

YEARLY REPORT 2021



DRAFT

Preface

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Table of Contents

Preface	2
The Nina Foundation.....	4
Management Board	4
The Scientific Advisory Board.....	4
The Angelman Syndrome Alliance	4
Mission of ASA	4
ASA Members	4
Postponing of International Conference 2021 Vienna	5
Community Advisory Board (CAB)	5
Training Program.....	5
Taskforces	5
Communication.....	6
News	6
Virtual meeting	6
Results 2020.....	6
Finances	7
Financial Balance.....	7
Profit and Loss Statement.....	8

The Nina Foundation

The NF has taken upon itself the task to create the international Angelman Syndrome Alliance. We are in the official board of ASA and we conduct all its daily work. We host the website of ASA, we keep the communication platform going, we do all the necessary paperwork, we keep our network in form, do public relations like with Eurordis, we work on the legal terms of the organization like setting up contracts with the scientists that do research for ASA, we take part in the community advisory board, keep connected with our scientific advisory board, set up meetings for ASA members and continue to build a strong and healthy international Angelman organization that works together like clockwork.

Management Board

The 4 Board Members are;

- Betty Willemsen – Chair person
- Jasper Cornelissen – Secretary
- Dennis Willemsen – Treasurer
- Martijn van Steensel – Legal advisor

The Scientific Advisory Board

Whereas in the past the NF had a full scientific advisory board. Nowadays only Ype Elgersma remains and advises the NF on medical / scientific matters.

The Angelman Syndrome Alliance

The Angelman Syndrome Alliance is a partnership of organizations from around the globe that are focused on supporting scientific progress that benefit people with Angelman Syndrome (AS). 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. Nina Foundation is a member of ASA and also a board member. We dedicate 60.000,- euro to the next research projects in Angelman Syndrome.

Mission of ASA

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 Members

In 2021 the following countries were represented within ASA as a founding member (country & organization name in alphabetical order):

- Austria - Verein zur Erforschung des Angelman Syndroms
- Belgie - Angelman Syndrome Belgie Hong Kong - HKASF
- France - AFSA Hungary - Magyar Angelman Szindróma Alapítvány
- Germany - Angelman e.V.
- Ireland - Angelman Syndrome Ireland
- Israël - Israeli Angelman Syndrome Foundation
- Italy - ORSA
- Japan - The Angel Society
- Netherlands - Nina Foundation
- Netherlands - Angelman Syndroom Nederland
- Portugal - Angel
- Spain - Asociacion de Syndrome Angelman
- United Kingdom - Assert
- Argentina - Angelman Argentina
- Hong Kong - HKASF
- Hungary - -

Postponing of International Conference 2021 Vienna

Unfortunately the Austrian parent organization had to postpone the conference in Vienna due to Covid restrictions. They will set a new date in 2022. The NF will organise a virtual meeting for the Members of ASA in 2021.

Community Advisory Board (CAB)

The Nina Foundation worked hard to initiate a community platform to work together as advisory board. We are proud to say we succeeded.

The International Angelman Syndrome Alliance (ASA) and the Angelman Foundation (ASF) announced a newly formed joint initiative: the Global Community Advisory Board. They will work together to represent the Angelman community as a unified voice when engaging with pharmaceutical companies looking to enter research programmes.

The CAB will act as a consulting service to stakeholders involved in the research, development, reimbursement and service provision of biomedical treatments or processes, including both scientific and policy-related issues.

Training Program

Supported by Eurodis, the European organisation for Rare Disorders, the Angelman CAB will be a group of trained advocates who use their knowledge and expertise to discuss and advise on the latest developments, challenges and issues related to medical treatments and procedures under development in in Angelman Syndrome.

Taskforces

To strengthen the ASA organization and increase the effectiveness, the boardmembers of Nina Foundation, facilitates and coordinates several taskforces to take responsibility for several themes.

Communication

Our communication needs an update on different levels. We wish to improve the quality of our information to the Angelman Community. That way we can make it clear what it is that ASA does. A taskforce is created.

News

We wish to introduce scientists, doctors and other Angelman related personalities to the Angelman community. We created a taskforce for that purpose and several interviews have been done. You find them on the website of angelmanalliance.org. This taskforce also organized a Q & A with professor Ype Elgersma on March 30.

Virtual meeting

To be able to meet was quite a challenge in 2020 so therefore we started with virtual meetings. A taskforce was able to set up to meetings. This way of getting together will be kept in the future as well.

Our goal is that every Angelman Syndrome patient and their family is able to be part of an Angelman community and to have access to the most up to date knowledge and help. By growing as a community we can anticipate to (future) needs of individuals living with Angelman Syndrome and their families. We want the Angelman Alliance to visibly grow with new members/countries. So the Angelman Community becomes stronger. A taskforce is created.

Results 2020

Looking back on the year 2020, we can state that good progress has been made in many areas as planned. In general:

- The evaluation report of three scientific research projects that the Nina Foundation helped financing, has been to everyone's satisfaction.
- Initiation of a Community Advisory Board
- Training program of Eurordis
- Strengthening the organization of the alliance with taskforces.
- Virtual meetings have been organized.
- Keeping overhead costs of NF below 1 percent of revenue.
- Preparing to start the next scientific research grant and processes.
- The Nina Foundation only works with 4 (unpaid) volunteers aka. The board.

Finances

The Nina Foundation cannot achieve a thing without the moral and financial support we receive from our members. We appreciate every contribution. Our special thanks to everyone who supported the Nina Foundation with their time and / or money. We continue to meet our goal of devoting nearly all of revenue to our goal. This makes us one of the few exceptions in the world of fundraising resp. spending.

Corona still continuing in 2021 has also taken it's toll on the NF finances. Hardly no donations were made, but we still managed to contribute to the ASA Grant (60.000). In order to finance the research, equity was used to pay for the bills. For 2022 onwards NF hold 130.243 euro in equity consisting of only liquidity on the bank accounts.

Financial Balance

ACTIVA		2021	
		Beginbalans	31-12-2021
LIQUIDE MIDDELEN			
Liquide Middelen			
1100	Rabobank - 1290.59.220	€ 104.148	€ 46.703,82
1150	Spaarrekening	€ 83.540	€ 83.540
		€ 187.687	€ 130.243
TOTAAL VAN LIQUIDE MIDDELEN		€ 187.687	€ 130.243
TOTAAL ACTIVA		€ 187.687	€ 130.243

PASSIVA		2021	
		Beginbalans	31-12-2021
VERMOGEN STICHTING			
Kapitaal			
800	Eigen vermogen	€ 187.687	€ 130.243
850	Resultaat boekjaar	€ -	€ -
		€ 187.687	€ 130.243
TOTAAL VAN VERMOGEN STICHTING		€ 187.687	€ 130.243
TOTAAL PASSIVA		€ 187.687	€ 130.243

Profit and Loss Statement

PROFIT AND LOSS STATEMENT		2021	2021
Nr.	Omschrijving	BEGROTING	Bedrag
Inkomsten			
8500	Giften en Donaties	€ 2.000	€ 1.148
8530	Sponsorbingo Loterij	€ 2.000	€ 1.619
8600	Periodieke Schenkingen	€ 220	€ 120
		€ 4.220	€ 2.887
TOTAAL VAN INKOMSTEN		€ 4.220	€ 2.887
Algemene Kosten			
4500	Accountants/administratiekosten	€ 100-	€ -
4530	Contributiekosten/abbonnementen	€ 100-	€ -
4570	IT kosten	€ 200-	€ 158-
		€ 400-	€ 158-
Kosten t.b.v. doelstelling			
5000	Gefinancierd Onderzoek	€ 60.000-	€ 60.000-
5100	Congressen, symposia, etc.	€ 4.000-	€ -
5300	Mutatie bestemmingreserves & eigen vermogen	€ 60.297	€ 57.444
		€ 3.703-	€ 2.556-
TOTAAL VAN KOSTEN		€ 4.103-	€ 2.715-
Financieringskosten			
4900	Rente en kosten Bank/Giro	€ 100-	€ 173-
		€ 100-	€ 173-
TOTAAL VAN FINANCIERINGSKOSTEN		€ 150-	€ 173-
RESULTAAT		€ 0	€ 0,00-