The Review

Official Magazine of the Cerebral Palsy Society December 2019

A UNIQUE CODE OF RIGHTS THE YOUTH ALLIANCE OPERATES BY

Cerebral Palsy Society
freedom & choice

Cerebral Palsy Society

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For information, advice and support on all aspects of cerebral palsy

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www.facebook.com/cpsocietynz

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For staff contact details, please go to page 23

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Dear Members And Supporters

I hope you have a wonderful build up to the festive season, a happy Christmas and a lovely summer! It's so good to see the beginnings of summer showing already.

We have had a great year and I want to share some of the successes. We are so proud of our:

- Social media presence, which has increased markedly, with lots of positive feedback from many of you
- Work with families: we have established a Family Engagement strategy, reconnecting with many of our younger families. We have also hosted a number of parent meetings, with opportunities to hear what is happening in research and therapies, plus some evenings to spoil our mums and dads. Early in the year we also trialed a very successful Give it a Go day in Auckland
- Work with young people, which has grown exponentially, including increasing the number of regions where we have a presence; providing opportunities for young people to learn about governance and leadership; and offering mentorship training, as well as developing a strong cohesive youth board. We are also incredibly fortunate and grateful to have a contract with the Ministry of Youth Development
- Face-to-face advocacy with children, parents, young and older people, including those with higher levels of CP and those who are non-verbal
- Boccia workshops, including a coaching workshop and a strategic planning session with the Halberg Foundation and Parafeds from around the country
- Ability to bring Iona Novak to New Zealand, where she updated health professionals, interested members and CP Society staff on current research. This session was live streamed so anyone around the country could watch it
- Sponsorship of Pia Stampe from the United States, who presented her work on intensive therapies to both our families and therapists
- Involvement in the launch of the CP Clinical Network, working with clinicians and therapists around the country, to develop best practice recommendations for early diagnosis and treatment of CP
- Opportunity to increase the products available for getThis&That, based on feedback from parents and members
- Our videos of "Children's Voices" and the Freedoms, presented by members of our Youth Alliance.

Best wishes for a safe and happy summer.

Regards, Gilli Sinclair, CEO

Calling North Shore Families

FAM (Functional Adaptive Movement) is looking for North Shore Families to participate in the newest addition to the FAM movement. Mike Hynard has now partnered with AUT to run classes for kids with CP, TBI &/or Spinal Cord injuries on Saturdays at 11am – spaces are still available. Classes are held at the North Shore campus on Akoranga Drive.

FAM
FUNCTIONAL ADAPTIVE
MOVEMENT

The CP Society is supporting this fantastic initiative and can see the benefits these classes are having for our members. Huge shout out to AUT for this opportunity. We look forward to exciting outcomes.

For more information, please contact:

- www.functionaladaptivemovement.com
- info@functionaladaptivemovement.com

Review Ad Rates

The Cerebral Palsy Society's quarterly Review reaches members and supporters across New Zealand and it's a great vehicle for advertising your small business, organisation or event.

RATES are as follows for print-ready ads:

- Half page ad, inside page - $250
- Full page ad, inside front or back cover - $400
- Full page ad, outside back cover - $500

NB - Reduced rates for inclusion in all 3 Reviews/year are available on request.

To place an ad, or for more information, please contact Aden@cpsociety.org.nz

FAM

FUNCTIONAL ADAPTIVE
MOVEMENT

FAM™ Program
(Functional Adaptive Movement™)

STRENGTH and CONDITIONING Program:

specifically designed to increase the overall health and wellness of those dealing with any disability.
These programs have proven to elevate the balance, coordination, confidence, strength, endurance, concentration, communication, capability, and life skills of participating "differently-abled" athletes. Offering the opportunity for all athletes to live more independent lives.

www.functionaladaptivemovement.com
Contact Michael at info@functionaladaptivemovement.com to get the full roster!

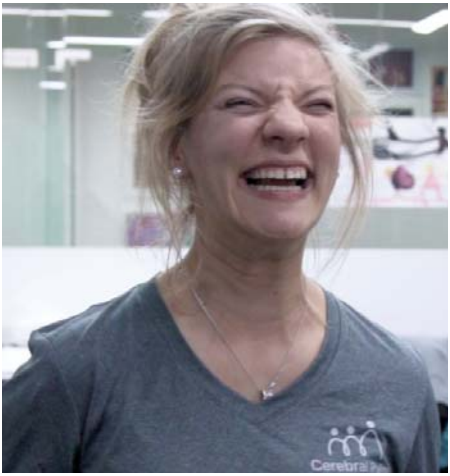
Cerebral Palsy Youth Alliance Member Pippa Huddleston On The Freedoms Campaign

The Freedoms campaign has been an eye-opener. On many, many levels.

I was volun-told to campaign for "the freedom to be accepted". On face-value, this was easy. But as I began drafting my ideas on the matter, I realised I didn't even know the definition of acceptance…what did it mean at its essence?

I love Google for many reasons finding the definition of words is at the top of the list. So now I had the definition of acceptance, I could find examples in my life where acceptance had been an issue…easy right? Wrong. Having a disability since birth gives you a certain immunity to behaviours that are shown towards you but are not displayed towards others. Thus, identifying instances in which I may not have been accepted by others took a lot of pondering.

I resorted to breaking it down by aspects of my disability that others may find "unusual". This was another revealing experience, as I consider myself an expert at forgetting I have Cerebral Palsy (CP). I brainstormed my "differences" and landed on two key things: my speech and my movements. Sussed! I almost continued to write my monologue with ease.



But why do people care?

Why should strangers care if I was bullied on the school bus, or if I can't get my point across in meetings?

The absolute last thing I wanted my Freedom video to be was a sob-story. I am a strong, independent woman with an awesome career I really don't have time for pity. I needed to make my Freedom relatable. This is the vital thing I love about the Freedoms. They are not just for youth with CP. They are not for disabled youth. They are not, even, for youth. The Freedoms are for everyone.

Now, I am not an avid social-media poster and have never posted something about myself that leaves me vulnerable. I honestly hit the

> LIVE WITH NO REGRETS. AND LIVE A LIFE THAT YOU'RE GONNA BE PROUD OF.
>
> -Kurt Petersen

“post” button then walked away for a couple of hours so I didn’t need to see the comments. Boy-o-boy am I humbled. The comments, shares, messages and phone calls were overwhelming. Realising that so many of my network relate to my Freedom video makes the whole nerve-wracking experience worth it.

The most profound message I received was from a friend I hadn’t talked to in a cou-ple of years. Beautiful, confident, gorgeous girl. She told me the video had made her reflect on the way she treats others. This was a real boost for me knowing that if my message had this effect on one person, it may well be mirrored in others.

> THE FREEDOM TO HAVE FUN IS SO MUCH MORE THAN HAVING AN ESCAPE FROM EVERYDAY STRUGGLES. AS A KID I LOVED TO READ, I STARTED READING ADVENTURE STORIES WHICH EVENTUALLY LED ME TO ...WRITE MY OWN STORIES.
>
> -Tim George

My final revelation was how my fellow Youth Alliance members told their story, and how I was able to relate in some way to each. This just highlights the universality of the Freedoms.

So, in summary, the Freedoms campaign has taught me:

1. It is important to know the definition of the words you throw around.
2. Self-reflection is powerful.
3. Realise the immunities you have built.
4. Everyone has trials, just manifested differently.
5. Telling your story is powerful, for yourself and others

Freedoms.... Cerebral Palsy YOUTH ALLIANCE

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Steptember-ites Rolled, Ran, Walked, Swam, Danced & More in 2019

STEPTEMBER

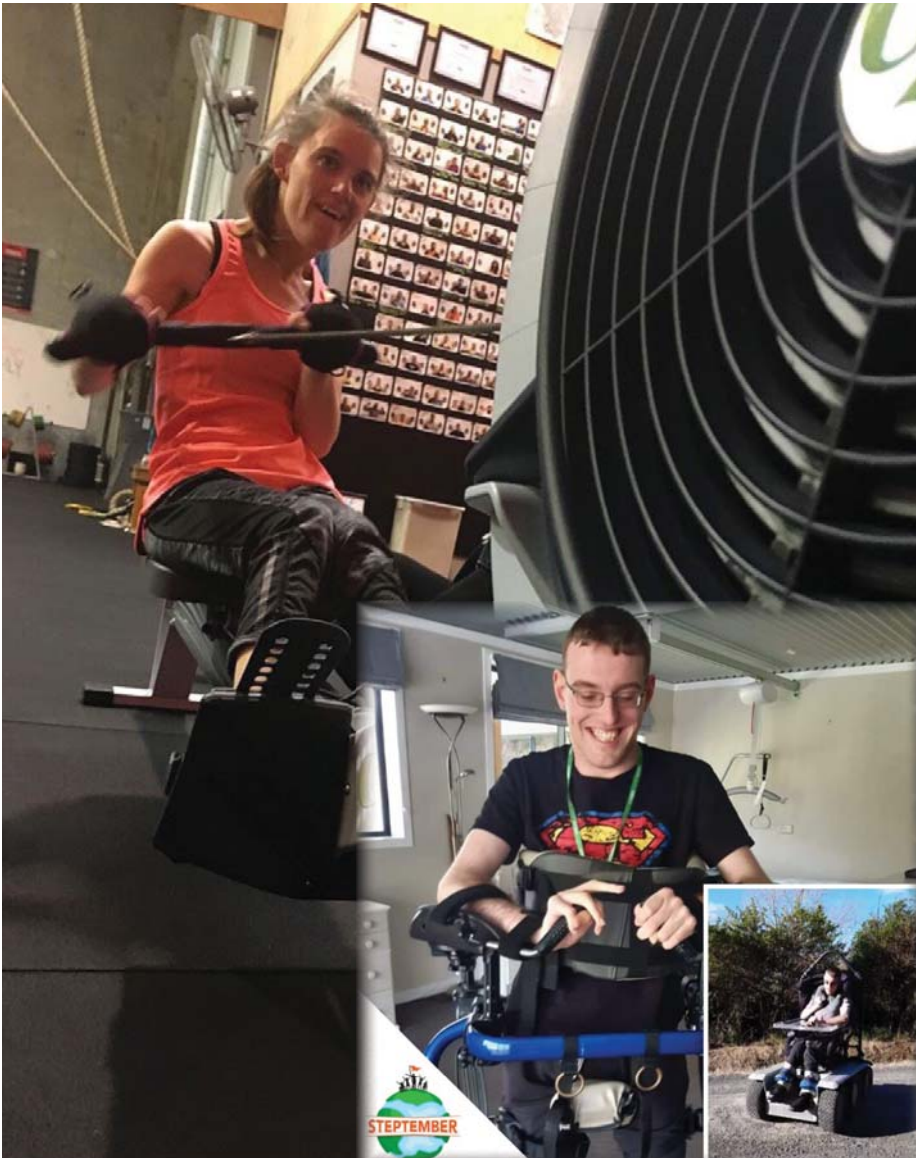
Making
space
for
greatness

Goodman

Thanks to the over 12,000 participants in Steptember 2019 this was a transitional year in which we out-sourced the project management and made some big changes, resulting in more funds raised per person than ever before and some great competition amongst both individuals and corporates. And a whole lot more publicity around the country, which helped raised the CP Society's profile a major bonus for us.

We cannot give you any definitive results before they're announced at our Awards Ceremony at the end of November, however, we will have a full report to you in the next edition of The Review. In the meantime, HUGE THANKS to all of our participants, especially our corporate partners and janda, our project managers. And extra special thanks to our global partner, Goodman, particularly the Goodman NZ team which helped sponsor an event at C.A.S.S. (Central Auckland Specialist School) and continues to support and encourage us in so many ways!

If you participated in Steptember 2019 and haven't already reached your fundraising target (and bravo to the #1 CP Youth Alliance team, which has they raised $1,000!), please do so before the end of November. If everyone does this we will make our target of $1.1 Million, which will enable us to continue enhancing our programmes and services to the CP community imagine the possibilities!



Global Day Marked With Multiple Events

Cerebral Palsy Society invites you to

SCHOOL LEAVERS FUNCTION!

December 3 - 4-6pm
CPS Office
8 Railway Street, Newmarket

Express an interest to Mke Ninces on mke@cpsociety.org.nz

CEREBRAL PALSY SOCIETY IS HAVING AN OPEN HOUSE EVENT

03.12.19 | 10:00 AM TO 12:00 PM

OPEN HOUSE

As part of World Disability Day, enjoy morning tea with us and learn about our organisation!

RSVP TO CPSOCIETY@CPSOCIETY.ORG.NZ BY NOV 26

December 3 marks International Day for People with Disabilities, a global movement to reflect, celebrate and learn.

Since its inception in 1945, the United Nations (UN) has outlined and reiterated its commitment to calling for the creation of inclusive, accessible and sustainable societies and communities most notably with the adoption of the Universal Declaration of Human Rights in 1948.

International Day of People with Disabilities belongs to all people, organisations, agencies, charities, places of learning all have a vital role to play in identifying and addressing discrimination, marginalization, exclusion and inaccessibility faced by many people living with disabilities.

International Day of People with Disabilities is one day on the international calendar, yet it symbolizes the actions we should take every day, in order to create diverse and accepting communities.

The Cerebral Palsy Society of New Zealand is one of the many organisations adding its voice to the global choir championing this day.

As part of this global movement, we are holding an Open House to welcome members of the Newmarket Business community into our workplace, to learn about what we do and to enjoy morning tea with us. In the afternoon we are also holding a School Leavers' function which is being spearheaded by our amazing Youth Alliance.

On 3rd December CPS is also partnering with Eden Park, New Zealand's national stadium, which will mark the occasion by turning their lights on in bright "CP blue". As a means of amplifying our biggest current social campaign, The Freedoms, we are thrilled to project key messages across three billboards in Auckland from Dec 1-8: 66 Fanshawe Street in the CBD, Nelson intersection (91 Newton Road, Eden Terrace) and the Goodman billboard in Highbrook (Highbrook Business Park in East Tamaki). So please look for them and continue to support the campaign!!

The Youth Alliance Reflects On A Colossal Year!

Cerebral Palsy
YOUTH ALLIANCE

2019: a year of expansion and great teamwork

Wow! Another year is coming to an end and it's time to reflect on our 2019 journey. The Youth Alliance has grown from an eight person board which meets once a month and is primarily based in Auckland, to a well-oiled machine which now also includes:

- 2 dedicated youth advocates
- 4 youth leaders across the country
- 3 new youth groups starting up in Christchurch, Dunedin and the Waikato

Our reach has seen meetings with the Hon Peeni Henare Minister of Youth Development, experts from Ernst & Young, Blind and Low Vision NZ, Dr Huhana Hickey, the NZ Youth Mentoring Network, and Ross McCook's Heart for Youth Trust.

While travelling up and down the country, I can never stop talking about how wonderful it is to have a "founding document", Our 10 Freedoms. Not only can these Freedoms be used to equip, inspire, and showcase the talents and passion for change by our governance board, they have now been transformed into a video series which is receiving both national and international attention and acclaim. Congratulations and thanks to everyone who has taken part in these videos, which highlight the importance of rights for those living with CP.

Next year we will be continuing our national reach, with groups of young people from across the country coming together for mentoring, leadership, and governance training.

Have a great Christmas and a jolly New Year!

Whisking Something Festive In Our Kitchen

"The Cookie Project is a social enterprise that employs people with disabilities to make delicious cookies." It is overseen by two extraordinary men, Eric and Graham. Once you meet them, as we did recently, you understand completely why The Cookie Project is so successful and impactful.

On 8th December, a group of Auckland CP members and staff, both children and adults, will be volunteering to make cookies yummy ones (believe me, we tested them very very more-ish!) short bread for the Christmas season and chocolate chip, the perennial favourite.

The Cookie Project will provide these cookies to us at cost and we will then sell them $10 for a bag of 20. They are made with pure ingredients in bags clearly identified as a joint initiative between the CP Society and The Cookie Project.

This is a test run, so we will only have 200 packages to sell please get in your orders today so you're not disappointed. Just send an email to hannah@cpsociety.org.nz and she will process it we apologize in advance: for this first run, we will need people to pick up their cookies at our Newmarket office and will not be able to post them to you.

If this initial trial is successful, we hope to do it again, and be able to ship cookies to people throughout New Zealand.

THE COOKIE PROJECT
COOKIES WITH A PURPOSE

Mighty Ape – a great and easy way for online Christmas shoppers to support the CP Society!

We're proud to be partnering with Mighty Ape this Christmas to raise funds for the CP Society. If you shop online, please consider doing your Christmas shopping through Mighty Ape 5% of sales will be donated back to us (nb there will be a few exceptions/items which will not be included in this offer).

Please use the link below when shopping with Mighty Ape to continue supporting CPS. The referral link is www.mightyape.co.nz?r=3724525

Happy Shopping!

Spookily Successful Hogwarts Fundraiser

We were honoured to be the chosen charity this year of Haunted Hogwarts, a Harry Pot-ter-themed fundraiser held in Wellington on the 30th and 31st of October. Members of the public were welcomed at several shows, which had sold out months in advance!

Guests visited platform 9 ¾, Ollivander's wand shop, the Great Hall of Hogwarts, and the Forbidden Forest. Over $3,000 was raised for the CP Society, for our children's programmes.

Haunted Hogwarts was a HUGE amount of work for Mindy Dalzell of Twig & Arrow and her team and we offer them our heartfelt thanks for choosing the CP Society to benefit from this amazing initiative.

Photo credit:
Candy Capco Photography

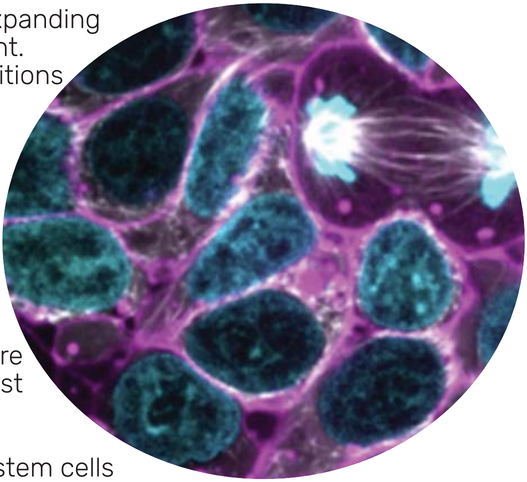
Good in the Hood

We'd like to thank Z (Zed) Energy for selecting the CP Society to be one of the beneficiaries of their Good in the Hood initiative during September.

This year we received funds from 4 of its locations: 1 each in Christchurch and Hamilton and 2 in Auckland. Patrons visiting these stations had a choice of 3 charities and allocated their token to their preferred charity, helping raise $3,398 for the CP Society!

This was much more than we'd ever received before, so a very big thank you goes to Z Energy, the operators of each of the 4 stations, and to those who voted for us.

Stem Cell Research and Development



Stem cells are an exciting and expanding area of research and development. Cerebral palsy is one of the conditions that is likely to benefit from the ability of stem cells to potentially lessen the impact of brain injury. An increasing number of studies are looking at the safety and effectiveness of stem cell treatments and how best to administer the treatment.

Below is a list of factors people are considering. These studies are first step to clinical application.

- **Stem Cell Types**: Different stem cells have different origins and different effects on the brain.
- **The Delivery Method:** It can be difficult to get stem cells to the target area.
- **Dosage**: It is important to consider what amount of stem cells is useful and safe.
- **Timing and Diagnosis:** The effect of stem cells can depend on the timing of both diagnosis and intervention.
- **Complications:** There needs to be more specific investigations into the potential complications of stem cells.
- **Follow-up Care:** Follow up care and intervention is crucial to making stem cells ef-fective and viable.

Attention is focused on limiting the impact of the original brain injury and minimising the impact of brain inflammation and subsequent damage in the days, weeks and months after the insult to the brain. CPS families have reported improvements in muscular control, quality of life, fine and gross motor as well as overall confidence and self-efficacy. However, more research needs to review these self-reported results.

For the full version of the article, please go to https://cerebralpalsy.org.nz/research/stem-cell-update-october-2019/

If you would like more information or references, please email amy@cpsociety.org.nz

Help Researchers

Help researchers understand your unique experience of CP diagnosis so that improvement can be implemented. Starship is conducting a study with the overall goal to lower the age of diagnosis of CP in NZ, improve early management pathways, and address any regional or ethnicity inequity in health service delivery. Better outcomes for children with CP start with earlier diagnosis / detection of high risk of CP to allow for earlier delivery of targeted interventions and preventative management such as hip surveillance.

Title: CP diagnosis experience

Age range: 10 or under (Born in 2009). However, anyone is welcome to submit their experiences regardless of age.

Study summary: A short survey asking parents about their experiences of their children being diagnosed with CP

https://curtin.au1.qualtrics.com/jfe/form/SV_2a8av2oBCH5ONY9

Has your child had SDR?

Selective Dorsal Rhizotomy (SDR) is an operation to reduce spasticity in CP. Many of our families are considering or have taken their child overseas for this operation. Researchers want to know about their experiences. The information will help us better understand the children in NZ who have had SDR so that we can work towards improving health service delivery for children with cerebral palsy across New Zealand.

If you give consent, a researcher will conduct a review of the clinical records of your child in relation to SDR. You won't need to do anything after giving consent. All the information is already collected.

If you would like to participate or receive further information, please contact the research officer at sdrproject@adhb.govt.nz

Gifts in Wills Programme

Exciting news! We're launching our Gifts in Wills programme.

We're always looking for ways to raise money to support the programmes, events and services we provide. The more income we have, the more we can do. Giving everyone the option to leave a donation to us in their Will is one way to do that.

You don't have to be wealthy to leave a gift. We understand that people will, and should, want to make provision first for their family and friends. A gift of any size will be appreciated, spent wisely and make a difference. This is our promise to everyone who leaves a donation to the CP Society in their Will.

"I truly believe in the work the Cerebral Palsy Society is doing. I've seen the difference they make to the lives of people with CP so wanted to leave a gift in my Will to them. It's not a large amount but I know they will spend it wisely, just like my other donations. It was an easy decision to include a gift to CP when I updated my Will."

"I'm not wealthy, I'm just an ordinary person who understands that bequests are an important source of income. They're essential to ensuring services can continue."
— CPS member

The Really Useful Guide to Updating Your Will

How to make a lasting impact for people with Cerebral Palsy throughout New Zealand

Cerebral Palsy Society
freedom & choice

A Will is very personal and we strongly advise consulting your legal advisor before drafting a new Will or updating an existing one.

If you are considering leaving, or have already left a gift to us, please let us know so we can chat about your wishes. For example, would you like your donation to be spent on direct programmes nationwide or in a specific geographic location? Or would you prefer to have it invested and the interest only spent?

To receive a copy of our new Gifts in WIlls brochure, or to have a confidential chat about your wishes, please contact Gilli Sinclair, our CEO at cpsociety@cpsociety.org.nz or call our free phone on 0800 503 603.

Boccia New Zealand Welcomes Our New President!

Boccia NZ is excited to introduce our new President Andy Henderson. Andy is based in Wellington where he lives with his wife Suzanne and two boys, Matthew and Daniel. Andy has worked for 22 years as a Branch Manager for Patton Ltd, a refrigeration wholesaler.

Andy first got involved with boccia in 2011 through ParaFed Wellington (now dsport) whilst looking for a sport for his son Matthew, who has Cerebral Palsy, to play. Andy has played a significant role in growing boccia in the Wellington region and often travels around the country with the Wellington team, attending regionally and nationally sanctioned events.

Andy first joined the board of Boccia NZ board in 2016 as a committee member and stepped into the role of Vice-President towards the end of 2017. He is also an internationally accredited referee, having attended competitions in Dubai and Sao Paulo (Brazil).

Andy brings fresh energy and enthusiasm to the role of President and is looking forward to the challenges ahead. Welcome Andy!!

Our Mum's Events

We have had an amazing year with events and working with our families across New Zealand.

Our Mum's events have been especially rewarding, fun and engaging. The Cerebral Palsy Society would like to thank everyone who made these events an experience to remember.

Our last Mum's event was held in our Auckland office and was a great evening. We would like to say thank you to Karen Middleton Reflexology, Monaco Nail Academy and Serenity Makeup, as well as Ara College who, has supported our Mum's events in Christchurch this year.

We are proud to be associated with them and allowing their students the opportunity to gain valuable work experience at our events.

Thank you all!

More Ways To Support The CP Society!

Giving Tuesday

Giving Tuesday is on Tuesday 3rd December this year, coinciding perfectly with International Day of Persons with Disabilities (more commonly known as World Disability Day). This is a global day of giving that is celebrated on the Tuesday following American Thanksgiving, Black Friday and Cyber Monday.

There are many ways to participate in Giving Tuesday that will benefit the CP community, including donating one hour of your pay and inviting your work mates to do the same visit our website for how to donate: www.cpsociety.org.nz.

You can also donate your time and/or your voice as an advocate of the work we do to support our community. Raising both funds and profile is key to our success and ongoing ability to offer programmes and services to people living with CP.

Payroll Giving

If your company has an employee/payroll giving programme, we'd love an opportunity to be part of it. So, if you're able to make an introduction to whoever is in charge of it, please get in touch with Sue at the CP Society: email sue@cpsociety.org.nz

Charity of Choice

Another great way to support our CP community is by getting corporates, organizations and/or schools to name us as their charity of choice. We will provide them with information, fundraising ideas and support as they engage with their staff, members and/or students, generally over a period of at least a year, to raise funds and profile for the Society. The opportunity to educate and inform people about CP is integral to our growth. For more information, please contact Sue: email sue@cpsociety.org.nz

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We thank the Trusts Community Foundation for their grant to print this magazine.

We are very grateful for their support.

THE TRUSTS Community FOUNDATION

Great Gift Ideas

Better than re-gifting any day! So often we receive gifts, especially at Christmas, that we don't want, need or even use. Here's a unique solution that is truly in the spirit of giving: why not ask your friends and family to buy meaningful presents for our CP community? Physical therapy or fitness sessions or even a Vibratrain gifts that will really benefit the recipients. We can provide you with a gift list to share with people.

Alternatively, in honour of the season, make a donation in the name of a special friend or family member and we'll send them a note, telling them of your unique gesture. Or, we'll give you a note/certificate to include in your greeting card to them.

And remember, giving isn't just for Christmas, this is a great idea for birthdays, weddings and other special occasions. For more information, or to receive a list of suggested gifts and prices, please get in touch with Sue: sue@cpsociety.org.nz

EDIBLE BLOOMS

Gift Differently

A very big thank you to Edible Blooms, our wonderful partner, which continues to support the CP Society in so many ways: from raising funds through Steptember and cause marketing campaigns, to providing product to Steptember winners and other initiatives.

We are so honoured and grateful that you've chosen the CP Society as your "cause".

Website Redesign To Encourage Easier Navigation

Get involved with CPS

Helping you to understand cerebral palsy and to make informed decisions

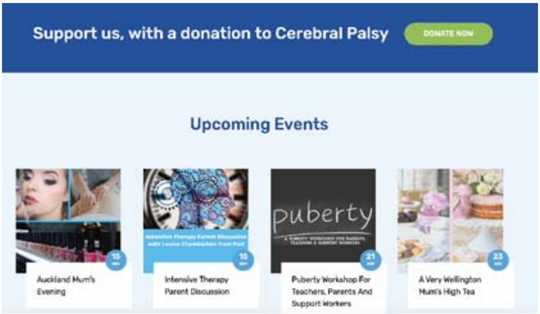
For the last several months, the Cerebral Palsy Society has been working to align its external communication. One of these outlets is the website, which we've recently redesigned to be more aesthetically pleasing and to encourage easier navigation to the services we offer.

Working with Cube Media, the new "look", specifically seen on the homepage went live recently and has received positive and engaging feedback. Great news as we are constantly striving to improve the experiences for our members.

After receiving the analytics for the website which showed where lands traffic, it was recommended that we make the following changes:

- The events pulled out of the banner rotator and given their scroll position
- CPS offerings a the top of the page due to high traffic volume
- A support and "Donate" function placed near the top of the page
- A photo strip added to the bottom of the page which will open up to an image and video gallery which is a first for CPS.

Over time there will be many changes to come but this is the start of projecting a better image whilst ensuring accessibility is priority.



Support us, with a donation to Cerebral Palsy

Upcoming Events

Auckland Mum's Evening

Intensive Therapy Parent Discussion

Puberty Workshop For Teachers, Parents And Support Workers

A Very Wellington Mum's High Tea

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