

SNUG camps for children affected by rare diseases: A dose of respite
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SNUG camps are for families of children with special needs and their families from rural NSW. The camps offer families the opportunity to access dental and other medical services (if needed), to enjoy time together as a family, to meet other families with similar experiences and to receive some respite from the challenges of their daily lives. To date there have been 5 camps attended by 30 children with special needs from 24 families, 33 siblings and 33 carers (including 7 grandparents and 5 foster/adoptive parents).

The evaluation of the camp indicates that the camps are fulfilling a need and are making a difference to families. Surveys completed by parents at camps 3-5 showed that:

- 90% strongly agreed the camps were a very worthwhile experience for them
- 95% strongly agreed they would recommend the camps to other families
- 80% strongly agreed the camps allowed their family to access health (mainly dental) services they would otherwise not have been able to access
- 79% strongly agreed the camps were beneficial for themselves
- 63% strongly agreed the camps were beneficial for their child with special needs
- 88% strongly agreed the camps were beneficial for their other children
- 80% strongly agreed the camps were beneficial for their family as a whole

Follow up six months after the first two camps suggest that some families have been able to use the information they gained from other parents at the camp (e.g., to access new resources, to gain confidence in dealing with health services) and that the families have continued to appreciate the respite and strengthening of family connects that occurred at the camp.

It is intended that families camp together with the same families every two years and it is hoped that this will help build the connection felt between the families.

By providing opportunities for university students to volunteer at the camps, SNUG is also providing students from a range of disciplines with a better understanding of issues faced by rural families living with a child with special needs.

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