

Dates for your diary

Rare Disease Day Celebrations

Sunday 28th February

- Auckland
- Christchurch
- New Plymouth

Details will be posted on the website closer to the date.

* If you are interested in hosting a Rare Disease Day event in your region, please contact Janet Simons gm@idfnz.org.nz.

Auckland Round the Bays Saturday 6th March

* Fantastic family day out, come along to participate in, or to cheer on the IDFNZ KIDS Foundation team.

Season's Greetings to all members and supporters

Many of you have faced medical challenges this year, and while some are through the toughest times, others are still living with the unknown. Stress takes its toll – we hope that this Christmas you can relax with family and friends, and draw strength from the love surrounding you. May you never feel alone. Wishing all of our families a peaceful, relaxing Christmas with the real message of the season filling you with love and hope.

Best wishes from the staff and Board of IDFNZ and KIDS Foundation

Celebrating the gift of life



Christmas is the season of giving, and there is no greater gift than the gift of life. For many of our families, their precious children have been given a second chance through organ donation. Christmas is the perfect time to remember these donors, with a mother's letter to an "unknown" donor, stories of recent transplant families,

and the journey of a fit and healthy 12 year old Jorden Edmonds, who is now living life to the full, thanks to her donor's gift of life. December is also Volunteer Awareness Month, and we give thanks to the many people and organisations who have so generously volunteered their time to support the Foundation this year.

2015 Reflections

December always causes us to reflect on the year gone by and 2015 has been a very special year for IDFNZ. Here are a few of the highlights.

Patient Centre Progress

After five years of fundraising for our patient centre project, the first stage of our long term goal has been achieved with the purchase of two brand new investment properties. This was made possible by combining accrued fundraising reserves and new grants from Belron World Conference Foundation and Smith and Smith Ltd.



This is an incredibly exciting step forward, achieving a solid investment asset base in the Auckland property market as phase 1 in our long term goal of a patient centre in Grafton. Already our properties have increased in value and are generating a return on investment which should enable us to work toward the next phase. Thank you to everyone who has helped with fundraising towards this goal.

New Logo

Behind the scenes, the Board has protected our intellectual property by creating and registering a fresh new logo for KIDS Foundation youth services and our All 4 Good community fundraising projects. We are very grateful for the donation of services by staff of Shieff Angland to complete this process.

2015 Reflections cont.

Support Services and Patient Events



Our usual assortment of coffee mornings, lunches, and family fun days have been hosted throughout the year.

Rare Disease Day and PI week activities have complemented these. Connecting families affected by these rare medical conditions remains a key strategy to strengthen and empower patient members and to help us understand how best to assist. The Christmas parties are a special highlight for all ages; coming together at Christmas is part of being a family. Thank you to everyone who has supported and participated in our events.



This year we hosted our first Christchurch Christmas party since the earthquake.

We had a great turnout of over 40 children and parents meeting first at the Go Potty ceramic studio to create

some unique Christmas platters together, and then for a simple lunch at Protocol. The children received early Christmas presents from KIDS Foundation, with Shania stepping in as Santa's helper. Thank you everyone who attended – it was a lovely day.

Respite Care Programme

Our respite homes continue to be a very special asset, offering healing family respite breaks in quite special environments. It is great to see high occupancy over the summer period – but don't forget that the homes can also be used for weekends and holidays outside of the peak season.

New Patient Resources

Throughout the year we have been able to print a wide range of new PID and Liver disease information booklets, textbooks and new patient diaries which all directly benefit family members. These will be sent out to patient members and supporting medical professionals in the next few weeks to ensure they have personal copies of all of our up-to-date information.



Sponsors and Supporters

A comprehensive range of services and resources have been made possible through the generosity of our financial supporters. Our Annual Appeal sponsors make it possible to continue and expand these core offerings which make all the difference to families facing the life threatening medical conditions the Foundation supports. Grants from trusts helped us to deliver specific projects and fully achieve the amazing results of the last year. Fundraising by members and staff helped to complete this work and to set aside special reserves for our visionary patient centre previously mentioned. The physical work of grassroots fundraising cannot be underestimated, as every person's efforts can be translated into a small step in achieving tangible goals which are very much worthwhile.

Our People

Jorden Edmonds

– Liver transplant recipient 2006

At school a couple of years ago I was asked to write about someone very important in my life. Someone who has helped shape the person I am today. For me it could be any one of a hundred (maybe more really) people who have helped get me to this point. This point in my life where I am running around the cross country track, swimming at the wharf with friends and hiking up Mt Hiraikimata to visit Biz Bell who works with the endangered Taiko.

This person I chose to write about I had never spoken to, but if I could I would say "thanks". This person is someone I knew nothing about, will never meet, but they are the very reason I am able to do all the things I can or want to do. He or she was my donor.

All the adults in my life know what I have been through and how sick I was. I didn't know much, just that every year we go to a service that makes my mum cry every time, and we get invitations to Christmas parties that we can't get to because we have to fly everywhere - one of the few bad things about living on an island. So I started asking her questions about my transplant. My mum says that's the thing about organ donation, you don't know exactly who they are or what they did in life - you just know what they did for YOU. It may just be ONE thing, but it the biggest most super thing they can do for another person. Actually she says it's not just what they gave to ME but to my entire family. I also wonder how many other people my donor saved. I know of one other. The person that received the other portion of their liver. I hope they are living a wonderful happy life too. We have a little catch phrase:

Liver Life, Worth Living ... Live a life worth living!

I was almost 3 when I had my transplant. I don't remember much about the time when I was sick. Just the things that my family tell me. I see lots of photos. I see how yellow I was. I'm always in a hospital room or waiting at the doctors. I think of how funny I look because I was always smiling. Sick people shouldn't smile so much?



I do remember the nice nurses and the vampires (the blood ladies with funny accents). I ate a lot of green foods. Peas, broccoli and silverbeet were my faves. I remember the playroom I had spent most of my time in. We used to call 26b our inner city apartment with a view of the sky tower. I remember my "friends" and know that some are now angels watching over us.

We live on Great Barrier Island. My parents are separated and we all live with my mum. I go to Okiwi school where my poppa is the Principal. He has taught here since 1989. We have 3 other teachers, one is my grand-uncle Brian. My Mum is here too. She helps out with lots of stuff but mainly PE and swimming lessons. She is also the coach of our local soccer team. She is very competitive and loves sports.

I LOVE SPORTS! I didn't always though. Only a couple of years ago I was sent to the naughty mat (by my mum) at swimming sports because I refused to participate. I used to think I couldn't do it. I thought I couldn't run as fast as other kids or swim as far. I thought that I would lose. My brothers and sisters (I have 2 brothers, 3 sisters) are all very sporty. They would always come first in everything. I also thought I was too sick to do anything.

Our People Continued

I was scared I would get hurt and have to go back to Starship. My Mum said, "Enough is enough, get out there or else, stop moping and start doing, all you have to do is try. Try then try harder". And so I did.

I am now a determined athlete. I play soccer, ripper rugby and netball. My Mum may be the coach of both grades in soccer but you have to earn your place in squad. I made squad. I am also in the swimming squad which I am very proud to be in. I participate in all our school sports events we do with the other two schools on the island. I have even placed first in most of them. Last year I participated in my first triathlon. I met Jonah Lomu and had a photo with him - he signed my rugby ball. Our local board and airline sponsored travel for me and two of my schoolmates. This year they did it again BUT we were able to take 15 people! I was voted the fittest kid in school this year by my teachers and school friends. I received the "Sportsgirl of the Year" trophy, my older brother received the boy trophy. I also received "The Hillary Award for Perseverance" - donated by OPC.

I have set myself a goal: I would like to play netball professionally or become an Olympic swimmer. I also want to do physiotherapy but who knows? I could change my mind and try another career as I really enjoy art and music.

I still regularly visit a vampire - but she is now a family friend/best-nurse-ever and we pretend we're on a set of Shortland Street. I still go into Starship, but only for routine check-ups and medication. I will take these meds forever but that's okay. I have been taking them for 12 years now so I'm okay with it. I'm okay with everything because now I know what it has taken to get me here.



A maori proverb (whakatauki) my family always recite goes like this ...

He manu e kai ana te miro no na te ngahere

He manu e kai ana te matauranga no na te ao



Translated it means: The bird that eats the miro - the forest is his/hers. The bird that eats knowledge - the world is theirs. It means we shouldn't limit ourselves to the same one thing but to expand and try anything and everything.

Leef Edmonds, Jorden's Mum

My name is Leef Edmonds and I am Jorden's mum. As with all Biliary kids, no two cases are the same. She was born a little early and she was jaundiced. This cleared, but returned as she grew older. She didn't have pale stools. She breastfed happily. She seemed very content. She did however ALWAYS have a temperature, sometimes a runny nose. This worked against young parents and I always felt judged. We never managed to get her childhood immunisations done as she was never "well enough". I always thought there was something not quite right with her. We lived in Auckland at this point and even with her many visits with Plunket and then to the doctors, nothing seemed to stand out - other than she was slightly yellow but that could just be her colouring I was told.

We moved to Northland when she was four months old. It was while at Whangarei Hospital (we thought her older brother had meningitis - he didn't) that she was seen first by a nurse on my request while awaiting blood results, and then by Dr Tuck. She was admitted the next day, and that was the beginning of our journey.

We were then sent to Starship where every test known to man was conducted. There was a lot of back and forth up and down the country - admission, discharge, re-admission. After many consults we were told she had 'Probable Biliary Atresia' - the probable part being that they usually conduct the Kasai procedure which allows them to make a conclusive

diagnosis. Jorden was too old for the Kasai and they didn't feel it would be beneficial for her to undergo such an ordeal without knowing the probability of success - there are no stats either way.

Now this is the point where it got hard. In the same conversation about confirming our daughter's probable condition and the deterioration of it, we were told she may not make it to her first birthday. Too old for Kasai, too young and too small for a successful transplant. How to recover from such news? In any case you can choose FLIGHT or FIGHT. I chose to fight.

My daughter has mentioned I am competitive. I think she should re-phrase that. I am determined. I asked what it would take for her to survive this, assessed all our options and chose LIFE. I chose life all-round. All the while we continued growing our family. She was on a cocktail of 10+ medications, some experimental, and her condition plateaued. We made it to the seemingly unreachable goal of 10kgs and she was listed. Almost 2 years to the day she received her lifesaving transplant.

Our journey has been one filled with struggles and overcome with joy, happiness and determination. I am always overwhelmed at the donor-recipient service. I never knew this person but with one selfless act as well as their family who consented, my life was made better. I would like to get to know their family in the future. The 4th of July 2016 will be our 10 year anniversary.

I encouraged Jorden's participation in sports. I wholeheartedly support it just as I would with any of my other children. Keeping fit and healthy is an achievable goal. I just make sure I am there on the sidelines if anything goes awry. It hasn't yet, and hopefully I'll be there watching her walk onto a podium in the future.

Leef Edmonds



Eric Morgan

Eric is an amazing three year old boy whose father passed away from a heart attack before I knew I was pregnant with him. At 17 months old Eric was diagnosed with Langerhans cell histiocytosis. The disease had invaded seven organs in his little body: skin, lymph nodes, bone, lungs, spleen, pancreas and liver. He required 64 days of chemotherapy in just 12 months. To date he has had 111 blood product transfusions (blood, platelets, plasma and albumin), countless needles into his scarred little veins, scars from biopsies, surgeries and procedures, has over 1500 beads of courage, and he sucks it up and gets on with it like it's nothing. Eric and I have spent a lot of time over the last 2 1/2 years away from my other three children during hospital visits.

Unfortunately the chemotherapy and the disease did irreparable damage to his liver. Eric waited six months on the transplant list before we were blessed enough to receive a deceased donor liver for him.

Eric is the happiest, strongest, and bravest boy I know. He toilet trained on a chemo pole before he was two. Eric was telling me to get the surgeons to "hurry up" before his transplant. He has learned how to run since he has his new liver and is now learning to ride a bike! Eric has the best humour and is incredibly thoughtful.

Because of all of the chemo and drugs, Eric has no immunity for long periods of time. He is on daily injections and social gatherings are almost non-existent. He has had pneumonia since we came home, with one night reaching minus 7 last winter. It is difficult to isolate him from the other children so he doesn't catch their bugs when they are sick. Our home needs wall insulation and has mould, it needs a re-roof also. I would like to make alterations to our bathroom and kitchen for hygiene reasons. No-one can tell us how long Eric's immunity will be comprised for. Any help we can get towards achieving a healthy, user friendly and safe home would be so appreciated!

Letter from Eric's Mum to his donor

I waited 184 days for an organ for my child. During that time I found the absolute limits in the core of my very being. In the beginning my child was "not well enough" to receive an organ. And you think to yourself, "Okay, I can accept that". So we get him a little healthier. Finally... Acceptance!!! He is on the transplant list!

After all the testing, bloods, scans, meetings and interviews, I thought to myself, "We got this! Now we just wait!" Just keep him well. I got told it could happen straight away, or not at all. I am a complete optimist though. Meanwhile he was on 14 medications every day. Plus continuous feeds through a nasal gastric. This meant getting up all hours every single night whenever the hose kinked, or ran out, and sometimes on special nights when I was super exhausted I might wake up to his nasal gastric tube dragged across my face and milk still getting pumped into my bed. And I can tell you there is nothing quite like waking up to the smell and feel of semi-digested stomach contents touching your face!

We got to know the pharmacist so well that after he finished work he would call in, and put meds in the fridge when we weren't home, while patting the dog. We could call or text the local paediatrician and get blood results, advice, script repeats or reassurance anytime, day or night. My boy was two at the time and knew all 14 drugs by name. He knew which ones tasted foul (I had to put those one down his tube). We would get specially brought in amino acids from overseas for his food intolerances - they would get posted halfway down the country from Starship and blended up fresh every day.

My boy is one of four children I am raising on my own. There is no-one else who knows all his meds. There are no sleep-ins or days off. I did not know at the time I would later be doing blood tests, subcutaneous injections, dressing changes etc myself if I ever wanted to have a semi-normal home life again.

At day 171 I lost the plot. I was in crying to my GP about how I couldn't do it anymore, and he gave me a number for a yoga lady... Hmmmmmm. yoga...

In the back of my mind I thought with him being healthier it may increase the chance for him to get an organ.... But if there aren't any organs... There just aren't any organs.... On day 184 we got the call in the night with a gift so precious there are no words....

Unfortunately for someone else this meant a loss. A loss so great, so incredibly huge! The same loss which had been my biggest fear for the last few years. That family thought of us. Complete strangers waiting for someone else's tragedy. I hated myself for thinking that way. Hundreds of unethical thoughts would cross my mind. Jokingly saying things to others but in reality there was a small amount of truth in my humor. Careful not to let the desperation consume me. The day had come, and they thought of us. There are no words... After our precious gift we can write a letter to the family.

I tried so many times. Every time I'd read it and think how lame it sounded. Months passed. Over 50 times I tried. How do you thank someone for their loss? How do you offer sympathy where our gain has been so incredibly huge it gave us life? I had already lost my children's Dad. I knew what it meant to lose someone! I still have my child, thanks to this wonderful family. I asked so many people! What should I say? "That one's on you" they would reply.

I feel like words are not enough. What if they never read it? Maybe I have been stressing out over nothing? I offered my deepest sympathies. I offered my greatest gratitude. I didn't know what else to say except ... Thank you... Because there are just not enough words in the world to thank someone for what they have given back to our family!

One very grateful Mummy

Help Angela create a warmer, safer home for Eric by donating on givealittle:

<https://givealittle.co.nz/fundraiser/ahealthyhomeforeric>

Any help will be very gratefully received!

Our People Continued

Oscar Berry

Our story began during the pregnancy of our second child. My wife Maaike was having her 20 week scan and the radiographer told us that there was an abnormality. This came as a huge shock, and we were advised that it could be a number of things, one of which was Duodenal Atresia. Subsequent scans ruled this out which was a huge relief although we knew we still had something to assess with the doctors once he was born.

So, Oscar was born, at a very healthy 5.3kg! And he was immediately scanned and found to have a cyst which could be related to a number of conditions. The only way to diagnose was to do a Kasai procedure. This procedure revealed that Oscar had the cystic form of Biliary Atresia. This meant that Oscar would most likely need a liver transplant before his teen years, although hopefully the Kasai procedure delays the need for this as long as possible.

Initially the Kasai showed good results, but then he went quickly downhill and was very jaundice. It became apparent that he needed a liver transplant soon. Oscar was placed on the list at age 4 months and I started being assessed as a live donor. This process was very involved and it took approximately two months to

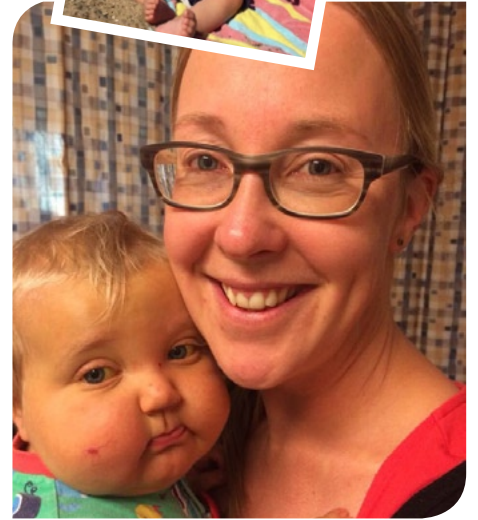
be accepted. Then we waited another two months for our transplant date.

The transplant day was very tough, especially given two out of four of us were being operated on. Thankfully it was successful and the road to recovery began. It was amazing how his colour changed almost immediately and his jaundice was gone.

Oscar was in PICU for a couple of days, before moving up to the ward. However he then had complications and required two further operations for bowel perforations. The final of these resulted in his abdominal muscles being left open.

He spent a further two weeks in PICU and this was an incredibly tough time. His condition was not progressing and it didn't seem like there was any chance of returning to the ward and onto recovery.

However, on Christmas day he was finally breathing for himself and was admitted back to the ward. Within a week we were back home, which very fortunately for us was nearby in Auckland. From here his progress was very positive. We spent the first three months post transplant keeping him shielded from potential bugs, but after this phase life started to return to normal. Oscar, while delayed, was starting to develop and this was great for us to see.



We were in constant contact with the Starship gastro team and they helped Oscar and us navigate the first year. Now we have just had the one year post transplant operation which involved abdominal muscle closure and a biopsy; the results have been relatively positive.

Oscar is now walking and talking and we are looking forward to our first normal Christmas. We are forever indebted to the amazing team of doctors and nurses at Starship whose expertise and support got us through the toughest time in our lives.

Hazel and Andrew Sim



Napier couple Andrew and Hazel Sim have been through a very tough two years. The joy surrounding the birth of their son Carter in January 2014 was quickly followed by the shock diagnosis of Alagille Syndrome and the imminent need for a life-saving liver transplant. The family were called to leave their home in Napier in August this year when a suitable liver became available; spending close to 4 months living at Auckland Hospital for Carter's transplant and recovery.

With two older sisters Lily and Mya to care for also, and Andrew's work commitments in Napier, weekly journeys to and from Napier became the norm; this lovely family was exhausted by the prolonged separation and considerable stress. Supported by KIDS Foundation throughout their long hospital stay, something extra was needed.

Enter Holiday Helpers Network Waiheke (HHN) – with the offer of a respite weekend to bring together the whole family for a healing, relaxing weekend.

The HHN weekend was amazing as always, the magic of Waiheke worked so well that Carter was actually discharged home to Napier in the week following. The family were so grateful for the kindness and generosity of the HHN team.

"I cannot say thank you enough for the incredible weekend that Karyn and Dan and all the lovely people that were involved in helping Holiday Helpers organise a respite break for our family to be together, relax and be away from the day to day hospital life we have become used to up at Starship.

"Everything blew us away from the home baked lasagne made for us the night we arrived to the incredible eco Bach that

Rochelle Watson

New Board Member

Hi, my name is Rochelle Watson and I have recently been elected to be the new treasurer for the Kids Foundation. Over the last few years I have been actively volunteering and helping when I can to give my support to Janet and her team.

Since my boys were diagnosed with CGD in 2010, IDFNZ has been a huge positive impact on our lives. And while things sometimes could be unsettled I always put up my hand to help out. Volunteering for such an amazing charity has given me a sense of achievement. My family and I have been very busy towards the end of this year, having had the opportunity to help out with the Razz Show and Armageddon, as well as dedicating a week away up north in Whangarei to sell fireworks and raise essential funds for the foundation.

It was an amazing experience and I hope to put my hand up to help next year as well. Upon doing all this it's been wonderful meeting other members and hearing their stories, with lots of laughs. By giving my time I feel this is the best way I can give back.

We would all love to see a much better year for us all, and if anyone wants to

give something back but don't know how please come and talk with Janet or myself. We would truly appreciate it. I hope you all have a safe and merry Christmas and a wonderful new year.



Charles and Nicky kindly let us stay in that was just in the most beautiful setting. Even though the weather was horrible, we were able to relax and enjoy just been together for the first time in a very long time. We can't forget the beautiful flowers Nicky organised from the wonderful



florists on Waiheke - they made the most gorgeous bouquet for us.

"Our thanks to Max from Stoney Ridge Winery for the lovely wine tasting and tour of the winery; he made us feel so welcome and was very informative. Andrew and the lovely people from the Oyster Inn, a stunning little restaurant. Andrew was just great with the kids and the food was amazing, we were so full we couldn't even fit in dessert... thank you so much.

"We decided to make our trip really special and decided while we were there that we would get married; after the hardest year we thought it would be a perfect time and we are so very grateful to Holiday Helpers Waiheke, Karyn and her husband Ian, Joe, Diane and Cath for been a part of our day and helping make it so special. We will never forget what you have done for our family. We are truly grateful to you all and now feel like you're all just a part of our family - thank you."

Hazel and Andrew Sim

Waiheke Island Breaks



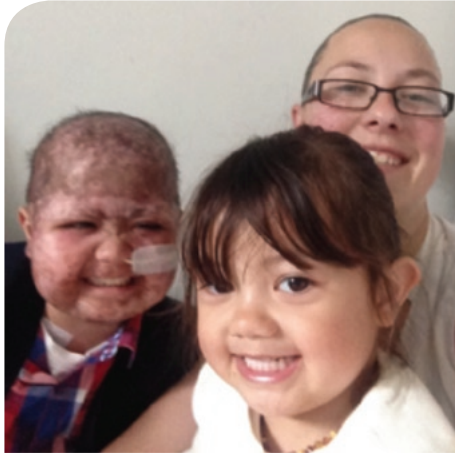
Holiday Helpers Network Waiheke Island (HHN) has generously assisted IDFNZ Foundation, arranging luxurious holiday breaks for selected families of bone marrow and liver transplant. It is very humbling to see their enthusiasm to help us and our cause. Six KIDS Foundation families have experienced this pampering over the last year; many thanks to Dan Harrop and Karyn Johnston of HHN for all their hard work coordinating these breaks with local Waiheke businesses.



Our Supporters

Smith & Smith “Angels” supporting KIDS Foundation families

In addition to their fundraising efforts and financial support of the Foundation, individual Smith & Smith staff members also have been quietly offering their



Izyiah with sister Kayle and Mum Dani

volunteer services to assist KIDS Foundation member's one-on-one. Over the last year volunteers have assisted specific hospital bound families with household chores that often get neglected when parents are flat out caring for their sick children for long periods.

Janet and Raj Swarmy were so grateful for assistance when young Mataru was hospitalised almost continuously for 16 weeks earlier this year.

“A big thank you to the ladies from Smith & Smith - they did a great job cleaning my windows inside and out. It's one of those jobs I never got around to after long days at the hospital. Thanks again ladies - Raj and I really appreciated it.”

The Noyer family of Auckland also benefited from a visit from Smith & Smith helpers Janette and Jess. Dealing with



Jemma and Shannon Busy at work for the Swarmy family

Young Izyiah' special health needs and bulky medical equipment in a 1 bedroom flat was not easy, so mum Dani was thrilled to be given the opportunity to move to a bigger home, but with her husband working away and two under 5 year-olds to care for, the logistics of packing, cleaning and moving seemed overwhelming. Luckily Janette and Jess came to the rescue and helped share the load with Dani.

“Thank you so, so much to Janette and Jess from Smith & Smith who kindly volunteered a few hours of their time to lend a hand. It was such a stress off my shoulders that they were able to go and do a clean at my apartment after I had moved out.

One less thing that I had to try and juggle with moving house and Izyiah (4) and Kaylee (2). Your kindness is very much appreciated.”

Charity Show Hosting

Held in Napier, Gisborne, Auckland, Wellington and Christchurch, these important events are part of the Foundation's 'giving back' programme to special needs families in the local community. We appreciate the volunteers who take time out to act as ushers and front of house helpers.

Volunteers helping with the shows this year included: Wayne and Matisse Reid, Chloe Billington and family, Adam Norris, Judith Dickson, Jim Higgins, Tania Chong and family, Philippa and Holly Whitney, Danielle Pope, Shirley and Dave Hunt, Jasmine Hunt, Alex Hunt, Christine Jenden, Rochelle and Michael Watson, Caleb Watson, Logan Watson, Vicki Tattley, David and Helena Hilliar, Sandra Hitchcock, Jill Ferguson, Joanna Gray, Poi Ng and In Ling Ng.

Orange Bins - An ALL4GOOD opportunity to support the Foundation

Auckland members can help the Foundation every time they clear out their wardrobes or household items this summer. Allseasons is a recycling company which has supported the Foundation for the last 4 years; we receive regular cash donations in return for the recycled contents of these bins. So watch out for our ORANGE bins with IDFNZ KIDS Foundation branding – a list of locations is available on our website. And

if you have household lots or bulky items to recycle, give the office a call and we can arrange collection.

We are always looking for new additional bin sites – if you know of a business, church or school with a suitable space for a clothing bin, please let us know. A cash donation is also made to the site hosting the bin as well as assisting IDFNZ KIDS Foundation. This is good as a fundraiser and community “giving back” option.



Annual Appeal list of Gold supporters

A huge thank you to all our Gold supporters of this year's Annual Appeal...

Vero Liability Insurance Ltd
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Alan Galbraith
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Joyce Farms Ltd
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White House Technologies Ltd
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Onehunga District Bowling Club
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Caroline Whitehead
Orora Beverage Cans & Closures
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Stiles & Hooker Ltd
Southwell School
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R D Hughes Development
Orange Homes Ltd
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Pak N Save Food Warehouses
Woods Harris Consulting Ltd
C W F Hamilton & Co Ltd
Macpac NZ Ltd
Independent Fisheries Ltd Woolston
Susan Doig
Treadwell Lawyers
Stand Childrens Services
Woodridge Homes Ltd
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Roy & Jan Mace Charitable Trust
Society Of Mary (Marist) Trust Board
Responsible Care NZ
Eftpos Paper & Ribbon Ltd
Webster Drilling & Exploration Ltd
Acton International Marketing Ltd
Urban Perspectives Ltd
Allied Telesis NZ Ltd
Aluminium Extrusion Co Ltd
Kokiri Marae Health & Social Services
Excel Digital Print Ltd
Masonic Lodge Aquarius No 466
Electricity Engineers Association Of NZ Inc
Freedom Medical Alarms
Brother International N Z Ltd
Power Systems Consultants NZ Ltd
Integration Works Ltd
Access Homehealth - Wellington

ADS Copiers
B C Contracting
Te Kohanga Reo National Trust
Andrew Sangster
Klee Plumbers Ltd
N Z School Trustees Association
Paddys Wholesalers Ltd
Mercer Group
The Impact Fund
Matai House Ltd
Stop In Charitable Trust
NZ Specialised Coatings Ltd
Hireways Ltd
Manawatu District Construction Ltd
Crest on Grey
Suzuki NZ Ltd
Wanganui Collegiate School
Atihau Whanganui Incorporation

The generous Trusts who supported us last year

The Belron World Conference Foundation
The FH Muter Trust
The EM Phazyn Trust
The New Zealand Children's Transplant Trust
The Trinity Foundation
The Southern Trust
Blue Sky Community Trust
The Four Winds Trust
COGS
The Endeavour Trust
The Mt Wellington Foundation Ltd
The Infinity Foundation
The Trillian Trust
The Lion Foundation
The Dragon Community Trust
The Pelorus Trust
North and South Trust
Pub Charity Inc.

Reaching Out Online

One of the hardest challenges for families with unwell children is the sense of isolation.

Your child's illness may mean that you find yourself constantly in and out of hospital. And even when you are home, it is simply too hard to leave, due to the risk of infection or contamination. The thought of taking your child to birthday parties where they can't eat the food, to parks where they can't touch the equipment, or on public transport where the air conditioning could expose them to illness... it's all too much. It can leave you feeling trapped, lonely and isolated, giving you the sense that no-one else could ever understand your situation, or how it feels to be you. Connecting with other families online means that while it

may be hard to leave the house, or you may find yourself in hospital for weeks on end, there is always someone there to reach out to.

SOCIAL MEDIA

While social media has its downsides, it can also give us an amazing opportunity to connect with other families in similar situations, not just in New Zealand but around the world. As well as many of our families being on facebook, there are also a number of groups on facebook that you can join, and all you have to do is search them up and ask to be added.

These are wonderful closed forums where you can ask personal questions to other families who will understand, about specific medication, treatments, concerns, solutions and ideas for making life easier.

It can be incredibly uplifting, just to know you are not alone and that there are other families who understand exactly what you are going through. You can also private message people on facebook, so if you see someone dealing with an issue that you have already been through yourself, it is great to reach out and offer support to them.

Charity Fireworks

A huge thankyou to everybody who got behind our Charity Fireworks fundraiser this year - we had a record 113 individuals volunteering their time to help the Foundation.

This was an amazing turnout and we are humbled by such an amazing response. A special mention goes to the store 'managers', some of whom took unpaid leave to spend a full week of their time on this project. Thank you to our wonderful volunteer heroes; together you helped the Foundation earn a donation of \$40,000 towards our patient centre project and services.



Joanna Grey
Jill Ferguson
Helena Hilliar
Chris Jenden
David Hilliar
Sandra Hitchcock
Poi Ng
Carol Gu
Lu Ling Ng
Lynette Patterson
Jaqui Porter
Erin Tattersall
Joy Jansen
Helen McGregor
Sheryl Webster
Fiona Platt
Sue Cammell
Libby Cammell
John McGregor
Lorna Child

Rochelle Watson
Logan Watson
Caleb Watson
Michael Watson
Adriaan Bosch
Tony Ellis
Ali Coombes
Lucy Ellery
Sanjay Sharan
Danielle Pope
Josh Sutherland
Liz Stellar
Adrian Cherry
Megan Cherry
Lester Connor
Matthew Mallon
Grant Tattley
Vicki Tattley
Mischa Tattley
Sharon Ingram

Rachel Jackson
Ben Pollard
Chuck Ng
Janet Simons
Shirley Davy
Traci Sailsbury
Samantha Sutherland
Jacqueline Smith
Janet Keeling
Lisa Dudley
Thomas Dudley
Grace Dudley
Noah Dudley
Jack Reckin
Rebecca Reckin
Peter Douglas
Fienney Douglas
Michelle Templar
Rose Dudley
Dianne Williamson

Penny Clover
Chris Blincoe
Ali Shailer
Matt Tlamill
Katy Shailer
Maddy Blincoe
Jack Keeling
Kirsten Cairns
Issac Cairns
Matt Cairns
Johan Pelser
Laetitia Pelser
Enrique Pelser
Marco Pelser
Anezke Pelser
Deanna Douglas
Helen Rutlege
Angus Brown
Karl Brown
Trish Reid

Lynne Shallard
Angela McGechie
Sinead Fisher
Jacqui Kuik
Andrew Greenfield
Michael Shallard
Gus Sonneveld
David Cooper
Thomas Tony
Phillip Ogle
Adian Brow
Bryden Henry
Flynn Cooper
Harry Cooper
Wayde Poppleton
Lukas Eldershaw
Asher McDonnell
William Janssen
Luke Shallard
Daniel Shallard

Andrew Sonneveld
Alex Kuik
Nicole Fickling
Hamish MacDonald
Asher MacDonald
Chris Bennett
Celia Allerby
Alex Verissimo
Daniella Verissimo
Sarah McGechie
Ruth Edgar
Mike Vanderleek
Nick Taylor
Steve Simons
Tabetha Gorrie
Covenant ICONZ
Te Puro Sea Scouts
Girls Brigade (Northland)
Girls Brigade
(5th Manurewa)

BLOGGING

If you find it helpful to record your journey each day, or week, as a way of letting go of some of the stress and challenging situations you are constantly being faced with, it can be very simple to start a blog through a site like Wordpress. This gives you the opportunity to write up your thoughts – as little or as much as you like – whenever you like.

When you set up your blog, you can choose to keep it private, to share it with selected friends, or to make it public. We recommend keeping it private, and just sharing the link with those you trust.

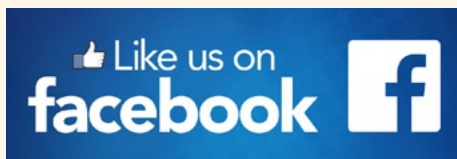
These are people who will support you through the hard times and the good times, and it can be a great way to let others know how you are feeling, without having to tell them.

Your blog will also give you an incredible digital record of your journey, to reflect back on for years to come, and to share with your children.

SHARING YOUR STORY

The Kids Foundation website is an incredible resource for newly diagnosed families, who are often in shock and not sure where to turn. They are also often feeling incredible scared and isolated, so being able to read the stories of other patients on our site is very important for them. We encourage you to share your story with us, not just to help these families, but also to help others in the community understand the challenges our children face.

It is these stories that also encourage companies to support our organisation, because they are able to connect with the individual children and families, and see the difference their support will make.



WHERE TO START

- Like the Kids Foundation facebook page and receive regular updates from us, both informative and inspiring! <https://www.facebook.com/KidsFoundationNZ/>
- Depending on your child's condition, there are all sorts of support groups on facebook – in try searching for Primary Immune Deficiency, Primary and Secondary Immune Disorders, Biliary Atresia, and Liver Transplant. These are truly wonderful forums.
- Check out Wordpress to find out how to start your blog – it's super easy! <https://wordpress.com/>
- Read the amazing stories already shared on our website by some incredibly brave and wonderful families... and then talk to us about sharing yours too so we can help others feel less isolated! <http://idfz.org.nz/our-families/>
- We are always happy to help, so if you are unsure about anything in this article, please email us at info@idfz.org.nz or private message us on facebook.

Medical Matters

ASCIA Conference

The ASCIA (Australian Society of Clinical Immunology and Allergy) Committee once again sponsored IDFNZ a complementary stand at the 2015 annual conference in Adelaide. The speaker programme and content was very interesting and of a very

high standard as always. As well as gaining new information for our members, we were able to showcase IDFNZ and connect with a wide range of medical professionals and patient groups.



Update On CVID Research

Members will be interested to read the latest information on the CVID research which IDFNZ helped Associate Professor Rohan Ameratunga and his team initiate a few years ago. Marvellous progress - well done!

"An international collaboration between Prof Bodo Grimbacher in Germany, Dr Vanessa Bryant and Professor Jo Douglass's group in Australia and a team in New Zealand has identified a new gene, NFkB1, which causes a rare immune defect. Common Variable

Immunodeficiency Disorder (CVID) affects 1:25,000 or around 160 individuals in New Zealand. The NFkB1 mutation appears to be found in a small number of CVID patients. The group in New Zealand is led by Auckland DHB immunologists Associate Professor Rohan Ameratunga and Dr See-Tarn Woon. They have identified the gene independently in a New Zealand family. The results were then combined with two other European/ Australian families published in the American Journal of Human Genetics.

For the individual New Zealand family concerned, this has very significant implications. For those affected family members it presents the possibility of earlier diagnosis and so treatment options can be deployed earlier, before primary immunodeficiency disorders advance to the stage of causing significant organ damage. It also means that they have the opportunity to undertake pre-implantation genetic diagnosis so avoid the gene presenting in future generations of their direct descendants.

This research used Whole Exome Sequencing, where all genes in the body are analysed to identify new gene mutations which cause disease. The team in Auckland consists of clinicians and scientists from Auckland City Hospital's LabPlus division and Associate Professor Klaus Lehnert from the University of Auckland's School of Biological Sciences.

Associate Professor Ameratunga said it is hoped the experience gained with this

research technique will soon be available to other patients suffering from primary immunodeficiencies in New Zealand. He also said the New Zealand research team wanted to express its gratitude to the family for participating in this cutting edge research. Auckland DHB Chief Executive Ailsa Clare said she spoke on behalf of the DHB in congratulating Associate Professor Ameratunga and Dr See-Tarn Woon and joined with them in thanking the Auckland Medical Research Foundation and the A+ Trust for their grant support."

On the web:

AMRF <http://www.medicalresearch.org.nz/>

A+ Trust <http://www.aplustrust.org.nz/>

Auckland Academic Health Alliance
<http://www.aaha.org.nz/>

University of Auckland Faculty of Medical and Health Science
<http://tinyurl.com/orv6o6r>

Medical Matters cont.

Hepatic Happenings

Update from Karyn Sanson

So far this year there have been 10 transplants in 9 children with more on the active list, waiting for ever precious donors. A big change has been the restructure of the CNS service. Cate has taken on a two year contract to help set up a new National Intestinal Failure Service, halving her time in her previous role and leaving space for a new CNS to join the team. It's great to welcome Meredith Foster to our team and she has now been with us almost six months. Meredith was previously a Staff Nurse and Nurse Educator on 26b. She brings with her a wealth of knowledge and passion for this service so we are very pleased to have her on board. Karyn continues a mix of seven days per fortnight with CNS and three days per fortnight working for the Paediatric Society in a network coordination role for both Gastro and Cystic fibrosis. Each patient now has an allocated CNS for support. This person will have the most detailed knowledge of your situation and the longer term goals. For basic day-to-day issues we have an acute phone so that families wanting to discuss an acute problem can phone in during the day and one of the team can assist. We take turns carrying the phone and the number is 021 837 870. Members may recall the team have been involved in a couple of awareness raising and fundraising ventures for KIDS Foundation this year; Karyn did the San Francisco Half Marathon to raise funds and all the team were involved with the Beware Yellow team in the Great Auckland Bed Race. It was the brightest yellow

cot you have ever seen and looked great. Unfortunately the wheels literally fell off partway around the course – they did finish though! While the Bed Race has been cancelled for next year, the team has started planning to enter a Beware Yellow team to walk or run the 'Round the Bays' race in Auckland. This raises funds for Starship and again helps us to raise awareness of Jaundice and Biliary Atresia. Families will be invited to join the team, so if you are interested, please keep the date free - March 6th 2016. In addition there has been lots of work to raise awareness amongst health professionals and with the help of Kids Foundation, Karyn went to Christchurch to the George Abbott Symposium with posters, flyers and pens to highlight the Beware Yellow message. This was a great opportunity to showcase the resources Kids Foundation have helped to develop and to target different professionals from around New Zealand. It is hoped there will be a number of professional sessions in 2016 to include midwives and Plunket nurses as well as other groups get the message out. Going into the Christmas period I know many of you will be celebrating the gift of life and like us will take a moment to think of the donors who made this possible. May 2016 bring a happy and healthy year to come where hurdles are overcome and your goals achieved.

Karyn Sanson

New IDFNZ Cooler Bags available for SCIG Patients



We are excited to be able to offer a limited number of these handy cooler bags to our patient members, to assist with collecting immunoglobulin supplies from the Blood Bank or transporting them when travelling over the summer.

These bags are a useful size, can be collapsed down to fit into the freezer and contain a cooler pack inside to make them effective. Contact your nurse specialist or the IDFNZ office to order your pack.

SCID New Born Testing Progress

Severe Combined Immunodeficiency (SCID) is a primary immunodeficiency disease. Babies with SCID appear healthy at birth, but without early treatment, most often by bone marrow transplant from a healthy donor, these infants cannot survive. It is imperative therefore that new born screening programs are established. As of November 2015 all but six states in the USA are now testing or trialling New

born testing for SCID. IDFNZ supports introducing the same testing here in New Zealand; immunology medical professionals and SCID patients are also adding their voice to this initiative.

Dr Jan Sinclair was recently invited to attend the National Screening Advisory Committee Meeting (NSAC), to support the proposal to add severe combined immune deficiency (SCID) to the new born

Screening Programme panel of disorders, and to contribute to the discussion.

NSAC has since endorsed the inclusion of SCID to the panel of disorders. This is a significant step forward. The next step is for the Newborn Screening unit to report back on implementation timeframes for NSAC to review the outcomes of the addition of SCID to the Newborn Metabolic Screening Programme.