



Yearly Report 2020

Preface

A lot of work has been done in 2020. We decided that we would dedicate our time towards the Angelman Alliance, to establish a healthy international organization that facilitates multiple Angelman Syndrome parent organisations to stimulate meaningful research in Angelman therapy. Always with our ultimate goal in mind, to find therapies for patients with Angelman Syndrome. We believe an international Angelman Alliance is the best way to realize our goal so we dedicate our precious time as volunteers and we do so with love. I want to start by thanking everybody who helps. You are like stars, we don't always see you but we know you're there.

The year 2020 was supposed to be about the Angelman trials. Multiple pharmaceutical companies were ready to start their trials with new medication for Angelman patients. But then Covid spreaded so aggressively that some trials had to take a step back in their planning.

It was good to see that nothing was postponed for long, eventually all scheduled trials could start.

The most exciting for us were the trials that started in Erasmus MC. In the year 2010 this hospital opened the first expertise center for Angelman Syndrome patients in the world, an initiative of the Nina Foundation. We thought it was important to start such a center so that there would be a specialized team of doctors who would be able to provide help with the special needs of patients with Angelman Syndrome. But above all we wanted to have a team that would be ready to start when the first medical trials would be available.

We did it, we can be proud to say that the Angelman Expertise Center in Rotterdam is part of the most important trials of the moment.

Very interesting this year, was the erection of the first global Community Advisory Board (CAB). This 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.

Thank you for your interest in Angelman Syndrome on behalf of all the board of Nina Foundation.

Betty Willemsen
Chair of Nina Foundation

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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.

NF Structure

The Nina Foundation has the following four corporate bodies;

- the Management Board;
- the Scientific Advisory Board;

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

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

The Scientific Advisory board is led by Ype Elgersma, Chair person.

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 2020 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
Netherlands - Nina Foundation
Netherlands - Angelman Syndroom Nederland
Portugal - Angel
Spain- Asociacion de Syndrome Angelman
United Kingdom - Assert
Argentina- Assert
Hong Kong
Hungary

Postponing of International Conference 2020 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 therefor 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.

Due to Corona 2020 has been a strange year. As a foundation we received a bit more donations than anticipated but this was largely due to one donation of 7.500 euro of a big Dutch Company. No payments have been made to research so almost all of the donations have been added to the equity of the foundation. IT costs were up due to lack of sponsors wanting to support the foundation. Below both the balance and profit and loss statements can be found.

Financial Balance

ACTIVA		2020	
		Beginbalans	31-12-2020
LIQUIDE MIDDELEN			
Liquide Middelen			
1100	Rabobank - 1290.59.220	€ 94.012	€ 104.147,70
1150	Spaarrekening	€ 83.540	€ 83.540
		€ 177.551	€ 187.687
TOTAAL VAN LIQUIDE MIDDELEN		€ 177.551	€ 187.687
TOTAAL ACTIVA		€ 177.551	€ 187.687

PASSIVA		2020	
		Beginbalans	31-12-2020
VERMOGEN STICHTING			
Kapitaal			
800	Eigen vermogen	€ 177.551	€ 187.687
810	Bestemmingsreserve First Call Angelman Alliance	€ -	€ -
815	Bestemmingsreserve Second Call Angelman Alliance	€ -	€ -
816	Bestemmingsreserve Third Call Angelman Alliance	€ -	€ -
840	Bestemmingsreserve Nina Nurse	€ -	€ -
850	Resultaat boekjaar	€ -	€ -
		€ 177.551	€ 187.687
TOTAAL VAN VERMOGEN STICHTING		€ 177.551	€ 187.687
KORTLOPENDE SCHULDEN			
Kapitaal			
1600	Crediteuren	€ -	€ -
		€ -	€ -
TOTAAL VAN KORTLOPENDE SCHULDEN		€ -	€ -
TOTAAL PASSIVA		€ 177.551	€ 187.687

Profit and Loss

STAND DER BATEN EN LASTEN

Nr. Omschrijving

2020

BEGROTING

2020

Bedrag

Inkomsten

8500	Giften en Donaties	€ 2.000	€ 9.132
8530	Sponsorbingo Loterij	€ 2.000	€ 1.784
8600	Periodieke Schenkingen	€ 220	€ 120
8620	Legaten	€ -	€ -
		€ 4.220	€ 11.036

TOTAAL VAN INKOMSTEN**€ 4.220** **€ 11.036****Algemene Kosten**

4330	Representatiekosten	€ -	€ -
4500	Accountants/administratiekosten	€ 100-	€ -
4530	Contributiekosten/abonnementen	€ 100-	€ 150-
4570	IT kosten	€ -	€ 595-
		€ 200-	€ 745-

Kosten t.b.v. doelstelling

5000	Gefinancierd Onderzoek	€ 20.000-	€ -
5100	Congressen, symposia, etc.	€ 4.000-	€ -
5200	Kosten Congres	€ -	€ -
5300	Mutatie bestemmingreserves & eigen vermogen	€ 20.080	€ 10.136-
		€ 3.920-	€ 10.136-

TOTAAL VAN KOSTEN**€ 4.120-** **€ 10.881-****Financieringskosten**

4900	Rente en kosten Bank/Giro	€ 100-	€ 155-
4950	Betalingsverschillen in- en verkoop	€ -	€ -
8090	Betalingskortingen en -kosten	€ -	€ -
		€ 100-	€ 155-

TOTAAL VAN FINANCIERINGSKOSTEN**€ 100-** **€ 155-****RESULTAAT****€ -** **€ 0,00-**