

The Review

March 2016



The Official Magazine of the Cerebral Palsy Society of NZ Inc

Cerebral Palsy Society of NZ

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Cover Photo

Meet the Interns (Grace Hwang, Elliot Yates, Travis Dixon)
See story on page 4

Any opinions, findings, conclusions or recommendations expressed in this publication are those of the authors and do not necessarily reflect the views of the editor or the Cerebral Palsy Society of NZ.

Page 3	Attention Young People!!!!
Page 4	Meet The Interns
Page 5	Update From Headquarters - Feb 2016
Page 6	Life as an 'Inbetweener'
Page 7 - 8 - 9	Introducing CP Society Scholarship Recipients
Page 10	Membership Database 2016
Page 11	GobabyGo New Zealand
Page 12	Rod Milner's Background & Expansion Plans
Page 13	We Can Always Dream
Page 14	Issues Discussed At M of H Consortium
Page 15	Consumer Report At The Consortium
Page 16	National Carer Matching Service
Page 17	Steptember, Bigger And Better Than Ever
Page 18 - 19 - 20	Meet The CP Society Staff
Page 21 - 22	CP Participants Wanted For Arthritis Research
Page 24	Coffee Group In Christchurch



Attention Young People!!!!

The Youth Advisory and Leadership group is a new initiative from the Cerebral Palsy Society. Feedback from over 50% of our members identified several groups of people they thought needed additional support/services. Providing additional support and services for young people was commented on most frequently.



In order to provide support for young people, we need to know what young people want for themselves.

Cerebral Palsy Society would like to support the development of Youth Advisory and Leadership Groups to help us provide support for young people- based on what they decide.

The purpose of this group would be:

To inform Cerebral Palsy Society about what is important for young people with cerebral palsy

Support Cerebral Palsy Society in designing and developing events and/or programmes for young people with Cerebral Palsy. These may be regular meetings, events, network opportunities, camps, social occasions - YOUNG PEOPLE CHOOSE and Cerebral Palsy Society will try to make them happen.

- To define and participate in events or meetings or networks- whatever you choose.
- Have fun, develop new skills, work in a group
- Network with other people
- Provide comments on issues that affect you

- Assist in feedback on issues Cerebral Palsy Society can then provide a youth perspective.

We are looking for interested young people from 15- 30 years in Auckland, Wellington and Christchurch. We will organise a series of 3-6 meetings for you to discuss what you would like. We really need young people to tell us. Our first meetings will be in April 2016.

If you are interested, please contact Gilli Sinclair at gilli@cpsociety.org.nz. Let me know if you are from Auckland, Wellington or Auckland. We will send you more information and let you know when our meetings are and would love for you to come.

Watch Out For The EVE Rimmer School Games 2016

Date: Friday 11th March 2016
Venue: Whakatane
Ages: 5 to 21 years – Primary, Intermediate and Secondary

For more information contact Zane Jensen on 027 PARAFED (7272333) or email zane@parafedbop.co.nz



Meet The Interns

Recently the Cerebral Palsy Society hired three new interns with cerebral palsy for an internship and they started on 7th December 2015. We are Grace Hwang, Travis Dixon, and Elliot Yates. Let's read what we have to say about our lives!

Grace Hwang

I'm a 25 year old Korean who studied Japanese language at AUT.

I want to develop my skills & expand my confidence. I want to go to Japan one day to experience a new environment. I find it quite a challenge in doing things like researching or writing articles, but I'd like to keep trying so that I get better each time I do research or an article.

Elliot Yates

I'm 26, Deaf and also have Cerebral Palsy. I use NZ Sign Language which is the native language of Deaf people in NZ. At the moment, I'm studying History (majored in English Literature) at University of Auckland on a BA. Glad to be here!

I wanted to experience what it's like as a person with disabilities in the world of work without pressures of potential employers discriminating against a person like me. If I can understand what it is like to work in a job, then I can be prepared for the wider world of working once I have graduated university. I also do this to add more to my social life.

In the future, I want to have a paying job after university so I can embark on travelling to other countries. Ultimately, I'd like to have jobs where I can write novels, comic books and do art.

One day I want to graduate from university by finishing all the classes and I want to get a paying job by doing a good job with this internship.



Grace Hwang, Elliot Yates, Travis Dixon

Travis Dixon

I come from a sign writing background, where I did more than 10 years as a billboard installer, and sign assistant.

The reason I chose to work here is that I thought it would be a great opportunity to develop a new skill set, also to meet, and interact with some new people, including those who have varying levels/types of Cerebral Palsy.

My dream would be for my business Your Surrounded.co.nz (customized numberplate surrounds) to grow into a large enough entity that it can become a weekly wage for me, and my partner. I would also like to buy a plot of rural farm land for my future wife, and kids.

The only obstacle I have really had to face is a balance issue due to my Spastic Diplegia, which I have overcome by using a walking aid (crutch).

Article Co-ordinated by Elliot Yates.



Update From Headquarters - Feb 2016

I hope you all had a happy and well deserved break and holiday and all the very best for 2016.

We are working our way through the programmes- trying to improve the effectiveness and efficiency of them for you. We are always keen on hearing your feedback especially with ideas of how we can improve.

The Grants process has been modified so please check the website before you apply. We're currently working on your ideas for improvement with get Out There. These will get updated on the website and on the forms as we progress. Needless to say we have taken your feedback very seriously and that has had an impact on the recommendations.

We are currently reviewing the remaining programmes and the Events and will ask for your feedback around specifics of these.

The money raised from September will help us resource new initiatives. Feedback from the members identified that the two main groups who could get improved support / service are young people and families with newly diagnosed children. We have several new initiatives around both of these which are mentioned in this Review. Please actively encourage any young people you know or anyone experienced at working with families who have a newly diagnosed member to connect with these initiatives.

We also won't forget adults with CP and will actively seek your advice on what support you would like and how we can improve what we do to suit you. We are reviewing our Events and social activities in Christchurch, Wellington and Auckland-



WCPI Meeting Feb 2016.

please help us by letting us know what you think.

We are delighted to have three interns who are doing amazing work for CPS. Elliot Yates, Travis Dixon and Grace Hwang have all made a significant contribution to our office and are working hard as volunteers demonstrating fabulous skills. If anyone has paid opportunities for our interns please let us know. We will work with you to support their transition and help out in any way preparing them to work with you. If you have an opportunity, please do not hesitate to contact me.

I was extremely privileged to attend the WCPI (World Cerebral Palsy Institute) meeting in Sydney for several days in February. This provided me with an opportunity to learn excellent things that are happening worldwide and broaden our horizons. There were representatives from Asia, Europe and the States as well as Australasia. It was so worthwhile.

Thanks

Gilli
CPS Chief Executive Officer



An 'Inbetweener' - it conjures up images of awkward teenage years, trying to workout where you fit in the world, before adulthood.

Well for myself it conjures up totally different and challenging scenarios. I tend to feel I neither fit perfectly into the DisAbility category or the Able-bodied world.

I have lived my entire 40-something years with right-sided hemiplegia. I don't need the use of a wheelchair (obvious sign of disability to the abled world) but I can't do shoe-laces up.

I have fantastic parents who never allowed me to wallow in self-pity growing up and I was included in everything my two brothers were doing, or made to do i.e. chores. This upbringing certainly set me up for the challenges of the 'real world'.

And though I am able to do most things, what people don't see is the mental effect in concentration needed to complete tasks etc. For example I try so hard not to walk with a limp, but when I'm feeling jaded the limp becomes obvious and especially at work I get inquisitive questions.

I have been discriminated against trying to fit into the able-bodied world due to my impairment when applying for jobs, the first time as an 18 year old looking for part time work at K-Mart where everything was going swimmingly in the interview until they saw my impaired arm and the attitude changed on the spot. Even now in my current workplace I feel discriminated because of issues using my own vehicle for work due to minor adaptations I need to drive a vehicle safely.

I actually feel at times guilty for thinking of applying for assistance from organisations such as CP Society or Workbridge because



I don't feel disabled enough to warrant the assistance over people with what I deem to be in greater need due to their own impairments.

I ponder "Because I have been raised in an abled-bodied world and have held down stable employment in the mainstream world ; does that mean I exempt myself from all outlets of disability support?"

Is this a scenario others out there have too?

I don't write this seeking sympathy, I realise life throws curve balls at everyone in one form or other, what I am hoping to achieve is to highlight the difficulty of being the triangle in a square or circle world!

Life as an 'Inbetweener' – am I able or disabled!? It may well end up being a lifelong question I keep asking myself and debating internally.



Introducing CP Society Scholarship Recipients

By Elliot Yates

Mark Wilson



Have you ever wanted to manage some kind of business and practise in finance as a person with cerebral palsy?

Mark Wilson does and he obtained a scholarship in 2014 from the Cerebral Palsy Society for completing a BA in Management Studies at University of Waikato majoring in finance and strategic management. Prior to that, he completed a Diploma in Business.

He considers the amount of stress in studying normal, as in not affecting his health or exacerbating his CP; he's feeling healthy.

However, his social life improved during studying at the University of Waikato; saying that he met a lot of like-minded people and gained a wider range of social networks in the course of studying.

He finds Finance & Strategic Management interesting because he wants to find out more about the share market and how it connects New Zealand with the rest of the world. Strategic management adds to the general perspective of the business world (and its associated sharemarkets) along with learning various business management techniques.


The Cerebral Palsy Society scholarship made his studying a lot easier, meaning there was no need to apply for a student loan, which as a result, the scholarship voided his financial burden. After his course fees are paid, he will complete his degree and then get a job in business and finance. He says that the scholarship assists with course fees, reader/writer tablet, books, transport, and any other assistance that is appropriate to the applicant's situation.

Miriam Jenkins



Miriam Jenkins is a traveler-scholar who can read Sanskrit!

Before the 2014 academic grant, she studied at the University of Otago and was accepted into the prestigious School of Oriental and Asian Studies at University of London. Unfortunately, she had to turn this down due to financial difficulties. A 2012 CPS grant enabled her to purchase a laptop with language keyboards embracing languages such as Sanskrit, Hebrew and Classical Tamil which she studied along with religion and theology.

The grant had made study possible for her, sidestepping most of the financial perils laying in wait for most NZ tertiary students. In 2013, she graduated from the Religious Studies programme at University of 



Introducing CP Society Scholarship Recipients

Otago, and even managed an outdoors sports store in Albany before travelling to the United States. The stress of studying affected her health. USA offered her what Dunedin couldn't in terms of recreation and exercise and her health improved afterwards.

Her field of study is in Classical era Tamil poetry written by women. She was introduced to it by Dr. Will Sweetman, a lecturer whom she respects. She wants to finish her MA then complete a PhD in her chosen field.

She thinks academic grants should be applied for because it cuts down on tuition fees!

Currently, she is living in Betsukai, Hokkaido, Japan as an assistant language teacher on the JET programme, working with school age Japanese students to improve their English.

Tara Hurley



Tara is now working at the Auckland Council for almost a year as a Graduate Planner on the Unitary Plan team. She assists this team with research & analysis options and has a career in Urban planning in her sights.

After an eight months break from study during which she helped run Cardrona's Adaptive Snowsports Programme and took in a trip to Colorado, she graduated from University of Auckland with a MA in Urban Planning (UP) during 2013-2014 using the 2013 academic grant from the Cerebral Palsy Society; Her BA degrees were in Economics and Geography studying at University of Otago. In total Tara studied for 6 and a half years at university.

Intense studying is a challenge to be faced, especially when it comes to her CP. She often becomes tired so she goes swimming twice a week to exercise and to relax.

Her dissertation focussed upon providing for better spaces within apartment buildings encouraging more interaction with other people and natural environments. UP led her to embrace the challenges of living spaces, for people in inner city apartments, across the globe.

She's glad that she successfully applied for the job she wanted. It wasn't easy for her. It was a year of ups & downs adjusting to work. She reckons that the MA was harder, though. Hopefully, it'll be smoother sailing later on.

Her advice for applying for the grant is: apply for the course you want. "No harm ever comes from applying. Once you're accepted, commit and persevere".



Introducing CP Society Scholarship Recipients

Leonie Brunt



Konnchiwa! That's "hello!" in Japanese as Leonie Brunt can tell you. She's studying social sciences as a BA major at AUT (Auckland University of Technology) with a special interest in Japanese as her minor.

Previously, she was awarded an academic scholarship by AUT called the CPA which lasted four years. She has only studied part-time, and her journey towards her degree took ten years. Three years out of these years, she had to pay out of her pocket and also had WINZ assist her with the Training Incentive Allowance. Finally, she finished her degree in 2015 with the CPS academic scholarship grant's help. During her time in AUT, she made some friends, and being at university enabled her to have a social life.

She feels fortunate to have had these grants. Her scholarship grant from the CPS enabled her to travel to and from AUT which was a significant cost previously.

After her degree's completion in 2015, she's relaxing and taking stock of life. Her plans this year are to either obtain a paid or volunteer job. Another plan this year is to take a Mana Moana course with CCS hopefully leading to something. Her study interests are public policy and sociology; both with a reference to how people with disabilities are treated and how they live.

Her advice to anybody considering the grant is: "apply because it is empowering and lifts financial burdens!"



Auckland Mobility Transport Limited

This year Gary welcomes his son Jason into the business.

Both look forward to another 17 years of servicing the disability sector.



- 17 years service
- Owner operators
- Transport on time
- NO booking fee
- NZQA approved drivers
- Competitive rates
- Hoist vehicles

Ring today - Bookings: 09 827 7032, Gary: 0274 830 746 Jason:021 441 315

Weekend work should be pre-booked to avoid disappointment

CP vouchers welcomed



Membership Database 2016

The primary research focus of 2016 is the building of the membership database. This resource will compile the CP through the Lifespan interviews into practical information on everyday realities of living with Cerebral Palsy as an adult. The particular focus will be on key life dimensions such as education, employment and coping strategies for particular events such as moving out of home or wanting to start a family.

The database will have three searchable features:

- CP level and type: individuals will be able to search based on information that is relevant to them and their circumstances. For example, the experience of someone who is non-verbal is quite different from an individual who has a milder form of CP, especially when it comes to the relevance of information about employment and social connection.
- Specific Topics: the research database will be divided by eight main topics that have been covered in the research to date. These include general CP profiles, aging with CP, physical health and fitness, independence and community, employment, social relationships and family.
- Age: Individuals experiences of CP tend to differ as they age. The research will be searchable by age bracket so that people can find information that is specific. For example, people who are past 50 will have a different experience of maintaining mobility than somebody who has just left school.



Amy Hogan - Researcher

The database will be designed to include simple graphs, key statistics and individual case studies. The membership database will be frequently updated as more interviews are analysed. We are always willing to accept new participants as this is a long term project. If you would like to be involved or would like further information on the progress of the membership database feel free to email me – details are listed below. I will be writing regular updates on the project's progress. Stop by our website and Facebook page to learn more.

Amy Hogan

Researcher

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GobabyGo New Zealand



GoBabyGo adapts electric ride-in toy cars (currently BMWs) to be used by children with impaired mobility.

The age-appropriate devices encourage interaction with siblings and friends, deliver therapy benefits, and help children develop spatial awareness and related skills in a way that's impossible when they are not independently mobile.

www.gobabygo.org.nz will tell you more about GoBabyGo, its background and how to apply.

GoBabyGo have given cars to nearly 50 children- many of whom have Cerebral Palsy.

The plan is to build cars for children in

- Auckland in April
- Hawkes Bay in May
- Taranaki and Christchurch in June
- Wellington in July
- Invercargill on August 6th
- Tauranga in September
- Auckland in October

If you are interested in one of these amazing cars or have any questions, please let us know. gilli@cpsociety.org.nz

All The Best, Janet

We wish to farewell Janet Chapman from the organisation. Janet started seven and half years ago and has been involved with most of the activities in the organisation. Janet specialised in events and has provided members with many fun filled hours at various events and Christmas Functions. The Cerebral Palsy Society appreciates the work that Janet has done in designing and developing the events and meeting members from all around the country. I trust you will join with me as we wish Janet all the best with the new stage of her journey. Best wishes, Janet.



Rod Milner's Background & Expansion Plans

I spent a very pleasant hour or so with Rod Milner and team who are the largest retailers of vehicles in NZ specialising in the disability field. Rod Milner Motors has been privately owned for the past 34 years by the man himself. (He has been in the motor trade for 53 years)

Twenty-three years ago he tapped into the disability vehicle market inspired, by his late wife Lee, who after becoming disabled found user friendly transportation nonexistent. Nowadays he deals exclusively with the disability vehicle market with 130 vehicles packed into his yard, with strong overseas contacts and a modification workshop manned by 3 guys, supervised by his son Darren. Rod Milner Motors also offers short or long term rentals of disability friendly vehicles.

However Rod often becomes frustrated and saddened by the bad choices people make. This was underlined when the interview was disrupted by a plea for help, via email, from a woman who was badly advised over a purchase she was talked into. The car she bought was an ill fit for her disabled husband.

Rod can't emphasise enough how vital it is to make sure everything is correct. In fact he does recommend choosing the vehicle first before the wheelchair if possible.

"Wheelchairs are getting bigger which makes it increasing more difficult to naturally fit into a vehicle. In most cases a solution can be found but please listen to us. We specialise in vehicles that accommodate people with disability. That's all we do," he said.

One of the first things Rod does when a new client arrives is whip out a tape measure as head room plays an important part in the vehicle you choose. It is one of the few advantages of being a shorty.



To put it bluntly being short gives you more vehicle options. Obesity is another problem that needs to be kept in check. (Rod gave my pot belly a prolonged stare when he revealed that fact!!!)

However by far the biggest problem is money, especially if you come under Ministry of Health restrictions. Lottery Grants can be available but there is never enough money available from this source to cover the amounts of requests being made on the funds. There is a strict criteria to try to satisfy those most in need.

Rod strongly feels the need to bring together everything and everyone connected with purchasing a vehicle, for a person with a disability, under one roof. He has plans to, in the near future, sell his Greenlane property and set up a undercover disability destination. His plans include buying a 10,000 square metres building with a permanent display of modified vehicles. There would be electric type buggies available on site to transport clients around the building. The complex will have different types of equipment as well like wheelchairs and scooters and it will have room for specialists like Occupational Therapists to help purchase the correct vehicle and equipment.

A one stop shop to cater for all the complex needs sounds, very exciting. As well as the



Rod Milner's Background & Expansion Plans

actual purchase of the vehicle you will receive financial advice and expert advice from specialists at floor level.

Rod delivers expert advice now. A couple of gems that came out of the interview were when purchasing a vehicle with a disabled child make sure you take into account the growth of the child. Rods calls it future proofing the family unit and when purchasing for an adult keep in mind the needs of the rest of the family. These types of advice may sound obvious but are often overlooked when the main focus is on the disabled person.

With decades of experience behind him Rod's future plans will be a major positive development for the disability community.

For further details contact Rod and co at 580 Great South Road Greenlane Auckland.

Phone:(09) 579 9632

Free: 0800 763 645

Fax (09) 571 0248

Email milner@ihug.co.nz

Ross Flood

We Can Always Dream

On 11th February the first UDM facelift NZ built Skoda Yeti rolled off the line for 2015, destined for Rod Milner Motors the newly appointed New Zealand distributor. This car is a now rationalised Euro spec full drive from wheelchair car, and has a number of detail refinements for quieter, more refined operation, as well as a larger more powerful 1.4 litre turbocharged direct injection engine.



If driving from your wheelchair is your thing this is your dream car with ABS Brakes, AirBags, Disability Enabled, Double Overhead Cam, EFI, Fuel Injected, Power Steering, Push Button Start Stop, Turbo, Alloy Wheels, Central Locking, Electric Mirrors, Electric Windows, Electronic Tailgate, Remote Central Locking, Reverse Sensors, Tail Lift, Air Conditioning, CD Player, Radio docking station for both front seats, wheel chair hand controls, fire extinguisher, electric parking brake and all button controls.

As mentioned above both front seats are interchangeable with an auto docking device so easy to switch around if you want to rest while someone else drives for you.

Mind you the dream car comes with a nightmare price but there is always Saturday's Lotto to win.

Of course there are far more affordable options in the yard at Rod Milner Motors catering for all situations and all different types of disabilities. Click on the website www.rodmilner.co.nz or ring Rod and the lads to see what they can do for you. Details above.

Don't forget to indulge yourself and click on the Skoda Yeti main page link. As I said above we can always dream. By Ross Flood

Issues Discussed At M of H Consortium

My last meeting representing parents at the Ministry of Health Disability Consortium was held in November and it was, as always, a very interesting few days.

It was great to finally meet Tony Voss who is the Society's consumer rep. This forum has representation from all facets of the disability sector so is a great networking opportunity. While we are all representing different groups of people, the issues are surprisingly generic. The most important issues affecting Cerebral Palsy Society Members are highlighted below:

Funded Family Carers – feedback on the recent review is now available on the Ministry of Health website.

Streamlining Contracts – providers will be delighted to see that the Government are looking to simplify contracts which will hopefully reduce administration – particularly for those who hold multiple contracts.

DSS Budget Increase - It was amazing to hear that Disability Support Services 2016 will receive \$1.120 billion - an increase of \$16 million on the 2015 year. It sounds like a considerable amount of funding but never seems to be enough!

Behaviour Support Service - Eligibility 0 - 65 years – huge issue with waiting lists highlighted by consortium. 1,000 people on the waiting list – Auckland and Christchurch have highest level of referrals with waiting times of a year or more. There was recognition that early intervention is best – but impossible with waiting times – request by consortium that more funding is put into this area.

Residential Services - The Ministry of Health are interested in gathering feedback from the users of residential



Sally Thomas

services. It is very important to capture the voices of all people (users rather than providers) and they are looking at different methods in order to do this using independent evaluators. The evaluators are hoping to be able to speak to 350 respondents before the end of 2016.

Peseta Sam Lotu-liga, Associate Minister of Health attended the meeting and was interested in hearing from the consortium about issues facing the disability sector. He welcomed people contacting him directly with any issues or concerns.

I have thoroughly enjoyed participating in these meetings over the past few years and the Society is now looking for a new representative for parents.

Best wishes to everyone for 2016 – it will be interesting to see what the year brings us!

Sally Thomas



Consumer Report At The Consortium

This was my first meeting, and it was with great apprehension that I sat down on day one, not knowing how I would cope, but after the first presentation things settled down and I began to relax.

Over the three days, I was able to make contact with some interesting people and able to learn a great deal about the Ministry Of Health's Disability Support Services Consumer Consortium and look forward to the next meeting.

Below is a list of highlights that were covered over the three days. Tony's full report will appear on the website

Revision of the New Zealand Disability Strategy Ministry of Social Development

Some of the key themes from the discussion were: More accessible environments for disabled people were advocated for, including work places, homes, public transport, information and technology.

The vital topic focused on providing all information to the person with a disability, this included funding, support groups, equipment etc. The right information at the right time was a popular theme along with support to make own choices. Use of advocacy if needed and recognition for this was also discussed. Everyone agreed that disabled people had the right to access and the freedom to take part in the community and their cultural environment.

Enabling Good Lives

Enabling Good Lives is a new approach to supporting disabled people that offers greater choice and control over



Tony surrounded by his family

the supports they receive, so that they can plan for the lives they want. In 2011, a group of people from the disability sector reviewed day options for disabled people and concluded a fundamental shift was needed to give disabled people greater choice and control over supports and their lives. Their report was entitled "Enabling Good Lives". Many of the family stories and perspectives are available on the Enabling Good Lives website. www.enablinggoodlives.co.nz

Obtaining Feedback from Disabled People Using Residential Services

An organisation have been contracted by the Ministry of Health to obtain feedback from disabled people using residential services, including those in 24 hour residential care. Residential service users will be asked about their satisfaction with services, and what works well, and what could be improved. This will involve face-to-face interviews with people (350 people) in residential care (in a targeted area). Interviews will be completed by peer interviewers (people with disability) on site at a range of residential services; this is also complemented by an on-line survey to reach more people.

By Tony Voss



National Carer Matching Service

Do you support someone who has Cerebral Palsy? Would you like to find care workers and relief carers in your area? If so, you may like to try the new National Carer Matching Service! It's free for those who receive Disability Support funding.

Carers NZ has launched this new online service in association with MyCare.

The National Carer Matching Service has been developed for people with disabilities and their families to help them easily connect with relief carers in their communities.

How much will it cost to use MyCare and the Matching Service?

It's FREE if you receive Ministry of Health Disability Support funding. This means you can use MyCare's Match feature at no cost. An information sheet about the National Carer Matching Service is attached or if you have questions about the service you can phone Carers NZ, 0800 777 797

What do I need to do to join the Service? contact your NASC and ask them for a referral to the National Carer Matching Service. Completing the easy online form will take just a few minutes www.app.mycare.co.nz

What happens next?

Once you have completed the form or your NASC has confirmed your eligibility, you will receive an e-mail welcoming you to MyCare Match. The email has some simple steps that will help you register.

How does the match service work?

Hundreds of support workers from around New Zealand already have created profiles at the MyCare website, and more



New service becoming popular

are joining every day. MyCare is an easy way for you to find and directly contact people in your community who are seeking support work. Once you've completed the online form you will be able to:

- Post jobs seeking relief carers in your area
- View profiles of available workers/ relief carers
- Directly message them to ask questions and make arrangements to meet for an interview
- View their skills, experience and training to decide if they may be a good match for your needs

Contact Carers NZ about the National Carer Matching Service: 0800 777 797 or email admin@carers.net.nz

Contact MyCare to find out what other services are on offer including an online matching service or have questions about a free upgrade trial offer: 0800 677 700 or email hello@mycare.co.nz

This information was sent in by Pauline Townsend Senior Manager MyCare Limited.



September, Bigger And Better Than Ever

September will be back again this September. If you don't know what September is, September is a global fundraising month which focuses on getting active and taking 10,000 steps a day for 28 days and raising funds for CP.

Shelly Reilly National Manager September reports that "after a very successful first year, the society is looking to grow both team numbers and fundraising dollars in 2016. Keep an eye out for me as I head around the country to promote the event to the general public and corporates. We are taking part in this year Women's Lifestyle Expos and will be at the shows in Dunedin 9-10th April, Palmerston North 30th April – 1st May, Hamilton 14th May – 15th May, Wellington 2-3rd of July and Tauranga 27-28th August.

Registrations of interest for the event will open on the 1st of April, and once again all members of the society will be invited to participate at no cost.

Eleven year old Kyla Old will once again be a September ambassador. Kyla and her class raised \$752.00 for the 2015



Kyla interviews the stars

September campaign. Last year the Cerebral Palsy Society provided Kyla with the opportunity to feature in the September Event Promotion which saw her interviewed on TV One's 'Kiwi Living' programme along with some other kids selected by the CP Society. In addition to helping with the Event Promotion; Kyla and her Room 8 Classmates from 'Our Lady of the Sacred Heart' Primary School raised funds for the Event by wearing Pedometers to school for the entire month. This was big news for the School and was well supported by the Teachers & Principal alike.

After her confident performance on 'Kiwi Living' Kyla was given a fantastic opportunity to co-present RedCarpet NZ TV's coverage of the NZ premier for 'Alvin & the Chipmunks – The Road Chip' Another confident and polished performance has lead to her being contacted by Ryan Talent Agency who along with some financial assistance from the CP Society are aiming to develop her natural acting talent. Who knows where this may lead.

We are bound to hear a lot more of this talented youngster. For further details of September go to www.september.org.nz



Kyla with friends



Meet The CP Society Staff



Gilli Sinclair
Chief Executive Officer (CEO)

I have had an extensive career in health and social services with a strong focus on mental health and suicide. I have been actively involved with designing and developing services with a strong emphasis on addressing previously unmet complex needs. Currently I am on several Boards including Make-A-Wish where I am currently on the International and Pacific board. I am also volunteering for Go Baby Go- organising purpose fitted BMWs for children who have difficulty with mobilisation.

I have loved my first six months working for CPS. It has been full of wonderful surprises and meeting with as many members as I can. I love the programmes that this organisation offers; I love the rich history and have really enjoyed my work here. I particularly enjoy working with the staff and Board and I'm incredibly impressed with their commitment, wisdom and knowledge.



Matt Slade
Accounts & Office Administrator

Originally from Christchurch, I moved to Auckland 10 years ago. During this time I have been involved in the sports industry, and the health and disability sectors. I have many roles within the society. I currently manage the accounts, I also manage the different programmes. I process the Grants and membership applications and manage the membership database.

In my spare time I enjoy gardening, sports, going to movies, spending time with family and travelling.



Michael Northcott
Project & Property Manager

My name is Michael Northcott, and I enjoy working for the CP Society. I especially enjoy the opportunity to be part of a team that assists people with Cerebral Palsy so that they are able to live better lives. I think the Programmes the Society offers makes a real difference to our members.

For the Cerebral Palsy Society I fulfil many roles including answering many of the incoming calls and queries. In addition I have the Welfare Officer role, and in conjunction with Auckland Transport carry out Total Mobility assessments.

Previously my roles for the CP Society included sourcing, purchasing, setting up computers and adaptive equipment plus training for members under the getConnected programme. Also Property Management for the Cerebral Palsy Society and then our business arm EAL (Essential Assets Ltd) prior to properties being sold.



Meet The CP Society Staff

I coordinate a number of projects including the getOnYour Trike programme, purchasing equipment and IT assistance for the office, and at times, for members. Assisting and supporting the CEO and other staff with their roles including mail out printing and coordination. Also other tasks as assigned it is important to me to find effective solutions for the Society; and for prospective, and existing members, address their queries and concerns where possible.

I enjoy swimming, reading, movies, repairing / building things, and coming up with workable and effective solutions to challenges. I especially enjoy spending quality time with friends, family, and loved ones.



Shelly Reilly

National Manager Steptember

Hello, I'm Shelly and I head up our major annual fundraising campaign 'Steptember'. Working closely with the Cerebral Palsy Alliance in Sydney, my role is to manager, market and promote Steptember to New Zealand, encouraging Kiwis to step up to the challenge for taking 10,000 steps a day in the month of September.

My background is in marketing, PR, sales and promotions mostly within the Travel & Tourism industry globally, but I've also worked on a number of TV productions and major sporting events. I utilise my contacts to spread the word, educate the New Zealand community about CP, and encouraging people to donate to the society. Since joining the Cerebral Palsy Society team in April 2015 we have raised \$385,000 in donation dollars, with this figure set to rise in 2016. Keep an eye out for more fundraising activities in 2016, including Auckland's 'Round the Bays' on the 6th of March, and of course 'Steptember'. Since joining the society I had the opportunity to meet and work with some amazing children and their families. As a mum myself of a 2 year old I'm passionate about giving all kids the opportunity to thrive and achieve their full potential.



Ross Flood

Writer & Researcher

My dual roles as editor of the Cerebral Palsy Society's "Review" and CP Society historian has enhanced my understanding of contemporary issues as well as strengthened my appreciation of the past. Sometime back I predicted that the majority of future generations of our disabled community will be far more educated than their predecessors. Armed with this education people with disabilities will be more aware of their rights and more assertive in demanding them. I believe the Cerebral Palsy Society has a wonderful opportunity to support these people and their families in their quest to reach their potential. I'm very enthusiastic with recent developments and have a strong desire to be part of the CP Society's future. I'm also looking forward to helping our older members who have struggled in isolation over the years. In my youth I was considered a unique sight when I travelled



Meet The CP Society Staff

to my local township in my motorised wheelchair. I'm pleased to observe that this mode of transport is now an everyday occurrence. Us oldies can now embrace this wonderful new world of technology thanks to the support of the CP Society.

I would like to encourage everyone to join the Cerebral Palsy Society to help build an exciting future for us all.



Amy Hogan
Researcher

As a researcher and writer, my primary responsibility is to oversee the research project 'Cerebral Palsy Through The Lifespan.' This work bridges the gap between the paediatric system and adulthood with an emphasis on everyday experiences. This is knowledge that was lacking when I was growing up with CP. Our members have been very supportive of my work to date. In 2015/16 I am collating the data collected into user friendly information sheets for members and their families.

A secondary part of my role is managing our Facebook page and canvassing the web and libraries for interesting stories on CP. My primary goal is to be informative but interesting with a particular emphasis on quality of life, maximising independence and having a laugh.

In my spare time I like to hang out with my menagerie of rescue and service animals, work in my garden, read as much as I can, spend time with my friends, eating out and going to the movies.



Paul Munckhof
Review Design - Webmaster

I have a long history with the CP Society. In the mid 2000's I was asked to join the Board and continued to serve there until 2010.

With a techy mind I am currently responsible for looking after the website by keeping it up to date. I also do the design layout of the Society magazine "CP Review" etc.

In my spare time I have a wide range of varied interests. I like listening to music, watching motor sport, have kept Aquarium fish for the last 40 years or so & budgies for the last 4 years, since my kidney transplant.

I have one interest which is probably not very typical for a person of my degree of CP. I really enjoy going into my garage and repairing anything mechanical. I have fixed many small engines plus my cars & have a diploma in small engine repair. My current project is restoring a 1960's mower.

Also something else that is unusual is that I was awarded the NZ Order of Merit in 2006 for services to disabled sport.



CP Participants Wanted For Arthritis Research

Final year medical student, Charlotte Trevella is seeking Cerebral Palsy participants to take part in a research project relating to arthritis. She is currently researching rates of Osteoarthritis and total joint replacement among adults with Cerebral Palsy in New Zealand. This project involves participants filling out a one-off anonymous 10 item questionnaire, which should take about five minutes. This questionnaire will be available online for potential participants to complete for a period of three months, between the dates 11/01/2016 and 11/04/2016. Following data collection, data analysis and preparation of an article will take around three months.

The reason that she is doing this research is that she has an interest in both orthopaedic surgery and cerebral palsy. International research shows there are higher rates of arthritis in individuals with cerebral palsy compared to the general population, and she is interested in whether or not this is the case in New Zealand as well. She is also interested in the rates of total joint replacement among people with cerebral palsy who suffer from arthritis, as there is a lack of research into this area both in New Zealand and worldwide. The aim of the research is to investigate rates of arthritis among individuals with cerebral palsy in New Zealand. The researcher also wishes to establish how many of the people with cerebral palsy and arthritis are receiving total joint replacements, and whether they find the operation improves their symptoms.

The expected results from this project will illustrate that arthritis is a common problem for people with cerebral palsy in New Zealand as it is overseas, and that people with cerebral palsy tend to be affected by arthritis younger than the general population. It will be interesting



Medical student, Charlotte Trevella

to establish whether rates of joint replacement for arthritis are also high among people with cerebral palsy, or whether they are receiving low rates of joint replacement, for example due to a conception that they will have poorer outcomes. This could help to inform medical practice in the management of people with cerebral palsy and arthritis.

If you choose to participate, you will be invited to complete a five minute anonymous online questionnaire, answering questions related to your level of mobility and any diagnoses of arthritis. Completion and submission of the survey will be taken to indicate that you have read this participant information and consent to be a part of the study. After you have completed the online survey, you will have the option of entering a prize draw for the Prezzy Card. ➡



CP Participants Wanted For Arthritis Research

If you would like to do this, you will be able to provide your email address in a separate online page which will not be linked to your completed questionnaire. On this page you will also be able to request a lay summary of the final study report. The summary will be sent out to the email address you provide once the research findings have been compiled. The summary will also be provided to the Cerebral Palsy Society for publication on their Facebook page and magazine. If you are a person with cerebral palsy who has never been diagnosed with arthritis, your participation is still highly valuable to the study. This is the only time-commitment required from you by the researchers. Because data is submitted anonymously, you will not be able to withdraw your participation once you have submitted the questionnaire.

Charlotte will collect the data via an anonymous online questionnaire powered by Survey Monkey. This will be stored on a password protected University of Auckland Computer for a minimum of six years before being deleted. The data you provide will not be used for any future research other than the project described in this information sheet.

The information you share with the researcher and supervisors will not be shared with any third parties. If the information you provide is reported or published, this will be done in a way that does not identify you as its source. Please note that in entering the optional prize draw, although your questionnaire will not be linked to your email, the researcher may see your email, and your participation will therefore not be completely anonymous. Your participation in the study will, however, be strictly confidential. A copy of the research findings will be made available to you via email, if you wish. When entering the prize draw, check the

box stating that you would like to read the study report, and a summary of study findings will be sent to your email once the research is completed.

This research project is under the supervision of Professor Susan Stott; Paediatric Orthopaedic Surgeon at Starship Hospital and Professor of Paediatric Surgery at The University of Auckland, and Mr. Matthew Boyle; Paediatric Orthopaedic Surgeon at Starship Hospital.

For more information on the study, please contact the principal researcher at ctre029@aucklanduni.ac.nz to request a Participant Information Sheet and the link to the online survey. Read the Participant Information Sheet before deciding whether or not you wish to participate.

After completing the survey, you will be given the option of submitting a separate online form with your email address to the researcher. This will allow you to enter the prize draw for completing the questionnaire, and / or to receive study results. Your email address will be stored separately from your survey responses.

For further information on the study, please contact the principal researcher, Charlotte Trevella, at ctre029@aucklanduni.ac.nz.

Website

Remember to visit our website regularly to keep up with the latest News & Notices

www.cerebralpalsy.org.nz



TA iQ the New Standard



What users have said:

The seat is so low, I can sit at a table, at my desk, drive a vehicle. At a cafe no one knows I am in a chair!

The iQ ride is so smooth, comfortable and fast.

All quality, no exposed wires, no visible control modules and real leather armrests.

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2. Excellent drive comfort, with independent suspension, no jolts over bumps.
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4. Cost effective, very sensibly priced, with all power options.
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Seat height:
Only 38cm / 15"



Suspension:
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Safer:
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Higher:
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Faster & Further:
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TA Indoor equals superior indoor maneuverability

With a very small powerbase, 56cm wide and 69.5cm long, and a turning radius of only 45 cm ensures maneuverability in bathrooms, small spaces, and narrow doorways is a breeze.

Sit at any table with a very low standard hi/low seat plate height of 40cm.

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Coffee Group In Christchurch

A Sweet Encounter

In Christchurch the CPS Coffee Group, organised by Michael Turner, is going from strength to strength. I popped along on December 1st to join in and see who was there. Numbers were down a bit, probably because the Christmas function at Orana Park had been held just two days before...that was a "roaring" success, with 93 people attending - thanks, Janet!

At the Coffee Group - held this time at the Garden Restaurant Cafe - young adults Olivia, Tyler and Mikayla caught up with all the goss over delicious desserts and coffee, which the Society pays for. Their mums and carers chatted away too, further along the table, "networking" they call it. One had a charity cookbook to sell and made quite a killing as we saw our Christmas present problems being solved on the spot. Even a couple of ladies seated nearby, not part of our group, bought one.

One mum commented the group gave people a good opportunity to catch up during the year between the larger social events.



Taking time out for a group photo

The group used to meet even second month, but now meets at 1pm on the first Tuesday of *every* month, except January. The number of attendees varies but sometimes 20 or more come along. Venues vary too, but are usually located near the central city. RSVP numbers are needed two days in advance, and please advise if you use a wheelchair. For more information, please contact Michael Turner on 388-5299 or email him on bexleymt@yahoo.co.nz.

Allison Franklin

Michael Turner Thanks Allison & Kathy

Board member Michael Turner wishes to thank Allison for the above article as it has spread the word to members and their families. "We had our first CP Coffee Group for 2016 last Tuesday and numbers were down a bit as 4 were away and 1 had a appointment but everyone enjoyed catching up on what each had been up to over the break." said Michael. Michael wishes to acknowledge his co-host Kathy who is a great support at these coffee events and wishes to emphasise the coffee gatherings are now on the first Tuesday of the month with the exception of January.

