

# Rett Syndrome Association of Australia Inc.

31st Annual General Meeting

2019 - 2020

**Saturday 31 October 2020**

**Via Zoom video conferencing.**

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**2019/2020 Annual General Meeting**



Date: Saturday 31 October 2020  
Time: 4pm (Australian Eastern Daylight Time)  
Method: Zoom video phone conferencing.

**Agenda**

1. Welcome.
2. Apologies received.
3. Receive and approve the minutes of the 2018/2019 annual general meeting which was held in Adelaide on Saturday 26 October 2019.
4. RSAA President's report.
5. RSAA Treasurer's statement of the Association's financial status and remote tabling of relevant documents.
6. Receipt of nominations from those persons wishing to serve on the RSAA Committee during 2020/21, followed by the election of its members, if required, and appointment of the Executive officers. The composition of the Committee during 2019/20 was as follows:

*Executive officers:*

President	Claude Buda (NSW)
Vice-President	Bill Callaghan (VIC)
Secretary	Dagmar Lockwood (SA)
Treasurer	Tony Cagliuso (SA)

*Other members:*

Sue Hallenstein (VIC), Family support co-ordinator	Kristy Klingner (SA)
Jayne Bowden (TAS)	Mary-Anne Rome (VIC)
Liz Davies (VIC)	Georgia White (NSW).
Caroline Dempster (WA)	
Olivia Gowans (SA)	
Eric Gowans (SA)	

7. Confirm or vary the amount of the RSAA membership fee which is presently \$35 for 1 year or \$90 for 3 consecutive years.
8. Resolution (s), if any.
9. Appointment of auditor (s).

## Introduction

It is my privilege, on behalf of the RSAA Committee, to present the Association's annual report for 2019/20. We felt that this period would be particularly challenging as our efforts to have drug trials conducted in Australia as well as staging the 2020 World Rett Syndrome Congress, were going to go up a notch or two. The challenges did come with the main one being totally unexpected and far-reaching.

## Administration

The Association continued having two Committees in place, one which dealt with day to day management; the other, with organisation of the World Congress. Each Committee met over the phone at least once a month. On behalf of all those involved with RSAA, I thank each Committee member for their support and for what they gave of themselves to others, during 2019/20.

## Clinical drug trials

An essential element to having pharmaceutical companies conduct Rett syndrome drug trials in Australia was frequent communications between RSAA and the pharmaceutical company concerned, Anavex Life Sciences Corporation (New York, USA), those hospitals which would manage the trial, and Australian Rett syndrome families. Also important from the Association's perspective, was that it could play an active role in assisting participating families with travel and accommodation. The process, although lengthy, had a successful outcome when Anavex decided it would conduct a trial of the drug Anavex 2-73 in Australia.

The Alfred Hospital (Melbourne) was the first Australian medical institution to be involved in the trial, with the Rett syndrome participants being aged 18 years and over. Over time, two more trial centres were established, one being at the Queensland Children's Hospital (Brisbane), the other at the Children's Hospital at Westmead (Sydney), with the participants of each being Rett syndrome individuals aged 17 years and under.

The publicity associated with the Australian trial has probably been influential in more expressions of interest being received by RSAA from other pharmaceutical companies looking at the possibilities of conducting drug trials here.

*At right: 5 year old Sofia Mironov from Canberra, is pictured receiving her first dose, be it Anavex 2-73 or a placebo, at the Children's Hospital at Westmead. Her mother, Monika, can be seen in the centre of the photo.*



## Rett syndrome research involving RSAA (excluding drug trials)

Following discussions with Newron Pharmaceuticals S.p.A., a biopharmaceutical company whose head office is located in Milan, Italy, RSAA was able to gain Australian participation in the first-ever international Rett syndrome 'Burden of Illness' survey which the company is sponsoring, along with participants in the US, UK, Germany and Italy. The survey is seeking input on the physical, emotional and financial challenges of Rett syndrome on patients, their families, caregivers and others.

In January 2018, the Association donated \$10,000 to Dr Wendy Gold (Kids Research Institute, Westmead) to kick start her study centred on "Developing gene correction therapy to treat Rett syndrome". On his own initiative, Brett Anslow (Sydney), father of 7 year Holly who has the syndrome, has been instrumental in taking support for the study significantly further in terms of the ongoing financial assistance it is receiving and increased Rett syndrome awareness. RSAA is very appreciative of his efforts.

### 9<sup>th</sup> World Rett Syndrome Congress

At beginning of March this year, our preparations for the World Congress were well advanced -

The venue in Surfers Paradise was locked in, accommodation could be booked

A website specific to the Congress was in place

Online registration was possible

An abstract submission facility, also online, was nearing completion

A third Congress update had been circulated worldwide

30 international and local presenters had accepted our invitations to speak, with more under consideration.



*Representing RSAA at the Rett Syndrome Europe Congress in Tampere, Finland, September 2019*

However, by the end of the month, we had made the decision to postpone the Congress for 12 months because of the impact that the COVID-19 pandemic was having worldwide. The likelihood of holding this event in Australia in the near future, or elsewhere for that matter, is still uncertain at present.

Positives that have resulted from the efforts made so far by our Association, have included -

The focus given to Rett syndrome in Australia and the research being conducted here

The machinery that is necessary in organising a Congress eg., website, online registration, etc., can be utilised by a national Rett syndrome Association should one wish to stage a future Congress

Being in communication with leading scientists in the field of Rett syndrome research such as Huda Zoghbi (USA), Sir Adrian Bird (Scotland), Janine LaSalle (USA), Alan Percy (USA), Nicoletta Landsberger (Italy), and from Australia, John Christodoulou and Helen Leonard; other specialists on the syndrome such as Susan Norwell (USA), Kathy Hunter (USA), Helena Wandin (Sweden) and Meir Lotan (Israel); and representatives from several pharmaceutical companies interested in participating.

### Liaison

RSAA concentrated heavily on alerting those persons/organisations involved with Rett syndrome who were located outside Australia, about the Congress. In addition, we reinforced existing relationships and established new ones at conferences held in Vienna (2016), Berlin (2017), Rome (2018), and more recently, Houston and Tampere.

Last October, Committee member, Eric Gowans, flew direct to Houston from Adelaide via Sydney, an arduous trip to say the least, to attend the Rett Syndrome Symposium in Houston which was hosted by scientists Huda Zoghbi and Adrian Bird. A few weeks earlier, I had flown to Finland to attend the 6<sup>th</sup> Rett Syndrome Europe Congress in Tampere, attendees at which, appear below.



### Liaison (cont.)

Unrelated to the Congress but another instance of liaison, was the agreement made between RSAA and the RettUK Association to share information resources when required.

### Support

The Association is extremely grateful for all the financial support that we have received over the past 12 months, be it from memberships, donations with Anavex Life Science Corporation being our major donor, and from fundraising activities. The latter included the 'Rett Syndrome Awareness Cup' organised by Valley Vicious in Victoria Lee Lawrence; a trivia night put on by the Kelly family and friends at the Toowoomba Bowling Club; a sell-out masquerade ball which took place in Adelaide and managed by Committee members Olivia Gowans, Kristy Klingner, Karen Rodda, Kirsty Sale and Dagmar Lockwood.

We are also very thankful for the assistance provided by Gary Grocott (Sydney) in the development of the Congress website <https://rettworldcongress.org/> and with the revamping of our Association's site <https://rettaustralia.org.au/>. Gary's 5 year old granddaughter, Daisy Bradbury, has Rett syndrome.

### In conclusion

While things didn't exactly turn out the way RSAA wanted them to during 2019/20 as a result of the COVID-19 pandemic in having to postpone the Congress, we still managed to play an important role in enabling drug trials, specific to Rett syndrome, to take place in Australia; informing families about them and providing direct assistance to those who participated.

Thank you to the members of the RSAA Committee, its Congress sub-Committee and its international non-scientific Congress panel, for their involvement, and to all those who supported the Association during the year and previously. RSAA will continue to do those things it feels will be of benefit to Australian Rett syndrome families and others, as well as investigate new initiatives which we feel might be beneficial for them.

Claude Buda

President

31 October 2020.

### Members of the RSAA Committee - 2019/20

#### Executive

Claude Buda (NSW) - President

Bill Callaghan (VIC) - Vice President

Dagmar Lockwood (SA) - Secretary

Tony Cagliuso (SA) - Treasurer

#### Relationship to Rett syndrome

Annelise's father

Joanne's father

Madeleine's mother

Raquelle's father.

#### Other members:

Sue Hallenstein (VIC)

Jayne Bowden (TAS)

Liz Davies (VIC)

Caroline Dempster (WA)

Olivia Gowans (SA)

Eric Gowans (SA)

Kristy Klingner (SA)

Mary-Anne Rome (VIC)

Georgia White (NSW)

May's mother

Jessica's mother

Alana's mother

Charlotte's mother

Greta's mother

Greta's grandfather

Lilly's mother

Jacinta's mother

Rose's mother.

### Members of the RSAA World Congress sub Committee - 2019/20

Sue Birch (WA) - Melanie's mother

Claude Buda (NSW)

Bill Callaghan (VIC)

Caroline Dempster (WA)

Kathy Stothart (QLD) - Anita's mother.

Gary Grocott (NSW) - Daisy's grandfather

Sue Hallenstein (VIC)

Dagmar Lockwood (SA)

Tony Cagliuso (SA)

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## **2019-2020 Rett Syndrome Association of Australia Financial Report**

### **Revenue:**

- Total Revenue for the 2019-2020 financial year of \$347,091.13,

The majority of this revenue came from 3 income streams

- **Membership** of \$7,418.38 more than double the previous year's membership income, the huge increase is mainly due to the fact that majority of new memberships and membership renewals were taken up for the 3 year rate of \$90.00.

RSAA had a membership of 113 members for 2019-2020

- **Donations** of \$241,104.22 up approx. 68% on the previous year
  - Everyday Hero, Go Fund Me, My Giving Circle & My Cause continue to be very good Fundraising streams for RSAA with the majority of donations coming from these sources are generally for around \$100 or less.
  - Pay pal is used extensively by donors to process payments.
  - 31 donations for varying amounts of between \$1,000 & \$5,000, mainly from individuals and businesses, or from fundraising activities held on behalf of RSAA.
  - 3 donations of between \$5,000 & \$10,000
  - A donation of \$25,000 from the Valley Vicious Football Club
  - 3 donations of amounts between \$25,000 & \$50,000
- **Adelaide Gala Ball** made a profit of \$57,097.81 for RSAA.

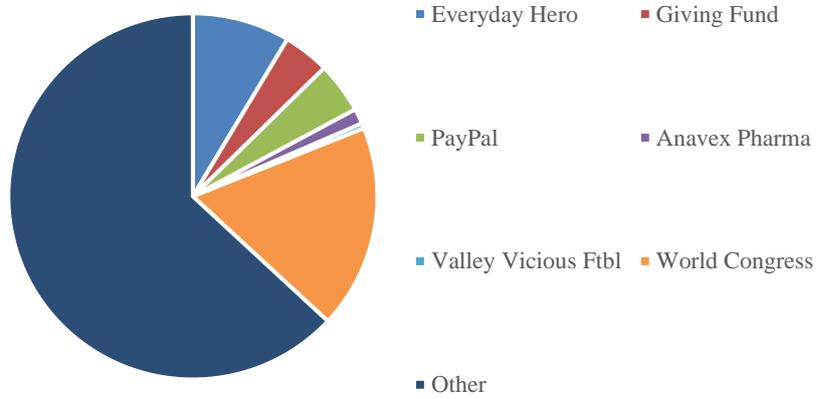
Social media is again proving to be a fantastic avenue of fundraising for our association, social media based platforms give Rett Syndrome good exposure and promote fundraising events.

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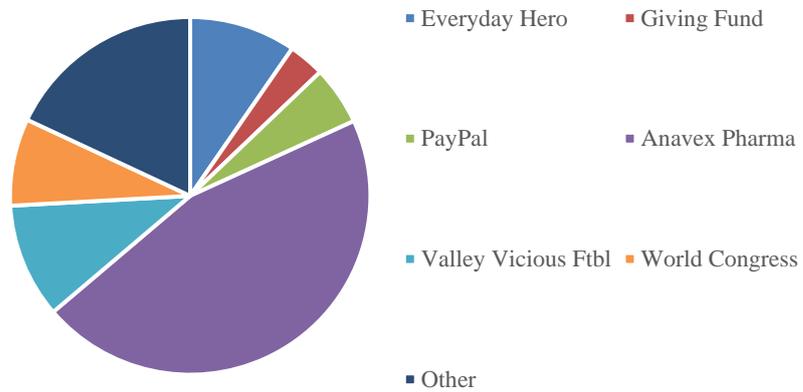
### **Expenditure:**

- Total expenditure of \$171,502.03. Some of the major expenses were;
  - \$81,837.61 Clinical Drug Trials,
  - \$37,614.55 for RSAA member events,
  - \$9,764.07 RSAA & Congress Website developments,

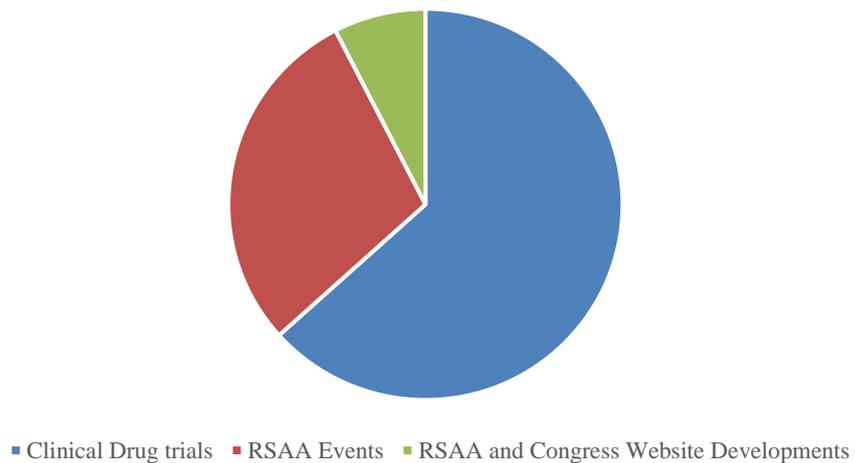
### Number of Donations Transactions



### \$ Value of Donations



### Expenditure



**Auditors statement**

**Balance Sheet**

**P & L**

**To be added asap soon as it arrivesback from auditor**

