

# The Autoimmune Blistering Diseases in Australia: Status and Services

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## KEYWORDS

- Autoimmune blistering diseases • Pemphigus
- Bullous pemphigoid

The term autoimmune bullous disease (AIBD) refers to a heterogeneous group of blistering conditions with varying rates of mortality and morbidity. A strong genetic component is proposed, supported by differing prevalence rates between countries. Australia, the smallest continent and the sixth largest country, has a population of just more than 22 million people,<sup>1</sup> with the majority living in the eight major state and territory capitals of Canberra, Sydney, Melbourne, Brisbane, Perth, Adelaide, Hobart, and Darwin (Fig. 1).

In 2008, there were more than 78,900 registered medical practitioners in Australia, with more working in major cities than rural and remote areas.<sup>2</sup> A shortage of rural doctors has resulted in reduced facilities and services to the rural and remote areas. To counter this, the various federal governments have developed programs and incentives to recruit, relocate, and maintain health practitioners in rural and remote locations. These issues now influence medical student selection, specialty training, and salaries.<sup>3,4</sup> Most, if not all, medical practitioners in Australia have had some exposure to rural locations as part of their career. Technological advances have recently been used to deliver

health care to rural areas. Teledermatology in Australia was first reported in 1999<sup>5</sup> and its use has increased owing to an expansion of technology and commonwealth funding.<sup>6</sup> Despite the paucity of published reports regarding the diagnosis of blistering diseases with teledermatology,<sup>7</sup> its use in Australia is promising for the provision of dermatologic services to patients in rural locations without access to a dermatologist.

There are more than 130 Aboriginal and Torres Strait islander doctors in Australia<sup>8</sup> treating indigenous and nonindigenous patients. There is marked inequality between indigenous and nonindigenous health in both rural and urban areas, sparking a recent commitment from the commonwealth government to increase funding and introduce measures to close the life-expectancy gap between the two groups.<sup>9</sup> The true incidence of AIBD amongst Aboriginal Australians is unknown, probably owing to isolation, itinerant lifestyles, lack of facilities, and cultural differences. Only one reported case of bullous pemphigoid has been reported in an Aboriginal Australian, though it is likely there are many others with an AIBD who have not been diagnosed.<sup>10</sup>

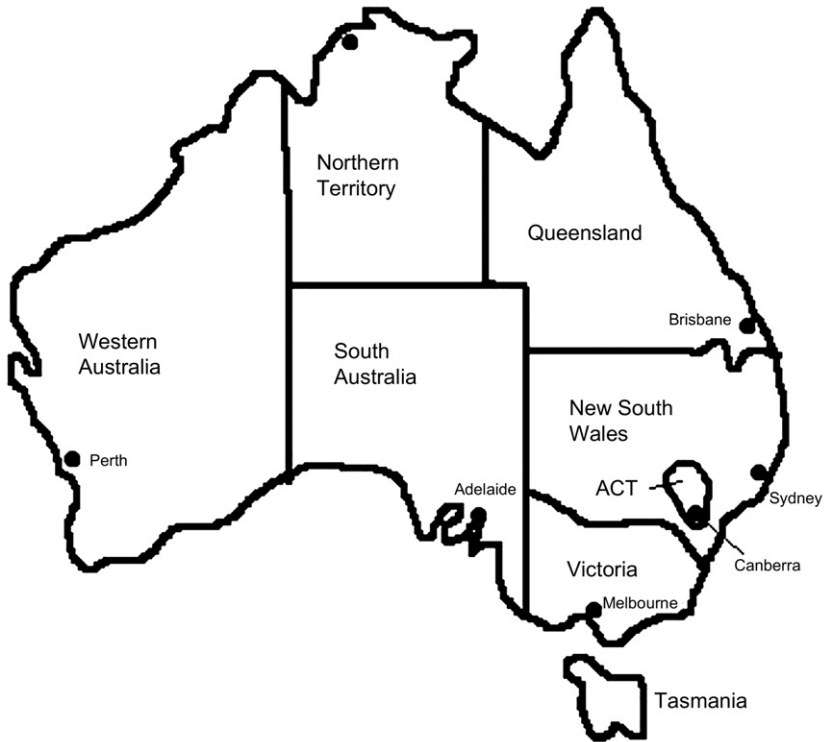
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**Fig. 1.** Australia, the smallest continent and the sixth largest country.

### AIBD REGISTRY

Because of limited data about AIBD in Australia, a registry has been set up to determine the frequency, mortality, and associated conditions. It is expected the registry will aid research in Australia by providing epidemiologic data, as well as by maintaining an up-to-date database with patient contact details.

The main purpose of a medical registry is to collect and categorize extensive amounts of data and information about a disease. The data can then be analyzed to facilitate research into the cause, pathogenesis, and prognosis of a disease. Registries play a significant role in the advancement of research in rare diseases such as AIBD by creating a greater awareness of the disease as well as providing an acceptable means to approach government and other institutions for financial and social aid.<sup>11</sup> In general, registries are either hospital-based or population-based.<sup>12</sup> Hospital-based registries gather information about patients who have attended a hospital. The AIBD registry in Australia is based on the Australian Epidermolysis Bullosa Registry, which was developed in 2006.<sup>13</sup> Ethical approval for the development and maintenance of a registry for AIBD was obtained in 2008. Patients with an AIBD are invited

to participate in this registry. Participation involves providing their names, contact details, and medical history, as well as giving permission to access their medical records from hospitals or other clinicians. This permission is vital in confirming the diagnosis, assessing the incidence of disease, and investigating the cause and potential triggers. The registry allocates each patient a registry number so that he or she becomes de-identified for research purposes. Audits of the registry are regularly performed to identify inappropriate collection methods and ensure reliable data.<sup>14</sup>

Most patients in the Australian AIBD registry are recruited from the practices of dermatologists in Australia. The practice of Professor Dédée F. Murrell, situated in Sydney since 1996, has provided the most patients to date. This practice has a specialist bullous clinic treating patients from all of Australia. Other dermatologists who have interests in AIBD and have contributed to the registry include Drs Belinda Welsh, Christopher McCormack, and George Varigos, all from Melbourne, Victoria, about 850 km from Sydney. It is the authors' intention to publish more extensively when there are a sufficient number of patients included because, currently, the AIBD registry includes only 37 patients.

The Australasian College of Dermatologists (ACD), ([www.dermcoll.asn.au/](http://www.dermcoll.asn.au/)) is the professional

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