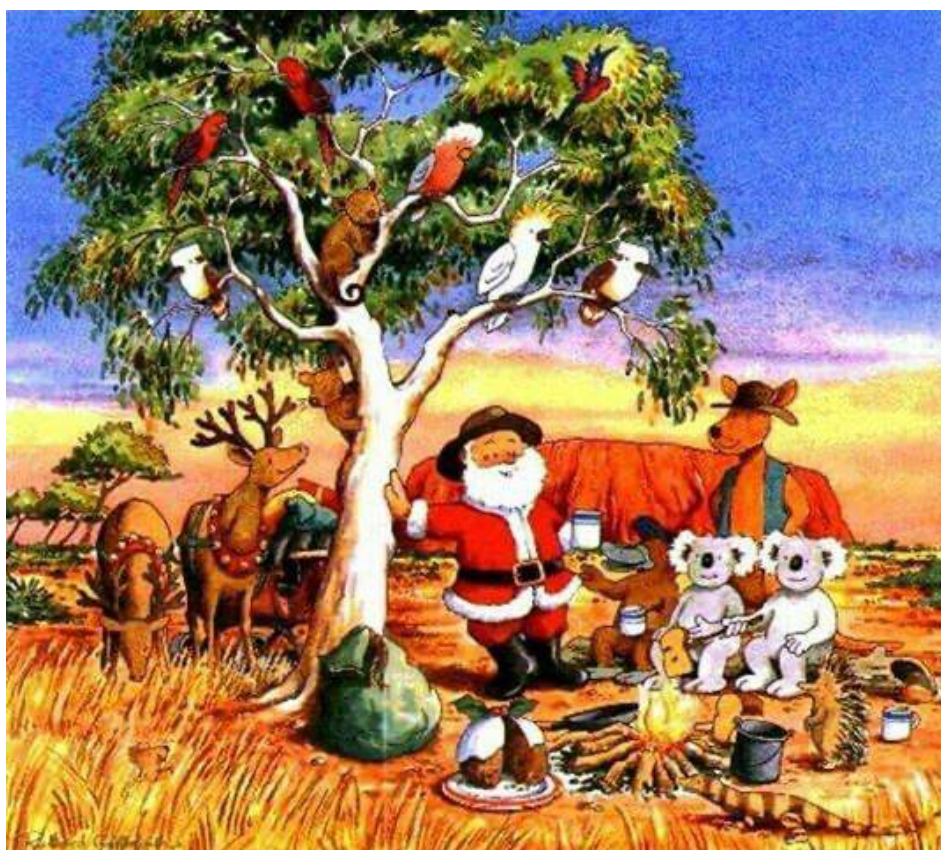




Short Statured People of Australia Inc.
THE NATIONAL JOURNAL
Summer Edition 2021
Issue No. 264
www.sspa.org.au

Est: 1968
Co-founders: George and
Rosemary Whitaker



Merry Christmas!

*SSPA wishes everyone a Merry Christmas
and a safe and Happy New Year!*

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National President

Sam's health hasn't been too well recently, so we send our good thoughts and hope he gets better soon.

Sam wishes everyone a happy and safe Christmas and is looking forward to seeing everyone in the new year.



A message from our VP/PAB liaison

Dear members,

I recently found this pic taken in 1999 with Dame Edna, at one of her shows in Sydney. My friend insisted we sit in the front row as he was keen to be part of her show, but much to his disappointment she was only interested in the female members of the audience. Hence, I was invited with others onto the stage. She dressed me in a feather cape and a blonde wig and announced that I was "A Great Australian Icon Kylie the budgie". All good fun!



Incredible that we are now into the second last month of 2021; where has it gone? As many of us were locked down for much of the last year we certainly faced challenges. One of them was knowing that we had to hold another Virtual Convention (VC) due to the closing of state borders. Although hard work, it was certainly rewarding to be part of the Virtual Convention (VC), learning new tech skills whilst catching up with friends and meeting new members.

Dwarfism Awareness Month has also come and gone. I hope you were able to view our great Dwarfism Awareness Day promotion on social media. Many thanks to all who participated, and a BIG thank you to Susie Roczo-Farkas for pulling it together at short notice. Moving forward, we are now in the process of arranging the 2022 face-to-face convention to be held

at Alexandra Headlands on the Sunshine Coast in QLD. Fingers crossed all goes to plan. The convention has been held there before and I'm told it's a popular spot, so I look forward to hopefully seeing you there ☺!

It takes a lot of time and effort for us to put events together so we certainly appreciate your support with participation and or attendance. We are a small volunteer organisation; running for 54 years on a shoestring budget with energy and input from committed volunteers. We welcome and encourage our new National Council members, as well as anyone who would like to help us throughout the year with social media promotion, writing articles for the Journal, assisting with virtual and in-person activities and supporting our programs (sports, arts, and mentor and peer network). The more the merrier and the more effective we are. ☺

Maree Jenner

Vice President and PAB Liaison Officer, SSPA

E: pab@sspa.org.au

DO MEDIA REPRESENTATIONS OF DWARFISM INFLUENCE SOCIAL PREJUDICE?

Hey, everyone! Lucia Bruce-Gilchrist here.

One of the subjects I'm taking for my HSC year is Society and Culture (SAC). For this subject, I have a major work as a part of my HSC – the major work is a personal interest project (PIP). For my PIP, I am undertaking a study to determine if representations of dwarfism in television influence social prejudice against people with dwarfism. To aid my research, I will be making at least two questionnaires – one for people with and one for people without dwarfism – which will be available for everyone in the SSPA over 15. On the 29th of October, an email was sent around by Katrina Reynolds containing the links to these questionnaires. I would greatly appreciate it if everyone eligible completes the survey. All responses would remain anonymous and would not be used for anything other than the purpose of the survey.

Thanks,
Lucia

From the Editor's Laptop

Hi everyone,

It was great seeing everyone online for the multiple events during the online convention



I've settled into my new job as coordinator of a creative writing studio and mentor for young writers, which I'm really enjoying. We're busy changing our programs and direction which we'll be launching in the new year and I'm super excited to witness the beginning of this new project. My story writing clubs have returned to the studio two afternoons a week and I'm loving it – there's more natural conversation throughout the workshops and it's a lot easier to help the younger kids and keep them focused.

So, we didn't win the student council election this year, but a few people from our party got roles. It was kind of upsetting at first as we'd put so much work and effort into our campaign, but it was a great experience running for student council, and I learnt a lot.

Here are seven lessons I've learned from running for student council:

- **The incumbents always have the upper hand**

We were fighting a hard battle right from the beginning. We knew it was going to be a challenge, but we were stubborn and determined. The incumbents were getting paid to run for student council again, whereas we had to fit this campaign in around our lives—our jobs, uni work, and other commitments, which was not an easy feat. We all had to sacrifice things (mostly our time and sanity) to get this campaign up and running.

- **Sometimes it really is about who you know**

At the end of the day, you can't win without votes, and to get votes, you need people on your side, you need big networks, and you need people to be aware of student council. It is a hundred times harder trying to reach students online (you have to do a *lot* of cold messaging which 99% of people ignore) than in person, where you can accost random uni students. So, thanks COVID, for adding another challenge (not really).

- **We need to prepare a LOT earlier**

This is where our campaign cost us – we needed to get our candidate statements and our policies on social media a *lot* earlier. We started chasing people for their statements way too late, so we didn't publish them until after people had received their ballots and most people had already put in their votes. Which is why we're going to start preparing for next year's campaign at the beginning of the year.

- **We need to get better at delegating to different people**

When you only have eight people (out of about thirty or so candidates) doing *all* of the work, things will suffer. Either in our personal lives or the campaign or both. We are human, we are not getting paid for this, we all have lives and jobs and uni and things that need our attention, a campaign takes a LOT of work and stress, things are going to be late or not up to a high

standard. We need to prepare earlier so we can delegate to other people and so we're not all scrambling at the last minute to get things done.

- **It's okay to say no without needing an excuse**

I was asked numerous times to take on multiple responsibilities because I was reliable and I had a hard time saying no because we were understaffed. I felt like I couldn't say no because then I'd be adding to everyone's already full plate; and they were desperate. But when I really couldn't do something, I felt like I had to come up with an excuse such as 'I can't do that because I'm flat out with my uni assignment' instead of just saying no. We need to normalise accepting 'no' without needing a reason why.

- **A good community/friendship is the most important thing**

The most important thing I got out of this experience was a fantastic group of people I can now call my friends. It gave me a new community when I was missing my student magazine community. This opportunity introduced me to a diverse group of people I never would have had the privilege to know and learn from if I hadn't taken this chance to jump into something new. We all have the shared goal of wanting change and wanting to make university life better for students.

- **There are other ways to make change**

Although being on student council is an amazing opportunity to make a big change in the student community, and gives you lots of great resources to do so, there are plenty of other smaller communities and opportunities where you can still make change, so we're putting our focus into branching out into these opportunities. Watch out 2022, because we're coming!

Kind regards,

Julie Dickson

Journal Editor SSPA

E: journal@sspa.org.au

The last date to receive material for the next edition of the National Journal will be the **1st March 2022**.

Please send all reports, news, stories, and articles to:
journal@sspa.org.au

MEET YOUR 2021-2022 SSPA NATIONAL COUNCIL

The SSPA is administered by a body called the National Council elected at every National Annual General meeting held at the National Convention each year.



Sam Millard
President



Maree Jenner
Vice President



Anthony Koedyk
Treasurer



Vicki Fallon
Secretary



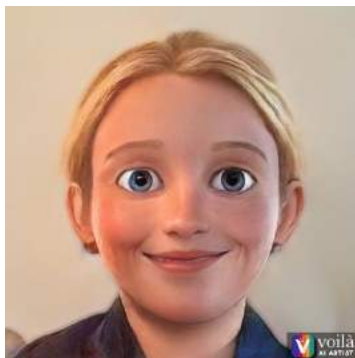
Katrina Reynolds
Membership Secretary



Beck Kim
Overseas Liaison Officer



Julie Dickson
Journal Editor



Kobie Donovan
Sports Coordinator



Graci Lynch
*Short Arts Collective
Coordinator*

Ordinary Councillors:

Jo Bracknell (WA)
Tom Carney (VIC) Marta Eyles (NSW) Suzann Franklin (WA) Hayley Gill (WA)
Rose Hobbs (VIC) Rachael Johnson (QLD) Francis Kelly (VIC) Oliver Lynch (VIC) Carly Myers (VIC)

Sue Palmer (NSW)
Troy Parker (NSW)
Peter Stone (WA)
Emily Vozzo (SA)
Keiran Watson-Bonnice (VIC)

Vicki Fallon – SSPA Life Membership Nomination



Vicki joined SSPA in 1995 with her husband Shane, son James and daughter Jade. In the same year, they attended their first national convention at Portsea, Victoria. This was to be the first of many conventions, 20 face-to-face and two virtual. Times have surely changed since Portsea.

Vicki must have enjoyed herself at the Portsea convention so much so that at the AGM, she put her hand up to be on National Council, which as noted by Francis, is quite a rare feat. This was the beginning of a very long tenure on National Council, 24 years and counting.

The various positions Vicki has held on National Council are:

- National Secretary: a total of 10 times (1996/1997, 1997/1998, 1998/1999, 1999/2000, 2000/2001, 2001/2002, 2006/2007, 2007/2008, 2019/2020, 2020/2021)
- Membership Secretary: a total of 10 times (2009/2010, 2010/2011, 2011/2012, 2012/2013, 2013/2014, 2014/2015, 2015/2016, 2016/2017, 2017/2018, 2018/2019)
- Council Member: a total of 4 times (1995/1996, 2002/2003, 2004/2005, 2005/2006)

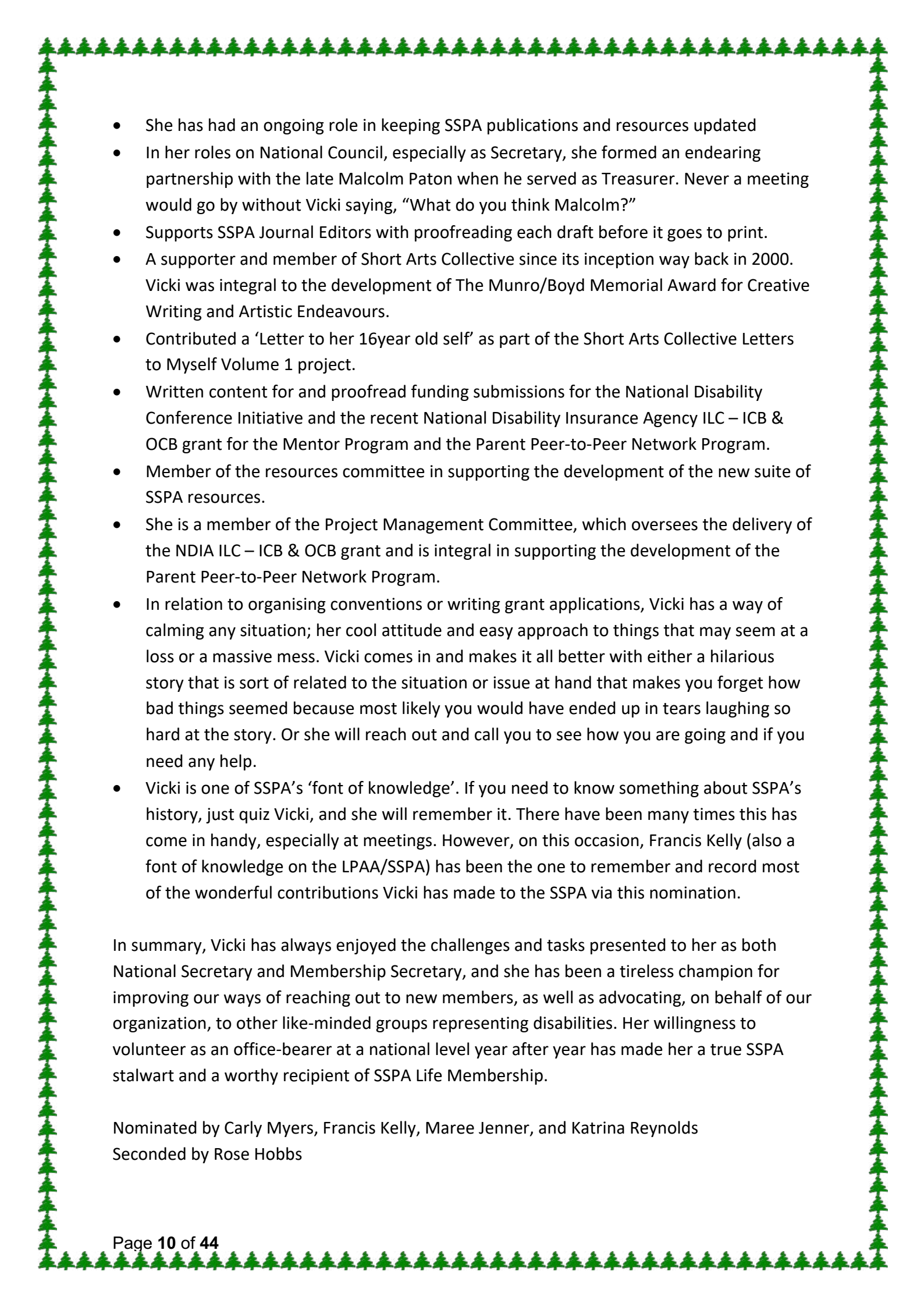
Vicki obviously did not think she was busy enough holding positions on National Council, so she thought she better serve on the New South Wales Branch as Secretary, a total of four times (2002/2003, 2003/2004, 2007/2008, 2020/2021), and as a Committee member also four times (2008/2009, 2017/2018, 2018/2019, 2019/2020).

She also holds the position of Parent Representative, which she has held for many years. In this position, she has supported countless new families coming into contact with the SSPA for the first time.

As busy as she already was, you would not be wrong in thinking, what more could Vicki possibly fit in? Yep, she turned her attention to assisting with the organising of the SSPA Annual National Conventions. No matter if they were in her state of NSW or not, she would also be happy to assist, especially members who were organising the convention for the first time, Vicki was there to help.

Now to acknowledge the incredible contributions Vicki has made over the years to the SSPA whilst in these numerous roles:

- In conjunction with Professor David Sillence, she established the framework which led to the establishment of the SSPA New Parent Representatives across Australia. This arose from a concern expressed by Prof. Sillence that the SSPA needed to improve its ways of integrating new parents and families into the SSPA. As a result, she had regular liaison with Prof. Sillence about its mechanics, development, and membership. Reports of New Parent Representative activities have since become a permanent National Council agenda item.
- Created and distributed the Information Folder (or Kit) for New Parents which were distributed to both State Branches and genetics clinics across Australia.
- Involved in the review of the SSPA Constitution (1997-1998)
- Drafted original SSPA Mission Statement (1997-1998)
- In her role as National Secretary, she lifted the profile of the SSPA when the opportunity presented itself with organisations such as the Association of Genetic Support of Australia (AGSA), People with Disability (PWD), and Physical Disability Council of NSW (PDC), and was an early promoter of advocacy, and having contact with other groups representing disabilities. She played a role in having the SSPA represented in such events as the AGSA Genetics Awareness Week. By being proactive in this area, she re-defined the role of National Secretary.
- Established the means to improve communications between National Council and the Professional Advisory Board (PAB) with her acting as an unofficial PAB liaison (2000)
- Involved in the production of Emily Neyland book (2000)
- Drafted SSPA Code of Conduct (2003)
- Updated Information Guide to Persons of Short Stature (2009)
- Contributed to the drafting of the SSPA Media Guidelines (2011)
- Author of 23 'Love Your Work' articles in SSPA Journal between 2006-2018 interviewing people of short stature about their careers, thereby promoting employment and career opportunities for people of short stature.
- Active in promoting the need for the SSPA to maintain and build on established contacts such as the Professional Advisory Board (PAB) to help our members

- 
- She has had an ongoing role in keeping SSPA publications and resources updated
 - In her roles on National Council, especially as Secretary, she formed an endearing partnership with the late Malcolm Paton when he served as Treasurer. Never a meeting would go by without Vicki saying, “What do you think Malcolm?”
 - Supports SSPA Journal Editors with proofreading each draft before it goes to print.
 - A supporter and member of Short Arts Collective since its inception way back in 2000. Vicki was integral to the development of The Munro/Boyd Memorial Award for Creative Writing and Artistic Endeavours.
 - Contributed a ‘Letter to her 16year old self’ as part of the Short Arts Collective Letters to Myself Volume 1 project.
 - Written content for and proofread funding submissions for the National Disability Conference Initiative and the recent National Disability Insurance Agency ILC – ICB & OCB grant for the Mentor Program and the Parent Peer-to-Peer Network Program.
 - Member of the resources committee in supporting the development of the new suite of SSPA resources.
 - She is a member of the Project Management Committee, which oversees the delivery of the NDIA ILC – ICB & OCB grant and is integral in supporting the development of the Parent Peer-to-Peer Network Program.
 - In relation to organising conventions or writing grant applications, Vicki has a way of calming any situation; her cool attitude and easy approach to things that may seem at a loss or a massive mess. Vicki comes in and makes it all better with either a hilarious story that is sort of related to the situation or issue at hand that makes you forget how bad things seemed because most likely you would have ended up in tears laughing so hard at the story. Or she will reach out and call you to see how you are going and if you need any help.
 - Vicki is one of SSPA’s ‘font of knowledge’. If you need to know something about SSPA’s history, just quiz Vicki, and she will remember it. There have been many times this has come in handy, especially at meetings. However, on this occasion, Francis Kelly (also a font of knowledge on the LPAA/SSPA) has been the one to remember and record most of the wonderful contributions Vicki has made to the SSPA via this nomination.

In summary, Vicki has always enjoyed the challenges and tasks presented to her as both National Secretary and Membership Secretary, and she has been a tireless champion for improving our ways of reaching out to new members, as well as advocating, on behalf of our organization, to other like-minded groups representing disabilities. Her willingness to volunteer as an office-bearer at a national level year after year has made her a true SSPA stalwart and a worthy recipient of SSPA Life Membership.

Nominated by Carly Myers, Francis Kelly, Maree Jenner, and Katrina Reynolds
Seconded by Rose Hobbs



Since the last Journal, the SSPA has been privileged to welcome the following new members:

- Elizabeth from NSW
- Samantha, Luke, and Gabriel from NSW
- Rhiannon, Paul, and Harriet from SA
- Vicki and family from NT
- Katheryn, Joel, Julie, and Violet Rose from NSW
- Tamika and family from NSW

And welcome back:

- Yana and Glenda from WA
- Fiona from Tasmania
- Glenda from Tasmania

We are so happy to have you as members of the SSPA, and we can't wait to chat with you, either online or at a face-to-face get-together. WELCOME!

Welcome to the Family

New members ... we'd love to meet you! If you'd like to introduce yourself, please send us a 'hello' with a couple of pictures to: membership@sspa.org.au

Skeletal Dysplasia Research and Study Project Ready to Go!

We hope that you enjoyed the virtual conference and found the health professional presentations to be useful. You may recall the two presentations by our health Professional Advisory Board team members Penny Ireland and Verity Pacey. Penny reported on results from their last research study, focused on a new tool to measure mobility and symptoms of pain and fatigue (the STEMS). Verity spoke about a new study they were about to commence which focuses on participation in daily activities and the NDIS. This study is now up and running.

Details are in the flyer attached or you can find more information here <https://redcap.mq.edu.au/surveys/?s=8YT4N3P98X> . If you are interested in supporting this research which will help the SSPA, advocate about the needs of individuals with skeletal dysplasia, please follow the link to find out more information and complete the survey if you choose. Any queries, please don't hesitate to contact Verity on verity.pacey@mq.edu.au or Penny on Penny.Ireland@health.qld.gov.au

Functional Performance & Participation of Individuals with a Skeletal Dysplasia



QRcode

[Link: Click Here](#)

We want to describe the functional performance and participation of individuals with skeletal dysplasia and identify challenges and restrictions with self care, mobility and public access. We hope the findings will help advocate for better funding access for people with skeletal dysplasias.

Are you interested in taking part?

WHO: Anyone with a clinical diagnosis of a skeletal dysplasia aged >14 years OR A parent/caregiver of anyone with a skeletal dysplasia aged <18 years.

WHAT: 40 minutes of your time to complete an [online survey](#) and [functional assessment](#) via phone or zoom. You will be provided with a summary of your individual results to share with your healthcare team if you choose.

HOW: Scan the QR code or click [here](#) to access more information

CONTACT: A/Prof Verity Pacey
EMAIL: verity.pacey@mq.edu.au
PHONE: (02) 9850 2795

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee, HREC Approval number (#33740). If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au).

Version 1.0 – 14/09/2021

MINECRAFT

The Minecraft Challenge at this year's Virtual Convention was a huge hit for the kids that participated. A dedicated Minecraft server was set up for the event with a huge SSPA sign as the participants entered.

The kids then went down to the challenge arena, where each participant was given an area to build in. The challenge for this build was 'tree houses', and as you can see in the pictures below, we had some amazing builders join the challenge.





Another Minecraft Challenge is Coming

There will be two sessions available which will be held in early January. Date yet to be set.

1. Children's session for children up to 16yrs of age.
2. Big kids session for anyone from 14yr old to 100. Yes, that means that the adults can join too.

I am looking for challenge ideas, so if you would like to participate, or have a great idea for a challenge, please let me know at membership@sspa.org.au.

Some ideas we are tossing around include:

- Castle building
- Maze building
- Underground troll city
- Christmas village
- Survival bunker pre prepared for a survival game in the future

There can be seven participants per session. So, if you are keen, book your spot now.

BINGO

Who knew what a hit our adults bingo session was going to be at this year's convention? Everyone I have spoken to says that they had a blast and are asking for an in-person bingo game during the 2022 convention.

I have to say a huge thank you to Rose Hobbs for being a fantastic bingo number caller. She had all of the bingo lingo down, kept me on task when I was too busy laughing, and was very entertaining.

Another thank you goes out to the wonderful ladies who broke out into song every time the number 17 Dancing Queen came up. Involvement like this is what makes bingo so much fun.

So cheers to everyone who participated, and yes, I will be bringing my computer and some bingo cards to the 2022 Convention, so keep an eye out for next year's program to be sure that you register for that event. We may even have real prizes next year.

See you there!

Katrina

CONVENTION YOUTH CATCH-UP

Hi everyone!

On the 26th of September, the SSPA held a Zoom catch-up for the 12-20s as a part of the virtual convention. We connected with the LPNZ and had some of our friends from across the Tasman join us, which we absolutely loved. It was the second time running this, and just like before, it was great to see everyone again and perhaps for some of us, to meet new people.

The shared experience of lockdown, which most of us were still in, allowed us to further reconnect with our friends, and of course, provided a great topic of conversation.



We spent the afternoon playing many fun virtual games and activities, including 'Skribblo' as well as an at-home scavenger hunt. These games were a great way for us to all bond with each other whilst having a good time.

Both of us thoroughly enjoyed planning and hosting this afternoon, and we look forward to many more in the future; hopefully next time in person!

Stay safe,
Lucia and Nethra



GET WELL SOON



Our good thoughts and best wishes are with our dear friend Rose Hobbs who is at present taking it easy in rehab.

We hope to see you up and around again soon,
Rose!

We are aware that a few of our members have recently undergone surgery. We are sending warm wishes to each of you for a healthy recovery.



DWARFISM AWARENESS MONTH

The SSPA, our members, and friends from around the world took to social media to show their support for Dwarfism Awareness Month. Here are just a few of their posts.



Liked by sam.r.millard and 1,420 others

james13chapman_ Yesterday was international dwarfism awareness day. My type of dwarfism is pseudoachondroplasia and this means that 1 in 1,000,000 people are born with my type of dwarfism. So I'm a pretty lucky dude. If your ever wondering what you can call someone with short-stature I would just ask for there name. You may think that we are limited to do things but I'm pretty sure I can do anything you can do and if I work hard at it I'll probably be better. I think short statured people are pretty dope and if you don't know any you should definitely get to know someone. Let's spread dwarfism awareness and instead of fearing differences let's embrace and notice how dope it really is.

Let's all be legends 🇺🇸



Melissa Bryant is 😊 feeling proud. ***
1 Oct. • 🌐

October is Dwarfism awareness month. There are 200 different types of Dwarfism. Jack has Achondroplasia the most common type. Jack can do everything we can do just in a different way. So proud of Jack and his resilience. His amazing attitude to simply push the hard things aside and get on with life is very inspiring. We love you so much Jack 🍀🌟👏



Becks Kim is at **Cala Mayor Beach**. ***
2 Oct. • Palma De Mallorca, Spain • 🌐

IT'S DWARFISM AWARENESS MONTH!

Though I usually take this month to share the difficulties of being different and educating people on how to approach dwarfism in general, this month Imma be sharing some photos and posts sharing the more positive sides of being the result of a funky mutant gene.



Throwing back to me not caring that I'm wearing a dress at the beach and just having the tiiiime of my life at my happy place.

#dwarfismawarenessmonth
#dwarfismawareness #dwarfism
#achondroplasia #stillcantcallmemidgettho
#kleinwüchsig #myhappyplace



**IN SUPPORT OF
THE OFFICIAL
DWARFISM AWARENESS DAY
WEAR GREEN ON
OCTOBER 25TH!**

Maree Jenner 6d · 🌐

Beautiful, dwarfism Awareness 2021 🍀 just like the beautiful Kingfisher I have dwarfism which is a rare condition to be born with. 🍀

Bird Species 27 Oct. · 🌐

Super Rare Dwarf Kingfisher



YOUTUBE.COM
Super Rare Dwarf Kingfisher

John Young is at Pingree School. 25 Oct. · 🌐

Proudly wearing green for #DwarfismAwarenessDay Thanks to all for your support. If you're wearing green, PLEASE add your picture below. #DwarfismAwareness



Becks Kim 26 Oct. · 🌐

| 25 OCT 2021 |
| DWARFISM AWARENESS DAY |

I am Becks.
And I have dwarfism.
Which means I am 1 in 20,000.

But I am also a strong woman.
A daughter and a friend.
A Christian.
A teacher.
A baker.
Aaand I'm a lil bit crazy too 🤪

I may not be as high-achieving as many of my other friends, but I do know that my big heart loves and cares about many things and many people. Being a dwarf can come with many hard cons, physically, emotionally and socially. However, days like today where we all stand proud really show how the pros outweigh it all and prove that it is really worth living a more unique life.

As stated above, I identify much more than just being a person of short-stature. However, my greatest identity comes from my Creator who made me with a purpose, and as His own special masterpiece.
"For we are God's masterpiece. He has created us anew in Christ Jesus, so we can do the good things He planned for us long ago" - Ephesians 2:10 NLT

So today, I stand proud and thankful to be more than just a dwarf. 🍀



Celebrating International Day of People with Disability

Vicki Fallon

My local council did a wonderful job this year, celebrating IDPwD on Dec 3rd, by involving a number of people with difference and disability in several activities around the city.



Bathurst Regional Council

November 29 at 7:30 PM

Celebrating International Day of People with Disability - Australia (IDPwD).

👋 Meet Vicki!

😊 What do you like about living in Bathurst?

Apart from the fact that Bathurst is an environmentally and beautiful place to live, I find it to be an inclusive, accepting, and friendly community where people always seem ready to smile and say “hello”.

🧠 What would you like the Bathurst community to know about people living with disability?

Whether it be a vision or hearing impairment, an intellectual disability, an acquired brain injury, an autistic spectrum disorder, a mental health condition, or a physical disability (such as mine); people living with disability are faced with a few more challenges during their life span than the average person. Therefore, they may require more support to fulfil the same goals, hopes, and dreams that everyone has.

Negative attitudes, stigma, and discrimination toward those with disability can lead to low self-esteem and a reduced participation in society by the person living with disability. ACCEPTANCE is a keyword in relation to disability ... acceptance of self, by the individual living with the disability, as well as community acceptance.

💡 What does an inclusive community look like to you?

The environment has an impact on the experience and extent of disability.

Among other things, an inclusive community may include:

- accessibility of the built environment and transport
- signage for sensory impairments
- accessible health, education, and support services
- opportunities for work employment for persons living with disability

In addition to the environment, positive and accepting attitudes contribute toward making an inclusive community.

📘 For more information visit <https://www.bathurst.nsw.gov.au/international-day-of-people-with-disability.html?fbclid=IwAR2c3TQm4NwVBicE6cJe8m1GuMr3JtZJhNNkgikiAuCSr4AIH7e0vdsL5dw>



Little People of New Zealand

Kia ora / Hello

Thank you for inviting us to be part of this edition of the SSPA Journal. For those of you unfamiliar with LPNZ (Little People of New Zealand), we started in 1969, and we support little people and their families much like SSPA. Over the last couple of years, the pandemic has meant we have been able to be more involved in SSPA's virtual conventions, which we have so enjoyed. We wish to build on the budding relationship between the two organisations, so here we are, doing just that! We are working closely between organisations to set up a more solid trans-Tasman relationship, and hopefully this will lead to some great things!

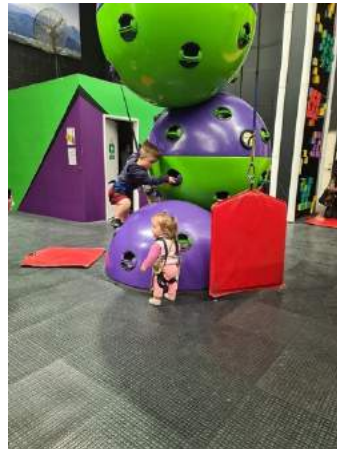
Conference 2021



Here in New Zealand, we have been relatively lucky throughout the duration of the pandemic. However, as an organisation, we have faced similar challenges to you guys, including having to cancel our annual conference last year and go online. This year, however, we were able to go ahead with our conference, albeit smaller numbers than usual due to some regions being in lockdown.



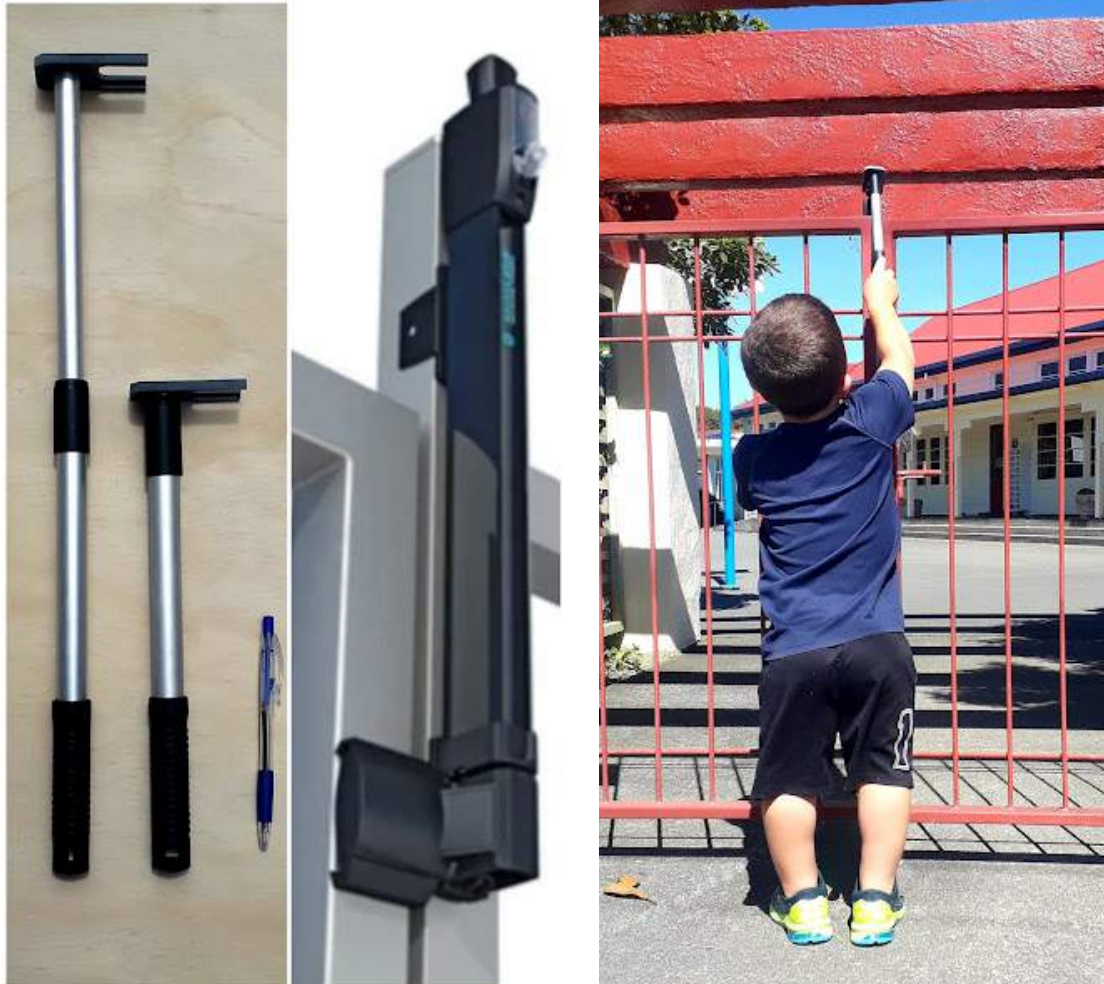
Up to 50 of us gathered in Tauranga for a long weekend over 22nd – 25th October. On Friday, we started with a meet and greet dinner on the first night to welcome everyone and meet some of the new families who have recently joined LPNZ. Saturday saw rock climbing and a formal buffet dinner with a few more members who had travelled there that day. On Sunday, we visited Fernland Spa Thermal Complex and then had a pot luck dinner at the home of one of our members. This was the last hurrah except for a small brunch with some members who hadn't left yet on the Monday. Overall, it was a fun weekend, and although it looked quite different to most years ... and we still have a virtual AGM to plan ... we had an amazing time and hope our members did too. Enjoy some of our photos from the weekend!



Jess Smith
Media Liaison, LPNZ

Reachlocks

Joe Howland



Kia ora. Thank you, SSPA for inviting me to share this with you in the current SSPA Journal. I am proud to share with you the “Reachlock”.

This reachlock came about with the birth of our son, when my wife was finding she was having to rely on a lot of people to allow her in and out of playgrounds, medical centres, or even the local pools for swimming lessons or hydrotherapy.

As our son grew older the need for independence grew so I sat down with a good ole pencil and paper and came up with a solution. A few trials and versions later and now I am offering this tool to you.

As my wife, son and I all have achondroplasia, please know this has been user needs tested in many different situations. The needs analysis for this innovation identified that this could be used for people of all abilities including wheelchair users also. Designed to enable users to gain entry when there is the security fence with a child lock system in place. Past customers

have also used them for a variety of other tasks, Grocery shopping, reaching the middle of a table, gate locks, light switches, picking up off the ground, and many more.

So, what is it I hear you ask?

The Reach lock is an innovation that can be stored in school bags, gloveboxes, handbags, backpacks, etc allowing for us short statured people to keep our independence in our day to day lives.

They are adjustable and telescopic with a locking function, allowing access to be achieved by people of all heights. See picture below, 10 year old Jonty accessing the school grounds on his own rather than waiting for a teacher etc.

They come standard size 300mm collapsed and telescopic to 480mm. Different sizes can be done upon request. Also can be personalised where needed.

\$30aud plus p&p to a max of \$15 A percentage of NZ/Australia sales will be donated to SSPA and or LPNZ respectively.

Note; A Reachlock is Assistive Technology (AT), so if you have NDIS supports the cost of the Reachlock is a disability related expense, therefore you can claim the cost from the Low Risk AT Consumables Budget

Joe Howland

Email: howland.joe@gmail.com

Two Historical Role Models

A couple of years ago, a fellow short-statured FB friend, Eugene Grant in the UK, had a tea towel printed with an image of **Benjamin Lay (1682-1759)**, who had Spondylo Epiphyseal Dysplasia (SED) dwarfism. What I found out about Benjamin resonated greatly with me, as Benjamin was a radical thinker for his time. He and his wife removed themselves from anything that was connected with slavery. They made their own clothes, were vegetarians, and were committed to animal rights over 300 years ago. The tea towel hangs proudly in my kitchen. Links to video & tea towel:

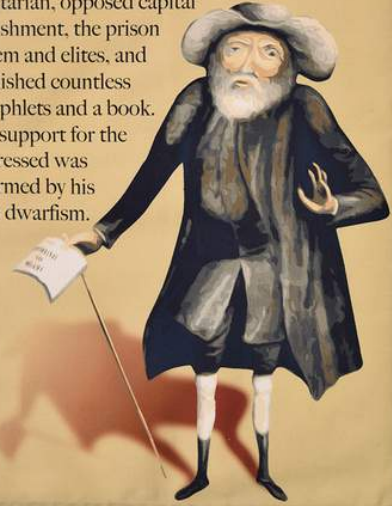
<https://www.youtube.com/watch?v=Rv3v9m6PY6c>

<https://www.radicalteatowel.com/tea-towels/benjamin-lay-tea-towel>



Benjamin Lay (1682-1759)

Born in England, he moved to America where, appalled by the mis-treatment of black slaves, he became one of the first white abolitionists and sought to persuade fellow Quakers that slavery was wrong. He made his own clothes in order to boycott slave labour, was a strict vegetarian, opposed capital punishment, the prison system and elites, and published countless pamphlets and a book. His support for the oppressed was informed by his own dwarfism.



Another great role model who appeared to have the same dwarfism condition (SED), was a brilliant man named **Charles Proteus Steinmetz (1865-1923)**. He was an innovator in electrical engineering, supplying many of the underlying formulas that made widespread electrical transmission possible. He was up there with Thomas Edison and Albert Einstein.

To find out more about him, view this video:

<https://www.pbs.org/video/wmht-specials-divine-discontent-Charles-proteus-steinmetz/>

All things considered, these two men and many others in the past are great role models who have contributed so much to society. I will continue to search for other role models to highlight in the Journal.

If you know of any, please feel free to share.

Maree Jenner

VP/PAB Liaison Officer

E: pab@sspa.org.au



CAREERS AND VOCATIONAL GUIDANCE FUND

The Careers and Vocational Guidance Fund is a Trust Fund especially set up to receive donations, invested in a capital fund, and to utilise these donations, and income generated from those donations, for the assistance of short statured people. The following circumstances would indicate generally the areas in which assistance would be granted –

but these are not exhaustive:

1. An allowance for a child who requires special coaching in a subject or subjects whilst still at school – this applies to either primary or secondary school
2. TAFE courses that are oriented towards a job situation
3. Business College
4. Vocational Guidance Test
5. University courses – assistance where necessary
6. Any other course of instruction which would lead to improvement of individual employment
7. Assistance with texts and/or technology that may be required at school.
8. Modification of assets (cars, home etc.)
9. Assistance to attend events such as Conventions, sports meetings (The Trustees also consider that courses or other assistance that help to improve self-esteem, and a sense of accomplishment, would be considered along with the original guidelines).

It should be noted that assistance is only available to a short statured person or a child of a short statured person.

As part of the concessions allowed by the Australian Tax Office, the Fund is required to assist those applicants who are in “necessitous circumstances”, that is, that the applicant would find it difficult to finance the above listed activities, due to limited income.

Applicants who feel they would qualify for assistance under the above guidelines are invited to apply to the trustees for assistance. The current trustees are: Rosemary Hobbs, Linda Henderson, Megan Lilly, Robert Millard,³ and Malcolm Paton. Decisions of the trustees are final.

Prospective donors are also reminded that the Fund is a Deductible Gift Recipient Fund, and so donations to the fund are tax deductible.

Rosemary Hobbs, Trustee, on behalf of the trustees.

Love Your Work

Vicki Fallon recently spoke to James Chapman regarding his part-time work as a shop assistant/skateboard instructor.

This is what James had to say ...

My part-time job is as an assistant in a local skate shop, and my main role is to teach people how to skate. My other duties include helping in the store, keeping the place clean by sweeping, dusting, and tidying up, as well as setting up the skateboards.

I began skating around a year ago when I started going to the skate park with my mates and thought I'd give it a go. I was used to riding a scooter up until then, but when I tried skateboarding, I just loved it.

It's good to skate because you can hang out and have fun with your mates at the skate park, but it's also a great way to get around ... it's better than walking!

Along with my friends, I've been a customer of the shop, "Skate Connection", since I started to skate. I happened to be in the shop one day when the owner offered me a job coaching kids, after giving me a trial out the back on one of their boards and seeing that I could skate OK. I think I was just lucky to have walked in when they were planning to implement classes for beginners and were thinking about hiring people.

I run thirty-minute classes not only for kids but adults too. I teach adults up to about fifty, who have purchased a skateboard and are actually skating for the first time.

The kids are pretty easy to teach as they are resilient and can take the falls, but I find you have to be careful teaching adults; it's a little bit scary because they can be more fragile.¹ The rule of the shop is that everyone should wear a helmet, and it's compulsory for those under eighteen, but whether people wish to wear wrist pads, elbow pads, and knee guards is a matter of personal choice.

I love working at the shop as they are awesome to work for. As well as being paid, I get to buy stuff wholesale, and I also get free stuff from time to time. They are also considerate of my disability by providing ladders and stools to reach shelves etc.

I love teaching people to skate, and the customers react well to my short stature, even though some may be a bit surprised at first.

My attitude is that people are naturally curious, and I don't mind the little bit of surprise when they first meet me. The little kids are usually a bit wide-eyed when they first meet me, but they are fine after a few minutes, and I think they relate to me well because I am closer to their size.



¹ *Vicki's note: At this point in the interview and on behalf of said "adults", I didn't know whether to be insulted or grateful for James' concern. LOL*

The only negative thing about my job is that it can be tiring, especially if I've been out all day and then have to stand up for 3 hours to walk around the skate park to teach people to skate. I can get tired and sore after work, so I just stretch out and rest when I get home. Putting up with a bit of soreness doesn't bother me because I really love what I do.

When it comes to finding a part-time job, my advice to other short statured teenagers is not to stress about getting a job if you aren't having success. Just stay on the lookout for a job doing what you would like to do, whether it be in a clothes shop or Maccas or a surf shop. It's a good idea to check out shops or businesses in your local community and build up a relationship with the people that work there; get to know the staff in those places. Don't be afraid to ask if there are any jobs available but don't be offended if they say "no".

Self-confidence is a big part of getting a job and meeting a prospective employer. Being comfortable in your own skin and accepting your difference really helps. Take skating, for example. I never worried about taking a fall when I was learning to skate; I had the confidence to not be embarrassed but to get up and try again. Being confident to chat to people is good as well.

Along with my part-time job, I also do an admin traineeship and attend school two days a week, so I am kept pretty busy. I'm very happy working in my part-time job and plan to remain there next year while I complete Year 12. Once we complete Year 12, some friends and I plan to take off in January 2023 to travel for twelve months. I'm really looking forward to that before coming back to study and train to be a PE teacher.



National Sports Update

By Kobie Donovan

<NOVEMBER>

Welcome back to another SSPA/SSSA Membership year. I'm proud to be elected once again as the SSPA National Sports Coordinator. Whilst admittedly, 2021 was unfortunately another year of cancelled events, I very much look forward to working with the SSPA in ensuring we host events in 2022. Please do not hesitate to contact me if you have any questions and or have sport-related stories to share.

World Dwarf Games Update:

Once again, the IDSF held an emergency online meeting to vote on the 2022 World Dwarf Games. After a majority vote, IDSF decided to postpone the 2022 World Dwarf Games until 2023 – still held in Germany. Another meeting of IDSF Board members will take place in December 2021 to review and evaluate world standing and the feasibility of having the games in 2023 (financially, international travel, and so forth). Australia will plan to attend 2023, and we will resume training (if possible) in early 2022. SSPA will send out correspondence and an expression of interest form to all members and interested athletes, January 2022, with the anticipation of our first training camp around March/April 2022.

Athletics Australia Disability Inclusion Group

SSPA is excited to be a part of the Athletics Australia Disability Inclusion Group. The focus for the Athletics Australia Disability Inclusion Group is to provide a national pathway for athletes to compete through AA sanctioned multi-class events; acknowledge, support, and encourage athletes outside of the Paralympic Pathway to participate in events run by or supported by the various organisations; support the Group's engagement with AA's Member Associations and encourage school students with a disability through AA's school programs. SSPA/SSSA is proud to strengthen our relationship and hopefully promote positive change for Short Statured Athletes.

Paralympics 2020 – Tokyo

Paralympics did not disappoint, and it was an incredible momentum shift with mainstream media coverage, fantastic performances, and great individual stories. Worldwide, there were a record number of short-statured athletes involved in multiple sports - Powerlifting, Table Tennis, Athletics, Swimming, and Badminton. Congratulations to our Australian Short Statured Athletes, Grant 'Scooter' Patterson and Tiffany Thomas Kane, who were multi-medallist in the swimming. With only three years until Paris 2024, we hope to see more short-statured athletes getting involved and potentially more Australians showing the world what Short Statured Athletes can achieve.



Kobie Donovan
Sports Coordinator
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Holly's Article

Holly Palmer was recently featured in an issue of Telluride about the adaptations she uses to snowboard.

When we think about our best days on the mountain, there is likely a magical dynamic involving those we are with. These are the days we feel support and inspiration from those around us. These are the days when we exceed what we thought ourselves capable of. These are also the days that inspire 16-year-old Australian snowboarder Holly Palmer. And, like all good ski stories, hers starts in Telluride.

Holly was born with achondroplasia, a common form of dwarfism. Holly refers to her condition as having short stature and explains, "I am smaller than people my age, but I can do everything you can do. I just sometimes find it a little more difficult."

A 2011 visit to family in Telluride connected Holly to the folks at the Telluride Adaptive Sports Program, which provides outdoor therapeutic recreation to individuals with disabilities. The then-5-year-old asked of them: "What can you do?"

The answer to that question would evolve over the next decade and offer astounding possibilities and experiences to everyone involved. On Holly's first-day skiing, however, all those years ago, there was no hint of future success. Because of her shorter limbs, her ski boots came up beyond her knees, causing pain. The day ended in tears.

TASP's team — which included Pete Garber and David Westveer — went back to the drawing board. They tried snowboard boots, softer than ski boots and with a lower cuff, and put Holly on an adaptive snowboard with a rider bar and tethers to help with balance and stability. "That decision was transformational," Holly says. "I have loved every minute on the snow ever since."

This alleviated the initial challenges but, according to TASP Program Director Tim McGough, everything equipment-related needed to be recon-

sidered. The nonprofit acquired a Burton Learn-To-Ride snowboard and custom-mounted the bindings to better match Holly's natural stance. And they kept fiddling. Says McGough, "She gave us all of her trust. Anything we wanted to try, she wanted to do."

Eventually, Holly was able to ride independently. "It really was amazing going down a hill unassisted for the first time," she says. Despite this progress, though, the equipment still wasn't perfect. And this is where the story moves beyond this small mountain town.

Enter one of TASP's incredible volunteers, Ken Bailey, an award-winning outdoor filmmaker. Bailey started documenting Holly's story and sent a short film to Burton in hopes of an equipment sponsorship. Through luck, karma and connections, the request initiated more than a sponsorship. It inspired a collaboration between Burton and software giant Microsoft, so designers at Burton could better engineer a custom snowboard and apparel for Holly.

After over a year of online meetings and collaboration between TASP in Telluride, Holly and her family in Sydney and the Burton team in Vermont, the gear was ready. "The people in Vermont were so into it," Holly says of the design process. "They really appreciated that my body is not suited to the equipment they produce for others and have built everything from scratch to match my needs."

Now sponsored by Burton and even featured on a billboard in Manhattan's Times Square, Holly was slated to debut her new gear in Australia this past summer. Although that has been delayed by Covid, Holly's enthusiasm is undiminished. "I am so excited. I love everything about snowboarding. It gives me freedom and the feeling I get is so great. The fact that I get to do it with people I love makes it even better." T



MEET HOLLY PALMER

TASP and Burton collaborate with young boarder for an inspiring outcome

BY JESSE JAMES McTIGUE



Photos courtesy of Telluride Adaptive Sports Program

telluride.com | 855.421.4360

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You can read the article here:

https://issuu.com/visit_telluride/docs/w21-22_issuu/39?fbclid=IwAR3GKhVqTsHMKT86CaEe9QVm_EiVEMefZgMtXlqILfumtvGoTPWq5y15Ki4

Safety in Exercise: Just Because We Can, Does it Mean We Should?

Kobie Donovan

Exercise is an integral part of staying healthy for everyone, particularly short-statured people. To prevent health problems and remain as independent as possible, people of short stature should make aerobic exercise, strength training, balance, and flexibility exercise a part of their weekly routine. However, not all physical activities are safe; just because we can do it, does it mean we should?

Kobie's Story

Deciding to push on as an elite athlete could be easy. Sure, I could continue physiotherapy, undertake joint replacement surgery; however, the inevitable is deciding how much I'm willing to sacrifice long term if I did choose to continue to push on.

Admittedly, I used to think I was invincible - physically able to do anything without injury. I was competitive, I was pushing my physical limits, and I enjoyed proving people wrong. Sport and physical activity have been and always will be an essential part of my life. I grew up playing a variety of sports from Soccer, Touch Football and Tennis. Then found my love with Athletics.

Medical Professionals don't read the following:

It would be naive of me to say that I never jumped on a trampoline, or rode a horse, or been quad biking down a dune, or even wrestled with my average height siblings as a child (despite being high risk for neck injury). Of course I did!

It is inherently normal to do everything to fit in, push the limits, and defy odds. Even into my early 20s I still thought my rare form of dwarfism gave me more opportunities to perform without injury. But hindsight shows how naive I was and how I almost pushed too far.

2017 World Dwarf Games proved a prime example; I was at my fittest and ready to take on four sports across five days. Unfortunately, in our second Soccer game, I collided at full force with the opposition Goalkeeper; placing my knee in a compromising position. The pain was immense at the time, but unsurprisingly and true to the Short Statured Athlete mentality, I continued. I had to withdraw from a few events but chose to contest my favourites in Athletics, winning the 100m and Javelin. High pain tolerance is not unusual for people of short-stature, and whilst advantageous, can also result in more damage. Two months later, when my knee still didn't feel 100% (and I was still training for Badminton), I got an X-Ray. To the shock of the Doctor and our World Dwarf Games Management, I had fractured my femur; the thigh bone above my knee. After rest, and physiotherapy, I was able to resume 100% of my activities, but it was then I started to



question myself, do I slow myself down and become more cautious or keep at it for as long as my body can hold up?

Eight months ago was my wakeup call; the moment I realised that I was not so invincible. I went for a run (like a hundred times before) an easy 2km jog on flat ground around my suburb. I felt fine upon arriving home, went through usual stretches and didn't feel anything out of the ordinary. Whilst it was very typical for me to wake up stiff and slow to move, on this occasion, it was very different; I could barely walk around the house due to intense pain, a pain I hadn't felt before. I knew it wasn't muscular or flared up arthritis; it was something more serious. Immediately I arranged a scan, and my intuition was correct. I was very lucky to pick it up early, and to avoid an emergency medical situation.

At age 27, and with nerve pain and clinical evidence of spinal and hip deterioration, I have come to understand the importance of being physically active, not for the sake of sports performance but rather for everyday tasks and general wellbeing. As a school teacher (Physical Education), I'm on my feet most days, taking an average of 12,000-18,000 steps. Many of which are at a 'power walking' pace because, true to form, Miss Donovan does lead the class lines and likes to prove her pace against the primary students (just to put them in their place) - I love my job. I know I need to be able to move throughout the day to continue working in this field. Running 100m in sub 20 seconds or throwing a Javelin over 20m are outstanding personal achievements but pushing my body further to perform purely to achieve a position, a spot on a team, or a medal does not justify the long-term impact and or the impact on my job. There is so much more to life than sport, and whilst I'm incredibly proud of my career thus far, I have come to realise that there are so many more rewards out there that still require a day-to-day fitness. How much am I willing to sacrifice to do so?



I cannot go on my long runs or compete in athletics at this moment of time. Still, I'm able to get through my days mostly pain-free, join in with the family for the occasional game of tennis, partake in a few PE lessons alongside the students, walk the dog and even mow the lawn. I still demonstrate Athletics Events as a coach, and I can confidently keep up with my friends on social outings. These things are considered essential and opportunities I do not wish to sacrifice. Sure, right now, I could probably go run 5km, sprint 100m or throw a Javelin with no problems, but for what gains? I still do Physical Activity 3-4 times a week; these sessions revolve around Rehab like stretches, targeted muscle strengthening exercises (bodyweight only), and basic functional movements. Taking this route buys me time from the inevitable surgeries down the track and ensures a level of independence.



Now, I'm not suggesting everyone needs to stop sport this instant or that we should "bubble wrap" short-statured people. But instead, remind everyone that we need to be cautious of the activities we choose to do. Doing a high-risk activity once or twice (like my trampoline days) is risky (not promoting this). Still, in most instances, not life-changing; but doing a high impact activity repeatedly over time, now that may change a life. So, when considering physical activity, consider the risks, consider your body and consider the purpose. Is it worth it long term?



Over the last 12 months, there have been significant conversations around safety in sport concerning short-statured athletes. Inclusion has been a great revolution over the past decade, with more opportunities than ever to participate. However, on the flip side we are seeing more short-statured athletes retiring earlier due to chronic pain and permanent lifelong injury. Around the globe during 2020/2021, six Paralympic short-statured athletes retired because of injury. These athletes came from sports of Athletics, Swimming, and Powerlifting. Four of which were under the age of 24. Most were still at the top of their game and should have contested Tokyo Paralympics, but instead, they were forced to retire. Beyond that, and closer to home, several members over the years have sustained severe injuries and or life-altering changes to their abilities. Now, to be clear, I'm not referring to the sport itself that eventually takes a toll, I'm referring to high-risk activities and or repeated activities related to the sport (see list at the end of this article).

Speaking to various short-statured athletes who have sustained long term injuries, the number one cause was Repeated Loading activities, and or Weights/ Gym Training. It was the repetitive high 'weight' exercises for some; and for others, it was an unsafe exercise or technique. In some instances, national coaches and team medical staff approved the activities safely without truly understanding dwarfism. Goes to show, that even the fittest short statured athletes, with complete medical teams around them cannot defy genetics and years of research.



To conclude, I haven't retired from Sport yet – I don't think I ever will. I do see myself resuming a sport soon enough but have learnt to take more caution, and not to try and do every sport at once. My advice to younger short statured athletes is still to get involved, pick the sports recommended by SSPA and or World Dwarf Games and if training, don't try to all the sports at once, take caution, listen to your body, don't overtrain for the sake of performance, consult a medical specialist before attempting any gym exercises involving weights or placing your joints in compromising positions, and most importantly don't ignore pain.

One of the reasons which inspired me to write this article, was the recent changes by Athletics Australia. Early this year, Athletics Australia decided to remove Long Jump as a "competitive event" for TF40 & 41. This decision was not taken lightly, and it involved multiple parties to ensure it was the right decision. Notably, the International Dwarf Sports Federation provided their research and position, which ultimately persuaded Athletics Australia. A decision that was supported by the SSPA/SSSA. Athletics Australia still allows participants to do Long Jump at Local competitions and state championships. However, a

medal will not be awarded. Whilst there are arguments for every perspective of this decision, I ask young athletes and parents to reconsider if appealing the decision – there is a reason why this event is not on offer at World Dwarf Games, there is a reason why medical professionals strongly oppose it, and there are countless adults with short stature who would tell you the risks are not worth it long term.

When talking about risk and injury long term, we know the occasional Long Jump at for example, an annual school carnival, is fine for most. The concern comes when repetitive jumps are performed at training and or weekly competitions. Sure, it can be done. Yes, some juniors have been doing it for a few years. But as hopefully my story shows (along with many other people's stories), we are kind of super athletes as juniors, but unfortunately if we continue to push the limits, the true extent of the damage won't be known until much later – when it's too late. Yes, there are some exceptional short statured people who have defied the odds and are still kicking on strongly as adults – good on them! However, that outcome is not a guarantee for all.

An Excerpt from a Statement provided by the International Dwarf Sports Federation:

IDSF and Medical Experts in Skeletal Dysplasia consider the following as long-term, high-risk activities (when participating regularly).

- Trampoline
- Gymnastics
- Diving
- Athletics - Long jump, Triple jump, High Jump and Hurdles.
- Cross Country - Uneven surfaces with incline/descents
- Contact Football/Rugby
- Soccer – Header and Slide Tackles
- Downhill Skiing
- Martial Arts – Sparring and or throwing
- Boxing/ Kickboxing
- Wrestling
- Summer saluting
- Horse Riding (if unable to control core/neck stability)

"IDSF and Medical Experts acknowledge that individuals have participated in the activities listed above; however, we must do what is suitable for most athletes as an international body. The following research outlines the significant risks associated with those with skeletal dysplasia. Individuals with skeletal dysplasia are at a higher risk of atlanto-axial instability, craniocervical constriction, low muscle tone, arthritis, foramen magnum stenosis and or ligament laxity."

What's happening around our Nation?



New South Wales/ACT

Hello everyone,

Apart from our meeting, held online on Monday 15th November, the last few months have been relatively quiet for the NSW/ACT branch.

However, we have plans in place for the next few months. So, stay tuned to social media for details about the following fundraiser and social gatherings:

- Saturday 21st May: a Bunnings fundraiser is planned for the Central Coast.
- A “Glamping Weekend”, also to be held on the Central Coast, is planned for the 19/20th of February.
- A Christmas get-together and pool party to take place on **Sunday 12th December**, to be held at the Palmer home at Bronte Beach.

Time: Kicks off from 12.30pm

Place: Once you RSVP to Maree Jenner via Messenger or email pab@sspa.org.au you will be provided with the address.

Please bring: something for the BBQ, a plate of salad, etc to share. And, of course, your swimmers!

Note: In line with NSW State Health Guidelines, we will be adhering to the requirement that all attendees over the age of 16 must be prepared to show vaccination evidence.



International Day of People with Disability- IDPwD

In the week leading up to the 3rd December I took part in celebrations in my local community of Bathurst to create awareness of disability and difference. Along with a few other people with disability, we participated in a number of activities that were initiated by Bathurst Regional Council. One of those activities involved me reading stories to pre-schoolers at the local library, and also at one of the local kindergartens, to introduce the smaller kids to the concept of “difference”. I thoroughly enjoyed it!

If anyone participated in IDPwD celebrations in their own communities, send pics to Maree Jenner at pab@sspa.org.au to be posted on our socials.

Here is a pic of me in action at the Bathurst Library. You can't see the kids but I assure you they were definitely there! LOL

Congratulations

More baby news in NSW!

Congratulations go to Ella & Alex Simak and grandma Alma (one of our NSW parent reps) on the birth of baby Kai (who knows how special he is by the cheeky grin he is giving in this pic).



Until next time I'd like to take this opportunity to wish everyone a peaceful and joyous Christmas and hopefully a COVID free 2022.

Vicki Fallon
NSW/ACT Secretary
E: info@sspa.org.au



NDIS and people with dwarfism

Maree Jenner
Email: pab@sspa.org.au

As part of the 2021 program for the VC, I coordinated the Medical/Professional Advisory Day program. As you would have seen in the program (either in the last journal or online), we were fortunate to have an excellent line up of PAB members, presenting on a full range of topics as listed below.

- **Professor David Sillence** *SSPA 50 Year partnership with Professionals: Medical Advisory to Professional Advisory – 21st Century Challenges.*

- Professor Ravi Savarirayan *Times are changing: New Therapies for Skeletal Dysplasia*
- Dr Penny Ireland *Achondroplasia – Creating Simple Solutions from Complicated Questions*
- Dr Louise Tofts *Medical Complications in Children with Achondroplasia & Adolescents with short stature*
- Alison Wesley & Tracy Tate *Birth to 2-years*
- Dr Lesley McGregor *Our SSPA – Not Just Achondroplasia*
- Dr Verity Pacey *STEMS to the NDIS – Supporting Advocacy through Research*

I also coordinated the informative **NDIS Presentation**. Kim Henderson not only gave the presentation but also attended the Q&A session. Kim is an NDIS Coordinator for Moorandah Local Council, Melbourne. In her role Kim is independent of the NDIS and we are most fortunate that Kim is happy for members to contact her with any questions. Feel free to contact Kim via my email address: pab@sspa.org.au

Due to popularity, the **Transition to School Session** returned this year, chaired once again by Krysten (mum to Maggie) and joined by Alison Wesley, OT and Tracey Tate, Physio, from WCH. As a result of this session SSPA is producing a “Transition to School Guide” for parents.

All of the PAB and NDIS 2021 presentations are available to view online:

<https://sspa.org.au/?p=4218>

Password: SSPA2021

Please Note: PAB & NDIS 2020 presentations are also online: <https://sspa.org.au/?p=4111>

Password: sspa20

Virtual Expo 3 vendors participated:

<https://www.thelittlehoestore.com>

<http://imjustsmall.com>

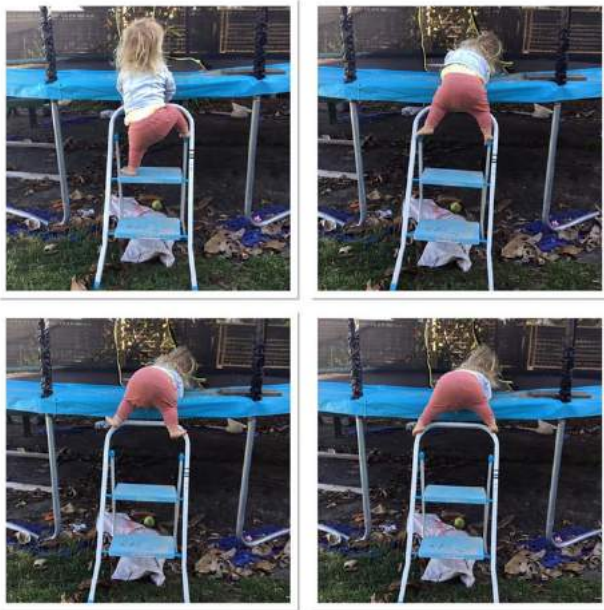
<https://totalability.com.au>

Each vendor provided an overview of their products and services, and then attendees went into breakout rooms to ask further questions. As www.aufaugenhoehe.design/en was unable to join the Expo, we rescheduled an interview with Sema (Founder) on the Monday evening. Good news is that Sema is very keen to continue working with us, so watch for updates.

The zoom recordings of the VC sessions will be uploaded and available on the website in the near future.

Made to Measure 2 was once again well supported. Many thanks to those members who provided pics of their hacks, tips and AT suggestions that helped to make the session a success. Here are a couple of hacks from young Jubilee; one showing tips for getting onto the trampoline & the other using her ‘yoga inspired way’ of holding her iPad between her feet.

☺ ☺



Employment tips and advice was co-presented by SSPA Patron Tina Zeleznik (CEO from Disability Works Australia), Nathan Kirby (Disability Inclusion Lead at Accenture Aust & NZ) and Sam Drummond (Discrimination Lawyer & IncludeAbility Ambassador). All three presenters are more than happy for members to make contact with them. Tina & Nathan can be contacted via LinkedIn and Sam can be emailed at samuelgdrummond@gmail.com

Royal Commission into violence, abuse, neglect and exploitation of people with a disability.

Disability Advocate Fiona Strahan did a great job in facilitating this session. We were very fortunate to have in attendance, Commissioner Dr Rhonda Galbally, Legal Counsel Kate Eastman and Dayla Rozsa-Brown from the counselling team. Prior to the session and on behalf of the SSPA, Fiona forwarded a list of 20 questions which were addressed by the panel. Listening to the questions & responses it become apparent as to why it is important for people with a disability to have their experiences and stories heard. SSPA is recommending that the Commission holds a public hearing on inappropriate behaviour toward people of short stature in public spaces. What we experience is not unique to us, as we know people with other types of disability experience similar violence and abuse in public. Together with Fiona we will run workshops to support people to request a public hearing, and to support them in writing, recording or drawing a submission. If you didn't attend and would like more information, please email pab@sspa.org.au

The zoom recordings of the VC sessions will be uploaded and available on the SSPA website in the near future.

ILC Individual Capacity Building Grant
SSPA Mentor Program

We are excited to have received 17 Expressions of Interest to act as mentors. It's also great that there are equal numbers of M & F applicants. We are now in the process of completing and finalising the onboarding paperwork, however Headspace is not able to start developing and or facilitating the 'Supportive Conversations workshop' until early 2022. In the meantime, mentors will be undertaking 'Youth Mental Health First Aid', developing peer to peer support skills, and connecting with one another either online or face to face.

Parent Representative Peer Support Program

We are happy to have received 12 Parent Representative Expressions of Interest for the Parent Peer Network, and we are hoping to get a couple more to strengthen the network. Once the onboarding process has been completed, we hope to set up an online meeting with Genetic Counsellors before the end of the year and arrange ‘Accidental Counsellor’ training early next year.

SSPA Programs Pages are set up on the SSPA website for ‘Mentor and Parent Representative Peer Network’; click the Programs tab for more information. Many thanks to our webmaster and also our project support volunteer, Susie Roczo-Farkas, who has provided much help with the social media campaign and is assisting with the setup of the training/orientation program.

Developing Achondroplasia Clinical Care Guidelines – facilitated by Dr Louise Tofts in conjunction with health professionals around the country. Marta Eyles (Isabella’s mum) and myself, are participating in the working group to provide lived experience to support the development of the Guidelines. Once completed the guidelines will provide consistent national standards of care, plus equity of access to NDIS and other support services. We are currently meeting online each fortnight.

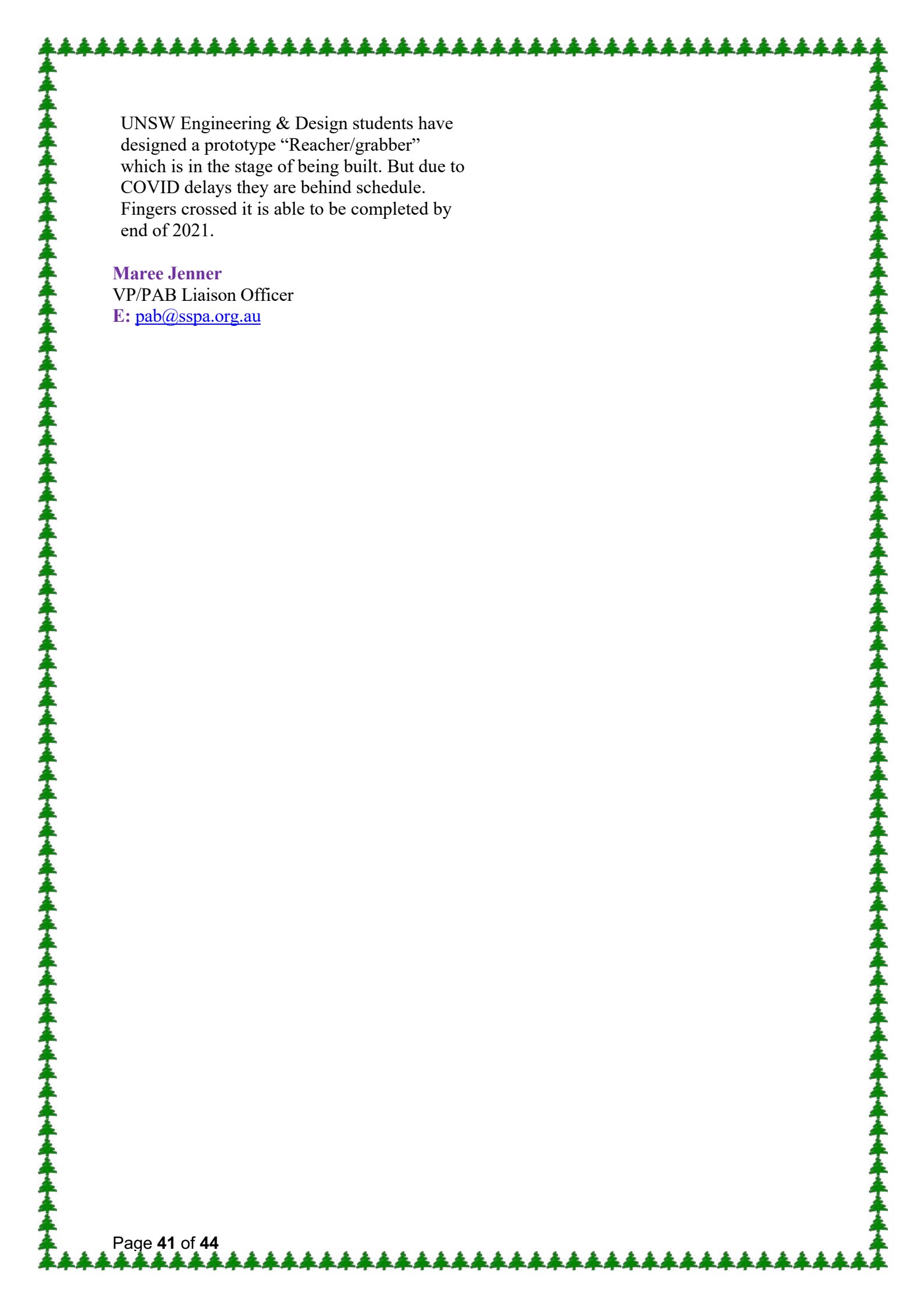
From STEMS to NDIS – Supporting Advocacy through Research

We are pleased to support Dr Verity Pacey’s students in their final year Doctor of Physiotherapy, at Macquarie University. The students are working on a research project to explore the experience for children & adults with skeletal dysplasia. They are looking at the NDIS and issues such as mobilising in the community, self-care strategies, functional performance, and public transport use and challenges. The focus groups, interviews and surveys will gather information which will help people to obtain access and the right supports from the NDIS.

Project with UNSW Engineering & Design

Getting items off supermarket shelves safely is a challenge for people with short stature/dwarfism. Some opt for online shopping, including home delivery and or Click & Collect etc which are great services. Others like myself, prefer to go into the store to get what they need, however ease of access poses a problem and can be a *BIG* time waster when trying to find someone to obtain items from higher shelves.





UNSW Engineering & Design students have designed a prototype “Reacher/grabber” which is in the stage of being built. But due to COVID delays they are behind schedule. Fingers crossed it is able to be completed by end of 2021.

Maree Jenner

VP/PAB Liaison Officer

E: pab@sspa.org.au

BOOK REVIEW

Prudie Woods



This book has been on my 'bucket list' for a long time! My beautiful Amelia Rose (Rosie) was born in 2011. When Rosie was seven-weeks-old, we discovered that she had achondroplasia, a diagnosis that we certainly weren't expecting but, always wanting the best for Rosie, we dived into the fabulous world of the short-statured community of Australia. As soon as Rosie could walk, she would pop her dad's work boots and Akubra on; she just wanted to be a cowgirl! Rosie was always desperate to ride horses, and she has done so in the past (very gently and at no great speed), but we know that her spinal care must be her first consideration, and she won't be able to muster cattle or ride horses like she wishes she could. However, the beauty of a book is you can do anything you wish within a story, so my initial inspiration behind *Rosie-May Blue: Mayhem at the Pet Show* was to create a children's chapter book in which Rosie could live out her cowgirl dreams! To give further

life to the story, my sister has created gorgeous hand-drawn watercolour pictures, which give the book a whimsical feel.

However, once I started to write the manuscript, the themes within the text became so much more than a cowgirl tale. I haven't stated in the story that the protagonist is short-statured or that she has achondroplasia. I want children to create their own image of Rosie-May—they don't need me to give her a label. Maybe short-statured readers will identify with Rosie-May, but I'm hoping that all readers will see a little bit of themselves in her because don't we all have something that makes us unique?

Ellie is Rosie's wonderful older sister, and she has had to deal with her share of 'meanness' at school. And as a teacher, I know that mean behaviour doesn't discriminate—anyone can be a target. In the story, I try to allude to the fact that meanies at school will pick on anyone, disability or no disability, and this isn't a reflection on the person who is receiving the mean behaviour. I'm hoping that the scene in the book where Rosie-May is teased gives families and schools a great starting point for discussion about what children can do when someone has been mean to them.

My Rosie has grown up on a farm, so another main theme running through the book is girls enjoying being part of the agricultural industry. The fact that my Rosie is female and has a physical disability is of no relevance to her—she currently aspires to be a farmer, and we know she has the tenacity to follow her dreams! I hope my little book inspires all children to do the same. And, of course, a mystery has also sneakily been included in the storyline!

The blurb from my book is as follows: Rosie-May Blue and her family have just moved to the township of Waterfall Way. When Rosie-May's pony, Carrie, goes missing, Rosie-May fears for the worst. Her newfound friend Ellie is a comfort at her new school, and together, they share a love of horse-riding. However, will their friendship survive the secret that Rosie-

May uncovers? Will the secret spoil Rosie-May's chance at winning a prize at the Waterfall Way Pet Show? Saddle up and join Rosie-May and Ellie for their first adventure together at Waterfall Way.

Rosie-May Blue would love you to follow her adventures on Facebook (Rosie-May Blue) and Instagram (@rosiemayblue), and her first book can be purchased from www.rosiemayblue.com, as well as online book stores such as Booktopia.

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* Denotes person of short stature

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NSW	Prof. David Sillence, Geneticist	Cheryl Cotton, Associate Genetic Counsellor
	Prof. Andreas Zankl, Clinical Geneticist	Alison Wesley, Senior Occupational Therapist
	Dr. Louise Tofts, Rehab Paediatrician	Dr Verity Pacey PhD, Senior Physiotherapist
	Tracy Tate, Senior Physiotherapist	Dr Debra Keenahan (PhD), Lecturer Social Sciences & Psychology, Uni Western Sydney
	Martin Pearce, Family Therapist/Psychologist	
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SA	Dr Lesley McGregor, Clinical Geneticist	
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WA	Dr Fiona McKenzie, Clinical Geneticist	Stephanie Broley, Genetic Counsellor

SSPA PAB Liaison Officer: Maree Jenner

Questions for our Professional Advisory Board may be emailed to the PAB Liaison Officer at:
pab@sspa.org.au

SSPA NATIONAL COUNCIL 2021-2022

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Membership Secretary Katrina Reynolds (ACT) membership@sspa.org.au	Sports Coordinator Kobie Donovan * (QLD) admin@sspa.org.au	Short Arts Collective Coordinator Graci Lynch * (VIC) info@shortartscollective.org.au

* Denotes person of short stature

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	Aboriginal & Torres Strait Islander (ATSI) Liaison Officer Karen Kelly (NSW) karenkelly@outlook.com.au	

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NB: Qld, SA and TAS are not officially formed branches. They are informal groups with the above named coordinators.

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