

In terms of monitoring, the regional registers provide valuable information on the incidence and prevalence of the diseases, which is necessary to determine the extent of the problem, as well as monitoring progress on addressing the situation. It is the monitoring function of the registers that is the focus of this bulletin.

A rheumatic heart disease control program was established in the Top End of the Northern Territory in late 1997. In 2000, the program was extended to cover people living in Central Australia and was fully operational in mid 2002 (DHA 2003). Geographically, the Top End program covers the northern part of the Northern Territory including coastal and island communities and deep into the desert bordering Western Australia. It includes the Darwin urban area and three health regions: Darwin Remote, Katherine and East Arnhem. The Central Australian program covers a large area of the Northern Territory, including Alice Springs and Barkly Regions, the Anangu-Pitjantjatjara lands in South Australia, the Ngaanyatjarra lands in Western Australia, and extends to the Queensland border (CARHDSC 2002). It does not extend to the Kimberley or Pilbara regions of Western Australia. Together the two programs cover a population of over 200,000 people.

# What the Top End and Central Australian registers tell us about incidence and prevalence

The registers collect data related to diagnosis, hospitalisations, compliance with preventive penicillin use, clinical progress, surgery and mortality (CARHDSC 2002). This information assists clinics in managing the care of people registered with the rheumatic heart disease programs.

## Incidence of acute rheumatic fever

Acute rheumatic fever is frequently under-reported because of difficulty in diagnosis and reduced awareness of the disease—therefore its true incidence is underestimated. The peak age of incidence of acute rheumatic fever is 5–14 years, but cases do occur in adults. The disease is rare in children under four years of age.

Incidence, as it is reported here from data provided by the registers, includes new and recurrent $^2$  cases.

In 2002, 58 people were diagnosed with acute rheumatic fever in the Top End of the Northern Territory—all were Australian Aboriginals, and females accounted for just over two-thirds of identified cases. Most cases (83%) were hospitalised and about a third of these (35%) were for recurrences. Aboriginal children aged 5–14 years accounted for 32 cases of acute rheumatic fever (55%)—a rate of 346 per 100,000 in this population. There were no reported cases of acute rheumatic fever among non-Indigenous children living in the area.

Data from Central Australia present a similar picture. In 2002, there were 27 cases of acute rheumatic fever. Of these, 30% (8 cases) were recurrences. The highest incidence rates were found in the 5–14 year age group (365 per 100,000).

<sup>2</sup> A recurrence is defined as a repeat episode of acute rheumatic fever three months or more after the last episode.

## Trends in incidence of acute rheumatic fever

Between 1989–93 and 1998–02, the incidence of acute rheumatic fever in Indigenous children aged 5–14 years in the Top End of the Northern Territory remained relatively stable with rates around 250 per 100,000 (Table 1). Falls in recurrence rates from about 40% in 1987–96 to 16% of all episodes in the late 1990s were also observed (Couzos & Carapetis 2003).

By contrast, the incidence of acute rheumatic fever in Central Australia increased with rates on average around 250 per 100,000 in the mid 1990s rising to an average annual rate of about 350 per 100,000 in 1998–02 (Table 1). In Central Australia, there was a recorded increase in incidence among 15–24 year olds over this period, rising from 83 per 100,000 in 1995 to 187 per 100,000 in 2002. In Central Australia, between 1995 and 2002, recurrences accounted for between 23% and nearly 60% of all cases of acute rheumatic fever. More importantly, before the program began in this region (pre-2001), recurrences accounted for 40% of cases on average, but these had fallen to 26% in 2001–02 (CARHDSC 2002).

These trends need to be interpreted with caution, however. For example, in the Top End, the population estimates for Indigenous children increased dramatically (by more than 25%) in the last ten years. So although the average number of new cases over this period has increased, the age-specific incidence has remained relatively stable. In Central Australia, apparent increases in incidence may simply reflect better reporting to the register, which was quite low in the early years (less than 50% of cases), but was estimated to be nearly 90% in 2001–02 (CARHDSC 2002).

	Top End		Cen	Central Australia <sup>(b)</sup>	
Year	Number	A ge-specific rate <sup>(c)</sup>	Number	Age-specific rate <sup>(c)</sup>	
1989–93	91	<b>254</b> <sup>(d)</sup>	n.a.	n.a.	
1994	18	204	n.a.	n.a.	
1995	13	148	8	198	
1996	21	238	13	319	
1997	14	159	9	222	
1998	24	270	12	295	
1999	23	254	18	440	
2000	14	154	16	388	
2001	19	210	11	265	
2002	32	346	15	365	
1998–02	112	245	72	351	

# Table 1: Incidence<sup>(4)</sup> of acute rheumatic fever among Aboriginal and Torres Strait Islander children aged 5-14 years in the Top End of the North em Terr i toryand in Central Australia, 1989-2002

n.a. Not available. (Acute rheumatic fever was added to the list of notifiable diseases in the Northem Territory in 1995, so notifications in Central Australia were not available before this time).

(a) Includes new and recurrent cases of acute rheumatic fever.

(b) Excludes those cases from South Australia and Western Australia that are serviced by the Alice Springs hospital, because of difficulties ascertaining denominator populations over time.

(c) Rate per 100,000 Indigenous children aged 5-14 years in each region.

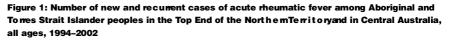
(d) Carapetis et al. (1996).

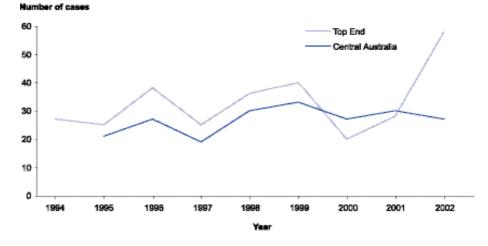
Sources: Top End Rheumatic Heart Disease Register and the Central Australian Rheumatic Heart Disease Register.



# Rheumatic heart disease

Assessing trends in the incidence of acute rheumatic fever is also hindered by the variability in the number of new and recurrent cases from one year to the next (Figure 1). For example, in the Top End between 2001 and 2002 the number of cases nearly doubled (from 28 to 58) whereas between 1999 and 2000 the number of cases halved (from 40 to 20). To date, the number of new and recurrent cases has been less variable in Central Australia, but the numbers are too small and inconsistent to assess trends.





Sources: Top End Rheumatic Heart Disease Register and the Central Australian Rheumatic Heart Disease Register.

## Prevalence of rheumatic heart disease

In 2002, there were 696 people with rheumatic heart disease in the Top End of the Northern Territory; 92% of these were Aboriginal and Torres Strait Islander peoples (643 cases). About twice as many cases were females (65%) compared with males (35%). Rheumatic heart disease was present in 54 children aged 5–14 (8% of all cases), all of whom were Indigenous Australians. Overall, the prevalence of rheumatic heart disease among Aboriginal and Torres Strait Islander peoples in the Top End was 17 per 1,000 in 2002, but rates were highest among 25–44 year olds where nearly 3% of the Indigenous Australian population in this age group is affected by the disease (Table 2).

In 2002, there were 283 cases of rheumatic heart disease in Central Australia. Of these, 267 cases (94%) were reported by Aboriginal and Torres Strait Islander peoples. This represents a prevalence rate of around 13 per 1,000 among Indigenous Australians compared with less than one per 1,000 among other Australians. Over two-thirds of cases of rheumatic heart disease in Central Australia were in the 15–44 year age group. The highest prevalence occurred among 15–24-year-old Aboriginal and Torres Strait Islander peoples (19 per 1,000, or almost 2% of this population) (Table 2).

	Top End		Cent	Central Australia	
A ge (years)	Indigenous Australians	Other Australians	Indigenous Australians	Other Australians	
5–14	5.8	0.2	7.6	0.0	
15–24	19.8	0.3	18.6	0.5	
25–44	29.4	0.8	15.8	0.4	
45+	18.6	0.8	14.9	1.4	
Total	16.6	1.7	12.5	0.6	

Table 2: Prevalence<sup>(a)</sup> of rheumatic heart disease in the Top End of the NorthemTerritoryand in Central Australia, 2002

(a) Per 1,000 population in each region.

Sources: Top End Rheumatic Heart Disease Register and the Central Australian Rheumatic Heart Disease Register.

#### Trends in prevalence of rheumatic heart disease

Despite a stabilising of trends in the incidence of acute rheumatic fever in the Top End of the Northern Territory, the reported prevalence of chronic rheumatic heart disease continues to increase. In 2002, there were 17 cases per 1,000 Indigenous Australians, compared with nine per 1,000 in 1995. This increase is likely to be due to an improvement in reporting and case finding, and better awareness of the condition and its symptoms, rather than an actual rise in the number of cases.

It is too early to assess trends from the Central Australian register.

# National data on acute rheumatic fever and rheumatic heart disease

#### Hospitalisation

Acute rheumatic fever is a serious disease and usually requires hospitalisation. Richmond & Harris (1998) reported hospitalisation rates in the Kimberley region of Western Australia as high as 80% for new cases of acute rheumatic fever and 73% for recurrences. In the Northern Territory, it is recommended that all cases of acute rheumatic fever be hospitalised for proper assessment.

Reflecting the incidence and prevalence of acute rheumatic fever and rheumatic heart disease obtained from the Top End of the Northern Territory and the Central Australian registers, the national hospitalisation rate for these diseases is much higher among Indigenous Australian males and females than among other Australians (Table 3). In 2001–02, the rate of hospitalisation for acute rheumatic fever and rheumatic heart disease among Indigenous Australian males was six times as high, and among Indigenous Australian females was eight times as high, as the rates among other Australians. These rate ratios were substantially higher than for other cardiovascular diseases.

In 2001–02, there were 341 hospitalisations in Australia for either acute rheumatic fever or rheumatic heart disease among those identified as Indigenous. This represents 15% of all hospitalisations for these diseases. The remaining 85% are likely to be for treatment of rheumatic heart disease among other Australians. These data cannot separate initial and subsequent hospitalisations for the same individual.