



Short Statured People of Australia Inc.
THE NATIONAL JOURNAL
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Est: 1968
Co-founders: George and
Rosemary Whitaker



Kiralee grade 7



Eleanor
Kindergarten

BACK to
SCHOOL



Jack grade 5 and
Harry grade 4

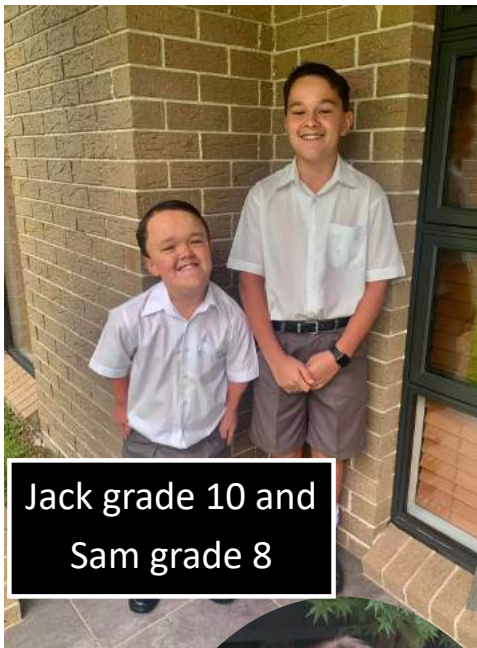


Lucia grade 11

Contents

| | |
|---|----|
| More Back to School Pics | 3 |
| National President’s Report..... | 4 |
| Vale – Jack Blair | 5 |
| Vice President’s Report | 6 |
| From the Editor’s Laptop | 9 |
| Welcome to the Family..... | 10 |
| Overseas Liaison Officer’s Report..... | 11 |
| National Convention and Sports Weekend Survey..... | 12 |
| SSPA National Convention..... | 13 |
| COVID Vaccines and People with Skeletal Dysplasias | 14 |
| Expression of Interest: SSPA Parent Peer Supportive Representative..... | 17 |
| Expression of Interest: SSPA Mentorship Program | 19 |
| Expression of Interest: Volunteer Project Support Officer..... | 21 |
| SSPA Resource Development Project: We Need YOU! | 23 |
| Parenting Tips and Ideas..... | 24 |
| Careers and Vocational Guidance Fund..... | 25 |
| Short Arts Collective..... | 26 |
| National Sports Update | 27 |
| What’s Happening Around Our Nation? | 29 |
| NDIS..... | 32 |
| Book Review | 34 |
| SSPA Reps, SSPA Professional Advisory Board, Editorial Policy | 35 |
| SSPA National Council Members; Committee Members | 36 |

More Back to School pics ...



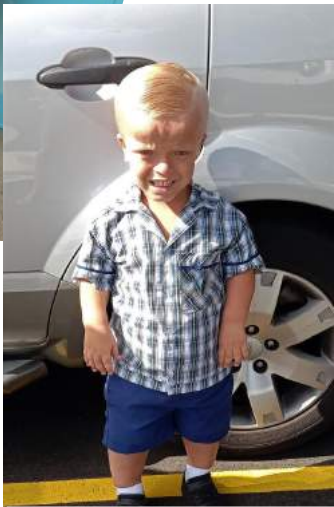
Jack grade 10 and Sam grade 8



Dominic grade 3



Tilly grade 3



Hudson grade 3



Alex grade 2 and Delilah 's first day



Maddie grade 6, Gemma grade 4, Aiden grade 2 and Liam prep

National President

You are never too old to set another goal or dream a new dream.'

- C. S. Lewis

Dear members,

Wishing you all a happy new year, and here's hoping 2021 is a great year ahead. I hope that this edition of the Journal finds you well and that you have started off the new year healthy and happy.



I am writing to you from Melbourne, having just come out of our third lockdown and still getting used to the new COVID normal. Let's hope that as vaccinations continue to roll out, we can continue moving in the right direction and 2021 can see us spending much more face-to-face time together. Speaking of the vaccine, I thank the SSPA PAB and Professor David Sillence for providing some further information about the COVID-19 vaccines for people with skeletal dysplasia, which I encourage you to read in this Journal.

National Council

The SSPA National Council has been busy this year advancing the preparations and roll out of the programs we are running, as a result of the NDIS ICB & OCB grant we received last year. In this journal you will find Expression of Interest Forms for both the Parents Peer Support Program as well as the SSPA Mentoring Program. I congratulate the Project Management Committee and the National Council on all the work so far. These program EOIs are now open. Anyone interested, please submit an expression of interest and get involved in these exciting projects.

The National Council was also able to begin another exciting project by running our first governance workshop in January. We thank Monica Ferrie from *Bold and Brave Consultants* for her help running the training. This training will allow the NC to become better placed to perform all the tasks required to function and achieve our goals. Upskilling NC members in areas such as running projects and events, grants and funding application and reporting, succession planning and risk management. Governance training will allow the individuals on NC to develop new skills, and with this, NC as a whole will become more robust; thus enabling us to maintain the longevity and future of the organisation.

2021 Events: National Sports Weekend & National Convention

As we have mentioned, along the journey this year we hope to be able to spend more time with each other face-to-face. This includes sporting events in some form (please keep an eye out for more information) and the 2021 National Convention that we are currently planning for South Australia later this year. More info to follow.

Online Events

Following the success of our online events over the last twelve months and the newfound technologies that COVID has introduced us to, we are working on a calendar of upcoming

online events to allow members to connect no matter where they are. Please keep a lookout for dates and times.

A reminder to everyone to follow our social media pages for all updates: **Facebook – Short Statured People of Australia** and **Instagram – sspa_au**

Looking forward to seeing you all soon.

Kind regards,

Sam Millard

National President – SSPA

E: president@sspa.org.au

The last date to receive material for the next edition of the National Journal will be the 1st of May 2021.

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



VALE - Jack Blair



It was with sadness that the SSPA recently learnt of the passing of Jack Blair, father to Michael. During the early decades of the SSPA (formerly known as LPAA), Jack played a significant role in the NSW branch. Through his relationship with the LPAA and his employment with NSW TAFE, Jack developed a special interest in the vocational education of people of short stature

With the aim of developing a practical resource that would add to the objectives of the association, eliminate stigma and remove misconceptions, Jack compiled the “Information Guide on Persons of Short Stature”. From conception to final publication, the project took several years to complete and along with the addition of photos from other branch members, it contained material that not only interested the general public but was utilised by social workers, clergy, doctors, employment officers, parents of short statured children and of course people of short stature themselves. The booklet, easily identified by its attractive green cover and interesting logo, was finally launched during the International Year of Disabled Persons (IYPD) in 1981. It became the number one resource of the association at that time; being considered the “greatest achievement of the NSW branch in terms of public awareness of short stature”.

We send our condolences to Jack’s family, especially his wife Nanette and of course Michael, Emily, and baby Lachlan. Our thoughts are with them at this time.

(ref. “Growing in Stature, 1968-1988” by Francis Kelly)

A message from our VP/PAB liaison

Dear members,

Here we are, in the second month of 2021 and I hope the NY has started well for you! Considering COVID is still continuing to impact and change the way we go about our daily life, I'd like to highlight a couple of COVID changes which I think are beneficial to me as a person of short stature.

The first is the advantage I find in social distancing. When standing in a queue or waiting at a counter I've often found that fellow shoppers lean either on or over me, infringing on the personal space above my head. Nowadays I don't hesitate to remind people of the need to stand 1.5 m apart, by saying, *'Please stand back on the cross/dot on the floor!'*

The second is the advantage I find in the wearing of masks, as they prevent the droplets of saliva I often feel on my face or glasses when people are speaking to me! So, I am more than happy for masks to be worn in busy public spaces!



The picture to the left was taken late last year whilst I was being interviewed for a podcast, **“Talking Inclusion: Small in Stature, Big in Life”**. I spoke with Bill about ‘growing up little’.

I enjoyed being involved in this podcast as the podcast series seeks to enable inclusive communities and greater diversity, by sharing stories of life experiences that are different from the norm. If you are interested you can listen to the podcast and others here:

<https://podcasts.apple.com/au/podcast/talking-inclusion/id1535935746?i=1000495028239&fbclid=IwAR3ARkN4BSxhseOJmaNKWotE26l8D3cJILqRCfrGMvhkyT8RRIEVavr6mYc>

As a person of short stature, inclusion of difference is something that I am passionate about. This leads me to tell you about the school inclusion awareness program I am facilitating through my work and which I will initially take into primary schools on the Central Coast. I am looking at extending the program to high schools and preschools later in the year. The program is called **“Different on the Outside, Same on the Inside”**. You can find more information here: <https://socialfutures.org.au/dotosoti/>



I look forward to engaging with the children to explore and talk about what it means to be inclusive of difference; focusing on the language used, their behaviour and how they can ask questions.

Whenever I encounter children in my community, I engage with them as soon as they notice me. This enables children to ask questions openly as opposed to them being turned away by the parent, which can be unhelpful. Engaging with the child can

present a positive opportunity to educate both parent and child and dispel the idea that difference is embarrassing.

I am hopeful that my involvement in designing and facilitating this program will provide me with skills to create an SSPA resource to be available online and easily downloaded by a school/preschool when a child of short stature enrolls.

I am very pleased to say that SSPA have endorsed the program, which is expected to play a part in reducing bullying by increasing awareness of the importance to be inclusive and accepting of difference.

In conjunction with the ILC Grant Project Management Committee, I am excited to be involved in setting up and coordinating the Mentor Program and the Parents Peer Support Program.

The Mentor program will be run in conjunction with Headspace, who will be advised by SSPA PAB psychologists.

The Parent Peer Support program will be run in conjunction with health professionals, genetic counsellors and psychologists from the SSPA PAB.



We are currently in the process of advertising for participants in both of these great projects so if you are interested in being involved please look for the Expression of Interest (EOI) in this Journal and on SSPA social media. Also in this Journal is an EOI for a volunteer support person to assist with some of the administrative/logistical tasks associated with these projects, so if this sounds like something you would be interested in, please let us know:

pab@sspa.org.au



As PAB Liaison Officer, I continue to receive enquiries via SSPA website/social media on a range of topics from allied health professionals, in regard to information on specific types of short stature, requesting assistance for home modification specifications, sourcing equipment and information for resources as well as support and/or information from PAB.

Through one of our parents, I was recently contacted by the Disability & Inclusion Manager at the organisation our parent works for, seeking advice on how to convey the message that they are an inclusive employer. They wanted to ensure that prospective applicants with disability (such as people with short stature) feel comfortable in applying for a position and to reassure them that their disability is seen as a plus or equal, as opposed to a negative. I still hear stories of short statured applicants applying for jobs, getting through to second interview, being asked to come in for a trial and on arrival being told that the position is now filled.

As people of short stature, we have a lot of strengths in areas other than height; problem-solving skills, the ability to look outside the box and especially resilience ... just to name a few.

After looking at the organisation's website, I communicated the observation that there were pictures of people representing diversity e.g. age, sex, race and culture, but no obvious pictures of anyone with a visible disability; *'a picture is worth a thousand words'*.

On further searching I found a couple of pics at the bottom of the page under the accessibility link; a Deaf woman using Auslan, and a blind guy with a guide dog. I suggested these two images be included with the other pictures on the top of the page, in order to represent inclusion upfront.

It was such a great initiative on behalf of the parent and her organisation to seek our advice in this way and I look forward to having the follow up chat with the Inclusion & Diversity Manager in the near future.

If anyone would like to contribute to this conversation please contact me via the email below.

Just to finish, I wanted to share this picture of young Jubilee on her way to her first day of Kinder. As mum Lucy said, *'Jubilee was wearing her Big Girl pants!'*

Lucy wrote, *'Jubilee cried herself to sleep last night because kinder starts tomorrow and she was so scared. Woke up twice during night crying and she didn't want to go. Woke up in the morning, announced she was wearing Batgirl to kinder, waltzed in and waved me off without a tear.'* Lucy reported later, *'She had a great day and met me with a smile when I came back, which she held until we almost reached the car when she started crying and wailed all the way home (and a bit after).'*

This reminded me that as much as we need a cry sometimes to be ready to put on our big girl pants - we also need a safe place to be able to take them off again. As I said, this girl. Never stops teaching me new things.'

Jubilee, and other children of short stature learn to wear their **Big Girl or Big Boy pants** early in life; increasing resilience and problem-solving skills as they grow up little!

#GoBatgirlJubilee

Maree Jenner

Vice President and PAB Liaison Officer, SSPA

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From the Editor's Laptop

Hi everyone,

As I sat down to write this editorial, I had no idea what to write about at first. I thought, what have I done in the past three months? When you last heard from me, I had just finished up being the Editor-in-Chief of *WORDLY* Magazine and *WORDLY* Online. I loved both things dearly and I threw myself into them so much so that they became my personality. If you asked me to tell you a bit about myself, I would jump straight into telling you about *WORDLY*.



Everyone told me to take some time to mourn, which I did (it felt like a huge loss), and now I'm okay with it. And they told me once I'd finished doing that, I should throw myself back out into the world and look for other opportunities—there will be plenty of editing/writing opportunities out there waiting for me when I was ready. It has been three months so I should've thrown myself back out into the world by now, I should be knee deep into another volunteer opportunity of some sort.

But the fact is, I'm not. I haven't put myself out there yet or actively searched for another project. In the past, majority of my time was spent doing volunteer projects and giving my all to everyone and everything else ... but not *myself*. The past three months have been about me. I have had time to breathe. I have had time to work on myself.

For one, I decided I wanted to try out studying psychology. I thought maybe being a psychologist would be a great long-term job for me, and people always told me psychology helps with writing as you learn about human behaviour and why people do the things they do, so it's a bit surprising when everyone I've told so far has been surprised to learn that I'm changing my career direction. (I'm not giving up writing, I never will). So I enrolled in a Bachelor of Psychology (Honours) at Deakin.

I studied two units over the summer, and I found so much of my time was taken up watching lectures, attending online seminars, and just keeping up with the weekly coursework, let alone the assignments. It made me think how did I ever have time to do extracurricular stuff outside of studying? It also made me realise I have an obsession with studying and learning (and I would have to leave uni *one* day, but that day isn't going to be until at least another four years.

One of the units I found very interesting—it focused on a different form of health behaviour each week and we kept a journal about a health behaviour we were working on. Also, the other main reason it was enjoyable was because it was incredibly easy. The other unit was a foundational psychology unit and was very much analytical and focused on experiments and you were either right or you were wrong. Which is all well and good if you were right, but I was always wrong, which wasn't something I was used to, since in my creative degree, the key to being successful was it was all about convincing someone why you were right—so I was in for a shock when I realised those persuasive skills would not be able to save me in this unit. In saying that, I somehow managed to scrape through and during the exam, I somehow realised I had actually learned something, and some things had stuck with me. It was hard, it was a slog, but somehow, I managed to survive.

I have also had time to work on my physical health. Like I mentioned above, I had to keep a health behaviour change journal for one of my units, so it forced me to focus on my health. I started regular personal training sessions. The biggest thing I learnt about myself was I

immediately jump to the conclusion of ‘I can’t do that’ without even having tried it first. Nicole, my personal trainer, doesn’t believe that for a second. She would give me one look and say, ‘Don’t give me that—you haven’t even tried.’ So then I would be forced to try, and I would stumble or falter a few times—and she *still* would not let up. And then by some miracle, I would successfully do it. It would be painful and hard, but I would have done it. She would be proven right and I would be proven wrong, and she would be my personal cheerleader shouting encouragement from the side-lines and saying, ‘I told you so!’ And then I would be like, ‘Oh, no. Now I have to *keep* doing it.’ And then she would see I would be able to do it and she would think it was *way* too easy for me (it was not), and she’d up the intensity, and the tortuous cycle would continue.

Another important thing I’ve learned is your body is stronger than your mind—your mind gives up long before your body is ready. In my boxing classes, after a gruelling forty-five minutes of punching, running, and core exercises, Mel, the instructor, would make us do five minutes of non-stop punching and to motivate us, she’d tell us, ‘You can do anything for ten seconds!’ Credit to her, it is a great motivating line, but to me and everyone else in the class (the ones who have actually been through hell while she stands on the side-lines), we’d question her ability to do maths (she was making us do five minutes of punching, not ten seconds), and after forty-five minutes of hell, we do not feel like we can survive another ten seconds of it. But then, somehow, we would survive and prove her right, and realise, ‘Oh, no. Now we have to do this all again next week.’

So, this is a reminder that it’s okay to take some time out and work on yourself. In fact, it’s *necessary* to take some time out for yourself. The world will be waiting for you when you’re ready.

Kind regards,

Julie Dickson

Journal Editor SSPA

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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

SSPA National Journal OLO Report

February 2020

Hello beloved SSPA members! This is Beck, your Overseas Liaison Officer (OLO), reporting to you from Cologne, Germany. Unfortunately, over this winter season, there has been a great spike in COVID-19 cases in Europe, so the past few months have seen us all back in lockdown, with harsh restrictions back in place. However, it's been interesting to observe how a number of European organisations have taken the opportunity to create online options for members to still be able to connect virtually during this season.



BKMF (Germany)

The BKMF have continued to be mainly quiet during this lockdown period. Unfortunately at the end of 2020, they had to make the call to cancel their Annual “Kleinwüchsig Forum” (their convention) that usually happens in May.

BVKM (The Netherlands)

The BVKM have been generally quiet as well, however, they send out hardcopy Journals to their members in the post. The Journals describe recent events that occurred in the BVKM (e.g. the Sports Weekend in September), as well as focusing on individual projects from their own members that celebrate their respective fields, talents and achievements. I most recently was able to attend their annual “Welcoming the New Year” event in January, which was moved online (thankfully!). Here, the members engaged in a lively “Disco Bingo” session together, before breaking off into breakout rooms to converse, catch- up and connect.

LPUK (United Kingdom)

The Little People of UK have been taking many steps in keeping the community connected during this lockdown period. Each month they have been running a number of “hobby” groups online, according to their members’ interests. Those interests include hosting a weekly Trivia Night, a Book Club, a Film Group, a Fashion/Clothing group, and a Travel Group.

DSAUK (United Kingdom)

The Dwarf Sports Association UK recently announced the cancellation of their Annual Sports Weekend in May. Despite this, they have been providing virtual meeting options that range across all ages and interests, including a “Wellbeing Cuppa & Chat” session to discuss mental health; an ‘Under 10’s’ group; a ‘Teenage Talk’ group; an ‘18-30’ group; as well as occasional social media sports challenges.

What questions do you have for these organisations?
Which organisations/countries would you like to hear from next? Would you be interested in connecting with people from other organisations? Ask me anything at olo@sspa.org.au

And finally, as many of you may have already heard, the IDSF (International Dwarf Sports Federation) recently announced that the next World Dwarf Games (WDG) have been pushed to 2023. Though it is best to hear all official updates/information from our Sports Coordinator/SSSA President Kobie Donovan, I am *very excited* at the prospect of welcoming you all to my current home city of Cologne, where coincidentally, the next WDG will be held!

Bleibt gesund und bis bald! Stay healthy and see you soon!

Kind regards,

Beck Kim

Overseas Liaison Officer SSPA

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NATIONAL CONVENTION AND SPORTS WEEKEND SURVEY

The SSPA needs your feedback to inform both the Convention and Sport committees on how best to plan and prepare for 2021. We are currently committed to designing a 'face-to-face' National Convention as well as a 'face-to-face' Sports Weekend, however mindful of current circumstances and the potential challenges ahead, we are seeking your opinion so that we can plan for the year.

The survey takes less than 2 mins to complete, please click the link below or scan the QR Code. This is your chance to have your say and help with planning.

<https://bit.ly/3qac5DK>



SSPA NATIONAL CONVENTION 2021

With the COVID vaccine roll outs currently underway and the Federal Government recently announcing the introduction of reduced airfares (Adelaide being one of the destinations), the SSPA remains committed to our plans of holding a face-to-face convention in Adelaide this year.

Where: Nunyara, 5 Burnell Drive, Belair SA 5052
<https://uvsa.org.au/locations/nunyara>

When: Sat 2nd October – Fri 8th October 2021

Note: The convention committee is certainly prepared to hold a virtual convention should the COVID situation change or if recommended to do so by the Australian Government Department of Health.



COVID VACCINES AND PEOPLE WITH SKELETAL DYSPLASIAS

In January, Little People of America (LPA) Medical Advisory Board published an information sheet on COVID-19 vaccinations in response to questions from LPA members. See link below:

<https://www.lpaonline.org/assets/documents/MAB%20COVID-19%20Vaccines%20Article.pdf?fbclid=IwAR2keulHdZei94j1CcDZa-BQbDcx9tkLM4w9Bg3k77E5AWMfPBi2J2ZfEbE>

As the LPA document relates to USA, we asked our SSPA PAB if they could provide information relevant to SSPA members here in Australia and Professor Silence willingly obliged.

COVID-19 IMMUNIZATION / VACCINATION FOR PEOPLE WITH SKELETAL DYSPLASIAS

People living with dwarfing disorders/skeletal dysplasias in Australia, New Zealand and our Pacific neighbours face a very different situation from that of people in the USA, Central and South America, UK and Europe. The early and strict quarantine restrictions at our borders since February 2020 mean that we have a very low incidence of COVID -19 infections, including serious infections needing intensive care. Most people know that regular hand washing (hand hygiene), social distancing and mask wearing can give us major protection against getting infected, spreading the infection to others and getting sick from COVID. To break the cycle of infection and transmission, our governments need to offer immunization in a tiered manner to the whole population.

The COVID-19 (SARS-cov-2) virus and its Variants

The coronaviruses are named for their appearance under a high-powered microscope. The surface of the virus is covered with proteins which stick out and this coating of spikes looks like a halo. The spikes which stick onto human cells have become the target of many vaccines.



COVID-19 is not the first coronavirus that public health officials have had to deal with. There have been two similar epidemics, SARS in Asia (2003) and MERS (2014) in the Middle East. These never spread to the whole world i.e. became a pandemic, as they were managed by Public Health measures. This meant that we were already preparing for an epidemic sometime, somewhere. Scientists were already working on a vaccine strategy for more than 15 years. There are over a hundred different companies developing vaccines at the present time and several vaccines have been through the cycle of testing for safety and effectiveness, called clinical trials. Four seasonal human coronavirus infections (Common Cold), circulate each year, mostly causing mild upper respiratory infections.

The Use of Vaccines to Prevent Severe Symptoms and Population Spread

COVID-19 is very infectious. It survives for several hours on body surfaces and on items that are handled. It can also be transmitted in the air through coughing, via droplets in the air and via air conditioning. Since January 2020, over 107 million people world-wide have been infected and over 2 million people have died. We want to avoid people getting infected and if exposed and symptomatic, to only have the mildest form of the infection.

Children have a much lower frequency of infection although a small number of children can have a very severe form of response to COVID known as Multisystem Inflammatory Syndrome (MIS). There have been no reported trials of vaccines for children under the age of 16 years, another reason why we should all get vaccinated to protect the children.

Similarly, with the elderly who have increased vulnerability and a high mortality, we need to vaccinate carers and then elderly people themselves. One of the best summaries of vaccine development and information for people in general can be found in the February 2021 edition of the magazine known as The Australian Prescriber (1). The Australian and New Zealand government websites on COVID-19 immunization/vaccination are excellent and are constantly updated (2, 3). bb

Vaccines Available and their Planned Introduction

In both Australia and New Zealand, vaccines have been approved by expert panels of doctors, pharmacists and scientists, before they are offered to people. In Australia this body is known as the Therapeutic Goods Advisory Committee. They have consulted with the WHO and the European Medicines Authority. Both countries are planning a staged program with a priority list starting with immunization for Quarantine workers including all staff who work at quarantine facilities and frontline workers such as nurses and doctors and workers in the Aged care systems. Depending on the availability of vaccine, it is then planned to offer immunization to other at-risk groups and eventually the whole population. There are 3 vaccines approved for Emergency use. These 3 vaccines are bioengineered to use cells in the person receiving immunization, to produce an immune response to the Spike protein on COVID-19.

- | | | |
|------|-----------------|---------|
| i. | BioNTech/Pfizer | 2 doses |
| ii. | Moderna INIAID | 2 doses |
| iii. | Astra Zeneca | 2 doses |

The BioNTech/Pfizer vaccine is ready to go and both countries expect that the first shipment of vaccine doses will arrive at the end of February. It has to be stored/transported and dispensed from a very low temperature container and that will mean that it is only given from centres with these facilities. The Moderna vaccine does not require such low temperature when ready to inject in people. The Astra Zeneca vaccine was developed with Australian assistance and will also be manufactured in Australia by CSL/Boehringer. It is more robust and does not need ultra-low temperature storage so it will be far more portable to non-urban centres and remote towns in our countries.

All the vaccines have to be injected, usually just under the skin on the shoulder, and the two doses are given several weeks apart. The amount injected is tiny. There may be some swelling at the injection site over several days and a small proportion of people immunized, may have a low-grade fever for a few days. These symptoms are minor compared to the infection.

Challenges for health workers and people with Short Stature/skeletal dysplasia

SSPA members know that there are over 300 different dwarfing disorders/skeletal dysplasias. The clinical, X-ray and genetic distinction is usually a huge challenge for most doctors or health workers such as public health nurses.

There are no body size or weight vaccine recommendations at present, but for most adults the vaccine dose does not need to be modified.

Special consideration must be given to those people with Skeletal Dysplasia who have some type of Immunodeficiency. The best-known skeletal dysplasia with Immunodeficiency is Cartilage Hair Hypoplasia (CHH). A recent review of the issues with regard to COVID-19 immunization with live vaccines in CHH and other syndromes with possible immunodeficiency was undertaken by the expert staff of the CHH registry (4). They concluded that individuals considered for immunization with a live vaccine should have recent and thorough immunological studies performed to assess their immunological response to injection with a vaccine.

This means that all people with skeletal dysplasia with any type of immunodeficiency should have a proper diagnosis and current immunological studies. The PAB will make this an agenda item for its next PAB round table as we will need a network of experts who can offer investigation in Australia and New Zealand to people with short stature who do not know their primary diagnosis. The 3 vaccines above are bioengineered and not live vaccines. Several inactivated vaccines are also separately being tested at the present time and these may be needed for some rare disorders.

Everyone must be aware that while Governments in Australia and New Zealand have moved quickly to develop diagnostic services and plans for progressive immunization against the original COVID-19/SARS-cov-2 virus, viruses keep changing. This is sometimes described as evolution in virus strains. We already know about a London strain, South African and South American. These are identified by sequencing the letters of the genetic code of each virus. It is hoped that the presently available vaccines will be effective. Vaccine manufacturers are already preparing to re-engineer the vaccines if this is not the case, similar to the way that Flu vaccines are updated each year.

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4. Vakkilainen S, Kleino I, Honkanen J et al. The safety and Efficacy of Live Viral Vaccines in Patients with Cartilage-Hair Hypoplasia. Frontiers in Immunology 11: 1-8 2020.

Professor David Sillence for the Professional Advisory Board
February 2021

EXPRESSION OF INTEREST: SSPA PARENT PEER SUPPORT REPRESENTATIVE

SSPA Parent Representatives currently provide important positive early intervention for families of short statured children of any age group.

Parent Representatives may act as the first contact for parents of newly-born short-statured child. The new parents are referred to the SSPA by the Genetics Clinics attached to Children's Hospitals in Sydney, Melbourne, Adelaide, Perth, Brisbane and Hobart. Support to the new parents, is provided either face to face, over the phone or online.

Between them, our parent reps around the country have a wealth of experience, practical knowledge and good humour, having raised at least one child with short stature. Some of our parent reps are short statured themselves.

SSPA Parent Peer network will be supported through the PAB Liaison Officer by SSPA Professional Advisory Board (PAB) health professionals; Genetic counsellors and psychologists who will meet quarterly online with the Parent Representatives to support them in the role, provide advice, information, resources etc.

Ideally our volunteers would be able to:

- Share experience and practical knowledge of rearing a child with short stature
- Convey hope and support to the new parents
- Listen openly and be a good sounding board
- Value diversity of perspectives and be non-judgemental
- Create social contact and connections
- Show genuine commitment to achieving a fulfilling peer support experience.

Parent Peer Support Volunteers will need to commit to at least 2 hrs quarterly for online meetings and be willing to take calls from parents of a short statured child (whether newly diagnosed or older), in order to connect and communicate with them.

If you are interested to be part of the Parent Peer Support Network, please fill out the attached form and email to Maree at pab@sspa.org.au by **May 1st 2021**, telling us about yourself and why you would like to be in this volunteer role.

Successful applicants will be selected from EOI's received. **Please note, Timeline is subject to change.**

EXPRESSION OF INTEREST FORM - SSPA PARENT PEER SUPPORT PROGRAM

SSPA Parent Peer network will be supported through the PAB Liaison Officer by SSPA Professional Advisory Board (PAB) health professionals; Genetic counsellors and psychologists who will meet quarterly online with the Parent Representatives to support them in the role, provide advice, information, resources etc.

As a Parent Peer Support Volunteer you will need to commit to at least 2 hrs quarterly for online meetings and be willing to take calls from parents of a short statured child (whether newly diagnosed or older), in order to connect and communicate with them.

Please return this form by **May 1st 2021** to Maree at pab@sspa.org.au

Name: _____

Male **Female**

Age: _____

Condition of Short Stature your child has: _____

Why would you like to be involved in this volunteer role? (feel free to detail any strengths you have that would compliment the role).

Do you have any previous peer support experience? (Note: You would not be excluded from the role if your answer is 'no').

Email contact: _____

Phone contact: _____

If you have any questions about the mentor program, please don't hesitate to contact SSPA.

EXPRESSION OF INTEREST: SSPA MENTORSHIP PROGRAM

We are looking for short statured adults over the age of 18 who are interested in participating in this exciting new program.

Young people of short stature often need support in dealing with the issues of “difference”, as they navigate a world built for average height people and contend with a society that places emphasis on appearance. As bullying and verbally abusive behaviour is often directed towards children/adults with a disability, the formalising of a mentoring program will effectively support our young members in building resilience for dealing with social issues, covert bullying at school, work and community.

SSPA is establishing a mentoring program with support from Headspace and PAB psychologists to upskill and empower the younger generation. The project will provide a structured leadership development opportunity for both young adults and teenagers of short stature. It will be achieved by training mentors to develop their communication and support skills, building confidence and self-esteem to enable all to positively achieve in the broader communities.

The mentoring program will deliver the following:

- Participation in training workshops, facilitated by professionals
- Provision of formal mentoring relationships established through linking mentees with mentors who have dealt with, overcome and succeeded in the struggles and challenges of growing up with short stature.
- Matching mentees to mentors, by age group, interests (vocational or recreational), gender, education or career interest and location.
- Opportunity for vocational skill development, matching of mentees to mentors (emerging and established) in the arts and sports etc.
- Successful mentors will have opportunity to undertake “Train the Trainer” to upskill new mentors.

Outcomes: Program will build mentors resilience and understanding of mental and ill-health; acquire skills to have supportive and energising conversations, and a clear understanding of roles and boundaries in supporting mentees. Understanding of pathways for escalation and support in difficult situations. Enhance capacity of the mentors to look after their own mental health

We are looking for volunteers who:

- Build rapport
- Share experience, rather than advice
- Care about the next generation’s success
- Are self-aware, enthusiastic and a positive role-model
- Open and active listener who provides quality feedback
- Willing to devote time to developing others, and eager to learn

- Show genuine commitment to achieving a fulfilling mentor-mentee experience for all

Mentor Volunteers will need to commit to possibly 3 days of training (including Youth Mental Health First Aid, Mentor training, and Train the trainer), and follow Mentoring Guidelines established during the training.

If you are interested to be part of the Mentor Program, please fill out the attached form and email to Maree at pab@sspa.org.au by 1 May 2021; telling us about yourself and why you would like to be in this volunteer mentor role. **Please note; Timeline is subject to change.**

Expression of Interest form - SSPA Mentorship Program

SSPA is establishing a mentoring program with support from Headspace and PAB psychologists to upskill and empower the younger generation. The project will provide a structured leadership development opportunity for both young adults and teenagers of short stature. It will be achieved by training mentors to develop their communication and support skills, building confidence and self-esteem to enable all to positively achieve in the broader communities.

As a Mentor Volunteer you will need to commit to possibly 3 days of training (including Youth Mental Health First Aid, Mentor training, and Train the trainer), and follow the Mentoring Guidelines established during the training.

Please return this form by **May 1st 2021** to Maree at pab@sspa.org.au

Name: _____

Male Female

Age: _____

Condition of Short Stature: _____

Why would you like to be trained in this volunteer role? (feel free to detail any strengths you have that would compliment the role)

Do you have any previous mentoring experience? (Note: You would not be excluded from the training if your answer is 'no')

Email contact: _____

Phone contact: _____

If you have any questions about the mentor program, please don't hesitate to contact SSPA.

EXPRESSION OF INTEREST: VOLUNTEER PROJECT SUPPORT OFFICER

Aim of the role is to assist the SSPA PAB Liaison Officer (LO) and Project Management Committee (PMC) coordinate the 2 current projects, the Mentorship Program and Parent Peer Network.

We are looking for a part time volunteer to:

- Support the PAB LO and PMC with the scheduling and coordination of project tasks
- Collation and formatting of training materials and information resources
- Communicate with and between participants and stakeholders
- Book travel arrangements for trainers and participants
- Utilise advanced skills of Microsoft Office Suite
- General administration duties as required

If you are interested to volunteer for this support role, please fill out the attached form and email to Maree at pab@sspa.org.au by 1 May 2021 telling us about yourself and why you would like to be in this volunteer Project Support role.

Successful applicants will be selected from EOI's received. **Please note, timeline is subject to change.**

Expression of Interest form - SSPA volunteer Project Support Officer

Aim of the role is to assist the SSPA PAB Liaison Officer (LO) and Project Management Committee (PMC) coordinate the 2 current projects, the Mentorship Program and Parent Peer Network.

Please return this form to Maree by **May 1st 2021** at pab@sspa.org.au

Name: _____

Male Female

Are you a person of Short Stature: Yes No

Condition of Short Stature: _____

Why would you like to undertake this volunteer role? (feel free to detail any strengths you have that would compliment the role)

Do you have any previous project experience? (Note: You would not be excluded from the role if your answer is 'no')

Email contact: _____

Phone contact: _____

If you have any questions about the mentor program please don't hesitate to contact SSPA.

SSPA Resource Development Project

We Need YOU!

The SSPA Victorian Branch has been awarded a grant from the Department of Health and Human Services to develop a suite of new resources for SSPA. These resources will aim to be informative and engaging to all new and existing members of the SSPA whether they are young or old.

We have two requests of our members to assist in making these resources fabulous, one being images and the other stories.

Images

To help us make these resources look engaging we need a series of images from our members to show short statured individuals and their families and/or carers doing everyday activities.

If you have photos on hand that is great, if you don't and want to contribute, it is okay if you would like to 'stage' the photos for the purpose of getting the best image depicting any of the below scenarios:

- At school
- At work
- At play
- At sport
- At art
- In the home – home adaptations
- Driving
- Catching public transport
- Shopping – grocery and clothing
- In the media (print or screen media including "Playschool")
- Short statured women's experience of pregnancy
- Or if you have any other ideas of scenarios that would be great then please feel free to take some photos.

All images have to be at least 1MB in size.

Please send all images or queries to carly.myers@sspa.org.au ASAP

Stories

We are after personal stories from parents and/or carers of short statured children (or adults) to use as 'examples' in our New Parent resource kit. We will conduct short interviews over the phone with a few questions to guide the conversation. It is up to you what you would like to share that would be of benefit to other new parents to know. It is also up to you whether you would like to be anonymous or not if your story/example is used in the resources.

If you are interested to contribute your story, please contact Keiran Watson-Bonnice via email at keiran.watson-bonnice@sspa.org.au by 30th March 2021

For both submissions of the images and stories, we will draw up a privacy and media release form for all contributions.

Finally, if you would like to contribute to the development of these new resources or have ideas of what you feel should be included please do not hesitate to contact Carly on 0430231557 or via email ssparesources@gmail.com

Parents Tips and Ideas

Taking your child for their first surgery is a very stressful time for parents no matter the age of the child. Who am I kidding? Every time you take your child to the hospital for surgery is stressful, be it their first time or their fifteenth. One of the things that I struggle with is packing what I think we will need. Though there are some items you can buy at the hospital if you have forgotten them, and the nurses always have some great ideas of how to make your child more comfortable, I have asked a few parents within the SSPA to help me compile a list of items you may wish to have with you that you may not have thought of.

- Your child will need loose fitting, easily removed clothes. Getting your child dressed to move around the hospital while they have cannulas and other tubes attached can be difficult. Pyjamas with a button-down front are great.
- There are TVs in most hospital rooms but if you can bring an iPad so that your child can watch the shows they like it does help. Just don't forget the charger! A favourite soft toy, book, or blanket will also comfort them.
- If a long stay in hospital is expected, a sheep skin can help to prevent bed sores post-surgery. You may also want to bring a real pillow rather than using the plastic covered ones the hospital provides.
- For day surgery, you will be tempted to only pack clothing for your child. Both of my children vomit after anesthesia and it usually happens when I am cuddling them. It is not much fun driving home in vomit covered clothes so make sure you have spares, even if they stay in the car.
- Snacks from vending machines and cafes are very expensive and many of us snack when we are stressed, so packing some snacks is helpful. As well as that, your child may not like the hospital food so some favourite foods can help make the stay easier.
- Make sure to pack a book and iPad for yourself as well and don't forget headphones. It can be very hard to sleep in a hospital and after a stressful day you may find that you are lying awake late into the night watching your child's oxygen levels and other stats.
- One thing I always do is pack a magazine or book, a drink, and something to eat while waiting to hear how the surgery went. The doctors do tell you to go and wait in a café saying that the surgery will take hours but I'm never good at being that far away and always spend most of the time just outside the recovery room. You may not eat, drink, or read as you are spending the whole time watching the doors for your doctor to come out, but it makes me feel better to be prepared just in case.

I hope this list gives you some good ideas and if you ever want to talk to parents who have experienced long hospital stays just let either me or your local parent rep know so that we can put you in touch with someone.

If you would like to share any tips, ideas or questions please email the journal editor or the membership secretary as we would love to hear from you.

Katrina Reynolds

E: membership@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 textbooks
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 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.



Hi everyone,

Short Arts Collective has been quiet following the success of the 2020 SSPA Virtual Convention. We are currently organising an AGM, which we're hoping all will attend. We'd really like your input on the 2021-2022 activities that we're looking to organise and put together for SAC. We'd love you to be involved with SAC as a member and/or as an individual looking to showcase your artistic practice or contribute your creative flair!

Please see below details to register your interest in attending the AGM.

When? On a Saturday yet TBA

Time? 10:30am (AEDT)

Where? via Zoom

Register in advance for this meeting:

https://us02web.zoom.us/meeting/register/tZ0ofuGuqz0jEtNvmUiXIwRB64ve_ecu9uzi

After registering, you will receive a confirmation email containing information about when the meeting will be held and how to join the meeting.

Kind regards,

Graci Lynch

Short Arts Collective Coordinator

E: info@shortartscollective.org.au



National Sports Update

By Kobie Donovan

<FEBRUARY>

SSSA AGM

Thank you to all those who attended the 2021 SSSA AGM. I'm pleased to announce our 2021-2022 committee.

Chairperson: Elected by SSPA – Kobie Donovan

Secretary: TBC

Treasurer: Anthony Koedyk

Committee: Anna Sydenham (NSW), Kaed Dawber (VIC), Kat Ramos (VIC), Laura Mladenovic (QLD), Tiana Holt (QLD), Lucia Bruce-Gilchrist (NSW), Sam Millard (VIC), Pete Stone (WA), Simon Franklin (WA), Mikey Spain (VIC)

The Committee are currently working out a 2021 plan to ensure sporting opportunities (in person) across the country occur. Stay tuned, and make sure you complete the SSPA Survey to have your say.

World Dwarf Games: Update

In light of the World Pandemic situation, the International Dwarf Sports Federation (IDSF) board has decided to postpone the World Dwarf Games. Germany will host the 8th edition of the Games in 2023, and Australia will host the 2027 World Dwarf Games.



The IDSF board (Australia represented by Kobie and Sam), met on Friday 29th January 2021 to discuss the ongoing impact of the world pandemic. All countries represented on the board gave an overview of their current circumstances. Many federations had similarities, with limited ability to conduct national games, training camps and fundraising opportunities. These are essential components for nations preparing to attend the World Dwarf Games. Additionally, it was clear that international travel is still restricted in many countries and will only resume after a vaccine rollout.

Considering the above points, it is clear that most federations would have been significantly underprepared to participate in 2022. The board understands the disappointment this may

bring to many; however, it is our duty to ensure all our participants' safety and ensure equity across the globe in terms of preparation and attendance.

Australia intends to resume preparations for training camps early 2022.

The Sspitfires are back ... 2.0

SSSA / SSPA Victoria are looking for committed players to form a roster for the 2021 Port Phillip Bay Basketball Season.

Training will be starting in March and the competition will be starting in May; running in conjunction with school terms, holidays breaks and long weekends. Games are on Saturdays in Melbourne at MSAC between 1-5pm. This is a great opportunity to be a part of a team, meet new people, and play some social sport while potentially preparing for the World Dwarf Games 2023. We are flexible with the age bracket and all skill levels are welcome. A great development and fitness opportunity.

To make this possible it comes down to having a solid depth of numbers in the team, with committed or flexible availability. If this is of interest to you or your child, even in the slightest, please contact Mikey Spain 0488364329 – SSSA Victorian Rep #letsssgoooo



Kobie Donovan
Sports Coordinator
E: admin@sspa.org.au

What's happening around our Nation?



Victoria

Hi everyone!

The Vic Group recently met at the Indented Head Community Hall for our January summer get-together. We met some lovely new families and were able to establish some great connections. Thank you to those who travelled far to come to our summer get-together. We really enjoyed meeting you and hope that you come to future gatherings.



One of the goals for the Vic Group in 2021 is to build our community base. It's really important that we continue to focus on supporting the individuals living with dwarfism, their families, friends, and carers. Victoria has been privileged enough to see the relaxing of some restrictions - which has allowed us to come together a little more freely and easily. We still have a long way to go - so let's continue to keep each other in mind whilst we ride the COVID wave together this year.

I found it really important to connect with the new families that we met and to hear about how they found out about us and what their journey has been like so far with their young children. I think it's really important that we hear from them understand what has worked, what has not worked, what has worried them and what they want to know.

In conversation with these families, it seems that there are those who feel there are some GP's and medical professionals not familiar with the rare genetic conditions of short stature.

This is certainly an area that I'd love to work on - as it's so important for new families to feel secure and supported during their pregnancy and whilst their child is still very young. We all know that you can't predict everything that you, your child, your friend, or your family member may go through as a person living with a condition of dwarfism - but let's try and support those that are starting this journey. As an adult, I know that I will never be able to explain my condition to everyone that I meet - but it would be so important for us as a community to work on how we can better identify ourselves and our needs to the professionals that can help us and others live a better life. This is a project discussion for another day, but one that we should continue to think about and start talking about as a community.

Stay Connected

I will be organising some future Zoom sessions, so we can stay connected. Please have a lookout for my email with the details.

Castlemaine Weekend: Vic Group Catch-up.

May 7: Free Evening/Arrival (for anyone traveling and looking to stay two nights)

May 8: Day activities to be organised, with an option for attendees to be involved in program activities or to explore what Castlemaine has to offer.

May 8: Evening activities and dinner for attendees. Details to be provided soon.

May 9: Free Travel Day - possible brunch get together.

Re. Accommodation: Big 4 Castlemaine

https://www.big4.com.au/caravan-parks/vic/goldfields/castlemaine-gardens-holiday-park?gclid=CjwKCAiA65iBBhB-EiwAW253WxHOdSCshNDR_tCyo7rcY6nrKbw7Yxy1aViRln0ZEcLb5QwSGUyKdBoCM20QAvD_BwE

There are plenty of options for those traveling and looking to stay overnight. I have been looking and have sourced the above location that will suit a group like ours. The location offers quite a variety of accommodation options and even has powered and unpowered sites for those looking to camp or bring their caravan. The location has facilities like a BBQ area and pizza oven - which is where we might find ourselves on Saturday night, for dinner, and for a group get together.

I have spoken to the site and was advised that a 10% discount may be provided to group bookings of 20 or more guests, with 'SSPA' as the booking reference. They have noted that it would be wise for anyone looking to book accommodation to do so a month in advance - so by the 9/10 of April - to be safe. I will be providing regular updates on the above weekend and will advise of any changes, in line with Vic Government and the updates they provide in relation to the COVID climate. We'll be together again soon!

Keep well and safe everyone. Stay strong. We'll get through this together. :)

Graci Lynch

SSPA Victorian Branch

E: graci.lynch@sspa.org.au

New South Wales/ACT

Hello everyone,



Well, at last we are able to report a face-to-face catchup! NSW/ACT members recently gathered for a branch meeting at the Blaxland home of Emily, Michael, and Lachlan Blair. Following the meeting the group adjourned to the Lapstone Hotel for a very yummy lunch. It was great to get together and enjoy each other's company after such a long time. Jenny and Prof Sillence were present on the day and we were all so pleased to see Prof looking fit after his recent surgery.



Speaking of catchups, a couple of months ago Maree Jenner had occasion to visit friends in the Blue Mountains, so Maree Smith and myself travelled from Blayney and Bathurst to meet Maree J in Lithgow. We spent a few pleasant hours at the Gang Gang Gallery where a friend of Maree J was exhibiting a series of art works. We then moved on to the Tin Shed Café (highly recommended) for lunch, before heading our separate ways.

As I wasn't very mobile on the day, I must give a shout out to both Maree J and Maree S for taking turns to push me around the gallery in a wheelchair. Good friends!

PS: It's always good to read any news about members meeting socially from time to time, so if any of you happen to do so, remember to take a few pics and send them in to Julie, our Journal Ed.

News from our Youth Coordinator Lucia

On the 18th December last year, Lucia and Beck hosted an SSPA Christmas party via Zoom, for members in the 12-20 age group.

Ten people joined the Zoom party which officially began at 5pm with a general catch up. After about twenty minutes the group participated in some online games that included "trivia", "this or that", and a scavenger hunt.

Before the party ended at 7pm, each person shared one positive thing that had happened during the previous year and also shared one personal goal they were aiming for in 2021. Lucia and Beck felt the Zoom party was a success and are hopeful that more online social gatherings can be planned for this age group in the future.

*NSW/ACT members extend their sympathy to Michael and Emily on the passing of Michael's father Jack Blair, who played a significant role in the NSW branch in the early decades of the association's development (see VALE in this Journal).
Our thoughts are also with Michael's mother Nanette at this time.*

Future events

The next social occasion for the NSW and ACT Branch will be a late summer BBQ and Pool Party at the Palmer's home in Bronte, Sydney.



Please bring something for the BBQ, a plate of salad etc to share, and your swimmers!

NOTE: RSVP to PAB@sspa.org.au to receive the address of the pool party

Looking forward to seeing you there!

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



NDIS and people with dwarfism

Maree Jenner
Email: pab@sspa.org.au

SSPA continues to advocate and work with NDIA/NDIS to assist with increasing their awareness of supports for people of short stature. To assist with you or your child's access application, I recommend that you mention the term "short stature" on the access form as well as the diagnosis of the condition, as this term is being added to the NDIS disability/impairment lists.

If anyone would like support with accessing the NDIS please email pab@sspa.org.au

In January, I received feedback from NDIS in regard to the PAB video presentations we provided to assist them with increasing staff knowledge on conditions of skeletal dysplasia. They advised "The presentations were provided in our weekly communications. Our staff were thankful to be provided with this information, particularly our quality development officers, who will be able to use this information to assist with future applications. These

officers also provide training during the on-boarding of new staff. Any additional resources are welcomed to assist in this process.”



As mentioned previously, I plan to make a few short videos which highlight the support needs and challenges for different ages and conditions of short stature. Please feel free to contact me as we are looking for members in the following age groups: 7- 18 years, 19 - 40 years, 40 and above years. Please note, it is very important that as well as achondroplasia, we also get a representation of members with the rarer conditions of short stature.

SSPA Facebook groups

SSPA NDIS Discussion Forum - is a place to ask questions, offer advice and share experiences of people of short stature on your NDIS journey.



SSPA Hacks & ideas group - is a place to ask questions, offer hack ideas and share them with others in the short statured community. Ideas/hacks that will make our vertically challenged lives that little bit easier. Please check it out and feel free to add your ideas or ask for suggestions etc.

When I presented “Made to Measure”, the home mods & assistive technology presentation during the Virtual Convention last year, I provided a range of ideas that people use to assist with everyday living. One of the items I mentioned was a bath shortener (pictured below) which I purchased in the Netherlands while I was living there. I treasure it immensely as it makes having a bath so much more pleasurable, not having to hang on to stop myself sliding down the tub. I recently tried to find it in Australia but with no success. However I found a company in Holland/Belgium that appears to still stock it. I sent them an email so will share any information when it comes.

During my search I came across another option which although more expensive than the bath shortener, could be just as useful. Who doesn't love a relaxing bath? As a majority of people with skeletal dysplasia require therapy supports to maintain mobility, a relaxing bath is often recommended. This piece of AT (assistive technology) is called a Bellavita Auto Bath Tub Chair seat lift (<https://ilsau.com.au/product/bellavita-auto-bath-tub-seat-lift/>). It is positioned in the bath so your feet rest comfortably against the end of the bath to prevent you from slipping down. See more information via the link below.



If you have an NDIS plan, I would see this as a disability related expense and therefore consider it to be reasonable and necessary, as it is value for money when you compare it to a bathroom modification. If interested I suggest speaking with an OT for an assessment.



Independent Living Centres in Australia stock them and they are NDIS registered service provider.

Maree Jenner
VP/PAB Liaison Officer
E: pab@sspa.org.au

BOOK REVIEW

Julie Dickson

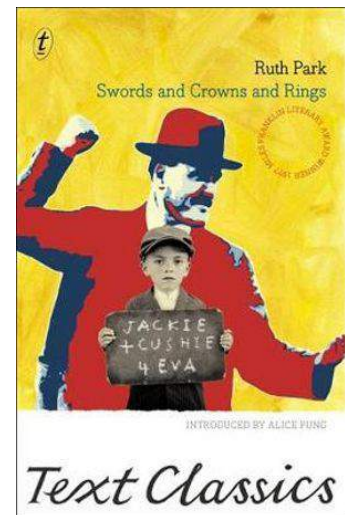
Swords and Crowns and Rings by Ruth Park is a literary fiction novel set in Australia from 1907-1932.

In rural Australia, Jackie Hanna is a person of short stature who was born into a working-class family. His next-door neighbour Dorothy 'Cushie' Moy was born into a wealthy family. They quickly form a close friendship. The novel follows the lives of Jackie and Cushie during their formative years as they try to find their place in the world. Along the way, they meet a wide cast of characters full of personality.

A recurring hardship for Jackie is the torment he receives for his short stature and being physically different, which was heart-breaking to read about. When this book was written, there was little public knowledge about people with short stature, so people weren't as accepting as they are nowadays.

Park's writing style is slow and languid and is rich in description. She paints vivid pictures of the Australian outback and the city, which transported me into the world inhabited by the characters. Park covers a lot of heavy topics such as abortion, death, and the Great Depression. She focuses on the characters' emotional journeys which made me become attached to Jackie and Cushie. When they suffered, I suffered alongside them, and when they triumphed, I triumphed with them. Although a lot of drama unfolds over the course of the novel, Park's descriptive writing style makes the story feel like it's going at a slow pace, which reminded me of the style of *Little Women*.

Although the characters face various hardships, Park celebrates the strength of the human spirit. I recommend this book for anyone who's fourteen years and older and wants to read an Australian literary fiction novel about the strength of the human spirit.



PARENT REPRESENTATIVES OF SSPA 2020-2021

| | | |
|--|---|--|
| ACT Katrina Reynolds membership@sspa.org.au 0430 123 116 | NSW Jenni Bruce jennib@pobox.com 0412 415 498 | NSW Alma Weber almaweb28@yahoo.com.au |
| NTH NSW Wilma Steain (02) 6554 8163 | NSW (REGIONAL) Vicki Fallon* secretary@sspa.org.au | NSW (HUNTER REGION) Dawn Bos* dbos153@gmail.com |
| NTH QLD Tina Glenwright * tgm761@bigpond.com | SA Emily Vozzo emily.vozzo@sspa.org.au | TAS |
| VIC Jenny Zeuschner brett@vigorella.com.au | WA Suzann Franklin suzann.franklin@sspa.org.au (08) 9041 3220 | |

* Denotes person of short stature

SSPA Patron

Tina Zeleznik
 Chief Executive Officer
 Disability Works Australia
 Tel: 08 8276 0900 or 1800 356 670

SSPA Professional Advisory Board

| | |
|--|--|
| NSW Prof. David Sillence Prof. Andreas Zankl; Clinical Geneticist Dr. Louise Tofts; Rehabilitation Paediatrician Tracy Tate; Senior Physiotherapist Mr Martin Pearce; Family Therapist/Psychologist | Ms. Cheryl Cotton; Associate Genetic Counsellor Ms. Alison Wesley; Senior Occupational Therapist Dr Verity Pacey PhD; Senior Physiotherapist Dr Debra Keenahan; PhD, Lecturer, Social Sciences & Psychology Western Sydney University |
| QLD Dr. Theresa Carroll; Rehabilitation Physician Dr. Penny Ireland, PhD; Senior Physiotherapist | Ms. Janet Danielson; Speech Pathologist |
| SA Dr. Lesley McGregor; Clinical Geneticist | |
| VIC Prof. Ravi Savarirayan; Clinical Geneticist | Mr. Robin Forbes; Associate Genetic Counsellor |
| WA Dr Fiona McKenzie; Clinical Geneticist | Ms. Stephanie Broley; Genetic Counsellor |
| SSPA PAB Liaison Officer: Maree Jenner | |

Got a question for our Professional Advisory Board? Send it to:

★ E-mail: pab@sspa.org.au

**SSPA NATIONAL COUNCIL 2020-2021
OFFICE BEARERS**

| | | |
|---|--|---|
| President Sam Millard* (VIC) president@sspa.org.au | Vice President Maree Jenner* (NSW) pab@sspa.org.au | Secretary Vicki Fallon* (NSW) secretary@sspa.org.au |
| Treasurer Anthony Koedyk* (VIC) info@sspa.org.au | Journal Editor Julie Dickson* (VIC) journal@sspa.org.au | Overseas Liaison Officer Beck Kim* (NSW) olo@sspa.org.au |
| 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 |

COMMITTEE MEMBERS

| | | |
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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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