



2019

Year End Report of ASA



ASA Board

Angelman Syndrome Alliance

31-12-2019



Forword

Sometimes we are happy with the small things that happen to us.
But this year it is quite a big thing that happened!

We were finally able to grow from a group of parent organizations that work together on projects to a proper international legal entity: The Angelman Syndrome Alliance (ASA).

That is why you are looking at the first Year End Report of ASA.

This year, dedicated members have put in hundreds of hours, working shoulder to shoulder on the structure of the organization. In this Annual Report, we are proud to share with you just some of the highlights of our tremendous work over the last year.

2019 was an important year for the development of the Angelman Syndrome Alliance and we look to the future with confidence.

Thank you for your interest in Angelman Syndrome on behalf of the board and all members of ASA,

Betty Willemsen
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 2019 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 Angelman Syndroms	Argentina - Angelman Argentina
Belgie - Angelman Syndrome Belgie	Hong Kong - HKASF
France - AFSA	Hungary - Magyar Angelman Szindróma Alapítvány
Germany - Angelman e.V.	
Ireland - Angelman Syndrome Ireland	
Israel - Israeli Angelman Syndrome Foundation	
Italy - ORSA	
Japan - The Angel Society	
Nederlands - Nina Foundation	
Netherlands - Angelman Syndroom Nederland	
Portugal - Angel	
Spain- Asociacion 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.

Management Board

The Management Board Members are appointed by the General Meeting held on at Leuven, Belgium on 22/06/. The 3 Board Members are;

- Betty Willemsen – Chair Person
- Peter Sel – Vice Chair Person
- Manuel – Treasurer

The Scientific Advisory Board

The Scientific Advisory Board are determined by the Meeting of Full Members. The Scientific Advisory Board consisted of;

- Hanoch Kaphzan
- Martin Scheffner
- Harald Sitte

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 2019 this Meeting has been held on the 22th and 23th Of June at Leuven, Belgium. Following topics are discussed in the Meeting;

- Founding of ASA
- Appointment of Board Members and Scientific Advisory Board
- How to Grow?
- Communication/PR
- ASA International Scientific Conference 2020
- Young Scientists
- Young ASA



Results 2019

Looking back on the year 2019, we can state that good progress has been made in many areas as planned. In general:

- Three scientific research projects granted with a total sum of 335.000;
 - Prof. Ugo Mayor
 - Prof. Ype Elgersma
 - Prof. Ben Philpot.
- Strengthening the organization of the alliance.
- Installment of a Scientific Advisory Board with three members: Hanoch Kaphzan, Martin Scheffner and Harald Sitte.
- Development of several procedures.
- Opening of a joined bank account for ASA.
- 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 2019, 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 2020, Vienna.
- 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 2020, 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 2019, 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 2019 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

ASA - Angelman Syndrome Alliance

INDIVIDUAL STATEMENT OF RESULTS BY NATURE

From January to December

Values in EURO

HEADINGS	NOTES	FISCAL YEAR	
		2019	2018
Profit and Loss			
Revenues			
Grants			
Members contributions		275 000,00	
Other Contributions			
Expenses			
Grants			
Researchers payments		(93 750,00)	
Other expenses			
EBITDA		181 250,00	
Depreciation and amortization expenses / reversals			
Impairment of depreciable / amortizable investments (losses / reversals)			
Operating result (before financing expenses and taxes)		181 250,00	
Interest and similar income obtained			
Interest and similar expenses incurred		(41,30)	
Income before taxes		181 208,70	
Tax over the period's income			
Net income for the period		181 208,70	



Revenues

The total amount of revenues come from members contributions. This revenues represent the full amount compromised by the members to fund the 2019 research grant. All members paid on time.

Due to Italian fiscal laws 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 has a revenue for ASA.
ORSA paid on time the full amount compromised.

Expenses

The research grant of 2019 was awarded to 3 different research labs for a total amount of € 335.000.

According to the protocols signed with the institutions only a part of this value was to be paid in 2019, and the remaining amounts will be paid in 2020 and 2021.

During 2019 the following amounts were transferred from the ASA bank account to the researchers;

- Professor Ugo Mayor - € 43.750
- Professor Ype Elgersma - € 50.000

Professor Ben Philpot's project, was funded directly by ORSA with the amount of €60.000.

The bank expenses were the only other expense ASA had in 2019 in a total amount of €41,30 .

Net Income for the period

The net income for 2019 was € 181.208, 70 and that was the amount on the bank account by 31/12/2019.

These results will transit to 2020 were ASA will continue to honor the commitments from the 2019 research grant (€ 181.250 to be paid in 2020 and 2021).

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.