



Annual Report

Autism Parents Association

Year ending 31 December 2021

Introduction

This Annual Report covers the period 1 January 2021 to 31 December 2021

For a second year, the Covid pandemic created significant education and working problems for people on the spectrum and their families. People experienced a huge blow to their mental wellbeing. Autism Parents Association (APA) committee members continue to be impacted in the same way with additional demands from their employers.

Despite the huge toll of the pandemic APA continued to support its members and initiated some key projects.

How our key initiatives were met over the period:

- ❖ The number official paid memberships in 2021 are 70 families, this is an increase of 53 members from 2020. The number of non paid memberships are in the year 2021 are 321.
- ❖ The total number of people registered on our closed Facebook support page is 1,832, an increase of 83 people.
- ❖ Escalated serious concerns on the mental health of autistic people who had to quarantine due to covid to the Ministry of Health
- ❖ Attended The Meeting Place Playground initiative for children with autism in collaboration with the Marigold Foundation. Launched 5th August.
- ❖ 2 Summer Sea inflatable social activities in collaboration with Quattro Water Park Bugibba in Summer 2021
- ❖ 6 social activities at Bugibba Water Park in collaboration with Parcs Malta in summer 2021
- ❖ Christmas Party held at The Club Arena
- ❖ Continuance of the service of our Parent Support Agents.
- ❖ Continuance of counselling service via an agreement with the university of Malta. This provision is available to paid members.
- ❖ Continuance Autism Community Library to APA paid members
- ❖ Collaboration on Autism Friendly Spaces to companies with Prisms Malta
- ❖ Active board members of the Malta Autism Advisory Council, under the remit of the Ministry of Wellbeing and Social Inclusion.
- ❖ Continued collaboration with The Club fitness centre to provide free sessions for paid APA members.

The Board of Administrators

During this period the administrators were:

Omar Farrugia, *President*. Youth Group Chairman. Duties include key communicator with government ministers, the Autism Council and Autism Europe. Escalates significant member issues with the relevant body.

Emma McEwen, *Secretary and Projects Manager*. Duties include administration, enrolment of new members, organisation of the counselling service, fund raising, handbook editor, board meeting minutes, compilation of AGM report. Organisation of parent seminars and children's activities. Publishes information on the private Facebook Support Group.

Brian Ferrante, *Treasurer*. Duties include compilation of all financial reports, payments.

Valerie Brincat, *Public Relations Officer and Parent Support Agent*. Duties includes provision of autism awareness talks and presentations, interviews on national television and all other media channels and provides one to one advise for parents. Organisation of parent seminars. Publishes information on the private Facebook Support Group.

Alishia Xuereb Jones, *Public Relations Officer, Parent Support Agent*. Duties includes provision of autism awareness talks and presentations, interviews on national television and all other media channels and provides one to one advise for parents. Organiser of the APA and The Club collaboration to provide free weekly training sessions to children, teens and adults on the spectrum. Duties on this project include taking bookings and coaching the attendees.

Jean Pierre Farrugia, *Assistant Project Co-ordinator*. Duties include communicating with various entities to protect the rights of those with autism and encourage inclusion. Main project driver on Autism Friendly Spaces.

Carmen Abela, *Committee Supporter and Parent Support Agent*. Duties include co-organising events for parents and children, provision of autism awareness talks and presentations and provides one to one advise for parents.

Gaby Galea Gusman, *Committee Supporter*. Duties include co-organising events for children and parents, communicating with various entities to protect the rights of those with autism and encourage inclusion and fundraising.

Joanne Sciberras, *Gozo Support Agent*. Duties include one to one support to parents.
Joanne is not a Board Member.

Silvan Magro, *Youth Group Coordinator*. Duties include overall responsibility of the organisation and running of the Youth Group (SIPT). Silvan is not a Board member.

Sharon Balzan, *Youth Group Administrator*. Duties include supporting the organisation and running of the Youth group (SIPT). Sharon is not a Board member.

With the onset of Covid the last physical meeting was February 2020. Due to the huge personal impact of work and schooling on committee members, monthly online meetings commenced December 2020.

Number of board meetings in the year – 10.

Rate of attendance – Board meetings are attended by 70% of board members.

Projects / Activities during the year

Key activities

Ims-2-trials

APA has been represented on the steering committee in the Autism Innovative Medicine 2 trials since the very beginning in 2018. This programme will run until May 2023. This programme includes a range of studies conducted by different groups. The aims of the study are

- Understand how autism, and its co-occurring health conditions, develop from before birth into adulthood
- Identify features of autism that which can be measured, called biomarkers
- Test new medicines that could become a treatment option for autistic people
- Build a network to connect researchers, clinicians, and the autism community
- Prepare Europe to pioneer large clinical trials of future medicines
- Improve and accelerate the process of developing new medicines
- Analyse and manage the data collected in research
- Explore how policies on autism can better support autistic people
- Develop educational tools to improve understanding of autism
- Put Europe at the forefront of autism research

These objectives correspond with the priorities of the autism community. Apa is also represented on the Medicines Working Group.

Together with lead researchers the working group has been working to decide on which molecules to include for a clinical trial. Autism community representatives were able for the first time to influence the decision and vote along researchers.

The activity raised euro 1,218 in sponsorship.

Public Relations

With this pandemic it was easy to note how the entire world has changed and was required to adapt to new regulations and safety protocols. How the association affected their public relations with our members and society was required to change as well—the ways we communicate completely changed in these past years. Covid-19 has shifted how us public relation officers communicate and do our duties. Some of these changes are more likely to remain.

We currently provide our informative meetings virtually or are offered hybrid (where the members are offered to attend the meeting personally as well). Online meetings have allowed more flexibility. It has been an advantage to many of our family members, as they were able to attend the virtual meetings in the comfort of their own home, without finding the need to find a carer for their ASD child, or because they were so tight in time that they were not managing to come to the live event.

Social media has played a pivotal role in keeping our members connected. While social media was an integral part of our society before, it has become even more important as a tool to stay connected when physically apart. Our Facebook closed group - Autism Parents Association Support Group, which currently has 1087 members. Our members have found this group very useful to find support, tips, visual resources, social narratives and any information they should require at that time. Human connection is important in our world, and, when we cannot gather in person, social media fills those gaps.

While it is hard to replicate the feeling of being together face-to-face, the pandemic's increased accessibility offers opportunities to bring more people and perspectives together, which may continue to erase geographic and physical barriers moving forward.

These past years of living through a pandemic have changed so many things in the communications world, but these trends are expected to stick around, even as we start to return to life more as it was pre-COVID. It is convenient for many of us and while the past year has presented many challenges, the opportunities to learn and grow have shown that the PR industry is sustainable, adaptable and resilient in times of crisis.

Public Relations and Autism Awareness Month

During April, Autism Awareness Month, the television program Gadget featured Augmented Access to Communication devices and raised awareness on Radio 103. APA created a number of Facebook adverts, in alignment with Autism Europe's communication strategy and were circulated throughout the month.

At the start of World Autism Month, The Marigold Foundation joined the rest of the international autism community by symbolically lighting up blue one of the highest points in Malta and certainly one of the most iconic, the Mdina Bastions.

This year's 'lighting up' event has an even deeper meaning since, apart from raising awareness on autism, it also expresses solidarity for the additional challenges that families on the spectrum have to endure while coping with social distancing and self isolation, which are necessary to contain Covid-19.

For a lot of people on the spectrum, having to stay within confined spaces for a prolonged period is a bigger challenge than most other people. These necessary steps lead to additional anxiety and stress for families where autism is part of daily life. Working hand in hand with the Autism Parents Association, The Marigold Foundation is expressing solidarity with all the families going through this challenging period and calls on society in general to be more supportive and understanding during this time. The annual symbolic gathering at Mdina Gate has this year been cancelled but the Foundation is committed to continue to raise awareness and help NGOs working in this field of autism throughout the year. This was reported in NewsBook on 2nd April.

Launch of Autism Community Library

APA launched the Autism Community Library on 17th February 2021. The first book showcased in the library was written by a member of our community – 9-year-old boy who has autism and is nonverbal. His book was recently published and kindly donated a copy to the library.

The objective of the library is to share information and knowledge at a time when most are suffering from financial constraints. The Autism Community Library will be lending autism guides and books to official APA members. The initial response to borrowing books has been low which we expect is due to covid concerns.

Continuance of Free Counseling for Official APA Members

During the period, APA continued to provide the counseling service via an agreement with the university of Malta. This provision is available to paid members.

Providing a formal support service for our members above and beyond that of our Parent Support Agents is a primary goal.

We are very grateful to Ronald McDonald House of Charities for providing free use of their facilities to host sessions when covid restrictions permitted. When face to face meetings were not possible the service was continued online.

Encouraging and facilitating Autism Friendly Spaces

APA is currently collaborating with Prisms to create Autism Friendly Spaces and Autism Friendly Hours. APA`s main role is to contact several prominent commercial outlets and entities to gauge interest in this inclusive label with a follow up technical meeting with Prisms.

Prisms is a Maltese NGO who have gained funding from Erasmus + to create a certification system for Autism Friendly Spaces. The research for the criteria was done by CRPD and Autism Europe.

APA`s intention is to maximize on the above by

- A) Increase society`s overall knowledge of autism and thus parents with children on the spectrum can reach out for any assistance- (This is to be done with the PR/Marketing teams of companies opting for this label)
- B) Increase the society`s overall acceptance for people on the spectrum by having trained people maintaining the sustainability of such initiatives.
- C) Autism Friendly Spaces Standards which shall be taken in consideration as early as the initial design inception especially in highly frequented places.

The main Eight areas which APA is consistently working on are the following:

- Supermarkets
- Restaurants
- Health services
- Offices

- Travelling – airport and transport
- Retail shops
- Museums
- Cinema

The three primary criteria which these outlets should satisfy are the following:

- A) Commitment to raising awareness and be part of the campaign for this project.
- B) Choosing a minimum of two employees to do the four online modules. They will be the main reference point to provide guidance to customers/clients regarding autism.
- C) Adjustment of physical spaces to better cater for people with autism.

APA together with Prisms contacted the following establishments are all in the process of getting the accreditation:

Malta International Airport- While we spoke to MIA to get the accreditation, we were impressed with their acknowledgement and attitude. They are already equipped with social stories, a person to assist a family with a member on the spectrum when getting to board the plane and not queuing to do the check-in. These are all measures reduce stress and really help people on the spectrum.

McDonalds- Mcdonald's management are working on refurbishing part of the airport outlet to accommodate a secluded area which will be less noisy and sensory-friendly. Both APA and Prisms had the opportunity to give feedback to their plans/layout in order to proceed. Training of the staff is underway.

Heritage Malta- For the time being working on a pilot project at the National Archaeology in Valletta, that if successful they will eventually implement in all museums. Some of the adjustments in the museum were the dimming of the lights and also promoting weekly autism hours (Wednesdays).

Gallarija Darmanin- The management of Gallarija Darmanin did the necessary adjustments such as the dimming of the light, switching of the music and further assistance during the autism friendly hours. Training was also provided to the staff.

Eden Cinemas- A monthly screening is still ongoing with free seating, pre-popped popcorn, turning off unnecessary lights and dimming of the lights in the auditorium so that it is not completely dark..

Eden Superbowl - Free sessions and training of the staff (however the management explained that noise control will be very difficult)

Esplora- APA together with Prisms met Esplora management to discuss how to enhance the experience for people on the spectrum when visiting. Today, Esplora would adjust the light and sound level at specific time/date. At these times fidget toys, ear defenders and weighted blankets are available. They have also heavily invested in a multi sensory room and quiet room for people who might get overwhelmed. A social story has been prepared and is available to download from their website.

Malta National Aquarium- Malta National Aquarium also had a very good background on autism. To date they provide a quiet room, fidgets, lanyards, and ear defenders. They also provide special hours and adaptations even on school outings for students on the spectrum. The management received the training by Prisms and a social story is also available from their website.

Unfortunately, the Management of the Valyou supermarket changed due to a change in the franchise and for the time being they have suspended the autism friendly hours.

Initiating Free Fitness Sessions for official APA members

2021 has seen The Club Fitness Centre move to their new premises in Qrendi. Works were carried out throughout the summer during which Minister Julia Farrugia Portelli held a press conference inaugurating the beginning of the works and the start of the partnership between The Club Fitness Centre and APA. By December the premises were ready to welcome APA members and on December 8th we as APA held our annual Christmas party for all our members at The Club Arena. As of 2022 APA and The Club aim to start welcoming APA members to free weekly sessions at the club to give our members a space where to train, get fit, receive a lot of sensory input from the obstacles present at the arena, and perhaps most importantly a space to socialize with their peers.

Joint Christmas Party and Launch of The Club Fitness Centre.

As previously mentioned, on Wednesday 8th December we were graced with beautiful weather to hold a joint Christmas party and showcase The Club Fitness Centre to our members. Both children and parents were free to explore the tinselled obstacles with our volunteer coaches helping and encouraging our members, and some parents too, to try out the obstacles and challenging them to a new adventure which all seemed to enjoy. This was followed by entertainment by a juggler and a magician. The fun continued throughout with a bubble machine, doughnuts, popcorn machine, free refreshments, hot food for the children and animators walking around with bags of surprise sweets and toys/fidgets.

The event raised Euro 195 .

Steering Committee members of the creation of a New Music School for children with different abilities.

APA continues to provide consultation and attends monthly meetings held by the Malta Trust Foundation regarding the launching of a new Music School for children with different abilities. In addition, we attended the launch of the school which was addressed by Her Excellency Marie Louise Coleiro Preca and Minister for Social Housing Roderick Galdes. At the start of this scholastic year Villa Bianca opened its doors to students and we as APA members have continued to give feed back on the running of the school with regular meetings between the steering committee still taking place.

SiPT – Social Integration Preparation for Teens.

Regretfully due to the pandemic in full swing we had no other option but to halt our SiPT programme until the pandemic eased off.

Upon reviewing the whole restrictions and health & safety requirements imposed by the health authorities we have collectively taken the decision to re-instate the program again from November 2021 onwards.

Currently the sessions are being held at the Ronald McDonald House of Charities HUB in Qawra and runs on a bi-weekly schedule. To make it more fun and engaging, we have re-designed the programme to cover the following topics (sciences, culinary journeys, lifestyle scenarios, social integration & environmental studies).

We are very pleased with the attendance as currently we are averaging between 13 to 16 participants per session and overall, we believe that the new setup is proving to be more engaging as participation is healthier than ever.

For us, this has always been a priority and we look forward to the continuation of this program, but we cannot conclude and not thank Mr Martin Xuereb and Mr Tonio Axisa from the Ronald McDonald House of Charities for their ongoing support. If it wasn't for their constant help and support, we wouldn't be able to continue this program and accomplish these milestones.

Our aims for the next 12 months are:

- ❖ To continue providing support to parents and families of those with autism via the close Facebook Support Group, one to one advise.
- ❖ To continue the trainee councillor placement contract with the university of Malta.
- ❖ To continue to escalate important matters to the relevant authorities to ensure equal rights and inclusion.
- ❖ To continue to encourage in schools, retail and businesses to be autism friendly spaces.
- ❖ To continue and expand autism community library for members providing access to books on autism to increase knowledge and understanding.
- ❖ To continue the free fitness sessions for official paid APA members according to social distancing restrictions.
- ❖ To continue to provide educational seminars to parents.
- ❖ To continue to provide social events to our families according to social distancing restrictions.
- ❖ Continue to liaise with CRPD, Ministry of Wellbeing and Social Inclusion and Autism Advisory Council to find out how many people in Malta have autism and their age group to enable Government entities to plan resources now and in the future.

Conclusion

We foresee that with the reduction of covid restrictions, APA will start to provide social activities which were not permissible over the last two years.



Emma Mc Ewen
Secretary and Projects Manager



Omar Farrugia
President - APA