



Year End Report 2021

Betty Willemsen



Foreword

It has been an exciting year, with multiple phase one, and even phase two, clinical trials to treat Angelman medication starting. We have a website in place to inform our community about all the trials and have joined angelmanclinicaltrials.com. A film has been made to explain the treatments being developed and as a team of 13 ASA members, we have been able to start a new round of our grant procedure to fund novel research on Angelman Syndrome.

Betty Willemsen
President of Angelman Syndrome Alliance



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Partnership of equals

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

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 for 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.

Formal establishment of ASA

We started the ASA back in 2012 during a conference in Rotterdam hosted by the Nina Foundation. Initially, we simply joined our financial efforts to stimulate AS research. In doing so we developed a well-organized structure for our ASA community. In June 2019 the founding members of the ASA established the ASA as a legal entity. We started the ASA as a project-based alliance with a few parent organizations. Over the years, we have become an alliance based on AS science and have gradually been attracting an increasing number of members.

Founding members of ASA

In 2019 the following countries represented the ASA as founding members (country & organization name in alphabetical order):

Austria – Verein zur Erforschung des Angelman Syndroms

Belgium – Angelman Syndrome Belgie

France – AFSA

Germany – Angelman e.V.

Ireland – Angelman Syndrome Ireland

Israel – Israeli Angelman Syndrome Foundation

Italy – ORSA

Japan – The Angel Society

Netherlands – Angelman Syndroom Nederland

Netherlands – Nina Foundation

Portugal – Angel

Spain – Asociacion de Syndrome Angelman

United Kingdom - Assert



Growth of ASA in 2021

A taskforce of three reached out to several AS parent organisations to find out about their interest in scientific AS research. We were able to welcome the following parent organisations as associate members to the ASA community:

Argentina – Angelman Argentina

Hong Kong – HKASF

Hungary – Magyar Angelman Szindroma Alapítvány

New Zealand – New Zealand Angelman Network

We continue to reach out to new AS organisations that want to join forces on research.

The difference between an ASA member and associate is that only a full member can formally vote on decisions. To be a full member you need to make a minimum contribution of 5000 Euro to the AS research grant programme.

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 at Leuven, Belgium on 22/06/2019. The 3 Board Members are;

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

The Scientific Advisory Board

The Scientific Advisory Board is appointed by the Meeting of Full Members. The Scientific Advisory Board consisted of;

- Hanoeh 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

Full members meet at least once per calendar year. In 2021, this meeting had to be held online due to the coronavirus pandemic.

Results 2021

Looking back on 2021, we can state that good progress has been made in many areas according to plan. In general the following has taken place:

- The grant process has been revalidated including the timeline
- The latest grant process started in March 2021
- The first phase of the grant process closed in July with 21 applicants
- The second phase of the grant process closed in December with three projects
- Evaluation of our Memorandum and 4 Year plan.
- Online application and voting mechanism fully updated.
- All processes of our organisation formalized.
- Structural improvement of the website and communication strategy.
- Became a member of the AS clinical trials website: www.angelmanclinicaltrials.com
- Finances increased in 2021 compared to the previous years.
- Excellent control over accounting and financial reporting.
- Keeping overhead costs below 1 percent of revenue.
- ASA members agreed to a 50€- euro annual fee to cover basic costs like banking.
- Organization of the next international conference in 2022, Vienna.
- Ten ASA members took part in the Eurordis training program: www.eurordis.org
- The community advisory board was formally established and announced: <https://angelmanalliance.org/index.php/cab>
- Czech Republic became an ASA associate: www.asgent.org
- We had a virtual formal ASA members meeting. Members have access to the video on our community platform.

Work in progress

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 better inform the AS community.

Following our progressive development, we will ask all ASA members and associates to actively help in taskforces. We will prepare a list of tasks so each member can decide what kind of support they can offer.



Furthermore, we need to evaluate and scrutinise our process to become a member or associate (due diligence).

We also need find time to instruct our ASA members and our scientific board on the procedures and (online) methods that we use. Everything is written in our statutes but people need reminding.

Finances

We continue to meet our goal of devoting nearly 100% of revenue to our cause. This makes us one of the few exceptions in the world of fundraising for achieving this level of responsible spending. The only costs are banking and website hosting. The board will continue try to also lower those costs. We did agree to a yearly fee of 50€- euro for each member to cover those costs.

The alliance only works with (unpaid) volunteers, we cover no costs at all. This includes general board members, scientific advisory board, community advisory board and taskforce members.

Financial Balance

ASA - Angelman Syndrome Alliance

INDIVIDUAL STATEMENT OF RESULTS BY NATURE

From January to December

Values in EURO

HEADINGS	NOTES	FISCAL YEAR	
		2021	2020
Profit and Loss			
Revenues			
Grants			
Members contributions		152 900,00	- €
Other Contributions		6 131,95	
Expenses			
Grants			
Researchers payments			(43 750,00)
Other expenses		(370,17)	
EBITDA		158 661,78	(43 750,00)
Depreciation and amortization expenses / reversals			
Impairment of depreciable / amortizable investments (losses / reversals)			
Operating result (before financing expenses and taxes)		158 661,78	(43 750,00)
Interest and similar income obtained			
Interest and similar expenses incurred			(198,77)
Income before taxes		158 661,78	(43 948,77)
Tax over the period's income			
Net income for the period		158 661,78	(43 948,77)



Revenues

The ASA members contributions in 2021 were 152.900€. This revenue is part of the members contribution to the 2021 grant (152.500€) and the annual fee (400€). It represents 96% of the overall revenue of ASA.

In 2021 we also had 4% (6.131,95€) of revenue coming from donations.

Expenses

Due to covid some of the research projects that were ongoing had delays and did not finish in 2021. Therefore, ASA had no expenses with Researchers.

The bank expenses represent 100% of our expenses in 2021 with a total amount of 370,17€.

Net Income for the period

The net Income for 2021 was 158.661,78€.

These results will transit to 2022 and will allow the ASA to fulfil its commitments to the 2019 and 2021 research grant winners.

