

# Chapter 11

## YEAH: One Story of Inspiration and Success

Alischa Ross

**About the Author** Alischa Ross is the founder and CEO of Youth Empowerment Against HIV/AIDS (YEAH). A community-based organization, YEAH is the first of its type in Australia focused on educating and empowering youth around issues of HIV/AIDS and sexual health. Starting as an impassioned idea, YEAH has grown to be the largest organization of its type in Australia today, becoming a leading voice for youth there and around the world. Alischa's drive and her vision are to shape a new generational approach to HIV and AIDS that is centred on life – protecting, valuing, and nurturing life to its full potential. YEAH's unique national approach is equally about the impact of AIDS locally and the impact on the world in which we all live. Alischa and the team at YEAH help young people recognize the issues surrounding HIV and AIDS as an incredible opportunity to express leadership for social impact, not simply because of the pandemic proportions of HIV and AIDS, but because it is through social disconnect that this deadly but preventable disease continues to consume millions of members of our human family. This chapter is the story of the genesis of YEAH, providing key insights and lessons along the way.

Nineteen years ago, I could not have imagined that I would end up founding Australia's first youth-focused HIV/AIDS prevention organization. Nineteen years ago, when I was 8 years old, my connection with HIV/AIDS began; my Mom, divorced and raising me as a single parent, was diagnosed HIV-positive (herein HIV+). It was the mid-1980s and the Australian social climate surrounding AIDS was one laden with fear. During that time, Australia's profound early response to what would become the worldwide HIV/AIDS pandemic was taking form.

### 11.1 AIDS in Australia

My introduction to HIV/AIDS in Australia began as a little girl, as a daughter whose mother had to face the realities of this disease; I not only grew up with the intimate experience of HIV in my family, but grew up with HIV/AIDS. What I mean is I am almost the same age as AIDS; I often point this out to other people of my age and younger. I am deeply curious: what was it like to live in a world without HIV/AIDS? I have only ever known a world in which it exists.

The history of community-based and nongovernmental HIV/AIDS organizations in Australia is a telling story of the social connections and divides between different demographics – the endless minorities within an already minority group of people living with HIV/AIDS (PLWHAs). Over time, these early connections and divides have shaped the current landscape of community and nongovernmental HIV/AIDS services, nearly three decades on.

In Australia, HIV spread rapidly during the early and mid-1980s amongst homosexually active men, and a fear grew that transmission of the virus would continue to spread rapidly to the broader heterosexual community though the injecting drug users (IDUs) (Bowtell 2006). Australia's political leadership recognized the need for a partnership approach with nongovernmental and community networks in formulating a framework for effective policy that could deliver public messages of prevention whilst also delivering treatment and care to those most in need. Partnerships were formed between traditionally marginalized civil society groups representing those most affected and at risk of HIV: the gay community, IDUs, sex workers and to a lesser extent hemophiliacs, together with researchers, clinicians, and PLWHAs (Department of

Health and Ageing 2005). Soon, complex webs of minority community groups were the ones at the forefront, working with government to shape the national response to HIV/AIDS. However, it was the gay social movement, those most affected, that was instrumental in driving this grassroots response.

At the time, it was difficult to understand how my family (my Mom and I) would fit into this evolving mould of what was to become the foundation of the HIV/AIDS sector in Australia. Mom was 28 years old, she was pregnant when she was diagnosed HIV+, and I was in primary school. I was growing up in middle-class suburban Australia. Women were not considered to be at high risk for HIV. As Mom and I searched to understand what HIV was and where we could go for support we recognized that the options were simply limited.

At that time, state and territory AIDS councils had been established across Australia with the majority being operated by gay men's health networks, and in some instances their focus extended to IDUs and others with bloodborne diseases such as Hepatitis C. In a time before the introduction of the first effective treatments for HIV, many PLWHAs were limited to accessing care at isolated infectious disease hospitals, and the prognosis was grim. The primary care message available to her and other HIV+ people at that time was the emphasized importance of embracing a healthy lifestyle in order to maintain general well-being and slow the progression of the virus. This message was delivered along with a strong warning that once this virus takes hold the likely outcome would be a slow and debilitating journey with a poor prognosis of recovery.

My younger sister, Elizabeth, born when I was 9 years old, contracted HIV from Mom during the labor, although it could not be clearly established that she was in fact HIV+ when she was born. Like many children born to an HIV+ mother, Elizabeth carried Mom's HIV antibodies and it would take time, we were told, before she would either eliminate those antibodies from her system or in fact test HIV+ herself. The best (and only) option then was to wait and see.

Little was known about HIV/AIDS in adults, even less was known about pediatric HIV/AIDS at the time, and consequently my infant sister had no option other than to be subjected to a range of experimental treatments in a bid to offer her some extension of life once it was apparent she was indeed HIV+.

I remember the frequent visits to Fairfield Hospital, the infectious diseases hospital on the outskirts of

Melbourne where the bulk of PLWHAs in Melbourne went to access treatment in those early days. Fairfield Hospital's sterile medical compound was broken by the somewhat eerie sense of peace and tranquility of the hospital's surroundings. Set beside the Yarra River, the grounds of the hospital encompassed large gardens where peacocks freely wandered and patients could stroll and reflect, as Mom and I did on many occasions. In the autumn of 1991, my sister Elizabeth died at the age of 18 months after a complicated battle that had seen her spend the last 3 months of her life confined to that hospital.

Much of what I have learnt since then has been profoundly shaped by the early experiences of watching my Mom and baby sister, Elizabeth, battle the physical and social challenges of this disease. A few years following my Mom's diagnosis, a small group of HIV+ women formed a support group, *Positive Women Victoria*. While the aim of the network was to offer support to HIV+ women, in an ad hoc way, the network also extended support to their children.

Mom became an active member of *Positive Women Victoria*, and as her experience of living with the virus grew, she felt compelled to use her story to give insight to others. Through a variety of PLWHA networks, she and other HIV+ speakers began to travel around their local communities sharing their personal testimonies and knowledge of the virus with students, business networks, and the general public. It was not long before I, at the age of 14, joined my Mom in publicly sharing my story of growing up with HIV; it was the same story, but delivered from two perspectives.

Mom's own health took a rapid downward spiral after Elizabeth's death and the doctors predicted that she had, at most, a few years to live. I had just celebrated my 11th birthday and could not grasp any real concept of how my life would be without Mom to take care of me. For most of my life it had just been the two of us, a team, and I was not old enough to go out to bat on my own. A turning point came one evening as we sat together in an emotional mess, when Mom made the commitment of a life time – she *promised* me that she would live to see me finish school and turn 18. Her doctors felt a sense of professional responsibility to warn me that although a positive will to live is testament of a person's strength of character, the likelihood of Mom's physical strength being able to sustain that many years with a failing immune system was not probable. The year was 1991.

Prior to this, in 1989, the first treatments for HIV (i.e., AZT) were introduced and with the breakthrough came the hope of extended quality and quantity of life for many of those already living with HIV/AIDS. By 1989, Mom had already been living with the virus for 6 years and despite having access to treatments, the results from taking them were less than desired. So, she volunteered to take part in a number of experimental treatment trials in the hope that she could find better results and prolong her young life.

In Australia, as in most other countries, the PLWHA community was isolated from the broader community by stigma, policies, and other barriers, and within that community, women, children, and heterosexual men were the *minority within the minority*. A few years after my sister's death, my Mom was encouraged by a nurse to connect with a young man, Michael, who was in his early 30s and had been recently diagnosed as HIV+. Michael had a young daughter and his marriage had recently broken down under the stress of finding out his HIV+ status. Given the lack of formal support networks for people in his situation, the nurse thought that Mom and Michael could find mutual support in connecting with each other.

Phone calls and long conversations about what they were both experiencing spearheaded an incredible connection, and before long, Michael and his daughter, Madeline, had become a part of our lives. Several years later, in June 1993 Michael and Mom married and cemented this companionship of shared experiences.

During this time, Michael had become increasingly interested in the support network of Positive Women Victoria, which Mom was still very much a part of, and he began being more involved in activities in the local HIV community. Michael became a public speaker, sharing his personal experiences of living with HIV, and along with two other young HIV+ heterosexual men set up an organization called *Straight Arrows*. *Straight Arrows* was established to support the needs of heterosexual HIV+ men and since then has evolved and continues to be a support network for HIV+ heterosexuals and their families.

My life did not differ greatly from that of most other adolescents; my teenage years were turbulent. However, I had the added issues of growing up in a family where both of the adults in my life were HIV+ and embraced, participated in, and exposed me to the culture and power of their respective community-based organizations.

As I got older, I increasingly became involved in HIV community activities with my Mom and I was confronting the difficulties of friends and their families' lack of understanding of HIV. As my peers were becoming sexually active, they considered me their primary source for information on HIV and many other related sexual health problems for which, I was no expert then. By the time I was 15 years old, I gave my first public presentation on my personal experiences of growing up with HIV/AIDS in my family at a World AIDS Day memorial event in Melbourne.

It was inevitable that at some point either Mom or Michael was going to get sick before the other and as it turned out it was my Mom. She had several severe HIV-related illnesses from the time I was 15 and spent increasing amounts of time in the hospital. By 1997, it became obvious that Mom was losing her battle with HIV and had deteriorated so much that she hardly resembled the healthy and energetic woman I knew as my Mom. It was my final year of secondary school and I struggled to keep my balance as I watched my Mom slowly wither away, our family unit break down, and dealt with the pressures of school, trying to finish and graduate.

I had never had a great interest in science until my last few years of secondary school when I discovered a bridge between my love for sport, the human body, and science. This opened up a whole new range of possibilities of what I was going to do with my life. Despite the adverse conditions in my family, I passed my final year of school with flying colors and decided to accept a university placement starting the next year studying Medical Science.

The year was 1998. My Mom had achieved her two promises – she had seen me finish school and turn 18. It was now my turn to make a promise. I promised my Mom that I would be okay without her. On June 8, 1998, at the age of 37, she slipped away peacefully in her sleep.

I did end up studying medical science at La Trobe University in Melbourne. Although it took me a few years to really come to terms with all that had happened, I thought I was getting my life back on track. From the moment Mom died, I severed almost completely all of my ties with the HIV/AIDS community and could not even bring myself to drive past the hospital that had become my second home over the last few years of Mom's life. As far as I was concerned, I had done my time with AIDS; it was time for a new chapter in my life!

### 11.1.1 *Reconnecting: The Conference Circuit*

Two years after Mom's death I found myself in Durban, South Africa, on my way to the XIII International AIDS Conference. It seemed like I could not stay away from my connection to HIV/AIDS for very long. Previously, about a year after Mom died, I randomly paid a visit to the hospital where she had spent her last months. The hospital was also home to most of the HIV services in Melbourne, including *Positive Women*, the first stop on my visit. As I entered the new offices of *Positive Women* I felt a strange familiarity despite being greeted by a strange face. A new woman was running the organization and for the first time in the organization's history it was headed by a non-HIV+ woman. We had a long chat and as it turned out that conversation had a profound impact on us both; Stephanie was new to the job, trying to find her way, and I found myself reconnecting. There was a brochure in the office with a group photo of some of the members and I pointed out Mom in the photo. Many of the old faces from *Positive Women* were still around, including Sonia, a woman whom my Mom had a very close friendship with. From that day onward I started to be involved again in *Positive Women's* community activities. The only problem was to logistically work out how I, as a non-HIV+ young woman who was the daughter of a previous member of the organization, could fit in! The rules and regulations of the HIV/AIDS networks had all been put in place to support PLWHAs and to try to provide them with environments where they could feel safe and respected. The problem is that these rules that are meant to provide confidentiality and privacy can often end up adding to the isolation of PLWHAs and widen the divide between their friends, families, and others who genuinely want to be involved.

One day after finishing classes at university, I received a call from Sonia at *Positive Women's* office asking me to drop by. Sonia and I had been having ongoing conversations; and given my experiences, she felt I would be a great advocate for HIV/AIDS in Australia.

It turned out that Sonia and some others members at *Positive Women* wanted to assist me in attending the XIII International AIDS Conference in Durban, South Africa. I decided it would be an interesting

experience and agreed to apply for a scholarship. Several months later, Sonia called me and handed over a letter that confirmed my scholarship to attend the conference.

I had never been to a conference before. Not even a small local meeting. I received a great deal of advice from many people regarding how to approach this major AIDS conference. People warned me of the enormity of this gathering; 20,000+ people from the science and medical community, civil society, government, and world leaders all trying to exchange information, ideas and network in the space of five days. I decided my focus was simply to be a spectator and soak in as much as I possibly could; I also figured a little networking would be on the agenda and so in July 2000, I set off for Durban.

I spent most of the flight in tears; partly because I was nervous traveling so far abroad on my own but mostly because the trip was opening up old wounds. The most profound aspect of the conference was realizing that although I had a deep and intimate connection to the issue, my understanding of HIV/AIDS was from a very Australian perspective and I really did not know very much about AIDS in the world. While at the conference I met a young South African man, Neo, who was the first person I had ever met close to my age who shared my same story; he had lost his mother to AIDS. However, the main difference was that Neo's story was so common in his local community that for him it was hard to find someone who did not share his story. By the end of 2001, the estimated number of adults and children living with HIV in South Africa was five million, while in countries like Australia where the spread of HIV had been relatively contained, a total of approximately 14,000 people living with HIV had been reported by the end of that same year (Joint United Nations Programme on HIV/AIDS & World Health Organization 2004), Neo was one of many people I met at the conference who had a personal connection to HIV and I saw how many of these people were dedicating their time and efforts to setting up HIV awareness programs to raise awareness in their communities.

The conference also opened my eyes up to the vast network of international health organizations, community groups, United Nations (UN) agencies and donors that were involved in the global response to HIV/AIDS. Many of these organizations were

completely foreign to me, names I had only read about in newspapers.

I returned from Durban amazed by two things. First, the staggering amount of time and energy I had witnessed that was being spent debating how to prioritize between treatment and care or prevention and education in response to the global pandemic. The second thing that truly startled me was the obvious absence of young people: Why weren't they involved in such a major gathering and being encouraged to participate more actively in the global response?

The following year, in 2001, my home city of Melbourne played host to the Asia Pacific Region AIDS Forum's Seventh International Congress on AIDS in Asia and the Pacific (ICAAP). Quite unexpectedly I was contacted by one of the local coordinators and asked if I could join a team to arrange a youth forum to take place as part of the congress. After accepting the invitation I soon realized that the youth forum had, in my opinion, a rather tokenistic value in relation to the whole program. In hindsight it is clear to me that my naiveté at the time was to expect that everyone present at our coordinating meetings would of course want to make the youth forum the biggest and best it could be.

I felt privileged to be part of the team responsible for coordinating the first youth forum ever to be held at ICAAP. The youth forum was a success on a number of levels. A large number of young people from a great many countries across the region were involved. Eight young people shared their stories and insights. It was the lessons learnt from that experience, however, that facilitated a new way forward for youth involvement at future international gatherings. A Youth Declaration (see Appendix 1) was produced as a result of the forum and was later adopted by UNICEF as a reference in addressing the needs, concerns, and ideas of young people across the Pacific in relation to HIV, their sexual health, and life development opportunities. The greatest lesson learnt was my own: recognizing that I have a place in all of this; and by that I mean I realized that I was going to dedicate a great deal of my energy to improving the opportunity for young people to respond to HIV/AIDS, but I did not realize the shape or depth that commitment was going to take in the years ahead.

Just prior to ICAAP, I was invited to attend a conference in Washington, DC, on stigma and health,

hosted by the National Institutes of Health (NIH). I received the invitation through a contact I had made in Durban – a public health professor working at the NIH who was intrigued by my story and was keen to help me foster connections in the field (Dr. Paul Gaist, the editor of this book). Given that I had just experienced a conference for the first time in my life only months earlier, to suddenly find myself at a second conference in the capital of the USA for a considerably high-level gathering was, in hindsight, an extraordinary chain of events. It showed me the power of networking as a pathway. But, looking back, I think my inexperience at that time actually helped me take the most from the situation.

“Inexperience,” as I call it, is what I believe has enabled me to just be me in the many extraordinary situations I have continued to find myself in over the past several years. I describe myself as inexperienced in the sense that I was in no way tainted by the expectation of understanding the bureaucracy and protocol of this or any of the other forums I attended over these years. Recognizing this, I continued to check in on myself as often as possible to ensure that I had not slipped into a way of operating that was simply driven by a prescribed way of responding.

## **11.2 Bringing Home the Lessons and Experiences to the Youth of Australia**

Since my first conference experience in Durban I had been contemplating the lack of exposure to HIV/AIDS information within the broader Australian community. In Durban I had been inspired by a small group of young people from South Africa who I had met during the conference. They had developed their own youth peer HIV/AIDS education program because quite simply they were desperate to protect themselves; they were watching their parents, teachers, and whole communities die in front of them. They knew what HIV was and truly believed they could do something about it. Over the next few years that passed since the conference in Durban, I became aware of an increasing number of youth-focused organizations raising



awareness around HIV/AIDS. At a point it seemed to me that almost every country I could think of – and even some I had not geographically heard of before – were setting up specific programs to educate their youth (that is with the exception of Australia). Historically, Australia had incorporated broad based public awareness of HIV with targeted campaigns as part of its response to the epidemic. But now, it was 2001, and it had been 14 years since the last Australian national HIV/AIDS media campaign had been aired on major commercial radio and television stations. I asked myself: What do the young people who were born after 1987 know about HIV/AIDS, locally and globally? Why does Australia not have a targeted program to deliver HIV/AIDS education to all young people, their parents, teachers, and the media?

I began investing my spare time in researching how I could set up a youth-focused HIV organization in Australia. My first thought was of my own experiences: of how I had grown up in a family affected by HIV, of my connection to groups and organizations bound by their common experience of HIV. In terms of the youth in Australia, I knew there were many more young people like me out there, most of whom probably had not had the chance to connect to either the local or the global issues of HIV/AIDS. I also saw the lack of support available to help someone like me through the experience of losing family members to AIDS as unacceptable and thought that maybe my role was to set up a support network for young people in that situation. So, I invested my energy into setting up something that could give young people the tools to understand the issues of HIV and AIDS and know how to respond to them, how to protect themselves and others. I felt this type of community-based service would have greater impact in improving community attitudes to HIV rather than establishing a support service for those young people who had lost someone to HIV/AIDS.

Prevention! *Prevention is the only cure we have*, or at least that is what the Australian HIV campaigns in 1987 had said and it seemed to be that they were still ringing true. I was now pouring all of the spare time I could manage, (in between university and trying to build some stability back into my life), into developing a plan of action. I kept thinking: *How do I start? And where do I start?*

## 11.3 Building a Community-Based Organization

### 11.3.1 What's in a Name?

Without even consciously realizing it, I had jumped on the conference circuit again. The following year, in 2002, I attended the International AIDS Conference in Barcelona, Spain. This time I submitted an abstract and was chosen to present a poster. (Honestly, I did not know what that meant at the time!) One night I was brainstorming ideas on how to get my youth HIV project going when I realized I needed a name. I could not keep referring to this as the “Youth HIV Project.” Or could I? When I thought about the community prejudice I had witnessed and still witnessed surrounding HIV/AIDS in Australia, it made sense to me that if my goal was to reach as many young people as possible and educate them about HIV prevention, I would have to find a way to attract them to the issue. The name had to sell, or at least create a curiosity and intrigue, while also having a casual feel to it. This project had to feel approachable to people who would not usually want to approach the issues of AIDS.

I began scribbling down key words that related to my idea: Inspiration, Empowerment, HIV/AIDS, Youth... this project was not going have an acronym as the title, but what is the harm in playing around with words, I thought, maybe you will come up with something? And there it was, the letters just jumped out; Y.E.A.H., Youth Empowerment Against HIV/AIDS. This name is one of the most important decisions I made in the early crafting of the project. To this day, there has not been an occasion where I call a new contact and say “Hi, I’m calling from YEAH” and they say, “where?” and I say “YEAH” and we both laugh and then the person on the other end inquires, “what’s YEAH?” and the ice is broken and I am free to introduce the concept of HIV/AIDS awareness. To this day I have no doubt that if we called the organization The Youth HIV Education Service, the only people likely to engage with us would be the people who already know and who already care about AIDS.

So, here I was with the opportunity to produce a poster for my second attendance at an international AIDS conference and I had a name for my yet-to-be-developed project. So a natural conclusion was to create a visual



**Fig. 11.1** YEAH Red Ribbon Logo. *The Ribbon*. The image uses silhouettes and objects that are associated with young people. The idea behind the silhouettes is to show the variety of interests that young people may have, without revealing their religion, race, social cast and class. Alongside them are objects that young people may come across in their day to day lives. Recognisable objects are laid out in the form of the symbolic “red ribbon,” the international symbol for HIV/AIDS, without physically showing it. The dominance of the ribbon reflects the aim of “involvement and participation of young people in every step of decision making, design, delivery and evaluation of youth programs and events.” *The Logo*. The concept behind the logo for “Youth Empowerment Against HIV/AIDS” is to portray a sense of individuality, freedom to speak, and leave ones’ mark. This was shown by hand writing the letters. The use of quotation marks around the letters Y, E, A, and H further enhances the idea of making a statement and being heard

image for YEAH. I had no resources available to me so I became resourceful! I approached design students at the university to see if someone could come up with a

symbol for YEAH. Hey presto, a graduate student, Christina took on the job and before I knew it YEAH had a logo and a whole image for itself (Fig. 11.1).

My magnificent poster and I headed off to Barcelona and returned three weeks later with piles of business cards and hundreds of new contacts who were eager to hear about YEAH’s development.

### 11.3.2 *The Evolution of YEAH: How We Started an NGO*

Energized by my growing sense of mission and now full of momentum, I registered myself with The Australian Taxation Office as a sole trader and YEAH as the “business name.” I was concerned that my genius title for the business might be taken and it is in my nature to move quickly on decisions without always exploring all the possibilities. I did not have a lot of guidance in how best to set up YEAH so my choice to register as a sole trader was primarily driven by the fact that I knew it is the simplest business structure to set up. A sole trader involves an individual trading on his/her own and holding sole responsibility for all debts and liabilities. By registering the business name, YEAH, I was able to operate as a sole trader under this name.

After investing in a considerable amount of research on my own I realized I was going to need to surround myself with incredible people who could help me formulate my plan for growing YEAH. One of the first inspirational individuals I made contact with was a woman by the name of Marion Webster who had a deep and intimate knowledge of the not-for-profit networks in Australia; she herself had been involved in the setting up of community organizations and had unique expertise in working with philanthropic and social networks. I met with Marion one afternoon and her first instruction to me was to do a SWOT analysis. My reply was something along the lines of “*a SWOT what?*” So, after a very basic run down on how to approach a business plan, I had just become conscious that I was actually wanting to start a business, albeit a not-for-profit business. I began my analysis of YEAH’s Strengths, Weaknesses, Opportunities and Threats (SWOT). Marion also shared with me another gem of advice: the dire importance of having great pro-bono lawyers (lawyers willing to donate their time) in guiding the registration process of a new

not-for-profit business. To this day Marion has been one of the most important mentor figures in guiding me through the challenges of working in the not-for-profit sector.

At the time, I had already begun having meetings with the State Health Department in Victoria, which provides the prime funding for all major state-based HIV/AIDS services. My meetings were to enquire into the likelihood of receiving seed funding to support the development and set up of YEAH. My vision for YEAH was always of a national youth HIV awareness program; however, I thought building YEAH as a Victorian model first that could then be rolled out across other states was the most appropriate approach. The state government health representatives I met with seemed interested in the concept and suggested I continue my research and planning and maintain contact with them as I went along.

This was a time of great fluctuation where I was considering advice from many sources and exploring all the possibilities for YEAH's future evolution. An option I considered at that point was whether YEAH was going to be best placed within already existing HIV/AIDS services and networks. I decided to meet with the peak (or primary) body for HIV/AIDS in Victoria – The Victorian AIDS Council (VAC). My approach was to see if VAC might be interested in considering incorporating YEAH as a project within their health promotion activities given that they did not have any broad based youth awareness programs already in place. Understandably, VAC's decision was that a broad based youth awareness project was not in accordance with their strategic priorities; like many other state based AIDS councils, VAC's focus is largely centered on gay men's health.

Armed with a loosely developed business plan and an ambitious agenda to get YEAH operating as soon as possible, I met with a law firm who specialized in not-for-profit tax law and company registration. It was made abundantly clear to me that the most common and appropriate way to set up a not-for-profit requires the formation and registration of a public company limited by guarantee. This means the liability of the company's members is limited should the company be "wound up" (or come to an end due to the inability to function efficiently and meet its financial responsibilities), making it a safer option for not-for-profits. Registration of any company through the Australian Securities and Investment Commission (ASIC) creates a legal entity separate from its members. Although a

not-for-profit company is different from a profit based company, both types are registered under the Corporations Act 2001 and have to comply with the regulations and guidelines of the Act (see Appendix 2). The goal would be to register YEAH as a charitable health promotion organization with a deductible gift recipient tax status that would allow the organization to collect donations over AU\$2.00 that were tax deductible. The lawyers advised me on how lengthy and tedious the process to obtain this type of company registration and tax status can be and suggested a short term alternative that would allow YEAH to begin operating and raising funds: find a pre-existing organization that already had this type of structure that would be willing to auspice YEAH as a project. I thanked the lawyers who had agreed to assist me in registering YEAH and left their office clutching an enormous amount of literature on charitable tax law.

I have never had a natural rapport with numbers. I find dealing with numbers and most things financial is like trying to read without my glasses; a completely pointless exercise. It was therefore nothing short of a miracle to find myself sitting down and page by page reading the documents on not-for-profit company structures, tax law, corporate governance, legal and fiduciary reporting requirements, and the list went on. The desire to build YEAH pushed me up the steep learning curve I was experiencing.

I returned once more to VAC to discuss the possibility of YEAH becoming a project under their auspice, with the long term goal for YEAH to achieve its own independent charitable status. Generously, VAC agreed and YEAH was now officially able to begin fund raising, something I realized was critical if I was going to have the money to even pay for some of the expenses that registering YEAH was going to incur.

### **11.3.3 *The Many Pots on the Stove***

Whenever I have attempted to tell the story of how it all began, I try to remind people that although I can recount a series of key events and conversations that guided the process of YEAH's development, things were not always particularly sequential. My conscious memory of the time when most of the planning for YEAH was taking place is of many elements happening at once. I felt like a chef with many pots boiling on the



stove; sometimes I would need to stir one to stop it from boiling over and other pots were okay just simmering away but over time they all require stirring because they are all cooking at once!

One of my most interesting travel experiences and opportunities to work in HIV/AIDS youth awareness occurred in early 2003 when I was contacted by a young Japanese man who had attended the ICAAP youth forum in Melbourne two years earlier. He informed me that Japan was set to host the seventh ICAAP and that the local organizing committee had decided that including a youth component in the conference to build on what was started in Melbourne was an important element of the conference program. The young man invited me to visit Japan some months prior to the conference to assist them with the development of the youth forum and raise awareness amongst Japanese youth to get involved in the program. I made my way to several universities across the country making presentations and running workshops on HIV/AIDS awareness, including information on general issues relating to sexual health. I was already sharing my plans for developing YEAH and my belief in the importance of country-based, youth-run, youth-focused HIV awareness organizations. Several months later I returned to Japan to prepare for ICAAP; however there was an international alert of an outbreak of Severe Acute Respiratory Syndrome (SARS), an infectious disease that had spread across several countries in Asia and resulted in a number of reported fatalities. Despite no reports of SARS in Japan, the outbreak became fuel enough for authorities to call for a postponement of the Seventh ICAAP. So it was official – an infectious disease postponed an infectious disease conference and all those involved in organizing the conference program flew to Japan to see what could be done about the re-scheduling of such a major event.

In early 2004, I made contact with a digital design company, JSA, whose contact had been extended to me through a friend of a friend. I approached them to see if they would be able to assist in developing a Web site for YEAH. JSA themselves were a relatively young company and despite their own limited resources made a commitment to support YEAH in developing a Web site and online communication pro-bono. The Web site was launched in 2004 and to this day, JSA continues to provide complete in-kind support in designing and maintaining YEAH's Web site and all online communication. YEAH's relationship with JSA has always

illustrated to me the importance of community partnerships and truly reveals corporate responsibility in action. This showed me the value of in-kind support, which I consider to be of equal or greater importance than corporations or individuals making financial contributions; suffice it to say I cannot even begin to put a financial dollar value on the contribution JSA have made to YEAH's ongoing success.

By the middle of 2004, I was well underway planning a fundraising event to "kick start" YEAH. The idea was that the event would let the community know of YEAH's existence whilst also providing an opportunity to raise funds to cover the set-up costs. The event was a community art auction. There were three reasons why I decided to host an art auction; I had a lifelong passion and interest in the fine arts, I had contacts in the art industry, and, judging by the vast number of community organizations that held art auctions, it seemed like a feasible approach.

An extraordinary woman who also played an instrumental role in mentoring me during this process was Jacqui Geia. She had coordinated community events in the indigenous music and arts scene for years and her contacts in the entertainment industry were second to none. Jacqui had been a close family friend and was deeply connected to my experience of growing up in a family affected by HIV/AIDS. To watch Jacqui in action was inspirational; she juggled and managed so many people from all walks of life and brought them together to create community events that raised the profile of her cause. A few years earlier it was Jacqui's guidance that had helped me to see my own capacity in running a series of small HIV/AIDS awareness events at a local homeless shelter. So, naturally, I asked her for her thoughts and advice on coordinating the art auction. It was Jacqui who taught me to think outside of the box, and I remain thankful to her for that gift to this day. I had already approached all of the major art venues in Melbourne, the National Art Gallery and Melbourne Museum to name but two. It seemed that unless you were booking a venue of that scale years in advance, not one site was available. It was early 2004 and I intended to have the show up and running for World AIDS Day, December 1 of that year; time was one thing I did not have on my side.

We went back to the drawing board and Jacqui agreed with me that going for a major public venue was going to be key to the success of the launch of YEAH. After all, HIV/AIDS was an issue that was never raised

in the mainstream public domain so if I wanted to challenge that, then YEAH's launch event had to break the mould. I went back to several of the same venues that had already turned me down and after persisting I managed to get a meeting with the manager of Melbourne Museum, Brett Dunlop. This man was clearly willing to give YEAH a chance and we began to explore the options of using alternative areas such as foyer space to host the show. With the support of the manager, I lodged an official submission with the board of directors of the Museum and with board approval we struck an agreement to host YEAH's art auction there.

The next few months of my life were consumed with meeting artists and encouraging them to support our show. My pattern became university by day and art gallery openings by night. It was a little embarrassing at times, turning up at events where you did not know anyone and trying to pitch a community fundraiser event; I felt like I was in the cold-call selling business. So, like any good sales person I developed my pitch line, but there was merit in my pitch. I decided that if I expected artists to go out on a limb and support an unknown, yet to be officially founded charity then I should acknowledge their efforts and in turn offer to split the proceeds. So that was the deal, if an artist was willing to take a chance on YEAH then I was willing to support the artists and perhaps build a lasting relationship for future events. (More on this in a bit.)

After considering many alternatives, one of the core ideas I was developing for YEAH's structure was to establish a base for it to exist within broader health environments than just the HIV/AIDS sector. Given that most HIV/AIDS services and organizations are situated close together in each of Australia's states and territories I thought it would be important for YEAH to be based in and around other health promotion organizations. I wanted to build a reputation in the community that our focus was on health promotion and disease prevention and that HIV/AIDS is an issue that can be dealt with in the same context as other broader health issues, and not just in the isolated context traditionally attached to HIV/AIDS. I approached Professor Rob Moodie, who I had first briefly met at the Sixth ICAAP meeting in Melbourne where he was the co-chair of the conference. At this time Rob was the CEO of VicHealth, the Victorian Center for Innovative Health Promotion. I was well aware that Rob had spent a great deal of his early career working within major international health networks including the World Health Organization (WHO) and the Joint United Nations Programme on

HIV/AIDS (UNAIDS) and had extensive expertise and a passion for issues around HIV and AIDS.

The conclusion I drew seemed obvious; I should approach Rob to see if he had any suggestions or advice to contribute to my plans for establishing YEAH. To say the least, it was an extraordinarily busy time at VicHealth when I approached Rob in early 2004. As one of the major local hosts, VicHealth was preparing for the upcoming International Conference on Health Promotion and Health Education. Rob was clear that he thought the concept of YEAH as a youth HIV education service was a much needed approach to HIV prevention in Australia. He then introduced me to a small team of young people who were preparing a number of youth-focused activities for the conference and suggested that I play a role in helping set up a youth forum to take place on a number of health issues during the conference program. It sounded familiar and so with great enthusiasm I set to work on coordinating a youth health promotion forum. It was a new experience to be in charge of arranging a forum that would not only have a youth focus but would be covering many health issues from body image to physical and mental health. Sexual health and HIV were of course part of the final program. In hindsight, being in a position to coordinate the forum opened my eyes up for the first time to many core concepts of health promotion; something I was sure I wanted to do through my work with YEAH but until then really had little insight into what it really was; after all I had no academic training and little background in these areas up until this point.

A few months before launching *The World We Live In* art auction (Fig. 11.2) and YEAH's kickoff as an official organization, I was once again off on a trip overseas to the Third International AIDS Conference in Bangkok, Thailand. It was incredible to see the change that had taken shape in the few years since I had been at the conference in Durban. For several months leading up to the Bangkok conference I had been corresponding with a group of local Thai youth who were busy coordinating a program for the first full scale youth forum to be incorporated into the main program. The number of young people attending the conference was at a record high thanks to a great deal of lobbying to increase scholarship opportunities for young people to attend. I had been offered a scholarship and was invited to present as one of the speakers at the youth forum. Little did I know that Bangkok was going to be one of the most life-changing, or perhaps YEAH-changing, conferences I had ever attended.

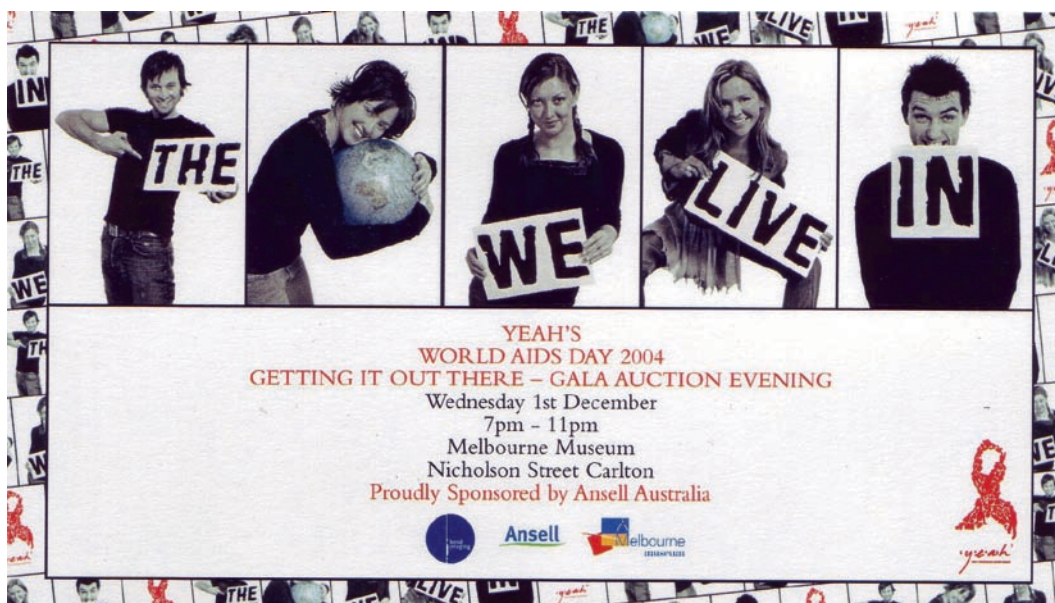


Fig. 11.2 YEAH's *The World We Live In* art exhibition and Charity Auction poster

The lawyers back home who were guiding me in the process of preparing to register YEAH had informed me that we were going to require a minimum of three directors to start a public company limited by guarantee. Up until this point I had really not given a great deal of consideration as to who the other two founding directors of YEAH might end up being. My only thought had been that it would be important to make sure that they were also younger people. From all the contacts I had in the Australian HIV/AIDS circles, there were no other young Australians that I was aware of at that point who had an interest in local issues surrounding HIV/AIDS.

I had heard a radio interview a few months earlier with a young Aussie guy, Stephen Hunt, who had decided to swim the English Channel to raise awareness and funds for two major HIV/AIDS trusts. Stephen was living in the UK and had left behind an acting career in Australia. He was now becoming increasingly involved with international youth networks on social justice issues but clearly had a passion to help in the global response to HIV/AIDS.

One afternoon at the conference I was running late for a youth session. As I sprinted to make it in time I ran past a poster in one of the foyers that caught my eye; it was the Aussie swimmer guy from the radio interview! Stephen Hunt was at the conference, he was advertising for sponsors to support him in his plans to swim the English Channel. I wrote down his contact details and

decided I'd try to "hunt" him down later in the day once my session was over. At the end of the youth session a young guy approached the microphone during question time and introduced himself as Steve from Australia; I knew I was not going to need to make that phone call in the afternoon and as soon as the session ended we made a bee-line for each other. We had much to share and only limited time, Steve was flying out from the conference that afternoon to head back to prepare for his swim. In that short time we realized the depth of our connection and it was decided; Steve wanted to be part of YEAH. I had found the first of my fellow founding directors.

On one of my last days at the conference I went to a film screening; it was the Asian premiere of *A Closer Walk*. The film was being heralded as the first global depiction of the human condition of HIV/AIDS. There was much fanfare in the lead up to the premiere. As I watched the film, complete with celebrity introduction and a short interview with the director, I was stunned by the story that unfolded. This extraordinary documentary followed the lives of children, women, and men from three continents. It had interviews with high level leaders, dedicated doctors, researchers, and careers, all of whom were impacted by and dealing with the effects of HIV and AIDS. That film touched my soul.

I returned to Melbourne excited by the prospect of Steve's involvement with YEAH and he made plans to

fly to Melbourne for the launch of YEAH and the art auction on World AIDS Day. The first inaugural *The World We Live In* art auction took place on December 1, 2004, and was a huge success. Through the auspice arrangement with VAC, we raised more than enough money to cover the basic registration costs to get YEAH officially up and running

### **11.3.4 Taking Another Step Forward: A Closer Walk**

I had been so preoccupied with the art auction that I had forgotten about many of the other events that had occurred in Bangkok including the film, *A Closer Walk*. One afternoon as I was going through the papers and business cards I had collected in Bangkok I thought of the film and the impact it had on me. Given my personal experiences of feeling the pain and loss caused by AIDS, I had always thought this had caused a certain level of desensitization in me to emotive films and stories about HIV/AIDS; I did not think a film could elicit such an emotional outpouring from me. I was remembering how, as I sat and watched the film with a dear friend of mine, a young doctor from Surabaya, I simply broke down. I realized then that this film tells the story. This film can show the world, especially those who are most disconnected from the realities of HIV and AIDS, the destruction and havoc this preventable disease is wreaking on the world.

I began searching the internet for information on the film. I found the Web site and pressed the button to send a comment to the creators of the film. As I typed my message I expressed my deepest thoughts on the film and my gratitude for their ability to capture, in such a heartfelt way, the harsh and painful realities of HIV and AIDS. On the Web site I had noticed that Australia was not listed in the countries where the film had been released and I found myself expressing my interest in wanting to help bring *A Closer Walk* to Australian audiences. I briefly remember explaining that I was in the process of setting up YEAH and although I professed to have no background whatsoever in film distribution, I would do whatever I could to educate myself on the process, should they (the directors of the film) be willing to work with me in bringing the film to Australia. I pressed “send” and hoped my message would not disappear out in cyberspace.

I could not believe my ears when a few weeks later my phone rang and it was Robert (Bob) Bilheimer, the writer, director, and producer of *A Closer Walk*, calling to discuss how we could make this happen. The most incredible thing is that within about 2 minutes on the phone, Bob had made it explicitly clear that he was delighted by my email request and the potential joy of working with someone whose motivation was founded in the simple passion of wanting to educate and inform the world about the plight of HIV and AIDS patients and the role we all have in stopping its continued spread. Bob simply said to me, “It sounds clear that you and I are on the same page, so let’s do this.”

I had made a commitment and so I set to work in discovering how and what I had to do to make this happen. I was fortunate to have a contact who I knew worked in film distribution in Australia and I approached him for advice. His response was simple: to put it in writing, draft a proposal outlining the plan for marketing, publicity, goals and desired outcomes, and he would have a look. I would never have written a proposal like that before. I sat and intently worked out a plan of action to release the film on DVD that could be promoted in schools as an educational tool. I would promote the film with a public screening on World AIDS Day and would develop a study guide to extend the capacity for the film to be utilized in schools and other educational settings. World AIDS Day was fast approaching and with my friend about to head off on an overseas trip, I rushed to his office with a finished draft of my proposal and a copy of the film.

A few weeks later I received a message that my proposal was well developed and of high quality. My friend was impressed and he offered the support of his company, *Hopscotch Entertainment*. They would become our industry partner and would assist with the technical requirements to release the film on DVD so we could package it as an educational kit. I knew that although the film was a strong title, their motive behind getting involved in the project was purely out of goodwill to support a cause they saw value in.

My friend at *Hopscotch* introduced me to a woman who had an extensive background in the film industry. Her expertise was in marketing and event management and she had worked on many of their titles. Karen Cochrane was described to me as an individual well suited to provide guidance and insight on YEAH’s project. On the day I met Karen I felt she was a woman with a deep passion for documentary and an intuitive



compassion in dealing with humanitarian and social issues of paramount importance. Kaz (Karen) and I began working together on the film project and with the enormous support of Heidi Ostertag, co-producer of *A Closer Walk*, the project began to take form.

In the beginning of 2005, I went to Sydney to spend a week with Steve (Stephen Hunt), my new co-director, to brainstorm ideas for YEAH and polish the business plan. It was while I was on that trip in Sydney that we recognized we needed to invite a person to come on board with us to take on the role of the third founding Director of YEAH, and I felt certain I knew whom I would like to extend that invitation to.

Although I had not know Kaz for a long time, I had no doubt that I knew her integrity and capacity as a person and felt certain she would bring incredible insight and experience to YEAH. With Steve's blessing I called Kaz and invited her to join YEAH's Board of Directors. After requiring some time to duly consider such an opportunity, Kaz responded by saying that as a mother and a woman who cares deeply about the state of the world in which she and her daughter live, she felt compelled to take on the opportunity and responsibility for helping grow YEAH. Steve, Kaz, and I established YEAH as a much needed service in the community. We were three, and by the first of March 2005, YEAH was fully registered as a Public Charitable Health Promotion Organization and in record time!

### **11.3.5 Networking: Ensuring a Strong Foundation**

The scope and success of *The World We Live In* art auction also helped us recruit our first corporate sponsor, Ansell. Their support allowed us to produce our first promotional materials for the event; flyers, posters, and of course YEAH-branded condoms. The impact of having media exposure and such a fantastic turnout at the event meant things were off and racing at full speed before Kaz, Steve, and I had really had the chance to collectively develop a fully integrated plan of action for YEAH as a whole. With the *A Closer Walk* project in full swing and the YEAH registration papers all processed, we formally thanked the VAC for their support in allowing YEAH to sit as a project under their auspices and explained that now

YEAH had achieved registration as a not-for-profit NGO with independent fundraising ability we were ready to stand on our own. The operational center for YEAH – YEAH headquarters, so to speak – had been set up in the lounge room of my apartment in the lead up to the art auction.

One afternoon, my flat mate who shared my small apartment came home and in the most loving and endearing way said, "I admire you dearly and fully support all that you are doing with YEAH, but the 10,000 condoms and flyers and books and all the other piles of things that are part of YEAH have finally blocked the last remaining opportunity for sunlight to enter the apartment and well, I think it may be time to find a new home for YEAH." We collapsed in laughter taking in the big picture mess that had become YEAH and was growing in our living room. I had to do something and fast. Given I was now living only minutes away from VicHealth I arranged an appointment and went back to see my friend Rob Moodie.

I met with Rob in early 2005. I had a clear direction in my mind and that's exactly what I shared with Rob; the need for all young people, including young Australians to have the opportunity to access comprehensive information on HIV/AIDS; the need for HIV and AIDS services and organizations to be integrated with, not isolated from, other health services; and the need to address HIV and AIDS as a sexual health issue, a local issue, and a global issue. Rob gave his full unrequited support; in his experience embracing this kind of new approach was just what was needed for a country that had an incredibly successful history to date in its approach to HIV prevention. We both appreciated the need for fresh ideas to ensure that Australia could sustain its strong response to combating the spread of HIV. Within one week, I had an official letter confirming that VicHealth would offer support to YEAH under its incubation policy to help foster the growth of new emerging health promotion initiatives. What that meant for YEAH was that courtesy of VicHealth we had a fully-equipped office space to operate out of, and access to all of VicHealth's staff facilities and IT support, not to mention access to a team of professional and experienced people who worked in health promotion. The same week as our registration papers arrived in March 2005, we moved into our new office.

One of the major hurdles we were still facing at that point was a lack of funding to support any paid staff in

driving YEAH's work. Up to this point, neither myself nor anyone else who was directly involved with YEAH had drawn a salary for their work. It was then that I decided to defer my studies and take on a full time voluntary role running YEAH. My decision was driven by the simple fact that if YEAH was to survive and succeed as a community organization it needed someone to run it. The only reason I was able to commit to volunteering full time for a year was that my Mom had left me a small inheritance when she died. Although this was meant to be my safety net to ensure I always had my basic needs covered, I used part of this to financially support myself while I worked without earning a salary. 2005 was the first year of YEAH's operations, and a number of volunteers assisted me from time to time in the basic running of the organization. But as I have come to learn, despite volunteers being an incredible support, they still require an enormous amount of time to train, monitor, and manage. Given that I was learning the ropes myself, I often found this aspect of managing volunteers a very difficult and exhausting process despite my deep gratitude for their efforts. A health promotion student who was near completion of her degree approached me to see if it would be possible for her to do her placement with YEAH and Kate's arrival as a regular volunteer over the next year was incredible. Having a student who had passion, interest, formal training in health promotion, and could be given the opportunity to take charge of projects meant that the experience was mutually rewarding. Kate became a dear friend, confidant, and a tremendous support. She was the first person I had ever worked so closely with on a daily basis on YEAH's activities.

On reflection, the end of 2005 was an immensely busy time. I had returned from a trip to Japan in mid-2005 where I finally had the chance to assist with running the Seventh ICAAP youth forum that had been postponed 2 years earlier. By this stage, I was presenting sessions on YEAH's development as a community-based NGO and in particular the unfolding of the *A Closer Walk* project. Kate had given me a sense of security in leaving the office unattended for a number of weeks when I needed to and did an incredible job of managing things in my absence. By October 2005, the study guide I had been researching and developing to accompany the DVD release of *A Closer Walk* was complete. YEAH launched the film with two public theatre screenings in Melbourne and Sydney. Both were followed by ques-

tion and answers sessions with a panel of people representing various aspects of the Australian HIV/AIDS sector. I was at the Melbourne screening where the panel for the question and answer session included a secondary school teacher and a year 10 student (equivalent to a fourth year high school student). To this day, I remember the impact that their responses to the film had on the audience and I recognized the importance of talking about HIV in a way that the public could connect to, and not just always relying on the experts in the field, despite their extensive knowledge.

World AIDS Day on December 1, 2005 saw YEAH present its second annual *The World We Live In* art auction event at Melbourne Museum. The event had been such a success in its initial launch the year before that we saw the value of building on the momentum of that first event and establishing *The World We Live In* as YEAH's main annual fundraiser. The 2005 event was yet again a success and enabled YEAH to raise much needed funds to keep the organization operational. The only other income being generated by YEAH was from the educational sales of the newly released *A Closer Walk* kit. Of the many guests who attended the 2005 art auction was a young woman, Hayley Matic. She had heard about YEAH's work and had connected with me some months earlier. Hayley also shared a strong connection to the issue of HIV/AIDS and had been working as a youth sexual health counselor. Hayley was now completing her Doctorate in Psychology and was keen to become involved with YEAH.

With the grand scale of YEAH's art event and film project overlapping, I was beginning to feel the pressure of full time voluntary work. Shortly after the art exhibition and auction the suggestion of seeking volunteers with specific skills to help manage the huge work load was raised at one of YEAH's monthly director's board meetings. We decided to advertise through film networks for a graduate student willing to volunteer to assist with the marketing and distribution of the *A Closer Walk* educational kit. Our prayers were answered when we met yet another talented young woman, also by the name of Kate. She had studied film producing and was very experienced in many areas of film. Kate was a powerful addition to helping grow our distribution of *A Closer Walk* across Australia. So the pressure began to lift, and it was me and the "Kates," and YEAH was flying along!

I was already feeling the buzz and excitement of all that had happened over the past few years and then

came one of the greatest honors of all; I was nominated for Young Australian of the Year. I received a phone call to let me know I had been chosen as a finalist for the prestigious award. Attending the award ceremony and hearing a synopsis of my story and achievements to date read out to the audience was one of my proudest moments. I did not win the final award but knowing I had been chosen amongst so many other incredible young people from across Australia and acknowledged for my work was an experience of a lifetime.

The year was 2006. The flow of meeting people continued, and by early 2006, Rob Moodie, my confidant and mentor, had introduced me to an incredible network of people. Rob has a gift of diplomacy and intelligence so well balanced with a grassroots understanding of how the “real world” operates that his connections and contacts were always inevitably well placed and right on cue. Rob introduced me to Bill Bowtell, a man who has been referred to as the architect of HIV/AIDS structures in Australia. Bill had been a senior advisor to Australian’s Minister for Health in the early 1980s when AIDS was first being raised as a global health concern. There is no question that when reviewing the history of Australia’s early response to HIV, Bill Bowtell has always been at the front and center in ensuring at the highest level, that Australia was engaged, laying down policy, and building partnerships that could establish the foundation for a national response.

Bill was now working for a major international policy advisory institute; however, his keen interest and expertise in HIV/AIDS remained constant throughout his work. At the time of meeting him, Bill was involved in establishing the Asia Pacific Business Coalition on HIV/AIDS, and on one of his visits to Melbourne, we arranged to meet up. He was impressed by YEAH’s work and I still cherish to this day a comment that he made: “I was part of developing Australia’s first response to HIV/AIDS. You and your work with YEAH is helping to shape a new response to HIV/AIDS here in Australia.” Bill and I kept in touch and he became a great mentor and guide in my work with YEAH.

I was already calling on several individuals to assist and guide me with YEAH’s development. I raised the issue of mentors at a monthly board meeting with YEAH’s Directors, and we decided to implement an official Advisory Board whose role would be to mentor and support the Directors in the strategic development

of the organization. Along with Bill Bowtell and Marion Webster, we invited Dr. Anne Mijch, Lorrelle Mandaru, Gina Greco, and Emma Morrissey to join the Advisory Board. Dr. Anne Mijch had specialized in infectious disease and HIV/AIDS since the early 1980s. Like many doctors working in the field of HIV/AIDS, Anne’s commitment to her patients was always above and beyond the call of her role as a doctor, becoming deeply involved in and caring for the social impacts on her patients. Lorrelle introduced the meaning of “corporate governance” to our board; the system within companies that provides direction and control, defines the rights and responsibilities of different stakeholders, outlines the rules and procedures for decision making and the structure through which the company objectives are set and measured. Lorrelle provided legal guidance and advice to the Directors on issues of Board structure and charity tax law while also being involved in many of our community activities as a volunteer. Gina had worked for many years with young people around issues of sexual health and sexuality. She was coordinating a small support network for HIV+ young people in Victoria and was a passionate supporter of YEAH’s work. We knew it was essential to have a representative on the Advisory Board who had a background in education. Emma brought great insight into the practicalities of how to engage teachers from a range of networks and unions.

Shortly after the establishment of the Advisory Board, two additional members were invited to join: Professor Roger Short and Jackie McCann. Professor Roger Short was a name I was already familiar with. Roger had specialized in sexual health research for over 40 years and had also worked on the international circuit at WHO and UNAIDS in the 1980s and 1990s. His introduction to the Advisory Board said it all: “I’m a Scottish, Pommy, Kiwi Sexologist who has ended up in Australia.” I could not have imagined what a gift it was to have Roger join the Advisory Board; his wisdom, knowledge, and stunningly simple way of approaching often very complicated sexual health issues continues to be a source of inspiration.

Rob Moodie was aware that strategically it would be paramount that YEAH have a key person from VicHealth represented on the Advisory Board, given it had incubated YEAH in its early growth stage. His recommendation was Jackie McCann, Director of Corporate Services at VicHealth. Rob could not have been more accurate in suggesting we invite Jackie to

join our team. Her sharp mind, direct approach, and commitment to YEAH's work have guided YEAH into many areas of growth and expansion over the past years. Although our Advisory Board comprises such a broad range of individuals, over time we have discovered that what makes it work is that they all work in a complementary way with each other and integrate the advice and guidance they give to YEAH.

I have referenced both my appreciation and passion for networking a number of times throughout the story of YEAH's development. The international conferences clearly played a major role in allowing me to formulate relationships within many networks. As time went on, our Australian networks also grew beyond the strict HIV organizations I had known as a child. YEAH's Directors and Advisory Board members also contributed a wealth of contacts to YEAH's ever growing database.

It was 2006, however, that presented the most incredible opportunity for networking. Courtesy of Bill Bowtell, I was able to attend the launch of the Asia Pacific Business Coalition on HIV/AIDS, which took place in conjunction with the launch of an agreement between Australia's Agency for International Development (AusAID) and the Clinton Foundation. Former U.S. President Bill Clinton attended the launch and I was able to meet with him and ask him his thoughts on the importance of young people's role in the global response to HIV/AIDS. I also made a number of other key business contacts at the event. These meetings spearheaded an opportunity to meet with senior state government politicians who began to take an interest in YEAH's work. With this new level of interest came a renewed possibility of receiving government funding to help sustain and extend YEAH's work. A series of incredible conversations and meetings with the state government took place over the first half of 2006. However, despite hosting several major events and receiving an incredible amount of media coverage on national radio, television, and print media, YEAH seemed to be no closer to receiving the government funding it so desperately required to sustain itself.

Hayley Matic had now returned from her travels, and after making contact once again with YEAH, was officially appointed as a Director on YEAH's Board. The Board was becoming a far more functional and polished unit, engaging in professional development to expand our skills and better able to

dedicate considerable time to addressing the key structural and strategic issues affecting the organization's future growth. Hayley forged a historical place on the Board as the first person to officially take on the official role of Chair. Prior to this I had absorbed the role of Chair as well as my role as CEO which is far from an optimal board structure. This important new structural change brought about a new energy and commitment, ensuring YEAH was prepared to survive and thrive.

By late 2006, YEAH achieved another key milestone in its work to date: the national distribution of the *A Closer Walk Educational Study Guide* (2nd ed). A printed copy of the guide was sent to every secondary school in the country, including distance education centers in remote areas of Australia's outback. Support from a number of industry partners made this possible, making up for the fact that YEAH did not have a single cent to spend on the printing, publicity, or distribution. Within weeks of its release, literally hundreds of schools, universities, and other educational institutes had purchased the film to use in conjunction with the study guide they had been sent, and it became obvious that a strong demand existed in Australia for HIV/AIDS educational materials specifically aimed at and designed for young people. As sales of our educational material continued to increase, so did online downloads of free educational materials from YEAH's Web site. By the end of 2006, YEAH was averaging over 6,000 visits to the Web site each month – hundreds more than many other major HIV/AIDS services had ever been able to generate. We were on the right track.

Everyone who was connected to YEAH had their own thoughts and opinions on why we had come so close, made all the supposedly correct connections, and yet had still not received the financial support from the state government that we needed for long-term sustainability. The Board concurred that YEAH's vision had always been a national one; therefore, perhaps YEAH needed to move on from the pursuit of working with state level departments and begin building inroads with the Commonwealth Government (the federal/national level government).

In August of 2006, I took on my most senior role at an International AIDS Conference; Co-Chair of the XVI International AIDS Conference main youth program task force in Toronto, Canada. Working with a team of five organizing committees, which included:



media; pre-conference preparation; advocacy; logistics; and a youth pavilion team, my co-chair and I had spent over a year preparing the guidelines and support activities for more than 1,100 young delegates who were attending. Given the long road that I had been on since I had seen only 30 young people participate in the AIDS conference in Durban in 2000, I had an immense sense of pride watching and participating in this first fully integrated youth program. Being part of the team in Canada allowed me to reflect on my own journey over the years I had attended the conferences and I realized how much history I had been involved in. The experience in Canada also taught me a great many things that I was able to bring home and share with local youth through YEAH's networks. One of the main involvements to come out of Toronto was my ongoing connection with The Global Youth Coalition on HIV/AIDS (GYCA). I was appointed GYCA's National Focal Point (NFP) for Australia and became an active member of the Asia Pacific regional team. Taking on this role allowed me to show other young Australians who want to be involved in responding to the global HIV pandemic the opportunity to be a part of an international youth network beyond the local focus of YEAH's work.

Upon my return from Canada, I began to follow up on the Board's decision to develop a relationship with the Commonwealth Government. The timing was perfect; the Department of Health and Ageing (DoHA) was preparing for the mid-term review of Australia's four National sexual health strategies: HIV/AIDS, Hepatitis C, sexually transmitted infections (STIs), and Indigenous Sexual Health. DoHA had issued a request for major sexual health services, research institutes, state health departments, and other major organizations working in those areas to provide reports on the implementation of the strategies. It was time to review what was working and what was falling short of having the necessary impact in improving and maintaining high levels of sexual health in Australia.

The climate on HIV/AIDS in Australia had been changing for a number of years. After years of low rates of infection with no increases, Australia had begun to see a steady rise in new HIV infections in 1994, followed by a sharp rise of infections between 2000 and 2006, that represented a 41% increase in new HIV diagnoses during those years (McDonald 2007). With the international reputation of having one of the most effective early responses to HIV/AIDS,

Australia was now in need of new approaches to address its rising rate of infections that were now presenting the country with the highest number of new HIV infections in its history.

YEAH had by this stage signed a Memorandum of Understanding (MOU) with VicHealth to clearly articulate and formalize the in-kind support that was being provided to YEAH. Together with VicHealth's assistance, YEAH drew up its first proposed operational budget outlining the best scenario that would allow YEAH to operate at full capacity at a national level. This new budget showed a three year forecast of the costs involved in rolling out three major programs at a national level while continuing to grow public interest through broad-based health promotion campaigns. The budget also highlighted the value of the in-kind support that YEAH was receiving from a number of sources (including the provision of free office space and facilities, Web site maintenance and IT support, and professional voluntary roles). This was a major change from the project based funding submission budgets we had been accustomed to preparing. Given there were no other organizations in Australia who had a strategic focus on providing all young people in the country with information on issues relating to HIV/AIDS, YEAH was in the driver's seat to establish itself as the primary body to carry out this work in partnership with other relevant community organizations and government departments in the areas of HIV, sexual health, and education. YEAH's approach was to utilize the office space and facilities provided free of cost by VicHealth as its headquarters. The Board felt that three full time staff would be adequate to maintain the workload of providing resources, outreach workshops, and community events to our ever growing database of clients through maximizing the opportunities to train and grow a national database of volunteers.

In early December 2006, I contacted DoHA. I placed a call to the switchboard and asked to be put through to the HIV/STI unit. The woman who answered the phone introduced herself as the Assistant Director and after the usual introduction from my end, "*I'm the CEO of YEAH*" followed by her inquiry into YEAH's identity, "*You're from Where?*," she sounded quite intrigued and so I asked her if she had a few minutes and if I could explain a little about what YEAH was and the work we were involved in. The Assistant Director agreed and I settled into a rather shortened summary of YEAH's

story to date. She was impressed to say the least. After I had rattled off the statistics of how many people were accessing our Web site and how many schools were using our resources came the loaded question, she said “*Who’s funding all of this?*” No guesses that my reply was something along the lines of, “*well that is one of the reasons why I am calling.*”

After my phone call with the Assistant Director, it was clear that DoHA (part of the Commonwealth Government), wanted to know more about YEAH and we also wanted to know more about how they worked, so, YEAH decided to submit a report at the mid-term review of the national HIV/AIDS strategy. In early 2007, on behalf of YEAH, I attended the national mid-term review forum, which consisted of state government representatives mixed in with a handful of representatives from the major national research institutes and national peak bodies including The Australian Federation of AIDS Organizations (AFAO), Scarlet Alliance (the Australian peak body for sex worker projects/organizations), and Australian Needle and Syringe Exchange Programs (ANEX). The forum consisted of a series of workshops that allowed participants to explore challenges facing the current national sexual health strategies and to develop new approaches.

What became clear over these two days was that young people were a core priority group for the prevention of STIs; however, they were not listed as a priority area in the HIV/AIDS strategy (Department of Health and Ageing 2005). The reasoning was simply numbers; Australian statistics showed that although there was a high number of STIs amongst young people, HIV rates were relatively low. The debate and dialogue that I participated in was making it clear to me that simple strategies to improve sexual health, especially amongst young people, needed to be implemented. These were approaches that I had learnt a great deal about through my experience in youth programs over the past seven years, as well as through the work of YEAH. The key point I raised was the government’s absence of youth participation in the dialogue around youth sexual health issues. They simply did not have any type of mechanism to support youth participation in that area. I recommended that empowering young people to be involved in the decision making process of new sexual health strategies could provide the government with insight and understanding into the issues affecting them and their sexual health. On almost every other level, the very people at risk of STIs and HIV have

been engaged directly by government; MSM, IDUs, PLWHAs, sex workers. So, where were the young people? I pointed out that the “young people” we were all talking about were significantly younger than me; that people in their teenage years, who I work with, even look at me in my 20s and think I am old! My message was clear: it’s time to engage young people in letting “us” know what their needs, concerns, and ideas are in relation to their sexual health. It is time to empower them to own the rights and responsibilities for their sexual health and to move away from negative messages telling them what, when, and how they should approach their sexual development. This was my platform for introducing YEAH to a vast range of key stakeholders. I provided the evidence as to why prevention targeting young people on all sexual health issues, including HIV, was vital for Australia to sustain a strong response to its share of the global HIV/AIDS pandemic. After all, it had been 20 years since the government had rolled out its Grim Reaper Campaign, Australia’s infamous HIV/AIDS awareness campaign that had been aired on national radio and television.

Early in 2007, Australia marked the twentieth anniversary of the Grim Reaper Campaign with a ripple in the national media, fueled by the creators of the original campaign, to raise the debate, *is it time for a new Australian HIV/AIDS awareness campaign?* The message the Grim Reaper campaign delivered to the public 20 years ago was still ringing true: *Prevention is the only cure we have.* But 20 years later, had we not learned more? The image of AIDS had changed. Bill Bowtell, a member of YEAH’s Advisory Board, was deeply involved in the creation of the 1987 Grim Reaper campaign. Bowtell states:

We can confidently say there are 100,000 young Australians who have come to Adulthood in the last 20 years who have not been infected with HIV or died from AIDS. Australia bought itself time but we didn’t buy immunity. People have lulled themselves into a great sense of complacency and false security that it’s all OK and it’s not (Cogdon 2007).

This had been Australia’s first and only national media campaign on HIV/AIDS and the young people in our community were not born when the campaign first aired. All of the founding members of Australia’s early 1980s’ response to HIV/AIDS, including past political leaders, gathered at an official event to mark the anniversary. I attended the event on behalf of YEAH and was saddened by the lack of support for

new approaches targeting young people at a time when HIV rates had reached an all time high.

### **11.3.6 New Approaches to Old Issues: Positively Promoting Sexual Health**

The level of innovative discussion and debate amongst YEAH's Board Members and Advisors, coupled with our use of new and pertinent evidence and research, is at the very core of why YEAH is able to offer new approaches to the same sexual health issues. Rising rates of STI's amongst young Australians say one thing – that young people are engaging in unsafe sex that leads to the transmission of disease. This is also the same behaviour that results in the spread of HIV. My experience as a HIV/AIDS and sexual health educator tells me that most (young) people do not know that having an STI increases your risk of contracting HIV if you are exposed to it.

It is true that some people are more at risk than others of contracting HIV because of a range of unsafe sex, injecting drug use, and/or other risky behaviours they may be engaging in. Targeting campaigns and interventions towards these groups makes sense, and Australia has done a very good job of targeting specific high-risk groups from the very beginning of its response to HIV/AIDS. Australia should continue to implement targeted initiatives, but this is not a reason to exclude educating the wider community, especially young people. Young people are a key target group when it comes to those most likely to be confronting their own journeys of sexual development and the broad range of other risks that life has to offer them both at home and when they travel beyond their country's borders.

## **11.4 Future Challenges and Opportunities**

The time is now. To date, YEAH has not been able to receive financial support from the state government and received its first grant from the Commonwealth government in September 2009.

So what will be YEAH's focus be in the years ahead? The world has increasingly been making many

commitments to fight HIV/AIDS. Australia made many commitments along with hundreds of other countries when it signed the 2001 United Nations General Assembly Special Session on HIV/AIDS (UNGASS) Declaration of Commitment. One of those commitments is to: *ensure that at least 95 per cent of young men and women aged 15 to 24 have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection; in full partnership with youth, parents, families, educators and health-care providers by 2010 (UNAIDS 2001)*. YEAH's goal today and into the future is to help Australia achieve this commitment.

Prevention is a concept that suggests an *investment to stop a problem from ever occurring*. It is sad to see that in doing such a brilliant job of targeting some groups of their communities, many countries have failed to deliver HIV prevention initiatives to the broad community, mainly because the problem cannot be seen. For example, in Australia the rates of HIV amongst young people are very low; therefore, we cannot warrant investing in prevention in the first place. This implies that we require a critical mass of young people to become infected first as the catalyst for implementing *prevention*.

YEAH has a large task ahead; delivering HIV/AIDS information to all young Australians. But how can you deliver this type of information without in turn addressing issues around sexual health? The answer is simple: you cannot. The Australian Research Centre for Sex, Health and Society (ARCSHS) conducted a National Survey over fifteen years, gathering data of Australian secondary school students on HIV and sexual health (Smith et al. 2002). The data shows that there is no group at greater risk of sexually transmitted infections than young people who are sexually active, including young same sex attracted youth.

Globally, young people under the age of 25 account for more than half of the world's HIV infections and AIDS is one of the main causes of adolescent mortality (Bearinger et al. 2007). It is foolish to think that Australian adolescents can remain risk free from HIV especially in the absence of comprehensive prevention education. YEAH has a role to play in trying to work with the government to implement a policy that ensures basic sex education is accessible in all Australian schools. Sex is about as normal and natural a human

experience as exists. So, surely talking about it can be done in a way that does not imply it is something to be embarrassed about or afraid of. This is how YEAH endeavours to deliver its content on sex – in a way that empowers young people to make informed choices that protect the physical and emotional well-being of themselves and their peers. YEAH is only part of that solution because it is going to take the whole community to shift its approach on sex before young people will feel totally supported and able to make informed choices on those issues.

#### **11.4.1 Making Sure We Were Qualified for the Job**

In early 2007, Dr. Zoe Wainer joined YEAH's Board of Directors. Zoe had a long standing interest in issues relating to sexual health. She had been involved in the establishment of a number of state programs aimed at increasing the knowledge and involvement of young doctors in delivering sexual health education programs, treatment, and care to young people. Zoe's presence and drive connected YEAH with a number of key medical associations including the Australian Medical Association (AMA) and the Australian Medical Student's Association (AMSA).

During the early months of 2007, YEAH's Board of Directors invested considerable time in improving the strategic planning for YEAH's activities. By this time, YEAH's list of projects and activities had grown so exponentially that we often found ourselves juggling dozens of small- and medium-sized projects with hardly any financial or human resources. The Board knew that spreading ourselves so thinly across too many initiatives and projects was having a detrimental impact on the work that we were capable of doing well, and therefore the board decided to go through a major strategic review process. The first step was to start by reviewing YEAH's documentation. Although YEAH had already developed a strategic plan, a board policy, and a number of other core documents, it became clear that many of these had been drafted very early on before YEAH had the chance to experience and experiment with different approaches to delivering its work effectively in the community.

As I mentioned earlier in YEAH's story, the organization had almost always been completely

voluntarily operated. A typical example of this is the number of undergraduate university students who have completed placements for their health promotion programs/courses working with YEAH. My lack of experience in not knowing how to best utilize the skills of these incredible students (like Kate, Gabby, and Melanie) has been frustrating. These are individuals who have continued to volunteer with YEAH well beyond the end of their placements with the organization. In 2007, I had a new type of volunteer experience, one that had a profound and lasting impact on both YEAH and me personally. Christine Baker had returned to Australia from England and was looking to volunteer her time in an organization during the last few months of her pregnancy. The difference was that Christine had an immense amount of experience in the field of public health and specifically, sexual health. She had worked on a major national sexual health program in the UK and also brought with her a level of professionalism that had been lacking in YEAH's approach to administration. Her presentation and timing to assist YEAH's Directors in our review of core documents was perfect. Over several months Christine worked with the Board of Directors and assisted the Board in drafting a complete operations manual. The process was not simply about documenting the history and work procedures of YEAH, but was also a learning process whereby we all had to detail every activity, right through to the high level structure and governance of the organization. The process took the Board on a path from reviewing our goals, through to the delivery mechanisms that would allow YEAH to achieve these goals. The process was extensive and exhausting and worth every minute when I look at the end product. The document that was produced continues to make me proud when I see how it reflects all the work, past and present, which YEAH has been involved with. The Board and all who come into contact with YEAH can be grateful to the wonderful guidance that Christine was able to provide. So my reflection on Christine's brief but intense involvement with YEAH left me with a sense that miraculous things can happen when the right person presents in the right place and everyone involved is able to recognize that it is the right time.

During 2007, I received invitations to participate in a number of intense leadership forums run by executive education institutes, such as the Harvard Club of Australia, government agencies, and policy think tanks.



The experience got me thinking: *what is leadership?* The emerging definition that holds true for me echoes, *that a great leader is someone who inspires leadership in others.* So I began to consciously ask myself “is this what I am doing?”

During the journey of establishing YEAH, I had come to crossroads many times and have often wondered if I was actually qualified for my job. There have been many times I have felt like I was navigating in the dark on certain issues and those around me often made it clear that I had far less experience than they had on certain topics. I had deferred my medical science degree to set up YEAH and did not have any formal academic qualifications to speak of. Early in 2007, I decided to go back to study; I applied to start my Masters in Public Health, despite not having finished my undergraduate course, and was fortunate to be granted a place. As I began studying epidemiology, statistics, public health, and the social sciences, I realized just how connected all my experiences were to the material we were covering in class. In our tutor groups, I always seemed to have stories to share about experiences that reflected the topics we were discussing: biomedical approaches to health versus psychosocial models; the impact of culture and social class on health; anthropology; social movements; health promotion; professional care; chronic illness narratives; stigma in health; research methods in public health; evidence-based medicine; and the list goes on! All the while I was engaging and learning the material, I was also having a profound realization: I did not know the theory, but in many cases I knew the content. I had lived many of these experiences. I had worked in an area that had allowed me to witness many of these experiences. I have a great deal to still learn, that is for sure. But the one thing I realized was that I am qualified for the job!

#### **11.4.2 From Low to Zero: Preventing HIV and Stopping AIDS**

My travels in 2007 took me to Sri Lanka. Once more I participated in ICAAP, this time advising and assisting the team of young people who were coordinating the youth program. I realize that I am now a young person who is getting older, and so my role in these things is beginning to change. Youth is a demographic group that we all belong to sometime but we transition from

it. I hold tightly to the opportunities and guidance I have received from the people who have mentored me. While I will continue to learn from them and others for decades to come, it is time for me to start to pass on some of what I have learnt so far. ICAAP was a great experience; I enjoyed my “new” role there.

After attending the Eighth ICAAP, I spent a few days in India and that journey was life-changing. I have had the privilege to travel to many different places and witness many different cultures, but being in Mumbai, India, opened my eyes up to a level of human suffering and divide that I have not seen anywhere else in my travels. I came home reinvigorated to do my work, but also realizing that YEAH is not something I can or will do forever. Actually, my goal is to spend no more than another 2–3 years in my role at YEAH. I have had the privilege in founding such an amazing organization. YEAH has a wonderful energy around all that it is involved with, and that is a reflection of all of the people who become involved in its work. A founder’s job is to lay a strong foundation, one that will be strong enough to create a stable base for whoever will take over running the organization in years to come. Once I have finished working with YEAH’s Board of Directors in laying that foundation, it will be time for me to move on.

2008 became a year of consolidation for YEAH. Despite the important steps that had taken place in 2007, I came to realize that the evolution of a not-for-profit strategy and structure is a dynamic and constant process. While the first few years of operating were about turning good ideas into projects and building partnerships, the need to continually improve the capacity to plan and evaluate the impact and purpose of our work was something that needed to become a centralized part of how YEAH functions.

By mid-2008, YEAH was facing the challenge of needing to replace our chair person who had served on the board for several years. This prompted the board to liaise with a number of organizations who specialize in the placement of highly skilled and experienced professionals from the corporate sector, linking them with opportunities to work with not-for-profits. It was through one such network, Leadership Victoria, that YEAH was able to successfully appoint Peter Caillard as the new Chairperson of our Board of Directors. Peter, a former recipient of Australia’s corporate lawyer of the year award brought with him a level of professionalism and energy that has both complemented and elevated

YEAH's capacity around governance and strategic direction. The positive experience of advertising for the position of Chairperson prompted YEAH to use similar methods to advertise for the role of treasurer. In late 2008, Amanda Campbell, a Chartered Accountant and Director of a major consultancy firm was successfully appointed to the role and the addition of the two new directors culminated in a feeling of achieving a new balance of skills represented at the board level. In addition, YEAH's Directors decided to invite Sue Podhorsky, the volunteer who had been tirelessly taking YEAH's board minutes for the past year, to officially accept the role of Secretary; and so, in a matter of months, the board had not only grown but had developed into a robust and reinvigorated team.

Although YEAH has always had a high influx of passionate people from across the community keen to volunteer their time, as CEO I have always struggled to find the best way to utilize those committed to helping us in our work. Managing people can be a job in itself and therefore I have continued to find it easier to work with a small number of core volunteers. The lessons that had been learnt during the appointment of our two new board members made me realize there was an opportunity to approach volunteer recruitment in the same way; to advertise specific position descriptions that would attract the right candidates with appropriate skills and time to commit to the role. This approach proved to be extremely effective and for the first time, it was YEAH that was driving the direction of our volunteers, not simply me trying to create opportunities for people who wanted to be involved. This is clearly how the commercial world works; by advertising employment opportunities that fit within the company's strategic direction and growth; therefore why should not the community sector embrace the same approach (albeit without the financial remuneration)? At the end of several months of advertizing for specific roles YEAH had appointed a number of highly qualified graduate students and professionals to take on project coordinator roles around media and public relations, IT, and Web site maintenance, and fundraising.

To take this approach a step further, YEAH was able to attract a number of industry professionals to work as volunteer mentors with younger student groups. One such project has been the formation of a team of students aged 16–19 who are working with a

senior journalist to produce YEAH's first regular communication for our stakeholders in the form of an e-Newsletter. This project is intrinsically linked to the Board's decision to consider a range of ways to improve the opportunity for community involvement in the decision making processes of YEAH. One such option currently under review is the implementation of a public membership program. While this is currently in a research phase, the concept would allow individuals, educational institutes, organizations, and other stakeholders to become members of YEAH, giving members the right to vote on strategic decisions and ensuring a strong community voice in shaping the future direction of YEAH. The research phase of the project is being lead by Dr. Andrew Smith and Denis O'Hara, members of Leadership Victoria's Experience Bank program. The program centres on connecting senior practitioners from across a range of industries and professions with opportunities to share their expertise with community-based organizations. While the final decision to introduce public membership will potentially be the most significant shift that YEAH has faced around structure and governance, the process of developing the research is in many ways as important as the final result. It is the process that is requiring YEAH's newly restructured Board to really analyse our stakeholders – a core component for understanding the effectiveness of any business, but something I believe is often overlooked in the community sector.

In mid-2008, YEAH developed a series of formal contracts with several universities to take on placement students from the areas of health science, nursing, and medicine. The contracts have enabled YEAH to dictate how many students we can manage at one given time and each candidate has been selected based on expressions of interest submitted in response to specific project briefs. The influx of students has drastically improved YEAH's capacity to appropriately resource projects but has equally added to the organization's experience to deliver training to young people. However it was in late 2008 that YEAH made its greatest leap forward in human resourcing when it was granted funding to take on the organization's first paid intern. Desiree Van Oss was selected as the successful MBA intern from Melbourne Business School. Desiree is now working with YEAH as the project manager of our HIV Positive Teens animation project;

a project aimed at bringing to life the stories of young Australians living with HIV using animation to protect their confidentiality. The presence of Desiree in the office two days a week has had a profound impact on my own energy and has added to my drive to grow YEAH into a national model for youth leadership; bridging the divide between the “us and them” way we look at AIDS in the developed and developing world.

In keeping with the patterns of the past three years, 2008 would not have been complete without travel. In June 2008, I received one of the highest honours: official accreditation to attend the United Nations High Level Meeting on AIDS to review the progress of the time bound goals of the 2001 Global Declaration of Commitment on AIDS. Attending the General Assembly was an incredible experience, one that was heightened by my opportune meeting with the newly appointed Australian AIDS Ambassador, Murray Proctor. Two months later, I was in Mexico representing YEAH at the XVII International AIDS Conference. Once more it was a privilege to be able to attend and to play a role as a youth spokesperson at the conference. Mid-week of the conference I was invited to attend a function hosted by Ambassador Proctor. In his speech to the invited guests, the Ambassador remarked that if anyone in the room had not heard of YEAH then they should make it their business to know the work that we do. With this recognition by Australia’s highest ranking official dedicated to HIV/AIDS, I was reminded of just how far YEAH had come and the respect with which it was held. Shortly after the trip to Mexico, another important opportunity and honour came, this time in the form of an invitation to attend the Waldzell Meeting, *A Global Dialogue for Inspiration*. I was selected as one of ten young social entrepreneurs’ worldwide to participate in the *Architects of the Future* program at Melk Abby in lower Austria. The Waldzell Meeting focuses on bridging the guidance of history and traditional wisdom with the findings of modern science to achieve a space of discovering new ways to think and experience the world and self and turn contemplation into action for social change.

At the end of 2008, YEAH was continuing to grow and change. YEAH had the largest number of young people to date volunteering in the office, a great deal

of international publicity, and a number of new projects gathering pace. And then to cap off the amazing year, I was invited to represent YEAH at the official launch of World AIDS Day at Parliament House on December 1. It was, to my knowledge, the first public launch of World AIDS Day organized and led by the government, signalling that the Government’s new leadership is committed to putting AIDS back fully on Australia’s agenda. With Ambassador Proctor’s help, I was able to meet with the Honorable Nicola Roxon, MP, Commonwealth Minister for Health and Ageing. In our discussion, she graciously acknowledged YEAH’s work over the years and assured me that our requests for funding and support would be followed up quickly. And true to her word, YEAH has since received several letters of follow-up correspondence from Minister Roxon.

So as 2009 begins, I am feeling extremely optimistic for the future of YEAH’s growth. But more than that, there is now a critical mass of people involved in Australia’s partnership approach to HIV who are recognising our capacity to deliver public health to the Australian community. The future for YEAH involves the creation of innovative projects, such as our efforts to partner with Australia’s largest international volunteer program, Australian Youth Ambassadors for Development. This will strategically align YEAH’s local training efforts with opportunities for young Australians interested in issues around AIDS to gain international experience. Another important effort is YEAH’s creation of an elective subject to be incorporated into the Bachelor of Medicine degree in Australia to increase the exposure of future doctors to the impacts of AIDS.

With a focus to build bridges and connect young people through participation, I have no doubt that YEAH will continue to play a guiding role in delivering public health both locally and nationally.

## 11.5 Reflections

On the eve of YEAH’s fourth anniversary, I can reflect and say that YEAH has helped me to grow, challenge, and create. It has allowed me to meet extraordinary people who simply by their presence in this story have not only changed my life, but

the lives of many. In the beautiful words of Karen Cochrane, my fellow founding director of YEAH, one main take home lesson in responding to HIV/AIDS or anything for that matter is to “find a little manageable bit that is achievable for you and to accomplish it.”

As founder and CEO of YEAH, my job is to work with my peers and fellow directors and volunteers of YEAH to make sure that as many young Australians as I can reach know about HIV/AIDS – what is happening locally, what is happening globally, and their place in doing something about stopping the continued spread of this preventable disease.

YEAH is the most experienced youth HIV education service in Australia, and it has been one of the most vocal advocates on these issues in the community and mainstream media over the past four years. Our goal is to help Australia achieve zero HIV prevalence. I do not think it is something that is easy to achieve, but I do think it can be

achieved. I want to encourage people to set their targets high. In my lifetime I do not want to only celebrate reductions in HIV infections, I hope to celebrate that fact that zero people become infected with HIV.

This has been the story of an incredible journey that continues. It’s been full of challenges, opinions, lessons learned, and goals discovered. It is easy in such a dynamic and turbulent area of work such as the HIV/AIDS arena to get caught up in looking at what you think others may not be doing well or what they could be doing to make it easier for you to achieve your goals. The greatest realization I have had was recognizing that YEAH’s work and future is about focusing on what we do well and continuing to do that to our highest ability.

And, in closing, I will also share that in all that YEAH does (and will do), I feel my Mom’s influence and I can see her wonderful smile of approval and support I remember so well (Fig. 11.3).



**Fig. 11.3** Anne Rogerson (*left*) and Alischa Ross (*right*) at the 1996 International AIDS Candlelight Vigil, Melbourne presenting the AIDS quilt panel they had made in memory of Elizabeth Anne, their beloved daughter and sister, respectively.



### Take-Home Messages/Lessons Learned

- Believe in your vision; when you turn your dreams into the story of how you live your life, they become the most powerful tool you have.
- Listen to the opinions and advice of others; not everyone sees your intentions from your perspective.
- Surround yourself with a broad range of people; older, younger, men, and women, with different interests and different approaches, the variety will add to your own approach and insight.
- Remember that everyone is a person who can be approached; whether they are royalty, the president of country, or have celebrity status do not be afraid to talk to the leaders in your community, they might just help you or offer great advice and if not, there is nothing lost.
- Do not be afraid to acknowledge your strengths and your weaknesses and when you do, make sure you invest in improving yourself.
- Approach your work with confidence knowing that you will always have something new to learn every day.
- Work out your strongest method of communication and make it work for you; communication is the key to building successful foundations that will sustain your work long after you are gone.
- Always be grateful for the help you receive; the community sector is built upon good will, something difficult to measure and easy to take for granted.
- If it has not been done before do not be afraid to break the boundaries regardless of the end result.
- Plan ahead; when your work is driven by a social agenda it is easy to become distracted by too many good ideas and lose the focus of your core work.
- Adopt business strategies; seek the skills you need to grow your work the same way a corporation would recruit the best candidate for the job.

- Set clear goals that you can measure the impact of your work by.
- Set a realistic pace for your strategic growth; if you grow your work too quickly it may overwhelm you; if you grow it too slowly people may lose interest in your vision.
- Treat volunteers with a balance of respect and responsibility; volunteers are voluntary staff that have rights and have targets and responsibilities to uphold if you want to grow your organization.
- If you need to raise funds for your community based work make sure the methods you use to raise funds are linked to your core work. This will help ensure that the time and resources you invest into fundraising is always advancing your mission.
- Be honest and transparent in the way you communicate your work, your successes and your challenges.
- Build partnerships with a broad range of stakeholders.
- Be persistent in all you do; many things require repetitive efforts before they come to fruition.
- Don't duplicate work that is already being done in the community; join others with common goals or build strategic alliances to fill new niches of community work that will complement the efforts of others.

**Dedication** This chapter is dedicated to my Mom, Anne Rogerson.

## 11.6 Appendix 1: Sixth International Congress on AIDS in Asia and the Pacific (ICAAP) (As Prepared by Members of the Sixth ICAAP Youth Forum Organizing Committee: Kim Davis, Alischa Ross, and Stephen Scott)

### 11.6.1 Youth Forum Declaration

We, the attendees of the Sixth International Congress on AIDS in Asia and the Pacific (ICAAP) Youth Forum have gathered in Melbourne, Australia, to discuss and

affirm our collective responsibilities in mobilizing against the spread and impact of HIV/AIDS.

We value this opportunity to ensure that the voices of young people are heard at the Congress and urge the Congress, regional governments, nongovernment organizations, HIV/AIDS activists, and the international community to endorse and act upon the following recommendations:

#### **11.6.1.1 Sexual and Reproductive Health**

- We affirm the rights of young people to adequate and accessible education, services and support on issues of reproductive and sexual health.
- We recommend that all measures be taken to centrally include to the greatest degree possible, the participation of young people in the design, delivery, and evaluation of sexual and reproductive health programs, in view of building these programs as accessible and relevant. We also recommend that young people themselves decide upon the methods, techniques and language of training for young people.
- We recommend that the needs of all young people, especially those from marginalized and vulnerable contexts and backgrounds, be met by sexual and reproductive health services and programs, including, where necessary, separate initiatives for these groups and on the basis of gender also.
- We recognize that there are differing levels of opportunity within and across cultures and that language represents a fundamental barrier to young people's education, involvement, and empowerment around HIV/AIDS. We urge that young people be centrally involved in developing language suitable for their own local circumstances that maximizes young people's capacity to mobilize around HIV/AIDS issues, regardless of caste, education, literacy, or skill level. We assert that the use of language must itself increase access to skills development for young people rather than exclude, isolate or perpetuate the disadvantaged status of many young people.

#### **11.6.1.2 Sex Education and Access to Health and Support Services**

- We recognize that the provision of sophisticated and detailed sex education is paramount if the use

of sexual and reproductive health services and programs is to be accessible and relevant.

- Such programs must explicitly contain detailed information about sex, sexuality in all of its diversity, puberty, sexual health, HIV/AIDS, contraception, abortion and family planning. We support appropriate and directed services for young people of diverse sexualities and environments that support young people's freedom to express, question, and explore their sexualities.
- We affirm the rights of all young people to be properly educated about their reproductive and sexual anatomies and be informed about the risk, symptoms and treatment of sexually transmitted infections.
- We support the provision of explicit and frank education programs in school environments as well as accessible education and information directed at young people not in school environments, especially marginalized young people such as young migrant workers, young refugees, incarcerated youth and untouchable youths. We urge the use of trained peers for these activities.
- We recognize that the HIV/AIDS epidemic both affects and infects children and young people and we urge governments and leaders across the region to recognize and respond to the needs of the increasing numbers of children and young people orphaned and affected by the AIDS-related deaths of family members.
- We stress the importance of having specific counselling dedicated to the needs of young people, both infected and affected.
- We demand that governments also address issues of discrimination, stereotyping, isolation and lack of support experienced by these young people.

#### **11.6.1.3 Gender Issues**

- We recognize that young women and girls are disadvantaged by socio-cultural contexts that oppress women and that this disadvantage extends to the degree that young women and girls can control and make decisions relating to their sexual and reproductive health.
- We recommend that determined effort be made to educate men from a young age about sexual and reproductive responsibility and gender equality.
- We recognize that gender inequality, while manifest in sexual relationships, must also be actively combated

by governments, policy makers, service providers and especially by the designers and providers of sexual and reproductive health services.

- We reject the use of culture as a justification for gender inequality and urge all political, religious and cultural leaders to challenge any cultural phenomenon that heightens HIV risk for young men and women.

#### 11.6.1.4 HIV-Positive Youth

- We recognize that the Asia-Pacific HIV/AIDS epidemic increasingly affects children and young people, representing a massive threat to the cohesion of the region's social, economic and cultural future.
- We urge all governments and nongovernmental organisations to recognize this fact and respond accordingly to the needs of all HIV positive young people.
- We defend the right of all HIV positive children and young people to have adequate access to anti-HIV drugs that have been adequately researched in terms of their effect on children's and young people's bodies. In addition, we recommend that all young people have access to appropriate supports in taking HIV treatment including nutrition, adherence support, HIV health monitoring, effective treatment of opportunistic infections and access to appropriate palliative care.
- We defend the rights of HIV positive young people to live free from stigma and discrimination and urge all governments to set in place provisions to ensure this outcome.
- We demand that HIV positive young people involved in HIV/AIDS related work be given every support and protection by the organizations they are working for, whether that work is paid or unpaid.
- We also demand recognition and responses to the complex support and care needs of HIV positive young people who have also experienced AIDS-related deaths among their families.
- We value HIV positive young people's access to peer support and urge that peer support groups or services be made widely available to all HIV positive young people.

#### 11.6.1.5 Drug Use

- We recognize that young people across Asia and the Pacific are increasingly affected by illegal drug use. In

particular, we recognize the increasing proliferation of injectable substances in the region as well as the increasing use of injection as a means of taking drugs. We alert governments and nongovernmental organisations across the region to the real and urgent threat that HIV/AIDS poses to young people who use drugs.

- We affirm the rights of all young people to access sophisticated and realistic drug education and harm minimization services including non-judgemental and culturally appropriate counselling, sterile procedures, needle and syringe exchange, safe injection spaces, appropriate education in relation to alternative routes of administration, substitution programs and rehabilitation services.
- We recognize the diversity of drugs accessible in different parts of the region and urge considered responses to the impact that drug use can have on young people's sexual responsibility.
- We demand an effective response to drug use that makes international producers and traffickers of drugs the subject of judicial intervention and incarceration and recognizes the health needs of small-scale users and addicts as paramount. We recommend that small-scale users and addicts be referred to appropriate drug support and rehabilitation services, rather than criminalized and placed in prisons.

## 11.7 Appendix 2: Registering Not-for-Profit or Charitable Organizations

The information in this guide provides general advice on the differences between a company structure and an incorporated association. Before you register your organisation, you should consider what structure best suits your organisation's purposes.

### 11.7.1 The Company Structure

Under a company structure, charitable or not-for-profit organisations will generally be registered as public companies that are limited by guarantee. Limited by guarantee means the liability of the company's members is limited to the amount the members undertake to contribute to the property of the company if it is wound up.

Registration of a company creates a legal entity separate from its members. The company can hold property and can sue and be sued.

Companies are registered under the Corporations Act 2001, which is Commonwealth legislation administered by ASIC. A company's registration is recognised Australia wide.

At the very least a public company must

- Have at least three directors and one secretary
- Have at least one member
- Have a registered office address and principal place of business located in Australia
- Have its registered office open and accessible to the public
- Be internally managed by a Constitution or Replaceable rules
- Maintain a register of its members
- Keep a record of all directors' and members' meeting minutes and resolutions
- Appoint a registered company auditor within 1 month of its registration
- Keep proper financial records
- Prepare, have audited and lodge financial statements and reports at the end of every financial year
- Send to its members a copy of its financial statements and reports, unless the member has a standing arrangement with the company not to receive them
- Hold an Annual General Meeting once every calendar year within 5 months of the end of its financial year
- Receive and review an annual company statement and pay an annual review fee. A charitable or not-for-profit company may be eligible for a reduced annual review fee if it meets the criteria under the definition of "special purpose company" in regulation 3(a), (b), (c) or (d) of the Corporations (Review Fees) Regulations 2003
- Lodge notices whenever changes to its officeholders, office addresses, constitution and its name occur

within specified timeframes as determined by the Corporations Act 2001. As a general guide please refer to "Legal obligations of a company" on our Web site at [www.asic.gov.au](http://www.asic.gov.au) for more information.

*Source:* Australia Securities and Investment Commission 2008

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