

LA CASA DI SABBIA Onlus

Born to support families of children with severe disabilities



2019 Activity Report & Budget

Introduction

In 2019, **La Casa di Sabbia** (Sand House) **Association** – born at the end of 2017 – has continued working on its main focus of supporting families with disabled children in their day-to-day difficulties.

The initiatives of our Association both support families on individual basis, and protect their rights vis a vis the public sector.

La Casa di Sabbia has received a significant, and often unexpected, help from many donors and supporters in 2019. A generous support not only in economic terms, but also through professional contributions. Many professionals (i.e. an engineer, a graphic designer, a digital market expert, a photographer), have put their expertise at our disposal. We also had several exchanges and fruitful cooperation with other Associations which often hosted us during their own initiatives. Furthermore, several public institutions (i.e. some schools and libraries) turned their attention to our Association.

Undoubtedly, this display of affection has boosted our enthusiasm, not only in continuing with the initiatives already launched in 2018 (such as “#abitooflife”, “Let’s play together”, the support group for siblings run by a psychologist), but also proposing new ones (like the initiative on the inclusion of pupils with severe disabilities at school through the use of new technologies).

La Casa di Sabbia has also accorded particular attention to the (free) legal assistance to families. We believe that it is difficult for families to live serenely, without ensuring them the respect of the severe disabled children’s rights, in particular regarding the adequate care at home and at school.

This **report**, after a brief reference to the structure and the objectives of our Association, **retraces the activities of its second year**, describing the initiatives carried out — including those which unfortunately have not (yet) paid off — and explains the main headings of the 2019 Budget.

A report looking at the achievements, but also at the steps forward.

Our Association proposes new targets for 2020, in hopes of strengthening its foundations.

We do wish to become a reference for those families who live “non-ordinary” difficulties, which make them stronger, precisely like our Association.

Have a good reading!

La casa di Sabbia Onlus' members

CONTENTS

Introduction	2
La casa di sabbia (Sand House) Onlus	5
Initiatives carried out in 2019	7
• #Abitoflife	7
• Summer Camps	11
• Disability does not leave on holiday	12
• Building and playing together — inclusive workshop	12
• Support Group for Siblings	13
• Let's Play Together	14
• Proposal for a law on care outside the Valle d'Aosta	16
• Reduction of attendance allowances in the event of hospitalisation	16
• Rights Protection	17
• Research on home care for children with severe disabilities	17
• Fundraising dedicated to Serena and her mom	18
• Summarising	21
Institutional Relations	22
Relations with the territory and other bodies	22
Communication and outreach	23
Donors and Supporters	30
2019 Expenditure and Budget	32
Our Thanks!	33
2020 Objectives	34
Support our Activities!	35
Association Info	36

La Casa di Sabbia (Sand House) Onlus

Who we are

La Casa di Sabbia (Sand House) Onlus is a non-profit Association established on 19 October 2017 by public act, to promote the equal treatment, the rights protection, and the fight against discrimination of persons with disabilities which are not in relation with ageing.

We are mainly dedicated to families with children with severe physical and/or mental disabilities.

The Association takes life since Hervé's history: a child born with a rare disease never diagnosed, that makes him completely disabled. He needs to be continuously assisted.

Hervé's story is similar to the story of many children and families who have been left out of the system.

The health system does not provide them with adequate answers for health care at home. Therefore, it is on families to look after their loved ones, who need special medical devices (nutritional pumps, aspirator, non-invasive breathing, non-invasive ventilation, etc.).

La Casa di Sabbia Association was born for emerging and giving visibility to this abandon, and claims the right to adequate care at home and at school for children with disabilities.

Households' energies are often absorbed by the disability and its care. It is important to put the entire family at the centre, offer siblings moments of serenity, and give them a future, without expecting them to become 'caregivers'.

What we do

La Casa di Sabbia approaches the disability as a whole. Our actions do not only focus on the disabled person, but look at the whole context: from family to school, from social and health services to the community.

The Association works mainly in the Aosta Valley Region (over 70 % of the resources are allocated to regional projects) and carries out the following activities:

- inform, protect, counsel, guide, train, provide economic assistance and support to families with disabled children and youngsters;

- support families in school integration pathways;
- develop innovative models and disseminate good practices to ensure the well-being of families with children with severe disabilities;
- strengthen proposals on plans, policies and programmes;
- promote studies and researches related to living conditions, and psycho-physical well-being of families with severe disabled children.

Associates

On the 31st December 2019, the Association counted 8 associates, 6 of which are founder members.

The Steering Committee is composed of the following members:

Agnieszka Stokwiecka — President

Sonia Furci — Vice-President

Patrick Creux — Administrator

Membership of the Association is open to whom shares La Casa di Sabbia's objectives and wish to contribute also through his/her participation in the management of the activities.

On 12 April 2019, the Associates' meeting approved the 2018 Annual Activity Report, the 2018 Budget and the 2019 Activities Programme.

Initiatives carried out in 2019

2019 was the second year of our activities. A very challenging, yet highly satisfactory year.

Thanks to the significant help from all those who have given us economic, practical and moral support, we were able to carry on (without interruptions) activities already in place and launch new initiatives.

In particular, we continued providing legal support to families in difficulty; offering some leisure moments and a bit of normal life to siblings of disabled children; organizing a psychological support for them; adapting and offering special toys to special children.

Furthermore, we focused our efforts on ad-hoc actions, like drafting and disseminating an appeal against the INPS (National Institution for Social Security) about the reduction of attendance allowances in case of more than 30 days of hospitalization.

The description of each initiative follows.

#Abitoflife

This is among the first projects we launched. It is designed for parents and siblings of children affected by highly disabling diseases, whose daily life ends up rotating around the rhythms of their loved ones' care. For them, looking after the disabled children means to plan all the activities (even the most trivial), altering family and relationship dynamics.

The parents often ensure the safety of their child 24/24h by learning to interpret the signals of his/her body and use medical devices. The need of having a nursing care at home (even for only a few hours per week) is rarely satisfied by the health services, which are generally insufficient or even absent, on this front.

Furthermore, often the households cannot afford the extra-curricular activities.

In many cases, the family budget is reduced because one of the parents does not work in order to look after the child with a disability.

#Abitoflife is a project designed to give relief to families with disabled children through concrete actions focused on three themes:

- granting health care at home by qualified assistance;
- paying siblings' extra-curricular activities fees (sport, language, music courses);
- covering costs for leisure moments between parents and siblings.

In 2019, we supported 12 families through #abitoftlife project, financing extra-curricular activities (sports, pet therapy, music, and dance). 2 families got financed the visit to amusement parks with the siblings. We received very good feedback and memories from parents and children.

Furthermore, despite a pediatric nurse in Aosta Valley is available for this initiative, no family has requested her support yet.

In 2019, **Catherine Bertone**, who is a Marathoner, a Mother and a Doctor, decided to support the "*sport section*" of our #abitoftlife initiative.

Sport is very important and even crucial for those in distress. Sport does not just mean leisure, entertainment, but it is a real life school. It helps accept the defeats, enjoy victories as well as small things every day. Sport is important to children for giving them the opportunity to know and express themselves whilst increasing their self-esteem and positive thinking.



Our #abitolife project was awarded of € 4,000 during the **10th Regional Volunteer Award** promoted by the Regional Council of the Aosta Valley, in collaboration with the “Amici Fiamme Gialle of the Aosta Valley”, the Lions Clubs “Aosta Host”, “Aosta Mont-Blanc” and “Cervino” and the Rotary Clubs “Aosta” and “Courmayeur Valdigne”, with the aim of boosting the development of volunteering in the entire region.



The expenditure incurred for #abitoflife initiative is € 4,254.

Summer Camps

In the family context, disability also affects siblings' life; parents devote less attentions to them; siblings are often forced to change their habits, and give up important experiences both for organizational and economic reasons.

Summer Camps are increasingly organized by private entities and as the cost ranges from € 80 to € 200 per week, they are not affordable for all households. **Summer Camps initiative is part of our #abitoflife project. It is conceived keeping in mind the importance of leisure moments for siblings.**

We have allocated part of the donations to **Summer Camp fees for 16 children**. During Summer 2019, we financed **45 weeks** of pure fun with peers at the Summer Camps, 38 of which in Aosta Valley, 3 in Lombardy, and 4 in Lazio.



Some moments of the "Summer Camps" & "Disability does not leave on holiday" initiatives

The Summer Camps initiative cost is € 5,343.

For #abitoflife initiative (including Summer Camps), we spent in total € 9,597.

Part of #abitoflife project has been financed by resources collected through the HelperBit platform.

Disability does not leave on holiday

Summer time is a very complicated period for families with severely disabled children. The schools are closed for about three months and there are little chances of socializing with peers.

In the Aosta Valley, Summer Camps are small and spread throughout the region; in most cases, they are run by small organizations, which often count on voluntary staff. Many camps are private: this implies difficulties to provide an educator on 1:1 basis.

However, in front of a severe disability, **it is essential to have a dedicated person to the disabled child** to allow him/her to enjoy the camp.

The expenditure for this initiative is € 1.141.

2 children with disabilities took advantage from **this initiative**. They had the opportunity to attend the Summer Camps (respectively at the Parish Centre's in Donnas and La Petite Ferme du Bonheur in Doues), while assisted by 2 professional educators.

Building and playing together — inclusive workshop

At the end of September, La Casa di Sabbia proposed to the Aosta Valley schools the “Building and Playing Together” initiative. It is an inclusive workshop on visual programming included in the Regional School Authority's offer.

This initiative aims to develop the computational thinking and strengthen the digital skills, promote accessibility and inclusiveness, while putting the needs of disabled children into the centre.

In 2019, **2 schools were involved in the initiative**: a primary school and a kindergarten. Expenditure for this initiative will be charged to 2020 Budget, at the end of the projects, and will mainly cover the following:

- for the first project (primary school): planning hours costs, classroom hours costs, informative materials, consumable for the children;
- for the second one (kindergarten): costs of the video recording hours.

Support group for siblings

The siblings are the target of another initiative, the **Support Group for Siblings of disabled children**, launched in October 2018 and still on-going.

The group, composed of 5 children, and led by the psychologist Alda Pallais (expert in childhood), regularly met in Gressan, at the Alkimea studio.

During the 2018/2019 school year, 7 group meetings (1 per month from November to May) plus 20 individual sessions for parents and children were organized.

Providing comparison, understanding and support, the group is an important resource for children. They read books, speak, draw, but also play. Their emotions are always in the background.

In 2019, the Association spent € 1,094 for this initiative.

The support group for siblings restarted in October 2019; 8 group meetings are foreseen for the school year 2019/2020.

Let's Play Together

Despite playing represents a privileged channel for all children to explore the outside world (establish interpersonal relationships, develop motor and cognitive skills, experience different roles, as well as discover their own creativity), for disabled children recreational activities are very often focused on therapeutic purpose only.

Toys specifically designed for children with special needs are, in general, very expensive. Families often cannot afford them. Furthermore, on the market, there is a lack of toys easily adaptable to special needs.

Our project intends to **adapt available toys by introducing radio-controlled mechanisms that can activate sound or brightness effects. These special toys are offered children with disabilities for free.**

In 2019 the Association made a search for toys to be adapted, selected some of them and created a catalogue of toys adapted to special needs. This initiative **involved 6 families**, who received and tested the toys.

The **Association has the following “special toys” available**, that can be offered to families:

- Frog bubble shooter
- Track with Penguins and Unicorns
- Various tracks with cars (Ferrari, Cars, Mini, Super Mario Kart, Paw Patrol, etc.)
- Unicorn that walks, neighs and lights up
- Multicolor lamp
- Various soft toys that walk, jump, emit noises and sounds

In this video, published on our Youtube channel, we show an example of the parcel that we sent to a family: [Let's Play Together](#)

Our initiative can be summarised in these few sentences.

We start from a classical toy and we adapt it to the needs of children with severe disabilities.



We bring at their place colour, sound or brightness effects that they can activate by themselves.



Our adapted toys are offered for free to our special children.

This is a **La Casa di Sabbia Association's** initiative

In collaboration with **Rotary**  **Club Aosta**

In 2019, “Let’s Play Together” project was presented in Aosta Valley in 2 occasions:

- In April, at “**Maison et loisir d’Aosta**”
- In May, at the “**EduTech Conference**” in Saint-Vincent

They represented 2 valuable and important opportunities to **present the initiative and raise awareness of the special needs of disabled children** who cannot use conventional toys.

In April, 2 members of La Casa di Sabbia met WeDo FabLab of Bellinzago Novarese to share our experiences.

For this initiative our Association spent € 2, 456.35.

This amount covered the expenditure for toys and their adaptation, buttons, and delivery costs.

“Let’s Play Together” Project was co-financed by resources collected via HelperBit platform and the Aosta Rotary Club.

Proposal for a law on care outside the Aosta Valley

Often, those suffering from serious or rare diseases are forced to go outside the Aosta Valley Region for frequent medical examinations and treatments not available in on-site facilities.

Costs of care outside the region are entirely in charge of householders.

Our Association believes that **the problem needs an institutional response**.

Therefore, La Casa di Sabbia intends to **promote a popular legislative initiative for the approval of a legislative text** that would regulate the matter.

We are cooperating with another Association, “Tutti Uniti Per Ylenia” and her founder, Sonia Furci, who shares this important goal with us.

The text of the popular law proposal was finalized and published on our website at the end of 2018. However, during 2019 our initiative was stopped due to the political instability in the Aosta Valley, which prevented us from launching the collection of signatures.

Reduction of attendance allowances in the event of hospitalization

At the end of Summer 2019, we provided families with disabled children with a draft of the **complaint to submit to the INPS** (National Institute of Social Security) **against the cutting of the attendance allowance** applied to children hospitalized for more than 30 days (for check-up or urgent treatments: pneumonia, surgery, etc.).

The Law establishing the attendance allowance states the suspension of the provision in the event of hospitalization for more than 30 days in an Institute. However, over the years, the INPS has interpreted this rule including also a hospitalization.

Our draft of the application became virally networked and in some cases INPS reverted its decisions.

In addition, **the data we acquired through our “access to documents” request were also referred to in a parliamentary question** presented by Ms Lisa Noja to the Minister for Labour and Social Policy on the matter.

The detailed information of this initiative is available on our website.

Rights Protection

This activity includes, on one hand, systematic actions at Public Authorities level, and on the other hand, legal advice to help families understanding their rights, interpreting the complex regulatory frameworks and supporting them in litigation.

This is a complex activity, often not formalized and difficult to be reported.

The Association committed to make more transparent the measures in support of families with disabilities. We asked several regions to publish the information concerning aids.

At least **40 families contacted us** for support during this year. In most cases, it was a first contact. In few others, legal assistance was needed.

La Casa di Sabbia cooperates with 2 lawyers, Alessandra Fanizzi (Court of Aosta), and Sacha Bionaz (Court of Ivrea).

In 2019, we requested Prof. Avv. Maurizio Rivera (Court of Turin), a legal opinion to verify whether the abusive exercise of the regulated professions (art. 348 of the Penal Code) applies to nursing care provided by domestic workers.

For this initiative, the Association spent € 7,118.74 for: court fees, costs of legal advice, travel expenses, cost of access rights to the court's judgments, and books on rights accessible to all.

Research on home care for children with severe disabilities

In 2019, we started a detailed work analysis of the legislation on home care of disabled children. Despite the national nature of the regulation (home care representing an essential level of assistance – LEA), each region organizes it in different ways: with national health system staff; with external staff hired through a call for tender or with temporary employment agencies' personnel.

In Italy, only few regions have put in place models for taking care of children with severe disabilities through the development of an individualized assistance project (IAP). In many cases, families are not involved in the development of these projects, and often there is not a real assessment of the care needs upstream.

Many regions grant care benefits (with or without reporting obligations) to caregivers or provide

families with vouchers for the purchase of services from accredited bodies.

The situation is very complex, and we do not have relevant data regarding the home care of severe disabled children.

In most cases, support measures (care allowances / vouchers) are granted following a household application and a public office's investigation. However, both parts suffer of a lack of knowledge.

In 2019 we **sent a letter to the responsible for the transparency of the Regions benefiting from the Fund for not being self-sufficient**. We requested to simplify, harmonize the access to the information and publish it under the grants, subsidies, and economic advantages section (in accordance with Article 26 of Legislative Decree No 33/2013).

According to Article 12 of Law N. 241 of 7 August 1990, Public authorities shall publish the acts by which they determine the criteria and detailed rules for the award of grants, subsidies and financial aids to public and private persons and bodies.

In particular:

- open calls further to the distribution of resources;
- access criteria;
- methods of assessment;
- rankings in compliance with Regulation (EU) on Privacy 679/2016.

The letter was also published on our website.

A few regions replied, and a short summary of the replies received will be prepared in 2020.

Furthermore, 1 member of our Association attended a conference in Milan organised by "Maddalena Grassi Foundation", where it was discussed the treatment of children with serious disabilities, the forms and resources (human and financial) involved.

Fundraising dedicated to Serena and her mom

During Summer 2019, we became aware of a child hospitalized in Lombardy for a two-month rehabilitation cycle, following a cancer that caused her disability.

Serena was in the hospital with her mom who could not afford the cost of the meals provided in the hospital (often parents who need to accompany children in a hospital and stay with them must

pay for meals).

Our goal was to raise € 372 (resources needed to pay for 1-month meals during the hospitalization). However, thanks to our community on Facebook, we managed to raise **€ 935**, which were fully offered to Serena's mom, to face the hospitalization calmer.

This situation confirmed how difficult is for families to deal with a disease and disability which require to spend a long time away from home.

**Questa raccolta fondi è terminata**
Grazie a tutti coloro che hanno fatto una donazione!



**Un pasto per la mamma ricoverata in ospedale assieme alla figlia**
Raccolta fondi di La casa di sabbia - ONLUS · 

Fai una donazione

 Invita

 Condividi

... Altro ▾

Importo raccolto: € 868 su € 372 

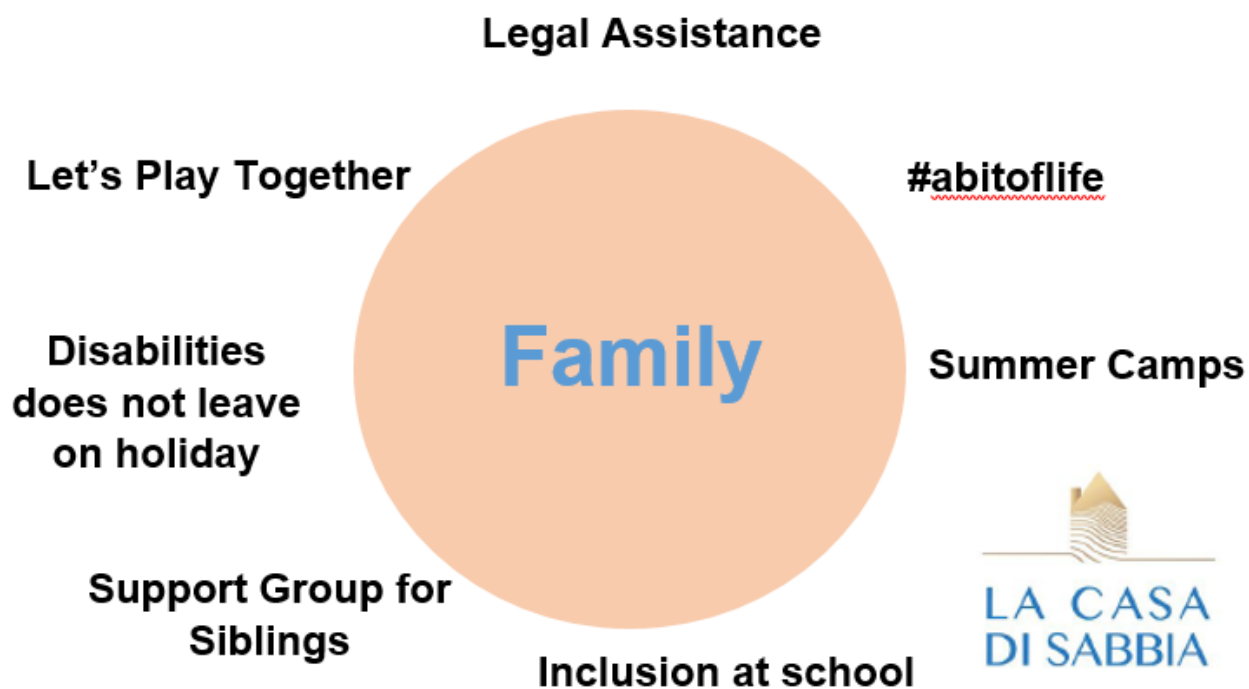
La raccolta fondi è terminata

A capture of our fundraising initiative for Serena and her mom via our Facebook page

Summarising

Last year, the Association supported more than 30 households. In more than 80 % of cases, they have benefitted from several initiatives of our Association.

We provided time and expertise of the members; we activated financial resources; and in some cases all kind of support available.



Institutional Relations

During 2019, the Association had contacts and relations with:

- **Ombudsman of the Aosta Valley**, to guarantee educators' service to children until the end of the school;
- **Saint Vincent and Issogne Library**, for the presentation of "Fairy tales from Expat World" book;
- **The Technical and Professional Institute (ISILTP) of Verres**, for "Let's Play Together" initiative;
- **Offices of the Aosta Valley Council**, for the law proposal on care outside the Aosta Valley;
- **Health and Social Services, Health and Social Affairs Department of the Aosta Valley**, to present #abitoflife project, and involve 3 social assistants who assisted 3 families through the initiative.

Relations with the territory and other bodies

In 2019 our Association also worked together with other Associations:

- **La Petite Ferme du Bonheur**: in Summer 2019, its Summer Camp welcomed a child with serious disability in Doues.
Thanks to this positive experience, we jointly submitted a project proposal in the frame of a call for proposal published by the Volunteer Services Centre. The project aims to train and ensure additional educators to children with severe disability who will attend the Summer Camps 2020 in Doues;
- **Parish Centre of Donnas**: following our agreement, the Summer Camp accepted an additional child with a disability and La Casa di Sabbia supported the expenditure of an additional educator.
- **Nati per leggere**: the Association helped us in preparing the first presentation of the "Fairy Tales from Expat World" book, and reading some fairy tales at Saint-Vincent Library.
- **Women emigrating abroad**: a group of Italian women living in the five continents who

wrote and offered the “Fairy Tales from Expat World” book to our Association.

La Casa di Sabbia published the book and used the proceeds for its activities. Several presentations by the authors took place around the world, helping to disseminate the message of the Association.

- **Scrapper Italia Association:** it granted our Association the greeting cards handily made for Mother Day and Christmas. The cards were distributed against a small offer.

Communication and outreach

La Casa di Sabbia Onlus communicated via traditional media, its own channels and its physical presence during events organized by other organizations / bodies.

In particular, the Association edited the website (blog with updates on our initiatives and comments on the legislation), the Facebook page and the Newsletter. These channels (website, Facebook and newsletter) allows us to stay in touch with our supporters, raise awareness and highlight relevant issues concerning the file of households with a severely disabled child.

In the absence of a front desk, our **online presence** helps us to reach families who need our support, who can be involved in our initiatives or whom we can provide administrative and legal information to. Most of the households contact us for help only after having followed our Facebook page for a while or read one of our posts.

You can have access to our presence on the media via the [Press Release page](#).

During 2019, La Casa di Sabbia took part in the following events/initiatives:

In February

- **Presentation of the “Fairy Tales from Expat World” book**, and reading of some fairy tales in Saint-Vincent Library. For this initiative, we collaborated with the volunteers of the Association “Nati per Leggere”.



Some moments during the presentation of the book at the Saint Vincent Library.

In April

- **“Maison et loisir d’Aosta”**: we presented the initiative “Let’s Play Together” and a prototype of Frog bubble shooter, adapted by the students of the ISILTP of Verres.

In May

- **Meeting with the WeDo FabLab** of Bellinzago Novarese to share mutual experiences and knowledge on the adaptation of toys for children with serious disabilities.
- **“Flowers and Tastes” market in Issogne** on Mother’s Day. The Association hold a stand with the cards donated by “Scrapper Italia Association” and the “Fairy Tales from Expat World” books, that were proposed against an offer.
- **Visit to the middle school of Quart and meeting with pupils** of the class IIB who created a calendar, and offered the profit of the initiative to La casa di Sabbia, in support of #abitoflife and “Let’s Play Together” initiatives.
- **“EduTech” Conference in Saint-Vincent**, organised by the enterprises incubator in collaboration with S. Vincent Municipal Library. The conference was devoted to Educational Technology, with a focus on educational robotics, central to the development

of future production processes and closely linked to the innovation and start-up system. In the frame of the conference, “Let’s Play Together” initiative was presented.



Above: Pupils of the school of Quart and EduTech Conference.

Below the market “Fleurs et Saveurs” in Issogne, and the meeting with WeDo FabLab Association

In June

- **Presentation of the “Fairy Tales from Expat World” book and our Association** at the Issogne Castle, in cooperation with the **Issogne Municipal Library**.

August

- **“La Festa del Dolce” in Brusson, organised by the “Non ti scordar di me” Association:** they offered the proceeds of the initiative to La Casa di Sabbia. Our members were present and distributed leaflets introducing our activities.

In September

- **“La Festa del dolce” in Champdepraz, organised by the Pro Giovani Champdepraz Association.** Part of the profits were offered to our Association, and part of them to the “Monelli dell’Arte” Association. Our members prepared cakes and biscuits, and distributed leaflets presenting our activities.
- **“Fair Pic Nic”, organised by Soroptimistic Association of Aosta:** the proceeds of the initiative were offered to our Association. Soroptimistic deals with the international protection of women’s rights. For our members the Pic Nic was also an opportunity to discuss the conditions of mothers-caregivers, who often have to leave their job to look after the disabled children.
- **“Supportive dinner” promoted by the Proloco of Chambave:** the profits of the dinner were donated to our Association. During the event, we had the opportunity to present La Casa di Sabbia’s initiatives.
- **Race “EdilEcoRun24” in Aosta.** La Casa di Sabbia took part in the competition with its team and **Catherine Bertone** was part of it, bringing the message of the importance of sport for children and especially for siblings of disabled children. We had a stand with our Association’s leaflets, the “Fairy Tales from Expat World” book, and the kinetics sand for offering fun to children.



Some members of our Race Team

In November

- **“Marché de Noel” in Gignod**, organised by the Friends of the Gignod Library. We presented the “Fairy Tales from Expat World” book and we proposed, against a small offer, the Christmas cards offered by Scrapper Italia Association.
- **Auction organised by “coscritti” (youngerst born the same year) during the patron saint day of Antey-Saint-André.**

The amount of the auction was offered to La Casa di Sabbia.



On the picture, the youngsters of Antey-Saint-André, Don Tomasz, the Mayor, Agnieszka, Patrick, Hervé and Anaïs

In December

- **“Christmas market” organised by Gressonsey-Saint-Jean Pro-loco:** our members sold the cards donated by Scrapper Italia Association and the “Fairy Tales from Expat World” book.

Also in 2019, the Association **cooperated with the photographer of Aosta, Stefano Scherma**, for his **photo project 'Faire avec'**. The project involved families with children or teens with rare diseases, with the aim of sharing their daily lives and raise awareness about disability. During the year, we had some photo shootings of Hervé's daily life, which were included in Stefano's project.

The project "Faire avec" was honored with the prize "for the best divulgation trough pictures, images and comic strips" in the frame of the VI Edition of the Prize OMaR for the Communication on Rare Diseases and Cancers. It is organized by the Observatory for Rare Diseases in partnership with the National Centre of Rare Diseases of ISS, Orphanet, Telethon Foundation and Uniamo FIMR Onlus.



Donors and Supporters

In 2019, a large number of direct donors (individuals) supported the Association. In addition, some organisations decided to offer La Casa di Sabbia the proceeds of their own initiatives or events.

In particular:

- [Aosta Rotary Club](#)
- [The “Castagneti d’Issogne” Association](#)
- [Middle school of Quart](#)
- [“Non ti scordar di me” Onlus Association of Brusson](#)
- [Soroptimist Association](#)
- [Pro Giovani Association of Champdepraz](#)
- [Pro-Loco of Chambave](#)
- [Parish and Municipality of Antey-Saint-André](#)

In the course of 2019, a number of companies and professionals supported our initiatives.

Below some of them:

- Federica Colombo, a young graphic designer, who cooperates almost free of charge with the Association. She put her professionalism at our service for graphic services: printed or web flyers, visiting cards, cover of our Facebook page, and graphics for the 5x1000 campaign, ensuring a coordinated image of the Association. [Here](#) you can have a look at our visual identity.
- Miss Pretty Sara, an entrepreneur who designs and produces in Italy a number of very high quality items (T-shirts). She decided to offer 2 % of the sales revenues to La Casa di Sabbia. [Here](#) you can find more about her activity.
- EdilEco, a construction company, which every year organizes in Aosta a 24 hours running race (the [EdilEcoRun24](#)). It offered us a stand in Piazza Chanoux to present our Association and raise awareness on disability.
- The [Brite Trend](#) marketing company which made available the skills of its employees to

realize “Our lives colours”, a video for our Association.

The video was awarded of € 1.000 prize in the frame of a TUA Insurance competition that will be used for our activities.

There are some donors and supporters (Associations, companies, professionals) who wish to remain anonymous. However, we care about thanking **all those who have contributed to supporting the activities of La Casa di Sabbia.**

The Association used different ways to raise funds:

- [Helperbit Platform](#) for two projects: #abitoflife and “Let’s Play Together”;
- PayPal;
- Bank transfer;
- Facebook via the “make a donation” button, which gives the possibility to send an offer without fees;
- Satispay

2019 was also the second year of the 5x1000 collection (for tax payers in Italy only).

Unfortunately, we do not know yet the amount and the list of donors neither for 2018, nor for 2019, because the data of the Agenzia delle Entrate (Revenue Agency) are not yet available.

2019 Expenditure and Budget

La Casa di Sabbia has a Cash Balance Sheet.

In 2019, we raised over € 41,000 in donations and spent over € 27,000 on all initiatives.

The two **most relevant initiatives** (with most time and resources allocated) are #abitooflife and legal assistance service.

These two initiatives are often complementary: the first one offers moments of leisure and serenity to families and siblings; the second one provides expertise to ensure rights protection to the households.

In 2019, the Association spent over € 24,000 for all initiatives.

The **Association's overheads** amount to € 926,02 (bank charges, PayPal transaction fees, website domain costs, certified e-mail and digital signature costs; communication expenses like leaflets, delivery costs, etc.).

Under **durable goods**, there is a laptop to be used for the activity "Let's Play Together" with Makey Makey, a printer and equipment (plastic containers) for the warehouse, for a total amount of just over € 1,400.

In addition, the Association spent € 1,153.56 for printing and sending 400 copies of the "**Fairy Tales from Expat World**" book, and 2.000 **promotional bookmarks**. The book was distributed against an offer of around € 18.

At the beginning of 2020, the Association had around 100 books on stock.

During the year, in addition to the already used fundraising channels (PayPal, bank transfer, HelperBit platform and Facebook "make a donation" option), we added Satispay.

The most successful channel for receiving donations was Facebook, through which we collected the highest amount of offers, without fees for the Association.

In 2019, the Association had a **management surplus of** approximately € 14,000, that will be used in 2020 to finance our initiatives, in particular #abitooflife, Summer Camps (with the aim of providing more educators to La Petite Ferme du Bonheur in Doues), and the legal assistance service. Furthermore, the Association intends to add three new activities for the next year.

The **budget is broken down into the individual initiatives**, with the exception of Indirect costs (general expenditure, communication, durable equipment), which are essential for the running of the Association but that represents a minimal part of the budget.

REVENUE		EXPENDITURE	
Description	Amount	Description	Amount
Donations	€ 41,514.27	Legal assistance	€ 7,118.74
Membership fees	€ 120.00	# Abitoflife	€ 9,597.00
		Let's Play Together	€ 2,456.35
		On the top of wheels	€ 700.00
		Support Group Siblings	€ 1,094.20
		Read together	€ 74.76
		Fairy Tales Expat World	€ 1,153.56
		Summer Camps	€ 1,141.00
		Overheads Costs	€ 926.02
		Durable Goods	€ 1,443.23
		Communication	€ 598.93
		Fundraising for others	€ 935.00
TOTAL REVENUE	€ 41,634.27	TOTAL EXPENDITURE	€ 27,238.79
Surplus	€14,395.48		

Our Thanks!

We would like to thank all people who, in 2019, supported us in several ways; through offers, press articles, blog posts, kind words, dedicated spaces and many actions in our favor. These gestures together made a big difference in the lives of many families.

Thanks to you, we can fight for a better life of families with children with serious disabilities.

2020 Objectives

- **Continuing** to **support** families with children with severe disabilities through: legal assistance to obtain adequate home care and support at school; #abitoflife project; 2020 Summer Camps initiatives; the support group for siblings;
- **Raise awareness** of the rights of families with severe disabled children and encourage them to claim for them;
- **Push more** the Public sector to apply the laws concerning appropriate home care already in force;
- **Strengthen** relations with the territory in order to reach more families with severely disabled children.

In 2020, in addition to the activities already undertaken, **we will be looking at three new initiatives.**

- **“Go higher with wheels”** to help families with disabled children and youngsters to enjoy the Aosta Valley mountains more easily.
The project intends to compile a guide of accessible and already tested paths for an “off-road” stroller; provide families with an “off-road” strollers (driving-assisted option available); offer nursing assistance to families; identify accessible accommodations (hotels, campsites and apartments) for families with special needs.
- **“Let’s read together”** to stimulate reading with children, in particular of books on diversity, disability and inclusion. A way to talk about complex issues in a soft and indirect way.
- **“Black cat adventure”** an application for Android and Ios tablets, developed by a team of professionals in Aosta Valley, and addressed to children with severe disabilities to create gaming and entertainment events on electronic devices.

Support our activities!

On the webpage www.lacasadisabbia.org/come-sostenerci there are many ways to support our Initiatives in favor of families with children with serious disabilities.

For Tax payers in Italy only, the easiest way is to give us your 5x1000 Tax Return.

Our Tax Code is the following: **91070580070**

You can send the link of our page <https://lacasadisabbia.org/5x1000/> to your friends (tax payers in Italy) and ask them to support us!

You can also ask for hard copies of the **5x1000 leaflets** and distribute them among your contacts.



Association Info

La Casa di Sabbia Onlus, Association
Fraz.Roisod 4d 11020 Gignod (Ao)
Tax code: 91070580070

Tel.+39 375 563 29 39

E-mail info@lacasadisabbia.org

Website: www.lacasadisabbia.org

PEC: lacasadisabbia@pec.it

[Facebook page](#)

[Newsletter enrolment](#)

[PayPal Donations](#)

[Satispay Donations](#)

Bank Transfer details:

for donations from Single Euro Payments Area our IBAN code is:

IT19P0306909606100000155600 – for donations from other countries IBAN:

IT19P0306909606100000155600 – BIC code (SWIFT): BCITITMM)

La Casa di Sabbia Onlus

Bank: Intesa Sanpaolo S.p.A

Authors of the report

Agnieszka Stokwiecka, Constantine Girod, Patrick Creux

This report was approved by the General Assembly of the members of La Casa di Sabbia on 14 February 2020, which took place in Aosta.