

# Our achievements over 40 years

## This Year

- Produced *In Safe Hands* - new educational resources for parents and teachers of school-age children living with TSC.
- Presented a two-day virtual Conference for the TSC Community and Health Care Professionals.
- Hosted 7 Zoom Education Events on a diverse range of TSC-related topics.
- Took Comedy for a Cure online, raising funds and providing great entertainment for families during the global pandemic.

## The 2020s

- Provided one-on-one support to our TSC Community via our new TSA Nurse Service.
- Pioneered publication of *Research Round Up* a quarterly newsletter focused on TSC-related research.
- Parachute Packs* launched - new resources to better inform individuals, families and health professionals at the time of a new or suspected TSC diagnosis.
- Comedy for a Cure fundraiser came to Sydney for the first time.
- Supported our TSC Community during the COVID-19 global pandemic.

TSA funded the first Australian genetics research project providing genetic testing for TSC.

Expanded peer support through production of film 'You Are Not Alone' telling the stories of four Australian families living with TSC.

Hosted the first combined conference for Australian health professionals and TSC families.

## The 2000s

## The 2010s

Successfully advocated for TSC medicines to be included on the Australian Pharmaceutical Benefits Scheme (PBS).

Provided over \$200,000 for a clinical trial of a cream to treat and prevent TSC skin tumours.

Connections made through TSA's work led to Australian researchers and patients being part of international clinical trials into new treatments for brain tumours, epilepsy, autism and developmental delays.

Published TSC Information pages giving people in Australia free access to up to date and accurate TSC information.

Expanded access to our education events through webinars and conferences in Brisbane, Perth, Melbourne and New Zealand.

Hosted the first TSC Connect event for adults living with TSC.

## The 1980s

- TSA founded as the Australasian Tuberous Sclerosis Society.
- First issue of *Reach Out* published.
- Launched social picnics for families.
- First family conference.

- National roadshow in 3 Australian cities.
- Leaders in the establishment of TSC International.
- TSA's advocacy led to the first Australian TSC multidisciplinary clinic at Sydney Children's Hospital, bringing together specialists from different disciplines to provide a whole patient approach to medical care.

## The 1990s