



N E D A

giving time

NATIONAL ETHNIC DISABILITY ALLIANCE

The stories of
four volunteers
from non-English
backgrounds
with disability

Arnold

the champion volunteer



Arnold Cielens is Deaf-Blind. He inherited glaucoma (eye disease) from his father. At the age of five he had no sight in his left eye and only tunnel vision in his right. He lost total sight at age 71. At age 79, Arnold can only hear someone speaking if there is no background noise. He also has a degenerative spine and severe pain in his lower back and left leg. He can hardly walk.

Arnold Cielens has volunteered for almost 100 charities over the last 50 years. He has collected more than \$500,000 in donations for charities such as:

- Freedom from Hunger
- Salvation Army
- Austcare
- Royal Society for the Blind
- Red Cross
- St Johns Ambulance
- Community Aid Abroad
- The Northcott Society (formerly known as the Crippled Children Association)

Over the years Arnold has been recognised for his volunteer effort. The Premier of South Australia has admired his work, as has HRH Princess Anne. Arnold's most

"Volunteerism is my sport, my recreation, my religion - everything."

precious awards include:

- Anzac of the Year Award for Commitment to the Community - 1983
- Certificate of Appreciation from the Crippled Children Association - 1972

Others include:

- The South Australian Premier's Certificate of Appreciation for International Year of the Volunteer - 2001
- Certificate of Recognition from the South Australian Department on the Ageing - 1988

FROM THE EXECUTIVE DIRECTOR

The National Ethnic Disability Alliance (NEDA) is a national consumer-based peak body in Australia for people from a non-English speaking background with disability, their families and carers.

NEDA has been successful in securing a grant from the Commonwealth Government's International Year of the Volunteer (IYV) 2001 Small Grants Program.

This publication - an oral history of four exemplary volunteers - will help ensure the tireless efforts of volunteers from a non-English speaking background with disability are recognized and celebrated.

Enjoy the read!

Lou-Anne Lind

EXECUTIVE DIRECTOR, NEDA

- Tee Tree Gully's Australian Citizen of the Year Award - 1982

For the past 20 years, Arnold has passionately campaigned for deaf-blind children in Australia. Because of his disability, Arnold was unable to complete primary school. He now lobbies governments to introduce specialist deaf-blind training for teachers in Australia (current training is only available in Europe). Arnold's dream is to ensure Australian deaf-blind children receive the education that he was denied.

"I have learnt to disregard my disability and work with my capabilities. If I can do something to help someone I will. I like to make people happy."

Arnold was born in Riga – the capital of Latvia - to a Russian mother and Latvian father. He started volunteering and caring for others from the age of five when his father became blind.

"I was his eyes," said Arnold, *"I had to take him to meetings with important people."*

When Arnold's father became blind he left banking and opened a newsagency opposite Riga Hospital. Arnold was the newspaper boy selling papers in the hospital.

"I met lots of beautiful people who were very sick. I spent time talking

to them and running their errands. This gave me good feelings."

Arnold has other memories of volunteering at a young age. Arnold's teacher once asked the kids if they could help harvest potatoes for an elderly war veteran – the entire class volunteered.

"It was raining. We were all dirty and tired. The old veteran was so happy, so joyful. His smile was a wonderful reward."

Arnold arrived in Australia at 29 years of age with his wife and two children. In Australia they had two more children. When his wife left him with four young boys (one with polio, three with the inherited glaucoma) Arnold struggled, often taking several jobs at a time to make ends meet, but he still found time for his volunteering.

"I collected money for the Crippled Children Society (now The Northcott Society) as a way of thanking them for helping my son."

Arnold went back to Latvia to visit his father in 1979. When asked what Arnold was like as a child his father replied,

"Son, you were a naughty boy, but you had a heart of gold."

Next year Arnold celebrates his 50th year of volunteering by selling badges on Anzac Day.

Diana

the political volunteer

Diana Qian was born with scoliosis (curved spine) and a congenital (from birth) condition that caused her to have webbed shoulders and fingers. Due to medical malpractice, Diana became paralyzed (unable to walk) at 10 years of age. Diana is a wheelchair user.



As the first person with disability to live on campus at her university, Diana Qian confronted discrimination, racism and sexism on a daily basis.

"To be Asian and a woman in a wheelchair was very difficult."

In response to this discrimination, Diana became a political volunteer. She played an active role in student politics and was elected onto the Student Association.

Diana's political passions also evolved outside university. She joined the Management Committee of the Multicultural Disability Advocacy Association - first as Treasurer, then as Chairperson – a position she held for four years. And in 1998, Diana was the NESB representative for the

"If you have a strong commitment to social justice then you definitely need to get involved voluntary work."

review of the NSW State Disability Services Act.

For the past four years, Diana has been the NSW representative on the National Ethnic Disability Alliance (NEDA). Her role involves ensuring grass roots disability issues reach the national peak body.

Diana works with others in NEDA to put the issue of people from a non-English speaking background with disability on the government agenda.

She is passionate about encouraging awareness and knowledge of disability issues in non-English speaking background communities.

Diana's lobbying and advocacy skills have also been incorporated into her paid employment.

"Volunteer work has built my confidence and opened the door to my career. I really value the experience I have gained."

Diana worked for almost three years as an advocate and lobbyist for People with a Disability (PWD). Her current position at the Attorney General's Department involves coordinating a training program for frontline staff to ensure the service they deliver is accessible to all customers including people with disability.

Diana was born and raised in Su Zhou, China. She had scoliosis – a genetic condition often caused by malnutrition and not unusual for Asian girls.

By the time she was four years old, Diana's curved spine was very severe. This did not prevent her from attending school - Diana enjoyed her schoolwork and was good at her studies.

Her fellow students were very curious about her disability. They would often point and stare at her.

"As a culture, the Chinese are very curious – so this behaviour did not bother me - it was culturally acceptable."

Diana's ambition was to attend university. However, to be accepted into a university in China, students have to undergo health checks. People with disability are not accepted.

In an effort to fix her disability, Diana's parents agreed to surgery. Unfortunately, the inexperienced surgeon broke her spine, leaving her paralyzed. Diana and her parents were devastated. Diana's mother quit her job and nursed her in hospital for the next two years.

Diana's father spent those two years writing to hospitals all over the world in an effort to find a solution for his daughter. In 1998, the Prince of Wales Hospital brought Diana to Sydney – this was a direct result of her father's perseverance and dedication.

"Volunteering is very exciting and empowering. It's about a sense of self-worth and a connection to society."

Diana believes a good volunteer should have passion, a commitment to social justice and a focus to achieve positive outcomes for the community.

She strongly recommends voluntary work to other people with disability.

Sailesh

the spiritual volunteer



At 20 years of age Sailesh Chand was diagnosed with a tumour (abnormal tissue growth) on his knee. His leg was amputated five years later. Unable to use an artificial leg, Sailesh walks with crutches.

"Service to mankind is like service to God."

Sailesh Chand is a very spiritual man who spends his days helping people achieve greater spiritual awareness.

Sailesh gets a lot from helping others and finds that he in turn receives his own spiritual enhancement through voluntary work.

"I get so much bliss from helping people. I really enjoy it. Service to mankind is like service to God."

Every Monday night Sailesh and his wife Marina hold a meditation and devotional singing group in their home. This group attracts up to 40-50 people at a time. All cultures and abilities are represented.

They are a very close group and often volunteer together in monthly community activities such as cleaning

up the seashore and mangroves around Brisbane's bayside area.

In addition to his volunteer work, Sailesh works several days a week at a local medical centre. He splits his duties between accounting, office management and massage.

Sailesh grew up in the town of Nausori in Fiji. Of Indian decent, Sailesh was the youngest of four girls and three boys.

His father died when Sailesh was 10 years of age. His mother, sisters and brothers raised him.

In 1991 Sailesh discovered a large tumour on his leg.

Sophie

the determined volunteer



Sophie Jasinski has Burgers disease (an affliction that causes arteries to clog up and results in a loss of circulation to the limbs).

Sophie lost her first leg at 29 years. She lost her second leg 10 years later.

"I don't know how this happened – I once had a cramp and from then on I had pain in that knee."

Doctors told him that his leg should be amputated. Sailesh went to the Mercy Hospital in New Zealand for the operation. However, he changed his mind at the last minute, as he was too afraid to continue.

His leg continued to give him a lot of pain and doctors told him he only had six months to live.

In 1994 Sailesh went to India. This trip was to have a profound affect on his life.

"I learnt many spiritual things – all about positive thinking and chanting."

"Positive thinking makes a huge difference. If you're positive in your life you can do things and make the most of the life you've been given"

Sailesh also learnt to adopt a new approach to his leg. His new way of thinking taught him that his body was irrelevant – simply a vessel for the soul.

"If the heart is open, the body will work."

In 1996 at 25 years of age Sailesh came to Australia to have his leg amputated. By this time his attitude towards being an amputee had changed. He was now ready for the operation and looked forward to a normal life without pain and suffering.

Sailesh had his leg amputated at Royal Brisbane Hospital in Queensland. After his rehabilitation he resumed a normal life by going back to voluntary work, studies and the paid workforce. He also met Marina and they married in 2000.

Sailesh believes everyone has a talent and recommends volunteer work to everyone including people with a disability.

"Volunteer work makes you feel better – makes you positive about life."

At age 29, with three kids and a second husband, Sophie Jasinski became an amputee.

"I lost my leg and I found out I was pregnant. Being pregnant was a blessing – I just had to think about the baby."

But 10 years later, Sophie was bitter about losing her second leg. She resented looking at people who could walk and had to deal with body image issues.

"I became very bitter. I was so resentful. My body image was poor - parts of me were missing."

After 18 months a friend who was dying of cancer put this into perspective for her.

"Volunteer work is both frustrating and satisfying."

"She said that she would gladly give up her legs if it meant she could see her kids grow up. This changed my view but I've have never accepted my disability – I've just learnt to live with it."

Sophie went back to work after the loss of her second leg. She also began her voluntary work.

Sophie finds volunteer work both frustrating and satisfying.

"It's satisfying because people are grateful for information. But it is also frustrating because many people from a non-English speaking background are not aware of services in this country."

Sophie feels culture plays an enormous difference to people accessing services.

"A lot of people from European countries will not even admit to their disability. They think there is a stigma attached."

Sophie has spent many years volunteering for organizations and working with people with physical disability. She spent 10 years as a Paraquad volunteer and many years working on advisory committees for

- the Ethnic Communities' Council
- the Australian Council of Rehabilitation of the Disabled (ACROD)
- Echo (local Bayswater club for the aged)
- People with a Disability
- Ethnic Disability Advocacy Centre
- National Ethnic Disability Alliance

In 1979 Sophie started the Amputees Association. For the next 10 years, Sophie and other volunteers visited people who had lost limbs – or who were in hospital waiting for the operation that would leave them an amputee.

"We would tell them the procedure and what came with it," Sophie said.

"No-one tells you what it will look like, what it feels like, or the effect it had on you."

When she was 18 months old, Sophie, her mother, two sisters and her grandmother were taken from Poland to Siberia, then Persia. From Persia they were taken to a refugee camp in East Africa where they spent the next eight years.

Sophie was 11 years old when she arrived in Fremantle, Western Australia. Sophie boarded at a convent school until she left at 16 years – to marry her first husband. He was killed three years later. Sophie remarried at 23 years of age – to a Polish man.

"My husband is very supportive about my legs. He once said to me... what's a pair of legs – just get on with life."

Sophie encourages all people to do voluntary work.

"Volunteering gives people an outside interest. A good volunteer is well-trained, kind, non judgmental and a good listener."

Are you from a non-English speaking background?

Do you have a disability?

Would you like to become a volunteer?

CONTACT

NATIONAL ETHNIC DISABILITY ALLIANCE (NEDA)

TEL 02 9687 8933

FAX 02 9635 5355

WEB www.neda.org.au



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NATIONAL ETHNIC DISABILITY ALLIANCE

40 Albion Street Harris Park
POST PO Box 381 Harris Park NSW 2150
TEL 02 9687 8933
FAX 02 9635 5355
TTY 02 9687 6325
EMAIL office@neda.org.au
WEB www.neda.org.au