

**UpsideDowns**  
education trust

# ANNUAL REPORT

2021-22

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# A message from the Chairperson

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Welcome to our 2021-22 annual report.

I'd firstly like to thank Sarah, Bea, Ella & Adrian for their efforts over a challenging year. Our staff, along with our board & other great volunteers mean we can continue to do what we do, supporting kids to find their voice.

Of course we couldn't do any of this without our generous donors, corporate partners, regular giver, and supporters, so a heartfelt thank you to all of you. A special thank you to the Lindsay Foundation for their continued generosity walking alongside 56 of our members.

It's been fantastic to see some of you over the year at the events we managed to sneak in amongst the lock downs. Hopefully this is a sign of things to come & we will be able to see more of you at more events over the next year.

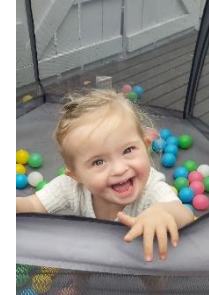
I don't want to give anything away but there is some great reading in the rest of this report, numbers we can all be proud of and a testament to our staff & board.



Board Chairperson, Chris Steenson, with his daughter, Chloe

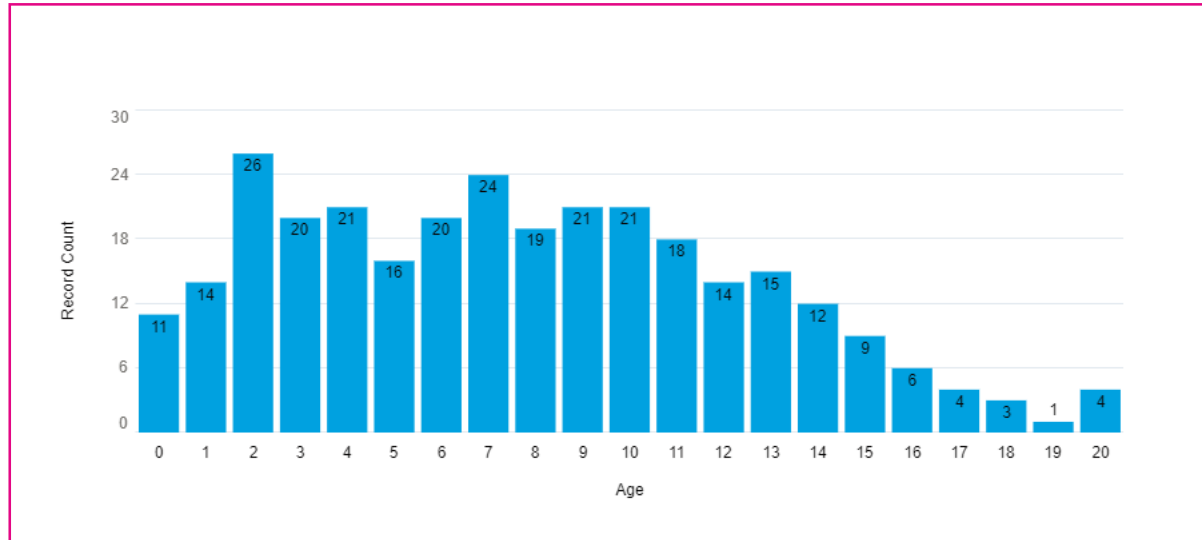
# UpsideDowns in 2022 at a glance

- It is now **19 years** since the UpsideDowns Education Trust was established in 2003 by a group of parents to support the communication journeys of children with Down syndrome.
- As of April 2022, we are funding the speech and language therapy of **299 children**.
- Our waitlist at time of writing is **5 children**.
- These children range in age from **birth to 20 years old**, with the majority being of primary school age.



George and Frankie are 2 new members

- The average time spent on our waitlist in 2021-22 was **3.8 months** – over a month shorter than last year.
- In total, **99 new families** were given funding for their child's speech and language therapy last financial year – the most ever in one year!
- The average age of an UpsideDowns member remains consistent at **7 years old**.

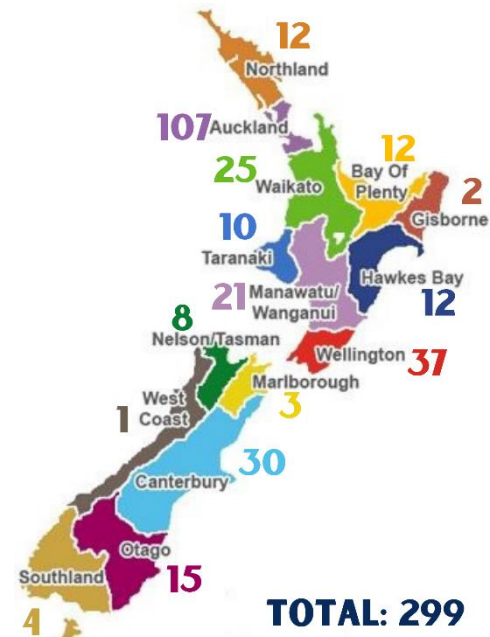


# Children supported by UpsideDowns: regions

Children supported by UpsideDowns by region  
March 2021

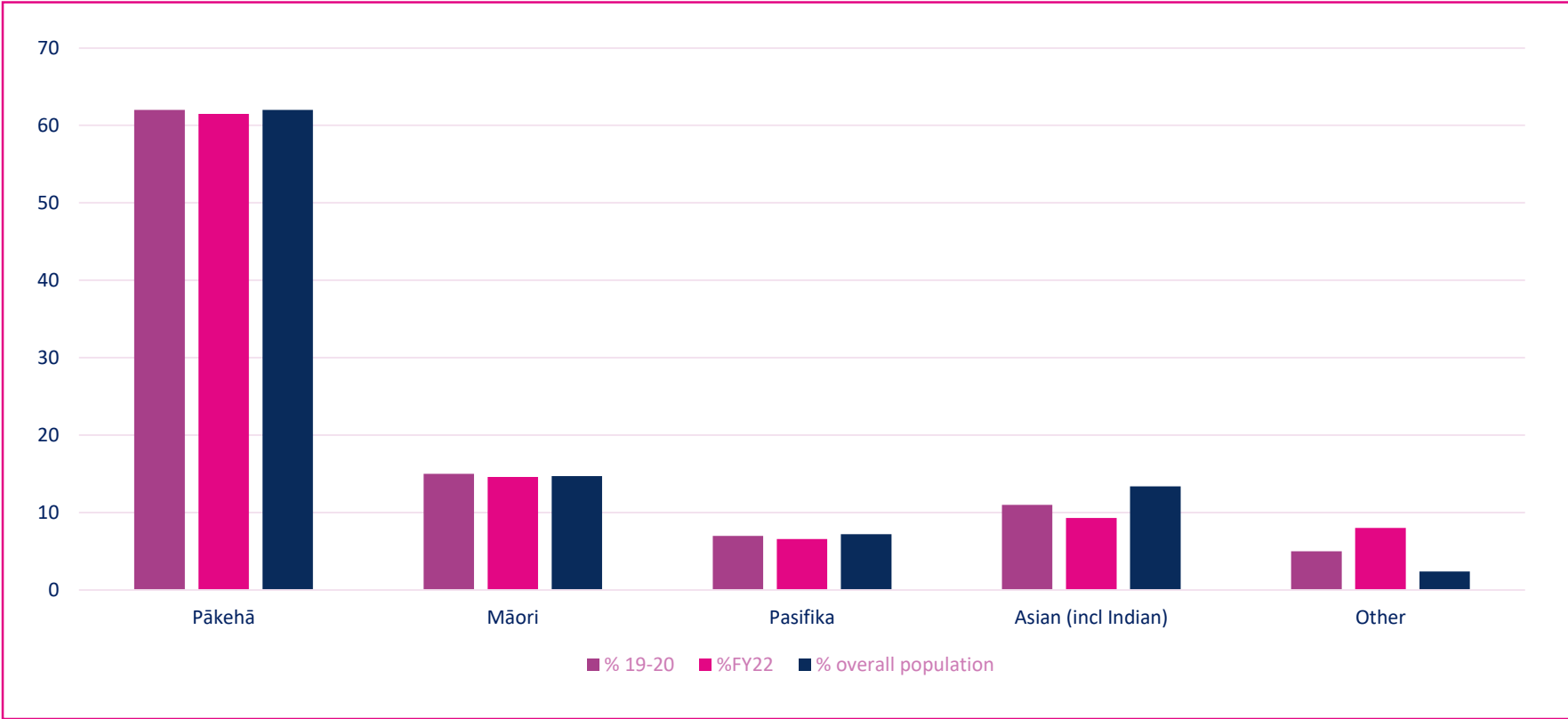


Children supported by UpsideDowns by region  
March 2022



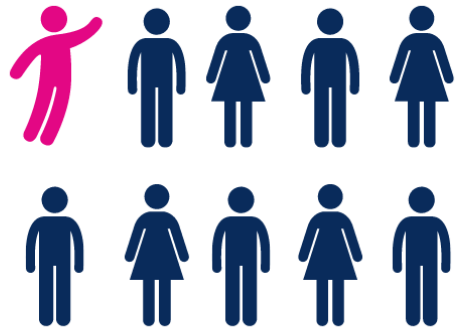
# Children supported by UpsideDowns: ethnicity

The graph below shows the ethnicity of current members who applied after June 2018 – the point at which we first started including this as an optional section on our application form.



# Proportion of Kiwi kids with Down syndrome supported by UpsideDowns

2016



*11% kids with  
Down syndrome  
funded*



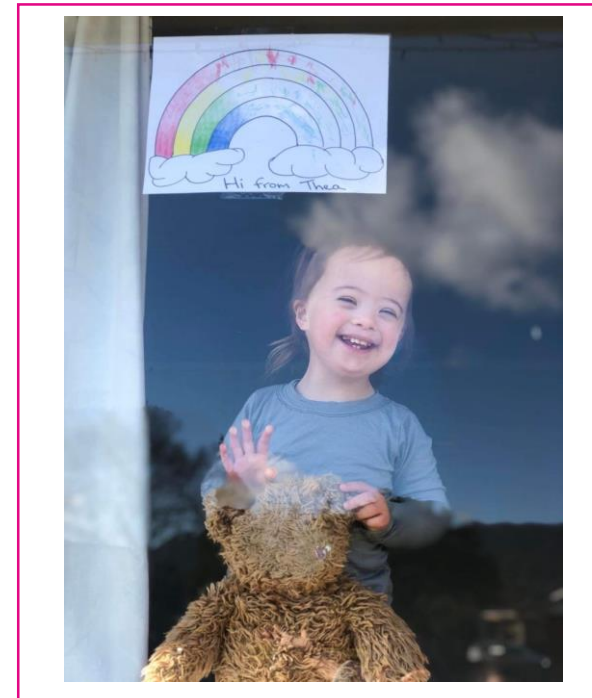
2022



*37% kids with  
Down syndrome  
funded*

# 2021-22: the challenges

- COVID-19 continues to shape how we operate as an organisation, with large in-person events still off the cards for now, and a particularly challenging period for our three staff members and the bulk of our volunteer Board who are based in Tāmaki Makaurau who had to work from home for several months, juggling kids and flatmates.
- The options for other funding sources continued to narrow as well, with many public grants and private business giving schemes on hold.
- Once again, our target for the number of speech and language therapy sessions funded was well below what we'd hoped, given the various lockdowns and the continued risks for our immune-compromised tamariki.
- We have seen a significant increase in the number of whānau funded by Option 3, our special financial hardship option. While this is generally a good thing – indicating success in our Outreach efforts and an increase in referrals from the Ministries of Health and Education as well as other organisations such as Down Syndrome Associations, it also demonstrates that more of our families are struggling at the moment.
- Both the Down syndrome community and Mt Albert were rocked by the tragic death of Lena Zhang Harrap. This was an incredibly challenging period, and we are extremely grateful for the collaboration and support of the New Zealand and Auckland Down Syndrome Associations over this time. We are also thankful for the generous support of Foundation North which allowed us to send hard-copy grieving resources and 'Seeds of Hope' to plant in Lena's memory, as well as free counselling sessions with professionals experienced in the mental health of people with intellectual disabilities and their whānau. Lena was loved and is missed by so many, a testament to the positive impact she had on so many lives.





# 2021-22: the upsides

- Our year got off to a fantastic start thanks to the incredible generosity and commitment of the Lindsay Foundation. Following on from their donation in 2020 which enabled us to take 33 children off our waitlist, the Foundation donated a further \$100,000 in April 2021 to take 23 more children off our waitlist and into funding! These funds represent a commitment of approximately six years of speech therapy for this group of 56 children. The Lindsay Foundation understand that communication is a long-term journey for our members, and we couldn't be more grateful for their investment in the potential of children with Down syndrome.
- In our last report, we discussed the upsides of more SLTs and more whānau embracing tele-therapy options as a result of the lockdowns. This year, we're excited to have developed this further, hosting a webinar on SLT for children with Down syndrome featuring the wonderful Fiona Kenworthy. This was incredibly well-reeieved and well-attended, leading to a follow-up hosted by the New Zealand Down Syndrome Association (NZDSA) as part of their 40th anniversary conference, and plans to make this a regular part of our calendar. This has also formed part of our Outreach efforts, with one family even signing up for membership during the session!
- It's easy to let the memory of the last five months of the year take over, but of course the majority of the year was spent with little or no restrictions, and we managed to host an excellent Quiz night thanks to our friends at Browne St, Avondale, and also a very special supporters event at Eden Park with Beauden, Jordie, and Scott Barrett. Nick and the team at Eden Park put the whole thing on for us free of charge at very short notice, and the evening concluded with some of our members and their siblings running on the floodlit Eden Park pitch, throwing and kicking rugby balls with the Barrett brothers, joined by some of our much-valued supporters. [In a subsequent interview with the NZ Herald](#), Brendan Lindsay described the evening as a “highlight in our life”, and everyone from the UpsideDowns team who was there completely agrees!



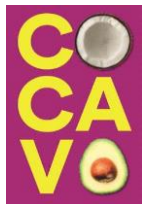
George Wong takes a picture of Beauden Barrett and Brendon Lindsay

- This was the first full year that our team has included a third staff member, Ella Pooley, originating the role of Fundraising and Digital Media Manager. It has made an enormous difference, as the financial statements attest to, but also in terms of what we can offer as a charity. The additional support has significantly improved the working environment for our other two staff members, and taking the pressure off fundraising requirements has enabled us to provide better support to our member whānau, ensuring SLT begins more promptly, and that communication between families, therapists, and education staff is optimal.

# Corporate partners 2021-22

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Here are all the wonderful corporate partners UpsideDowns worked with this year. We love that each and every one of these relationships is unique and tailored to the people involved. Every one of these businesses really believes in what we do. Please consider choosing these businesses where you can!



# What can you do as a business?

Many businesses support charities through employee plans, payroll giving, related charitable trusts, or directly. Other businesses could support us directly through sponsorship. If you know, work for, or run a business that you think might be willing to support the Trust and could make an introduction, we could arrange a presentation by the Trust to them.

## Giving in-kind

In order to support our work, we run at least one fundraiser per year. For these fundraisers to be successful, we need to find dozens of silent and live auction items.

Donating products, vouchers, or services to these auctions makes a huge difference, and can provide an excellent marketing opportunity for your company. From small hampers or a bottle of wine, to fishing charters or jewellery, your in-kind donation can go a long way at an UpsideDowns event.

## Partnership

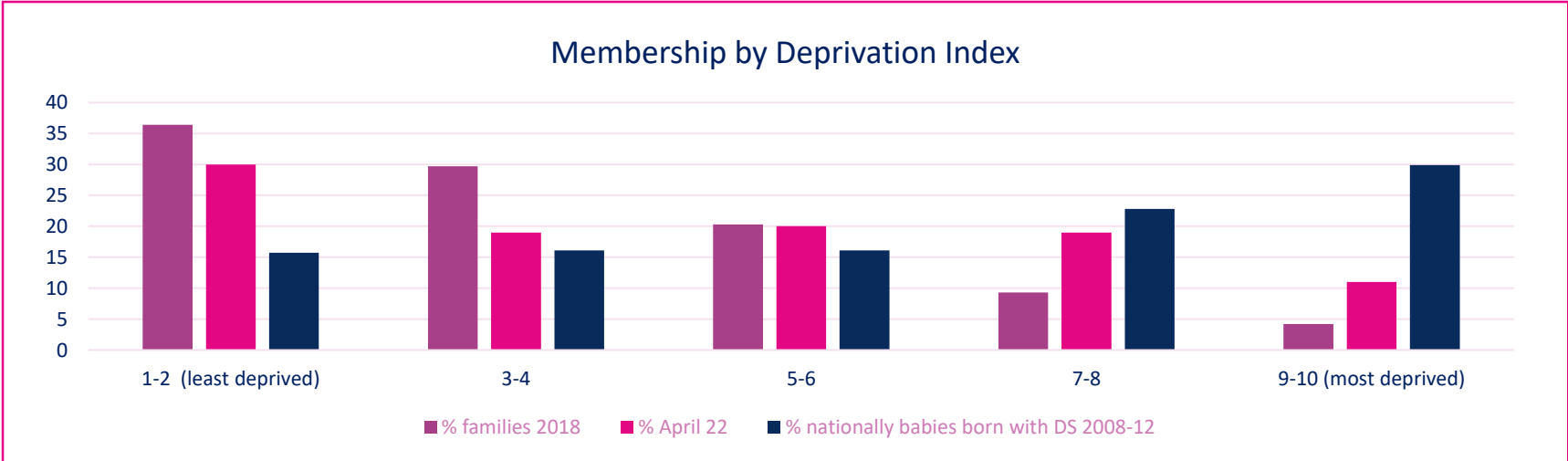
Corporate partnerships are a great way for the not-for-profit and the private sector to work in tandem to the advantage of both. UpsideDowns can provide a business with great promotional opportunities, and staff with a real connection to the amazing children we support. Email [sarah@upside-downs.co.nz](mailto:sarah@upside-downs.co.nz) to find out more about partnering with UpsideDowns.



Jordie and Beauden Barrett, Sarah Paterson-Hamlin, Scot Barrett, and Eden Park CEO, Nick Sautner at Eden Park, August 2021. Eden Park have been partnered with UpsideDowns since 2020.

# Outreach

- COVID-19 has made it difficult to work on our Outreach project, much of which relies on connections with groups and setting up specific group sessions in different parts of the country, all of which need to meet in person. However, we are continuing to see the ripple effects of work conducted since the start of the project in 2018, including ever-increasing referrals from organisations such as Taikura Trust, CCS, Vaka Tautua, Ohomairangi, DHBs, and others.
- The graph below demonstrates that our direction of travel is very positive, and that UpsideDowns continues to be a more equitable organisation for all children with Down Syndrome In Aotearoa. However, we are aware of certain areas of the country where our impact isn't what it should be, and this will be the focus of the next tranche of our Outreach work.
- As mentioned on page 10, our Outreach went virtual during lockdown, with an online webinar on SLT for children with Down syndrome led by Fiona Kenworthy. We were able to reach many new families through this session, including many who had never heard of us before. Most attendees were parents, teachers, and teacher aides who were really struggling with the effects of lockdown. Increased digital equity in Aotearoa meant this was a highly effective tool that we will continue to utilise, but we're looking forward to getting back to in-person groups as well!



# Individual donors in 2021-22



- Thank you to all of the generous One Percent Collective donors who choose UpsideDowns as one of their charity partners.
  - There are now 275 people who give regularly to UpsideDowns as part of the Collective – 38 more than last year!
  - This represents 48% of our individual donations for the year and 96% of our regular giving!
  - Regular giving means so much to us at UpsideDowns because of the long-term commitment we make to whānau. With One Percent taking on the significant administration burden as well, we really can't recommend this method of support enough!
- Thank you to **Hannah, Heera, Virginia, Hilary, John, Carole, Justine, Laurie, and Vicky**, our superstar direct regular givers.
  - Thank you to the 53 individuals who gave to us through our website this year.
  - Thank you to Deco in Titirangi for hosting our donation point tap device.
  - We would like to acknowledge incredibly generous donations from the Nielson family, the Hickson family, the Petrolheads Hawke's Bay, the Barker family and the "Old Guys Lunch" group, Samar Kand Trust, Hayley Ammundsen, the Hopkins family, Circle of Friends, and Emma Howard-Smith.
  - And last but certainly not least, thank you to **Suzanne Shaw**, a brilliant volunteer ensures all our website donors get their tax receipts on time.



Miles is 13 and has been receiving SLT through UpsideDowns since he was a baby back in 2010!

# What can you do as an individual?

## As a member

The UpsideDowns Education Trust is a membership-based organisation. The families that the Trust supports are members of the Trust. In return for the Trust's support, its members are asked to also support the Trust in ways that they can manage. Support could come in the form of time, skills, or connections. These are some ways that families and their networks can support us.

- Send us high-quality photos of your child – we're always on the lookout for these!
- Get involved in our Auckland-based fundraising events if you live in Auckland.
- Run your own fundraising activity – anywhere! For instance, a school mufti day, a marathon or half-marathon run, a movie night, a quiz night, or put on a show. These have the added bonus of raising awareness in your community.
- Ask someone you know who runs a business to consider partnering with us, or donating in-kind.

## As a supporter

- We use the services of printers, designers, photographers, and other people who can help us to promote ourselves. If you have

these skills and could give us some time, that would be great. If you have other skills and would be willing to donate your time, why not consider auctioning your skills at one of our annual fundraising events?

- Become a member of the OnePercent Collective and donate on a regular basis

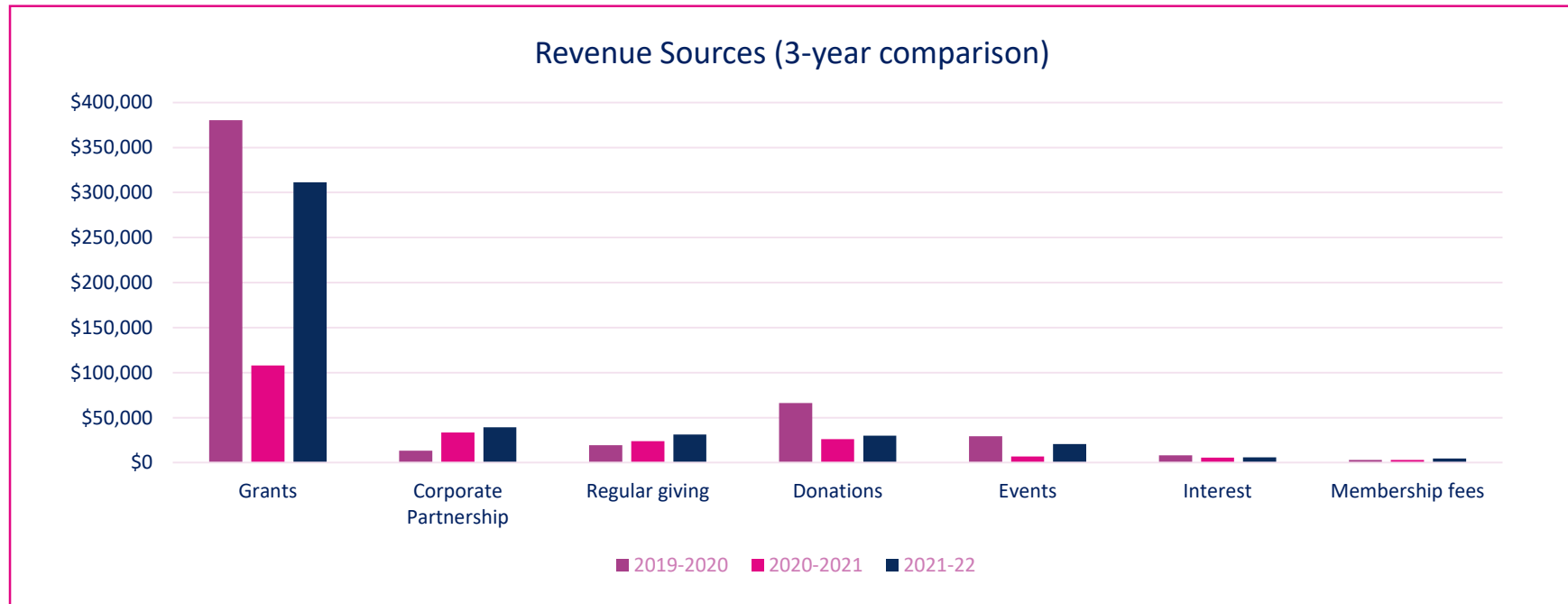


Lucy (right) ran a marathon and raised over \$1,000 for speech therapy for kids like her friend Charlie (left)

# Revenue

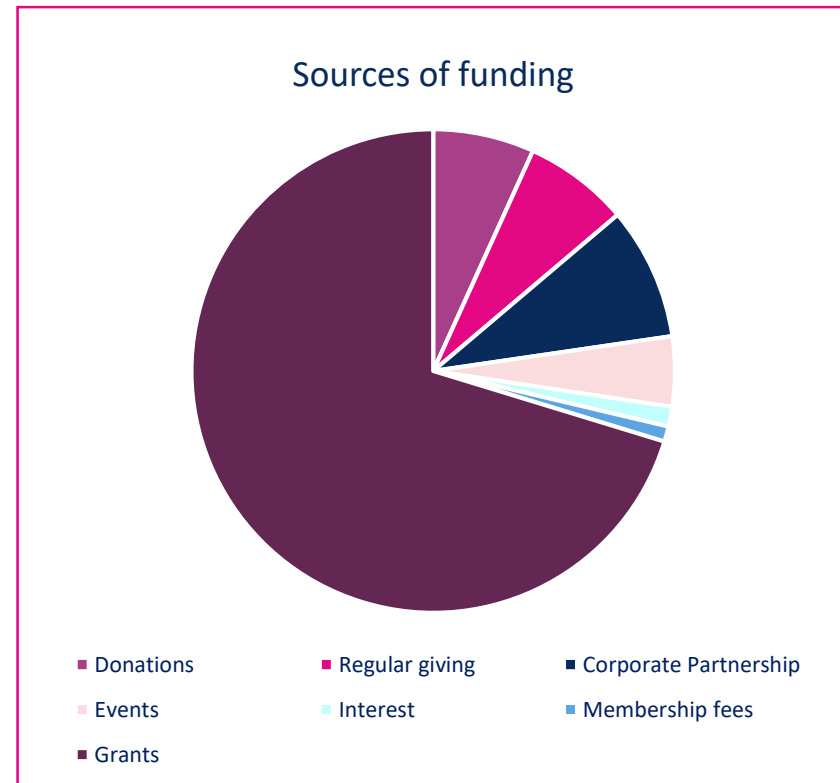
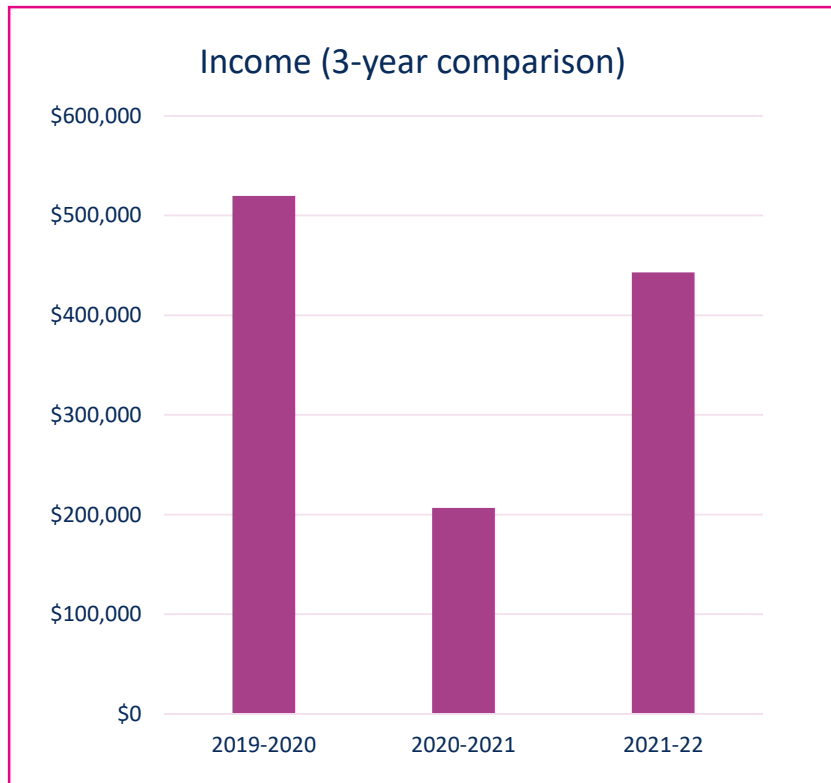
Event income and interest continue to be affected by COVID-19, which has also limited the options for diversifying our income to be less reliant on one-off grants. However, income from corporate partnerships and regular giving continue to steadily increase, making our long-term commitment to whānau increasingly solid.

As in the 2019-2020 financial year, the massive impact of the Lindsay Foundation’s generosity can be clearly demonstrated in this graph. The entirety of these grants are recognised in the year in which they are received, however it is helpful to note that their use is ring-fenced for the duration of the membership of the 56 specific children funded by the Lindsay Foundation (see page 10), which is estimated to be an average of just over five years.



# Revenue sources

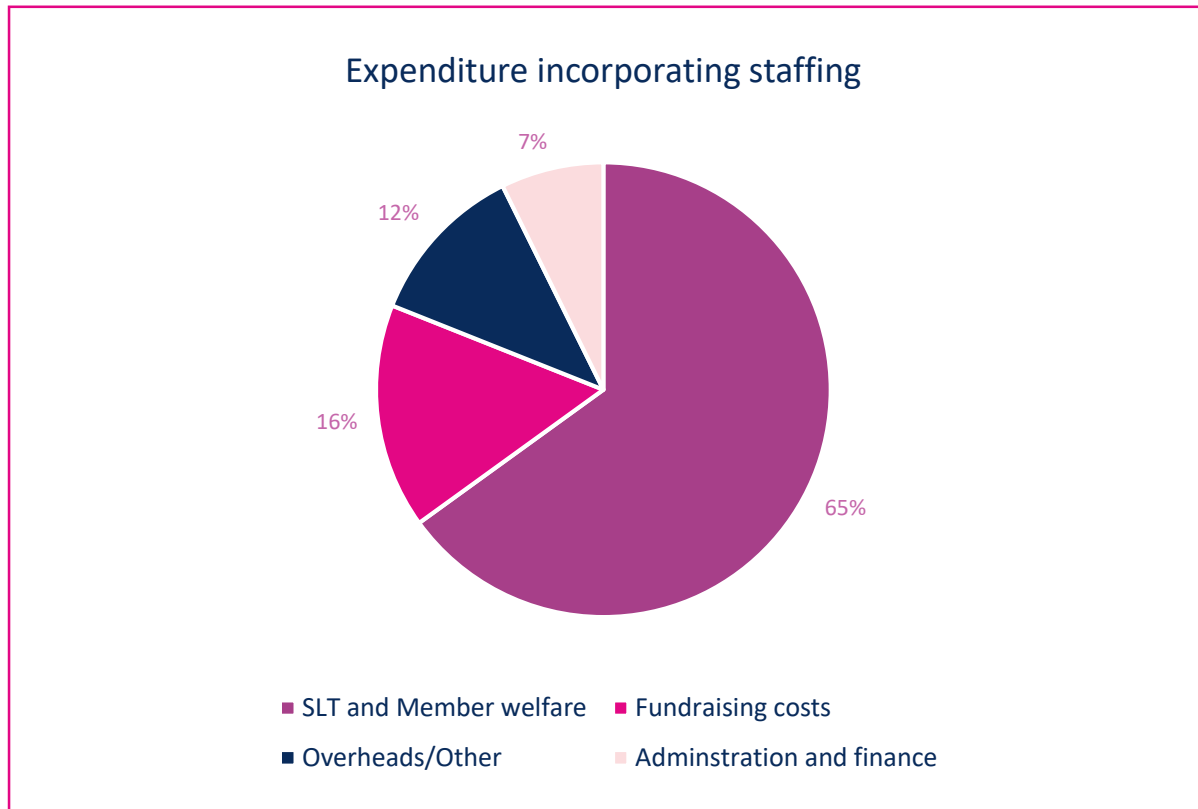
Our income has improved significantly this year, thanks to the Lindsay Foundation, the re-opening of several grants after the initial uncertainties of COVID-19 had ebbed, a tentative return to small-scale events, Government COVID-19 support for businesses, and of course, the addition of a new staff member to support our fundraising. Thanks to all of these things and the generosity of our wonderful supporters, we were able to make up for last years' deficit and to take on an unprecedented number of new whānau, significantly reducing wait time. We are hoping the coming year brings a natural improvement in income diversity, but this will also be a focus for our team going forward.





# Expenditure

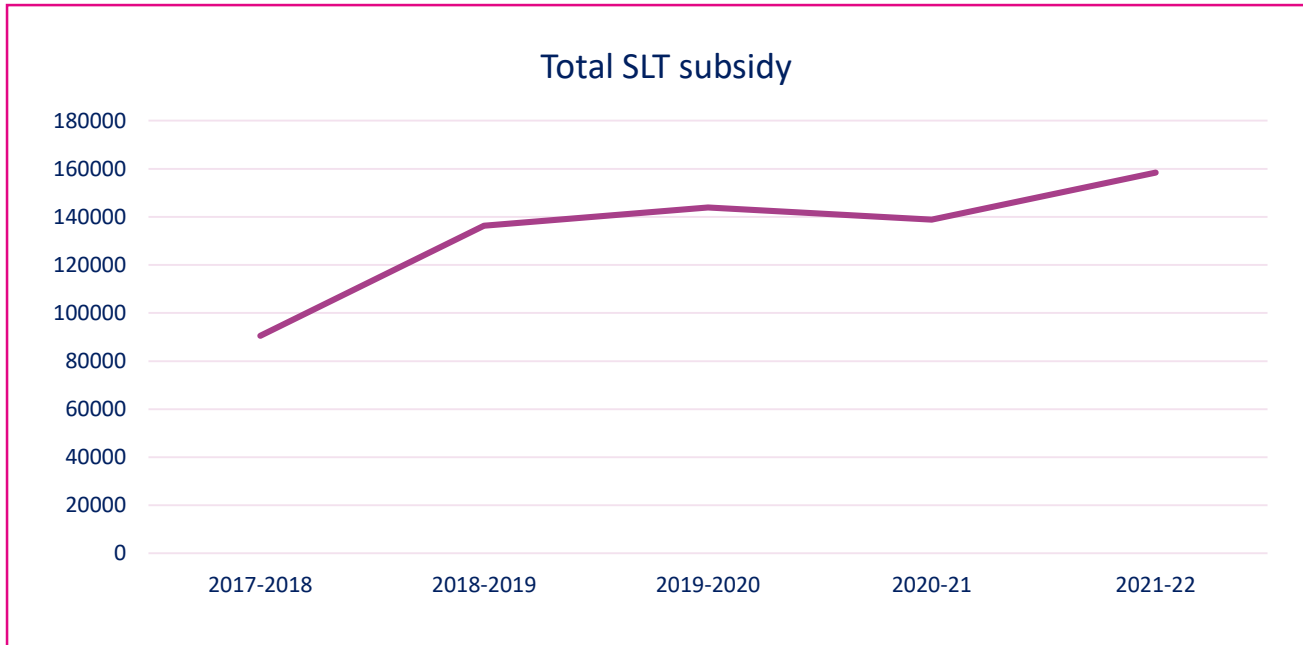
- The graph below demonstrates how our costs break down once staffing is incorporated.
- Speech and language therapy continues to outstrip all other items by a significant margin.



- Having fundraising support has also meant that we have been able to keep up with the workload of our significantly larger membership base.
- This year, member welfare has included expenditure on free counselling for Auckland whānau affected by the death of Lena Harrap, thanks to the support of Foundation North.
- In total this financial year, we spent \$143,968 on speech and language therapy, representing **2527 sessions** with NZSTA-registered professionals. That's just over \$5,000 more than was spent last year, and an additional 224 SLT sessions.

# Expenditure

- The graph below demonstrates the stagnation in the amount we've been able to spend on speech and language therapy, despite the significant increase in membership (and attendant financial planning), as a result of the many sessions cancelled due to lockdowns, and the need to protect a largely immune-compromised population.
- However, it also shows that costs are beginning to return to more in line with what we would expect, due to a reduction in restrictions as well as continued uptake of tele-therapy options.
- With our new premises, we are looking forward to some of these sessions taking place on site, providing an opportunity to further engage with our members as well as to bring costs down for all involved.



Emma (8), in her SLT session

# Financial summary

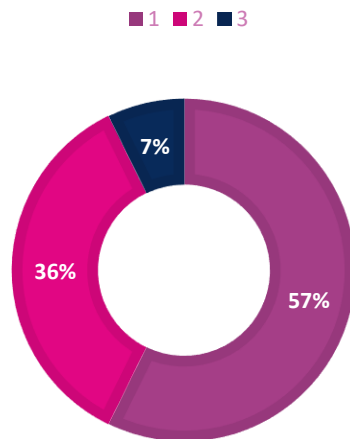
Revenue	2021-22	2020-21
Donations	\$103,185	\$80,757
Fundraising events	\$18,400	\$8,243
Grants	\$311,300	\$107,783
Membership fees	\$4,530	\$3,180
Interest	\$5,838	\$5,641
<b>TOTAL</b>	<b>\$443,253</b>	<b>\$205,604</b>
<b>Expenses</b>		
Speech and language therapy	\$160,979	\$138,811
Fundraising	\$4,432	\$4,265
Staff salaries	\$117,985	\$94,468
Overheads/Rent/Other	\$30,916	\$20,078
Outreach	\$1,909	\$2,260
<b>TOTAL</b>	<b>\$316,221</b>	<b>\$264,147</b>
<b>NET SURPLUS (DEFICIT)</b>	<b>\$127,032</b>	<b>(\$54,277)</b>

This year's encouraging surplus consists primarily of funding ring-fenced for future financial years, but it does also restore us to our target of reserve funding following last year's deficit.

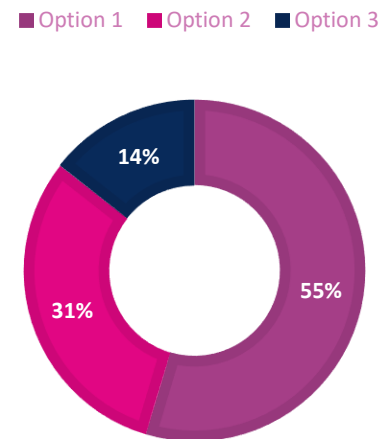
# Subsidy options

- These graphs show us how families chose to use their speech and language therapy funding over the last financial year.
- Option 1 (50% of SLT costs up to \$2,000 a year) continues to be the most popular for families, enabling their children to attend sessions fortnightly on average.
- The most significant change is in the number and percentage of whānau utilising Option 3, our special financial hardship option, in which we pay 100% of SLT costs directly to the therapist. This has increased from 6% in the 2019-20 financial year (10 children) to 14% (39 children) at the conclusion of the 2021-22 financial year, reflecting the ongoing success of our Outreach programme.
- We are hopeful that this year's increase to the annual caps for all funding options will enable greater frequency of attendance for families of all budgets going forward.

## Funding Options 2020-21



## Funding Options 2021-22



# Our team 2021-22

## Volunteer Trust Board

- Chris Steenson – Chairperson
- Paul Batters – Treasurer
- Pooja Sundar – Secretary
- Andree Pearson – South Island Representative
- Tom Pedlar
- Nick Ling
- Viv Alborough
- Sally Rayner
- Abhinav Sridhara
- Phil Venables
- Ainslie Templeton
- Trevor Alborough
- Connie Rivas – Board Shadow (PWC)

At our AGM in June 2021, we were thrilled to welcome Abhi, Ainslie, Phil, and Trevor to the Board, all of whom bring a wealth of experience and previous volunteering for UpsideDowns to the table.

After 7 years' dedicated service, Paul Batters is handing the Treasurer reins over to Pooja as the financial year concludes. We are also saying mā te wā to Ruth, Nurain, and Karmen, who have stepped down from their Board positions. Enormous thanks is due to all four for their commitment over the years.

From January 2021 to April 2022, Ella Pooley did a spectacular job of establishing the new role of Fundraising and Digital Media Manager. We will miss her immensely as she begins new adventures overseas, but we're very pleased to welcome Adrian Hatwell to the role, who has a wealth of excellent experience and skills that are already making their mark.

## Staff

- Sarah Paterson-Hamlin – Chief Executive Officer (and dishwasher)
- Bea Traub – Administrator
- Ella Pooley - Fundraising and Digital Media Manager (outgoing, April 2022)
- Adrian Hatwell – Fundraising and Digital Media Manager - (incoming, March 2022)



(From left) Nick, Tom, Abhi, and Pooja at the 2021 Quiz

# Premier community sponsors 2021-22

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# Major community sponsors 2021-22



*Managed by Public Trust*



# Events in 2021-22

Within 2 weeks of this past disrupted year, we managed to squeeze two excellent events.

## Quiz Night 2021

- Our first in-person event in nearly 2 years, we held a slightly different-looking Quiz to in the past, enlisting the help of our friends at Browne St, Avondale.
- Tickets were sold out over a month in advance, and the evening itself did not dissappoint.
- Thanks to raffle tickets, auction items, and contributions from drinks sales thanks to Browne St, we were able to raise nearly \$10,000 at an incredibly low cost, making this event a similar net revenue to our more traditional 'DIY' quiz evenings from the before-times.

## Barrett brothers and Eden Park sponsors event

- Only 12 days later, and organised in record time after a unique opportunity arose, we were hosting a new kind of event for us – a gathering and celebration of some of our amazing supporters.
- Beauden, Jordie, and Scott Barrett joined our staff, Board members, and some of their children, to host representatives from half a dozen organisations that make our work possible and who were able to make it along with relativley short notice.
- Eden Park, led by their CEO and friend of the Trust, Nick Sautner, provided the venue, food, and drink entirely for free, with Nick himself guiding the group down to the pitch through the players' entrance, where kids and adults alike enjoyed a kick-about with the Barrett brothers under the floodlights. It was truly an unforgettable experience, and a real highlight for all present.



Quiz Night at Browne St



Scott Barrett and UpsideDowns' member, Josh, play rugby at Eden Park

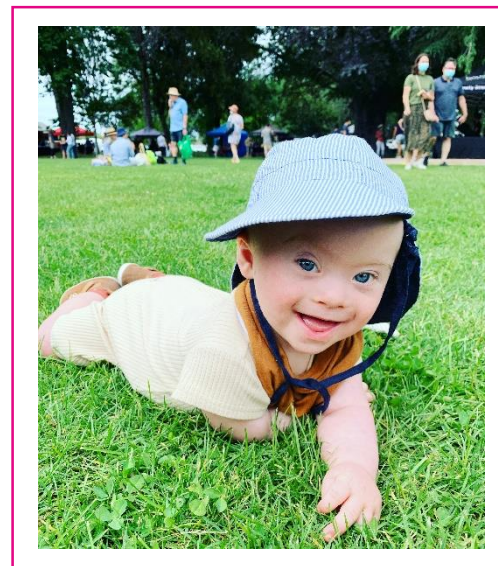


# Some messages from our whānau

If you are reading this report, you are probably a supporter of our little charity in some way, shape, or form. What better way to express our appreciation to you than by signing off with some of the incredible feedback we received from our families this year!

“It's so surreal to hear him like that. I'd almost resigned myself to never hear him clearly. I know it's not perfect but from where he comes from... it's huge.”

“Such a breakthrough in his communication. Definitely seeing progress with the input from Kristen, which will be truly life changing for Sam. Thanks again for connecting us, she is amazing, and of course for the funding we receive from Upside Downs. Private SLT would never have been an option otherwise.”



“We are so very thankful for the opportunity to give our daughter the best chance we can with speech therapy through your amazing support.”

“The difference this is making in Matthew's life and our family's life is extraordinary. I will be forever grateful for you and your team to be able to provide regular speech language therapy to Matthew, which wouldn't have been possible without you.”

“Ensuring they have ongoing opportunities to improve their communication skills and their speech is something we owe our children. With the help of UpsideDowns we have been able to hold up our end of the bargain.”