

# THE FIRST STEP...



## Dear Readers,

Here it is! The new edition of our beloved newsletter. As you know, there are always many fundraising events dedicated to CABSS especially during the Christmas season. For the third time we held an event at Teatro Sistina thanks to the relationship established with the Artistic Director Massimo Romeo Piparo who gave us the opportunity to see one of the most acclaimed musicals, "Mamma Mia!".

In December, for the first time, CABSS was the beneficiary of the funds raised at the Pomellato event thanks to the collaboration established between CABSS and Pomellato. The jewellery maison celebrated their 50th anniversary and showed their support to CABSS on this special occasion. In addition, we were also invited once again as guests at the My Cup of Tea event.

I am happy to announce that, Dr. Stefania Fadda Director of CABSS, took the reins of the European Society for Mental Health and Deafness (ESMHD), becoming President on January 1, 2018. The election was held during the "Deaf People and Personality Disorders" International Conference last October in Bilbao where Stefania Fadda presented on the impact multisensory early intervention on deafblind children.

The "Fulbright - Roberto Wirth" scholarship has been renewed for the 2018/2019 academic year. The scholarship offers the opportunity to specialize in an area related to deafness and to contribute, once the scholar is back in Italy, to the well-being of deaf preschool children. The winner of the scholarship will have the opportunity to study in the United States at the prestigious Gallaudet University in Washington D.C.,

the only bilingual university (American and English Sign Language), fully accessible to deaf students. Lisanna Grosso, our 2017/2018 scholar, is currently in the United States living out her American dream!

I also invite you to read part one of the article dedicated to CHARGE Syndrome, a rare disorder that is one of the major causes of deafblindness. As you read the article, keep in mind that the word "CHARGE" is an acronym of the most common characteristics of the syndrome.

Kindest Regards!



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## ESMHD Bilbao 2017

### Stefania Fadda becomes the new President of ESMHD

We're happy to announce that our Director, Stefania Fadda, as of January 1st, 2018 became the new President of the European Society for Mental Health and Deafness (ESMHD), taking the place of former president Ines Sleeboom-van Raaij, a noted German Psychiatrist. Doctor Fadda, is the first Italian President of the prestigious international organization and was elected at the Annual ESMHD's General Meeting on October 20, 2017, in Bilbao, Spain.

At the meeting, two new members of counsel were also nominated, Alex Hamilton (England) and Nora Olazabal Eizaguirre (Spain) giving ESMHD further prestige alongside manager Renata Sarmento (Spain), honorary treasurer Lea Strandberg (Sweden), and executive members Tiejoo van Gent (Holland), Maria Gascón (England) and Johannes Fellinger (Austria).

ESMHD is an international organization that has promoted mental health in deaf people in the childhood, teenage and adult years since 1986. In particular, it pursues the objective of developing and promoting appropriate prevention, assessment, diagnosis and treatment programs, which allow all deaf people to achieve psychological well-being and full social inclusion.

Dr. Fadda, has been a member of the ESMHD Council for 10 years. She is a Psychotherapist and Psychologist who did her specialization in Mental Health and Deafness in the Clinical Psychology PhD program, at Gallaudet University (U.S.A.). She has been the Director of CABSS since 2008. Under her guidance and with the support of President Roberto Wirth, the team at CABSS established the first early intervention program for deaf and deafblind children aged 0 to 6 and their families.

She has presented at numerous scientific meetings of international importance and has published books and articles in the field of "Psychology and Deafness" and "Mental Health and Deafness".



From left: Ines Sleeboom - van Raaij and Stefania Fadda

### CABSS at the forefront of the ESMHD International Conference "Deaf People and Personality Disorders"

Dr. Stefania Fadda and other prestigious professionals in the field of deafness and mental health, came together from all over the world for the conference on "Deaf People and Personality Disorders", organized by ESMHD, at the Bilbao - Basurto hospital in Spain. The conference was held on the 19th and 20th of October 2017. The aim of the initiative was to address the issue of the mental health of deaf people and personality disorders and to raise awareness about new methods of assessment, diagnosis and treatment. The presentation done by Dr. Fadda, "Step by step ... growing together at CABSS. The impact of early multisensory intervention", illustrated the impact of early multisensory intervention on deafblind children, utilizing a case study of a child, "Alessio" who attended the early intervention program at CABSS. Alessio completed the program at CABSS in the summer of 2017, at the age of 7. When he arrived he was just two years old, his hands clenched in small fists and his body held in the security position,

protecting himself from the external world. An individualized early intervention program was designed for him at CABSS that took into account his personality, strengths and challenges. His program was adapted and modified as he grew. The more Alessio was exposed to a variety of stimuli the more he became open and learned how to trust, use his hands to touch, explore and learn about the world around him. He also was able to maximize the use of his residual senses (hearing/vision) and learn to integrate, process and understand information coming from the external environment. He developed skills and concepts and acquired a method of communication appropriate to his needs. Furthermore, with the support of CABSS, Alessio had the opportunity to attend kindergarten and later primary school. At CABSS, Alessio's parents were actively involved and were offered psycho-educational support. Thanks to services at CABSS, Alessio's

parents strengthened their ability to advocate in favor of their child, learned to recognize his needs and to respond to them appropriately. They also strengthened the emotional bond they have with Alessio by learning to interact with him effectively. At the conference, other professionals presented on: "Mistakes, Misconceptions and Misdiagnosis of Medical and Psychological Symptoms in the Deaf Population" by Ines Sleeboom van-Raaij, former ESMHD President and Psychiatrist specialized in Deafness and Mental Health (Holland); "Mental Health of Children and Adolescents: Implications for Therapy" by Tiejoo van Gent, Psychiatrist specializing in Child Deafness and Mental Health (Netherlands); "Reaching the unreachable: a novel therapeutic approach" by Alexander Hamilton, Forensic Psychiatrist, and Michelle Bertulis, Speech Therapist (England); "Countertransference and Deaf Patients" by Nora Olazabal Eizaguirre, Psychiatrist, and Veronica Pousa, Clinical Psychologist (Spain).



## CHARGE SYNDROME - Part 1

One of the leading causes of deaf-blindness is Charge Syndrome. CHARGE syndrome is a genetic disorder with multiple sensory, physical, and behavioral anomalies. Babies are often born with life-threatening birth defects and spend many months in the hospital. They typically undergo 10 surgeries and other treatments, before the age of 3. They experience difficulty with swallowing and breathing problems making life very challenging. Most children have vision loss, hearing loss, and balance problems that can delay their development and communication. They may also have deficits in every sensory modality and exhibit challenging behaviors. However, despite these insurmountable obstacles, children with CHARGE syndrome often far surpass their physical, medical, educational, and social expectations. When the child's medical situation stabilizes, parents are then able to focus their concerns on their child's development, communication, and education.

It is important to understand that every child born with CHARGE has a unique set of features - no two children are alike. It is an extremely complex syndrome that differ from child to child.

The name "CHARGE" refers to a cluster of features seen in children diagnosed with CHARGE. The letters in CHARGE stand for:

- **C** - Coloboma of the eye
- **H** - Heart defects
- **A** - Atresia of the choanae
- **R** - Retardation of growth and/or development
- **G** - Genital defects
- **E** - Ear anomalies and/or deafness

Although CHARGE syndrome is usually sporadic, there has always been evidence that it is caused by a genetic factor. In 2004, a gene for CHARGE (CHD7) on chromosome 8 was identified and was found in over 90 % of CHARGE patients and is now a recognizable genetic syndrome with a known pattern of features.

However, it is important to note that 10-20% of individuals with CHARGE do not have an identifiable pathogenic CHD7 variant and not every CHD7 variant causes CHARGE. Although genetic testing positively identifies nearly two thirds of children with CHARGE syndrome, diagnosis is still largely clinical.

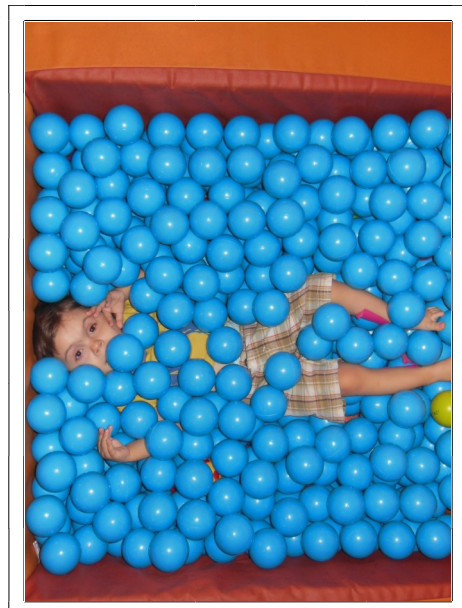
When it comes to communication, about 60% of children with CHARGE acquire symbolic language and communicate with signs, spoken language, and/or visual symbols. The mechanics of speech may be affected by craniofacial anomalies, clefts, and breathing problems. Language development can be delayed due to multiple sensory issues, motor deficits, and delay in establishing an appropriate communication system. Success in acquiring symbolic language is often a result of children being engaged in communication training before the age 3, success in dealing with, understanding and acquiring the right hearing/visual devices to compensate for hearing and vision loss and the ability to walk independently. Children who do not acquire symbolic language may learn to utilize higher forms of prelinguistic communication such as use of gestures and vocalizations. Since children with CHARGE often demonstrate a high rate of repetitive behaviors, parents and caregivers may find it challenging to assign meaning to potential communication acts.

There is evidence that early intervention by professionals specialized in deafblindness can enhance the acquisition of symbolic language that is crucial to communication development, social interaction, and learning. Early and constant intervention that addresses the multiple medical, communication, sensory and behavioral needs can greatly enhance the quality of life for children with CHARGE syndrome.

For more medical information about CHARGE please see [www.genetests.org](http://www.genetests.org). The CHARGE Syndrome Foundation publishes a "Management Manual for Parents", which covers medical information and developmental information on CHARGE. The Manual is available in pdf format on the Foundation website [www.chargesyndrome.org](http://www.chargesyndrome.org).

Source:

<https://www.chargesyndrome.org>



# ACTIVITIES AND PROJECTS

## CABSS speaks about school and deafblind children at the ebook presentation, “Back to School”

An important component of the work that CABSS carries out focuses on the rights of deafblind children and education. Our director Stefania Fadda addressed this theme during the "Back to School" ebook presentation held on September 20, 2017 at the Microsoft office in Milan. The ebook was created by the Alley Oop ([www.alleyoop.ilsole24ore.com](http://www.alleyoop.ilsole24ore.com)), a blog that was conceived and edited by journalist Monica D'Ascenzo, who provides a forum for journalists from the Sole 24 Ore group and independent writers. "Back to School" describes the issues that exist within schools today in a real sense, highlighting the complexity and challenges that teachers and parents face on a daily basis.

On September 20th, teachers shared what was new and positive in the Italian scholastic world as well as the gaps that still need to be addressed. Dr. Fadda participated in the debate voicing the issues about school from the point of view of deafblind children.

At Italian schools there is still isn't a figure that is specialized in deafblindness to work with children who are deafblind. This professional figure is known abroad as an Intervenor. In Italy, there are communication assistants for the deaf and tiflodidatta for the blind. CABSS is actively committed to addressing this situation in hopes that a specialized figure for the deafblind will be added to the multidisciplinary team at school. CABSS supports deafblind children with transition into kindergarten and primary school. CABSS also supports educators in adapting the school environment making it accessible and inclusive for deafblind children by encouraging such things as the use of handrails, tactile paths, visual and auditory adaptations. CABSS gives suggestions of how to introduce, create and utilize

tactile, auditory / or visual cues within the school environment such as (corridor, classrooms, cafeteria, bathrooms, playground) and makes suggestions of how to organize the classroom to make it more accessible from a mobility standpoint such as arranging the desks in a systematic way where there is clear path to the door.

CABSS gives suggestions to how the child who is deafblind can be included in class and group activities with his/her peers. For example, creating tactile pins to identify peers/self when participating in group activities or interacting one on one with his/her peers.

In addition, CABSS offers support in program planning and how to adapt school activities. Once the child has successfully transitioned into the school environment, CABSS continues to provide support to the child and meet with school personnel.



Stefania Fadda during her presentation at “Back to School”



Stefania Fadda speaking at “Back to School” ebook presentation



## The 2018/2019 "Fulbright - Roberto Wirth" Scholarship

President Roberto Wirth and the Fulbright Commission for Cultural Exchanges between Italy and the United States are pleased to announce that the 2018/2019 Fulbright -Roberto Wirth scholarship will soon be available. Candidates must be Italian citizens enrolled in their second year of university or who have already graduated and have obtained a degree.

The winner of the scholarship will fly to the United States to study at Gallaudet University in Washington D.C., the only bilingual university in the world (American and English Sign Language) fully accessible to deaf and hard of hearing students. The new scholar will have the opportunity to specialize in the area of deafness at the prestigious American University and to contribute, once he/she is back in Italy, to the well-being of deaf children.

The scholarship was established in 1992 by Roberto Wirth, who has been deaf from birth and always sensitive to the specialized needs of deaf children. With the commitment of Dr. Wirth, and the support of the Fulbright Commission, the scholarship has enabled many young deaf students to become professionals of excellence in the field of child deafness for over 25 years. Moreover, it has also meant that countless Italian deaf children have benefited and have been inspired to make their dreams come true.

The scholarship is part of the Fulbright Program, conceived in 1946 by the U.S. Senator J. William Fulbright and today is considered the oldest and most extensive government cultural exchange program in the world.

To apply for the scholarship, candidates must complete the application form. It can be downloaded from the [www.fulbright.it](http://www.fulbright.it) website and sent to the Fulbright Commission no later than February 28th, 2018.



Gallaudet University, Washington D.C.

## Lisanna Grosso shares her experience with us from Gallaudet University

Lisanna Grosso is now halfway through her studies at Gallaudet University. In fact, she is about to start her second semester, after which she'll pass on her knowledge and experience to the next scholarship winner for the 2018/2019 academic year.

Lisanna is a concrete example of the benefits that the scholarship brings to Italian deaf children, something that Roberto Wirth hoped that it would do right from the initial creation of the scholarship. In fact, at the age of three, Lisanna started school and was accompanied by Daniele Chiri, her teacher who is deaf and who had just returned from Gallaudet University as a "Roberto Wirth" scholar. In 1994 Daniele Chiri helped to launch an experimental bilingualism project, at a school in Cossato (BI). Now Lisanna is the Roberto Wirth Scholar following in the footsteps of her preschool



teacher. She has so many ideas, a strong desire to learn and today Lisanna is a highly motivated to work towards making her dreams come true. "I am in Washington, D.C., overseas, far from home. Do I miss Italy? Maybe I do, maybe I don't, I can't say for sure, because I'm still too excited to be here, at the famous Gallaudet University. For years I've dreamed of coming here and now I'm really here!!!".

Maybe she really misses Italy but she feels so lucky to be at Gallaudet, "As soon as I arrived I found really kind people, who helped me to settle in and made me feel comfortable in this "big" country. What do I mean by "big"? It is exactly like what you see on American Television programs. It's all true ... the cars are really big! The glasses are tall and long. "Normal" supermarkets are equivalent to our "iper" supermarkets!".

Lisanna makes us smile, and shared with us her amazement of Gallaudet: "Gallaudet is a real Deaf community. Everyone signs in ASL

(American Sign Language) even those who are not deaf. Accessibility is 100% (...). Wherever you walk you see fluttering hands. Wonderful! All lessons are entirely in ASL".

Lisanna will have the opportunity to learn both theoretically and practically. She will gain valuable experiences as a professional and learn various teaching methods that utilizes an array of materials and that will encourage the development of preschool aged deaf children. Among the new learning materials that she will be exposed to for deaf children in the States, the scholar will also focus on how to create bilingual (American Sign Language / English) eBooks .

Thanks to this incredible experience and learning opportunity, Lisanna will expand her professional portfolio, which, when she returns to Italy, will allow her to implement, in collaboration with CABSS, services for deaf children and their families in Northern Italy.

# FUNDRAISING

## "Mamma Mia!", one of the greatest musicals of all time, and the protagonist of the CABSS Christmas event

"When a show succeeds as a result of combining quality and public appeal, it really is a true victory! 'Mamma Mia!' Mania: 76,530 tickets went fast and the musical was quickly sold out at one of the largest Italian theaters ". The words of Massimo Romeo Piparo, Director and Producer of the musical, which expresses his deep satisfaction for the success of the Italian version of one of the most famous musical comedies of the 2000s.

The musical "Mamma Mia!" was the protagonist of the CABSS and ANLAIDS Lazio's Christmas event. The musical took place at the historic Teatro Sistina, a splendid Roman location offering the public the opportunity to see some of the most popular musicals.

On December 19th, hundreds of supporters of the non-profit organizations found themselves in the heart of the capital to attend a musical that not only offered great music but also romance and humor.

Once the curtain was raised, the set was spectacular, a lovely seaside resort with (11,000 liters of water on stage), a moored boat, bridge, a mother, daughter and three possible fathers.

A romantic story that leaves the crowd in awe and suspense but also in delight with an array of upbeat and moving musical pieces as the story progresses.

The musical comedy, made by an entirely Italian production, boasted a cast of actors who are loved by the public: Luca Ward in the role of Romolo Desideri (Bill), Paolo Conticini in the role of Sam Carmichael, Sergio Muniz in the role of Enrique Luz (Harry) , Sabrina Marciano in the role of Donna Sheridan, Eleonora Facchini in the role of Sofia (Sophie) and Jacopo Sarno in the role of Sky.

Before the show some of the supporters of CABSS Onlus and ANLAIDS Lazio, attended a Christmas cocktail at the enchanting Hotel Hassler where guest exchanged Christmas greetings around the gorgeous Christmas tree and toasted in anticipation of the upcoming Christmas holidays. At 9 pm, all the guests arrived at the theater where the renowned journalist, Margherita de Bac, specialized in writing about rare diseases from the Corriere della Sera, presented the presidents of the non-profit organizations, Roberto Wirth and Massimo Ghenzer

to the audience. De Bac also spoke about both organizations and how although they have different objectives they share a common approach. The funds collected during the evening will be utilized, by CABSS for the subsidization of early intervention programs for deaf and deafblind children, and by ANLAIDS to support AIDS dissemination and awareness projects at schools.

We would like to give a heartfelt thanks to Ms. de Bac for her generosity and all the sponsors who helped to create an unforgettable evening.

**Gold Sponsor:** Private Banker Leopoldo Barocci, Sportnetwork, Studio Legale Consolo

**Silver Sponsor:** Piccinelli del Pico Pardi & Partners, Working Group

**Bronze Sponsor:** Blu Insurance Broker, Emotions in Rome, Studio Legale Compagna

**Technical Sponsor:** Helèn Profumerie



From left to right: Patrizia Ferri and Massimo Ghenzer, ANLAIDS Lazio; journalist Margherita de Bac; Roberto Wirth and Stefania Fadda, CABSS Onlus



## Pomellato in Favor of CABSS Onlus

On the 30th of November, 2017, Pomellato dedicated the presentation of their new collection "Iconica" to CABSS in celebration of their 50th year anniversary.

Synonymous with creativity and color, Pomellato was founded in Milan in 1967 by Pino Rabolini. His avant-garde approach utilizes sophisticated colored stone combinations, unique gem cuts and visionary designs that are impeccably crafted.

On the evening of November 30th, loyal donors of CABSS and a selection of Pomellato's prestigious clientele were welcomed at the Piazza San Lorenzo in Lucina

boutique, in the heart of the Roman Trident, to admire the some of the most exquisite pieces of jewellery.



*From left: CABSS Onlus President Roberto Wirth and Pomellato Store Manager Giuseppe Zaza*

During the event, the President of CABSS Onlus, Roberto Wirth, and the Store Manager of Pomellato, Giuseppe Zaza welcomed guests and informed them that part of the proceeds from the sales made that evening and the following 20 days would be donated to the deaf and deafblind children of CABSS.

Thanks to Pomellato, and to the generosity of those who purchased jewellery, we were able to offer a baby girl who is deafblind and previously on the waiting list the opportunity to attend the early intervention program at CABSS.

## My Cup of Tea - The 2017 Christmas Edition

Last December, CABSS Onlus was, once again, the protagonist of four of the five days of the Mycupoftea's Lifestyle for Xmas" event.

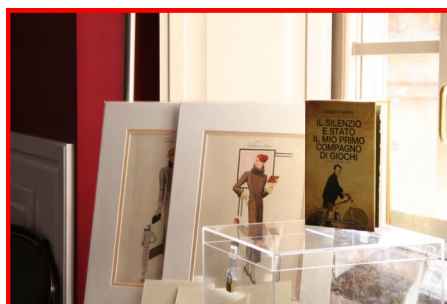
"My Cup of Tea" is a lifestyle, a state of mind, created from the passion for Italian creative excellence. The organizer Flavia Muzi Falconi presented new Italian designers and artisans who displayed their original creations.

The event was designed to engage the public and offered: fine food and wine tasting, atelier floral decorations, workshops for children, book presentations and philanthropy initiatives.

There was a stand present at the event dedicated to CABSS from Wednesday December 13th to Saturday December 16th.

A solidarity raffle was also organized with prizes donated by boutiques in support of deaf and deafblind children: Battistoni; Choc; Coin; Creo Bistrot; DAN; Duca Jewellery; Eufemi; Gaia Moncada; Hasler; Home's; Il Puntaspilli; Jupissimes; Le Trou; Macocò; Macri; Manu Solaro; Mondomestre Skira/MMS; Amorvero; Nespresso; Newtop; Otello; Hairdresser da Giusy; Piumini Danesi; Planeta; Playxtreme.it; Maria Teresa Perfumery; Rossano Ferretti Hairspa; Scotia; Tirso Hair.

We sincerely thank the "friends of CABSS", and the generosity of the many women who dedicated their time to make this possible: Giulia, Alessandra G., Alessandra M., Bianca, Dina and Paola.



*CABSS Onlus' stand at My Cup of Tea*

# FUNDRAISING

## Support us!

**Bank transfer** made out to the Centro Assistenza per Bambini Sordi e Sordociechi Onlus, Piazza Trinità dei Monti 6 – 00187 Roma.

Banca CREDEM

IBAN: IT91 J 03032 03201 010000004258

BIC/SWIFT: BACRIT21318

**Non-transferable check** made out to the Centro Assistenza per Bambini Sordi e Sordociechi Onlus and sent to the Centro Assistenza per Bambini Sordi e Sordociechi Onlus, Via Nomentana 56 – 00161 Roma along with your information (name, surname, address and phone number).

**Donate Online** at our website: [eng.cabss.it](http://eng.cabss.it).

### PLEASE NOTE

**Your donation is tax deductible!**

## Donate your 5X1000!

Supporting Centro Assistenza per Bambini Sordi e Sordociechi Onlus is easy; make the decision to donate your 5x1000. You can allocate a portion of your income to a non-profit organization.

All you have to do is write down **CABSS' tax code in the space provided and sign.**

Remember that the 5x1000 does not replace the 8x1000 and you can donate to both. In the case that you decide not to donate be aware that the portion originally designated in favor of nonprofit organizations will go directly to the government.

**Children need your support!**

**TAX CODE**  
97350450587

## Support CABSS directly from the U.S.A.!

American citizens can now make a tax deductible donation to CABSS directly from the U.S.A. by taking advantage of tax deductions that support charities based in the U.S.A. (Sections 501 (c) (3) and 509 (a) (1) of the Internal Revenue Code). Here's how you can support CABSS from the United States:

By making an **online donation** on the KFBUS website: [www.kbfus.org](http://www.kbfus.org) and clicking on "Donate Now" and selecting "Giving Option 1: Non-Profit Partners Overseas" "Assistance Center for Deaf and Deafblind Children (IT)".

Sending a **cheque** to: KBFUS 10 Rockefeller Plaza, 16th Floor, New

York, NY 10020. It is very **important** that you make sure to indicate in the memo section of the cheque that your donation is going to: "Friends of the Assistance Center for Deaf and Deafblind Children";

Through **wire transfer**. Please contact CABSS for more information.

For more information please visit:

[www.kbfus.org](http://www.kbfus.org)

[eng.cabss.it](http://eng.cabss.it)



**Purchase your copy today!**

**A portion of the proceeds from the sales of the book will go to CABSS Onlus in favor of deaf and deafblind children**

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