself up as a new employer. I found someone locally who was experienced in these processes, she held my hand and steadied my nerves – I also got advice on specific queries I had from the VV's via the Trust.

Q What's been the biggest surprise in having the help?

A I had a dream the night after my first PA started – I think that dream was about the realisation my life was going to expand again and get easier, it was such a profound relief I cried that morning when I woke up.....

... being an Employer really doesn't seem to be that difficult.

Q Was there anything about the process that you didn't anticipate?

A Having a review of my needs and financial situation just 6 months after being initially assessed (regular reviews are part of the self-

directed support system, I will get used to that), and the fact that being an Employer really doesn't seem to be that difficult.

Liz Buckle

Fitness Foreword

Following the NACAC event in October 2013, a number of beneficiaries, inspired by the sessions on weight loss and exercise, identified ways to make some lifestyle changes. By sharing their stories we hope to inform and inspire others.

If you have found a way to make changes to your lifestyle, either finding a form of exercise that you enjoy or managing to lose weight successfully, please do contact us if you are willing to share your experiences, as we know that our readers enjoy hearing of others successes.

It's never too late to improve

By Ed Freeman

I have battled with my weight problem from the age of eleven after giving up my prosthetic legs and starting to use an electric full time.

Over the years my weight significantly increased and I went from one fad diet to another without any long term success. At the age of 19 it was suggested my metabolic rate was measured and I was informed to lose

weight permanently my calorie intake had to be around 900. It was initially a great success but after a few months I started to increase the calories (I have the appetite of an able bodied man of my age) and not keep any record of what I was eating. Feeling that I was failing, I gave up!

I was totally inspired and realised I had a choice and the ability to change my future.

I yo-yo dieted until about six years ago, when I thought it impossible to eat well and still keep the fat off. For four years my weight ballooned and I turned a blind eye to it. Gradually I was becoming less able. I started to find it difficult to cut up food, drive my van, transfer from my wheelchair to the toilet and even sit up in bed. I put it all down to getting old. I was after all in my 50's! I even thought my arms must be shrinking (not that my chest was getting bigger). I wasn't very happy with the situation at all and my future was looking pretty bleak.

By keeping a record it not only kept me on track but turned it into a competition with myself

Fortunately at this point I attended a NACAC Meeting and one of the speakers, Simone Illger told a story of her battle with a weight problem and how she successfully beat it. I was totally inspired and realised I had a choice and the ability to change my future. As soon as I got home I downloaded the application (myfitnesspal) that Simone recommended. I filled in my details and



away I went. Every day I input what I eat and drink and the app adds up my calorie intake. Each week I weigh myself and put that into the app too. The app then produces a chart of my weight loss.

By keeping a record it not only kept me on track but turned it into a competition with myself and in just two months I lost 21 pounds and this was without

..... in just two months I lost 21 pounds and this was without exercising.

exercising. Eating by way of calorie control has now become a way of life. It means I can eat what I like, just as long as it's within the calories allowed. Occasionally on holiday or at a party etc., I will exceed my limit, but I no longer feel guilty that I have and then give up. I just eat less for the next few days and get back on track.

Now I can cut up my own food, drive my van and transferring from my wheelchair is a breeze. I no longer sit up in bed, I spring up... I have now regained the abilities I had lost to over indulging in food and drink for so many years.

I know this is a lifelong battle but it's a battle I will win!

Achieving my goal weight with Slimming World

By Jacqueline Thomas

I suppose problems with my weight started in my twenties. Even though I was fairly active in comparison to now I was aware I was gaining weight but couldn't understand why! I watched what I was eating but people who I bumped into who I

Even though I was fairly active in comparison to now I was aware I was gaining weight but couldn't understand why!

hadn't seen for a while used to say "you've put some weight on". Yes it did hurt, although I'm sure they didn't mean it nastily but was merely an observation from them.



It wasn't until I was trying to conceive in my late twenties that through a simple blood test, I was diagnosed with an underactive thyroid gland, also called hypothyroidism. This is when the thyroid produces less thyroid hormone than it should, which causes the metabolism to run too slow. At the time I had never heard of this condition. Amongst other symptoms, one of the common signs of this was unexplained weight gain. It is not usually a serious condition and can generally be treated successfully by taking daily medication to control the levels but needs to be monitored regularly by testing the blood.

From that time (1990) the weight dropped off me initially and I felt much better in my health but gradually I felt the weight slowly creep back on. I don't know why other than my arthritis was getting worse and I was in a lot of pain. It was like a vicious circle because as my weight increased I found it harder to walk round and exercise so my weight increased even more.

It wasn't until I was forty (1992) when my friend bought round some scales in the month of June and standing on them made me realise that I had gained a whole 2 stone! I was horrified. Even though I didn't think I had changed my eating habits much I knew I couldn't carry on the way I was going. I decided to do something about it and followed the advice of my friend/PA Gail who had 'done' slimming world before. By Christmas of the same year I had lost that 2 stone and felt again much better for it.

I could barely walk round the house without being in pain in my knees and hips.

Again a number of years on and my weight slowly crept back on but this time I could tell it was more than the 2 stone I had previously put on and had lost. I could barely walk round the house without being in pain in my knees and hips.

At the end of March 2013, my daughter Katie asked me to go to our local Slimming World Club with her and I thought if I'm going to accompany her I might as well join myself! This was when the reality really hit home and I had to face up to how much weight I had gained - to be in my healthy BMI range I needed to lose at least 3.5 stone! I was mortified.



I came home armed with books and food diaries but to be honest I was a bit sceptical at the time because not only did I have an under active thyroid but my mobility wasn't great either and thought I wasn't going to lose the weight and there wasn't much point "me doing it"!

I was encouraged by Katie and Andy, my fiancé, and thought I will see how it goes. The first week I lost 3lb, although Katie lost 6lb and I thought nevertheless mine is still a loss. Week by week I attended the group and each week I came home pleased with a loss of 1-2lb a week. By 24 April I had been given an award for half a stone and by 15 May I had lost a stone. At this point I thought I can keep doing this. The weight was coming off, albeit slowly, but it was coming off.

I did stick to it religiously though and I can honestly say it wasn't easy. This time, I think because I had committed to attending a group I was determined I was going to keep it up. The only person I was letting down

at the end of the day was myself and I didn't want to face the shame (as I felt it anyway) in front of everyone else having to admit that I'd had a gain each week.

I was also seeing visual differences in the mirror and obviously my clothes were getting much too big for me. Also, my mobility seems to have improved. I can now find myself standing for longer periods of time and walk round the house without being in so much pain.

I would certainly urge anyone else who has thought about wanting to lose some weight to just do it. I feel I am proof that it can and does work.

By the end of 2013 I had lost 2.5 stone with just one stone to get to my target weight I had set myself. I could see light at the end of the tunnel. I WAS going to get to my target weight. It was more difficult though towards the end and the weight seemed to be slower than slow but I'm very proud to say that I got to my target weight of 8 stone 7lbs on 2 April 2014 (exactly 53 weeks) after I joined Slimming World and have become a Target Member which means as long as I stay in a bracket of 3lbs under or 3lbs over my target

weight I no longer have to pay the £5 a week to attend the support group. For me it's not about paying the money each week but about maintaining my new healthy weight.

I still go most weeks to the group to encourage other people and talk with friends whom I have met on this journey too, which I thoroughly enjoy and I would certainly urge anyone else who has thought about wanting to lose some weight to just do it. I feel I am proof that it can and does work.

If it hadn't have been for Katie I wouldn't be in the position I am now. I feel so much better in myself. I can move around a lot easier and it has given me new found confidence as well as health benefits such as not contracting diabetes and having normal blood pressure, both of which I know are associated with being overweight.

I have been chosen by fellow members of my Slimming World group to be receive the title of Miss Slinky 2014

I've been at my target weight now almost a year and intend keeping it that way. I feel much better for it.

I felt very honoured recently to have been chosen by fellow members of my Slimming World group to be receive the title of Miss Slinky 2014 and as a result to be automatically entered into the national competition. I didn't win the national title but then I wasn't really expecting to. There are a lot of people out there who have lost a considerable more amount of weight than I have but I am proud of my achievement.

I have managed to keep my weight off by still sticking with the slimming world plan and of course attending group each week, which keeps me focused. I have FREE life long membership now providing I keep within 3lb under/over my goal weight.



My Journey to Losing Weight

By Bob Hepple



Early December 2012, I was asked by my Doctor to attend a clinic at our local surgery, which as being held by a visiting Diabetic Specialist, my diabetes at this point was becoming uncontrollable, the medication needed to control my sugar

levels, imposed other issues and was affecting my life on a daily basis.



The next stage in my treatment as my sugar levels continued to be unstable, would leave me with no option but I would become insulin dependent! The Specialist recommended a change in my medication, eating habits and exercise.

I am a four limb deficient, exercise and movement was an issue, I was already suffering joint pain, the change in medication helped but I still have to plan my morning activities, as the combination of tablets can upset the tummy, so that left me with making changes to my eating habits.

Food! I stopped eating potato, rice and I never liked pasta, I increased my salad intake daily, cut out bread, I never ate large plates of food so quantity wasn't an issue, cut out salt, this was hard, as I don't have very good taste buds, desserts! I have a sweet

... my sugar levels have dropped significantly, to the point I have now been taken off some medication ...

tooth but fortunately my wife doesn't and we would waste more than we ate, so we just stopped buying or making cakes etc.

taken off some medication, I have lost over a stone in weight and I have gained back the ability to move around much easier.

I have maintained my diet, it hasn't been easy and at times boring but the results are, my sugar levels have dropped significantly, to the point I have now been

I am still continuing my journey!!



Weightloss without exercise

By Cathy Hillock

I have been aware for a long time that I was overweight and really need to do something about it, but I just couldn't seem to find the will power to focus on the task.



I was and on certain days still am a comfort eater. I was 12st 7lbs (at just 3ft 10 inches!) at my heaviest which disgusted me but still didn't inspire me. After coming home from the NAC meeting in October I downloaded My Fitness Pal App, and started counting calories. I didn't set myself any stupid goals and never made a big thing about going on a diet. I set my daily allowance at 1200 calories which was probably too high but one I could cope with. Slowly the weight began to come of a 1lb one week 2lb some weeks. I started to notice my clothing was getting bigger I was a size 18 in a skirt now if the skirt is elasticated I can wear a 14, those with fixed waist came down to 16. Friends and family started to notice the change but if I am totally honest when I look in the mirror I can't honestly see the weight loss, my clothing is what I see changing.



Exercise would be a help but I have so much joint pain, which probably is due in some part to my weight, I can't do any impact exercise. I have recently though managed to find a swimming pool which is not far from here and can be hired out privately for £20 for one hour this may seem steep but I can take up to 6 people with me and that will spread the cost, if I want. I hate using public pools but will if I have to.

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... I can now wear a necklace my niece bought me for her wedding 6 years ago.

I am now 11st which I am extremely pleased with and once I start swimming weekly this should improve the

weight loss and hopefully my body shape.

The thing that I am most pleased with is the fact that I can now wear a necklace my niece bought me for her wedding 6 years ago. It never went round my neck and now I can wear it with pride 6 years to late but I am delighted.



Up-date on the Firefly Project

By Simone Illger

In April 2010, the Departments of Health in England, Scotland, Wales and Northern Ireland made a grant of £26 million to Thalidomide-impaired people to help them address the exceptional health and health-related needs they experience.

What is the Firefly Project?

The Thalidomide Trust has asked Firefly to carry out a three year evaluation of the grant to provide evidence of the impact of the grant on the health and well-being of individual Thalidomiders, and assess how the grant has enabled individual Thalidomiders to reduce future health needs. Firefly are working with a group of 60 Thalidomide-impaired people across the UK to explore their experience in depth, as well as linking with wider work being carried out by the Thalidomide Trust's National Advisory Committee on the costs of living with Thalidomide impairment.

..... assess how the grant has enabled individuals to reduce future health needs.

2013 Report

Firefly's 2013 results, the report is now complete and a 2 page lay summary is nearly ready to put up on Trust website.

Liz Newbronner, the Researcher working on the project is offering to examine the responses from the 2013 questioning further, to write topic-papers on those subjects of most interest and use to the Trust.

The 2015 Questionnaire

It was decided that the two main subjects for topic-papers will be a) employment and b) beneficiaries' experiences of using health and care services. Firefly will complete these topic-papers by April 2015.

Liz Newbronner was tasked with examining the transcripts from the interviews for reasons as to why Thalidomiders had either changed what work they did, reduced hours or indeed, given up work altogether.

Liz was advised that figures and quantitative information relating to loss of earnings and pensions would be particularly helpful from a campaigning point of view and to enable a very real understanding about the true costs for those affected by Thalidomide.

The main thrust of the 2015 questionnaire will be repeating a generalised set of questions about employment, with a comprehensive set of questions around health problems and experiences around the involvement of health and social services.

It's planned to use questions to ask about experiences of getting support from social services, perceived deterioration, changes in personal circumstances and the knock on effect of these, whether beneficiaries feel they are getting the right support, their experience of both primary and specialist healthcare. Questions will also explore whether people have given thought as to

how they will manage in the future and whether they're expecting to change where they live in the future (Paradise) or what their concerns are should the health grant come to an end.

A proposed timetable was circulated showing how the monitoring project will progress over the next 16 months so that progress can be monitored and reported to meetings and deadlines achieved.

Fit for the Future

By Simone Illger

A letter and questionnaire were sent out on the NAC's behalf from the Trust offices in November 2014. A total of 45 responses were received back and the results of those questionnaires are summarised below.

Over the coming weeks, Trust staff will be calling a number of beneficiaries who are known to HealthLink to establish their interest in attending the event.

We are presently looking at suitable venues in which to hold the event which will take place in the Autumn of 2015 or Spring of 2016.

In the meantime, if you didn't respond to the questionnaire, a copy is attached for you to complete and return as soon as possible. We would really value hearing your thoughts and ideas on what would work for you and make this event as useful and as interesting as possible.

Summary of Fit for the Future Questionnaire – as at 14th January 2015

The questionnaire was sent out via email and by post to beneficiaries on 20th November 2014 asking for responses to be sent back to the Trust by 12th December 2014.

Responses

A total of 45 responses to the Fit for the Future event have been returned, summarised as follows:

Topics to be covered at the event

Most of the suggested topics were ones which people would like to hear about, with pain control and relief coming out on top. Less popular subjects were ear reconstruction and prosthetic ears, corrective eyesight surgery, mobility and wheelchairs and limb prosthetics plus supporting and caring for elderly parents being less popular. The numbers over the popular topics were fairly well spread around both health and well being and finances / planning for the future.

Format of event

Most people wanted to hear from expert/professional speakers, and other suggestions for formats were equally supported, with "small group discussion" being the least popular format for the event.

Location of Event

17 out of 45 respondents were happy to travel anywhere in the UK to an event. North/Midlands/South/London were more or less equal (11 or 12 votes each) in terms of

preferred location, with Northern Ireland, Scotland and Wales all being roughly equal and having 8 or 9 votes each.

Length of event

A Saturday to Sunday evening was the most popular choice (17 votes) followed by Two days with overnight stays (14 votes). 8 votes were given to a one day event (10am - 5pm) and 11 votes to a one day and one overnight event.

Financial contribution

Most respondents (19) selected that they were willing to make up to £100 contribution towards the event (the highest amount) followed closely by 15 people being willing to contribute up to £50 towards the event. 6 people said they'd be unwilling to make any financial contribution.

Accommodation requirements

11 people said they'd need an accessible room, 28 people said they'd need car parking, there were 10 wheelchair users and 22 people said they'd be bringing someone with them (PA or family member).

Assistance

Over half of respondents (25) said they'd be interested in having some "general" support at the event (carrying, opening doors, etc). I think this figure was particularly interesting and supports my personal view that "general" support at any event we organise would be extremely valuable and welcomed by those attending. 19 respondents said they'd bring their own personal assistant along.

National Advisory Council to The Thalidomide Trust

Members: Mikey Argy
Freddie Astbury
Rowland Bareham
Karl Davies
Nick Dobrik – Chair
Simone Illger
Darren Mansell
Louise Medus-Mansell
Craig Millward
Steve Sinclair
Guy Tweedy
Philip Williams

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St Neots
Cambridgeshire PE19 8ER

administration@thalidomideTrust.org
www.thalidomideTrust.org

Date: March 2015



HELP TO PLAN THIS EXCITING EVENT!

Dear Beneficiary

Fit for the Future is an event being organised by the National Advisory Council in conjunction with the Thalidomide Trust.

You may have heard or read about this event in the past (it was previously referred to as “Fit for Fifties”), but we are now making it happen! The event will take place in 2015.

Many life issues are becoming more important to Thalidomiders as we enter our fifties. We need to know what YOU would like from the **Fit for the Future** event, in terms of format, location, subject matter, etc.

We would be really grateful if you would complete the attached questionnaire, adding your own ideas, thoughts and requirements to enable us to plan and organise an event that is what YOU want it to be.

A handwritten signature in black ink that reads 'N. Dobrik'.

Nick Dobrik

Campaign Up-date

Mikey Argy & Phil Williams

Please forgive us if we have not always communicated as regularly and in as much detail as you would have liked. We are over-worked and prioritise the "doing" rather than "talking" about doing or about what has been done!

Some sensitive matters we simply can't share immediately and though giant strides are being made, it is still awkward to share information easily, cheaply & quickly with every beneficiary reasonably simultaneously. However, you know you can contact us at any time. Or monitor the web-site www.fiftyyearfight.org

Progress remains encouraging. But we must never relax. We must work harder.

In the UK, we are fortunate we have the experience, the time & the team to campaign; run on a very very tight budget & many of us pay some of our own costs. Our overseas colleagues are not so fortunate but we are lending them as much assistance as possible.

EU Campaign Activities

There is so much happening.

It is very important that we work together. Especially in the EU. The steps are:

1. Meet the German Government at a ministerial level
2. Show the evidence to them so they accept they have a moral responsibility to help us all. They must act quickly on humanitarian grounds.

3. Then each country will obviously have different financial needs to present separately

In the UK & in Sweden (inc Denmark & Finland) we already receive some money from our own Governments. We have formal structures in place. But we are still very different to each other in the way our Thalidomide impairment is assessed and how the money distributed. In the UK, we have a 'Securing Our Future' Report and can demonstrate how much we need per person in the UK. In addition, we are very lucky that it is known who the Thalidomide survivors are. You might be interested to know that since 2005, the Trust has accepted around 20 new Thalidomide survivors.

In Spain & Italy, their circumstances are very different to ours and indeed to each other. The vast majority of Thalidomide survivors have still had very little, if any, financial assistance! They are very loosely organised and in Italy there are two different representative groups.

..... we are still very different to each other in the way our Thalidomide impairment is assessed and how the money distributed.

4. The German Government agrees a deal with each country as the amounts, mechanism of payment, terms & conditions will inevitably be different.
5. We will all meet up for a big party to celebrate; maybe a NACAC or possibly at a book launch. See below.
6. The pressure from outside Germany and within, from her national politicians and media, will build. The German Government will have to go after Grunenthal to obtain a contribution or even a full refund of all the money it has paid out. The Wirtz family will finally be named, shamed & made to pay. A key part of this will be the publication of a book by Dr Martin Johnson & Professor Ray Stokes. Professor Stokes is at Glasgow University. He is one of the leading experts in the world in post war European Business History. We all know who Dr Johnson is after 14 years as Director of the UK Thalidomide Trust. This book will tell the truth, the whole truth. It is being finalised now. There is a publisher. It will be a big book launch.
7. All European Thalidomide survivors, including us, can have an improved quality of life with the majority of their everyday needs being met. Living in dignity. But whatever we get, it will still never be enough. Of course.

The German Government will have to go after Grunenthal to obtain a contribution or even a full refund of all the money it has paid out. The Wirtz family will finally be named, shamed & made to pay.

EU

All seven Political Group Presidents have definitely now committed to write to Chancellor Merkel. We have seen six of the letters and understand as many as five have been posted already. This has hardly ever happened before.

The EU is speaking with one voice on this issue as many senior MEP's are advising us.

- Every MEP has most recently been hand delivered a colour A5 leaflet. We have visited every office, over 700, on foot
- Every German MEP has just been hand delivered a colour A4 leaflet, in German, that is more focussed on how they particularly can help us
- The Group Presidents will be raising our campaign at a Council of Presidents. This is a regular meeting they have with EU President Schulz.

..... they will be coordinating a joint Press Conference in the EU in a few months; ideally May.

We have nearly met all the Press/Media directors of each Group. At the end of February, they met and on their Agenda, item 5, they talked about our campaign. We understand they will be coordinating a joint Press Conference in the EU in a few months; ideally May. **This is very rarely done.** They accept our argument we are a unique group in a unique position needing a unique solution. As soon as we are told it is happening and the date, we will let you know. Depending on

the exact details, it maybe possible for UK Thalidomide survivors to attend if you want to. But of course, this would be down to you to organise and fund. The more the merrier! At least one Group President has already agreed to attend and we are trying to secure the agreement of the others. This will be incredibly powerful politically.

- We anticipate a meeting with European Parliament President Schulz at some point in the next few months.
- We are also chasing a meeting with Commission President Juncker and will keep you posted if we make any progress.
- We are organising appointments with a few Commissioners to brief them in person. This is a political issue, not a legal or procedural matter.
- We should have a story in the German media soon around how British helped the Contergan Stiftung. The 800 or so European Thalidomide survivors, including the British, outside that Settlement need help now & we will list every action that is happening in Brussels & our individual countries.
- The Spanish recently had a very successful Demonstration in Madrid & a showing of the film about the History of Thalidomide in Spain. We arranged for a journalist, Caroline Scott, from the Sunday Times to be there in Madrid for 4 days! She has written a large story about the Spanish to be in the Magazine in March/April.

German Government

The political pressure appears to be building.

Germany does not get to choose those issues on which she takes a moral stance.

We remain ready and willing to meet the German Government at a time and place of their choosing. However, this must be on the right basis. Our red line, supported by our supporters & advocates including the FCO & Health Ministry here is that we mustn't simply meet a civil servant who wants "to restate the Government's position". This is a very serious matter and requires the attention of a Minister too.

Irrespective of the principle at stake & the practical cost/efficiency issues of impaired negotiators travelling back & forth to Germany, you should be aware **the German Government gave the seven or so different Federal Contergan Groups the run-around for decades meeting low level officials until two of our campaigners, Guy Tweedy & Nick Dobrik, got them all organised, providing resources & materials, leading directly to their six fold plus increase of E130m per annum announced in April 2013.** We need to start negotiations off on the correct basis.

UK Campaign Activities

You will recall we always talk about a pincer movement; actions in the both the EU & in the UK to bring pressure to bear on the German Government.

The goal is to receive financial assistance from the German government to the Thalidomide Trust for our unmet health needs, as identified in the Securing Our Future report.

In the UK we have so far met over 150 MPs. All have agreed to help support the campaign, and they have been writing to the Health Minister, the European Minister, and the German ministries. Some are asking questions in the House. If you want to keep up with these questions and their answers you can go to [google.com/alerts](https://www.google.com/alerts) and input the word thalidomide. You will then get notifications any time thalidomide is mentioned.

The key points here include:

The UK British MP Open Letter (OL) has over 220 signatures currently.

- The UK British MP Open Letter (OL) has over 220 signatures currently. Michael Moore MP has sent a copy to the German Ambassador and asked for a meeting. The Ambassador replied saying he has forwarded the letter to Chancellor Merkel but ignored the request to meet *Mr Moore has reissued the invitation but still not received a response so will be pursuing this. We phone the MPs every day encouraging them to sign the Open Letter and to meet with us. Your letters you send to your MP enable us to reach more MPs, particularly those sticky ones; and having your name that we can quote to the MPs really does help open doors. We have received 263 postcards so far so thank you all for your ongoing support.*

- The 4 Health Ministers from Westminster and each Devolved Administration have written a joint letter to the German Government.

- Andy Burnham, Shadow Secretary of State for Health, has had the green light from Ed

Ed Miliband has given the green light to requesting every Labour MP to sign this OL

..... meeting is booked with Prime Minister David Cameron.

Miliband to contact every Labour MP requesting they sign this OL and this note should go out shortly. This is helpful in the short term in boosting already significant numbers (members of Government & post holders are not ordinarily permitted to sign of course) but also longer term if Labour were to form (part of) the next Government. The cross party support is invaluable in the House

- We have a meeting booked with Prime Minister David Cameron in early March.
- In Scotland, efforts are underway to secure a debate in Holyrood followed by every MSP signing their own Open Letter to Chancellor Merkel.
- In Northern Ireland, we enjoy the support of the MLAs and in Wales efforts are being ramped up.

A well respected leading paper , the Sunday Times(ST), are fully engaged. They will do an Editorial at the right moment; probably when we are actually in negotiations. . One issue you should be aware of is that our key arguments are dry political stories which won't necessarily make the cut. So occasionally we may get a story that is not exactly on message, per se, but will still be helpful in the short term (German Government) & very good in the longer term (Grunenthal) . We anticipate a reasonable Magazine spread soon focusing on the Spanish story, but tying in how British are helping them, particularly in the EU & how we helped those in the Contergan Stiftung. Our award winning News Journalist, George Arbuthnott, is planning his third article for next few weeks. The ST are designing a logo to put on all their Thalidomide stories.

*the Sunday Times
are fully engaged.*

- Many British Thalidomide survivors wrote to their Westminster MP recently asking them to take two further actions on our behalf. We have had well over 260 postcards back already. Thank you so much as this grass roots support is what will get us over the line.
- We are receiving very helpful advice from a leading PR firm, on a pro bono basis. We would like to thank trustee Marlene Winfield for introducing us to this firm.
- There is a new Award winning film coming called 'Attacking The Devil' about Sir Harold Evans and his time as Editor of the Sunday Times, when the Thalidomide Scandal first become widely known back in the day. It has its premiere in New York in early March and a worldwide release in the autumn. Some independent observers are tipping it as a candidate for an Oscar in the documentary category next year. We will share some clips with you in due course but we do not have them yet.

*We are receiving advice from
a leading PR firm, pro bono,
thanks to trustee Marlene
Winfield.*

This update is very long sorry; but it is comprehensive & brings you totally up to date as at 27th February 2015.

If you need to contact the UK side of the campaign team you can do so at: thalidomidecampaigner@gmail.com."

How You Can Help

You have done so much incredibly helpful stuff already including regularly writing to (& visiting) your MPs then returning your postcards to the office. Many of you gave attended Events & Exhibitions in London and around the Devolved Administrations. Thank you.

All our supporters and advocates are very well briefed. They understand our campaign, are fully engaged and know who the Campaign Team members are. There is a core group receiving lots of practical support from many other hard working Thalidomide survivors playing to our strengths in the EU, London and the Devolved Administrations.

If you have any suggestions or you want to contribute practically, please do not hesitate to contact us. There is plenty of work to go around. As we have the big picture and know what is planned, we can help you with what you want to do so it dovetails with the overall strategy.

one of the greatest strengths of the UK Group is that we are a single, unified body with a democratically elected Council.

Yes, we have the odd disagreements and squabbles amongst ourselves! But one of the greatest strengths of the UK Group is that we are a single, unified body with a democratically elected Council. As we have become increasingly user led, this has led to a reasonable improvement in our position since April 2003. =

Let's carry on playing to our strengths.

If you require any additional information, please do not hesitate to contact us.

The Campaign Team

Volunteer Technology Action Group

By Roz Hepple

Now A Reality – Introducing – Aquarius Porta-Bidet



On behalf of us all, we would like to give a big, huge “Thank You” to Bob Hepple. We are proud to have Bob as part of our team; he has now been crowned affectionately the “BOG GOD”.

We want to commend him for his unwavering effort to find a portable cleaning aid. VTAG noticed and appreciated his attention to detail and relentless determination to find and develop a quality product for our community.

Bob’s search to find a portable cleaning aid began six years ago, at all the exhibitions he visited, in the UK and Germany, he made it his mission to target all the companies who were exhibiting automatic shower toilets, made himself known to these companies as he wanted to encourage them to see that there is a need out there for a portable cleaning aid.

Late 2012 Adrian Westbrook of ‘Brook Miller Mobility’ had been invited to attend a meeting where Bob gave a demonstration of a prototype cleaning aid. Adrian was very impressed with the concept and wanted to work to progress the idea into reality an acceptable working product that was portable and easy to use.

With Adrian’s support, we were able to demonstrate/promote a prototype of this product at our regional meetings where the delegates are all beneficiaries of the Trust, and the response was positive and enthusiastic.

Adrian had enthusiasm, a vision and knowledge towards the end goal. VTAG and especially Bob never gave up hope in being part of something that will change many people’s lives.

Gone are the days of worrying, and in some cases with embarrassment, of being assisted by another with such a personal task - that private moment you only want to share with oneself.

AQUARIUS PORTA-BIDET & FREE CARRY CASE – PRE-ORDER DEPOSIT PRICE OF £50

www.aquariushygiene.com

Pre order the Aquarius Porta-Bidet today for only a £50 deposit and receive a free carry case worth £25.

£195.00 including delivery

The portable bidet is the flagship product of Aquarius and is the ideal alternative to the fixed bidet systems offered by Clos-o-Mat and Geberit. Wherever you are in the world, whether at work or play, the Porta-Bidet means there are no more worries about cleanliness when traveling away from home.



**No More Travel Worries with
The Aquarius Portable Bidet**

Feeding Aids Neater Eater

One of the tasks that I have been set to do this year is to research feeding aids that might be helpful to those beneficiaries in our community who are unable to feed themselves, and those of us who are starting to struggle to feed ourselves due to stiffening joints.

One of the companies that I have been tasked to get in touch with is 'Neater Eater'. I have emailed them about a possible demonstration of their product and it is possible that this may take place on the 9th March, so watch this space for further reports. Here is a snippet about this item. A modular system, the Neater Eater eating aid is designed to enable people to use their own movements to feed themselves.



This device makes it the ideal solution as a feeding aid for those with special needs.

- Increases independence
- Encourages social interaction
- Helps maintain dignity
- Improves posture and mouth control
- Invigorates interest in food and mealtimes to improve nutrition
- Assists carers

Manual Eating aid and useful Electronic feeding aid

The Neater Eater eating aid has many modular variants tailored to the individual's ability and needs. This manual feeding aid was initially designed using viscous fluid damping, to smooth out essential tremors associated with ataxia. The Neater Eater system evolved to provide an eating aid which has the scope to provide solutions to a very wide range of clients with differing challenges. The robotic electronic programmable Neater Eater completes the solution portfolio to enable users without the ability to connect with the arm system, the means to feed themselves successfully through an automated feeding aid.

Who Can Use It?

People with: cerebral palsy, multiple sclerosis, motor neurone disease, head injuries, spinal injuries, rheumatoid arthritis, muscular dystrophies, limb amputations, ataxia, strokes, Parkinson's disease, learning difficulties and many others. As you can see from the photographs and from the extensive list of people with various disabilities who can use it, it is well worth a look at, and I will keep you posted on my findings.



J-SAY – by Mandy de la Mare

I have been beta testing a special piece of software called ‘J-say’, which allows me to use speech recognition software alongside my screen reader. It enables me to use speech recognition software to turn out large pieces of work.

J-say is a product that is the most reliable in linking a screen reader with Dragon and is well worth the money, and you can find further information for this product on the following website:

<http://www.hartgen.org/j-say>



Apple Products ipads and iphones

I am still using Apple products like the iPad generation 4 and when the iPhone 6+ came out last year I purchased that too. I’m getting on really well with that as it’s slightly bigger than the average iPhone, which makes it easier to use with my toes. So much so I don’t have to use a stylus when I’m using screen input, but on the whole I tend to use Siri whenever possible.



Siri is fairly good at recognising what you say and a good speech recognition software but I wouldn’t say it is as good as Dragon Naturally Speaking,

However their built in screen reader Voice over is brilliant and can read a lot more things than my screen reader on my computer and of course the one good thing about Apple products is that they come with assistive technology built in. Apple products are expensive but if you were to sit down and work out how much you spend on the assistive technology on an average PC then I don’t think there would be much difference.

Please do get in touch with us regarding gizmos and gadgets and other items you may like us to look at for you and to further research.

Remember! You can contact Anne Horton or Roz Hepple. HealthLink has access to the data base of DLF (Disability Living Foundation) or you contact them direct: www.dlf-data.org.uk

Mandy de la Mare

REHACARE 2014

On the 23rd of September Bob Hepple & Rowland Bareham travelled to Düsseldorf to attend one of the biggest shows in Europe, REHACARE.

Bob: “I had not attended the show for two years, my thoughts being to miss a year and new and more exciting products would be on show, and I was not disappointed.”

There were 7 halls devoted to Mobility, Every Day Living, IT and Personal Care Products. I present a snapshot of products that caught my eye and that I think would be of benefit to our community. I spent 2 full days from 10 in the morning to 6pm. Trawling the halls, this is not a show for the faint hearted as it is very overwhelming to anyone who has not attended before, fortunately I am a hardened attendee, so here we go onto a few of the products I found.

On my last visit I had found a company called “Genny Mobility” <http://www.gennymobility.com/Genny.aspx> which have a larger than life image, they specialize in using the technology of the Segway scooter enabling wheelchair users to incorporate the most up to date technology in their everyday lives.

This year an explosion of companies have joined the Segway Band Wagon, “Freee” <http://www.freee.de> and “MobilityCube” <http://www.mobilitycube.de> to name a few.

I met up with fellow German Thalidomiders, Sophia and Bianca, who introduced me to “MobilityCube”, a company basing their chair on the Segway, I found this company extremely friendly and helpful, here is a picture of me and one of their supporters.



You can view videos of “Freee” and “MobilityCube” products on the Trust Website <http://www.thalidomidetrust.org>.

As a wheelchair user (both manual and electric), I take keen interest in the latest materials and while I am, as I describe myself, a 4 Limb Deficient it has always been difficult to get a very light weight manual chair either rigid or folding.

Wheelchair manufacturers always think you have to have redundant legs to use a chair that are especially light weight. Just check out RGK for instance and you’ll see what I mean.

Now, there’s a new player in town called “Motion Composites”, <http://www.motioncomposites.com/en/> who now offer full carbon framed chairs that are very cool and very light, and yes they fold!

I measured the weight of the swing away frame against my chair and it was substantially lighter.

These are available from Devinci Mobility.



At REHACARE there is an abundance of vehicle adaption companies in attendance, some of which are difficult to deal with. "Paravan" have a control system that is used in the UK and goes by the name of Space Drive.



A new option is a Swiss company called "Joysteer" who had on demonstration their joystick steering system. I have tried both and while both systems have excellent features, "Joysteer" I felt gave feedback to the driver.

It is worth a look if you are thinking of driving by wire these days

<http://www.joysteer.ch/index.php?id=34&L=2>

A short video can be seen on the Trust website <http://www.thalidomidetrust.org>

Rowland: "Unlike for Bob, I am of the more faint-hearted kind and found going round all the exhibits hard work."

However, I did travel around all the seven halls. What I am able to report on this time round, following my presentation on iPad apps (applications) at the last hearing-impaired conference, is some interesting interfacing hardware that could work with various iPad apps that might be of interest to our community.



Quha Zono

The Quha Zono is a wireless gyrosopic mouse designed for special needs. It provides accurate and intuitive computer access with just small head movements! Or you can actually attach it to any part of your body and move that part instead (such as one's hand or foot or any other appendage).

They claim compatibility with all available computers and iPad tablets and iPhone smartphones. Following a quick setup time, instant access is available to your computer, iPad and/or iPhone.

It is available in the UK – just goto www.quha.com and follow the 'where to buy' link to find details for Toby Churchill Ltd, In Cambridge.

HouseMate - The claim is that this allows you to do everything from one device, you can turn on the room lights, close the curtains, change the channels on the TV, turn up the heating, answer a phone call, send some texts, and browse the internet.

The hardware is HouseMate which works in conjunction with an app called 'ClickToPhone' to do all of these things. The app allows for use as an environmental control. <http://www.click2go.ie/>.

It is difficult to gauge how useful this product is, but I thought it worth mentioning as the potential is immense and is worthy of further investigation.



These are only a snapshot of some of the product we looked at, you can see our full report and video's of our visit to REHAcare on the VTAG page on the Trust website. <http://www.thalidomidetrust.org>

Events - Your VTAG members will attend some of the following events:

- **NAIDEX 2015 Birmingham NEC on 28th – 30th April** www.naidex.co.uk
- **Disability Awareness Day** on Sunday 12th July 2015 **Walton Hall Gardens**
- Europe's largest voluntary led disability exhibition. www.disabilityawarenessday.org.uk
- **Mobility Road show 2015** in Donington www.mobilityroadshow.co.uk
- **Sight Village Birmingham 14th – 15th July 2015** www.qac.ac.uk
- QAC Sight Village comes to The New Bingley Hall, Birmingham. This is an event for people who are blind or partially-sighted, for professionals supporting and advising VIPs and for all businesses and other

Please let us know if there is anything, on your behalf, you want us to look out for.

Contact us! VTAG would love to hear from you, if you have heard of or have visited an event that could be of interest to our community.

As always, we encourage feedback from you and we will respect confidentiality. You can contact any of the VTAG members by email:

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Roz Hepple:	rozzlyn@btinternet.com
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Rowland Bareham:	rowland@rbareham.co.uk

Thank you for reading. VTAG Members: Mandy, Roz, Bob and Rowland.

Contact Us

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

The next edition will be published in the spring of 2015. If you've any feedback from this newsletter or would like to contribute to the next edition, please contact the newsletter editor, Simone Illger. simoneillger@virginmedia.com

Tel: 01189 670218

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."