IDFNZ intouch

Immune Deficiencies Foundation of New Zealand

December 2013

Upcoming Events

The IDFNZ Board and staff would like to wish members and supporters Merry Christmas and Happy New Year

Key events to look forward to in 2014:

IT'S OUR BIRTHDAY!

In 2014, IDFNZ celebrates 25 years of patient support for PID families

28th February 2014

RARE DISEASE DAY

Promoting awareness of liver disease

29th April 2014

World Day of Immunology

2nd May 2014

PID National Conference – All welcome

Family Conference 2014

Help us to celebrate 25 years of IDFNZ supporting PID patients. More information will be provided nearer the time but be sure to add this to your diary!

Visit our new online shop

www.idfnz.org.nz/shop

A Christmas message from the Chair, Vicki Tattley

Another year has flown past with lots happening within the Foundation and amongst our families.

In October we held our AGM. This year three positions were available for four-year tenure and were filled by Laura Hannah, Katy Brown and me. Laura, an adult patient member, has been on the Board for a number of years and her experience is invaluable. Samantha Sutherland, a transplant parent, sadly decided to stand down after serving two years as our first transplant parent representative. Over her time on the Board, her contribution has been significant and she has played a huge role in the development of educational initiatives for liver transplant children/families – thank you Samantha – we will be keeping in touch with you, never fear. Katy Brown has been co-opted onto our Board for the last two years, making a huge contribution to our Foundation communications, and now takes up the elected transplant position on the Board.

We were very saddened to see Judith Dickson, our Chair of the last three years step down. Recognition is well deserved for Judith who is a very humble, hard-working lady for whom I have the greatest respect and admiration. Judith has been a member for over 20 years and in her role as Chair, helped to steer us through some difficult times as we faced a recession and the money available to charities diminished. Judith has kindly elected to stay on the Board, for which we are very fortunate. I was asked and voted into the vacant role of Chairperson. If I am able to represent the organisation as ably as Judith has, I will be well pleased. She will also be there to support me as I transition into this role.

At the AGM we welcomed Miriam Hurst onto the Board as our second Medical Advisory Panel (MAP) representative. Our medical panel has been in the process of re-forming and we are very fortunate to have a wide representation of wise and willing advisers. We are immensely appreciative of the volunteer time and advice our doctors give to our organisation.

On this note it is timely to remind our members that IDFNZ receives NO government funding and to operate we must be self-funding. We feel that the cost of illness to families is large enough and therefore have never charged a subscription to join. In order to raise funds, you will be aware that we have held a number of different activities this year – RazzaMaTazz, and fireworks fundraisers to name a few – and we have called upon our members to assist.

To those who volunteered - thank you so much. I must also recognise some of our individual members who have raised amazing amounts for us this year, with the likes of the Auckland Marathon and All for Good. I find it hard to put into words our thanks to these individuals for their personal achievements for the good of our organisation. We must also thank Smith & Smith who are always willing to help out where they can in volunteer roles.

Due to the support of so many, we have had a good year with fundraising but encourage you all to contribute in whatever way you can as we move into another year of fundraising. It is important to remember that without such help we cannot provide the services we do.

I look forward to meeting many of the Auckland families at our Christmas party. I would like to take this opportunity to wish everyone a Merry Christmas and a Happy New Year. For some of you it will be a case of just getting through this period without hospitalisation/illness (for five years in a row when our son was small we spent every Christmas Day at the after hours – the first year we got through the day was amazing), so to those who face this uncertainty, or to those who have suffered the loss of loved ones, take care, my thoughts are with you all.

Bone marrow transplantation for PID

A growing number of PID conditions can now be treated by BMT. It can sound very daunting to parents considering this treatment for their children, this article is aimed at answering some of the many questions asked. In addition we have included three personal stories from some of our PID families that have experienced first-hand what BMT is all about.

Bone marrow transplantation (BMT) is now a cure for many primary immunodeficiency conditions with huge advances in the last twenty years in success, survival rates and the range of PID conditions able to be treated by BMT.

What is bone marrow? Bone marrow is a soft, spongy tissue found in the centre of bones. It is responsible for producing the three main types of blood cells: red blood cells, white blood cells making the cells of the immune system and platelets. All of these start off as immature cells called 'stem cells'. These cells mature in the bone marrow and are then slowly released into the blood stream. A bone marrow or stem cell transplant involves collecting healthy cells from a matched donor and introducing them into the PID patient . These new healthy stem cells then start to make fully functional white blood cells capable of fighting infection.

What is involved? The PID patient receives bone marrow (or sometimes stem cells collected from the umbilical cord blood of babies), from a donor who shares the same 'tissue type' as them and is therefore called a 'match'. Two types of match are normally considered: a perfectly matched related donor, this is usually a brother or a sister, or a well-matched unrelated donor. Occasionally, a less well matched (mis-matched) donor may be considered. In order to allow for these new cells to grow and develop the patient has to undergo 'conditioning' involving chemotherapy to make space for the new stem cells and to suppress the immune system to encourage acceptance of the new cells

How long does it take? BMT involves a long (on average 6-8 weeks although it may be longer) stay in hospital during which time the patient is looked after in an isolation room on a transplant ward. This ward will have more restrictions on visiting, diet and hygiene than a general ward. This is because during transplant the patient's immune system is low and extra precautions are necessary to protect them from infection.

What is BMT Success? In recent years, there has been steady and significant progress in BMT techniques and recent results for PIDs are now extremely good. Survival and cure are now equivalent with either a matched sibling or well-matched unrelated donor and reach 85–90% in specialist centres designated to transplant PID patients. Whilst transplantation is generally best tolerated in childhood, successful outcomes are now possible in young people and adults using new transplantation techniques. However, bone marrow transplant is not without risk.

What are the risks? The main risks are infection and Graft-versus-Host disease (GvHD). In GvHD the new bone marrow from the donor may recognise the patient's cells as 'foreign' to it and react against them. GvHD can cause problems with the skin, liver and bowels. Also, immediately after the BMT, the patient remains very immune-deficient and susceptible to infection. It may take 4 - 6 months for the new immune system to grow and function properly and during that time, prophylactic antibiotics and immunoglobulin will need to be taken.

BMT should start to be considered soon after a diagnosis of a PID. This is because better outcomes are usually achieved if those affected do not have a history of serious infections or inflammatory problems. This means that doctors will want to test siblings to see if they are a tissue-match, or if they are not they can then start to find a well-matched unrelated donor. The doctors are also then able to give appropriate counselling over a period of time to help people make this important decision once a suitable donor is found. Individual risk factors and suitability should be discussed with doctors and nurses involved in your care. It is important to remember that although a person's PID may be cured by BMT, the inheritance issues of passing their condition to future offspring still remain.

A growing list of PID conditions that can be treated by BMT includes: various forms of SCID, CID, CGD, HLA, Omenn syndrome, other T-Cell deficiencies, Wiskott-Aldrich syndrome (WAS), DiGeorge syndrome and Shwachman-Diamond-syndrome, various Diseases of immune dysregulation and Immunodeficiencies with hypo-pigmentation. Talk to your immunologist for more information.

Article adapted from http://www.piduk.org

Iziyah's journey through CGD and BMT

Meet Iziyah - a bubbly 2 year old Auckland KIDS Foundation member battling rare primary immunodeficiency disorder Chronic Granulomatous Disease (CGD).

Iziyah is a fun, loving, and smart two-year-old boy despite having developed several serious infections in his life so far, requiring hospitalisation at Starship for days or sometimes weeks.

In February this year he developed a severe pneumonia that caused an abscess to grow in his right lung. Because of this he had a lobectomy and the right lower third of his lung was removed. When the doctors found this, they did further blood tests and found that Iziyah had a rare PID condition called Chronic Granulomatous Disease (CGD).

CGD is a rare 1 in 300,000 genetic condition that means his body can't fight bacterial or fungal infections. He was on preventative antibiotics and anti-fungal medicines at home as well as an injection to help protect him for 4 months awaiting bone marrow transplant. They found him a donor and he was listed for transplant.

Whilst in the bone marrow transplant unit, his mum Dani stayed with Iziyah and his seven month old sister Kaylee at the hospital. His dad worked full time but visited after work every day.

Dani expected to be there for a minimum of two months, possibly much longer depending on how Iziyah's body reacts to the new cells. She said, "IDFNZ Kids Foundation have helped us so much, I was able to get in touch with another mum with a PID son who had been through BMT and that was extremely helpful. The food vouchers for the cafe help a lot."

Dani kindly agreed to share Iziyah's journey through bone marrow transplant to eventual cure of CGD to encourage other parents facing this life saving treatment for their PID child. Visit her diary on the IDFNZ website to read their amazing story:

http://www.idfnz.org.nz/kids-foundation/stories/details/iziyah.html

Resilient Riaa's long road to recovery

Riaa Jasuja is an active five-year-old who loves riding her bike, going to school and spending time with her parents and baby sister. It's hard to believe this bundle of energy spent the first five months of her life in hospital, struggling to survive.

Riaa was born 12 weeks premature. When her mother Anita and father Vishal took her home, she seemed to be doing well until one day they she noticed wasn't breathing properly and had white patches in her mouth. Even though doctors gave her the "all clear", the parents felt something was wrong. They took Riaa back to Waitakere Hospital, where the doctors agreed to admit her for observation. Riaa threw up everything she ate, and a blood test finally revealed that Riaa's T-cells were not developing. Riaa was diagnosed with a Severe Combined Immune Deficiency (SCID).

A Starship Hospital specialist, Dr Virginia Wotton, confirmed the parents' concerns that Riaa wasn't breathing correctly and she was placed on oxygen. Tests showed Riaa had pneumocystis carinii pneumonia (PCP), so she was given Intravenous immunoglobulin (IVIG) for a month to top up her B-cells.

Starship Hospital became the family's home and Anita and Vishal appreciate all the support they got there, especially as their relatives lived in India. But when they learnt Riaa was immune deficient and they would need to give her IVIG regularly, they were not sure what that meant and how it would affect their lives.

Riaa's SCID condition was so rare, her blood and urine samples were sent to London, Melbourne, Sydney, London and Boston. "It was like a no man's land," says Vishal. "The doctors identified what she had but it seemed there was no definitive treatment."

The couple says specialists Virginia Wotton and Jan Sinclair were "amazingly helpful".

Once home, the parents kept Riaa in a protective environment; they sanitised and kept the house warm, which meant expensive power bills. They also faced the added anxiety of Riaa's development as she was born premature.

Every month tiny Riaa needed antibiotics and other fluids injected intravenously. As she was prone to infection, she spent much of her first year of life at hospital or indoors at home. The specialists decided a bone marrow transplant (BMT) was essential to boost her immune system. Her BMT donor was from Sydney, with a 6/6 match which meant an 80 percent success rate.

The first step was chemotherapy, and the side effects added to the challenges Riaa and her parents faced. After an infusion of Antithymocyte Globulin (ATG) to suppress her immune system, she developed mucositis, a painful inflammation, from her throat to her digestive tract and was in so much pain that she was on morphine for a week. Then she developed veno-opcclusive disease (VOD), slipped into a coma and spent days in the ICU.

Continued on page 4

Riaa Jasuja with Smith&Smith staff and her new bike, made for her by the Smiith&Smith team

Continued from page 3.

"But luckily our daughter is a real fighter," says Anita. "She survived and her bone marrow started to regenerate."

As her immunity improved, so did her physical health and her confidence. Now she is a chatty girl who loves to read, draw and play games.

"As a family, it's reminded us how important a healthy life is," says Vishal.

"We're more spiritual; our priorities have changed. You can buy medicine but you can't buy health."

It's been a long road to recovery, but the family is looking ahead. Their second daughter, Nyraa 14 months old, has had an easier start to life and is thriving.

Riaa takes medication daily and has regular specialist medical checks.

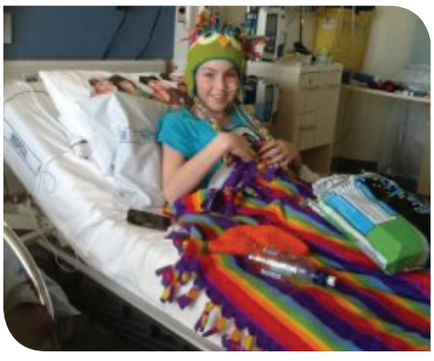
"But she's full of life now," says Anita. "She loves going to places like the zoo and the aquarium. It's been difficult as our family is back in India, but we owe a lot to Starship Hospital and the doctors and nurses involved, and we also appreciate all the support we get from IDFNZ."

Hannah is battling a rare combined immune deficiency and BMT

Introducing Hannah, a stunning 12 year old patient member from Invercargill

Hannah Capil was a healthy girl of nine years old when she came to her parents with a cough. What unravelled was a journey that the family is still on.

Hannah was first admitted to Christchurch hospital for 38 days in June 2010, as doctors first suspected that Hannah may have cancer. Many tests later, she had been screened for a wide range of possible medical conditions. "She had been through every medical team you can think of, with various medical complications - from respiratory, pain, ear nose and throat, opthalmology, haematology, immunology and gastrology," says her mum.



The first diagnosis of an immune deficiency was determined whilst at Christchurch Hospital, and confirmed when sent to Auckland Starship Hospital to be assessed by the Paediatric Immunology Specialist team. Hannah joined IDFNZ Kids Foundation when she was diagnosed with a PID in September 2010.

Hannah was finally diagnosed with an extremely rare combined immune deficiency condition. This rare genetic condition meant that her immune system could not fight infection. This particular PID condition is so rare Hannah is believed to be the only patient affected in the whole of Australia and New Zealand at the present time.

Having identified the medical condition, Hannah's trials were not over, as treatment posed new challenges for her. IDFNZ Kids Foundation was initially able to help with much needed information, contact with support staff and a practical medical alert bracelet as treatment options were discussed. The Capil family were also linked with other PID member families in the South Island, though Hannah's condition was in many ways unique.

Initial treatment involved monthly intravenous plasma infusions (IVIG) administered at her local hospital. Unfortunately Hannah found the treatment painful and suffered severe side effects as well as problems with vein access. A home treatment of sub cutaneous plasma infusions on a three weekly basis was also trialled using SCIG pumps donated by IDFNZ Kids Foundation. This treatment was also found to be problematic for Hannah, so bone marrow transplant was pursued.

Admitted to the Starship bone marrow transplant unit, the Capil family embarked on bone marrow transplant with Hannah - her younger sister Emma being her courageous donor. The BMT process involves intensive treatment - Hannah was to be in isolation on the BMT ward for a number of months. With Mum and Dad by her side Hannah had wonderful support -however she really missed her brother, sister, grandparents and friends who were such a long way away in Invercargill. With the help of IDFNZ KIDS Foundation and loving grandparents, her brother and sister were at least able to visit to cheer her up.

Hannah and her parents kindly agreed to share her BMT journey to help other PID families undergoing this lifesaving treatment in future. Surrounded by mainly cancer patients in the BMT unit, mother Lisa was grateful to be able to chat to another KIDS Foundation member who had previously experienced a successful BMT.

By keeping a diary, she was able to share the sort of details that she knows will benefit others.

http://www.idfnz.org.nz/pub/news/hannah-capil-rare-combined-imm/files/140_days_Hannah_bmt_diary_.pdf

Anyone who has followed her diary will recognise this has been a really tough time for the whole family. Hannah's case was especially complex and her stay in hospital was much longer than anticipated. Luckily things are now looking better and Hannah is beginning to smile again as her body slowly recovers. To prove this she has allowed us to post a few photos of special moments over the past few weeks when she has been allowed to make short visits off ward to meet some of her favourite stars.

The biggest smiles of all came on the 21st November, on the day she was finally discharged from the BMT unit (151 days after arriving in Auckland for BMT treatment). Well on the way to recovery now, the family will hopefully remain in Auckland for daily clinic visits, for just a few more weeks, before being allowed home just in time for Christmas

Medical Matters

Medical Advisory Panel Update

The IDFNZ Medical Advisory Panel (MAP) met on 26th September. We emerged as an expanded and reinvigorated MAP. I am pleased to announce that Dr Miriam Hurst, Adult Immunologist and Immunopathologist, Auckland City Hospital, was appointed to join me as IDFNZ Board MAP representative, to represent the needs of our adult Primary Immunodeficiency (PID) patients.

I will continue on the Board representing paediatric patient services. At the meeting, new MAP members were also nominated/endorsed by the MAP. I am delighted to report that the MAP now consists of 14 members (listed below), all with special knowledge and interest in immunology. We have complementary skills and the ability to provide the IDFNZ Board and membership with expert advice and guidance in regard to key and emerging medical issues facing patients with PID.

Thank you to these members for electing me to the vacant MAP Chair position. My goal is to have us work together as a committee, alongside the IDFNZ Board, exploring how we can meet the wider needs of the PID patient community. Our first project for 2014 is the PID patient conference, which will mark the 25th anniversary of IDFNZ and World Day of Immunology. We hope to have some interesting ideas to bring to the seminar, so mark the date – Friday 2nd May 2014, Butterfly Creek.

Thanks to the existing and newly nominated MAP members: Dr Jan Sinclair, Dr Penny Fitzharris, Dr Peter Flanagan, Dr Richard Steele, Dr John O'Donnell, Dr Kahn Preece , Dr Andrew Baker, Dr Karen Lindsay, Dr Anthony Jordan, Dr Miriam Hurst, Janice Capstick, Susie Lester and Simone Stephens. *Happy holidays and safe travels!*

Dr Shannon Brothers
IDFNZ MAP Chair and Board Representative

Parenteral Nutrition Down Under

Parenteral Nutrition Down Under (PN-DU) is a self-funded, not-for-profit support group for consumers and carers in New Zealand and Australia on Parenteral Nutrition (PN). PN is food in a liquid form which is delivered via a catheter in a vein close to the heart, when it is not possible to eat regular food due to a problem with the digestive system. The nutrients are in a bag of sterile solution which is infused through the intravenous catheter with a pump. All connections and procedures must be aseptic, to minimize infection risk from bacteria entering the bloodstream.

After training to manage their PN themselves (or by their parents/carers), most people can leave hospital to continue their therapy at home. This is known as Home Parenteral Nutrition (HPN). The number of people in this part of the world on HPN is small – less than 40 children and adults in New Zealand – and the reason patients end up on this life-support therapy is as a result of 'intestinal failure' which encompasses a wide range of congenital problems and digestive diseases.

HPN is a very complex and highly specialised life-support therapy and not knowing anyone else on HPN can be quite isolating and challenging.
PN-DU was established in early 2009 by a consumer passionate about support, best practice and equality for all HPN consumers and carers. As a group our motto is to "support, research and inform consumers, carers and providers of Parenteral Nutrition for intestinal failure", and we aim to do this through our website, our quarterly e-newsletter "Drip Line", brochures, our private discussion forum, as well as consumer and carer meetings and social gatherings. We recently held our inaugural PN-DU Auckland gathering and hope to organise another one before the end of the year. We are also involved in various projects, groups and conferences to help raise awareness of HPN.

It is encouraging to have contact with The KIDS Foundation and to hear about the great work and support this group offers PID children, teenagers and their families. If any of your members would like to know more about PN-DU, please feel free to contact us at contactpndu@gmail.com or visit our website:
www.parenteralnutritiondownunder.com

Family Conference 2014

Help us to celebrate 25 years of IDFNZ supporting PID patients. Inviting PID patients and families from all over New Zealand. Excellent guest speakers for the adults combined with a fantastic fun programme for the children. More information will be provided nearer the time but be sure to add this to your diary!

IDFNZ Immune Deficiencies Foundation of New Zealand

The Kids Foundation key immune deficiency support

Hereditary Angioedema network goes live

HAE Australasia is proud to have launched its online home at http://www.haeaustralasia.org.au. The website offers resources and information for patients, physicians, healthcare providers and caregivers of hereditary angioedema patients. Olivia Willard, who represents New Zealand patients as a director of HAE Australasia, says the group is passionate about its role of providing hope, advocacy and awareness for HAE patients and their families across Australia and New Zealand.

"We are also gearing up for the next HAE Australasia annual patient meeting in Adelaide next March," she says. "Two New Zealand families attended the gathering in Brisbane last May and found it really useful meeting other families and hearing from Australia's leading medical experts."
One New Zealand HAE patient has just started a trial of Icatibant, a self-administered drug that has been used successfully in Australia for two years.

All4Good is the fundraising arm of IDFNZ / KIDS Foundation, allowing us to work with schools, businesses and individuals to raise valuable funds for our foundation.

At the beginning of the year we asked members and supporters to help us by getting behind a range of grassroots fundraising projects.

We have been thrilled by your enthusiastic response – here are just some of the many projects we would like to share with you demonstrating ALL4GOOD being practised in schools, workplaces and even in sporting events.

Thank you so much to everyone who has participated to help IDFNZ KIDS Foundation.

ALL4GOOD Schools

Thank you to all schools and preschools who participated in our 2013 ALL4GOOD schools fundraiser; in addition to raising almost $8000 in funds for KIDS Foundation, those participating all reported having a positive experience from supporting their community. Activities included simple mufti days, raffles, sausage sizzles and sales of work. Some schools combined these activities with lessons around the immune system, awareness of Primary immune deficiency disorders and their impact on children affected by these conditions. Others took the opportunity two reinforce basic rules of good hygiene, germs and how the body is protected by the immune system.

Gisborne Montessori School held an Orange day which was great fun for the children but still carried all important messages; teachers said, "Children are learning to help others and getting a sense of community while learning about the immune system".

We would also like to thank Lions Clubs around New Zealand for getting behind our event and encouraging local schools to particpate. Many thanks to KIDS Foundation members who called on local schools and clubs to support ALL4GOOD.

Lucky winners of the All4Good competition draw were:

1. Beachlands Primary School, Auckland
2. Gisborne Montessori School
3. Jack' n' Jill Pre-school, Hamilton.

Beachlands Primary School, Auckland

ALL4GOOD Auckland Marathon

What better incentive can there be to run a marathon in memory of a beloved child? Julian Ng was devastated when his oldest son Callum was diagnosed with a rare PID condition called Wiskott Aldrich syndrome at 10 months of age. This is one of the rarer PID conditions. Unfortunately despite his parents intuitively understanding he needed specialist help, and taking all of the right steps to get the PID condition diagnosed, Callum died in Sydney's Children hospital at only 16 months of age whilst awaiting a bone marrow transplant that could have cured his condition.

Determined to never forget his precious firstborn, Julian decided to turn his love of running into a way of making a difference and honouring the memory of Callum. "As a tribute to Callum's brave fight, I wanted to help raise some money to support families in a similar situation to what we have been through". Julian signed up to compete in his first ever full marathon at the adidas Auckland Marathon on 3rd November 2013.

He used the event to raise funds for KIDS Foundation. A keen runner Julian trained hard to progress from his usual ½ marathon to run a full marathon, and set himself an additional challenge to get his times down. He certainly achieved his goal coming 31st out of a total of 2,733 race finishers.

Callum with parents Julian and Cate

Great effort Julian – and many thanks for choosing to raise precious funds for IDFNZ KIDS Foundation. We will make sure these funds benefit other children facing similar challenges to Callum.

Last year Shirley Davy, ran her first half marathon to support IDFNZ Kids Foundation. This year she too raised the bar, not only running herself, but also leading a whole family team to run the full Auckland marathon. The team was named in honour of Sam – her handsome young son who has complex medical needs and has spent much of his life in hospital .

When Sam Davy was born, his parents Shirley and Francis were told he was unlikely to survive a year. Sam's rare condition results in severe gastrointestinal failure. Beating the odds has meant spending more than half his life in hospital. KIDS Foundation , has helped by supporting Sam and his family.

Despite a very busy year with many hospital visits, operations and general chaos wrecking her plans for serious training – Shirley and the team managed to complete the course. Her determination once again shone through, to raise precious funds for the Foundation that helps support Sam. And if that wasn't enough – guess who was on duty selling fireworks at the KIDS Foundation Botany stall the following day? Thank you Shirley!

It is humbling to know that members like the Davy family can think of others even when their own lives are so volatile as a result of constant medical emergencies.

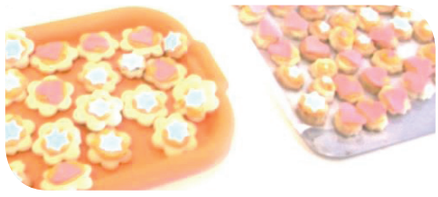
Sam Davy

Gisborne Montessori hold 'Orange day' for IDFNZ / KIDS Foundation

Gisborne Montessori had a day to raise money for the Immune defficiency foundation. The whole preschool, three classrooms paticipated with dressing up and baking something to sell.

One class, beehive one, where the idea originated as we have a family that belongs to the KIDS Foundation, dressed up in orange and had a coin donaation for doing this. They also had a baking day where the parents had pre-ordered their cookies so we knew how many to bake.

The head teacher brought in already made cookie dough, and the children helped roll and cut out biscuits and baked batches of cookies. Teachers helped by bringing in more cookies they had made at home and the children iced them on the day of dressing up. In total, we iced 150 cookies.



A big thank you and Season's Greetings to all our wonderful supporters this year:

- NZ Children's Transplant Support Trust
- ANZ Staff Foundation
- The Infinity Foundation
- CSL Behring
- Delloit Community Involvement Fund
- Four Winds Foundation
- Endeavour Community Foundation
- Smith and Smith Ltd
- Trinity Foundation
- Blue Sky Community Trust
- Pub Charity Inc
- The Dragon Community Trust
- EM Pharazyn Charitable Trust
- FH Muter Charitable Trust
- COGS
- Pyro Company Fireworks Ltd
- Holiday Helpers NZ Waiheke Island
- Annual Appeal Supporters
- Wishlist supporters
- Circus Quirkus

ALL4GOOD Community

Fun, fireworks - and a rip-roaring fundraiser!

Business is booming: Pyro Company CEO Len Julian (left) with IDFNZ volunteers Vicki, Aiden and Mischa Tattley

Colourful fireworks not only brightened up the night sky throughout New Zealand on Guy Fawkes in November - they also helped raise thousands of dollars for the Kids Foundation/IDFNZ.

Thanks to our sponsors, Pyro Company Fireworks Ltd, and a host of wonderful volunteers at five fireworks stalls throughout Auckland and Whangarei, our annual Guy Fawkes fundraiser was a huge success. The stalls were managed by the Auckland and Whangarei Board members with the help of some amazing volunteers who gave up days of their time to help the Kids Foundation. Special thanks to community helpers ICONZ, Girls Brigade and BMAFC Beachlands Maraetai Soccer Club volunteers who ran our Manukau and Botany stalls as a combined community fundraiser, and to Smith & Smith Glass staff who helped out as part of their Giving Back programme.

Thanks also to the site owners who allowed space for our stalls, including Mitre 10 Mega (Manukau, Botany and Whangarei), Alexandra Park Raceway and Dental Today.

And big thanks to Pyro Company Fireworks Ltd Director Len Julian, who decided to support the Kids Foundation last year, when he was inspired by long-time IDFNZ members Grant and Vicki Tattley.

"Fireworks are great for families of all ages, and it's been part of the New Zealand lifestyle for generations," says Len. "I have children myself and when I heard about the great work the Kids Foundation does, I was glad to help." Vicki and Grant Tattley ran the stall at Alexandra Park for four days, helped out by their children Aiden and Mischa - when they could take a break from studying for exams.

As one volunteer said: "I didn't know anything about fireworks but I learnt a lot after a few hours of selling them. We had something for everyone - family packs and sparklers for the younger children, up to the 'Armageddon' packs for the serious fireworks fans who love lots of noise as well as spectacular sky rockets. We also handed out brochures explaining how to use fireworks safely and to take care of animals". "Customers were really happy to support Kids Foundation, and we could reassure them that they were getting good quality fireworks. A lot of people also bought some for special events like Diwali or New Year's Eve."

After this year's success, the Fireworks event is set to be a major part of IDFNZ's annual fundraising campaign.

Christmas Appeals

As you work up to enjoying Christmas with friends and family, please spare a thought for our patient members who will most likely be in hospital over the holidays. Here are a few you will remember from previous newsletters:

Madison Merrick - Spending Christmas in England

Madison may experience her first white Christmas this year – by December 25th she will have spent 7 full months in Birmingham awaiting her intestinal transplant.

Those months have been very eventful – she has experienced her first travel by air, first time abroad and first period of time living outside of hospital (albeit very close by and for short bursts!) Unfortunately she has also had periods of being really unwell, admitted to hospital many times, more surgery – and a lot of homesickness for New Zealand. 2014 brings with it uncertainty as Madison patiently waits to be listed for transplant. Sending lots of love and Christmas good wishes to Madison and Alana from her friends at KIDS Foundation.

Anyone wishing to send Madison a message or Christmas gift, visit www.fundraiseonline.co.nz/MadisonMerrick/

Zoe Edwards - Hoping for a cure in 2014

Di George Syndrome caused Zoe to be born with a severe heart defect and without a thymus, affecting her whole immune function and leaving her vulnerable to life threatening infections. Last year, this brave little girl from Whakatane underwent both open heart surgery and Thymus transplantation, meaning she has spent most of her short life in hospital. Treatment still continues as Zoe's immune system struggles to respond, and her doctors are now exploring stem cell transplantation and a possible repeat Thymus transplant in the USA.

2014 looks to be another year of more medical procedures and long hospital stays for this gorgeous toddler and her family. Zoe's parents are thankful that early diagnosis of PID has allowed time for these life preserving treatment options to be explored, giving the family hope that they will receive the miracle they so desperately need to build a functioning immune system for Zoe and save her life. Wishing Zoe and her family a very merry Christmas and all the best for 2014.

Give hope to Zoe and her family - Give generously at http://www.fundraiseonline.co.nz/ZoeEdwards

Ashton Cresswell – Spending Christmas in Starship

This young Palmerston North baby has been in hospital since July. Born with SCID, Ashton has been fighting hard to survive; he is now in the process of receiving a bone marrow transplant which will hopefully correct his immune function and allow him a normal life in the long term. His mum has been by his side in Auckland and his older brother and sister have been in the care of his grandmother. This family has really faced hard times as they uplift Ashton and focus on getting him well. We are sorry your first Christmas will be in hospital Ashton – but we wish you good luck for a quick recovery in 2014, and look forward to seeing you at the next KIDS Foundation Christmas party.

Anyone wishing to send Ashton a message or Christmas gift, visit https://www.givealittle.co.nz/cause/ashtonsfight