



**UpsideDowns**  
education trust

# ANNUAL REPORT

2019 - 20

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# A message from the Chairperson

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Welcome to our 2019-20 annual report. This document is now our fifth in this format and serves to review last year's operations, discuss our plans, and to provide information on the Trust and our activities.

## **The Trust's activities**

The UpsideDowns Education Trust exist to support families to provide speech therapy for kids with Down syndrome. We finished the financial year in March 2020 supporting 200 families. In 2019-20 we have again been able to grow the number of families that we support. 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.

## **Outreach project**

2019-20 was the third year of our Outreach initiative. As previous readers of this report will know, most of our members find out about us through word of mouth, and then approach us for support. One consequence is that many of the families that would most benefit from our support either don't know about us or feel unable to approach us a variety of reasons. The Outreach initiative is our way to address this gap. We have invested in proactively building networks to reach out to families that would benefit from our help. It is fair to say that this has proved even harder than we expected when we started this journey, but we are slowly but steadily making a difference and we are committed to continuing this work.

## **Events**

2019-20 was a quieter year on the events front. We had a planned year off our regular Share the Dream event and, like so many other events, COVID-19 was not kind to our 2020 quiz night plans. We did, however, enjoy a great movie night in early December. We will be back in 2021 and we look forward to seeing you at an event then.

## **Corporate partnerships**

As at March 2020, UpsideDowns has active partnerships with eight 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, I encourage you to do so.



# A message from the Chairperson

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## **Barrett family support and profile raising**

You may have heard of the Barrett family – a few of them play a bit of rugby. In the 2019-20 year we were huge beneficiaries of the support of the entire Barrett family in raising the profile of the importance of speech therapy for children with Down Syndrome and of the UpsideDowns Education Trust. I would also like to acknowledge the amazing efforts of Paddy Gower in raising our profile on Newshub in 2019. The results of the publicity were incredible. Supporters of all kinds reached out to us, and many more families heard about us and have applied to become members. New supporters of UpsideDowns include the Lindsay Foundation, ICAP, Simpson's Flooring Xtra, Powershop, Cocavo, and many generous individuals.

## **Other supporters**

The Trust also continues to be the beneficiary of hugely generous support from a range of other organisations and individuals. I would particularly like to highlight the Hugo Charitable Trust, the Howick Freemasons, the Hugh Green Foundation, the Potter Masonic Trust, the Joyce Fisher Charitable Trust, and the One Percent Collective. Their support in 2019-20 continues to put the Trust in a financial position to grow the support for families that we haven't been able to consider before.

## **Financial situation**

In 2019-20 we again had a solid financial year and reported a small surplus for the fourth year running. As a small Trust it is challenging to balance the multi-year financial commitment that we make every time we commit to support an additional family, with the mostly one-off and uncertain nature of our income. One consequence is that we are conservative about the number of families that we can support.

given us the confidence to grow the number of families that we support and to continue to invest in our Outreach project.

## **People**

As in previous years we have seen some changes on the UpsideDowns board. In 2019 Jason Wong stepped down from the board although he continues to be a huge contributor to the Trust in other ways. We welcomed onto the board Sally Rayner, Pooja Sundar, Glenn Beaman, Karmen Wilson and Viv Alborough. I would also like to recognise the ongoing contributions of Andree Pearson, Chris Steenson, Nick Ling, Nurain Janah, Paul Batters, Ruth Young and Tom Pedlar to the board. I would also like to acknowledge the fantastic work that Sarah Paterson-Hamlin, Beatrice Traub and Solitaire Henare do for the Trust. They make the job of the board easy and we continue to see the evidence of their professionalism and dedication in the success of the Trust.

## **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.



Adam Barker, Chairperson

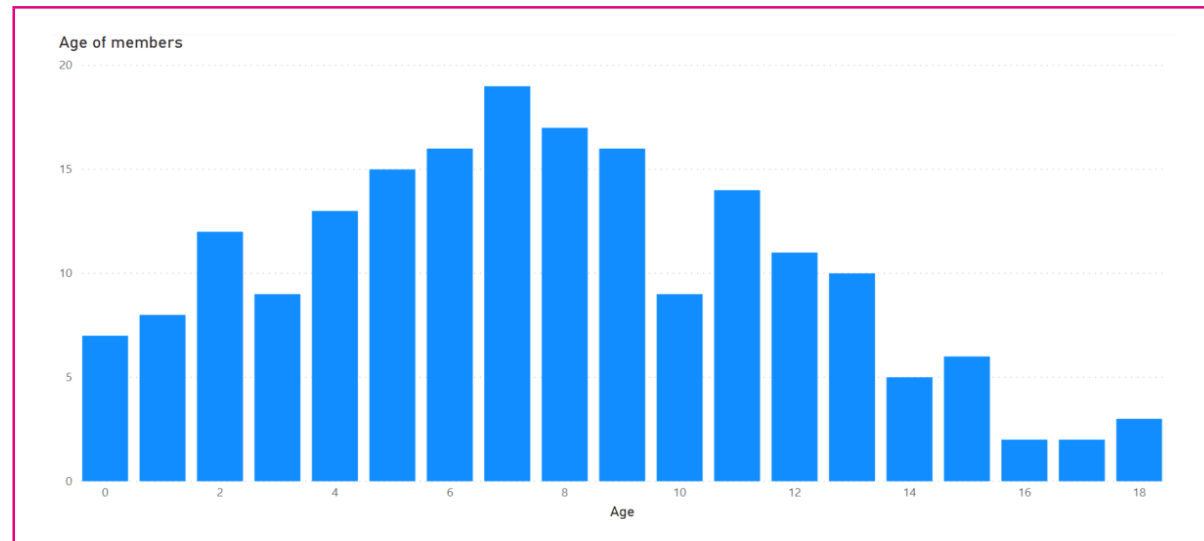
# UpsideDowns in 2020 at a glance

- It is now **17 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 2020, we are funding the speech and language therapy of **195 children**.
- Our waitlist at time of writing is **21 children**.
- These children range in age from **birth to 19 years old**, with the majority being of primary school age.



Kyla is one of 51 new members

- The average time spent on our waitlist in 2019-20 was **four months**
- This year we had our biggest ever intake of **33 children** – there's more information about this on p.11
- In total, **51 new families** were given funding for their child's speech and language therapy.
- The average age of an UpsideDowns member remains steady at just over **7 years old**.



# Children supported by UpsideDowns: regions

Children supported by UpsideDowns by region

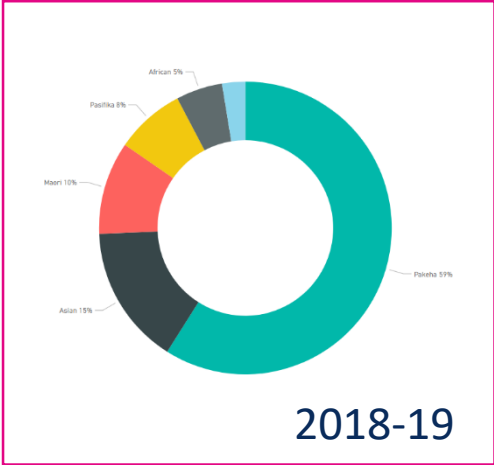
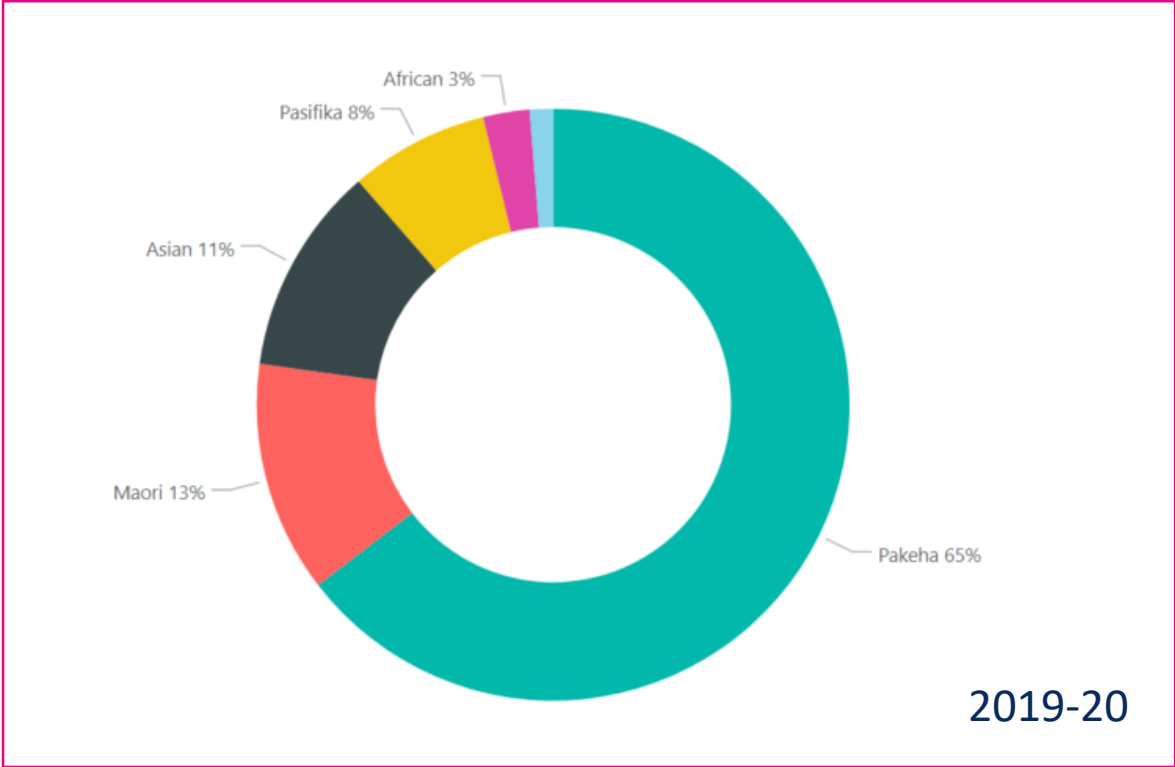


Overall population by region (as a proportion of 195)

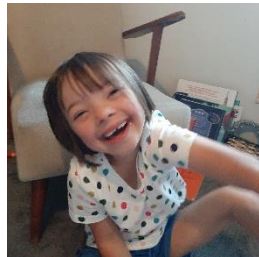
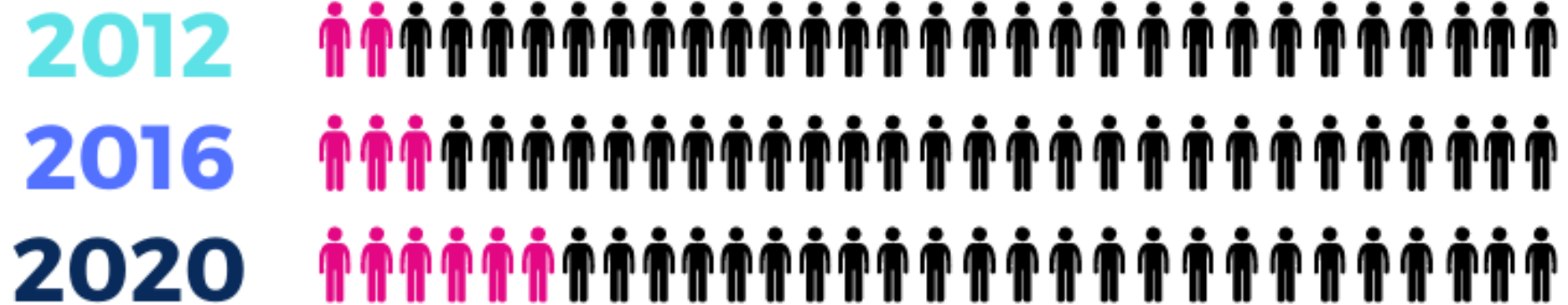


# Children supported by UpsideDowns: ethnicity

The graph below shows the ethnicity of members who joined since June 2018 when we first started including this as an optional section on our application form. We are pleased that this year's graph is closer to the general population spread of New Zealand, and that Māori have become the second largest ethnic group among our members (13%), as it is in the general population (16%).



# Proportion of Kiwi kids with Down syndrome supported by UpsideDowns





# Barrett family support

- In 2019, the Barrett family of Taranaki became game-changing supporters of our charity. Beauden Barrett had long been providing valuable auction items for fundraisers, but this year the whole family stepped up to make an enormous, permanent difference to UpsideDowns.
- Over the first half of the year, we worked with the Barretts, their agents, and Craft Media Workshop to produce high quality videos introducing Zara, the seventh of eight Barrett siblings and the only one rocking an extra chromosome. The videos also promoted the essential work of UpsideDowns, encouraged donations, and spoke of the importance of treating people with Down syndrome equally.
- In mid-2019, Paddy Gower and Newshub got involved, and released two stories on consecutive evenings in August. The result has been extraordinary.
- Our profile as a charity has leapt up, bringing with it increased donations, increased membership applications, and increased understanding from the wider community of the communication challenges facing people with Down syndrome as well as the lack of government support currently in place.
- The next page demonstrates the impact in some of the numbers, but beyond the financial implications, we know this had had a massive impact on how people with Down syndrome are perceived in schools and communities, which has certainly made every ounce of effort worth it.



*“My older boys are walking around the school like they own the place because they have a little sister with Down syndrome, just like the Barrett brothers! They’re very cool to everyone now.”*

*“Heart warming. Powerful. Positive. Inclusive. Beautifully produced. Superb communication. Thank you.”*

*“Loved this story brought a tear to my eye, you can really see the love, what a wonderful cause!”*

# Barrett family support

**\$7,149**

given in one-off donations received in August, compared to an average of \$120 per month.

**214%**

increase of visitors to our website in 2018-19 compared to previous years.

**3 million**

views of the first Newshub article on Facebook alone.

**13**

new regular donors through One Percent Collective, bringing the total to 79.

**14,804%**

increase in Facebook engagement on the UpsideDowns page the week of the articles.

**50**

UpsideDowns members receiving regular, individualised speech and language therapy as a direct result.

# Lindsay Foundation

- The Lindsay Foundation are one of the incredible organisations that heard about us as a result of our exposure this year.
- They came and met with us, listened to the challenges we had, talked about how we work and the difference we make.
- One thing they really took on board was the long-term commitment we make to each family we take off the waitlist – up to twenty years!
- They also understood that, while it was fantastic that the Newshub coverage had alerted many families to our presence, the resulting influx of applications was more than we could currently cope with.
- That's why, in February 2020, they donated an extraordinary **\$160,000** so that we could make a long-term commitment to the 33 children with Down syndrome that were on the waitlist at that time.



*“The Lindsay Foundation’s main focus is to support individuals and organisations who make a positive impact specifically, but not limited to, the areas of animal welfare, children, disabilities and health. Inspiring and lifting those who are making changes.”*

# Events

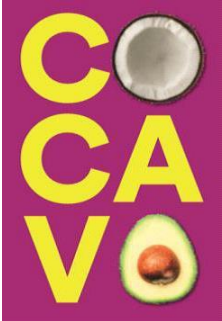
- 2019-20 got off to a great start thanks to the amazing efforts of the Payton family. Otis Payton's Dad, Joe, ran the Hawke's Bay marathon in an incredible three hours and four minutes, placing 28<sup>th</sup> out of 662 runners!! Not only this, but they also raised around **\$14,000** for UpsideDowns!!
- The Allen family were behind a major drive among the team at Simpson's Flooring Xtra in Canterbury and across the country in the wake of the Barrett family publicity, raising **\$3,600**!
- Having held Share the Dream in March at the tail end of the 2018-19 financial year, and with our Operations Manager on maternity leave for part of the year, we only ran one fundraiser ourselves in 2019-20, our famous annual Quiz Night!
- The Quiz night theme this year was Superheroes and it was held at our wonderful regular venue of Gladstone School Hall in November rather than our traditional winter timing due to that maternity leave.
- Over 100 people came along, quizzed beautifully, dressed even more beautifully, and raised around **\$14,000**!
- Just before Christmas, former Board Member, Jason Wong, and newest Board Member, Sally Rayner, organised a special advanced screening of the new film, Peanut Butter Falcon, as a fundraiser for UpsideDowns.
- The event brought the community together to enjoy this very special film starring Zack Gottsagen, and raised over **\$4,000** for the Trust!



# Corporate partners

This year, UpsideDowns developed relationships with more businesses than ever before, as well as continuing to work with some fantastic familiar friends. These partnership are rich in their variety, with contributions including auction items, percentages of sales, venues, scholarships, calendar printing, promotions, and of course, those much-needed funds for speech therapy!

Here are all the wonderful corporate partners UpsideDowns worked with this year. 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

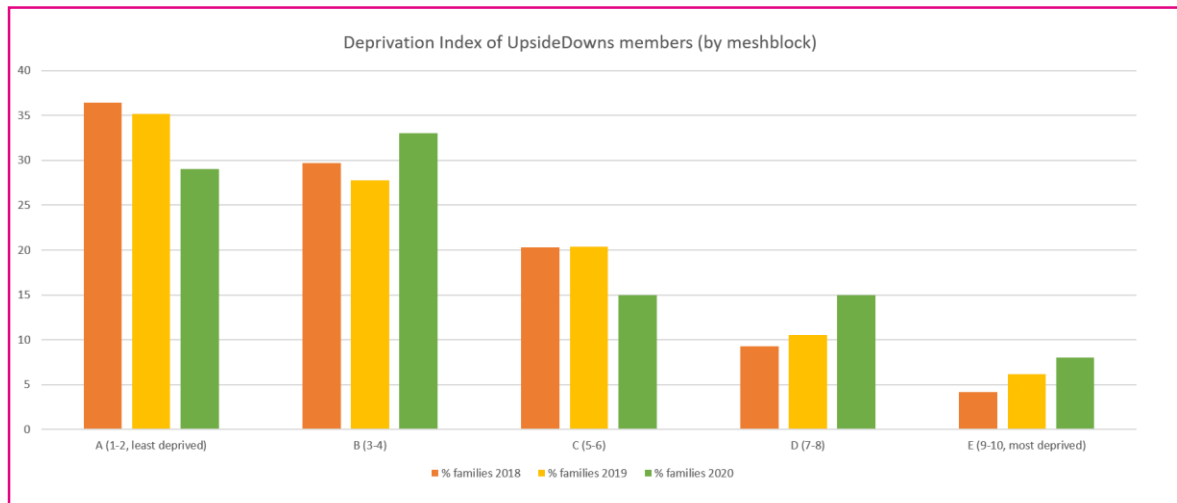
Corporate partnerships are a great way for the not-for-profit and the private sector to work in tandem to the advantage of both. UpsideDowns can provide a business with great promotional opportunities, and staff with a real connection to the amazing children we support. Email [sarah@upside-downs.co.nz](mailto:sarah@upside-downs.co.nz)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



The team at ICAP on their annual charity day, with Emily Grace and her big sister, Bella.

# Outreach

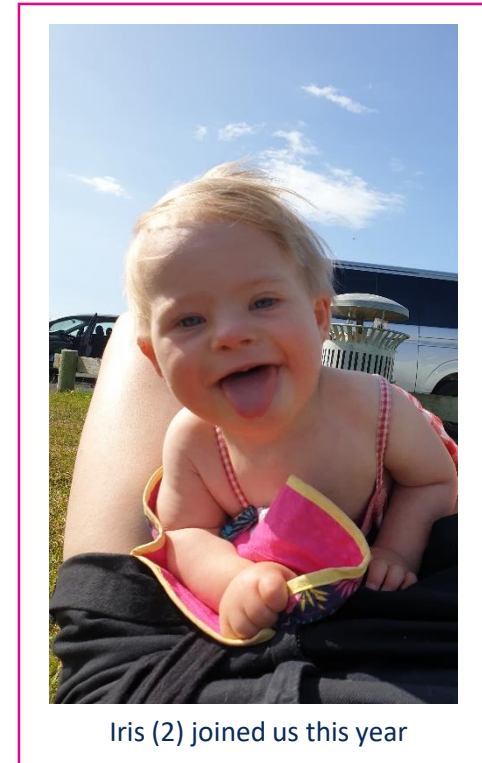
- The Outreach project continues to improve the equity of UpsideDowns' operations. The graph below shows that we are making slow but steady improvements in increasing access to speech and language therapy for children with Down syndrome from New Zealand's most deprived communities.
- Our special funding option for families facing financial hardship (Option 3) is now used by nine families, five of whom were new to UpsideDowns in 2019-20. Many other families have become members as a result of Outreach efforts, even if they are on Options 1 or 2.
- As demonstrated by the graphs on p.7, the ethnicity of members who came on board since 2018 is now also more reflective of New Zealand's population.
- Being able to provide information in relevant languages to community groups and different networks has been very valuable, and our Outreach Co-ordinator, Solitaire Henare, has done great work spreading the word about UpsideDowns among families who would otherwise not have received this support.



# Individual donors in 2019-20



- Thank you to all of the generous One Percent Collective donors who choose UpsideDowns as one of their charity partners.
  - There are now 179 people who give regularly to UpsideDowns as part of the Collective.
  - This represents 26% of our individual donations for the year and 98% of our regular giving!
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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 193 individuals who gave to us through our website this year – an all-time high!!
  - Plus all those who supported fundraisers, wore mufti, bought auction items, had their cars washed, and anything and everything else. You're all making an incredible difference!



Iris (2) joined us this year



# 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?

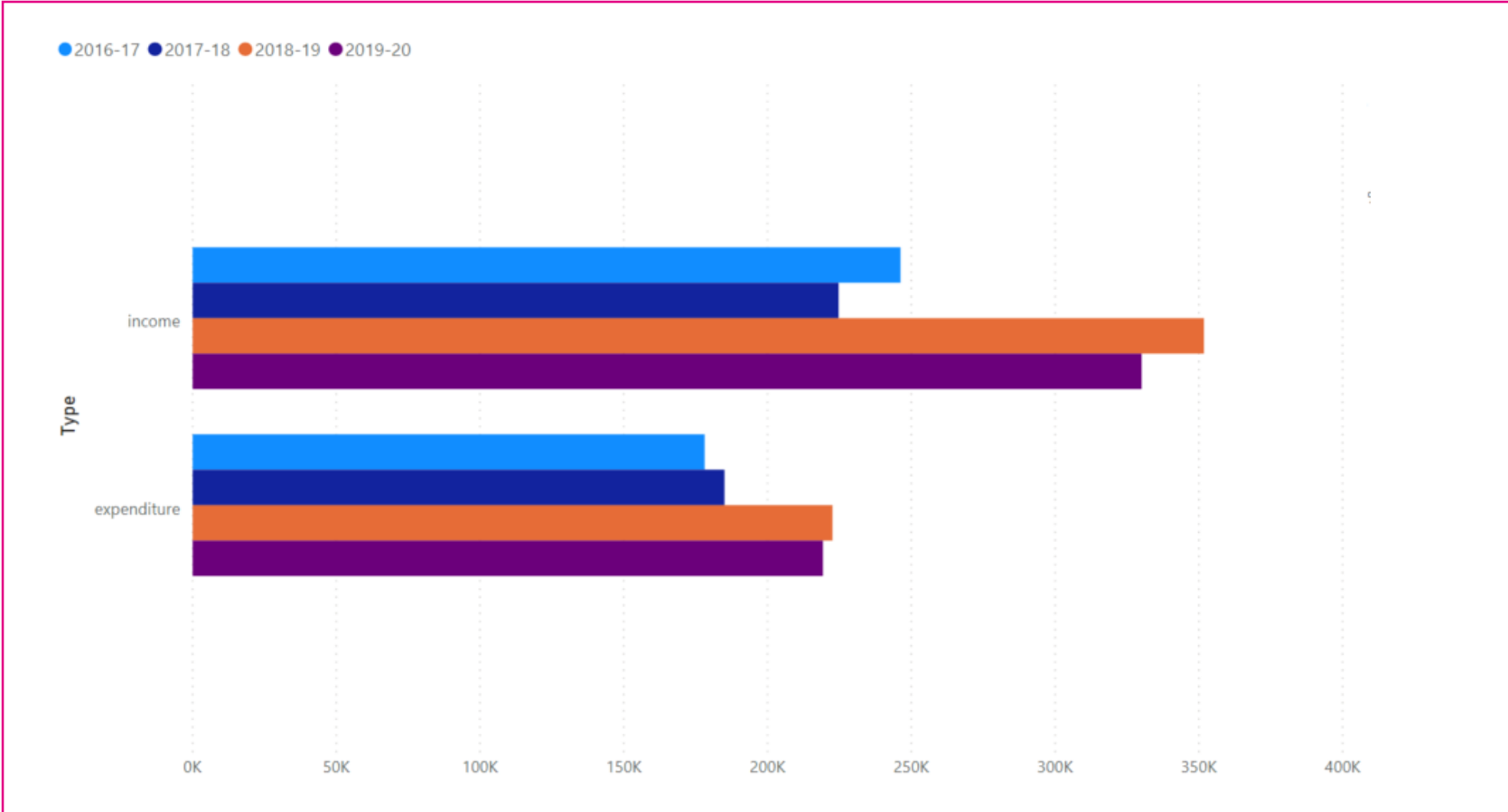
- Donate your birthday or special event to us through the Good Registry
- Become a member of the OnePercent Collective and donate on a regular basis



Hannah Barrett joining in the UpsideDowns fundraiser at the Home & Lifestyle Show, Eden Park, 5 March 2020

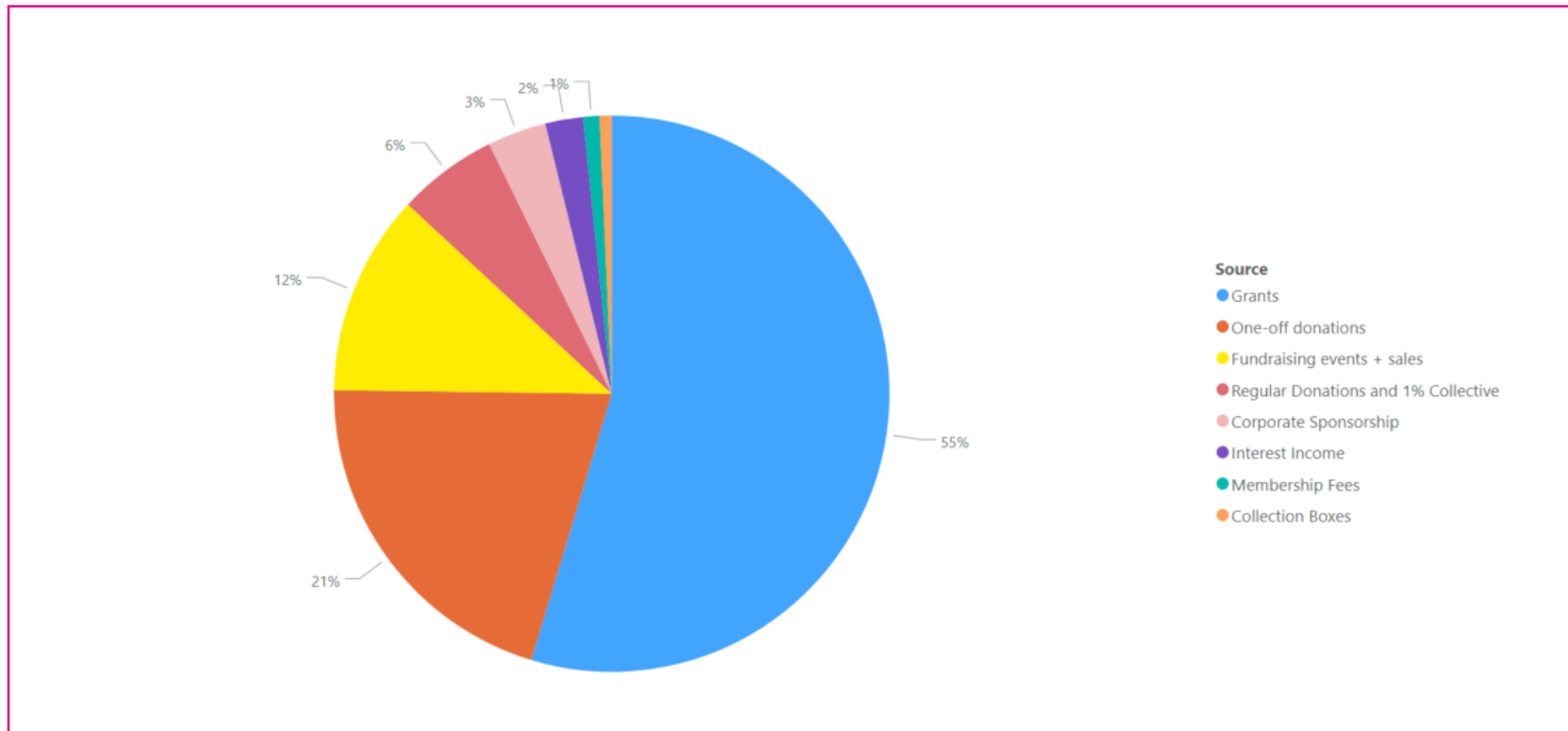
# Financial summary

The figures in the following section are not finalised and are subject to minor changes. However, they are accurate to the best of our knowledge and give a good picture of UpsideDowns' finances over the 2019-20 financial year.



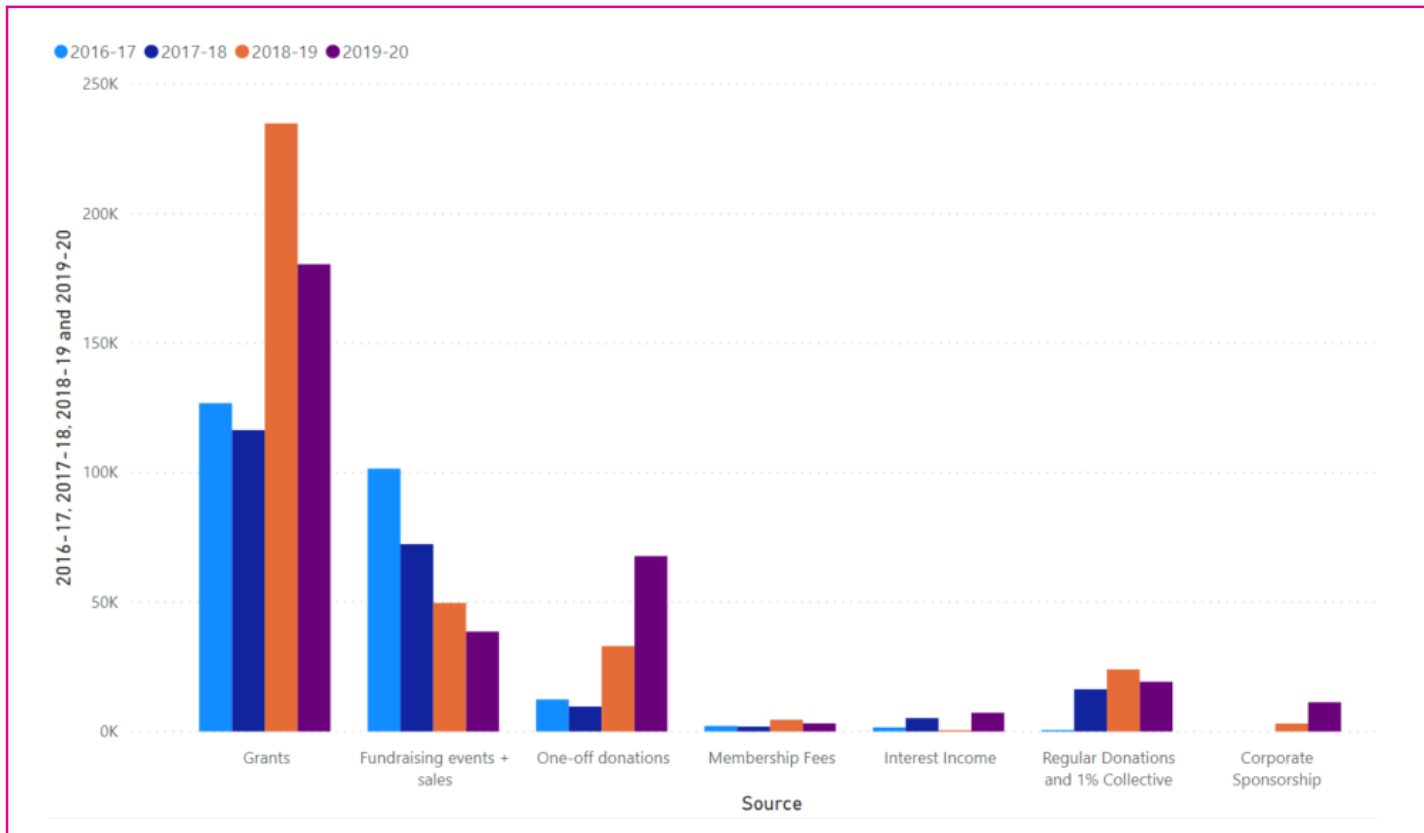
# Revenue

Our income continues to be predominantly grants-based, with a reduced representation from fundraising events this year due to not holding a Share the Dream event. We are pleased that our income continues to diversify and rely less heavily on grants and events. Our grant revenue has reduced from 67% last year to 55% this year, our one-off individual giving has increased dramatically from 9% to 21%, and corporate partnership is now in-line with the New Zealand average of 3%.



# Revenue sources

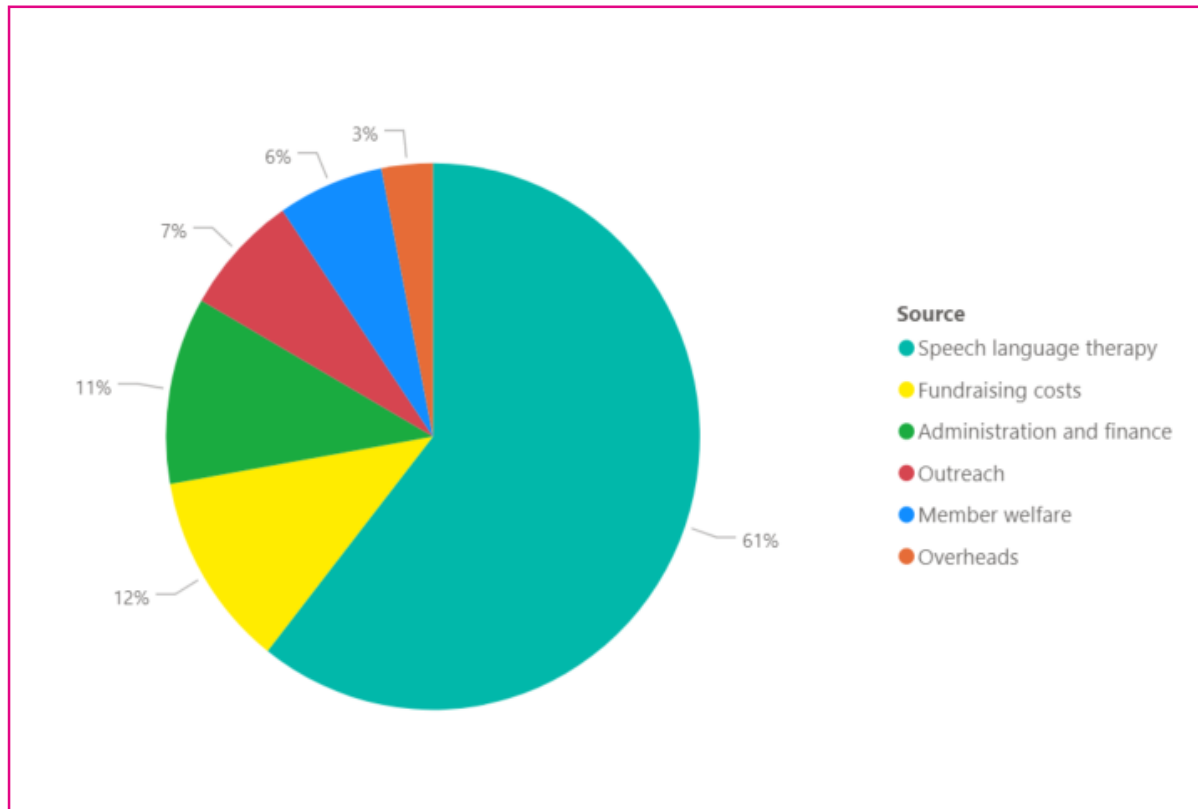
- Our overall income continues to increase and diversify, as we endeavour to accommodate our rapidly increasing membership.
- As a result of the Barrett family support (p. 9-10) and improving our online donations process, one-off donations have increased significantly.



- Having focused on corporate partnerships over the past 24 months, this area has also burgeoned, increasing from \$0 in 2017-18, to \$3,057 in 2018-19, and now to \$11,323 in this most recent financial year.
- Our focus on fundraising events has continued to reduce in the light of successful grant applications and the high cost involved with putting these events together.
- We are looking forward to holding some exciting events in 2021 however, in recognition of the significance of the '21' year for our community!

# Expenditure

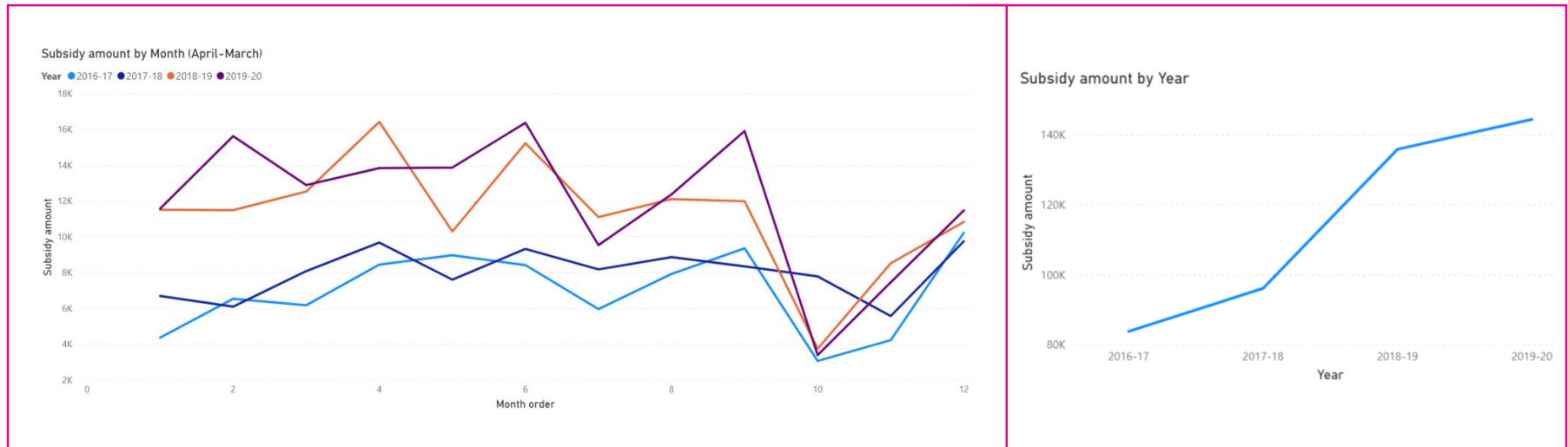
- The graph below demonstrate how our costs break down once staffing is incorporated.
- We are very proud that we have been able to **raise a total of \$330,000** this year at a cost of less than \$30,000 (the yellow section of the graph).



- Our efficient fundraising has enabled us to accept over 50 new families into membership as well as honouring our commitment to the 158 families in membership at the outset of the year.
- As our Outreach project continues to become more self-sustaining, these costs have also gone down from 10% last year to 7% this year.
- In total this financial year, we spent \$136,314 on speech and language therapy, representing **2,297 sessions** with NZSTA-registered professionals.

# Expenditure

- The graphs below demonstrate how speech and language therapy (SLT) funding has developed over the past four years.
- The graph on the left demonstrates that the overall cost of SLT per month has continued to increase with each year, although regularly reduces significantly each January during summer holidays.
- The graph on the right shows that our annual SLT costs have risen rapidly as our membership has increased. These have gone from just under \$84,000 in 2017 to over \$144,500 at the conclusion of this financial year.
- Although this increases the pressure on our fundraising efforts, we see this as a huge success as it means significantly more children with Down syndrome are receiving the regularity, consistency, and quality of SLT provision that they need.



# Finances summary

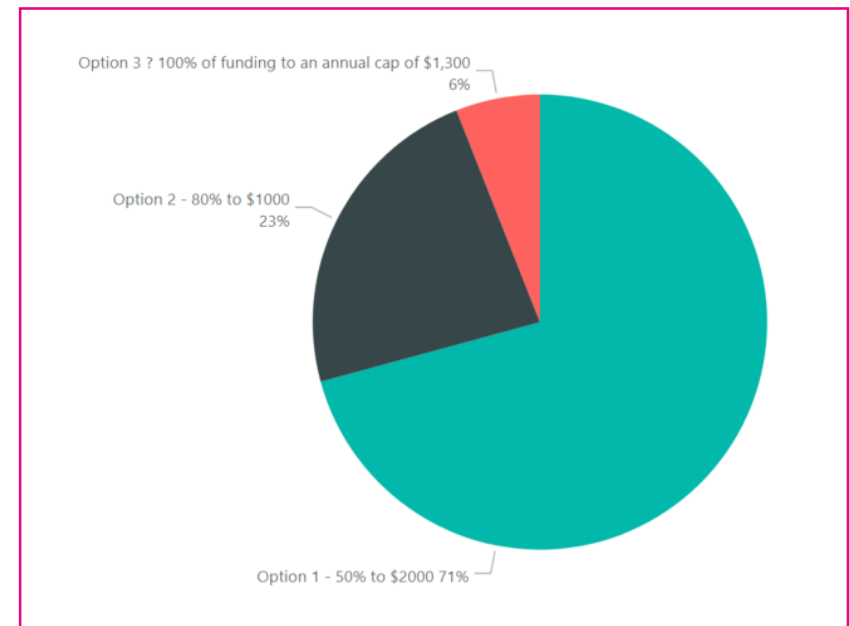
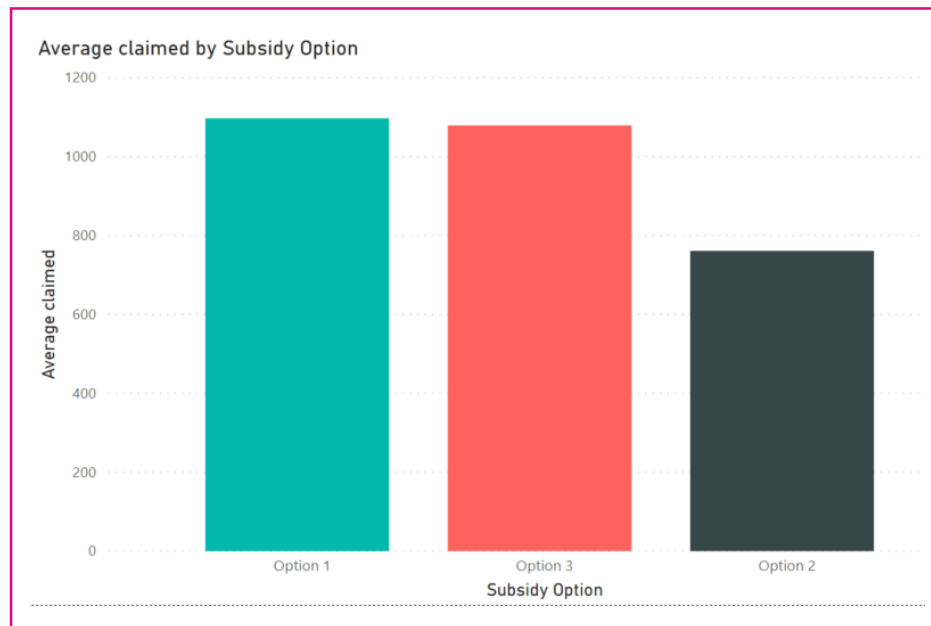
Revenue	2019-20	2018-19
Donations	\$100,369	\$62,975
Fundraising events	\$38,584	\$49,636
Grants	\$180,500	\$174,900
Membership fees	\$2,985	\$4,335
Interest	\$8,135	\$7,648
<b>TOTAL</b>	<b>\$330,573</b>	<b>\$299,494</b>

Expenses	2019-20	2018-19
Speech and language therapy	\$143,968	\$136,315
Fundraising	\$10,688	\$10,839
Staff salaries	\$61,096	\$70,000
Overheads/Other	\$4,294	\$2,549
Outreach	\$723	\$3,603
<b>TOTAL</b>	<b>\$226,821.92</b>	<b>\$223,306</b>

This year we have once again achieved a surplus. This means that we can continue to clear our waitlist with reasonable regularity, taking into account the very long-term commitment we make to each family. Our financial prudence over the past few years has also insulated us, thus far, from the effects of the global pandemic, for which we are incredibly thankful.

# Subsidy options

- These graphs show us how families chose to use their speech and language therapy funding over the last financial year.
- As has been the case since the introduction of Subsidy Options 1 and 2, 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 2% last year (3 children) to 6% at the close of this financial year (10 children).
- Option 3 is being increased to a cap of \$2,000 per year, up from \$1,300, which will now allow these families to access more regular SLT for their children.

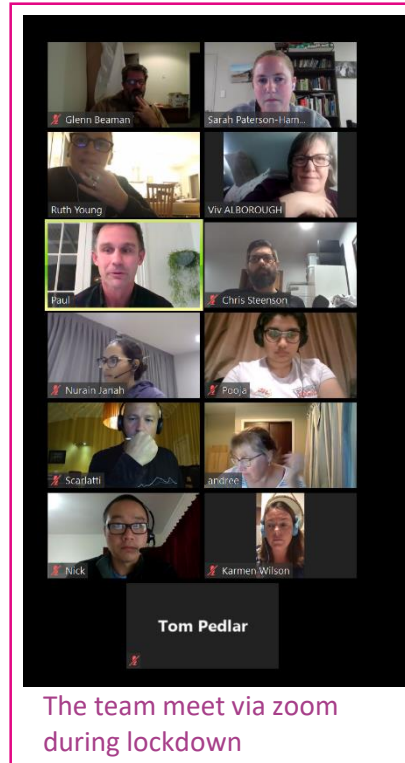




# Our team 2019-20

## Volunteer Trust Board

- Adam Barker – Chair
- Paul Batters – Treasurer
- Pooja Sundar – Secretary
- Andree Pearson – South Island Representative
- Viv Alborough
- Glenn Beaman
- Nurain Janah
- Nick Ling
- Tom Pedlar
- Sally Rayner
- Chris Steenson
- Karmen Wilson
- Jason Wong
- Ruth Young



## Staff

- Sarah Paterson-Hamlin – Operations Manager
- Bea Traub – Administration Assistant
- Solitaire Henare – Outreach Coordinator

- After many years of loyal and incredibly valuable service, we are very sorry to farewell Jason Wong from our Board this year. However, we are thrilled to welcome his equally brilliant wife Sally Rayner in his place!
- We also welcomed Glenn Beaman, Karmen Wilson, Viv Alborough, and Pooja Sundar to our team this year. All of our volunteer Board members bring so much to the organization, and we are very lucky to have such a fantastic group at the helm.

# Major community sponsors in 2019-20

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# Major community sponsors in 2017-18

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Samar Kand Trust



Lustrum Invictus



# Covid-19



- Like every aspect of life, UpsideDowns was affected by Covid-19 and continues to feel the impact. We also need to be prepared for future infections in New Zealand, as the virus continues to surge overseas.
- Our winter Quiz fundraiser, a Wellington street collection, and other small fundraisers were cancelled.
- Several grant funders temporarily suspended applications, and others wrote to warn us of reduced budgets in the coming months reducing the likelihood of success. We anticipate that our grant income in particular will be affected over the next 1-2 years as a result of the crisis.
- The majority of members were able to take their speech therapy online thanks to the incredible effort of many of the speech and language therapists around the country and the hard work and dedication of whānau.
- One really positive affect of this, is that families who were struggling with the travel requirements of speech therapy have been able to continue with a combination of in-person and tele-therapy sessions, enabling them to attend more regularly.

- During Alert Levels 4 and 3, Sarah posted daily Makaton sign videos which are now available as a YouTube playlist.
- 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.



# Some messages from our parents

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 receive from our families! Thank you for being with us for this extraordinary year.

“Thanks for your ongoing support, the change in Tymon's speech since he started speech therapy is amazing!”



“We are pleased to say we think Adam's speech is coming along well, and having the support of the Upside Downs Trust is hugely helpful for us all, we really appreciate it.”

“Her speech therapy is working wonders at moment we are having a language explosion. Thank you for helping us!”

“It's the most amazing organisation in the world, basically!”

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

“We can't express enough how much this opportunity for Nyah means to us.”