Sanfilippo
Children's Foundation

2016 OUR YEAR IN REVIEW

WHAT WE'VE ACHIEVED TOGETHER IN 2016

JAYDA
HANNAFORD
2006 – 2016

Our mission is to fund medical research so a cure can be found in time for children battling Sanfilippo today and those born with it tomorrow.

IN MEMORIAM

Jayda Hannaford

In 2016 we lost a much-loved Australian child to Sanfilippo Syndrome. Jayda Hannaford from Gunnedah in country NSW lost her battle to Sanfilippo in October 2016. Jayda was just 9 years old but touched the hearts of everyone she encountered in her short life.

We had the pleasure of meeting Jayda and her family on several occasions. Jayda was also the star of a news story about Sanfilippo broadcast on Network 10 'The Project' in 2014.

Jayda is sadly missed by her loving parents Anna and Craig Hannaford and her little sister Lucy.

We would like to dedicate this document to Jayda's memory. Jayda is pictured with her loving family on the cover.

Cover photography: Carly Donnelly Buggalugs Photography.

CONTENTS

Photo: Tim Bauer / Fairfax Syndication.

A message from our Founder

In 2016 my husband Allan and I both participated in our Foundation's signature event the Sanfilippo 1000 – Big Feet for Little Feet, training and running a 28km leg of a trail run along Victoria's Great Ocean Road.

It was an incredible experience, giving me a rare opportunity for reflection – to contemplate (while running) and look back at the last three years since forming the Foundation. I have to say it has been quite the adventure. An adventure I wish with all my heart that we weren't on – but an adventure nonetheless.

With each kilometre run, I was reminded of the generosity and compassion of others from all corners of the world and from all walks of life. On this adventure, we have seen so much generosity – not only generosity of funds, but generosity of spirit, time and energy.

We are firm believers that when like-minded people work together, scientific leaps and accelerated change is possible. And that's why we have made it our mission to fund medical research so a cure can be found in time for children battling Sanfilippo today and those born with it tomorrow.

We were thrilled in 2016 to see the start of the Abeona Therapeutics gene therapy clinical trial in the USA, and eagerly await the outcome of the Australian regulatory process which is underway.

However, even if this treatment works, sadly not all children with Sanfilippo will be eligible – some have different sub-types of the condition or may not meet the criteria for other reasons. We also know that if successful, this will be the first generation of such a therapy and further work will need to be done to fine-tune and optimise it.

So, with that in mind, in 2016 we moved in to the next phase of our research strategy. We extended our esteemed Scientific Advisory Board (SAB) to help us to identify research and clinical trial opportunities. You can meet this incredible group of professionals on page 16.

In 2016 we ran our inaugural funding round and made a global call for research projects. Our SAB reviewed applications and we are proud to announce that we have selected five new projects to fund.

We are extremely excited about the progress that might be made by funding these projects. Our focus is on science that shows potential to either halt progression of Sanfilippo, reverse damage caused by the condition or improve the quality of life for children who suffer from it.

You can read a summary of each of the research projects selected for funding in 2016 on page 7.

People sometimes ask how their small donation can really make a difference, and there can be a perception that research is a black hole. But the fact is that relatively small amounts of investment can deliver amazing returns and outcomes for rare diseases like Sanfilippo. Under our new funding program we can get an incubator research project up and running for under $100K.

If you're curious about who's who at the Sanfilippo Children's Foundation, please turn to page 17 to meet our team. However please keep in mind our team of employees is only part of the picture. More so than ever, the success of our work lies in the strength of our partnerships – and there are many organisations, communities and individuals to thank.

To our Board and Scientific Advisory Board, I thank you for your continued guidance, positivity and unwavering support. To our corporate partners, your support is invaluable. To our donors, I thank you for your ongoing generosity and commitment to our cause.

To the families who face Sanfilippo every day, thank you for your passion, energy and your strength. You are the reason we do what we do.

We must also acknowledge the many volunteers who contribute to our Foundation events and community fundraisers. Without the support of this optimistic and energetic group of people, we simply could not do all that we do here at the Sanfilippo Children's Foundation.

I'm incredibly proud of just how far we have come – there is so much behind us, but still so much ahead! Please continue to walk with us in 2017, or better yet why don't you run or even cycle with us by joining our SFSuper Series. Contact us to find out how.

With gratitude and hope,

Megan Donnell

WHAT A YEAR!

5 NEW RESEARCH PROJECTS FUNDED

Announced funding of five research projects - pioneering new research in the neglected field of Sanfilippo, which could provide the missing piece of the puzzle.

6 RESEARCHERS & CLINICIANS

Gathered the best minds in the field of Sanfilippo to form the Foundation's esteemed Scientific Advisory Board. Ran 1st full grant round and have funded 5 new research projects.

RESEARCH MANAGER APPOINTED

Appointed a research manager to our team to help draft science-related communications and manage our research funding program.

20 PRINT ARTICLES PUBLISHED

INCLUDING AN ARTICLE IN NATURE JOURNAL

In 2016 over 20 print articles were published about the vital work of the Sanfilippo Children's Foundation, including an article published in 'Nature Journal', an international journal of Science.

RAISED ALMOST $200K IN A SINGLE EVENT!

The Sanfilippo 1000 brought together 52 runners, 10 cyclists and more than 1000kms collectively covered in each event.

8,185 FOLLOWERS

ON SOCIAL MEDIA

Social media is a key way we engage with our supporters and potential donors. In 2016 our organic Facebook reach alone peaked at 16,000 people while we have 822 Twitter followers and a growing audience on Instagram.

Other Highlights from 2016!

- Volunteer Tom Miles won Australia Day Award 'Manly's Citizen of the Year' on 26th January. Tom Miles was nominated by the Sanfilippo Children's Foundation.
- On 29th February (International Rare Disease Day) US biotech Abeona Therapeutics announced Federal Drug Administration (FDA) approval of its gene therapy trial. As part of the FDA announcement, Australian kids with Sanfilippo were pictured on the Nasdaq tower in Time Square, New York.
- Announced Foundation's expanded Research Strategy and associated Research Funding Program. Ran 1st full grant round and have funded 5 new projects.
- In March the Hope for Kyuss campaign hit $100,000, doubling its original target. In October Hope for Alec reached $50,000 after just a year of fundraising and the Hope for Skye campaign hit its $50,000 target in December following its launch two years ago.
- Started our Regular Giving Program: Become a Star for Sanfilippo.
- Families with children battling Sanfilippo met Prime Minister Malcolm Turnbull at a function at Kiribilli House.
- Article published in 'Nature Journal', international interdisciplinary journal of Science, about gene therapy with a profile of the Sanfilippo Children's Foundation.
- Introduced new mascot 'Gemmi the Giraffe'. We chose a giraffe as their long necks stretch towards the highest branches or things thought to be "out of reach" just like our Foundation stretches towards a treatment and one day a cure for Sanfilippo Syndrome.

SCIENCE UPDATE

Research Funding

In 2016 The Sanfilippo Children's Foundation launched its Research Funding Program which aims to support research that has strong potential to halt disease progression, repair damage and improve quality of life. We believe that investment in these areas is essential to bring desperately needed treatments to the clinic.

Research Focus Areas

OUR RESEARCH PROGRAM WILL CONSIDER FUNDING PROJECTS THAT ADDRESS THE FOLLOWING:

HALT DISEASE PROGRESSION

- Enzyme replacement, gene therapy, cell therapy and other emerging therapies to stop progression of Sanfilippo
- Strategies to enhance the effectiveness of emerging therapies
- Halt disease progression early to optimise brain development

REPAIR DAMAGE

- Repair and reverse cell damage caused by Sanfilippo
- Broad application of neuroregenerative treatments, for example repurposing approved drugs
- Opportunity to collaborate with researchers working on other neurodegenerative diseases

IMPROVE QOL

- Improve quality of life of children/adults with Sanfilippo
- Palliative care and symptom management specific to Sanfilippo

Research Principles

THE FOLLOWING PRINCIPLES UNDERPIN OUR RESEARCH STRATEGY & APPLY TO EACH FOCUS AREA.

FUND THE BEST RESEARCH

FUND RESEARCH RELEVANT TO OUR OBJECTIVES, REGARDLESS OF GEOGRAPHY, DISCIPLINE OR RESEARCHER.

FOCUS ON TRANSLATIONAL RESEARCH

DRIVE RESEARCH SHOWING TRANSLATIONAL PROMISE, TO GIVE PATIENTS EARLY ACCESS TO EMERGING THERAPIES.

ENCOURAGE INNOVATION & COLLABORATION

ENABLE INTERNATIONAL COLLABORATION. COLLABORATE WITH OTHER FUNDING BODIES TO CO-FUND PROJECTS.

BUILD NEXT GENERATION CAPABILITY

SUPPORT FUTURE RESEARCH LEADERS EARLY IN THEIR CAREERS & ATTRACT RESEARCHERS FROM OTHER DISCIPLINES.

Research Projects funded by Sanfilippo Children's Foundation

High throughput drug screening

This project, to be carried out at the Hospital for Sick Children in Toronto, Canada, involves screening ›6,000 compounds using a Sanfilippo cell model and a further 7,000,000 drugs using computer modelling to identify those that might be effective for Sanfilippo.

The project, led by Associate Professor Andreas Schulze, will focus on an approach known as "substrate reduction" which aims to reduce the production of harmful sugars in the brain. If effective drugs are identified they could be used to treat not only Sanfilippo Types A, C and D but also Hurler (MPSI) and Hunter Syndromes (MPSII). We have negotiated to co-fund this project with Cure Sanfilippo Foundation (USA), our contribution will be AUD$224,000. We are also thrilled to have the support of the Petersen Family Foundation who have committed to helping us fund this project with AUD$50,000 over 2 years.

🇨🇦 Translational | 2 YEARS | AUD$448,000 | **A** B **C** **D**

Investigating the role of brain lipids (fats) in Sanfilippo

We are funding a one-year project to be carried out at SA Pathology, Adelaide, Australia led by Associate Professor Maria Fuller.

Sanfilippo has a catastrophic effect on brain cells, one aspect of which involves the disruption of fat metabolism which is thought to impact on proper brain development and function. This project will investigate the role of fat in the brain in mice with Sanfilippo and whether it might be possible to develop a treatment that normalises fat metabolism.

🇦🇺 Incubator | 1 YEAR | AUD$90,900 | **A** B C D

Optimising gene therapy

There are currently several gene therapy clinical trials underway for Sanfilippo and this project at the University of Florida led by Dr. Coy Heldermon will build on this work. The project will test several different modifications to existing gene therapy technology, along with different ways of administering it, to find the best combination for Sanfilippo Type B.

We have negotiated to co-fund this project with Sanfilippo Initiative (Germany), our contribution will be AUD$45,000.

🇺🇸 Incubator | 1 YEAR | AUD$90,000 | A **B** C D

Neural and mesenchymal stem cell mediated gene therapy

Researchers at the University of Florida led by Dr. Coy Heldermon will investigate the potential of two different types of stem cells as a therapy for Sanfilippo Type B. This approach may be able to halt progression of Sanfilippo by supplying deficient enzymes and also reduce inflammation in the brain which is understood to cause significant damage in the disease. A major advantage over other potential therapies is that the stem cells may also be able to reverse some of the damage already caused prior to diagnosis and treatment. We have negotiated to co-fund this project with Cure Sanfilippo Foundation (USA), our contribution will be AUD$45,000.

Incubator | **1 YEAR** | **AUD$90,000** | A **B** C D

Gene therapy for Sanfilippo Type C

Sanfilippo Type C is more challenging to treat than the other subtypes because of the way the deficient enzyme works with the cells. For this reason, a different gene therapy approach is required and this project, led by Dr. Brian Bigger at Manchester University is focused on optimising treatment for this sub-type.

We have negotiated to co-fund this project with Jonah's Just Begun (USA), and the international H.A.N.D.S Consortium. Our contribution will be AUD$90,000.

Incubator | **1 YEAR** | **AUD$130,000** | A B **C** D

Research Round-up

Gene therapy news

Abeona Therapeutics was given the green light to start a Sanfilippo Type A gene therapy trial in February 2016 and dosed the first patient in the USA in May. Encouraging results were presented in October from the first group of three study participants 30 days after they had received a low dose of the therapy. They reported that the treatment appears to be safe and there were encouraging signs that the gene therapy vector is crossing the blood brain barrier and having a biological effect. On the back of this, the company has been given permission to treat more children at higher doses.

The Sanfilippo Children's Foundation has committed USD $1 million (est. AUD$1.3 million) to Abeona on the proviso that a clinical trial site would be established in Australia. The regulatory approval process is currently underway and it is expected this trial will commence in the first half of 2017. A trial site is also planned for Spain.

Enzyme replacement therapy news

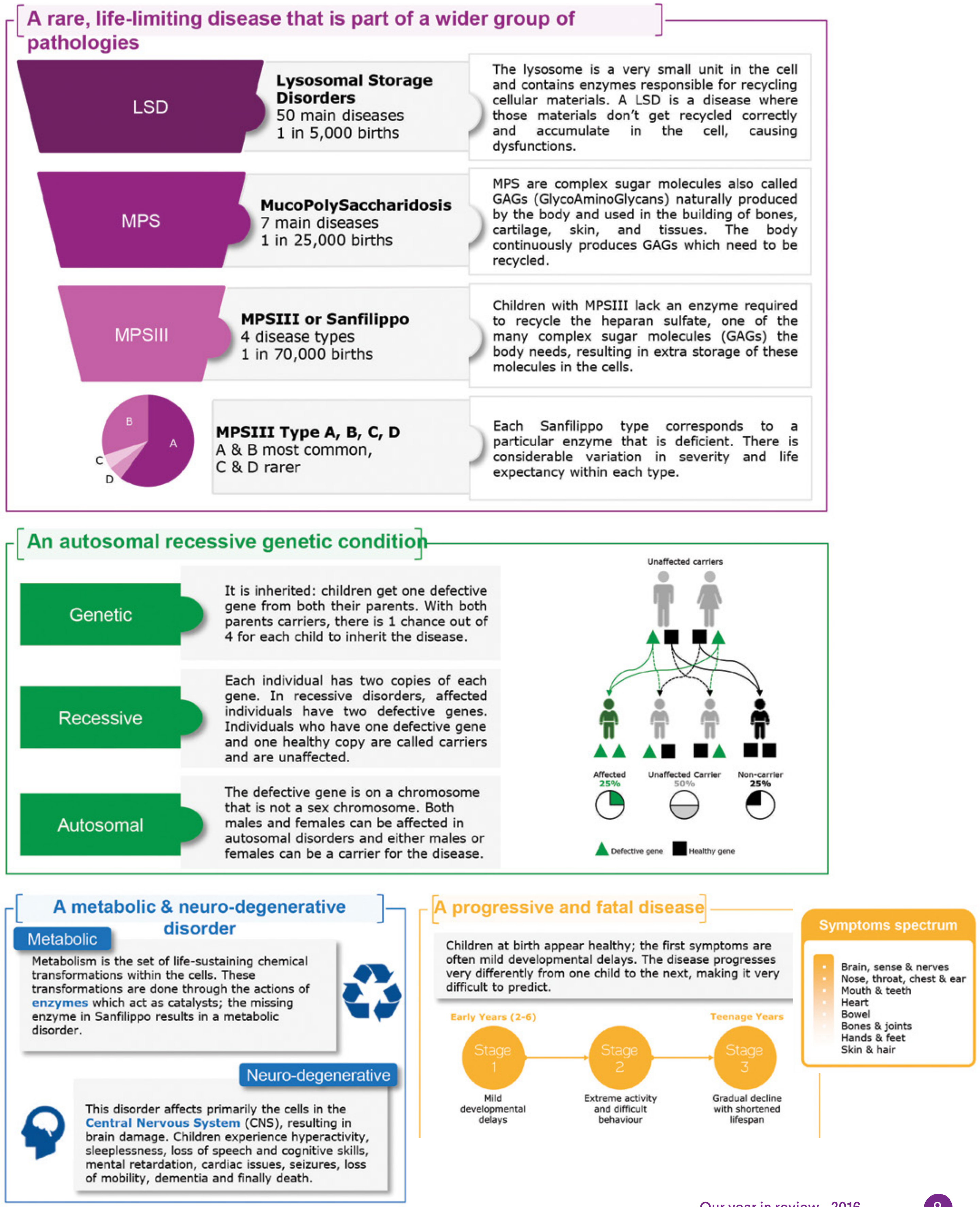
In July Alexion reported positive preliminary results from its clinical trial of enzyme replacement therapy for Sanfilippo Type B which is being conducted in the UK and USA. The treatment involves injecting the enzyme that is missing in Sanfilippo Type B into the blood stream once every two weeks. After 24 weeks of treatment, there appeared to be a stabilisation of symptoms in most of the 11 children in the trial. These encouraging results will allow the trial to continue and all children will move onto higher doses.

BioMarin has also started a clinical trial of enzyme replacement therapy for Sanfilippo Type B. In April the first patient was enrolled which involves weekly injections into the brain (intracerebroventricular infusion). This trial is being conducted in several sites globally with Melbourne approved as one of these sites.

In August the pharmaceutical company Shire Pharmaceuticals announced the closure of its enzyme replacement therapy trial for Sanfilippo Type A, citing the treatment had failed to slow cognitive decline. They made it clear that the program closure was not due to safety issues.

THE DISEASE

The following information provides a better understanding of the disease Sanfilippo (MPSIII).



A rare, life-limiting disease that is part of a wider group of pathologies

Lysosomal Storage Disorders
50 main diseases
1 in 5,000 births

The lysosome is a very small unit in the cell and contains enzymes responsible for recycling cellular materials. A LSD is a disease where those materials don't get recycled correctly and accumulate in the cell, causing dysfunctions.

MucoPolySaccharidosis
7 main diseases
1 in 25,000 births

MPS are complex sugar molecules also called GAGs (GlycoAminoGlycans) naturally produced by the body and used in the building of bones, cartilage, skin, and tissues. The body continuously produces GAGs which need to be recycled.

MPSIII or Sanfilippo
4 disease types
1 in 70,000 births

Children with MPSIII lack an enzyme required to recycle the heparan sulfate, one of the many complex sugar molecules (GAGs) the body needs, resulting in extra storage of these molecules in the cells.

MPSIII Type A, B, C, D
A & B most common,
C & D rarer

Each Sanfilippo type corresponds to a particular enzyme that is deficient. There is considerable variation in severity and life expectancy within each type.

An autosomal recessive genetic condition

Genetic: It is inherited: children get one defective gene from both their parents. With both parents carriers, there is 1 chance out of 4 for each child to inherit the disease.

Recessive: Each individual has two copies of each gene. In recessive disorders, affected individuals have two defective genes. Individuals who have one defective gene and one healthy copy are called carriers and are unaffected.

Autosomal: The defective gene is on a chromosome that is not a sex chromosome. Both males and females can be affected in autosomal disorders and either males or females can be a carrier for the disease.

A metabolic & neuro-degenerative disorder

Metabolic

Metabolism is the set of life-sustaining chemical transformations within the cells. These transformations are done through the actions of **enzymes** which act as catalysts; the missing enzyme in Sanfilippo results in a metabolic disorder.

Neuro-degenerative

This disorder affects primarily the cells in the **Central Nervous System** (CNS), resulting in brain damage. Children experience hyperactivity, sleeplessness, loss of speech and cognitive skills, mental retardation, cardiac issues, seizures, loss of mobility, dementia and finally death.

A progressive and fatal disease

Children at birth appear healthy; the first symptoms are often mild developmental delays. The disease progresses very differently from one child to the next, making it very difficult to predict.

Symptoms spectrum

- Brain, sense & nerves
- Nose, throat, chest & ear
- Mouth & teeth
- Heart
- Bowel
- Bones & joints
- Hands & feet
- Skin & hair

OUR FAMILIES

Every family has a story. These are just some of the Australian children battling Sanfilippo Syndrome.

Isla and Jude are brother and sister. Seven-year-old Isla likes playing with her dolls, dress-ups and watching 'Peppa Pig'. Five-year-old Jude will start "big school" in 2017. He likes his sandpit, playing with diggers and riding his bike. Isla and Jude love their therapy dog, a black Lab named Remy. Isla and Jude's parents are hopeful that one day there might be a treatment available for their children or as a legacy to them.

www.hopeforislaandjude.com

Four-year-old Kyuss loves to ride his quad bike and feed the chooks on his grandparents' farm. He charms people wherever he goes. Last year he started to catch the bus to kindergarten. He loves to wave goodbye to mum Nikki and his pet dog named Hope. His family all live in hope.

www.hopeforkyuss.com

Eight-year-old Peter touches many hearts. While Sanfilippo has stolen his words, his beautiful eyes speak a thousand words. Last year Peter's little sister Natalie was diagnosed with Cancer (Wilms Tumour) and is undergoing treatment. All Peter's family wants is for him to also have a chance of treatment.

www.hopeforpeter.com

Read more about the experiences of Australian families who are impacted by Sanfilippo Syndrome. Visit our website **sanfilippo.org.au**

Seven-year-old Skye loves to swim and going to the park with big brother Luke. She enjoys swinging high in the air and isn't afraid of the flying fox! Skye was born on Christmas Day and is a true gift to her family. Her parents worry Christmas Day will not always be a double celebration.

www.hopeforskye.com

Five-year-old Jacob loves dancing to The Wiggles, splashing in water and playing with his little sister Alexis. He likes to run and jump and bursts with energy. His grandmother Debbie says Jacob wakes up beaming and brightens every room he enters. His family fear he will one day lose his beautiful spark!

www.hopeforjacob.com

Nine-year-old Meckenzie pursues life with joyful and reckless abandon. Her favourite thing to do is meet and greet new people, she is truly gregarious with an infectious personality. Her parents and big brother Kyle adore her beyond measure and treasure every day they have with her.

www.hopeformeckenzie.com

Ten-year-old Alec loves swimming, listening to stories and camping holidays. He has a special bond with his big sister Sienna. His mother Michelle says a smile and a cuddle from Alec can make the hardships of a day disappear. All his family wants is for Alec to be surrounded by understanding and love.

www.hopeforalec.com

CAMPAIGNS & APPEALS

Sanfilippo 1000: $196,500

The 2016 Sanfilippo 1000 – Big Feet for Little Feet was one of the highlights of 2016, raising $196,500. 52 runners, 10 cyclists and more than 1000kms were collectively covered across both events. At the heart of the campaign were two Great Ocean Road events: the 100km Surf Coast Century and a 171km bike ride from Anglesea to Port Campbell. Competitors raised funds via sponsorship and by supporting various fundraisers in NSW and Victoria throughout the six-month campaign period. Thank you once again to all our incredible participants and our generous platinum sponsor Experian, gold sponsors SAS, CoreLogic and Panthera Financial, goods-in-kind sponsors RG Running Groups, SSRS and other sponsors Malouf Pharmacy and Label Creations.

St. George Foundation: $42,500

In July we received a grant of $42,500 from the St. George Foundation. The Sanfilippo Children's Foundation was one of 12 community organisations who received a share in the St. George community grant round. The grant will go towards coordinating targeted information for children affected by the disease and their families in Australia. The Foundation was thrilled to be a recipient of the grant.

ASX Thomson Reuters Partnership Race & Charity Horse Race Day: $36,680

In 2016 we became a beneficiary of the ASX Thomson Reuters Charity Foundation, which helps Australian-based disability and medical research charities by organising fundraising events in conjunction with the financial markets (these events include a sailing regatta, golf day & gala dinner). The ASX Thomson Reuters Charity Foundation distributes $1.5 million across 30 charities. In exchange, our Foundation supplies volunteers to these events and is required to sell art union raffle tickets with proceeds for every ticket sold going to the Foundation. In June 2016, the ASX Thomson Reuters Charity Foundation also hosted a Charity Horse Race Day at Rosehill. The Foundation sold several tables to our network of supporters with proceeds from every ticket going to Sanfilippo research.

Sumptuous Sounds Event: $30,000

A fusion of music and food was the delicious concept behind our inaugural Sumptuous Sounds dinner held at Pilu Restaurant in Freshwater, Sydney in August – the first in a series of unique dining events. The inaugural event featured the music of hipster harpist Jake Meadows and combined the mouth-watering tastes of Taylors Wines (major sponsor) with the award-winning food of Giovanni Pilu and raised $30,000 for the Foundation. The event was managed by a committee of passionate volunteers, and guests were treated to an evening of fine food, fine music and fine wine! Planning is underway for 2017's Sumptuous Sounds event … so watch this space.

Corporates

There are many causes that the corporate sector support but this year we forged a partnership with the Macquarie Group Foundation and staff from the Group's Sydney Compliance team fundraised for our Foundation, raising $10,000 with a morning tea, bingo night and collaborative butterfly artwork project. We also continued our relationship with Kimberly Clark Australia and its Sales Team which selected the Sanfilippo Children's Foundation as part of its Free Choice Fundraising campaign. Kimberly Clark was also nominated by our Foundation in the Research Australia 2016 Leadership in Corporate Giving Award for the creation of the KCA Walkathon for Sanfilippo.

Direct mail campaigns

In 2016 we undertook a direct mail and email campaign for the End of Financial Year (EOFY) tax appeal. We raised $53,185 in cash gifts generously given by individuals and households. We also asked our supporters to consider becoming a regular monthly donor.

Our Christmas direct mail and email campaign generated almost $40,000. We featured Australian families with children battling Sanfilippo and their 2016 Christmas wish list – a cure for Sanfilippo. Our message was simple: more funds will bring more potentially life-saving research projects to life and give these children a chance to enjoy more Christmases with their families. A social media campaign followed in which families and supporters posted photos of themselves with home-made signs saying: "All we want for Christmas is a cure for Sanfilippo".

COMMUNITY FUNDRAISERS

The Sanfilippo Children's Foundation is very much a grassroots organisation. In 2016, the Foundation was supported by 70 community fundraisers, generating just over $90,000. As these figures show, collectively community fundraisers have a huge impact and the awareness they raise is immeasurable! Indeed it's ordinary, everyday people who continue to help us make a difference.

A significant proportion of the total money raised was from initiatives run by families with children battling Sanfilippo, as part of their Hope For campaigns. We take our hats off to these families who manage to balance the demands of raising a medically-complex, special needs child (or in some cases multiple children) and a hectic family life with fundraising and spreading awareness of our cause.

Our families with children battling Sanfilippo and their stories continue to inspire their respective communities to join our fundraising efforts and this year was no exception. In 2016 there were BBQs, group fun runs, online auctions, birthday donations, workplace and team lunches, school discos, movie nights, cricket matches, market stalls and more. Pictured are just some of the highlights of community events from 2016.

IL DIVO DIVA SUMMARY - BELGIUM, EUROPE

The Sébastien Izambard Official Fan Club, a group of worldwide Il Divo fans, raised AUD$8,765 in 2016.

HOPE FOR JACOB GARAGE SALE - GREYSTANES, SYDNEY

Hope for Jacob garage sale raised an impressive $9,000 bringing much hope for Jacob and his family.

PURPLE STUMPS CRICKET DAY - LILYDALE, VICTORIA

Purple theme at Lilydale Cricket Club's cricket final which raised $3,000 for the Hope for Kyuss campaign.

HOPE FOR PETER LAUNCH CAMPAIGN - CONDELL PARK

The Chalhouy family raising awareness for the Sanfilippo cause and even scoring a 'selfie' with Prime Minister Malcolm Turnbull (pictured).

TRIVIA NIGHT - BRISBANE, QUEENSLAND

The 'favourite era' dress-up themed trivia night in Brisbane raised $6,000 for the Hope for Alec campaign.

TOUGH MUDDER - BRISBANE

Michelle and Chris Morrice competed in the Tough Mudder in Brisbane along with 17 friends. The team raised $8,108 for the Hope for Alec campaign.

SUN RUN - MANLY, SYDNEY

A group of runners ran in the 2016 Sun Run from Dee Why to Manly, raising $6,525.

TOUGH MUDDER - SYDNEY

Fiona Higgins and Alex Lagelee Kean raised $6000. Here's their 2016 Udder Mudders and Brudders team.

THANK YOU!

Our pro-bono suppliers

These professionals and suppliers have provided much-valued ongoing time, material and resources to our cause free of charge.

LEGAL SERVICES

Jane Ann Gray

GRAPHIC DESIGN

Alex Moller

TRAINING

Anita Lund – Trainers Direct

EVENTS

Jo Bilous

MEDIA / VIDEO PRODUCTION

The Construction Site Studio
Way up High Films

PHOTOGRAPHY

Cris Mahony, Little Love Photography
Adrienne Gilligan Photography
Melissa Straughton Smile Photographics
Nigel Stevens Photography
Tanya Tindale, Tindale Images
Ryan Clark, Clark Imagery

THE TEAM

Meet our Scientific Advisory Board

In 2016 the Sanfilippo Children's Foundation announced the expansion of its esteemed Scientific Advisory Board (SAB). The SAB provides informed guidance to help identify research and clinical trial opportunities. The members of the SAB are individuals, with significant scientific knowledge, experience and expertise relevant to Sanfilippo and/or associated research disciplines.

The SAB reviews applications submitted for funding and provides recommendations on projects to be funded, as part of the Foundation's new research strategy. All members of the SAB provide expertise on a pro-bono basis and receive no remuneration from the Foundation. The current members include:

Professor Ian Alexander

BMedSci MBSS (Hons), PhD, FRACP (paeds), HGSACG, FAHMS is head of the Gene Therapy Research Unit, a joint initiative of Sydney Children's Hospital Network and the Children's Medical Research Institute in Sydney.

Professor John Hopwood

AM FAA, Chair of the Sanfilippo Children's Foundation Scientific Advisory Board, former Head Lysosomal Disease Research Unit, Affiliate Professor at University of Adelaide, officer of the Order of Australia, Australian Academy of Science Fellow and SA Scientist of the Year.

Dr. David Ketteridge

MBBS, FRACP (Paediatrics) is a metabolic physician and General Paediatrician at the Women's and Children's Hospital in Adelaide.

Professor David Ryugo

BA Psych, PhD Psychobiology is a Professor of Neuroscience at the Garvan Institute of Medical Research in Sydney.

Dr. Nicholas Smith

MBBS (Hon), DCH, FRACP, PhD (Cantab) currently heads the Department of Paediatric Neurology at the Women's and Children's Hospital in Adelaide.

Dr. Michel Tchan

BMedSc, MBSS, PhD, FRACP is a clinical and metabolic geneticist and Head of Department, Genetic Medicine at Westmead Hospital in Sydney. He is also the Deputy Chair of the Sanfilippo Children's Foundation Scientific Advisory Board.

Sanfilippo Board Members

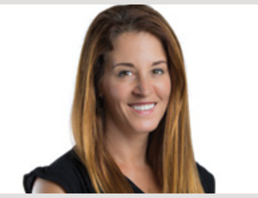
Angeline Veeneman
Patient Information & Programs

Daniel Madhavan
Investment & Networks

Mark Arnold
Strategy & Governance

Megan Donnell
Founder & Executive Director

Sanfilippo Team Members



Megan Donnell
Founder & Executive Director

Ingrid Maack
Communications & Community Fundraising Manager (Part-time)

Kristina Elvidge
Research Manager (Part-time)

Zoe Field
Business Manager (Part-time)

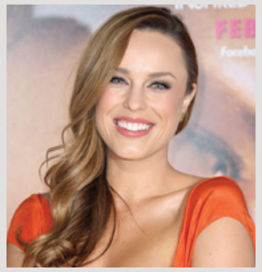
Erene Keriakos
Bookkeeper (Part-time)

Remy
Director of Team Well-being (Full-time)

Sanfilippo Ambassadors

Please note all members of our Board and our Ambassadors provide services on a pro-bono basis and receive no remuneration.

Sébastien Izambard
Singer from pop opera group Il Divo



Jessica McNamee
Australian film & TV actress

Sonia Marinelli
TV news reporter, Channel 9

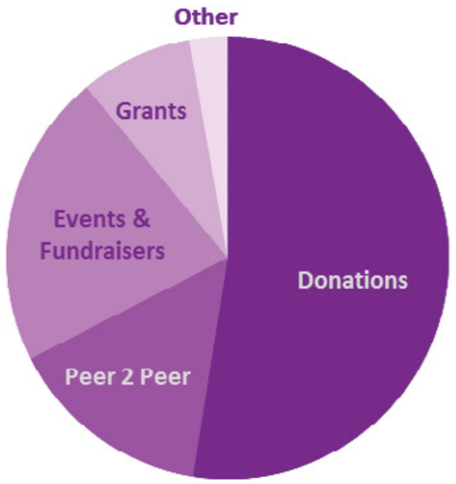
Dan Illic
Comedian & radio host

Catherine Bouchier
Soprano opera singer

THE FINANCIALS

	FY15/16	FY14/15	FY13/14
INCOME			
DONATIONS	$526,533	$387,996	$371,825
FUNDRAISING ACTIVITIES	$365,609	$384,278	$121,736
NON-GOVT GRANTS	$82,380	$87,100	$15,000
INTEREST	$22,116	$13,970	$2,248
MERCHANDISE	$5,850	$6,795	$912
TOTAL INCOME	**$1,002,488**	**$880,139**	**$511,721**
FUNDRAISING COSTS	$132,926	$106,940	$42,312
OPERATING EXPENSES			
ADMINISTRATION	$141,334	$56,191	$10,223
MARKETING	$12,306	$17,694	$564
PROGRAMS	$50,682	$21,781	$3,402
SURPLUS	**$665,239**	**$677,531**	**$455,220**

For a full copy of our audited report, please contact us via email info@sanfilippo.org.au



Please become a Star for Sanfilippo!

You could save a life!

To fund potentially life-saving medical research projects, we require ongoing reliable funding so that we can plan ahead. Donors who contribute monthly are very valuable to us, allowing us to commit to long-term initiatives.

This type of donation is very cost-effective and is a simple one-off set up, so is convenient for donors too.

TO SIGN UP TO BE A STAR FOR SANFILIPPO TODAY
call 1800 664 878 or go online at www.sanfilippo.org.au

Bequests

PLEASE CONSIDER LEAVING A GIFT IN YOUR WILL TO THE SANFILIPPO CHILDREN'S FOUNDATION

A legacy or bequest can be the most important gift you ever give. By remembering the Sanfilippo Children's Foundation in your Will, you are helping to ensure a better quality of life for future generations of children born with Sanfilippo Syndrome.

Every child deserves a future and – by leaving a gift in your Will – you are giving hope to children with Sanfilippo and their families. Thank you.

How to leave a gift in your Will

If you're considering leaving a gift to the Sanfilippo Children's Foundation in your Will, we would love to talk to you, discuss some of the options available and hear about the areas of our work you would like to support.

We are grateful when people decide to include a bequest to the Foundation as bequests are a source of income for the vital work we do. We appreciate family and loved ones should always come first before a charity gift.

We strongly advise that you seek advice from a qualified professional when making or updating your Will, but if you would like information about our bequest program, please get in touch.

> "Two of my beautiful grandchildren have Sanfilippo Syndrome. Each of these children was born perfect and appeared to have the best start to life. But Sanfilippo is a degenerative disease and health problems are developing month by month. Of course the Sanfilippo Children's Foundation is included in my Will. I try to get everyone I know to do the same - to bequest money to the Foundation too!"
>
> **– Evelyn**

Thank you!

Thank you to our valued supporters, donors, sponsors, suppliers, volunteers and fundraisers. We couldn't do what we do at the Foundation without you!

THE SANFILIPPO CHILDREN'S FOUNDATION PARTNERS WITH:

Global Genes®
Allies in Rare Disease

genetic alliance
australia

NORD®
National Organization
for Rare Disorders

rare voices
AUSTRALIA

lindfieldprint
+ COPY CENTRE

CLARK
IMAGERY

AM

This Year in Review document has been produced by professionals who have discounted and/or donated their time and services. We would like to thank designer Alex Moller, the team at Lindfield Print and Copy Centre and Ryan Clark at Clark Imagery.

Sanfilippo
Children's Foundation

Sanfilippo Children's Foundation
PO Box 475,
Freshwater, NSW, 2096,
Australia
E info@sanfilippo.org.au **T** 1800 664 878