

# **Australian Parliamentary Delegation**

Brazil and the United States of America 14–27 July 2024

REPORT | JANUARY 2025



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# Members of the Delegation

# Leader of the Delegation

Senator Penny Allman-Payne
 Senator for Queensland
 Australian Greens

# **Delegates**

- Senator Wendy Askew
   Senator for Tasmania
   Liberal Party of Australia
- Senator Louise Pratt
   Senator for Western Australia
   Labor Party
- Senator Maria Kovacic
   Senator for New South Wales
   Liberal Party of Australia

#### Officials

Ms. Apolline Kohen
 Delegation Secretary

# Introduction

This report gives an account of the Senate Community Affairs Committee parliamentary visit to Brazil and the USA in July 2024. The parliamentary visit aimed to support the committee's ongoing work in the policy areas of healthcare and affordable housing. In developing the program, the committee agreed to focus on:

- Models of healthcare programs in Brazil, including community health workers (CHWs) programs and First Nations health;
- Affordable and social housing;
- cancer and rare cancer research; and
- health topics related to recent and ongoing work undertaken by the committee.

# Acknowledgements

The delegation developed the program with the assistance of the International and Parliamentary Relations Office, the Department of Foreign Affairs and Trade, the staff of the Embassy of Australia in Brasilia, the staff of the Embassy of Australia in Washington DC and the staff of the Australian Consulate General in New York. The delegation is greatly appreciative of the work that was undertaken to develop an engaging and pertinent program to support the committee's work in the areas of primary health care models, First Nations health, rare cancers research, Lyme disease, menopause and affordable housing.

Prior to departure, the delegation received helpful and informative briefings from the International and Parliamentary Relations Office, the Department of Foreign Affairs and Trade, the Australian Security Intelligence Organisation, and the Department of Parliamentary Services.

During the visit in Brazil, the delegation was accompanied by officers from the Embassy of Australia in Brasilia, led by Her Excellency Ms Sophie Davis, Australia's Ambassador to Brazil. In the USA, the delegation was accompanied by officers from the Embassy of Australia in Washington DC, led by His Excellency the Hon Dr Kevin Rudd AC, Australia's Ambassador to the United States and the Australian Consulate General in New York, led by Consul-General Ms Heather Ridout AO. The Ambassadors, Consul-General and their staff, provided comprehensive briefings and logistical assistance throughout the visit. The delegation is greatly appreciative of the effort made to accommodate its needs and to ensure a successful visit.

The delegation particularly wishes to thank:

#### In Brazil

 Mr Grant Morrison, Deputy Head of Mission and Ms Antonella Zugliani, Policy Officer, who developed the visit program for São Paulo and Brasilia and provided ongoing support during the visit.

#### In USA

- Ms Laura McKenna, Visits Manager, who was very helpful in finding alternative accommodation and providing logistical support when the delegation was stranded in Atlanta due to the CrowdStrike faulty upgrade, which affected companies and services worldwide, including airlines.
- Mr Chris Munro, Director Public Diplomacy and Chief of Staff to Consul-General Ridout, who developed the visit program for New York and provided support during the visit.
- Mr Cameron Hunter, Senior Research Officer, Trade, who developed the visit program for Washington DC and provided support during the visit.

Finally, the delegation would like to thank all the individuals and organisations that graciously gave time to meet with the delegation and expresses appreciation for the warm welcomes and hospitality received.

Senator Penny Allman-Payne

**Delegation Leader** 

# Report of Activities

#### Monday, 15 July 2024 – São Paulo

On its first day of meetings, the delegation met with representatives of the São Paulo State Department of Health, Habitat Brazil and the Women's Entrepreneurship Network.

#### State Department of Health of São Paulo

The Department is responsible for formulating the state policies and guidelines, which are guided by the principles of the Unified Health System (SUS). Through the SUS, all residents can access free, comprehensive services, including primary, outpatient specialty, mental health, and hospital care.

The delegation met with representatives of the Department of Health (the Department) led by Dr Priscilla Perdicaris, Acting Secretary. The Department is responsible for overseeing the administration, delivery of care and hospital coordination of the 645 municipalities in the state of São Paulo comprising over 44 million people (25 per cent of the Brazilian population). In Brazil, the administration and delivery of health care are handled by municipalities or states. Dr Perdicaris explained the key principles of the SUS, which include:

- a universal right to comprehensive health care;
- decentralisation with responsibilities primarily given to state and local governments; and
- social participation through the formulation and monitoring of the implementation of health policies through federal, state, and municipal health councils.

The discussion then focused on what works well, the challenges and opportunities faced by the Department in its effort in delivering person-centered care and focus on prevention. Challenges include the ability to deliver a holistic approach, the fragmentation of services, the diversity of populations and vulnerable cohorts.

#### Habitat for Humanity Brazil

Habit for Humanity is an NGO, which has a presence in more than 70 countries. Habitat for Humanity's vision is for everyone to have a decent place to live. Habit for Humanity Brazil focuses on local and scalable housing projects and solutions.<sup>1</sup>

The delegation met with Ms Margaret Uemura, Ms Juliana Motter and Mr Elias Ambrosioi who gave an overview of the activities the organisation runs in Brazil. This includes projects to provide access to water and sanitation for vulnerable populations in urban and rural communities. The delegation also heard about the organisation's advocacy work, including the *Zero Evictions Campaign*, which started during the Covid-19 pandemic.

The delegation was particularly interested in *Minha Casa Minha Vida* (My House My Life), a government program aimed at facilitating home ownership for low-income families. First established in 2009, it was replaced by the *Casa Verde e Amarela Program* in 2021 during the Jair Bolsonaro Government. However, with the change of government, *Minha Casa Minha Vida* was fully resumed in 2023. The program is means tested and offers subsidies and affordable financing options, including lower interest rates. Priority is given to vulnerable cohorts, including families with people with disabilities, women who are victims of domestic and family violence, elderly people, who have lost their housing due to natural disasters and Indigenous people. The program has delivered an impressive number of dwellings, but criticisms of the program include the lack of access to basic services such as public transport, education and health because the housing projects are often located in far-flung urban periphery.

#### Women's Entrepreneur Network

The delegation ended its first day of meetings with discussions with Ms Ana Fontes, founder of *Rede Mulher Empreendedora* (Women Entrepreneur Network – RME). RME supports women to achieve economic and financial autonomy through training, business support services, access to financial resources and market access. Ms Fontes is also part of the Women20, an engagement group of the G20, which proposes policy recommendations to better the lives of women and girls to the G20.

The delegation was impressed by the successes of RME and its strategies to ensure women in business have access to training and mentoring. The delegation

<sup>&</sup>lt;sup>1</sup> For further information, see, Habitat para a Humidale (accessed 7 January 2025).

also discussed the importance of financial independence in the context of fleeing domestic violence. This led Ms Fontes to inform the delegation of the Brazilian ground-breaking legislation on domestic violence called the Maria da Penha Law after a women's rights activist who was left paraplegic by her violent husband. The legislation, passed in 2006, increased punishment for domestic abuse offenders, established domestic violence courts and required authorities to institute 24-hour shelters for victims of household domestic abuse. Importantly, the law empowers judges to issue temporary restraining orders.





Delegates at the Department of Health (left) and with the Women's Entrepreneur Network (right)

# Tuesday 16 July - São Paulo

The delegation visited a community housing construction project and met with the Municipal Housing Secretary, Mr Milton Vieira in São Paulo before flying to Brasilia.

#### Site visit

The Municipal Housing Secretary, Mr Milton Vieira, welcomed the delegation at a social housing construction site in the Vila Olimpia neighborhood, in the South Zone of São Paulo.

The delegation heard that the housing project, called *Conjunto Habitacional Coliseu*, is located where the Favela do Coliseu used to be. Some of the families who lived in the favela will come back to live in the new housing complex as well as people who are on the municipality social housing waitlist. The delegation learnt that, in São Paulo, social housing tenancy is for life and tenants pay 15 per cent of their income. Eligibility criteria include that a prospective tenant earns a maximum of three times the minimum wage.

Mr Vieira showed the delegation the different types of apartments which will be available to tenants, including a two-bedroom apartment and an accessible apartment designed for tenants with low mobility and / or wheelchairs users. The delegation also visited areas designed for community activities and the outside playground. The delegation noted the fit-for-purpose design and quality of materials used, which are likely to contribute to low-maintenance costs and extend the longevity of the building.





Delegates with Mr Vieira, Municipal Housing Secretary, posing in the playground of Conjunto Habitacional Coliseu housing project (right) in its final stage of construction.

#### Wednesday 17 July - Brasilia

On its first day in Brasilia, the delegation had several meetings with officials, visited two medical centres, went to the Federal Senate and ended the day with a dinner hosted by her Excellency Ms Sophie Davis, Australia's Ambassador to Brazil.

#### Basic Health Unit and Specialist Health Unit clinics

First, the delegation visited the Centro de Saude n°13, a Basic Health Unit (UBS). A UBS provides general practitioner services, dental services, vaccination services, pathology tests and is also a pharmacy. The objective of the UBS model is to reduce hospital admissions. It is a key component of the SUS (Brazil's universal healthcare system) and all services are free of charge. Representatives of the Ministry of Health and officers working in the clinic conducted the tour of the facility. The delegation was able to view the different areas of the clinic and to observe how patients interact with the services. The delegation learnt that the facility is open on weekdays from 7.00am to 7.00pm, and that the most common reasons for visiting the facility were: hypertension, diabetes, vaccination, dental needs and pre-natal check-ups. The delegation was interested to hear about workforce needs and challenges. The delegation was informed that UBS clinics in cities are well staffed, but that UBS clinics in regional areas were facing workforce shortages. As the delegation was expressing interest in better understanding patients' flow and referrals to specialised services, officials offered to take the delegation to a nearby obesity specialist clinic. The clinic offers services aimed at treating obesity and related comorbidities, including diabetes and cardio-vascular diseases. The objective is to provide holistic care with access in one place to a team of specialist clinicians, nutritionists and psychologists. The delegation was appreciative of the opportunity to visit another health facility and better understand how the system works.







Delegates visiting the Centro de Saude n°13.

#### National Housing Secretariat

The delegation met with Mr Hailton Madureia, the National Housing Secretary and officials from the Ministry of Cities to discuss federal housing policies. First, the delegation and officials talked about the housing shortages in both countries as well as the current cost of living crisis, which is pushing more people into housing stress. Like Australia, the delivery of the housing programs is the responsibility of state and local governments. The two main programs funded by the federal government (approximately 20 billion Brazilian Real per year) are:

- NovoPAC, which addresses inadequate housing through improving existing housing stock; and
- Minha Casa Minha Vida program (My House My Life), which addresses
  housing backlog and future demand through social housing building
  projects. As discussed in the meeting with Habitat for Humanity Brazil,
  the program expands access to home ownership through access to low
  interest rates for low-income families.

Officials explained that to expedite the construction of new housing stock to an 18-month delivery it has implemented direct procurement mechanisms and partnerships.

# Ministry of Health

The delegation met with officials from the Ministry of Health, including Ms Evelin Brezerra da Silva, Director of Community Health Strategy and Policies; Ms Doralice Severo Cruz, General Coordinator of Oral Health; and Mr Fabio da Silva Sartori, Secretariat of Primary Health Care. The meeting was an opportunity to further discuss the SUS (Brazil's universal healthcare system) and strategies to ensure all residents, including in remote areas, have access to healthcare. In addition to Basic Health Units (UBS), several initiatives to reach vulnerable populations have been created:

- Riverside Family Health Team (nurse + doctor) regularly accessing remote communities via boats;
- Street Clinic Team (nurse + social worker + psychologist) connecting with homeless people;
- Prison Primary Care Team (nurse + doctor + dentist at a minimum) to deliver care in prison; and
- Mobile Dental Unit to deliver dental care in remote areas and areas without UBS centres.

The delegation and officials reflected on the challenges associated with delivering care in regional and remote areas.

#### **National Congress**

On arrival at the Senate building, journalist Ivan Godoy from Radio Senado asked for an interview with the delegation. The delegation agreed and was interviewed on topics related to Australia's parliamentary history and the delegation's work.<sup>2</sup> Established in 1997, in addition to coverage and streaming of the main votes and events of the National Congress, Radio Senado offers programs presenting the works of committees, discussions on major national issues with experts and parliamentarians, and a musical program focusing on Brazilian music. After the interview, Mr Godoy gave a tour of the Senate building, including facilitating access to the Senate chamber. Of note, the delegation felt privileged to have the opportunity to be on the floor of the Senate chamber whilst it was sitting, reflecting it would not have been possible for a delegation to do the same in the Australian Senate.

#### Dinner at the Ambassador's residence

In the evening, the delegation was welcomed by Her Excellency Ms Sophie Davis for a dinner at the residence. The delegation was very appreciative of the hospitality and the opportunity to share experiences and views on a range of topics with diplomats from the US, UK, New Zealand and Japan embassies as well as Brazilian academics and experts.



Delegates with guests and Her Excellency Ms Sophie Davis

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<sup>&</sup>lt;sup>2</sup> Audio interview: <u>Senadoras australianas destacam importância da presença da mulher no Legislativo —</u>
<u>Rádio SenadoSenadoras australianas destacam importância da presença da mulher no Legislativo — Rádio Senado</u> (accessed 3 January 2025)

# Thursday 18 July - Brasilia

The delegation had meetings with health officials and went on a site visit prior to its departure to Rio De Janeiro.

#### Secretariat of Indigenous Health - SESAI

The delegation met with officials from the Secretariat of Indigenous Health (SESAI), including Ms Lucinda Tremembé, Assistant Secretary and Ms Milena Kanindé, Head of the Cabinet, SESAI is responsible for all aspects of Indigenous Health, It coordinates and executes the National Policy for Health Care for Indigenous Peoples and manages the Indigenous Health Care Subsystem in the SUS. The officials provided an overview of the Indigenous population, explaining that there are 305 Indigenous groups totaling around 1.7 million people (less than one percent of the population) speaking over 200 languages and/or dialects. From the Amazon rainforest to the Atlantic Forest and urban areas, Indigenous peoples live all around the country and may have vastly different social and professional circumstances. The delegation noted the complexity of access to remote areas. and that there were still uncontacted peoples (groups who avoid all contact with outsiders). Officials stressed the importance of Indigenous leadership and Indigenous participation in the development and delivery of all the SESAI health policies and programs. The committee was advised that Indigenous healthcare is designed and implemented with the Indigenous users of the services, which leads to better outcomes. While the officials noted the ongoing concerns around workforce training and recruitment, the committee was impressed to learn that 52 percent of the workforce delivering Indigenous health care was Indigenous. The committee noted some similar challenges in Australia in relation to Indigenous health, including connectivity issues to enable the effective delivery e-health and managing patients with chronic conditions in remote areas.





Delegates with health officials from SESAI.

#### Site visit to CASAI Brasilia

The delegation was very appreciative to have the opportunity to visit a CASAI, an Indigenous Health Support House, just outside Brasilia. The CASIA is a support house for Indigenous patients with complex needs living in rural and remote areas who require travel to cities for diagnosis and hospital treatments. Patients travel with a companion (often a family member) and are housed in a CASAI, which in addition to accommodation provides healthy culturally appropriate food, coordination of transport to medical appointments, onsite nursing care, and education for children. CASAI coordinators are Indigenous and work with patients to ensure they get the care they need during their stay. Ms Eugénia Calazans, the Director, gave a tour of the facility and introduced a few patients to the delegation, who generously shared their experiences with the committee and allowed the committee to see their rooms. The delegation noted that there are also activities available, including access to an art and crafts room. The delegation was invited to view some of the art made by patients.

After the visit, the delegation traveled to the airport to catch a flight to Rio de Janeiro.





Delegates with a young patient and his mother and Ms Eugénia Calazans giving a tour of the facility.

# Friday 19 July – Monday 22 July

After a night in Rio De Janeiro, the delegation boarded a flight to Atlanta with a connecting flight to Washington DC. However, due to the CrowdStrike faulty upgrade, the delegation was unable to travel to Washington DC for the next three days. The original schedule had allowed the weekend as private time in Washington DC. Instead, the delegation spent most of its weekend trying to

reorganise flights and waiting at Atlanta airport. The delegation was able to travel to New York on Monday 22 July, ahead of its meetings scheduled for Tuesday 23 July. The scheduled meetings in Washington on Monday 22 July were postponed to 24 and 25 July 2024. The delegation thanks the staff of the Australian Embassy in Washington DC for their hard work to reschedule the meetings and their assistance in locating the delegation's luggage, which was temporarily lost amid delayed and cancelled flights.

#### Tuesday 23 July – New York

The delegation had a busy day of meetings prior to traveling to Washington DC in the evening. The delegation thanks the consulate for hosting the meetings with Project Lyme and Let's Talk Menopause in the consulate offices.

## Project Lyme

The delegation met with the Executive Director, Mr Noah Johnston and the Board Chair of Project Lyme, Ms Ali Moresco. Founded in 2016, Project Lyme's mission is to eradicate tick-borne diseases through awareness and education, advocacy and supporting research. The Chair, who lives with chronic tick-borne diseases, outlined to the delegation the key issues faced by people with tick-borne diseases in the USA. These include a lack of recognition, a general lack of education, issues with testing methods and accuracy, difficulties with getting a diagnosis and lack of funding. Currently, it is estimated that more than 470,000 cases are diagnosed and treated each year in the USA. Project Lyme has developed a range of educational information to better understand tick-borne diseases and support patients, which is available on their website. Project Lyme has put in place tick surveillance projects in Florida and the Bay Area in California, as tick-borne diseases are particularly prevalent in these areas.

The delegation also heard about the various initiatives undertaken by the US government over the years. This includes the establishment of the Tick-Borne Disease Working Group by Congress in 2016 to provide subject matter expertise, review federal efforts related to all tick-borne diseases, and to examine research priorities. The Working Group delivered its final report in February 2023 and made a series of recommendations in relation to access to care and education, prevention, diagnosis, and treatment.<sup>4</sup> The delegation indicated that the committee

<sup>&</sup>lt;sup>3</sup> Project Lyme, Home - Project Lyme (accessed 2 January 2025).

<sup>&</sup>lt;sup>4</sup> US Department of Health and Human Services, *TBDWG 2022 report to Congress,* February 2023, <u>TBDWG Reports | HHS.gov</u> (accessed 2 December 2024).

was considering undertaking a short inquiry as a follow-up to its 2016 inquiry into *Growing evidence of an emerging tick-borne disease that causes a Lyme like illness for many Australian patients* and would contact Project Lyme if proceeding with the inquiry.<sup>5</sup>

#### Let's talk menopause

The delegation met with Ms Donna Klassen, co-founder and CEO of *Let's talk menopause* and Ms Marie Capozzi, Chief Operating Officer. *Let's talk menopause* was established in 2020 with the goals of empowering women to navigate all stages of menopause, advocating for the medical community to invest in caring for women throughout the menopause, educating the public and connecting women to find community and support throughout menopause. *Let's talk menopause* runs several programs, including podcasts, webinars and events to educate the public and support women throughout perimenopause and menopause. Its advocacy work includes the public awareness campaign *#NotJustInYourHead* to ensure menopause is no longer a taboo subject.

The delegation explained that the Community Affairs References Committee was undertaking an inquiry into the issues related to perimenopause and menopause in Australia. The delegation talked about some of its findings, including that most women do not receive adequate support to manage their symptoms both in the health system and in their workplaces. In discussing similarities and differences between the two countries in relation to the treatment of menopause symptoms, the delegation learned that a research study found that 74 percent of women in the USA who seek care for menopause and perimenopause are left untreated by their doctors. Like Australia, the costs of menopause treatments in the USA can be prohibitive and many women do not access care due to financial barriers.

The delegation was particularly interested to hear about the *Menopause Research* and Equity Act of 2023 aimed at supporting menopause research, mid-life women's health research, and finding new treatments for the symptoms of menopause.<sup>8</sup> Importantly this legislation would provide funding certainty and

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<sup>&</sup>lt;sup>5</sup> On 20 November 2024, the Senate referred an inquiry into the access to diagnosis and treatment for people in Australia with tick-borne diseases to the Community Affairs References Committee for inquiry and report by 26 March 2025.

<sup>&</sup>lt;sup>6</sup> Let's talk menopause, <u>Let's talk menopause</u> (accessed 2 January 2025).

<sup>&</sup>lt;sup>7</sup> Senate Standing Community Affairs References Committee, <u>Issues related to menopause and</u> perimenopause, September 2024, (accessed 2 January 2025).

<sup>&</sup>lt;sup>8</sup> H.R.6749 - Menopause Research and Equity Act of 2023 (accessed 2 January 2025).

enable long-term research projects. *Let's Talk Menopause* is running a campaign to support this proposed legislation.





Delegates with Project Lyme team and (left) and delegates with Let's talk Menopause representatives in the offices of the Australian consulate in New York.

### Memorial Sloan Kettering Cancer Center

The delegation had the privilege of meeting with several prominent oncologists, surgeons, researchers and physicians working for the Memorial Sloan Kettering Cancer Center (MSK). The Centre maintains one of the world's most dynamic programs of cancer research, with more than 120 research laboratories focused on better understanding every type of the disease. MSK conducts one of the largest clinical research programs in the world.

Dr Bob Li and Dr Larry Norton welcomed the delegation and gave a presentation on the US-Australia Cancer Consortium. Whilst collaboration between the USA and Australia in cancer research is not new, this public-private initiative started in 2024 and focuses on international data sharing with a cloud-based system for collaborative research and expanding access to clinical trials. The consortium aims to address the disparities in cancer burden, screening, diagnosis, and treatment outcomes, especially among Indigenous populations and underserved minorities in the USA and Australia. To support the initiative, Australian philanthropists Kay Van Norton Poche and Gregory Poche donated \$20 million to help establish centers in Sydney and at MSK. The cancer centers support exchanges between USA and Australian trainees, increase the number of cancer patients able to take part in clinical trials of new treatments, and speed up the development of new drugs by the pharmaceutical industry. During the roundtable, the MSK team talked about

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<sup>&</sup>lt;sup>9</sup> The delegation met with Dr Bob Li, Dr Larry Norton, Dr Nancy Lee, Dr David Solit, Dr Vivan Strong, Dr Julia Glade Bender, Dr Damon reed, Dr Shakeel Modak, Dr Peter Kingham, Dr Alan Ho, Dr Justin Jee, Ms Mary Warren, Mrs Kaylie Johnson, Dr Tatiana Erazo, Mr Andrés Martinez.

paediatric cancer research and the difficulty in pressuring pharmaceutical companies to produce less toxic drugs suitable for children. The delegation was particularly interested to discuss access to clinical trials, noting the difficulties for Australian families to access international clinical trials for rare cancers in children. The delegation heard about the Solving Kids' Cancer charity, operating from the USA and UK, which funds innovative preclinical research and early phase clinical trials. Another topic discussed was the Global Cancer Disparities Initiatives (GCDI) at MSK. It is estimated that by 2030, approximately 75 per cent of cancer deaths worldwide will occur in low- and middle-income countries. Reasons for this global shift in the burden of cancer include increasing life expectancy, growing urbanisation, rising population levels, and lifestyle changes in low- and middle-income countries. In particular, Dr Kingham, Director of Global Cancer Disparities Initiatives talked about the African Research Group for Oncology (ARGO), which focuses on cancer research and training initiatives in Nigeria.



Delegates with MSK researchers and Consul-General Ms Heather Ridout AO (at the centre)

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<sup>&</sup>lt;sup>10</sup> See, Senate Standing Community Affairs References Committee, <u>Equitable access to diagnosis and treatment for individuals with rare and less common cancers</u>, including neuroendocrine cancer, May 2024, (accessed 2 January 2025).

<sup>&</sup>lt;sup>11</sup> Solving Kids' Cancer (accessed 2 January 2025).

# Wednesday 24 July - Washington DC

The delegation had a full day of meetings in Washington DC.

#### Studio 27 Architecture

The delegation met with representatives of Studio 27 Architecture. Studio 27 Architecture has delivered numerous projects for the government and NFP sectors, including social housing projects, schools, and shelters for women escaping domestic violence. The discussion focused on two projects built in Washington DC: *The Aya*, an affordable housing project, which provides emergency housing for families and *La Casa*, a permanent supportive accommodation for men.

The Aya is one of the housing facilities constructed by the District of Columbia to battle homelessness. It is part of the Homeward DC, a program to end long-term homelessness in Wahington DC. It provides temporary housing and wrap-around services for up to 50 families. It mostly serves young mothers with small children and the average stay is between three to six months. As part of the design, it has spaces for children of all ages to play and do homework. Meals are served on site and adults have access to computer labs for education and employment opportunities. There is a case worker assigned to each family and a clinic onsite. The Ava was designed in collaboration with the community. Studio 27 Architecture first met with an advisory team of local residents to identify their needs and preferences. This included a strong desire to preserve green space, a building with no specific front door to avoid 'back of house' activity, a building with no direct street views on windows and security to prevent domestic violence incidents. According to Studio 27 Architecture, The Aya model is working because it is codesigned with the local community. Rather than a shelter, La Casa provides permanent supportive housing for 40 men. It provides private units with full living spaces, kitchens and bathrooms for chronically homeless men. It also provides access to medical and social services. The stability of permanent housing provided by La Casa helps residents develop healthier and more independent lifestyles. One of the design challenges was to create a 'home' rather than an institution. The Studio 27 Architecture team also provided an overview of other types of social housing projects the firm had been involved in, stressing the importance of co-design and listening to communities' needs.



Delegates with Jake Marzolf from Studio 27 Architecture

## Senate Committee on Health, Education, Labor & Pensions and Senate Committee on Banking, Housing, and Urban Affairs

The delegation spent the rest of the morning meeting with US Senate committee staff and members. Firstly, the delegation met with senior advisers to the Committee on Health, Education, Labor & Pensions (HELP) chaired by Senator Bernie Sanders. The meeting started with a discussion around the similarities and differences between the USA and Australia committee systems. The delegation learned that the HELP committee meets on average every four to six weeks and comprises 11 Democrats and 10 Republicans. In addition to the committee, there are also three subcommittees focusing on policy issues related to Children & Families, Employment & Workplace Safety and Primary Health & Retirement Security.

Australia's Hepatis C strategy was discussed during the meeting as it is an area of interest for the HELP committee Ranking member Senator Bill Cassidy. Another area of discussion was the Older Americans Act (OAA), which supports a wide range of health and social services programs for older Americans. The discussion focused on proposed amendments to address the current unmet needs of millions of older Americans through a substantial increase in funding and key provisions to enhance services, including in nursing homes. 12

The delegation then met with Senator Cynthia Lummis' staff. Senator Lummis is a member of the Senate Committee on Banking, Housing, and Urban Affairs. Most of

<sup>&</sup>lt;sup>12</sup> The Senate unanimously approved the reauthorization of the OAA on 10 December 2024.

the meeting was spent discussing housing, including social housing, home ownership and housing affordability. Like Australia, housing is a matter for the States and there are only limited tools available at a national level to directly address affordability and housing stock levels. The delegation learned that there was very limited social housing in the USA and that the main federal program for rent assistance is the Housing Choice Voucher Program, which is administered by local public housing agencies. A family that is issued a housing voucher is responsible for finding a suitable housing unit where the owner agrees to rent under the program. The subsidy is paid directly to the landlord. Under certain circumstances, the voucher can be used to purchase a home. Susues around the challenges of mortgages were also explored, including the fact that most mortgages in the USA are on a 30 years fixed term, which means that some families get stuck as they cannot easily move dwellings.

#### National Cancer Institute and Clinical Center

The delegation spent the afternoon at the National Cancer Institute (NCI) meeting key NCI researchers and visiting cancer research laboratories. 14 The NCI staff gave a presentation about their collaborations with Australia before taking the delegation on a tour of the building and research facilities. The NCI is the leading federal agency for cancer research and training. Funded by Congress, the bulk of the budget supports grants and cooperations conducted at universities, medical schools, hospitals, cancer centers, research laboratories, and private firms in the USA and abroad. For the financial year 2023, it supported 85 research grants with collaborators in Australia through its Center for Global Health. This included collaborations with researchers from the University of Melbourne, Peter MacCallum Cancer Centre, UNSW, the University of Sydney and Monash University. The projects are diverse and include research on treatment, early detection, prevention and certain types of cancer such as breast cancer, leukemia, colorectal cancer and lung cancer. The visit provided an opportunity for the delegation to further discuss issues around data sharing and standardisation of data collection across countries. The NCI researchers mentioned the EU Platform

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<sup>&</sup>lt;sup>13</sup> For more information, see, <u>Housing Choice Vouchers Fact Sheet</u> (accessed 3 January 2025).

<sup>&</sup>lt;sup>14</sup> Members of the NCI team present: Dr Kimryn Rathmell, Director; Dr Satish Gopal, Director, Centre for Global Health; Dr Brigitte Widemann, Chief, Pediatric Oncology Branch; Ms Anne Lubenow, Chief of Staff, Office of the Director; Ms Holly Gibbone, Deputy Director, Office of Government Relations; Ms Sana Haider, Presidential Management Fellow; Dr John Clod, Pediatric Oncology Branch; Dr Mary Frances Wedekind Malone, Pediatric Oncology Branch; Dr Jaydira Del Rivero, Surgical Oncology Branch; Dr Nitin Roper, Developmental Therapeutics Branch; Dr Karlyne Reilly, Pediatric Oncology Branch; Dr Rosandra Kaplan Pediatric Oncology Branch; Dr Rosa Nguyen, Pediatric Oncology Branch.

on Rare Disease Registration as a good initiative to tackle the fragmentation of rare disease patients' data. 15

The NCI staff then gave a tour of the pediatric oncology unit and research laboratories. The delegation was particularly interested to build on its committee work on rare cancers and discussed the need to accelerate access to international clinical trials for Australian families. NCI staff talked about the International Rare Cancers Initiative (IRCI), which aims to facilitate the development of international clinical trials for patients with rare cancers. <sup>16</sup> NCI researchers also explained how the Rare Tumors Initiative leverages existing NCI expertise in basic and clinical science studies of rare tumors to identify and more effectively translate potential new therapies. The NCI Rare Tumor Initiative was launched in 2013 to foster closer collaborations between basic and clinical scientists, patient advocacy groups, and industry partners in the field of rare tumors. The strategy is for investigators with expertise in genetics, genomics, proteomics, molecular biology, imaging, tumor models, pharmacokinetics, pharmacodynamics, biomarkers, and clinical trial development and execution to work together to facilitate the development of therapeutic approaches.



Delegates with NCI staff.

<sup>&</sup>lt;sup>15</sup> For further information, see, EU RD Platform (access 6 January 2025)

<sup>&</sup>lt;sup>16</sup> For further information, see, <u>IRCI</u> (accessed 3 January 2025).

# Thursday 25 July - Washington DC

Fors its last day in the USA, the delegation had a series of meetings before flying back to Australia via Dallas.

#### Breakfast with His Excellency, the Hon Kevin Rudd AC

His Excellency, the Hon Kevin Rudd AC, welcomed the delegation at his residence for a breakfast meeting. It was an opportunity for the delegation to discuss with the ambassador the purpose of its trip and reflect on the crucial need to further support the collaborations between the US and Australia in the field of rare cancer research. The delegation talked with the Ambassador about the upcoming US elections and Benjamin Netanyahu's address to Congress the day before (24 July 2024). The delegation thanked the ambassador for their warm welcome and praised the embassy's staff for their work before leaving to attend meetings in Capitol Hill.



Delegation with His Excellency the Hon Kevin Rudd AC at the Ambassador's residence.

#### Meeting with Dr Kim Schrier

The delegation met with Dr Kim Schrier, a member of the US House of Representatives for Washington's 8<sup>th</sup> district. Dr Schrier was a practicing pediatrician before entering politics and is passionate about healthcare. She is a member of the Committee on Energy and Commerce and of the Subcommittee on

Health.<sup>17</sup> Dr Schrier was interested in hearing about the Australian committee system, the way preselection occurs for Senators in Australia and the work of the Community Affairs committees. The delegation talked about the committee inquiry process and reflected on the importance of aiming to reach consensus, especially when inquiring into policy matters related to health. The delegation gave as examples of a bipartisan approach to health issues its recent work on rare cancers and menopause. The meeting was also an opportunity to have discussions about the COVID-19 responses in both countries and the current issues relating to abortion rights in the USA.





Delegation meeting with Dr Kim Schrier

#### Office of Senator Bernie Sanders

The delegation met with the senior advisers to Senator Bernie Sanders, Chair of the Senate Committee on Health, Education, Labor & Pensions. Senator Sanders' advisers were interested to hear about the inquiry into menopause and perimenopause and more broadly about Australia's reproductive health policies. The discussions then focused on research, development and access to medicines. The delegation was interested to hear more about the 21st Century Cures Act 2016 (the Act), which has helped fund many of the initiatives discussed during the earlier meetings with the NCI, MSK and Project Lyme. The Act was designed to help accelerate medical product development and bring new innovations and advances to patients who need them faster and more efficiently. It comprises provisions for research and development in relation to mental health and

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<sup>&</sup>lt;sup>17</sup> For further information about the committee and its work, see, <u>Committee on Energy and Commerce</u> (accessed 6 January 2025)

<sup>&</sup>lt;sup>18</sup> For further information, see, <u>Public Law 114–255</u> (accessed 6 January 2025)

substance disorder, precision medicine and vaccines. Finally, the discussions turned to health workforce and aged care workforce issues in both countries.

## D.C. Policy Center

The delegation met with representatives of the D.C. Policy Center (D.C. Center); a think tank dedicated to the development of local public policy in the context of the District of Columbia (DC). The meeting focused on housing policies. As background and to open the discussion, the delegation spoke about the current housing crisis in Australia. D.C. Center staff explained how affordability remains a live issue for renters in DC. Recent D.C. Center's work on housing policies includes creating an affordable housing model for essential workers in DC with applications across the US, a study on the impacts of rent control, and the review of the Tenant Opportunity to Purchase Act (TOPA).

The proposed D.C. Center affordable housing model is based on inclusionary conversions where a portion of existing units are converted into affordable units for workers making less than the area median income through a small private-sector subsidy. <sup>19</sup> The delegation was particularly interested in the study of rent controls in DC. DC rent control laws date back to 1973 and have been amended over time to allow some flexibility for increases if capital improvements are undertaken. According to the D.C. Center study, rent controls as a single measure to create affordability is not sufficient. As such, D.C. Center is of the view that the city should make it easier and more attractive for investors to build new rental units.

In relation to TOPA laws, the delegation learned that these laws exist in Washington D.C., San Francisco, Minneapolis (and a few other places). It gives tenants the right to make the first offer on their building if the landlord decides to sell it. In municipalities that adopt TOPA, multi-family property owners notify tenants and the municipality when they decide to sell a property. Tenants can form a tenant association, made up of tenants in at least 51 percent of the tenant-occupied units. The tenant association can designate its rights to a non-profit organisation or local housing authority, or partner with an affordable housing purchaser. TOPA neither brings in additional revenue nor requires additional expenditures. It allows municipalities to adopt tenant right-of-first-refusal ordinances. D.C. Center has started some work on the intent, impact, and future of TOPA, with recommendations for reform.<sup>20</sup>

<sup>20</sup> For more information on D.C. Policy Center research agenda, see, Housing (accessed 6 January 2025).

<sup>&</sup>lt;sup>19</sup> For more information, see, Housing for workforce (accessed 6 January 2025).

#### Office of Science and Technology Policy - White House Cancer Moonshot

The delegation went to the White House to meet with Dr Catharine Young, Assistant Director of Cancer Moonshot Policy and International Engagement. Dr Young provided some background information on Cancer Moonshot and then, explained some of the international initiatives underway involving Australia. Launched in 2016, the Cancer Moonshot is a White House initiative to accelerate cancer research, foster greater collaboration, and improve the sharing of cancer data. It was paused during President Trump's first term in office and reignited by President Biden in 2022. The Cancer Moonshot initiatives are funded through the 21st Century Cures Act 2016, public-private partnerships, and philanthropy.

The mission is to reduce the deadly impact of cancer and improve patient experiences in the diagnosis, treatment, and survival of cancer. Dr Young described the Cancer Moonshot's goal as to 'end cancer as we know it'. Dr Young emphasised that improving the lived experience of patients, their families and loved ones is a fundamental driver of Cancer Moonshot. Since 2016, Cancer Moonshot has enabled progress in key areas, including immunotherapy treatment, childhood cancer research, mapping tumors, expanding cancer prevention and early detection, engaging with patients, addressing drug resistance, collection and sharing of cancer data and collaboration and outreach.

The delegation was interested in the Cancer Moonshot initiatives involving Australia. Dr Young talked about the engagement of US Ambassador Caroline Kennedy in fostering the US-Australia Cancer Moonshot collaborations. A major collaboration is the Quad Cancer Moonshot initiative between Australia, USA, India and Japan to prevent cervical cancer (was launched in September 2024). Australia's contribution is to expand the HPV vaccine immunisation programs in Papua New Guinea, Malaysia, Timor-Leste, Solomon Islands, Vanuatu, Tuvalu, Fiji, Nauru and beyond. The contribution from Australia is a public-private partnership between the Australian Government and the Minderoo Foundation.

The meeting was also an opportunity to reflect on the challenges to access diagnosis and treatment for people living in rural and remote areas. Dr Young indicated that there was currently a range of initiatives in the USA aimed at increasing the use of telehealth.

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<sup>&</sup>lt;sup>21</sup> U.S. Embassy & Consulates in Australia, <u>U.S.-Australia Cancer Moonshot initiative</u> (accessed 7 January 2025).

<sup>&</sup>lt;sup>22</sup> Minderoo foundation, Media release, 21 September 2024 (accessed 7 January 2025).

#### **Arlington County Board**

The last meeting of the delegation was with Libby Garvey, Chair of the Arlington Country Board and board member Takis Karantonis. The topic for discussion was Arlington County's housing policy and programs. Arlington is an urban county in Virginia located directly across the Potomac River from Washington DC. It has become a town mainly of government workers. It is also home to Nestlé USA and Amazon headquarters. The existing zoning laws dating back from the 1930s and the expansion of Arlington after World War II created housing supply issues. In 2020, the County began its Missing Middle Housing Study (MMHS) to explore how to increase housing supply and diversify its range of housing choices. This resulted in amendments to zoning laws, which excluded multi-family buildings or townhouses on nearly half of the land.<sup>23</sup>

The Chair of the Arlington Country Board also talked about the Crystal House Apartments project (Pentagon City), which will have 655 additional committed affordable units when fully built out. The County went through a competitive process to select a developer for the site and has signed with APAH (now called True Ground Housing Partners), an NFP developer.<sup>24</sup> The first phase of construction is currently underway. The delegation noted the prominent role of partnerships with the NFP sector and/or large companies such as Amazon to build affordable housing across the county.

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<sup>&</sup>lt;sup>23</sup> In March 2023, the County adopted expanded housing options to allow to build duplexes, semi-detached, sets of 3 townhouses, and small multiple-family buildings with a maximum of six units. However, this has been challenged by some residents in court. In September 2024, the court overturned the Alington Board's adoption of the Expanded Housing Options zoning amendments. In November 2024, the County Board voted to appeal this ruling. At the time of writing, there has not been further ruling on the matter.

<sup>&</sup>lt;sup>24</sup> For further information about True Ground Partners' initiatives and housing models, see, <u>True Ground Housing Partners</u> (accessed 7 January 2025)