

# CYSTIC FIBROSIS Victoria

# ANNUAL REPORT 2016

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#### **CFV Mission**

To increase the wellbeing and quality of life of people living with CF, and promote broader awareness of CF and how it affects the community.

#### **CFV** Vision

Lives unaffected by CF.

#### **About Cystic Fibrosis**

Cystic Fibrosis (CF) is the most common inherited, life threatening illness affecting young Australians and there is currently no cure. It is a seriously life-limiting condition requiring relentless treatments, significant daily medications, physiotherapy and frequent hospitalisation. People with CF are constantly fighting infections, battling malnutrition and struggling against exhaustion.

CF primarily affects the lungs and digestive system due to a malfunction in the exocrine system, responsible for producing saliva, sweat, tears and mucus. People with CF develop an abnormal amount of excessively thick and sticky mucus within the lungs, airways and the digestive system. The mucus hinders digestive functions of the pancreas and traps bacteria in the lungs causing recurrent infections which lead to irreversible damage. Lung failure is the major cause of death for someone with CF.

More than 700 Victorians are currently living with CF and one in 25 is a healthy and generally unaware carrier of the defective CF gene. Despite major advances in the treatment of CF, only 50% of those born with this condition currently reach their late thirties. Greater understanding, better treatments and increased support is now needed.

#### **About Cystic Fibrosis Victoria**

Cystic Fibrosis Victoria (CFV) is the peak community not-for-profit organisation working with and for people with CF right across the state. Its mission is to assist everyone affected by CF to be well and live fuller lives and to promote broader awareness of CF and how it affects our community.

CFV provides information, support and guidance to people living with CF and their families. It advocates for services and systems that support the CF community and seeks to raise awareness, understanding and funds for services and research.

CFV was founded in 1974 by a group of parents of children with CF and became an incorporated Association in 1984. It is governed by a voluntary Board comprising representatives of the CF community and those with particular expertise in advancing the mission of CFV.

As more than 70% of CFV income is derived from fundraising, it relies heavily upon the generosity of the Victorian public as well as private philanthropic sources. CFV is striving towards lives unaffected by cystic fibrosis but it can't do it alone. It takes a whole community to care for and conquer CF.



#### **Chairman's Report**

I am again pleased to present the 2016 Annual Report for Cystic Fibrosis Victoria Inc. on behalf of your Board.

We have continued to manage our funds efficiently, maintain our governance requirements, mitigate our risks and provide our programs and services in line with our strategic plan. The CEO and her team have continued to work with focus on meeting our Mission in line with our Vision (please refer to the CEO's Report for more details).

The Members of CFV have for some time asked CFV to undertake or support research. We have now established a cash reserve from recent surpluses specifically for research projects. Additional cash has also been



received to add to this reserve from donations and bequests marked specially for research. This has created the financial confidence to source some research projects.

The establishment of the Board's Large Steps Forward (LSF) subcommittee, which I described last year, has led to the identification of 13 potential research projects, has assessed each of them and submitted two projects for consideration by the Board.

The first of these was approved. It is an Australian based concept study to test the ability of healthy genes being transferred in nanoparticles through the mucus in the lungs of people with CF. The progress made so far has been very positive and we expect an outcome within several months. This project is costing \$149,000. Assuming this concept study is successful and then passes clinical trials this will benefit everyone with CF. Andrew Venables, CEO of Loxegen Pty Ltd, who is undertaking the project, has been invited to speak about this project at the AGM.

The second project is at the final business plan stage. The LSF subcommittee will continue to assess further research projects.

In addition to our programs and services and these research projects, CFV is undertaking two other important areas of longer term actions.

Firstly, we have made significant progress in Victoria with the Community Education Campaign on Carrier Screening (CECCS). As you may be aware there are approximately 200,000 people (4% of the population) in Victoria who are carriers of the CFTR gene changes and 95% of these people have no knowledge that they are a carrier. This program for Victoria, which was generously funded by the Rotary Club of Balwyn, is mostly complete and a great success. The concept of CEC on CF Carrier Screening was discussed with all the State and Territory CF organisations and CFA via Federation meetings and we have achieved their support to take the program across Australia to inform the one million carriers. The limiting factor in undertaking this is to find a source of funding (approximately \$200,000). Secondly, in March 2016 CFV was approached by CFNSW to consider whether CFV would be interested in merging the two state entities. There had already been some discussion across the Federation about how inefficient it is for 3300 people living with CF in Australia being served through 8 separate CF organisations with 8 boards, significant duplication, difficulties in making decisions, etc. Our Board considered this opportunity would improve the efficiency of both the states. So, following discussions and due diligence, both Boards agreed to progress the merger up to the point of putting resolutions to the members of each state. The resolutions whether to merge or not will be put to each of the state General Meetings in March/April 2017. The same detailed information about the potential merger and the Resolutions will be circulated with the papers for each of the General Meetings.

It takes a lot of resources to achieve what CFV does each year. The Board is impressed by, and very appreciative of, the number of people who freely commit their time and skills to this important cause. A huge thank you to all our volunteers, supporters and donors without whom we would not be able to provide anywhere near as many of the programs and services as we do, or raise anywhere near the funds required. The Board thanks you all. Whether you volunteer your time or make a financial donation or both we sincerely appreciate your generosity.

I acknowledge and appreciate the professionalism of our CEO, our dedicated staff and our many volunteers including our Board Members. It is a pleasure to work in such a committed organisation. Without this

#### **2016 BOARD**

Ross Fraser MAICD BE(Hons) (Chairman)

Katherine Kaspar BA LLB (Hons), Grad Dip Legal Practice (Vice Chair)

> Rod Naismith CA, CTA (Treasurer)

> > Julie Noonan MBA (Hon Secretary)

Dr Sarath Ranganathan MB, ChB, MRCP, FRCPCH, FRACP, PhD

Reuben Trussler BVsCom

Louisa Walsh BPhysio (Hons)

**Tony Nicholls BBM**, DipBus(Marketing)

#### **MEETINGS ATTENDED**

Ross Fraser, Chairman	6
Katherine Kaspar, Deputy Chair	4
Rod Naismith, Treasurer	6
Tony Nicholls	5
Julie Noorman	5
Sarath Ranganathan	3
Reuben Trusler	4
Louisa Walsh	5

commitment we would not be able to provide the programs and services, create the research opportunities and undertake further improvements.

Ross Fraser Chairman

#### **Chief Executive Officer's Report**

It is with great pleasure that I once again report back to our members about the work we have been engaged in over the past 12 months. It has been a very full year of programs, services, events, fundraising activities and advocacy work and I believe we have had some significant successes. As in past years I believe that our Strategic Plan provides an appropriate framework through which to report our activities and measure our progress.

Strategic Goal 1 – Delivering innovative and responsive programs and services that meet the needs of people living with CF, reduce isolation, and support families and carers.



We have continued to provide support to our members across a variety of areas throughout the year.

Support while in hospital:

Our Boredom Buster Bags, for children and adults in hospital, were provided by Brody and Ellie's Helping Hand. Our Helping Hand Hampers and accommodation support are provided to members from regional Victoria while they are in hospital in Melbourne.

Hospital visits:	113
Boredom Buster Bags delivered:	100
Helping Hand Hampers provided:	53
Accommodation support (days) funded:	124
TV rental while in hospital (days):	5,262
Vic Patient Transport	
Assistance Scheme (VPTAS) support:	20

Social and peer support activities:

- 8 x support dinners (3 in Melbourne and 5 in regional Victoria)
- 3 x activities for siblings and offspring (1 in Melbourne and 2 in regional Victoria)
- 1 x event for partners and adult siblings
- 1 x afternoon tea for newly diagnosed families
- I x afternoon tea for grandparents
- Support activities (attendees):
- Remembrance Service (attendees):
- Peer support requests:
- Peer support match ups:
- Peer volunteer training programs offered:
- Peer volunteers:
- PEPTalk online peer support (members):



In addition to developing our own peer support network, in March we were invited to share our experience in running peer support programs and presented a workshop to 10 peer support leaders from various groups for the Genetic Support Network of Victoria. CFV also conducted a training session for Cystic Fibrosis South Australia (CFSA) peer support volunteers.

As part of CFV's goal to participate in providing a supportive national service where people with CF don't fall through the system as they travel interstate, we continued to liaise with the other state CF organisations. For example, with CFSA we trialled a collaborative service where we provide support for their members coming to Melbourne for transplant. This support includes a city orientation, public transport information and a myki card, assistance in finding key services such as a local supermarket and pharmacy. We believe that people with CF should not have to struggle with 'over the border' issues when facing significant health issues and our aim is to make their Victorian experience as helpful and seamless as possible.

Our health and wellbeing support programs are also well utilised

Thanks to generous donations from supporters and corporates we were also able to distribute a range of tickets and gifts to the CF community, including:

- 14 six-month passes to Fitness First gyms
- 80 chocolate Easter bunnies
- 40 Christmas food hampers for families in need
- Over 80 tickets to AFL games
- 4 tickets to the Australian Open
- 8 tickets for the Melbourne Christmas Party for Special Children
- 5 tickets for the Variety Christmas Party
- 20 movie tickets to a special movie screening of 'The Secret Life of Pets'
- 7 Aerogen Go nebuliser complete systems and 5 Pari Boy SX nebulisers were given to individuals and families with CF who were unable to purchase the physio equipment they needed.

Financial support:

#### Information Services

Our Community Conference was well supported with almost 100 people in attendance and we continued to provide information and support to both the CF and general community over the phone, via email, or face-to-face. This includes participating in teacher education days at the Royal Children's Hospital and the Monash Children's Hospital, and providing information to schools, kindergartens and child care centres.

School and childcare can often be a time of significant stress for students and families as they juggle school, clinics and hospital stays whilst managing their CF. CFV will increase our support for schools, students and families in 2017 through two new programs – Study Buddy, funded by Newman's Own Foundation and CF Smart Online, funded by the Ian Potter Foundation.

#### **Community Membership Survey 2016**

In early 2016 we conducted a membership survey to inform and measure the success and impact of the work that we do, and to help guide the planning of our future services. The survey included collecting information about the effectiveness and appropriateness of events, programs and support services, communication and campaigns. Overall the five most helpful programs and support services are:

- 20% reimbursement
- Physiotherapy grants
- TV rental while in hospital
- Fitness grants
- Advocacy for people who have CF and their families.

A full copy of the report is available to members and is located on the CFV website

# Strategic Goal 2 – Advocating at both an individual and systemic level for supportive systems and environments for people with CF and their families and carers.

Our advocacy work over the past 12 months has continued to support Cystic Fibrosis Australia (CFA) in their systemic advocacy campaigns around medicines such as Kalydeco and Orkambi. Toward the end of 2016 we heard the devastating news that Orkambi was rejected for listing on the PBS and Kalydeco (for 2 - 5 years old) was deferred. In addition to supporting CFA's initiative CFV developed a campaign to target Victorian Federal parliamentarians in 2017.

At a local level our advocacy work has included assisting and supporting individuals from our community across a variety of areas including employment, housing, accessing government benefits, legal and hospital matters. It was pleasing to see that after 18 months of advocating on behalf of members who attend the Alfred CF clinic, the Alfred CF Consumer Advisory Group finally came into existence. CFV is a member of that group and there are four people with CF who represent the community as part of this group.

Additional local and systemic advocacy work included a range of activities such as:

- Providing feedback about care and services at the key CF centres.
- Lobbying for Wi-Fi access for patients at The Alfred and Monash Medical Centre.
- Providing feedback on the implementation of the new infection control procedures at the Royal Children's Hospital and the Monash Medical Centre.
- Participating is a range of consultations such as the review of the Victorian Patient Transplant Assistance Scheme (VPTAS), the Patient Voice Initiative to discuss the development of a framework to incorporate a broader patient-driven perspective into health care decision making and Pharmaceutical Benefits Advisory Committee (PBAC), and government reviews and consultations related to health care reform, disability services and the NDIS.

# Strategic Goal 3 – Raising broader community awareness of CF, with a particular focus on increasing awareness and reaching carriers

#### **Communications**

Communication and media plays a pivotal role in raising broader community awareness and the development, production and publication of all media material created by CFV is purposefully aligned with the broader strategic goals of the organisation.

Social media has always been an area of strength for CFV and Facebook allows us to be very responsive to the community. We make a concerted effort to keep our members and wider community updated on relevant matters through social media, monthly e-news, and direct mail. On average over 50% of people open and engage with this content. The CFV website was visited 49, 228 times in 2016, a 12.87% increase from 2015.

Our 65 Roses magazine is also an important tool in raising awareness both inside the CF community and beyond. In 2016 CFV proposed to the other CF organisations in Australia the possibility of a national magazine and CFV will be developing a magazine with national input for distribution mid-year 2017.

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#### **Carrier Screening**

The Community Education Campaign on CF Carrier Screening (CEC) which was funded initially by the Rotary Club of Balwyn, continued to raise awareness about CF and CF carrier screening.

During the year CFV, together with The X Gene produced and released two short videos about CF carrier screening. The videos were uploaded to Facebook, YouTube and the CFV website where they have had over 3,000 views. The videos have received positive feedback across Victoria, and Australia, and in the US with Cystic Fibrosis News Today uploading and sharing one of the videos. A fact sheet on CF carrier screening was developed with the Victorian Clinical Genetics Services (VCGS), and articles were written for the Genetic Alliance Australia and Genetic Support Network of Victoria newsletters. Work has now

commenced on the implementation of a National Carrier Screening Campaign with funding being sought from various Foundations and Trusts.

# Strategic Goal 4 – Supporting and contributing to quality research which is relevant to people with CF, and facilitating its dissemination

During the first part of the year the CFV Board Sub Committee 'Large Steps Forward' reviewed a wide range of projects that could be considered for funding. The decision was made, and announced at the 'Night for CF' Gala Ball, that CFV would fund a proof of concept study for a gene therapy to address the key cause of morbidity in CF, which is lung disease. The approach uses a bio-degradable nanoparticle which has been developed for cancer treatments. Reports thus far have been encouraging.

There are a large number of research projects around Australia that are worthy of support and CFV continues to explore projects for further funding opportunities. One of the main criteria for project funding is the capacity of that project to report back on key milestones and progress.



# Strategic Goal 5 – A financially robust, sustainable and effective organisation with an enthusiastic and thriving team

In March 2016 CFV and CFNSW started exploring the possibilities of merging our two organisations. Our overarching goal was, and remains, to provide the best possible benefit to our communities. Currently there are 8 CF organisations in Australia serving 3300 people with CF and their families with considerable duplication occurring between us. We believe that by merging CFV and CFNSW we will be able to realise greater efficiencies in our operations, exploit economies of scale by centralising some functions and thereby provide a better service and greater benefit to our CF community. A merged organisation will also have greater access to funding from private sources such as Foundations and Trusts. A merged organisation will still be able to manage individual state government contracts and in the short to medium term will ensure that funds raised in a specific state will contribute to the community of that state.

A significant amount of work has been done over the past 10 months to determine the best possible structure. There will be even more to be done should the resolution to merge, which will be put to the membership at the AGM, be successful.

#### **Trusts and Foundations**

We have experienced significant support from various trusts and foundations during 2016. The generosity of these organisations means we have been able to move forward with some wonderful new initiatives to help people living with CF. The Study Buddy program has enabled us to engage a part time employee with an education background to work with students living with CF who are at risk of falling behind at school. The Ian Potter Foundation's grant has enabled CF Smart to be enhanced as a state of



the art website for educating teachers around the needs of students with CF. Finally, we started work on a website for families of newly diagnosed children aimed to support new parents in the first two years of their child's life. These projects will be ready in 2017. Every year we witness the positive impacts that the continued support of GW Vowell, the Joe White Bequest and William Angliss provide. We are deeply appreciative of this support which enables us to deliver these programs and services to our members.

Name The Pierce Armstrong Foundation	<b>Funding Target</b> Siblings events in 4 locations in Victoria
Ian Potter Foundation	CFSmart website and e-learning modules for teachers
GW Vowell	Physiotherapy equipment and Fitness Programs for low income individuals, TV hire, and transplant assistance
Joe White Bequest	Physiotherapy equipment, Fitness programs and emergency financial assistance
Lord Mayor's Charitable Foundation	General operations
Equity Trustees Ltd	Emergency accommodation for families
The Andrews Foundation	Physio and massage equipment for Monash Medical Centre
The Marian and EH Flack Trust	Physiotherapy equipment, Fitness programs and emergency financial assistance
Newman's Own Foundation	Study Buddy Program – includes a part-time employee to work with students with CF
Harcourts	To fund a physiotherapy massage therapist for the massage program at Monash
William Angliss	Emergency accommodation for regional families and emergency financial assistance
Mazda Foundation	To fund a physiotherapy massage therapist for the program at Monash, and Study Buddy equipment such as laptops and iPads for disadvantaged students
Flora and Frank Leith Charitable Trust	Equipment for disadvantaged students such as laptops, software and ipads
Vertex Pharmaceuticals	Development of a website for Newly Diagnosed

#### **Community Fundraisers**

We are so grateful to all our community fundraisers who work very hard to raise awareness and funds to support CFV's work with individuals and families affected by cystic fibrosis. A huge thank you to everyone who organised, participated, donated and supported our 2016 community fundraising heroes. Activities included a debutante ball, movie nights, cake stalls, tea parties, yoga events, casual dress days, tin rattling, raffles, sausage sizzles, trivia nights, birthday parties, school activities, neighbourhood lemonade stands, metafit classes, busking and many more. Each and every activity contributed to funding our programs and services.

We are especially heartened by the efforts of our smaller supporters – the children – cousins, neighbourhood friends, and siblings who organise small fundraising events such as icy pole stalls and lemonade stands. While the funds raised are important, the support and care each and every one shows through their actions is as important. This gives true meaning to the saying that 'it takes a community to care...for CF'.

#### Community fundraising events 2016

- Twenty/Twenty Cricket Fundraiser
- FinancePath Charity Golf Day
- Fitness with Friends/Metafit Class for Bella
- St Pauls Fundraiser
- Breathe Easy Cocktail Party & Golf Day
- Breathe Easy Golf Day
- CF Football Round Skye Football & Netball Club
- Cranbourne East SC Camping at School
- Mt Waverley Secondary College
- Heathmont Jets Football Club CF Round
- Charity and Fun Ladies Lunch

- Mimosa Homes Casual Dress Day
- Canteri Bros Construction BBQ
- Freedom Riders Australia
- Cycle for CF Adelaide to Melbourne
- Women of Rye Charity Lunch
- Bunnings Sausage Sizzle
- Chadstone Harlequins Cricket T20 Match
- CF Fundraising BBQ
- Panarcadian Assoc of Melbourne Mother's Day
- Keysborough Golf Club Charity Event
- Christine Doran Tatra Luncheon



#### Major fundraising events 2016

Around Australia 65 Roses month is celebrated in May with the primary goal of raising awareness of CF in the wider community as well as raising funds through various activities and events. In 2016 armed with fresh roses (courtesy of Wafex) our wonderful volunteers braved the chilly temperature of Melbourne's CBD to sell roses and tin rattle on the last weekend of May, helping raise over \$10,000 in two days. Over \$65,000 was raised from tin rattling, rose and merchandise sales, challenges and fundraising events.

Our 'Festival for CF' on March 12<sup>th</sup> attracted significant attention at Federation Square. Many stopped and watched the entertainment which gave CFV the opportunity to talk to people about CF and the challenges that families and individuals face managing the condition. While Festival for CF was originally part of 65 Roses month in May, in 2016 the festival was moved to March in the hope of better weather and a larger crowd. The festival would not have been the success it was without the support of our dedicated volunteers, event partner City of Melbourne and our wonderful ambassador and MC Keegs (Keegan Bakker) from Fox FM.

# We also conducted a variety of other fundraising events throughout the year including:

#### **EVENT**

Great Strides Melbourne Great Strides Bendigo Crazy Hair Day A Night for CF – Gala Ball Festival for CF PARTICIPANTS 1100 230 44 291 Public Event

#### Appeals

A big thank you to our community and corporate partners who helped make the appeals successful. Growth of these appeals is a strong indicator of increased engagement with our broader

community. Promotion of the appeals was particularly strong with an initial appeal letter going out to members, past donors and wider community members, which was then supported by a strong social media campaign, distribution through our magazine and e-newsletter, as well as multiple EDM's leading up to the closing date of the appeals.

#### **Corporate Support**

Thank you to our corporate and organisational partners who helped us make 2016 such a success.

- Alcohol and Drug Foundation
- Antarctica Flights
- Brodie and Ellie's Helping Hand
- Carpet Call
- CF Nightingales
- East Malvern Community Bank Bendigo Bank
- Hawthorn Football Club
- Maurice Blackburn Lawyers
- Powersource Promotions
- Runner's World Magazine
- Rotary Club of East Keilor
- RACV
- Triple M Morning Show
- The Melbourne Costume Group
- Rebel Legion
- 501<sup>st</sup> Legion

- Anna Blatman Gallery
- Bendigo Advertiser
- Country Racing Victoria
- City of Melbourne
- Den Interiors
- FinancePath
- Leader Community Newspapers
- Mimosa Homes
- Rotary Club of Balwyn
- Ricoh
- Ros Ritchie Wines
- Technipro
- Wafex
- The Commonwealth Staff Social and Charity Club (CSSCC)

#### **Government Funding**

Approximately 25% of CFV's funding comes from the Victorian State Government through the Home and Community Care (HACC) program which provides support for our advocacy, peer support and information services.

#### **Bequests**

CFV were very fortunate to receive a number of bequests in 2016. We are grateful to all those who provided a gift to CFV through their Will. Of particular note was a significant bequest from the Estate of Mr Herbert George Pearson of Wangaratta. Just over 80% of this bequest has been allocated to research for a cure.

#### Volunteers

The not-for-profit sector relies heavily on the support of volunteers and CFV is no different. In 2016 there were four major events in which we needed help from volunteers in order to ensure the event was successful. We are fortunate to recruit volunteers from a variety of sources including our own community. We also use a small bank of regular volunteers in the office where tasks are largely administrative. Over the year we had 168 people volunteer with 83 of them being returning volunteers.

In 2017 we will be launching our recognition program for volunteers. We understand and appreciate how integral volunteers are to CFV and we hope that this program will highlight the amazing work that is completed by our volunteers and also encourage them to volunteer on a regular basis.



The speaker program was also a focus last year as it such an important program when trying to raise awareness within the wider community. Over the year we had 16 different events for our volunteer speakers. The type of presentations varied from formal talks at Rotary clubs and educational institutions, to more casual talks at school assemblies and community fundraisers.

We are very grateful for the gift of time and skills that our wonderful volunteers so freely give.



**CTOP** 

State

Government

#### In Conclusion

It has been a very busy year at CFV as we continue to support and assist individuals and families affected by cystic fibrosis. We are profoundly grateful to those members of our community who support our work by fundraising, volunteering at events, attending activities and supporting and encouraging each other.

I would like to thank CFV's Board of Directors and particularly our Chairman, Ross Fraser. Leading and managing an organisation can be challenging and it is only when one has the support and confidence of an engaged Board that organisations can thrive.

We are a very small team focused on doing big things. We would not be able to achieve what we do without all staff being prepared to give that little bit extra. I am very proud of the team at CFV, they are all extremely committed to the task of supporting our CF community, as individuals they are skilled and team oriented, and like our volunteers, they have big hearts! Thank you for all that you do.

Finally, to those individuals and families in our community affected by cystic fibrosis, I would like to reassure you all that CFV will always act in your best interests, and we will never give up in ensuring your voices are heard.

and

Karin Knoester

Chief Executive



# .....Another strong year consolidates CFV's financial position to continue to improve all lives within the CF community....

#### **TREASURER'S REPORT**

I am pleased to report that CFV has delivered a result which will enable CFV to continue to support all of the CF community in the short and long term.

In the past few years, CFV has consolidated and improved its financial results. This is vitally important to the organisation and the CF community to ensure that CFV can continue to support and improve the lives of all within the CF community.

Similar to last year the charity and not for profit sector continues to face challenging times with competition to secure valuable funds and resources. I am therefore



delighted to report that CFV has been able to improve its result compared to last year.

The improvement in the current years result is a credit to the entire CFV team continuing to focus on operating a lean organisation to ensure that the value of support services, advocacy, community communication and programs delivered to the community is maximised. It is noted that the value CFV delivered to the community was achieved with a similar level of income, compared to the prior year.

In 2016, CFV has continued to take a balanced approach of delivering upon the immediate needs of the community whilst at the same time considering future investments into long-term projects, which the Chairman has outlined in his report.

In 2016, CFV generated an increase in our cash holdings of \$121,210. The cash position provides long-term viability to CFV and continues to provide comfort to members that CFV will be well placed to support all members of the CF community.

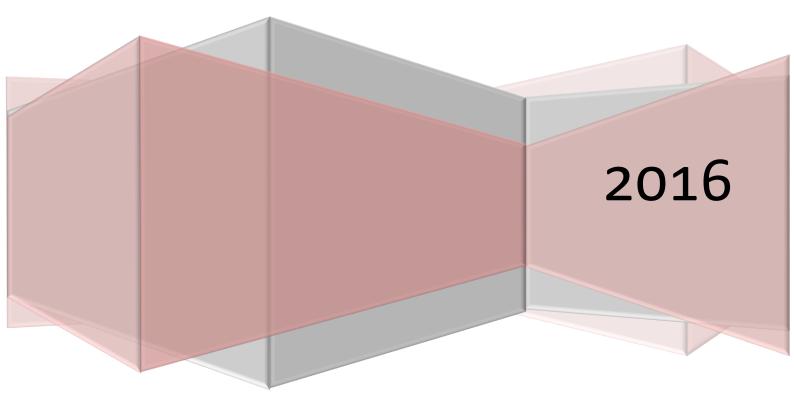
During the year, the Board continued its research, investigation and consideration into a number of strategic initiatives with the objective of seeking to make a significant positive impact on the lives of those in the community. In light of our financial position, CFV was able to make its first significant investment into research. The Board is continuing to work hard to explore further opportunities to improve the lives of all those touched by CF.

I commend to you the financial statements for the period 1 January 2016 to 31 December 2016.

R D Naismith, CA, CTA CFV Treasurer

# **CFV Financial Reports**

As prepared by William Buck



#### FINANCIAL STATEMENTS

# Statement of Profit or Loss and other Comprehensive Income

for the year ended 31 December 2016

	2016	2015
INCOME		
Members income	11,119	12,141
Government Funding	346,857	381,451
Interest Received	28,671	30,116
Donations, Grants and Sponsorships	540,056	499,847
Fundraising	342,598	361,672
Other Income	64,979	51,902
TOTAL INCOME	1,334,280	1,337,129
Less: EXPENSES		
Events and Merchandising	234,271	209,570
Education, R&D Advocacy	102,656	72,853
Client support, Development and service	459,147	498,788
Community Communications, Detection and Awareness	131,150	104,373
General Operation	283,305	370,083
TOTAL EXPENSES	1,210,529	1,255,667
Profit for the Period	123,751	81,462
OTHER COMPREHENSIVE INCOME		
TOTAL COMPREHENSIVE INCOME FOR THE YEAR	123,751	81,462

The accompanying notes form part of these financial statements

#### Statement of Financial Position

As at 31 December 2016

	Note	2016	2015
ASSETS			
CURRENT ASSETS			
Cash and cash equivalents	2	1,539,786	1,418,576
Trade and other receivables	3	25,769	7,867
Other current assets	4	13,422	22,429
Inventories	5	19,574	12,842
TOTAL CURRENT ASSETS		1,598,551	1,461,714
NON-CURRENT ASSETS			
Property, plant and equipment	6	1,342,759	1,364,738
Prepayments	4	86,826	¥
TOTAL NON-CURRENT ASSETS		1,429,585	1,364,738
TOTAL ASSETS		3,028,136	2,826,452
LIABILITIES			
CURRENT LIABILITIES			
Income Received in Advance	7	142,697	60,566
Trade and other payables	8	61,624	83,343
Provisions	9	66,062	48,541
TOTAL CURRENT LIABILITIES		270,383	192,450
TOTAL LIABILTIES		270,383	192,450
NET ASSETS	-	2,757,753	2,634,002
EQUITY			
Reserves	10	1,102,223	1,102,223
Retained earnings	11	1,655,530	1,531,779
TOTAL EQUITY		2,757,753	2,634,002

The accompanying notes form part of these financial statements

#### Statement of changes in members funds

for the year ended 31 December 2016

	Retained Earnings	Reserves	Total
Balance at 01-Jan-15	1,450,317	1,102,223	2,552,540
Comprehensive income			
Profit for the period	81,462	2	81,462
Revaluation of land and buildings	¥	-	i≊7
Total comprehensive income for the period	81,462		
Balance at 31-Dec-15	1,531,779	1,102,223	2,634,002
Comprehensive income			
Profit for the period	123,751		123,751
Revaluation of land and buildings	<b>5</b> .		-3.
Total comprehensive income for the period	123,751		123,751
Balance at 31-Dec-16	1,655,530	1,102,223	2,757,753

#### Statement of cash flows

for the year ended 31 December 2016

	Note	2016	2015
CASH FLOWS FROM OPERATING ACTIVITIES			
Donations, member and fundraising receipts		1,369,838	1,330,719
Interest		28,671	30,116
Operating Payments		(1,272,633)	(1,172,833)
NET CASH PROVIDED BY/(USED IN) OPERATING ACTIVITIES		125,876	188,002
Receipts from Property, Plant & Equipment			15,727
Payment for Property, Plant & Equipment		(4,666)	(27,643)
NET CASH PROVIDED BY / (USED IN) INVESTING ACTIVITIES		(4,666)	(11,916)
Proceeds from / (repayment of) Borrowings			(32,339)
NET CASH PROVIDED BY / (USED IN) FINANCING ACTIVITIES			(32,339)
NET INCREASE/(DECREASE) IN CASH HELD		121,210	143,747
CASH AT THE BEGINNING OF THE YEAR		1,418,576	1,274,829
CASH AT THE END OF THE YEAR	2	1,539,786	1,418,576

The accompanying notes form part of these financial statements

#### NOTE 1: SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

The financial statements cover Cystic Fibrosis Victoria Inc as an individual entity.

#### Basis of Preparation

The financial report is a special purpose financial report prepared in order to satisfy the financial reporting requirements of the Associations Incorporations Reform Act 2012. The board has determined that the association is not a reporting entity.

The financial statements have been prepared on an accruals basis and are based on historical costs, modified, where applicable, by the measurement at fair value of selected non-current assets, financial assets and financial liabilities.

The following is a summary of the material accounting policies adopted by the association in the preparation of the financial report. The accounting policies have been consistently applied unless otherwise stated.

#### a. Income Tax

The Association is exempt from income tax by virtue of section 50-45 of the Income Tax Assessment Act 1997

#### b. Inventories

Inventories are measured at the lower of cost and net realisable value. Costs are assigned on a first in first out basis.

Inventories acquired at no cost, or for nominal consideration are valued at the net realisable value as at the date of acquisition.

#### c. Property, Plant and Equipment

Each class of property, plant and equipment is carried at cost or fair value as indicated less, where applicable, any accumulated depreciation and impairment losses.

#### Property

Freehold land and buildings are shown at their fair value (being the amount for which an asset could be exchanged between knowledgeable willing parties in an arm's length transaction) based on reporting periodic valuations by external independent valuers, less accumulated depreciation for buildings.

#### d. Depreciation

The depreciable amount of all fixed assets, including building and capitalised lease assets but excluding freehold land, is depreciated on a straight-line basis or diminishing value basis over the asset's useful life to the entity commencing from the time the asset is held ready for use.

The assets' residual values and useful lives are reviewed, and adjusted if appropriate, at the end of each reporting period.

#### e. Employee Benefits

Provision is made for the association's liability for employee benefits arising from services rendered by employees to the end of the reporting period. Employee benefits that are expected to be settled within one reporting period have been measured at the amounts expected to be paid when the liability is settled. Contributions are made by the Association to an employee superannuation fund and are charged as expenses when incurred.

#### f. Provisions

Provisions are recognised when the association has a legal or constructive obligation, as a result of past events, for which it is probable that an outflow of economic benefits will result and that outflow can be reliably measured. Provisions recognised represent the best estimate of the amounts required to settle the obligation at the end of the reporting period.

#### g. Cash and Cash Equivalents

Cash and cash equivalents include cash on hand, deposits held at call with banks, other short-term highly liquid investments with original maturities of three months or less. Bank overdrafts are shown within borrowings in current liabilities in the statement of financial position.

#### h. Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable after taking into account any trade discounts and volume rebates allowed.

Interest revenue is recognised using the effective interest rate method, which, for floating rate financial assets is the rate inherent in the instrument.

Donations and bequests are recognised as revenue when received, unless they are designated for a specific purpose, they are carried forward as income received in advance in the statement of financial position.

Grant revenue is recognised when the entity obtains control over the funds, which is generally at the time of receipt. If conditions are attached to the grant that must be satisfied before the association is eligible to receive the contribution, recognition of the grant as revenue will be deferred until those conditions are satisfied.

All revenue is stated net of the amount of goods and services lax (GST).

#### i. Trade and Other Payables

Trade and other payables represent the liabilities for goods and services received by the entity that remain unpaid at the end of the reporting period. They are recognized when the association becomes obliged to make future payments resulting from the purchase of goods and services.

The balance is recognised as a current liability with the amounts normally paid within 30 days of recognition of the liability.

#### j. Goods and Services Tax (GST)

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Australian Taxation Office (ATO).

Receivables and payables are stated inclusive of the amount of GST receivable or payable. The net amount of GST recoverable from, or payable to, the ATO is included with other receivables or payables in the statement of financial position.

Cash flows are presented on a gross basis. The GST components of cash flows arising from investing or financing activities which are recoverable from, or payable to, the ATO are presented as operating cash flows included in receipts from customers or payments to suppliers.

#### NOTE 2: CASH AND EQUIVALENTS

	2016	2015
CURRENT		
Cash at bank and on hand	398,941	420,591
Short-term bank deposits	1,140,845	997,985
TOTAL CURRENT	1,539,786	1,418,576
TOTAL	1,539,786	1,418,576

#### RECONCILIATION OF CASH AND CASH EQUIVALENTS

Cash and cash equivalents at the end of the financial year as shown in the statement of cash flows is reconciled to items in the statement of financial position as follows:

	1,539,786	1,418,576
Short-term bank deposits	1,140,845	997,985
Cash and cash equivalents	398,941	420,591

#### NOTE 3: TRADE AND OTHER RECEIVABLES

	2016	2015
CURRENT		-
Trade & Sundry Debtors	25,769	7,867
Provision for Doubtful Debts	÷	
TOTAL CURRENT	25,769	7,867
TOTAL	25,769	7,867

#### NOTE 4: OTHER ASSETS AND FINANCIAL ASSETS

	2016	2015
CURRENT - OTHER ASSETS		
Prepayments	13,422	13,967
Accrued Income	8	8,462
TOTAL CURRENT	13,422	22,429
NON CURRENT - OTHER ASSETS		
Prepayments	86,826	-
TOTAL NON CURRENT	86,826	y <b>-</b>
NOTE 5: INVENTORIES		
	2016	2015
CURRENT		
At cost - Finished Goods (Merchandise)	19,574	12,842
TOTAL CURRENT	19,574	12,842
TOTAL	19,574	12,842

#### NOTE 6: PROPERTY, PLANT AND EQUIPMENT

	2016	2015
Freehold Land		
Freehold Land at fair value (a)	1,081,000	1,081,000
TOTAL FREEHOLD LAND	1,081,000	1,081,000
Buildings at fair value (a)		
At fair value	219,000	219,000
Less Accumulated Depreciation	(14,716)	(7,358)
TOTAL BUILDINGS	204,284	211,642
Fixtures and Fittings		
At cost	243,266	242,178
Less Accumulated Depreciation	(238,410)	(237,466)
TOTAL FIXTURES & FITINGS	4,856	4,712
Office Equipment		
At cost	135,013	165,669
Less Accumulated Depreciation	(103,267)	(129,201)
TOTAL OFFICE EQUIPMENT	31,746	36,468
Motor Vehicles		
At cost	28,909	28,909
Less Accumulated Depreciation	(20,240)	(17,723)
TOTAL MOTOR VEHICLES	8,669	11,186
Computer Equipment		
At cost	40,632	40,632
Less Accumulated Depreciation	(32,995)	(29,176)
TOTAL COMPUTER EQUIPMENT	7,637	11,456
Other Assets		
Cabin holiday Units	99,779	100,323
Accumulated depreciation	(95,212)	(92,049)
TOTAL OTHER ASSETS	4,567	8,274
TOTAL PROPERTY, PLANT AND EQUIPMENT	1,342,759	1,364,738

Land and building situated at 80 Dodds Street, Southbank were revalued on 31 December
2014 by the Board based on an assessment by Charter Keck Cramer of the property's market value

#### NOTE 7: INCOME RECEIVED IN ADVANCE

	2016	2015
CURRENT		
Grants and Revenue Received in Advance	142,697	60,566
TOTAL CURRENT	142,697	60,566
TOTAL	142,697	60,566

#### NOTE 8: TRADE AND OTHER PAYABLES

2016	2015
	_
61,624	83,343
61,624	83,343
61,624	83,343
	61,624 61,624

#### NOTE 9: PROVISIONS

	Employee Benefits	Total
PROVISIONS		
Opening balance at 01-Jan-16	48,541	48,541
Additional provisions	45,218	45,218
Amounts used	(27,697)	(27,697)
Closing balance at 31-Dec-16	66,062	66,062
ANALYSIS OF TOTAL PROVISIONS	2016	201
CURRENT		
Provision for Employee Entitlements	66,062	48,54
TOTAL CURRENT	66,062	48,541
TOTAL PROVISIONS	66,062	48,541

#### NOTE 10: RESERVES

	2016	2015
ASSET REVALUATION RESERVE	C. III	
Opening balance at 01-Jan-16	1,102,223	1,102,223
Transfers from retained earnings	<b>2</b> 1	
Transfers to retained earnings	17. I	.=)
Revaluations	5	
Closing balance at 31-Dec-16	1,102,223	1,102,223
TOTAL RESERVES	1,102,223	1,102,223

#### NOTE 11: RETAINED EARNINGS

2016	2015
1,531,779	1,450,317
123,751	81,462
1,655,530	1,531,779
	1,531,779 123,751

#### NOTE 12: SEGMENT REPORTING

The association operates in the charity sector providing services to all the Cystic Fibrosis community and members within Victoria.

#### NOTE 13: ASSOCIATION DETAILS

The registered office and principal place of business of the Association is:

Cystic Fibrosis Victoria Inc 80 Dodds Street SOUTHBANK VIC 3006

#### STATEMENT BY THE BOARD

The board has determined that the association is not a reporting entity and that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

In the opinion of the board the financial report:

- 1. Presents a true and fair view of the financial position of Cystic Fibrosis Victoria Inc. as at 31 December 2016 and its performance for the year ended on that date.
- 2. At the time of this statement there are reasonable grounds to believe that Cystic Fibrosis Victoria Inc will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the Board and is signed for and on behalf of the Board by:

...... Ross Frase

Chairman

Treasurer

Rod Naismith

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Dated this 16 day of March 2017



# Cystic Fibrosis Victoria Inc.

Independent auditor's report to members

# **Report on the Audit of the Financial Statements**

#### Opinion

We have audited the financial report of Cystic Fibrosis Victoria Inc., which comprises the balance sheet as at 31 December 2016, the income and expenditure statement, statement of changes in members funds and statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies, and the statement by members of the Board.

In our opinion the financial report of Cystic Fibrosis Victoria Inc. presents fairly, in all material respects, the financial position as at 31 December 2016 and its financial performance and its cash flows for the year then ended in accordance with the financial reporting requirements of the Associations Incorporation Reform Act 2012.

#### **Basis for Opinion**

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Report section of our report. We are independent of Cystic Fibrosis Victoria Inc. in accordance with the auditor independence requirements of the Associations Incorporation Reform Act 2012 and the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110 Code of Ethics for Professional Accountants (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### **Emphasis of Matter – Basis of Accounting**

We draw attention to Note 1 of the financial report, which describes the basis of accounting. The financial report has been prepared to assist Cystic Fibrosis Victoria Inc. to meet the requirements of the Associations Incorporation Reform Act 2012. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

CHARTERED ACCOUNTANTS & ADVISORS

Level 20, 181 William Street Melbourne VIC 3000 Telephone: +613 9824 8555 williambuck.com





#### Responsibilities of the Board for the Financial Report

The Board of Cystic Fibrosis Victoria Inc. is responsible for the presentation of the financial report in accordance with the financial reporting requirements of the Associations Incorporation Reform Act 2012 and for such internal control as the Board determine is necessary to enable the preparation and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

#### Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with the Australian Auditing Standards, we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Board.
- Conclude on the appropriateness of the Board' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the Incorporation to cease to continue as a going concern.



 Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

We communicate with the Board regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

William Buck Audit (VIC) Pty Ltd ABN 59 116 151 136

A. P. MARKS Director

Dated this 20th day of March, 2017, Melbourne