



BEYOND FIVE

The Face of Head & Neck Cancer

ANNUAL REVIEW | 2018/19



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CHAIRMAN'S MESSAGE

Welcome to Beyond Five's first Annual Review.

Head and neck cancer is complex, but Beyond Five's mission is simple: to improve the quality of life of everyone affected by head and neck cancer across Australia through education and access to support and to raise awareness of the disease.

As we mark our third anniversary, we continue to deliver trusted, quality information to people affected by head and neck cancer through our website. We remain grateful to our expert contributors from across Australia and New Zealand who give freely of their time to keep this information up-to-date.

Special thanks go to our community of supporters including corporate partners and donors whose contributions are key to ensuring the sustainability of our activities. It is only by having a strong supporter base that we will be able to continue to raise awareness and provide support to people affected by head and neck cancer. This involvement is also crucial to helping us meet our new strategic priority of advocating for head and neck cancer to form part of the public sector funding and health policy agenda.

As Chairman I have had the pleasure of working with Beyond Five's committed team and Board of Directors. In April 2019 we welcomed our first non-clinical Board Director, Terrie Gibson, who in her short time with Beyond Five has made a valuable contribution, guiding discussions to ensure our future sustainability and assisting to develop a blueprint to ensure our priorities reflect the needs of our community.

Finally we'd like to thank every person living with head and neck cancer, their families and friends: your strength and resilience continues to inspire us to make a positive change now and into the future.

PROFESSOR JONATHAN CLARK
CHAIRMAN



OUR ORIGINS

Beyond Five was the first Australian not-for-profit supporting head and neck cancer patients and carers. It was founded by a team of leading clinicians who saw first-hand the profound impact of head and neck cancer and were passionate about driving change.

Their personal commitment to Beyond Five's vision has resulted in a unique collaboration of patients, family members, carers and clinicians working to educate, support and reduce the cancer burden in some of the most disenfranchised cancer patients.



OUR VISION

To save lives and ensure no Australian faces head and neck cancer alone.

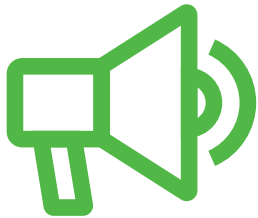
OUR MISSION

To raise awareness about head and neck cancer and to improve the quality of life of those affected, through information and access to support.

OUR COMMITMENT

- Preventing** head and neck cancer and promoting early detection
- Providing** information and access to support to patients, family, caregivers and health professionals
- Prioritising** head and neck cancer in national health policy

OUR STRATEGIC PRIORITIES 2020-2023



RAISE AWARENESS NATIONALLY

Educate all Australians about head and neck cancer to increase early diagnosis and encourage prevention.



PROVIDE VITAL SUPPORT

Empower all patients and carers to better navigate their head and neck cancer journey, by providing a central source of information and support.



INFLUENCE PUBLIC POLICY

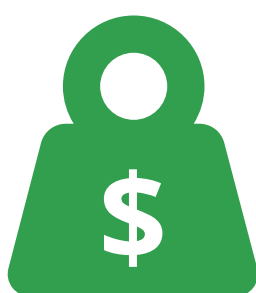
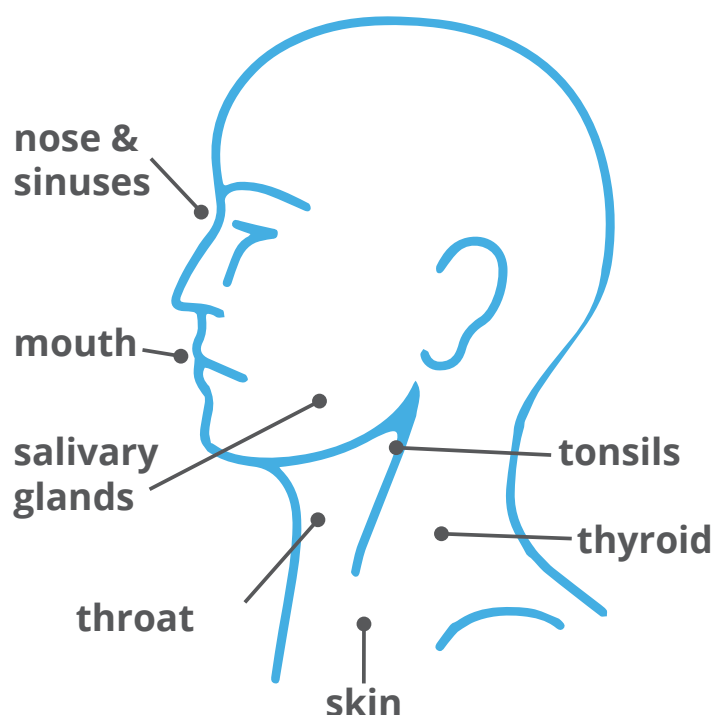
Engage with government to advocate for dedicated public sector funding for head and neck cancer prevention and patient care.

Beyond Five is taking steps to build new partnerships and identify new sources of funding to support its transformation into a national organisation with a powerful impact on the increasing incidence of head and neck cancer in Australia.



HEAD AND NECK CANCER AUSTRALIA – A SNAPSHOT

A COMPLEX SET OF CANCERS



**ECONOMIC COST OF
HEAD AND NECK CANCER
PER PERSON IS
TWICE THAT
OF BREAST CANCER⁴**

34%²

increase in head and
neck cancer in the
last 10 years.

5,212¹

new cases in 2019

17,000¹

people estimated to
be living with head
and neck cancer^{1,2}

58%³

higher in low socio-
economic areas

72%³

higher in remote
areas⁴

HEAD AND NECK CANCER AUSTRALIA – A SNAPSHOT

71%¹

Five year survival rate.³

1,200¹

1,200 Australians will die from head and neck cancer in 2019.

OROPHARYNGEAL CANCER^{*5}

Number of cases caused by human papilloma virus

70%⁶

2019

20%⁶

1987–1995

*Tonsil & base of tongue



INDIGENOUS AUSTRALIANS AND HEAD AND NECK CANCER

5th Most commonly diagnosed cancer⁷

42% Higher in remote areas⁷

3.4% More likely to die than non-indigenous Australians⁷

1. Cancer Australia, Head and neck cancer statistics <https://head-neck-cancer.canceraustralia.gov.au/statistics>. 2. AIHW, Head and neck cancers in Australia <https://www.aihw.gov.au/reports/cancer/head-neck-cancers-australia/contents/table-of-contents>. 3. Cancer Australia's National Cancer Control Indicators August 2018 <https://ncci.canceraustralia.gov.au/>. 4. Cost of Cancer in NSW, Access Economics/Cancer Council NSW 2007. 5. Human Papillomavirus and Oropharyngeal Cancer Among Indigenous Australians: Protocol for a Prevalence Study of Oral-Related Human Papillomavirus and Cost-Effectiveness of Prevention <https://www.researchprotocols.org/2018/6/e10503/>. 6. Cancer Council Australia <https://www.cancercouncil.com.au/head-and-neck-cancer/>. 7. Cancer in Aboriginal & Torres Strait Islander people of Australia <https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/contents/cancer-type/head-and-neck-cancer-c00-c14-c30-c32>

WHY IS HEAD AND NECK CANCER DIFFERENT?

Head and neck cancer is incredibly complex and diverse. It includes more than 10 different cancers that can affect a person's mouth, tongue, salivary glands, skin or voice box.

In Australia nearly 5,000 people are diagnosed with a form of Head and neck cancer each year and more than 17,000 people are living with the side effects of the disease.

In the past, smoking was the most common cause of head and neck cancer typically affecting areas like the mouth, throat and voice box.

However, what many people don't know is that today in Australia, many head and neck cancers are due to other causes; including the human papilloma virus - the same virus that causes cervical cancer and which can affect young, otherwise healthy, non-smoking men and women.

The cause of other cases is unknown and so it is important, particularly for men over 40, to be vigilant and have any neck lumps or mouth sores that don't heal checked by a doctor.

Head and neck cancer can be brutal. It affects a person's identity unlike any other cancer. It's a cancer that you see in the mirror. It's a cancer that you see in the behaviour of the person sitting next to you on the bus.

While many people survive the disease, the cancer can leave a person unable to speak, it can leave them with devastating facial disfigurements and take away basic abilities that we all take for granted like eating, breathing, speaking, drinking and swallowing.

"I have witnessed first-hand how improved access to information can remove some of the uncertainties and fill voids with hope."

Nicole, Gold Coast QLD



"When I went out people would stare at the swelling and graft on my neck so I decided to name the graft 'Percy' and got my wife Iris to draw a 'smiley face' in texta on 'Percy'.

What a difference that made, people smiled instead of stared."

Ross, Adelaide SA



DID YOU KNOW?

13 people are diagnosed with head and neck cancer every day.

EARLY DETECTION AND EDUCATION IS KEY

THERE IS NO SCREENING FOR HEAD AND NECK CANCER

Reducing the risk – What you need to know



QUIT SMOKING



LIMIT ALCOHOL INTAKE



PROTECT CHILDREN WITH
THE HPV VACCINE



DON'T IGNORE
A NECK LUMP



BE SUN SMART



DON'T IGNORE
A MOUTH ULCER

2018-19 HIGHLIGHTS

OUR REACH



41,767

New website visitors in 2018-19
– a 246% increase from 2017-18.



60

Hospitals across Australia and New Zealand received Beyond Five patient cards and posters for newly diagnosed patients.



209,853

Views of Beyond Five 3D animation and patient videos.

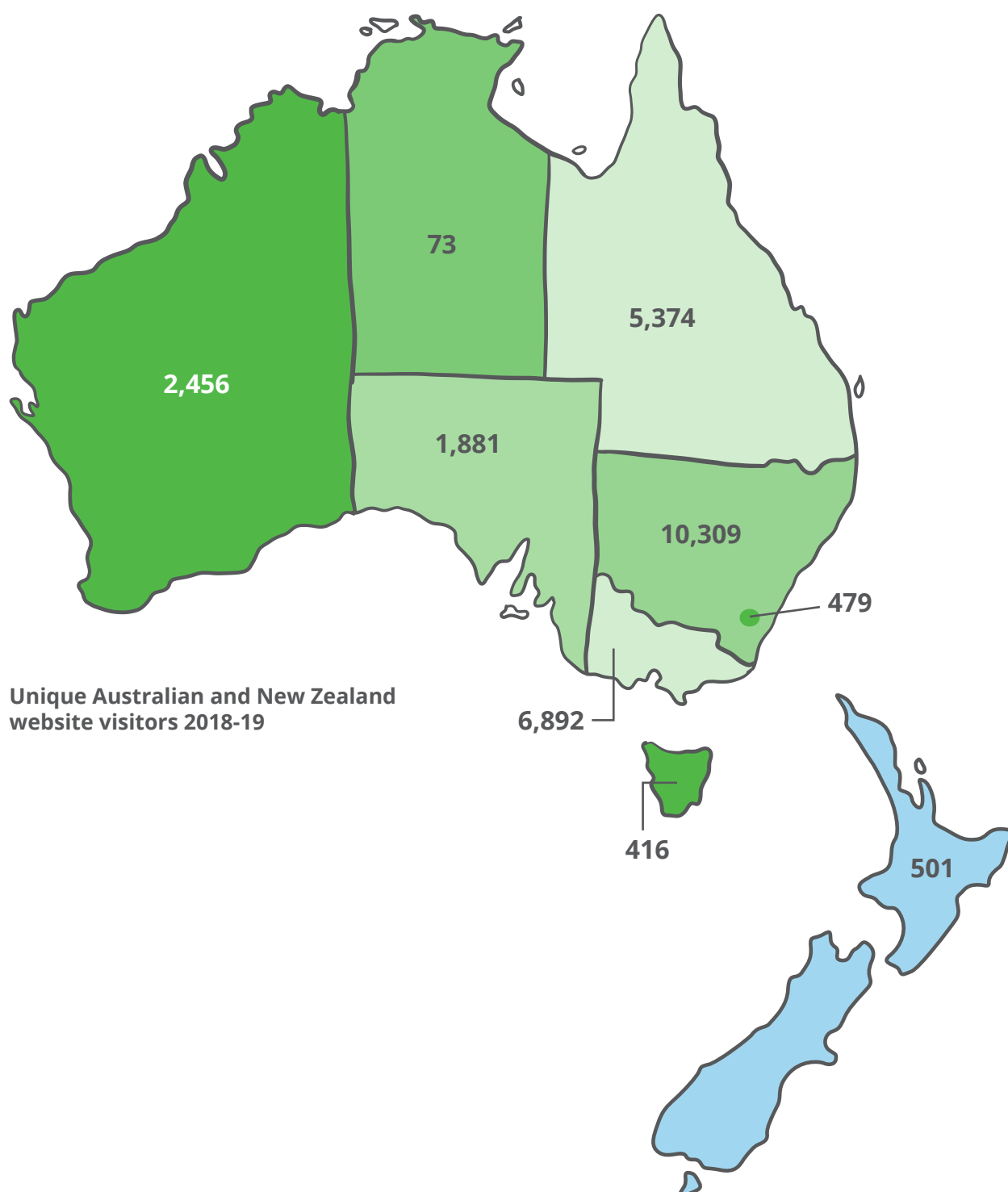


700

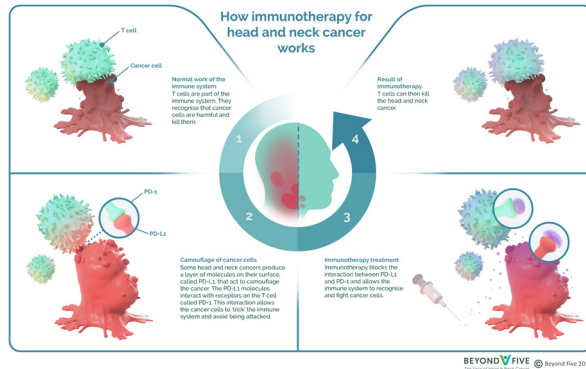
Patients and healthcare professionals received our Quarterly Newsletter across Australia and NZ

EDUCATION & AWARENESS

The Beyond Five website has over 60 information sheets, 3D animations and patient and carer videos. Our resources help people affected by head and neck cancer to better understand their type of cancer and navigate their journey. This year over **60 hospitals** received free resources to give to newly diagnosed patients and family members.



NEW RESOURCES



Immunotherapy for head and neck cancer

In May we published a new infographic to help explain what immunotherapy for head and neck cancer is and how it works. This new resource gives people the facts they need to make an informed decision with their cancer care team.

beyondfive.org.au/Treatment/Emerging-Therapies/Immunotherapy



BEYOND FIVE
The Face of Head & Neck Cancer

Head and Neck Cancer Podcast Series

Head and Neck Cancer:
A Patient's Experience

Jeffrey Condon
Former patient, Perth



Podcast Series

We launched our first Head and Neck Cancer Podcast series in July thanks to a grant from the Brady Cancer Support Foundation in Western Australia.

Developed for patients, family and friends, the podcasts cover some of the most frequently asked questions for people recently diagnosed or just commencing treatment for oropharyngeal cancer.

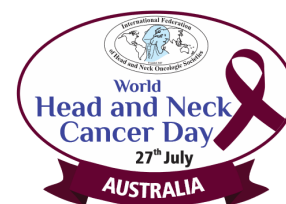
Hosted by Julie McCrossin, radio broadcaster, journalist, former head and neck cancer patient and Beyond Five Ambassador, the podcasts feature interviews with clinicians and a former patient.

beyondfive.org.au/News/B5-Podcasts

DID YOU KNOW?

There are no resources to support over 1,000 people from culturally and linguistically diverse backgrounds with head and neck cancer?

WORLD HEAD AND NECK CANCER DAY

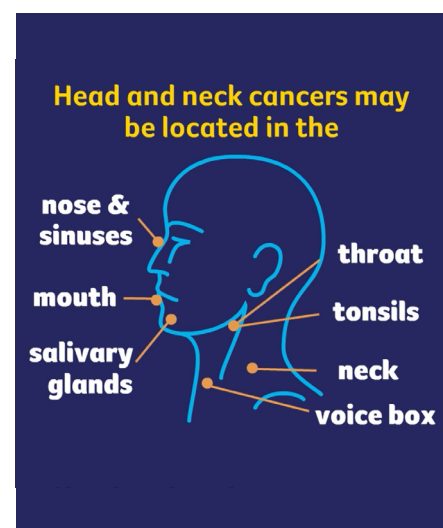


When Beyond Five Ambassador, Marty Doyle, was diagnosed with head and neck cancer 14 years ago public awareness in Australia was very low. In 2015 Marty was involved in organising the first Head and Neck Cancer Awareness Day in Australia.

Fast forward to 2019 and thanks to the pro bono support of the team at Bauer Media our awareness advertisements reached over 2 million people as part of World Head and Neck Cancer Day on 27 July.

Over 30 free WHNCD Resource packs were sent to hospitals across Australia to support head and neck cancer staff hosting public information stalls.

We also joined forces with Cancer Council Australia and the Australian Dental Association of NSW via social media to raise public awareness of the signs and symptoms of head and neck cancer to encourage prevention and early detection.



DID YOU KNOW?

Head and neck cancer is the second most common cause of cancer death for Indigenous Australians.

PARTNERSHIPS

Thanks to the support of leading head and neck cancer professional bodies including the Australian and New Zealand Head and Neck Cancer Society, the Otolaryngology Head and Neck Nurses Group and the North East Melbourne and Western and Central Melbourne Integrated Cancer Centres, Beyond Five had the opportunity to present to over 500 health care professionals, patients, family and friends over the past 12 months helping to raise awareness of our resources to ensure people get the information and support they need.



AUSTRALIAN AND NEW ZEALAND
HEAD & NECK
CANCER SOCIETY



www.ohnng.com.au



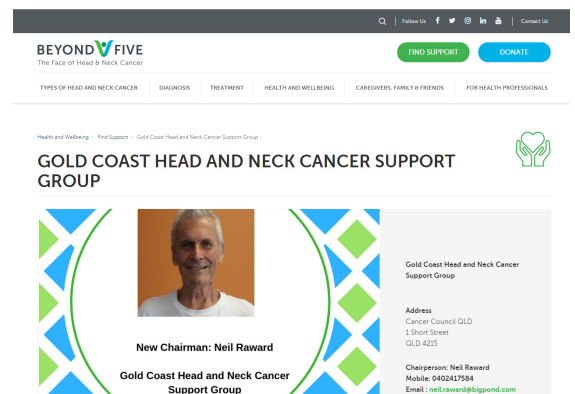
Healthdirect Australia

We were invited to become a Healthdirect Australia information partner in September 2018. Healthdirect Australia is a government-funded service, providing quality, approved health information and advice. This partnership will help us reach more people across Australia looking for information about head and neck cancer.



SUPPORT GROUPS

The Beyond Five website offers head and neck cancer support groups across Australia and New Zealand a dedicated page to share details of their support group, upcoming meetings and contact details. This centralised portal makes it easy for people affected by head and neck cancer to find out whether there is a support group in their local area and also provides links to online support groups.



"Joining a support group for head and neck cancer patients, or even starting your own is an important part of recovery. There is a genuine need for them."

Arthur, Central Coast NSW



OUR COMMUNITY OF SUPPORTERS



SOUP FOR THE SOUL

20 - 27 July

Soup for the Soul

Twenty five events were held across Australia as part of our second Soup for the Soul event from 20-27 July.



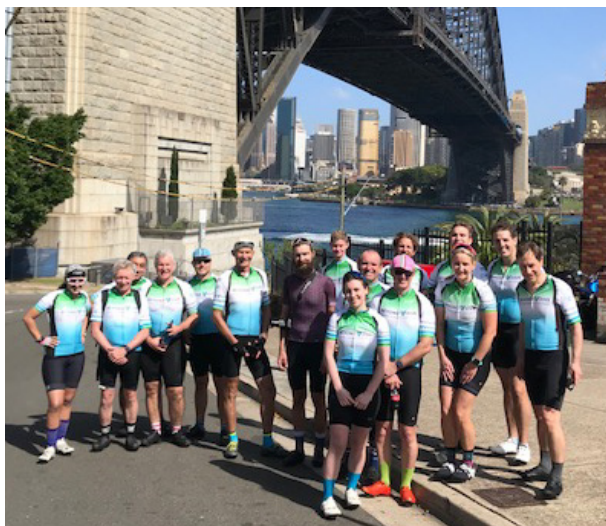
"Supporting initiatives like Soup for the Soul is so important for raising awareness of head and neck cancer. I always have to explain to people what head and neck cancer is. It remains one of the least known cancer types and makes up such a tiny proportion of all cancer cases. This doesn't lessen its impact though!"

Head and neck cancer changes the lives of those who live with it. With increased public attention, funding and media coverage, we will have better resources to provide our patients with better and more-timely treatment and rehabilitation."

**Danielle Stone, Senior Speech Pathologist,
Royal North Shore Hospital NSW**

#RideBeyondFive

The inaugural #RideBeyondFive was held in September thanks to the enthusiasm of ride organisers, Beyond Five director Prof Bruce Ashford and Beyond Five supporter Dr Trevor Gardner. Save the date for 2020 – Friday 16 October!



OUR COMMUNITY AMBASSADORS

From meetings with local MPs, hosting Soup for the Soul events and attending forums across the country, our Beyond Five Ambassadors have each had a busy year helping to raise awareness of head and neck cancer. Thank you for your continued support.



Mrs Denyse Whelan



Ms Julie McCrossin



Mr Marty Doyle

DID YOU KNOW?

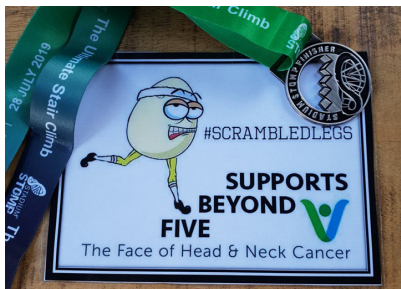
Three Australians are diagnosed with mouth (oral) cancer every day?

"When I went through my treatment, I had a lot of questions about my cancer. You need someone to talk to and reliable information when battling this disease."

Mick, Sydney NSW



COMMUNITY SUPPORT



WHY SUPPORT HEAD AND NECK CANCER?

Most people in Australia have never heard of head and neck cancer. No national awareness campaigns exist. There are no screening programs.

Beyond Five receives no government funding and relies on the generous donations from individuals and the community, grants and corporate support to fund our education and awareness activities.

Our aim is for Beyond Five to become a household name in Australia so that everyone knows what head and neck cancer is and how it can be prevented and detected early to give people the best chance of survival possible.

We are determined that anyone affected by head and neck cancer, regardless of where they live in Australia, or their financial situation, knows about and has access to evidence based information and the support they need before, during and after treatment.

"I had never found another person with cancer 'like mine' until I met Fergus who had seen my story on the Beyond Five website. I cannot tell you how good it was to share with someone else who understands the need to have coffee in a particular way and more."

Denyse, Central Coast NSW



DID YOU KNOW?

Up to 45% of people treated for head and neck cancer will experience problems with swallowing, known as dysphagia?



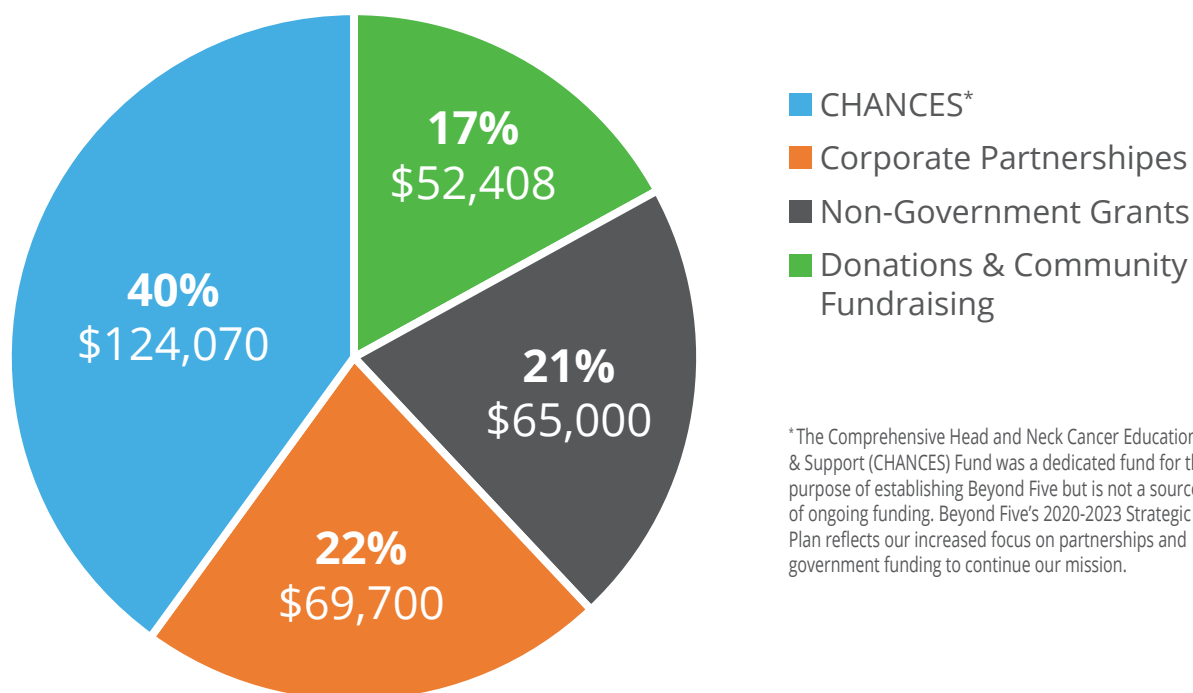
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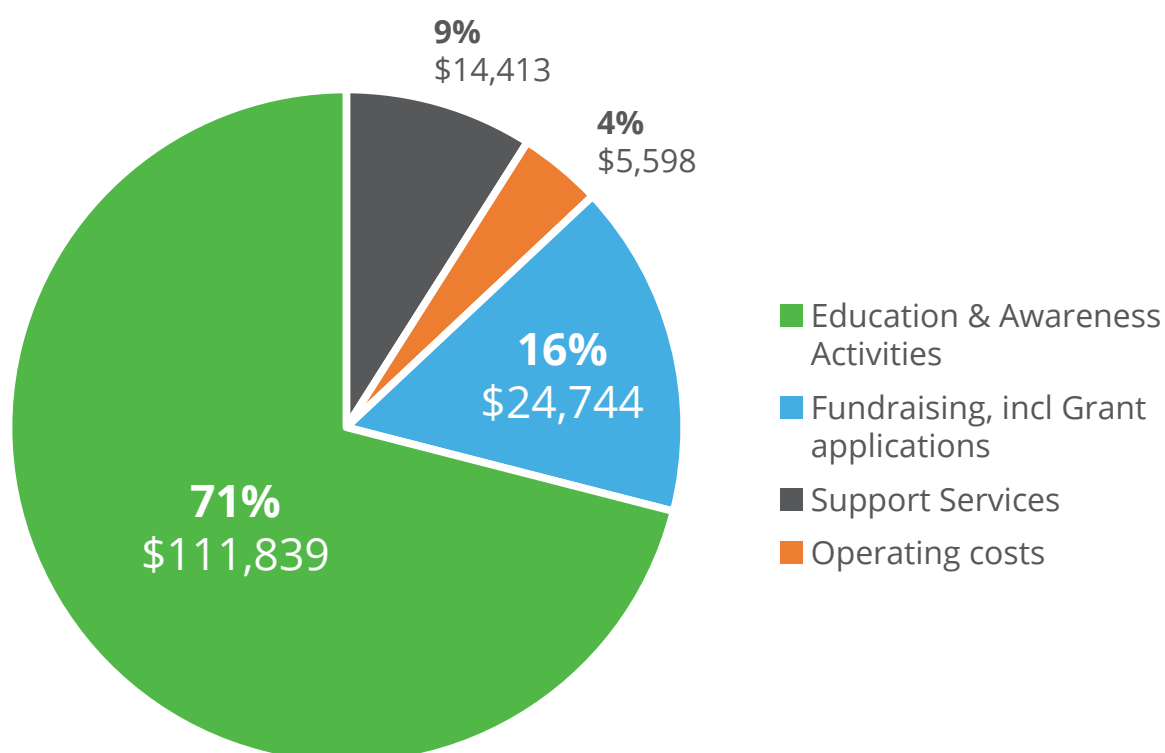
FINANCIAL SUMMARY
FOR THE YEAR ENDED 30 JUNE 2019



2018-19 INCOME SOURCES



2018-19 EXPENDITURE



OUR THANKS

Board of Directors



Prof Bruce Ashford



Prof Jonathan Clark



A/Prof Ardalan Ebrahimi



Ms Terrie Gibson



A/Prof Dion Forstner



A/Prof Carsten Palme



Dr Purnima Sundaresan

Staff



Nadia Rosin

Expert Contributors

Beyond Five is very fortunate to have head and neck experts around Australia and New Zealand contribute to the development and review of content for the Beyond Five website. Their involvement helps us to provide information that is based on the best available evidence and clinical consensus.

Learn more about the Beyond Five team and our expert contributors
beyondfive.org.au/About-Us/Meet-our-team

OUR THANKS

Our Corporate Partners



Pro Bono Partners



Trusts and Foundations





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