

# Year End Report of ASA

2022



ASA Members

AS parent organizations from  
Austria, Belgium, France,  
Germany, Ireland, Israel,  
Italy, Japan, Netherlands,  
Portugal, Spain, United Kingdom  
and the Nina Foundation

ASA Associates  
AS parent organizations from  
Argentina, Hong Kong, Hungary



#### ASA Board

Betty Willemsen, Chair of ASA  
Peter Sel, Vice-Chair of ASA  
Manuel Trocado Costa Duarte,  
Treasurer of ASA

#### Scientific Advisory Board (SAB)

Dr. Hanoch Kaphzan  
University of Haifa  
Dr. Martin Scheffner  
University Konstanz  
Dr. Harald Sitte  
University of Vienna  
SAB contact  
harald.sitte@meduniwien.ac.at

#### Community Advisory Board (CAB)

Pharmaceutical companies can  
consult the CAB, a joint force of ASA  
and ASF (USA) to represent the  
interests of the AS community.

#### ASA / CAB contact

Betty Willemsen  
info@angelmanalliance.eu  
www.angelmanalliance.org

## Forword

The year 2022 is a year of restart after the pandemic that has slowed down many activities globally.

After the Covid break, Asa finally had its annual Bi conference 2022 in Vienna.

An expected success, considering the latest developments and trials underway by pharmaceutical companies.

There was an interesting exchange and collaboration between researchers.

The new formula, which also provides space for new researchers with many more relationships. Asa's commitment is to bring together as many researchers as possible and integrate in the future the presence of students who in the future may be passionate about the study of AS.

We carry with us the ever-closer hope that something extremely positive will happen for our kids.



There was the appointment of the new Board, and with a big hug we thank Betty and the outgoing directors with the hope of continuing with THE SAME intensity and teamwork to achieve the goals.

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Our group has grown further with the addition of new members and expanding exchange opportunities.

Finally, we want to thank the associations - the members of Asa, for the work of their volunteers who, with their activities, allow Asa to promote the Launch of the new Grant 2023.

President of Angelman Syndrome Alliance



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## Establishment of ASA

In June 2019 the founding members of the Angelman Syndrome Alliance (ASA) got together to erect ASA as a legal entity. We started ASA as a project based alliance with a few parent organizations and during the years, we became an alliance that is trustworthy and attracted even more members.

Starting June 2019, we not only confirmed the aim of international cooperation, but also realized that each ASA member is entitled to all rights and privileges of membership as provided in the bylaws of the alliance. The members devoted a great deal of time and attention to this important process.

## Partnership of equals

The Angelman Syndrome Alliance is a partnership of small organizations from around the globe that are focused on supporting people with Angelman Syndrome (AS), their loved ones, carriers and clinicians. Each ASA partner contributes with the available funds and we work as equals, supporting each other, being all part of the community of family members of people with AS.

In 2022 the following countries were represented within ASA as a founding member (country & organization name in alphabetical order):

ASA MEMBERS	ASA ASSOCIATES
Austria- Verein zur Erforschung des Angelan Syndroms	Argentina.AngelmanArgentin
Belgium-Angelman Syndrome Belgie	Hong kong - HKASF
France-AFSA	Hungary - Magyar Angelman Szindròma Alapltvány
Germany-Angelman e.V	New Zealand – New Zealand Angelman Network
Ireland-Angelm Syndrome Ireland	Angelman Czech Republic
Israel-Israele Angelman Syndrome Foundation	Angelam Ukraine
Italy-Or.s.a	
Japan-The Angel Society	
Netherlands-Angelan Syndroom Nederland	
Netherlands-Nina Foundation	
Portugal-Angel	
Spain-Asociasion de syndrome Angelman	
United kingdom-Assert	



## Mission

Our mission is to grow and support scientific knowledge about AS that can create fundamental and lasting changes in therapy for people with Angelman Syndrome; so that parents, therapists and clinicians can improve the quality of life of those with AS.

Together we identify research that challenges our knowledge of AS today, to enable us to develop solutions for future therapies. The alliance focuses its investments on innovative science, with our ultimate goal to find therapies for patients with Angelman Syndrome.

## ASA Structure

The Angelman Syndrome Alliance has the following four corporate bodies;

- the Management Board;
- the General Meeting;
- the Meeting of Full Members; and
- The Scientific Advisory Board.

### New Management Board

The Management Board Members are appointed by the General Meeting held in sept 17 2022 at Vienna. The 5 Board Members are;

- Manuel Trocado Costa Duarte (Portugal) - President of ASA
- Conny Schendler (Germany) - Vice-President of ASA
- Katie Cunnea (England) - Research
- Emanuele Bedon (Italy) - Secretary
- Thomas Schramm (Austria) - Treasurer of ASA

### The Scientific Advisory Board

Board determines the New Scientific Advisory Board; the Scientific Advisory Board consisted of;

- Prof. Hanoch Kaphzan (Israel) – Chairman
- Prof. Olga Peñagarikano (Spain)
- Prof. Jill Clayton-Smith (United Kingdom)
- Prof. Luis Pereira de Almeida (Portugal)

### The General Meeting

The General Meeting takes place every month with the members of the Management Board.

### The Meeting of Full Members

At least once per calendar year a Meeting of Full Members is convened.



In 2022 this Meeting has been held from the 15th to the 18th Of September at Vienna, Austria. Following topics are discussed in the Meeting;

- Founding of ASA
- Appointment of new Board Members
- Appointment of and New Scientific Advisory Board
- How to Grow?
- Communication/PR
- Young Scientists

## Results 2022

Looking back on the year 2022, we can state that good progress has been made in many areas as planned. In general:

- Two scientific research projects granted with a total sum of 340.000;
  - Dr. Simao La Rocha ( PHD) and dr. Evguenia Bekman ( PHD) of associaCao do Instituto Superior Tecnico Para a Investigacao e desenvolvimento (IST-ID)amount 170000€
  - Dr Ilaria Tonazzini-Dr Laura Baroncelli;Prof Roberta Battini of Nanoscience Institute-CNR Pisa Italy amount 170000€
  -
- Strengthening the organization of the alliance.
- Installment of a Scientific Advisory Board with four new member Prof. Hanoch Kaphzan (Israel) – Chairman; Prof. Olga Peñagarikano (Spain),Prof. Jill Clayton-Smith (United Kingdom),Prof. Luis Pereira de Almeida (Portugal)
- Development of several procedures.
- A solid communication platform for the ASA members is put into place. This gives us all full transparency in documents and discussions.
- Structural improvement of the website.
- Also in 2022, finances increased compared to the previous years.
- Keeping overhead costs below 1 percent of revenue.
- We have excellent control over accounting and financial reporting.
- Organization of the next international conference in 2023 IN Spain.
- Preparing to start a second scientific research call.
- The alliance only works with (unpaid) volunteers. This includes general board members, scientific advisory board and committee members.

## Work in progress

In addition, there are many other notable successes. On a few points, we have not been able to achieve the progress that we desired. For example, our website has been updated but still needs work so we can inform the AS community more and better. Because of our good development, we urgently need to increase the number of committee members who



want to commit to the Angelman Syndrome Alliance. The current human capacity is becoming a limitation for our growth.

To grow as an organization we also have a program in place for new members but we need to actively contact parent organizations to introduce them to ASA.

For the current year 2022, we have therefore proposed a number of things with which we want to strengthen our organization and increase our effectiveness. Everything focused on achieving our goal.

## Finances

The Angelman Syndrome Alliance cannot achieve a thing without the moral and financial support we receive from our members. In 2022, in addition to a number of large financial commitments, we received a number of smaller amounts. We know that some donors have to impose restrictions on the money they give us. That is why we say, we appreciate every contribution. Our special thanks to everyone who supported the Angelman Syndrome Alliance in 2022 with time and / or money.

We continue to meet our goal of devoting nearly 100% of revenue to our goal. This makes us one of the few exceptions in the world of fundraising resp. spending.

## Financial Balans



**INDIVIDUAL STATEMENT OF RESULTS BY NATURE**  
From January to December

Values in EURO

HEADINGS	NOTES	FISCAL YEAR	
		2022	2021
<b>Profit and Loss</b>			
<b>Revenues</b>			
Grants			
Members contributions		44 613,60	152 900,00
Other Contributions		830,17	6 131,95
<b>Expenses</b>			
Grants			
Researchers payments		(75 000,00)	
Other expenses		(295,44)	(370,17)
<b>EBITDA</b>		<b>(29 852,67)</b>	<b>158 661,78</b>
Depreciation and amortization expenses / reversals			
Impairment of depreciable / amortizable Investments (losses / reversals)			
<b>Operating result (before financing expenses and taxes)</b>		<b>(29 852,67)</b>	<b>158 661,78</b>
Interest and similar Income obtained			
Interest and similar expenses incurred			
<b>Income before taxes</b>		<b>(29 852,67)</b>	<b>158 661,78</b>
Tax over the period's Income			
<b>Net Income for the period</b>		<b>(29 852,67)</b>	<b>158 661,78</b>

Board: \_\_\_\_\_

### Revenues

The total amount of revenues come from members contributions. These revenues represent the full amount compromised by the members to fund the 2022 research grant. All members paid on time.

Due to Italian fiscal law, ORSA (Italian Angelman Association) did not transfer the money to the ASA bank account but directly to the researcher institution. For this reason, the value was not accounted as a revenue for ASA.

ORSA paid on time the full amount compromised.

### Expenses

The research grant of 2022 was awarded to 2 different research labs for a total amount of € 340.000.

According to the protocols signed with the institutions, only a part of this value was to be paid in 2022, and the remaining amounts will be paid in 2023 and 2024.

During 2022 the following amounts were transferred from the ASA bank account to the researchers;

- Dr Hugo Mayor project was paid by Asa with Amount of 50.000€ in January
- Dr. Tonazzini project , was paid by Asa with the amount of 25.000€ in August, While it was funded directly by ORSA with the amount of €85.000 in

The other expense ASA had in in a total amount of €295,44 .

### Net Income for the period

The net income for 2022 was € 29.852,67 and that was the amount of 266.069.54€ on the bank account by 31/12/2022.

These results will transit to 2023 were ASA will continue to honor the commitments from the 2021 research grant 255.000€ to be paid in 2023-2024.

Current revenues only cover the cost of the research grants. Bank expenses and future expenses that may occur will need to be cover by additional revenues.

ASA board will work on additional source of revenues and will present them to the members.

