



**UpsideDowns**  
education trust

# ANNUAL REPORT

2020-21

# Contents

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1. A message from the Chairperson
2. UpsideDowns in 2021 at a glance
3. Children supported by UpsideDowns
4. Covid-19: challenges and upsides
5. Corporate partnership
6. Outreach
7. Individual donors
8. Revenue
9. Expenditure
10. Financial summary
11. Subsidy options
12. Our team
13. Community sponsors
14. Events
15. Some messages from our whānau

# A message from the Chairperson

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Welcome to our 2020-21 annual report. We hope this document provides some insight into our year gone by & provides information on the Trust, our plans & our activities.

## **The Trust's activities**

The UpsideDowns Education Trust exists to support families to provide speech therapy for kids with Down syndrome. Even with the challenging year we have all faced in 2020-21, we have again been able to increase the number of families that we support. As of April 2021, we provide funding for 232 families, that is around 25% of kids in New Zealand with Down syndrome and is an achievement we should all be proud of. It is always a fantastic feeling to admit new members into our community and we are incredibly grateful to all our supporters who have enabled us to do this.

## **Events**

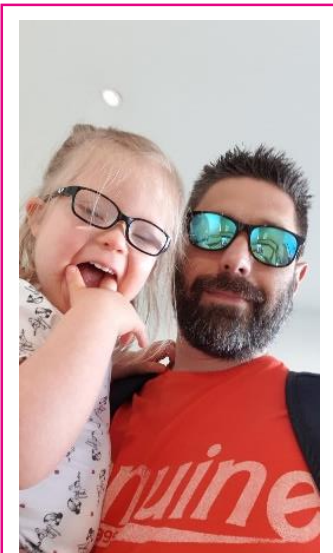
2020-21 was understandably quiet on the events front, as we entered the financial year in Alert Level 4. We managed to embrace technology and run a successful virtual fundraiser many of you were part of. We have also confirmed we're holding a Quiz night in late July – this is incredibly exciting and we look forward to catching up in person. We have more plans for later in the year for at least one more in-person event so keep an eye on our social media channels.

## **Corporate partnerships**

Over the past year, UpsideDowns has active partnerships with ten businesses. All of them support us in different ways and they are acknowledged later in this document. If you have the chance to support any of these great businesses, we hope you are able to do so.

## **Other supporters**

The Trust also continues to be the beneficiary of hugely generous support from a range of other organisations and individuals. We are incredibly lucky to be able to continue to diversify our income stream which puts the Trust in a financial position to grow the support for families that we have not been able to consider before.



New Board  
Chairperson, Chris  
Steenson, with  
daughter, Chloe

# A message from the Chairperson

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## **Financial situation**

In 2020-21 we unfortunately saw an (understandably) significant drop in revenue due to Covid-19. Thankfully, many of the grants received in the previous financial year were ring-fenced to enable continued multi-year support for families. Being a small Trust, it is a constant challenge to balance the ongoing financial commitment that we make every time we begin the long-term support of an additional family due to the mostly one-off and uncertain nature of our major income streams. One consequence is that we are conservative about the number of families that we can support. The generosity of our donors and supporters in 2020-21 has again given us the confidence to grow the number of families that we support. We would particularly like to acknowledge the ongoing generosity of the Lindsay Foundation, who are now funding 56 of our members. Their donations were given either side of this financial year, but look out for further detail on this in our next Annual Report!

## **People**

As in previous years, we have seen some changes on the UpsideDowns board. Adam Barker has stepped down after an impressive tenure, including 7 years as Chairperson. You may have noticed the picture was different at the beginning of this report and I'll admit they have been some pretty big shoes to fill. We were devastated at the passing of Glenn Beaman in late 2020 shortly after his resignation from the Board after 18 months of service. Glenn was the beloved father of one of our members, Tiah. Nurain Janah has made the decision to step down from the board this year. We'd like to thank Nurain for her valued contributions to the board and are grateful to be able to continue to call upon her in an advisory capacity. I would like to personally thank the rest of the board, Sally Rayner, Pooja Sundar, Karmen Wilson, Viv Alborough, Andree Pearson, Nick Ling, Paul Batters, Ruth Young and Tom Pedlar. Your ongoing contributions are greatly appreciated. As some of you may know, Solitaire Henare, our Outreach coordinator has accepted a full time role outside of the Trust. Thank you Solitaire for your contribution over the last 3 years to enable us to support families we may not have otherwise been able to. Finally I would also like to acknowledge the amazing work that Sarah Paterson-Hamlin, Beatrice Traub and Ella Pooley do for the Trust. Their professionalism and dedication in the face of adversity over the last year has ensured the success of the Trust. This makes the job of the board an easy one and we continue to grow our support of kids with Down syndrome.

## **Getting involved**

I, along with rest of the board, hope that you will get involved with the Trust. You can assist us by donating items for us to auction at our fundraising events and encouraging your friends to attend with you. We'd also appreciate introductions to potential corporate partners as we'd love to grow our corporate engagement. We hope you will continue to support us to fulfil our core mission – to increase the communication, independence, and confidence of Kiwi kids with Down syndrome.



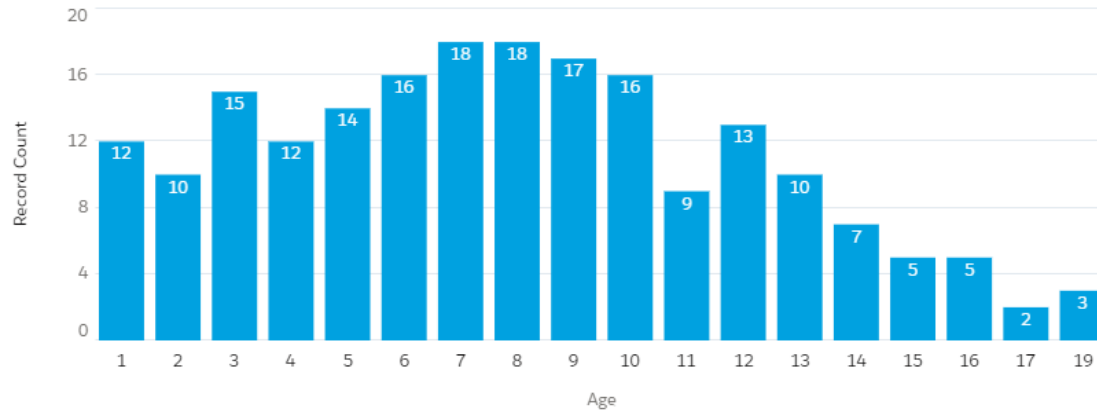
# UpsideDowns in 2021 at a glance

- It is now **18 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 2021, we are funding the speech and language therapy of **232 children**.
- Our waitlist at time of writing is **21 children**.
- These children range in age from **birth to 20 years old**, with the majority being of primary school age.



Aria and Toby are 2 new members

- The average time spent on our waitlist in 2020-21 was **5 months**
- In total, **26 new families** were given funding for their child's speech and language therapy last financial year (plus 30 more in April 2021!!).
- The average age of an UpsideDowns member remains consistent at **7 years old**.

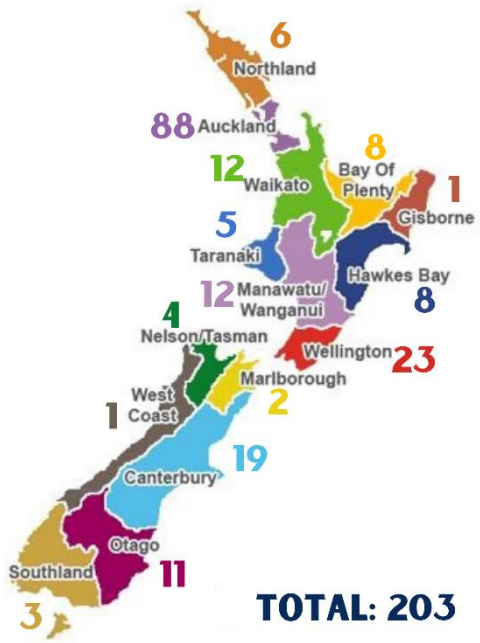


# Children supported by UpsideDowns: regions

Children supported by UpsideDowns by region  
March 2020

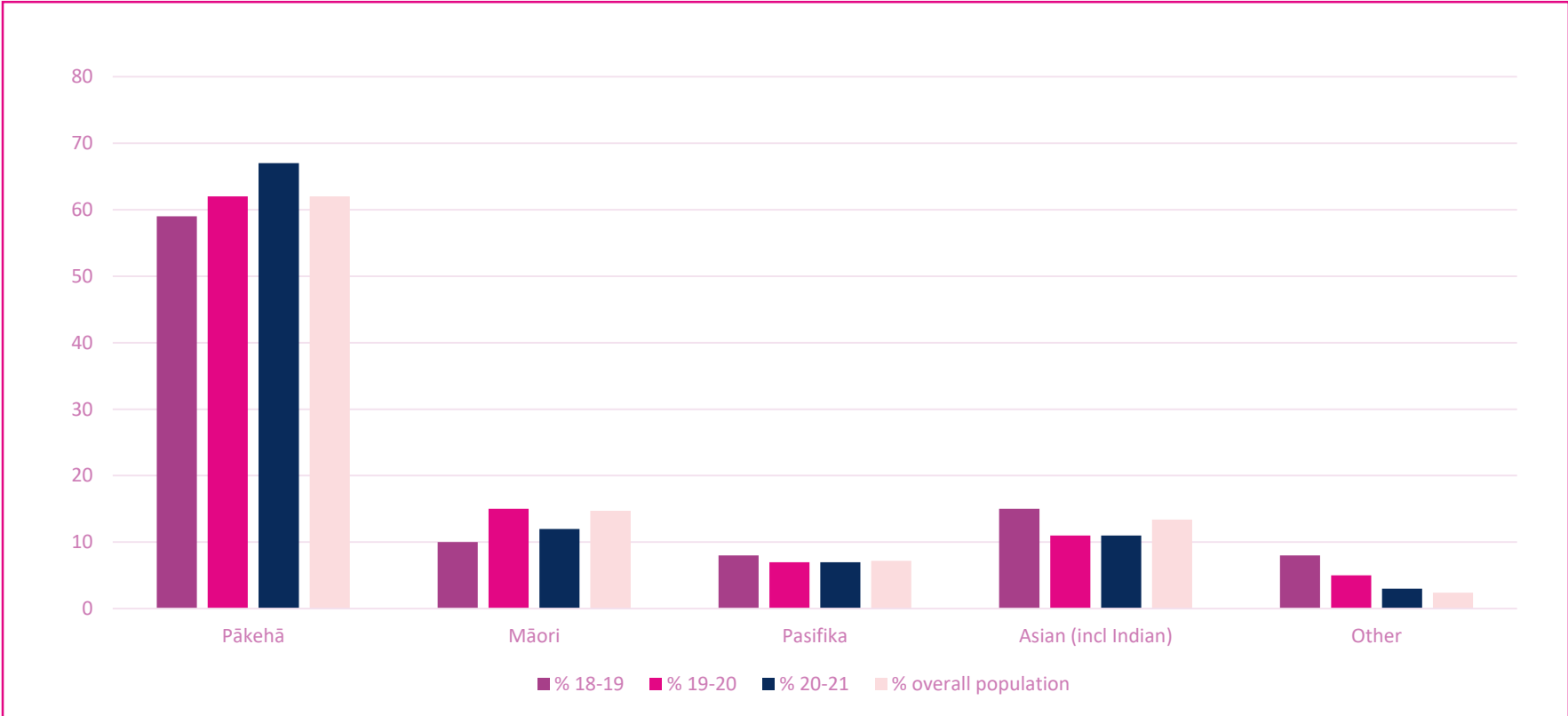


Children supported by UpsideDowns by region  
March 2021



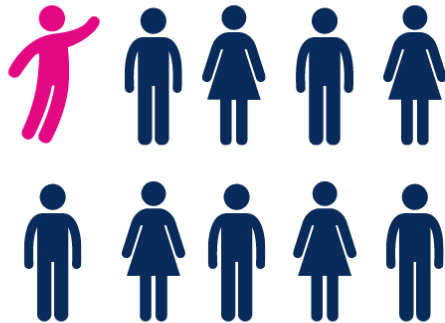
# Children supported by UpsideDowns: ethnicity

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

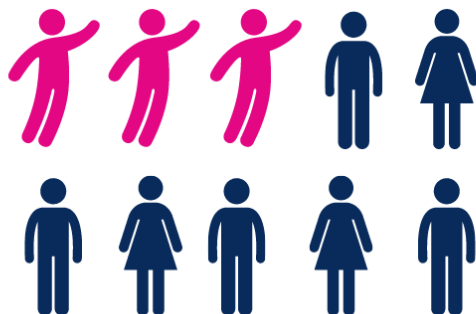
2016



*11% kids with  
Down syndrome  
funded*



2021



*28% kids with  
Down syndrome  
funded*



# Covid-19 – the challenges

- This past year has clearly been one like no other, for UpsideDowns as for the world. We feel very fortunate at UpsideDowns to have been concluding our best fundraising year ever in March 2020, just as the world began to lock down and the future become increasingly uncertain.
- It was thanks to this that we were able to reassure our families that their funding was secure, and to continue operations without cutting any core costs. However, it did mean that we were able to take on as many new families this year as we had hoped.
- As you will see in the later financial section of this report, UpsideDowns did make a loss of just over \$50,000 this year, in keeping with the revenue we would usually expect from the fundraising events we have had to forgo.
- Our fundraising events are not only a means of ensuring we can fund speech therapy for our members, but also an important touchstone for the community and our team. We are therefore very excited to be able to organise events for 2021!
- If you are familiar with our annual reports, you will notice a leaner community sponsors section than usual, as many grantors had to cancel or postpone their grant rounds as a result of Covid-19. We are hopeful that some of the funds we have been able to access in the past will re-open, and many already have, but we also accept the reality that some of these avenues are permanently curtailed.
- UpsideDowns, like many charities, has to fundraise a year or more in advance for their expected upcoming costs, with funds coming through each financial year predominantly being utilised in the following financial year. As a result, we did not qualify for the initial wage subsidy, despite losing a significant amount of income as a result of the lockdown in the months that followed. This was feedback that many charities provided to the Government, and later wage subsidies were accordingly altered (see next page).



# Covid-19 – the upsides

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- Every day of Alert Levels 4 and 3, Sarah (and her kids) released a short video introducing a different Makaton sign. These were a fun way to keep in touch with our members, and provide some (hopefully educational) entertainment. These are now collected as a Youtube playlist on the UpsideDowns channel.
- We maintained contact with the Ministry of Education to ensure that special education needs were not being ignored during lockdown, and received confirmation of the Ministry's directives to schools regarding the distance learning needs of children with intellectual disabilities.
- Thanks in part to ours and others' feedback from the original wage subsidy, we were able to receive the Covid-19 Resurgence Support Payment and the March 2021 Wage Subsidy due to significant Covid-related decreases in revenue on previous years. We are very grateful to MSD and the IRD for their user-friendly and efficient application processes.
- During Alert Levels 2-4, we were able to waive our usual policy and covered cancellation charges for therapy sessions.
- One major upside of Covid-19 for our whānau has been the dramatic increase in availability of remote speech therapy (tele-therapy). This has been of particular benefit to our rural members, some of whom have been able to access SLT for the first time as a result.



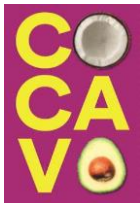
Sarah,  
Lonan  
and baby  
Ezra in  
one of  
their  
lockdown  
videos

- The process of establishing better tele-therapy options for our whānau in the initial stages of the pandemic led to much more direct contact with the 50 or more speech therapists we work with, and has accordingly developed much stronger relationships and better understanding between us.
- Overall, we feel incredibly grateful to have experienced the last year in Aotearoa and under the circumstances we were in by March 2020. However, we're certainly glad to be welcoming a post-Covid era!

# Corporate partners 2020-21

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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

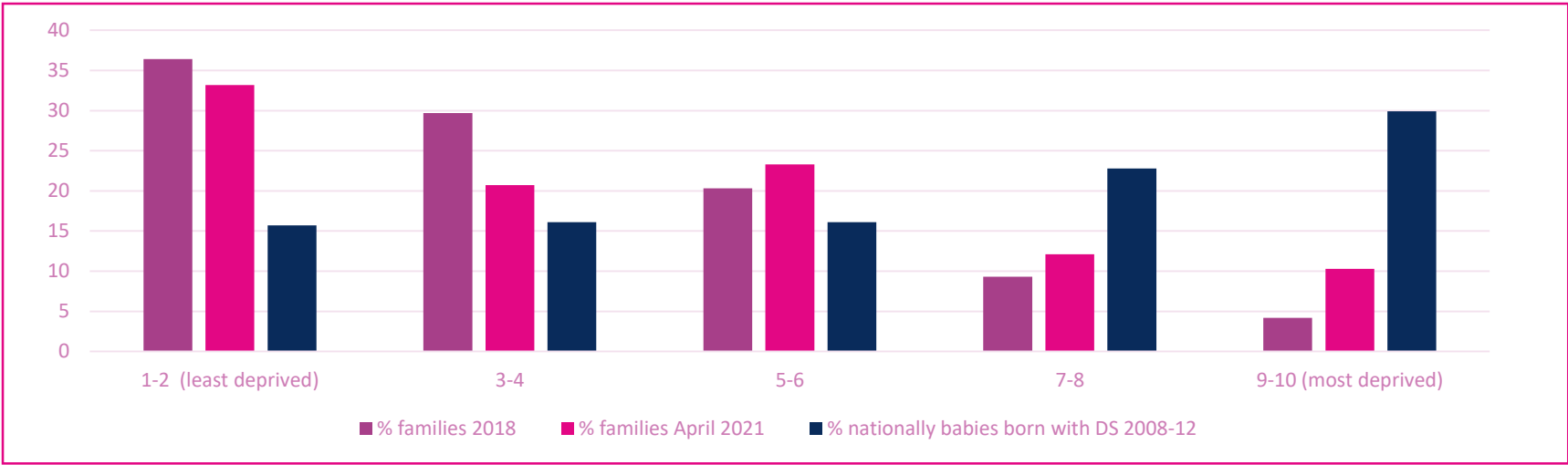
Corporate partnerships are a great way for the not-for-profit and the private sector to work in tandem to the advantage of both. UpsideDowns can provide a business with great promotional opportunities, and staff with a real connection to the amazing children we support. Email [sarah@upside-downs.co.nz](mailto:sarah@upside-downs.co.nz)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



Some of the Powershop team collecting in Masterton for UpsideDowns – this was the fourth attempt thanks to Covid – but we made it!!

# Outreach

- The Outreach project continues to improve the equity of UpsideDowns’ operations. The graph below shows that we continue to make slow but steady improvements in increasing access to speech and language therapy for children with Down syndrome from New Zealand’s most deprived communities.
- Our special funding option for families facing financial hardship (Option 3) is now used by 21 families – a major increase on last year’s total of nine families. Many other families have become members as a result of Outreach efforts, even if they are on Options 1 or 2.
- Unfortunately, our wonderful Outreach Coordinator, Solitaire Henare, had to leave us this year for a full-time position with the Ministry of Health. We have benefitted so much from her wisdom and hard work since 2018, and she will be missed.
- We have also not received a further instalment of funding from the Hugo Charitable Trust this year, which was how the project was able to take place. As a result, we will not be hiring a replacement for Solitaire at this stage, although our Outreach efforts are continuing, and we are working with organisations such as Te Kōhanga Reo National Trust, Taikura Trust, Vaka Tautua, The Asian Network Incorporated, and as many DHBs as we are able.





# Individual donors in 2020-21



- Thank you to all of the generous One Percent Collective donors who choose UpsideDowns as one of their charity partners.
  - There are now 237 people who give regularly to UpsideDowns as part of the Collective.
  - This represents 47% of our individual donations for the year and 99% of our regular giving!
  - For a better idea of how much this means to us, check out this story: <https://www.onepercentcollective.org/stories/upsidedowns-real-world-impact>
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- We are also so appreciative that the team at One Percent changed their payments from quarterly to monthly from March-July 2020 in order to alleviate the pressures caused by Covid-19 on their partner charities.
  - 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 Reynolds, Heera Kim, and Virginia Vuleta**, our superstar direct regular givers.
  - Thank you to the 112 individuals who gave to us through our website this year.
  - We would like to acknowledge incredibly generous donations from **Dove Electronics, the PWC foundation, LINK Auckland North Shore, Penny Hickson, Rod and Diana Barker, Gerard Sheehy, Mohit Singla, and attendees of the funeral of Glenn Beaman.**
  - And last but certainly not least, thank you to **Suzanne Shaw**, a brilliant volunteer who helps us with our donation receipts.



Luke has now been receiving funding for six years



# 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. The possibilities are endless! These have the added bonus of raising awareness in your community about kids with Down syndrome.
- 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

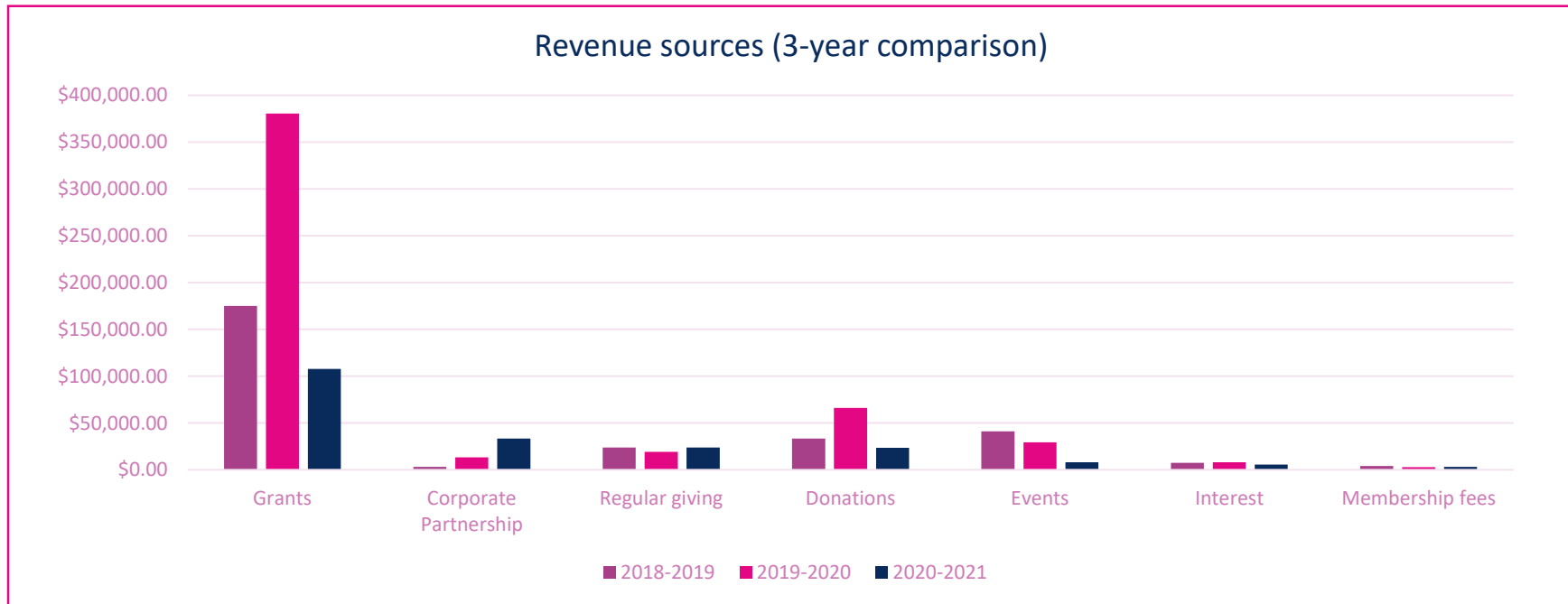


UpsideDowns alumna, Amber, takes a collection at the Black Ferns game.

# Revenue

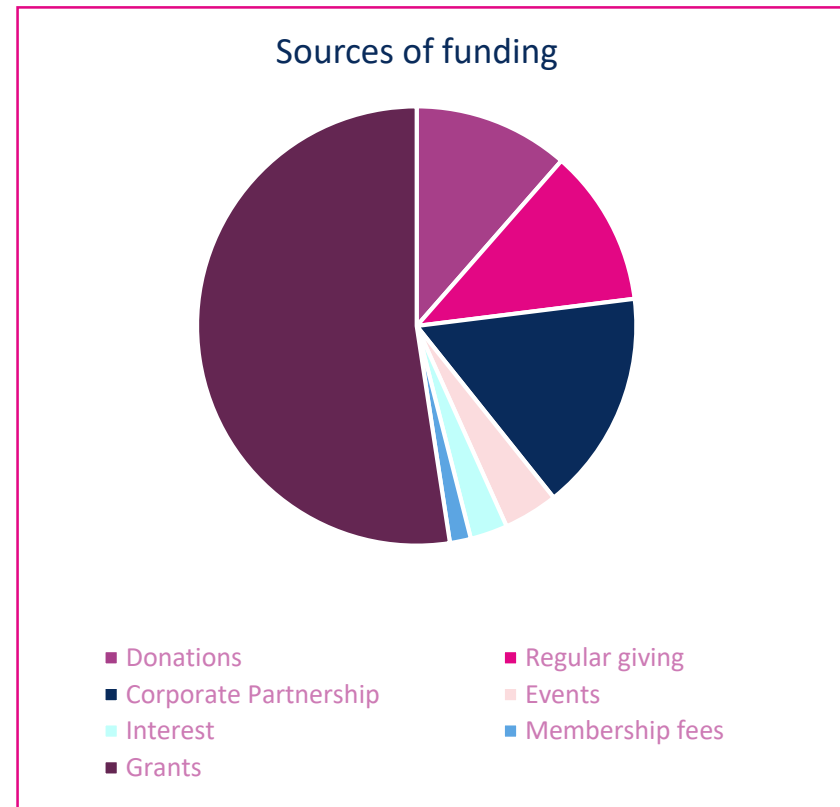
In our last report, we expressed our gratitude for our increasingly diversified revenue streams that relied less heavily on grants and events. After a tumultuous year, we are even more grateful for these developments. Many grants were put on hold or cancelled in 2020, and of course all events had to be indefinitely postponed. Understandably, one-off individual donations also reduced. However, regular giving and corporate partnerships all increased, and the initial lockdown period saw an increase in one-off donations as well, reflecting the positive and generous response of so many New Zealanders to the pandemic.

On the advice of our wonderful, pro-bono auditors at KPMG, we are now recognising grant income in the year it was received, rather than the year it was intended for spending in. This is why 2019-20 grant income appears to have gone up from the 2019-20 report, and why the apparent dramatic dip in 2020-21 grant income is not as concerning as it first appears, though it does reflect the realities of Covid-19 (see p.9).



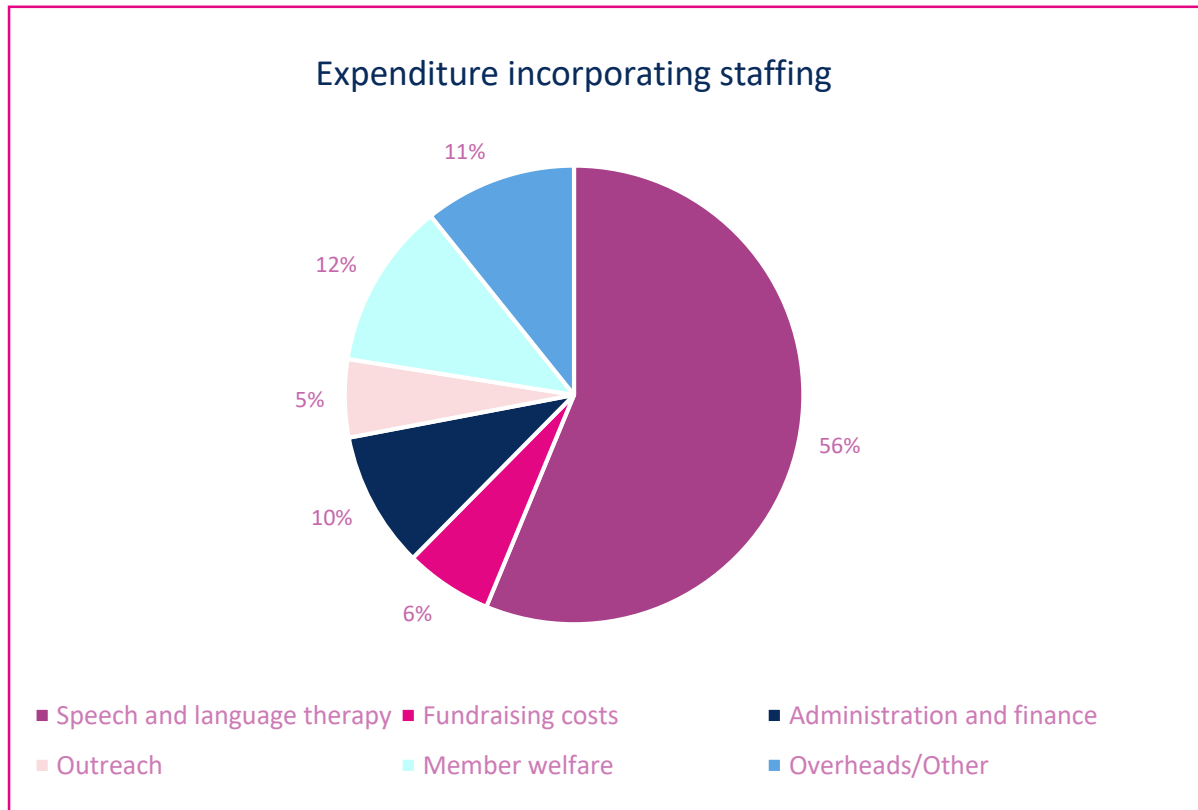
# Revenue sources

This year has seen a significant drop in revenue as a direct result of Covid-19. However, many of the grants awarded in 2019-20 were ring-fenced for the 2020-21 financial year. Our income does continue to diversity significantly on past years, and we hope this will stand us in good stead for what will hopefully be a more 'normal' year to come. Our policy has long been to keep 1-2 years' of operations in reserve for a rainy day, and that prudence has served us well during this pretty rainy Covid-19 period.



# Expenditure

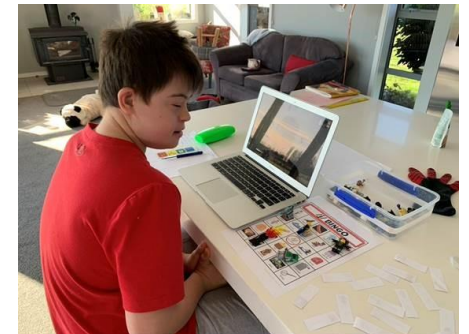
- The graph below demonstrates how our costs break down once staffing is incorporated.
- Speech and language therapy continues to outstrip all other items by a significant margin.
- As our membership has grown, the resources required to maintain our high standard of member welfare has also increased.



- Our efficient fundraising has enabled us to accept 26 new families into membership as well as honouring our commitment to the 195 families in membership at the outset of the year.
- We continue to see an incredibly impressive return on investment for our fundraising activities, with every dollar spent on this bringing in \$13.20 for children with Down syndrome.
- In total this financial year, we spent \$138,811 on speech and language therapy, representing **2,302 sessions** with NZSTA-registered professionals. That's over 100 more than last year, despite all the lockdowns!

# Expenditure

- This graph demonstrates how, despite a significant increase in membership of over 25% in the 2019-20 financial year, spending on speech therapy did not increase significantly.
- Although the primary reason for this is clearly the lockdowns (all of which occurred in the period being reported on), we believe increases in SLT costs to be a part of the landscape.
- This is why the Board are currently engaged in a review of the Funding Options, so that increased costs are recognised as well as realistic limits placed on our resources. Any changes will be announced in advance of 1 April 2022.



# Financial summary

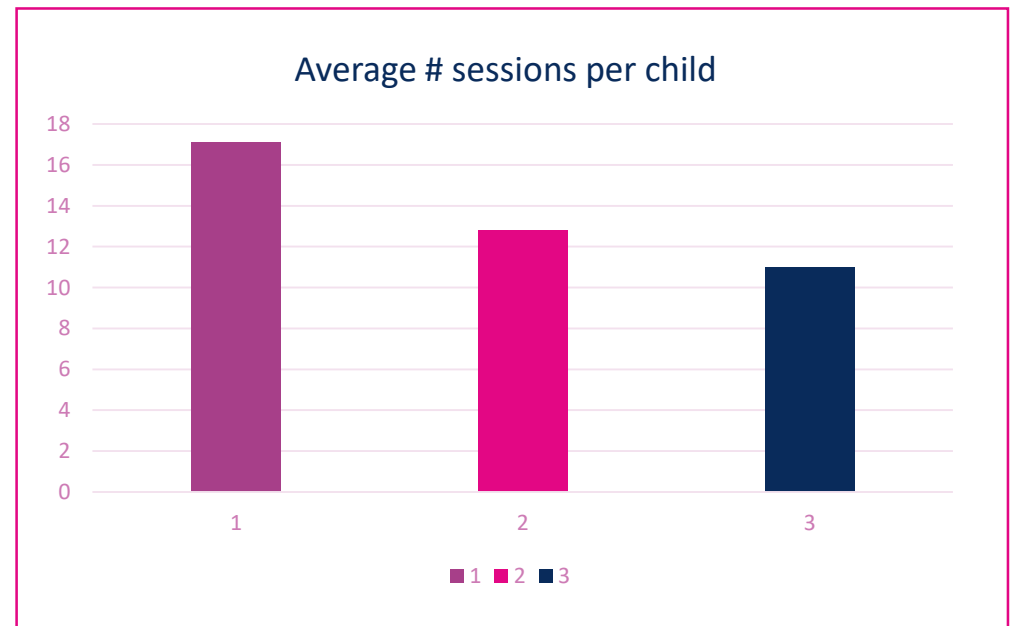
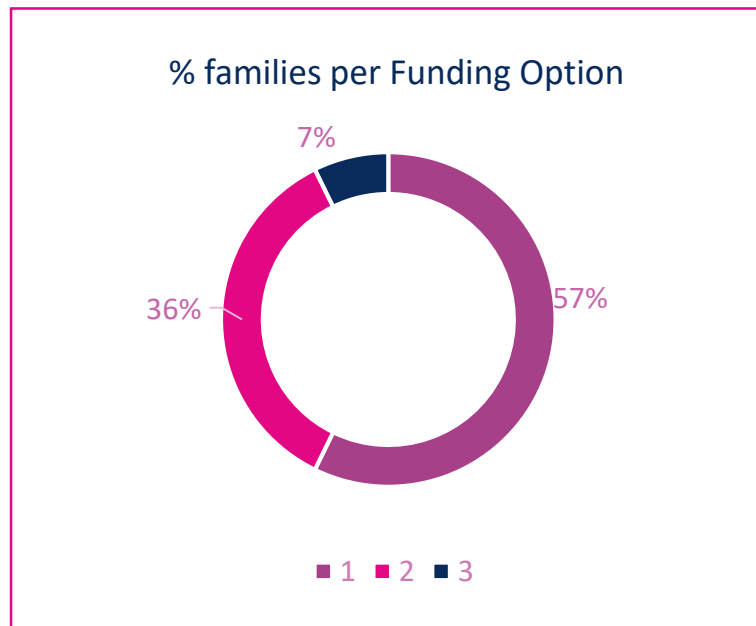
<b>Revenue</b>	<b>2020-21</b>	<b>2019-20</b>
Donations	\$80,757	\$98,934
Fundraising events and calendar sales	\$8,243	\$29,385
Grants	\$107,783	\$380,500
Membership fees	\$3,180	\$2,880
Interest	\$5,641	\$8,135
<b>TOTAL</b>	<b>\$205,604</b>	<b>\$519,834</b>
<b>Expenses</b>	<b>2020-21</b>	<b>2019-20</b>
Speech and language therapy	\$138,811	\$143,967
Fundraising	\$4,265	\$10,619
Staff salaries	\$94,468	\$59,580
Overheads/Rent/Other	\$20,078	\$5,811
Outreach	\$2,260	\$723
<b>TOTAL</b>	<b>\$264,147</b>	<b>\$220,700</b>
<b>NET SURPLUS (DEFICIT)</b>	<b>(\$54,277)</b>	<b>\$309,752</b>

For the first time since 2015-16, we have concluded the year with a deficit. This was both planned and expected, given Covid-19 and the unprecedented success we enjoyed in 2019-20 following the Barrett whānau partnership, though as discussed on p. 19, the total cost of SLT for the year was less than we had hoped for. Adding a new staff member and moving into our own office have also added to our costs.



# 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 number of families utilising our special financial hardship option has increased from 6% last financial year (10 children) to 11% (21 children) at the outset of the 2021-22 financial year, reflecting the success of our Outreach programme. The graph below represents the funding options chosen for the 2020-21 financial year.
- We are hopeful that the planned review of funding options will enable greater frequency of attendance for families of all budgets in the 2022-23 financial year and beyond.



# Our team 2020-21

## Volunteer Trust Board

- Adam Barker – Chairperson (until 31 December 2020)
- Chris Steenson – Chairperson (from 1 January 2021)
- Paul Batters – Treasurer
- Pooja Sundar – Secretary
- Andree Pearson – South Island Representative
- Tom Pedlar
- Ruth Young
- Nick Ling
- Viv Alborough
- Sally Rayner
- Karmen Wilson
- Glenn Beaman (outgoing, October 2020)
- Nurain Janah (outgoing, March 2021)

After nearly a decade of incredible service, including 7 years as Chairperson, Adam Barker stepped down from his role on 31 December 2020. The Trust is so grateful for Adam's steady guidance and remarkable generosity and he will be missed. We are very fortunate to welcome Board member Chris Steenson as our new Chairperson from 2021.

We were devastated at the passing of Glenn Beaman in late 2020 shortly after his resignation from the Board after 18 months of service. Glenn was the beloved father of one of our members, Tiah.



Adam and Kieran



Ella



Chris, Chloe, and Lea

## Staff

- Sarah Paterson-Hamlin – Chief Executive Officer (and dishwasher)
- Bea Traub – Administrator
- Solitaire Henare (ongoing, December 2020) – Outreach Coordinator
- Ella Pooley (incoming, January 2021 - Fundraiser)

Although Solitaire will certainly be missed, we know her new full-time role is a great opportunity for her, and she remains in touch with UpsideDowns.

Ella has been a very welcome addition to the team this year, and we're looking forward to her involvement going forward!

# Premier community sponsors 2020-21

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Joyce  
Fisher  
Charitable  
Trust



# Major community sponsors 2020-21

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**Silk Route Trust**



# Events

- It is with gratitude and a bit of surprise that we are still able to include an events section of this report!

## Probables v. Possibles

- In November 2020, UpsideDowns was recommended as the second partner charity for the Black Ferns Probables v Possibles rugby match. The Possibles team were playing for us, while the Probables represented the Graeme Dingle Foundation (NZ Rugby's official partner charity).
- Our staff and many of our members experienced a fantastic week of joining in with training sessions, presenting playing jerseys to the team members, lining the players' tunnel, and even being given some 'skills and drills' training by some of the Black Ferns! It all culminated in an absolutely thrilling game, in which our team were victorious, winning 28-19!
- AIG presented both us and the Graeme Dingle Foundation with a cheque for \$10,000 at the conclusion of the game – an emotional experience after a tough few months.

## Virtual Mission

- Although Auckland was experiencing Level 3 lockdowns near the time, we couldn't let World Down Syndrome Day in the auspicious year of 2021 go uncelebrated!
- From 21 February 2021 – 21 March 2021 (World Down Syndrome Day), over 100 participants all over the country ran, walked, swam, and prammed in a Virtual Mission all around Aotearoa, from Cape Reinga to Rakiura/Stewart Island and back again.
- Thanks to their efforts, we were able to raise over \$11,000!
- The best part about the Virtual Mission for us, was being able to include and energise members and whānau and supporters from every corner of Aotearoa, not just the main cities as live events require. Thank you to everyone who joined in – we're keen to do it all again so watch this space!



Probables v Possibles



Our virtual running route

# 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! Thank you for being with us for this extraordinary year.

“We have found your service AMAZING!!! Very grateful to the service you provide our family to help Harry learn to talk.”



“Please pass on our thank you to the Trust for the funding that we receive. It really is a game changer for Nikolai to access SLT. The words thank you really don’t cover it as it’s been massive to us as a family to make sure that Nikolai can communicate and participate to the best of his ability. The Trust has been a life line most definitely.”

“Communication is connecting to others and as I watch my son I know how important it is for him to connect.”

“Online lessons so much more effective for Kaden. A great outcome from Covid-19 for us! Many thanks.”

“Thank you so much for your help with Amber’s SLT. She is an amazing communicator thanks to your support. “