IDFNZ intouch
KIDS FOUNDATION
Issue 3, 2017

Dates for your diary

Razzamatazz Shows 2017

September 2nd
Christchurch, Middleton Grange Performing Arts Centre- 12pm & 3pm.

September 9th
Riley Centre, Wellington High School- 12pm & 3pm.

September 16th
St Cuthbert's School 12pm & 3pm.

September 17th
St Cuthbert's School 12pm & 3pm.

Other Events

September 30th
IDFNZ AGM, Miramar Golf Club, Wellington.

October (date tbc)
IDFNZ New Zealand Blood Service event, Wellington 6.30pm.

October (date tbc)
Christchurch Patient meeting.

November 2nd to 5th
Fireworks Fundraiser. Please support us!

Xmas Parties 2017

Dates coming soon for Auckland, Christchurch and Wellington members. Check the website for details.

IDFNZ Mid-year Report

Thank you to all members and supporters who have assisted with our regular campaigns promoting the early warning signs of PID and Paediatric liver disease. April is our PID awareness month and June our Beware Yellow month – allowing time to convey these important messages to save and improve lives. Taking the time to read and pass on our information and postings is helping us to spread our message through the community.

Ask any parent or patient member of IDFNZ diagnosed with a rare disease "what could have made a difference?" their response will almost always include "getting a diagnosis earlier" or "knowing the meaning of early symptoms or clues to their medical condition". By promoting the early warning signs consistently, we can make a real difference and start an informed conversation between concerned families and health professionals.

Our membership has had a significant boost this year with a flux of newly diagnosed patients of all ages as well as new supporters, indicating that we are making a difference, and are reaching our target audience. Our presence on social media is growing and it is wonderful to see members sharing experiences and supporting others.

The Patient events held so far, this year have been well supported and more are planned for the second half of the year. We encourage members to stay connected. On September 30th, our AGM is to be held in Wellington this year – an opportunity for local members to come along to meet the Board, including our new Chairman Adriaan Bosch; all members are most welcome to attend, we would love to catch up with you and hear your ideas.

The Annual appeal has been in full swing with fantastic support from businesses around New Zealand; the Razzmatazz Benefit shows are scheduled for September in Christchurch, Wellington, and Auckland - tickets are being sent out now.

Our annual Fireworks community fundraiser is being planned again for November – locations of our stalls are still being finalised and we will need volunteers to manage sites over the 4 day sales period, as well as casual volunteers to assist for a few hours at a time.

If you can't spare time to help on a site – you can still assist by promoting our products and pre-selling to friends, family, and work colleagues. See our website for order forms of popular Pyro company favourite's available for pre-order. Remember all proceeds go towards supporting the IDFNZ KIDS Foundation services provided free to members.

This edition of In Touch is once again filled with some amazing and courageous member stories from a wide sample of the patients and families IDFNZ supports.

We hope that it brings encouragement to any of you feeling overwhelmed or alone in dealing with your health concerns. Hearing the stories of others can be empowering.

IDFNZ Shining a light on PID Awareness

We are pleased to report that the IDFNZ "Living with PID Campaign", our contribution towards World PID Awareness week April 22-29th, was a huge success. PID awareness has reached a wider audience than ever in New Zealand this year via social media, website and printed newsletters and magazine articles.

The Facebook campaign was developed to increase public awareness around PID - and more specifically this time, adult patients. We wanted to reach the 70% of undiagnosed individuals struggling with their health, not realising there is an underlying immune problem.

We also highlighted that, once diagnosed, NZ can provide world class care via our public health system unlike some other countries

The IDFNZ Facebook campaign alone reached **54,000 individuals;** We included a 60 second mini video which stirred interest and helped spread the message around PID. Over 6,249 visitors took action and viewed the video over the 6-day period of PI Week.

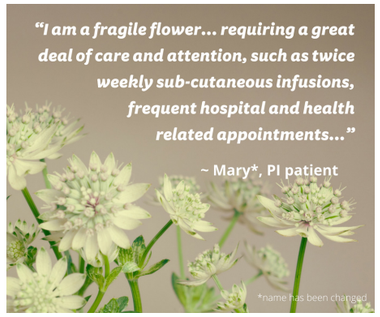
Early warning signs of PID were brought to the attention of the general public and primary health care providers; stories were shared to highlight how individual patient members achieved a firm diagnosis relating to these warning signs, and their subsequent improvement in health and quality of life once under immunology specialist management of their PID medical condition.

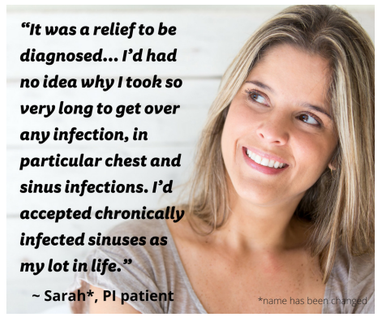
We set out to present examples that related to parents of new-borns and young children, and received a very positive response from all over New Zealand and overseas. The conversation buzzed as individuals shared experiences and passed on information.

Children's posts

We also started a much-needed conversation around conditions such as CVID which is often diagnosed in late teens through to adults of all ages. The response from this group of members was really encouraging and had a wonderful flow on effect – with many enquiries from the general public seeking more information.

Adult Posts





A huge thank you to everyone who shared their personal story and to the storytellers and engaged users who actively responded with comments and feedback through the campaign.

The key outcomes include a flux of new IDFNZ PID members of all ages from across New Zealand, and many more individuals now armed with comprehensive information packs to start a conversation with their GP around exploring PID as a possible cause of their undiagnosed health problems.

Supporting this activity, the ASCIA online GP training information was also well promoted by IDFNZ to prepare GP's for patient enquiries concerning PID.

Our People

Colleen Twine

It can happen to anyone.

My grandfather was one of those men gassed in the trenches with mustard/chlorine gas, he was invalided out and spent the next 30 years in and out of hospitals critically ill. I remember his wheeze and hacking cough. A tip for all of us. In later years he walked, come rain or shine. Instead of the 7yrs of life predicted, he died at 84yrs!!

I was a fit and healthy young lady, I danced and swam competitively. At 19yrs of age I had the lead dancing role in "Brigadoon", was hostess for my home city of the year, worked and completed a dancing examination. The next year I became an airhostess and flew for 6 years.

My husband was also with the airline, so I was mum and dad a lot of the time to my two wonderful boys. We renovated 4 homes, and I've since renovated the 5th by myself and my friends. I was a swimming teacher/tutor while the kids were young, moving on to coaching as they did. I figured it was a great way to work and be with your kids! This is when my troubles began.

I seemed to have respiratory infections except when I was away from the pool. I had heaps of antibiotics getting sicker over the next 20 years! I went doctor to doctor trying to sort out my problems. At this time, I was beginning to think it was all in my head!

Finally, a respiratory specialist who had just read an article in the medical journal put the puzzle pieces together. I am allergic to chloramines from the indoor chlorinated pool. GAS! I now have huge sympathy with my grandfather and his mates in the trenches in World War 1!!!!

I was still getting sick. Finally, lab tests at Auckland hospital showed virtually no immune system. CVID! That was over 8 years ago. I have built up to infusions every 3 weeks (I tried sub-cut but it wasn't for me).

Like my granddad all those years ago I too get a wheeze and a cough and spend time in hospital most years. Unlike him I also have immune problems, with new ones seeming to pop up all the time. The one I hate most is the constant need of a toilet. (I have one in my van for emergencies)!! Ferry's work well, but busses are a mission. Every trip away from the house has to be carefully planned. A couple of years ago I went to Australia. My lovely immunologist organised infusions for me. I was staying with my son and started getting sick. My intensive medical kit wasn't working and my lad took me to his local Manly Hospital. I was admitted to intensive care and proceeded to give the family a bit of a fright. The thing worrying me most was I had to get out of Manly Hospital to get the arranged infusion at another hospital! My kids don't invite me to stay now!

We are so lucky in New Zealand; the hospitals and staff treat us well and for FREE!!!!

We are so lucky to have IDFNZ to tuck us up under their wing, with all the super sponsors who care and support us!! THANK YOU!!

Colleen

Deborah Lennon

It's taken me weeks to get around to writing this because of fatigue, which says it all.

I am doing this because I have gained a lot from reading other people's stories, including American patients' accounts in IG magazine sent by IDFNZ.

I was born seemingly very healthy but developed ENT/milk problems at preschool and was on sulphur drugs in the 50's after a burst ear abscess. My middle-class background protected me at school as I was not exposed to many sick children.

At 6 the paediatrician investigated me for TB, but luckily it was chronic bronchitis followed by anaemia for years on end with daily iron. T&A operation was performed aged 17. Upper respiratory tract and chest infections continued on lifelong. A nasal cautery was done in my 30's.

At university, I got viral meningitis but excelled academically and won a PH.D. scholarship, a Fulbright and briefly lectured at university before going to the U.S.A. doing research.

My health made it very difficult and I could not finish my PH.D. and lost my promising career. The lack of sympathy was stunning. In 1991, a cyst was drained with a needle followed by a nasty anaerobic (bacteria) abscess three weeks later. This resulted in years of on and off Mastitis infection (mammary duct ectasia) which has only just stopped.

Simultaneously there have been teeth abscessed, infection under crowns, root canals, urinary infections, a kidney stone with pseudomonas (resistant bacteria) infection, sepsis following a D&C, pleurisy following a knee operation, Epstein Barr, herpes viruses, fibroids, osteoarthritis, small airways disease, cataracts (early), Hashimoto's thyroiditis with very long courses of antibiotics, for years on end.

I was fortunate to have a good G.P. for 14 years who diagnosed 'immune disorder' in 1988 without testing, based on the history. Later under an immunologist (private), I self-referred to in 2008 I got investigated and diagnosed with CVID. IVIG started in 2010. Lately food poisoning (E Coli) hit me. I am now 64 and have been unable to work. The financial, social and familial repercussions have been enormous.

Deborah

Medical Matters

The journey of modern immunoglobulin replacement to New Zealand

How did we come to use the current immunoglobulin therapies' to treat primary immune deficiencies? Looking to recent times there appears to have been great gains in the treatment of primary immune deficiency in the last few decades. While this is true the first small steps towards modern treatment actually started in the late 19th century.

Research looking towards blood as a treatment for disease started as early as 1890. At this time Emil von Behring and Shibasaburo Kitasato showed that injecting healthy rabbits with blood serum from rabbits with tetanus could protect healthy rabbits from disease (Eilb,2008). von Behring also worked with Erich Wernicke around to show this worked for humans with diphtheria. He began using this as a treatment for people with illness. This was a crucial step for the future as it showed that blood had protective properties. von Behring received a Nobel Prize in Physiology or Medicine at the first Nobel awards in 1901 for this work (Grundmann, 2001). From this time he and others started to measure, standardize and develop the antitoxins (now known as antibodies) found in blood for the treatment of patients.

By 1910 blood serum was used to treat infectious disease, allergy and cancer. To do this blood serum that carried a specific disease molecules (antibodies), was given to patients' with that disease. During this time animal blood serum was used to treat humans, as animals were noted to carry the same diseases as people. As a result this treatment caused a condition named serum sickness. Serum sickness is a reaction to the blood serum causing the person receiving it to become unwell. It was noted that when human serum was used in treatment there was less serum sickness and other harmful side effects (Eilb, 2008). Human serum became the first choice treatment from this time. Animal products were not removed completely, as even today some very well processed animal plasma is used safely in medical treatments although not immunoglobulin replacement.

The next improvement was to measure and identify the parts of blood serum. The method of measuring individual blood serum parts improved with the development of electrophoresis in 1938 (Eilb,2008). Electrophoresis is the separation of molecules by their size and electrical charge. The molecules travel with electricity at different rates so separate out (MedicineNet, 2013). Electrophoresis made it easier to identify and measure the individual proteins of immunoglobulin.

Now that the measurement and identity serum parts existed, the next step was to separate out the plasma from the whole (red) blood. Plasma is the clear part of the blood containing antibodies and other proteins. This occurred in the 1940's with the need to treat injured soldiers with plasma during World War II. Dr Edwin J. Cohn from Harvard developed a process named fractionation. This worked by using ethanol (alcohol) and temperature to separate the plasma from blood and separate each of the proteins from plasma (Marketing Research Bureau,2017). This process is still used to produce many of the immunoglobulin products commonly used today.

Then came 1952! The first primary immune deficiency case is identified. Dr Ogden Bruton describes a young boy that is unable to fight any childhood infections. Dr Bruton measures no immunoglobulin antibodies in the boy's blood. He treats this boy with subcutaneous immunoglobulin (SCIg) which allows the boy to become free of infection. The condition becomes known as Bruton's Agammaglobulinaemia (Eilb, 2008). From this time classification and treatment of other primary immune deficiencies are uncovered. Later research discovers an inherited link which is passed through the mother. A faulty gene in the X chromosome is passed to mainly sons who have no immunoglobulin antibodies. The gene Bruton's Tyrosine Kinase (BTK) was discovered in 1993 from that time the deficiency was renamed X-linked agammaglobulinaemia (Immune Deficiency Foundation, 2013).

Through the decades following Bruton's discovery, immunoglobulin treatment was generally given into the muscle (IMIg). Intravenous immunoglobulin (IVIg) had been used but due to frequent severe reactions especially in children it was rarely chosen as a treatment (Merler, 1970). While IMIg helped improve the health of people it was painful, time consuming and had its own issues with unwanted reactions.

Through the 1970's IVIg products began improving and became safer as a treatment. IVIg then became the standard therapy. During the 1980's a group of patients contracting hepatitis C through IVIg led to further improvements in screening, testing, processing and quality control processes (Eibl, 2008). The early 1980's saw the development of concentrated immunoglobulin which was give through a slow infusion with rapid push at the end of that decade (Wong, 2015). SCIg infusions became the first line treatment through some parts of Europe. During this time New Zealanders were either using IMIg or IVIG.

During the 1990's safety issues to prevent infections being spread through immunoglobulin use were improved upon (Eilb, 2008). While most patients in New Zealand were using IVIg at this time there were a small number of patients unable to tolerate IVIg. These people were using a normal immunoglobulin (NIg) preparation produced for IMIg and giving it under the skin as a subcutaneous infusion with good effect. This NIg infusion consisted of multiple smaller vials that often need to be given numerous times per week.

A study to introduce New Zealand users to a SCIg product in 2007 with plasma collected from New Zealand donors and processed by Commonwealth Serum Laboratories (CSL) Ltd in Melbourne. This study was to review the safety and effectiveness of this new product. In 2013 this product became available as the commercial product named Evogam. While this product became the main SCIg product used in New Zealand there was now also other international products available if needed.

Currently in New Zealand slightly more than half of people with primary immune deficiencies requiring immunoglobulin replacement are using intravenous infusions at hospitals or clinics with the rest using subcutaneous infusions at home in the community. The ability to have both these products available allows for flexibility and choice for those requiring treatment.

Thanks to the pioneers in blood research and immunology current research and development continues to improve to treatment choices for those that requiring immunoglobulin replacement.

Written by Simone Stephen Immunology Nurse Specialist

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IDFNZ Patient Services Available to all registered patient members

Support of patient members and families includes:

- Support visits where requested – at home or hospital
- Information relating to specific medical conditions, treatment, welfare entitlements, advocacy and referrals to other support agencies where needed.
- Networking and connecting with other patient members
- Patient Education events
- Library service , free loan service
- Various Social events for patients (and families/ siblings) in your region

Family grants and financial assistance towards approved medical expenses; all patients can access application forms from Support staff.

Financial assistance typically includes:

- Parking vouchers to help subsidise hospital car park expenses
- Hospital café vouchers for long stay patients
- St Johns ambulance membership assistance (when available)
- Chemist vouchers towards prescription medications (when available)
- Travel grants for family support and visitation of family members for long stay patients (liver transplant/BMT/etc.)
- Other items / assistance may be considered on a case by case basis
- Patient Education events
- Library service , free loan service
- Various Social events for patients (and families/ siblings) in your region

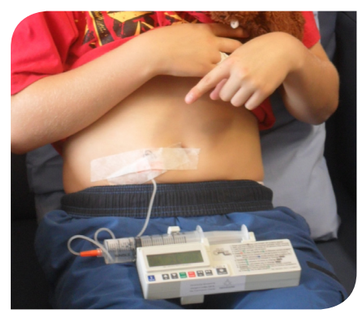
Approved medical equipment and supplies can also be applied for through Support staff. Examples include:

- SCIG pump for PID patients (in conjunction with your immunology team)
- Courier service to home deliver SCIG consumables (not Plasma)
- Chiller bags for transport/ storage of SCIG supplies.
- Epipens (must be prescribed by your GP)
- Medical diaries
- Medical bracelets (available for purchase)

Respite care facilities are available at 4 locations in New Zealand, families can apply for holiday breaks at greatly subsidised cost. Families recovering from transplant or extended hospital admissions may receive complimentary vouchers for free stays.

- Red Beach, Auckland
- Mangawhai Heads
- Otaki Beach
- Bannockburn

The Foundation also offers up to 6 selected families Waiheke breaks each year in conjunction with Holiday Helpers Network Waiheke Island



From Our Teenage Patient Members

Coping With CVID

I was 14 years old and just about to finish my first year at college when I fell sick. At first it was just a cold which should have been fought off by my body's immune system.

But then it developed into pneumonia and I was admitted to hospital for 10 days as I had become very unwell. On the day I was supposed to be leaving the hospital, I had a visit from the Immunology Department who basically said that I had CVID, Common Variable Immune Deficiency. When they said that, it was like everything in my head made sense. For all my life I had always had blocked sinuses and it seemed like my colds were constant throughout winter and summer. My Auntie and Uncle on my Dad's side have immune deficiencies too, but my Dad doesn't show any sign of them so I didn't realise I had the chance of having the deficiency. By the time I was released out of hospital I was in a pretty bad way, mentally and physically. I had lost about 5 kg from the pneumonia when I felt too sick to eat, I had missed exams after a year of working hard and now I had an "illness" which would stay with me for all of my life.

I was scared that my whole life would change because of CVID. I thought my friends would ask me questions about it and judge me for it. I was in the top netball team at school, I did rock climbing and running and I was pretty fit and sporty before my pneumonia. I thought I would have to give up the sports I love. In fact, I couldn't have been more wrong and I am still fully involved in many sports. When I was diagnosed with CVID, I had to go into hospital once a month to get 200ml of immunoglobulins put into me so that my immune system could keep functioning like it should. After about 4 months of going into hospital and getting the treatment injected into my veins, I realised that it wasn't working for me as I had small veins and it was a lengthy process getting the IV needle in. I decided doing the sub cut procedure at home would be better for me.

So, after three training sessions, my Mum and I were ready to start doing it at home. Obviously, I was nervous because I associated the infusion with pain. I was scared that I wouldn't be able to do it and would have to go back to the hospital and miss a day off school each month. Luckily, once I had done it at home I got used to the feeling and was happy to continue with the process. Now, almost 6 months since I found out about my condition, I have gotten used to living with CVID. It doesn't affect my sports or school life and after having the treatment I never feel sick or unwell. I find my life is back to the way it used to be before I got sick, well except for the fact that now I am well and my immune system is working like it should. Thank you to the staff at immunology at Starship hospital for being so helpful and understanding, you guys are amazing!

By Olivia Thompson

Recent Events – IDFNZ PID Members "Going In Style" to the Movies

As part of PID awareness week, PID members in Auckland and Wellington came together for a movie event, enjoying the humorous new release "Going in Style", a movie that appealed to a wide audience. With coffee and treats afterwards, members could mingle and chat together; many helpful conversations took place and friendships initiated.

There are further PID events planned for later in the year – please keep an eye out for these in our newsletter and on the IDFNZ Facebook/website.

www.idfnz.org.nz

Imogen Constantine

Being a teenager isn't easy. There are those uncontrollable rushes of emotion both good and bad, the first crushes and first heartbreak, the pressure of school and home, and the want to be treated as an adult even if you aren't quite ready for it yet.

Imagine for a moment that you are already experiencing all of this and then another bombshell is dropped on you – you need a liver transplant because yours is too damaged to continue functioning. For those of us who have never experienced this it can be hard to think of let alone wonder how to deal with something of that magnitude. This was, however, Imogen Constantine's reality. At just 14 years old, she was shocked to learn from her doctors that she needed a liver transplant.

Unfortunately, this wasn't the first diagnosis Imogen and her family had received regarding her liver. When she was three she contracted giardia and a liver test indicated that something was wrong. Imogen recovered but continued to suffer from heartburn.

Then, the Constantine family had been told that Imogen at just seven years old had Autoimmune Hepatitis and Primary Sclerosing Cholangitis

(PSC). Autoimmune Hepatitis causes inflammation and damage when the immune system attacks the healthy cells of the liver, while PSC indicates that the bile ducts within and connected to the liver are inflamed and can be seriously damaged. The doctors who diagnosed and treated Imogen had hoped that multiple medications could keep her liver healthy enough to function but there was no guarantee. By December 2015 tests showed that her liver was shutting down.

Shock didn't seem to cover how Imogen felt when she heard the bad news. She had been feeling fairly fine, only a little tired, and lacking in energy and unmotivated to go out or spend time with friends. However, none of that seemed bad enough to point to her needing a new liver. After feeling fine for so long, it was a surreal experience to be told that her only chance of survival was a liver transplant.

As seems to happen quite a lot, after the diagnosis Imogen went downhill quickly. After an intensive round of bloods and tests, she was put on the transplant list and was able to return home to rest and stay healthy until the call came that a match had been found. She admits she spent a lot of time on Google reading up about her procedure. The thing that kept her positive was joining a Facebook group for those who had gone through a transplant and had the same diagnosis, as well as reading their stories.

Her family also say that the support given to them by Kids Foundation was invaluable, and knowing that IDFNZ was there if they ever needed anything including a holiday away in one of the Foundation's holiday homes, gifts at birthdays, and an ambulance pass was a great resource. For seven months Imogen and her family waited for the call that they had to return to hospital so she could have the surgery to replace her liver. When it finally came in June of last year, it was a relief. On June 29th, Imogen finally received her new liver.

Then came the next step in her recovery. Prescribed a lot of medication when she was first post-transplant, Imogen came to her next big hurdle. After battling anorexia only a short time earlier, she had to contend with a large amount of weight gain caused by the steroids she had been given. After everything she had been through, this became the hardest thing she had to face through her transplant journey.

Now Imogen is nearly sixteen and is coming up to her one-year anniversary post-transplant. A biopsy and tests to check her liver function is the next step to get through. Being monitored closely in the first few weeks post-transplant to now only having monthly blood tests has also helped her move forward in her recovery. Her medications have been cut down to three – an antibiotic, a steroid and her anti-rejection medication – and life is improving. She wants to finish school at Long Bay College which has become a lot easier now that she is healthy. Her love of yoga, singing and being with her friends has also made life a lot more enjoyable.

The story of a teenager going through the stress and fear of a liver transplant can be hard to hear but Imogen Constantine's story is one of hope, life and the will to face whatever is coming head on.

She is an inspiration and her story is one that will help many others facing illness and surgery to fight to survive just as she has done.

IDFNZ - Beware Yellow Campaign

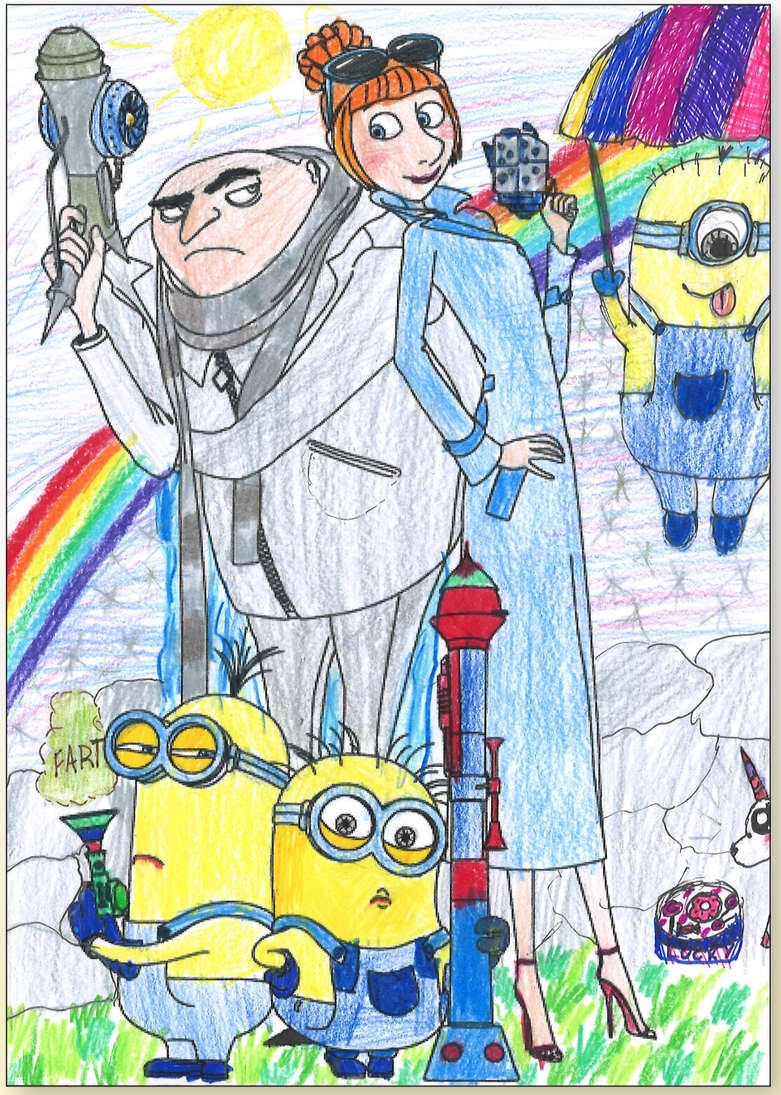
In June, our energy went into promoting the "Beware Yellow message" targeting expectant mothers and mothers across New Zealand to communicate the early warning signs of paediatric liver disease in new-born babies. This was achieved using social media, website, and advertising strategies.

The Facebook campaign was supported by a 60 second video, patient stories and a Despicable Me 3 Fundraiser event taking place at the end of the campaign.

Running for over 3 weeks the campaign material was viewed over 41,000 times, with over 1,000 engaged users interacting and sharing our message.

We were awarded over 900 likes and the material became a hot topic of discussion for close to 600 storytellers sharing experiences as a result of the campaign. This is really encouraging as we succeeded in engaging with our target audience.

IDFNZ kids Foundation also sponsored printing of the Beware Yellow early warning signs in the 2017 Bounty books which are distributed free to Birthing centres and Maternity hospitals across New Zealand and handed to all new mothers. Coupled with the posters, pens and other printed materials we provide free to Midwives, GPs and Plunket Nurses we are making a solid effort to spread this important message.



Isobel Age: 11yrs.

Recent events

We ended Beware Yellow Month with a special viewing of **Despicable Me 3** in Auckland. We were thrilled with the support we received and sold out all of the tickets for this event. The movie was fun with lots of cheeky Minion's humour. Everybody enjoyed attending and appreciated the Minion goodie bags and snacks.

Congratulations to the lucky family winning the jumbo Minion gift pack!

The winner of the Beware Yellow colouring competition was Isobel Bezart from the North Shore.

Giving Back on Beware Yellow Day

After everything she's been through, Lilly Thoresen wanted to give back to those that had helped her through some of the hardest times in her life.

She wanted to make sure that her school knew that there were others out there who needed support as they struggle through illness and liver transplants. She decided to organise a Beware Yellow Day at her school to raise awareness and money for IDFNZ Kids Foundation. She succeeded.

Raising $630 dollars, Riverdale School has generously given their time to make sure their students and the families that are a part of the school know more about what we do here at Kids Foundation. Lilly and her mum wanted to start this annual tradition to help give back to the Foundation as a thank you, and to enable us to continue to support our members.

Lilly encouraged her school to put on a mufti day where everyone came dressed in yellow and gave a gold coin donation. The entire school got into the spirit of the day having fun and enjoying themselves.

Amazingly, Lilly and her mum have even volunteered their time to help two other schools organise Beware Yellow Days for the next school year, and hope they too will become an annual occurrence.

Well done Lilly, her family, and Riverdale School. Your efforts are much appreciated and the Foundation is very grateful for all the effort you put into supporting us.

BEWARE YELLOW

Lexi Fitness

Born on the 9th March 2016, Lexi Fitness seems like any other 15-month-old. She's always on the go, loves walking everywhere, and adores her older brother and sister.

There is no way to tell by just looking at her that she has been through so much in her short life. However, if you sit down with her parents and speak with them, you will hear the rest of Lexi's story.

At just three weeks old, Lexi was taken to the paediatrician by her worried parents, Gabrielle and Mark. They knew something was wrong but didn't know what, and the paediatrician couldn't give them a diagnosis either. The next few months followed with Lexi continuing to deteriorate. Although she had jaundice (a yellowing of the skin and whites of the eyes indicating bad liver function) it wasn't as noticeable because of her olive skin-tone. However, the white of Lexi's eyes showed the yellowing of jaundice clearly. Still worried they were admitted into Starship for bloods, a liver biopsy and ultrasound to try and discover what was wrong.

At four and a half months old, on 22nd July, Lexi, Gabrielle, Mark and their family were finally given a diagnosis for Lexi's illness; Biliary Atresia. Their little girl's abdomen was hard and swollen, she was small for her age, and she wasn't putting on weight causing great concern. In addition to the Biliary Atresia diagnosis, it was also found that Lexi has Polysplenia which means she has many small accessary spleens which do not work rather than one, full-sized, normal spleen.

The next step came in the form of a Kasai, a procedure to bypass the blocked bile ducts of the liver to try and prevent more damage to the organ through built up bile. Doctors weren't optimistic before the operation as Lexi had been diagnosed so late, and when they went in during surgery on 1st August, they found her liver was too damaged for the Kasai to have any effect. Her family was told that their little sister and youngest child would need a liver transplant.

Lexi was put on the transplant list and underwent a one-week transplant induction. This time was used to help Lexi's family understand the steps that needed to be taken before and after her transplant, as well as ensuring she was healthy enough to go through a liver transplant. She was started on TPN (IV nutrient) to help her put on some much-needed weight as well. Thankfully the family live locally so they didn't have to stay at Starship. Instead, they travelled there three nights a week so that Lexi could receive the TPN.

Mark, Lexi's dad, put up his hand to start the process that would assess him for a live liver donation. He completed almost all the tests and things looked like they were on the right track for him to be a liver donor for his daughter. Sadly, the family was delivered another blow. Near the end of the testing process, Mark was informed that he had a problem with his blood which excluded him from being able to donate part of his liver to Lexi. Devastated, the Fitness' turned to their family and friends and amazingly, Mark's best friend Reuben Hardie, stepped forward; he agreed to donate part of his liver to little Lexi.

During this time, Lexi's name stayed on the donor list as Reuben went through the testing process. The Fitness' were called into Starship once while he was being tested as another donor liver had become available, however, this liver was found to be not viable and the family was sent home again.

Finally, on 23rd November 2016 Lexi's transplant went ahead. The surgery went smoothly and things started looking up for the sick little girl. Apart from a bile leak six days post-transplant which was caught in time and corrected in surgery, she healed quickly. Now, Lexi has monthly bloods and check-ups to monitor her liver function levels as well as attending clinics to make sure she is healthy and doing well. Her family has nicknamed her 'Teeny' because she was so small before her transplant.

Gabrielle and Mark are grateful for Starship doctors and nurses who they say are amazing, as well as the gastro team and other medical professionals at the hospital who helped save their daughter. They are thankful for the service Starship provides as well as the support they received from Kids Foundation. Not only did the Foundation they help with hospital parking vouchers but Mark and Gabrielle were amazed by their generosity in providing Christmas presents for Lexi as well as her siblings.

Now at seven months post-transplant, Lexi is an energetic little girl who enjoys the swings at the park, any and all dogs, picking up anything she can get her hands on and putting them into the drier, and moving things around the house.

She had a rocky start to life but now, with the medical knowledge and emotional support provided for her and her family, she has the chance to thrive, grow and live a full happy life.

Lilly Thoresen

Imagine for a moment that your child of three has only just gone through years of blood tests, multiple surgeries, a liver transplant, nausea and vomiting, fear and pain, and then, when you think the worst is over, they are diagnosed with cancer in their lymph nodes.

To many this is, thankfully, a world away from what their children must experience in the first few years of life. Unfortunately, this was reality for Lilly Thoresen and her family.

Born at 36 weeks due to her mother suffering from preeclampsia, Lilly had an abrupt entry into the world. She was jaundiced and at 9 weeks old her mother asked her Plunket nurse what she needed to do. She was told to put Lilly in the sun. When this failed to help, and with a persistent feeling that something was wrong with her baby, Tina took Lilly to the GP. From there Lilly was sent to Palmerston North Hospital for tests and started to be tube fed. These tests revealed the diagnosis for Lilly's problems – Biliary Atresia.

At ten weeks old, Lilly had a Kasai ordered by the specialist who had come from Wellington to review her case. The procedure was meant to clear out her liver's bile ducts but ultimately it failed. Lilly then spent months in hospital as doctors tried to find another way to deal with her illness. Her swollen stomach was just the outward sign that her liver was failing and, in the end, a liver transplant was her only option for survival.

The family flew up to Starship and were admitted for 12 weeks as Lilly had to be stable and healthy enough to have a transplant, as well as undergo different tests to make sure the perfect donor was found for her. Her father, Luke, put up his hand to donate part of his liver for the transplant. On 4th May 2010, Lilly had the 16-hour surgery that would change her life forever.

After being in PICU for two to three weeks after transplant, she was sent back to the ward on a Friday, only to return to surgery on the Sunday with a swollen stomach. Her bowl had been nicked in the operation and a new surgery lasting 10 hours was performed to fix the problem as well as insert a stoma bag. This caused Lilly a lot of pain because the adhesive used to secure the bag caused a bad reaction as she has sensitive skin. The family spent one year in Ronald McDonald house ensuring Lilly was healthy enough to return home.

However, when they got back home Lilly was sick again with what was thought to be Rotavirus and cause vomiting and diarrhoea. Back to hospital she went and she became so ill that her family nearly lost her. Flown back to Starship,

bloods were ordered and after two bone marrow tests, the possibility of cancer was mentioned. Devastated but unable to anything but try and stay hopeful and think positive, the family waited for more results. The tests, sadly, came back positive and Lilly and her parents were given the devastating diagnosis of post-transplant cancer in her lymph nodes.

With an amazing amount of strength for such a small body, Lilly made it through Chemotherapy and enjoyed two years of good health. And then, in 2013, things started to go bad again. Lilly would vomit and choke on her food and had diarrhoea constantly.

In August of that year the problem was found to be EoE (eosinophilic oesophagitis), meaning that her oesophagus became inflamed after reacting to medications and continual vomiting, which damaged the tube that connects her mouth and stomach. Even now she is fed through a tube and must be gluten, dairy and tree nut free to help limit the damage done to her oesophagus.

Lately, Lilly has been dealing with kidney stones in both kidneys, enduring constant pain without the hope of relief from an operation as her body is so small the surgery would be too difficult to do. She can't walk long distances and her immunity is all but non-existent. Constantly sick and tired, Lilly attends school from only 9am to 1pm and must rest for hours once she returns home. Every Chicken Pox season is a constant worry because Lilly must go into isolation for 28 days so she doesn't contract them. Help from the government is limited to 3 hours a week of tutoring during the Chicken Pox season and after a long battle with Lilly's school, they finally understand that she needs extra help and have provided two teacher aids during school hours.

Every six months, Lilly goes back to Starship to have tests for her liver and scopes to check her oesophagus with a gastroenterologist, and every month she has bloods and tests to check her progress. She also has mild bronchiectasis, asthma, cataracts from having to take steroids for too long that need to be monitored and fears needles and blood. To help her with some of her fear, Lilly's parents have made sure she speaks with a psychologist about her anxiety, flash-backs of what she has been through, and her inability to breathe properly when she panics.

Lately she has even been remembering things that happened to her when she was younger and sounds and smells can trigger her anxiety.

Lilly is soon to be eight years old and is trying to live as normal a life as she can. Although small for her age, suffering from hair loss from Chemo treatments, in constant pain from kidney stones and unable to walk too far, do too much, or even attend school full time, her mum says she is a happy, cuddly, and caring little girl. Wanting to give back to those who have helped her, Lilly has also helped organise a Yellow Day at school on 30 June to fundraise for IDFNZ.

With a gold coin donation, she hopes to raise awareness as well as funds. She has also completed a 2.5km walk to raise awareness as well. Hoping to give back, Tina, Lilly's mum is involved in helping two other schools in their area organise their own Yellow Mufti days. They hope that these will become annual traditions in each school.

After almost loosing Lilly three times in her short life, Tina and Luke make sure to celebrate every anniversary of Lilly's transplant with a gift while Lilly takes her father out somewhere special and makes him a gift as a thank you for donating part of his liver to save her. The present she gave him just recently on her 7th Anniversary post-transplant was a picture she made of the two of them with wings, flying to Starship to save her.

Although facing such adversary in such a short life, Lilly Thoresen has grown and thrived amazingly. She is a happy girl who loves her school friends, wants to be an artist when she grown up, and thinks of others who may need her help. The strength of her parents and the hope they had in her survival is amazing and we wish them and Lilly all the best for the future.

Sponsorship & Fundraising

Thanks to our Charitable Trusts

A huge thank you to all the Charitable Trusts who have supported our foundation over the last year. Your backing enables us to provide for our members and their families in every way possible, as well as giving us the means to offer free events and support services. We are grateful for all that you do and look forward to continuing our partnership as we move forward.

Smith and Smith Giving Back
North and South Trust
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COGS Auckland City
Trinity Foundation
Mainland Foundation
Trillian Trust
Dragon Community Trust

Calling all Volunteers!

Our annual Fireworks Fundraising Appeal is almost upon us and we are looking for volunteers to help man stalls and sell fireworks.

In association with Pyro Company, the fundraiser will be held from 2nd to 5th November. The stalls will be set up in Auckland, Wellington, Whangarei and Christchurch.

We had over 100 volunteers last year and raised an amazing $27,000 toward patient support services. It was a great effort and we think we can keep up the momentum this year. So, if you and your family and friends love fireworks, please support us by helping to sell, manning a stall, or buying your fireworks from one of our containers.

If you want to stock up on fireworks for birthdays and other celebrations through the year, we encourage you to buy from us and help support IDFNZ KIDS Foundation.

Pre-purchase your fireworks as well as take bulk orders from friends, work colleagues and family. Orders must be paid for in full and we will organise for you to pick up your fireworks from the nearest KIDS Foundation stall.

Your continued support is important to us and is the way we are able to continue helping our members and their families.

Three good reasons to be part of our ALL4GOOD Community Fireworks Fundraiser:

1. **You love the good family fun of quality fireworks**
2. **You have a heart to help our special needs children as part of your club or school Community Service**
3. **You want a new way of raising funds for your own community group or school.**

Check out our website for more information.